

Using the TUNGSTEN approach to co-design DataDay: a self-management app for dementia

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Chapter 11

Using the TUNGSTEN Approach to Co-design DataDay: A Self-management App for Dementia



Arlene Astell, Erica Dove, Chris Morland, and Steve Donovan

11.1 Introduction

User expertise illuminates people's motivations for using technology (Hassenzahl 2011), including the reasons that they do or do not use applications, devices and services. Identifying user's priorities aligns with the current or 'third wave' of HCI, which embraces the experience and meaning-making of the technology user(s) (Bødker 2015). When working with people living with dementia, expertise from families can also deepen one's understanding of potential users' motivations for and challenges experienced when using new technologies, particularly at home (Astell et al. 2009). In healthcare settings, frontline staff are also experts in understanding the technologies they both use and support, as well as the challenges to innovation and implementation within their services (Astell and Fels In Press).

At the present time there are no disease-modifying therapies for dementia (Bennett 2018; Mehta et al. 2017), but current and future technologies could provide practical, affordable and scalable solutions (Astell 2019). Globally, the majority of people live with dementia at home, supported by family, friends and the wider community (Prince et al. 2015). Thus, what is needed are accessible and affordable digital solutions that

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empower people with dementia to live as well as possible at home (Astell and Semple 2019). This requires partnership with people who have dementia in order to identify their priorities, needs and aspirations and to co-design new digital solutions targeting these.

TUNGSTEN or ‘Tools for User Needs Gathering to Support Technology Engagement’ (Astell et al. 2018a) is an approach to technology design and development that views the intended users of new applications, services and devices as ‘experts’ (Astell and Fels In Press). As a core project of AGE-WELL, Canada’s Network of Centres of Excellence on ageing and technology (AGE-WELL 2019), TUNGSTEN is partnering with older adults to co-design technologies that people want in their lives. We do this by bringing together older adults, formal and informal caregivers, clinicians, policymakers and technology developers in facilitated workshops comprising hands-on activities related to technology adoption and service development. The TUNGSTEN tools are generic and can be applied to any technology topic with any population.

This chapter describes the use of TUNGSTEN tools in a recent co-design project with people living with dementia, family caregivers and clinical teams. This chapter focuses on the co-design sessions with people living with dementia and family caregivers and illustrates the benefits of the TUNGSTEN approach for co-designing with this population.

11.2 Co-designing with People Who Have Dementia

Co-design is broadly defined as the process of designers and people untrained in design working together in the design and development process (Tseklevs et al. 2018). Co-design encourages a wide range of people to contribute to the formulation of a problem as well as its solution. This involves including end users as experts regarding their own needs and experiences, and how these relate to the design of a solution (Ibid). When using a co-design approach, the researcher or designer’s role shifts from translating user needs to facilitating conversations with users that encourage people to engage with one another and test out new ideas (Ibid).

Until recently people living with dementia were largely excluded from the co-design process due to negative perceptions and low expectations about their abilities (Astell 2019). However, a growing body of examples of co-design with people living with dementia including Favilla and Pedell’s (2014) collaborative music, Lazar et al’s. (2016) Creating and Sharing art and Rodgers (2018) ‘dementia tartan’ are challenging this. DataDay came from several previous technology projects and interactive workshops with people living with dementia. Some of these early projects were also instrumental in developing what has become the TUNGSTEN approach. For example, the Computer Interactive Reminiscence and Conversation Aid (CIRCA: Alm et al. 2004) project identified the need for creative ways to elicit the views of people living with dementia and keep them at the forefront of innovation (Astell et al. 2009). Using an iterative development and test design process over 12 months, a multidisciplinary team co-designed CIRCA with people living with dementia and

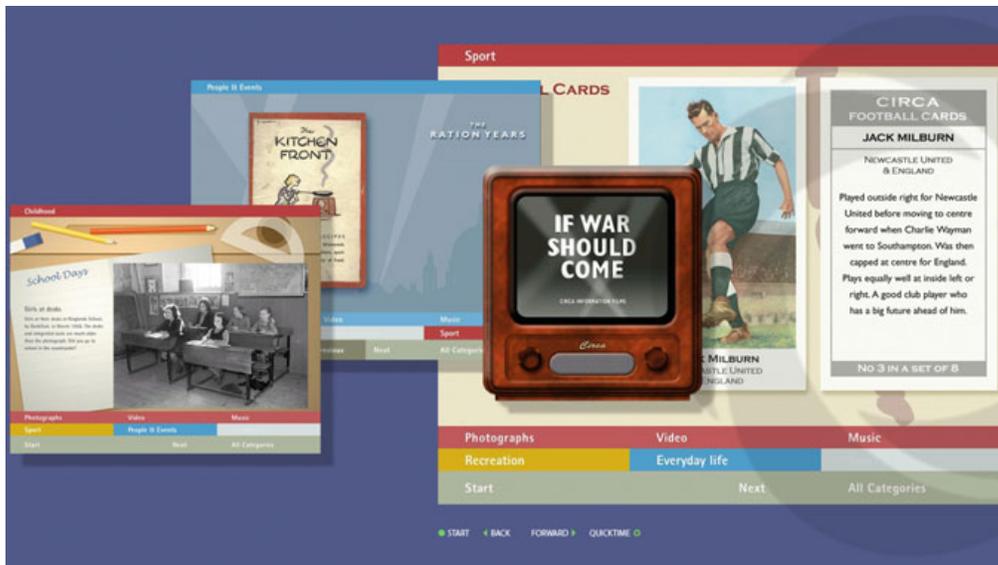


Fig. 11.1 Iteratively developing CIRCA interface

caregivers to produce an intuitive interface that people with dementia can use to select conversation topics (Gowans et al. 2007; Fig. 1.)

The success of the co-design approach can be seen in the benefits of CIRCA, which acts as a ‘cognitive prosthetic device’ for people living with dementia by mitigating their working memory difficulties in conversation, rendering them equal partners in communication (Astell et al. 2008). Using CIRCA positively changes professional caregivers’ perceptions of the people they care for (Astell et al. 2009b), and impacts their caregiving relationships (Astell et al. 2010). CIRCA has been further developed to accommodate diversity (Purves et al. 2014), and an eight-week group intervention using CIRCA in long-term care significantly improved cognition and quality of life of people living with dementia (Astell et al. 2018b).

Building on this co-design success, the same team who developed CIRCA went on to partner with people living with dementia to develop interactive digital games (Living in the Moment: LIM). This partnership saw iterative development and testing of 30 novel activities over three years (Astell et al. 2014a). Video recording was used to capture interactions with physical artefacts and touchscreens, from which LIM identified the types of prompts people with dementia need to play digital games independently. For example, the LIM studies highlighted the importance of immediate feedback when a person with dementia touches the screen (Astell et al. 2014b). The LIM findings led to the AcToDementia project (www.actodementia.com) and consolidation of accessibility settings in digital applications specifically for dementia (Jodrell and Astell 2019).

A further co-design project with community-living older adults developed the Novel Assessment of Nutrition and Ageing (NANA: Astell et al. 2014b) toolkit to support self-management of their health and well-being. Nutrition is particularly important in later life but avoiding late-life malnutrition is dependent on a number of

factors including physical, mental and cognitive health (Astell et al. 2018a). NANA was co-designed with older adults as a self-report tool that they could use every day to keep track of what they eat and drink, as well as their mood, cognition and physical activity.

As with CIRCA and LIM, each component of the NANA toolkit was iteratively developed with older adults as experts (Astell et al. 2018c). Over the course of 42 sub-projects, more than 530 older adults (aged between 65–91 years of age), 53 nutritionists, 15 health professionals and 90 working age adults co-designed all aspects of the toolkit, such as developing the food tree for meal selections and selecting camera function, which is required when taking photographs of meals. This iterative approach to co-design confirmed the essential need to make all design decisions, from large (e.g. concept, content) to small (e.g. fonts, colours, layouts), in partnership with the users (Astell et al. 2018).

Co-designing over four years with hundreds of older adults also confirmed their willingness to use new technologies in their homes, as well as their comfort with recording and completing nutrition, mood, physical activity and cognitive measures on a daily basis (Astell et al. In Press). The four NANA modules were validated against currently available gold-standard measures for nutrition (Timon et al. 2015), cognition (Brown et al. 2016), mood (Brown et al. 2018) and physical activity (Astell et al. 2014b) and have been shown to be predictive of future depression (Andrews et al. 2017). These findings demonstrate the accessibility and acceptability of NANA as an everyday technology for older adults, as well as the feasibility of collecting reliable data from older adults within their own homes (Astell et al. 2018a).

11.3 TUNSGTEN Tools

The experiences of co-designing CIRCA, LIM and NANA were gathered together in TUNGSTEN to provide a framework and practical tools for technology innovators to work with older adults as experts (<http://tungsten-training.com>). The TUNGSTEN Tools were developed as a resource for the AGE-WELL network to foster involvement of older adults at all stages of the technology development process. The aim was to encourage all technology innovators to partner with older adults right from the start of their projects by providing a range of easily adoptable techniques supported by use cases.

To get people started with this approach, we provide step by step guidance for three TUNGSTEN activities: (i) Technology Interaction, (ii) Show and Tell and (iii) Scavenger Hunt (Astell et al. 2018b). Each of these activities has been developed to uncover different aspects of user needs in relation to technology. Each activity can be offered as a standalone session or they can be combined into a longer workshop.



Fig. 11.2 Technology Interaction session

11.3.1 Technology Interaction

Technology Interaction involves providing participants with a ‘mystery box’ filled with an array of off-the-shelf devices in their original packaging (with batteries or access to power outlets; Fig. 1). Working in pairs, participants have ten minutes to get their chosen device(s) assembled and working. Each pair then provides feedback on their progress in the ten minutes, such as the positives and negatives of their chosen device. Technology Interaction is usually run as an ice breaker activity to empower all attendees to feel comfortable speaking about technology within a group setting. It also provides insights into what features influence people’s immediate impressions of new technologies out of the box, and whether they will persevere with trying to get them working or quickly abandon them.

11.3.2 Show and Tell

Show and Tell involves attendees demonstrating one device of their own that they love and one they have abandoned, plus their reasons for making these decisions. ‘Devices’ can include hardware, software or other artifacts that people use in their daily lives (e.g. wall calendars). The information generated through Show and Tell provides insights into what factors influence people’s adoption decisions, particularly in regard to self-purchases versus gifts or prescribed items.



Fig. 11.3 Individuals with dementia testing the NANA application

11.3.3 Scavenger Hunt

Scavenger Hunt requires workshop attendees to visit stations set up around the room, each showcasing an emerging or prototype technological innovation. Examples of emerging technologies at recent TUNGSTEN workshops include assistive robots, virtual reality cognitive exercises and smart home systems. Attendees are asked to engage with each emerging solution and provide feedback using device-specific evaluation forms, which contain questions about the usability and potential applications of the innovation. Scavenger Hunt provides attendees with opportunities to interact both with innovations at an early stage and with their inventors for mutually beneficial exchange of ideas.

TUNGSTEN is essentially a mindset for partnering with individuals who come from outside of research and development, the so-called ‘people untrained in design’ (Tseklevs et al. 2018) to provide their expertise on what is important to them. The TUNGSTEN approach evolved over a number of years as an alternative to focus groups. Using interactive methods that engage all participants in the sessions as equal contributors is both more successful at fostering co-design and also more rewarding for all parties involved (Astell et al. 2018a).

11.4 DataDay—A Self-management Application for People Living with Dementia

An example of the TUNGSTEN methods in action can be seen in the co-design of DataDay. DataDay is a self-management app created by combining the NANA

modules with ReMind, a prototype scheduling and reminding app (Citrus Suite 2019). Given the success of using NANA on a large (tabletop) touchscreen monitor (Fig. 3), and the increasing popularity of portable mobile devices among older adults (Pew Research Center 2017), it was always intended that DataDay would be developed as a mobile application. This was informed by three earlier sessions with people living with dementia who tried out the original NANA application and provided feedback on what they would like to see in a revised version (unpublished data). This led to the conceptualisation of DataDay as a self-management application to support individuals with dementia from the point of diagnosis.

The DataDay co-design process with people living with dementia and family members caring for a person with dementia was facilitated through a series of workshops. That is, the TUNGSTEN framework and tools informed the development of each session to empower people living with dementia, family members and health-care staff to co-design the app and portal, although it was not limited to the three TUNGSTEN tools listed above. Each attendee gave consent to be video recorded and their images to be used. Here we describe the app development steps of DataDay to illuminate the application of TUNGSTEN in practice.

Workshop 1: Technology Adoption

The first two interactive workshops were held in the community with people living with dementia, their family members, and health and social care providers to inform the initial design of the app's interface. The first technology adoption workshop (January 2018) focused specifically on participants' perceptions of different sized 'smart' devices, including tablets and smartphones. In addition to Show and Tell, Technology Interaction and Scavenger Hunt, participants were invited to identify what they did or did not like about each device, including tablets, e-readers and smartphones of different makes, models, shapes, screen sizes, interfaces and button layouts. Technology facilitators were identified: "*We liked the fact that it was easy to turn on and that it's small and really portable.*" And also technology obstacles: "*... not intuitive to use. There's too many buttons—the average person with memory challenges would have difficulty to remember the steps required to run it.*"

Workshop attendees discussed the types of devices they currently used, as well as the ways in which they used these specific devices (e.g. communication, reminders, navigation, etc.). Several participants owned and used a smart device, while those who did not were familiar with and intrigued by the concept of adopting these devices. Several stated that they were interested in purchasing a smart device but did not know where to purchase one or which variety to buy, highlighting the need for guidance and support both before and after acquisition. This workshop identified key features within existing smart devices that are of importance to older adults, such as the size of the screen and the number and location of buttons. These initial discussions also provided important understanding of when and how people living with dementia are currently engaging with smart devices and why they use them. The workshop also confirmed the need to leverage the functionality and potential benefit of mainstream devices, given they are desirable, 'sexy' and increasingly accessible, without any of the stigma often associated with 'devices for old people' (Astell



Fig. 11.4 Leisure apps

et al. 2019). In response to these discussions, it was decided that DataDay would be developed primarily as a tablet-based application, although smartphone use would also be possible.

Workshop 2: Technology Use

The second technology workshop (February 2018) with new participants, examined their current app use, focusing on health, wellbeing and self-management, in addition to what they liked and disliked about current apps. The three TUNGSTEN activities were again used to elicit people's experience and preferences for apps they currently used and their reactions to unfamiliar ones. Many participants reported using calendar apps to keep track of appointments and social events. Similarly, participants also reported using apps that supported communication with others, such as friends, family members and health and social care providers. Thirdly, apps that supported participation in leisure activities (e.g. playing games; Fig. 4) were also used by many of our workshop attendees as engaging pastimes. These discussions allowed us to gain an understanding of whether and how older adults, including people living with dementia, currently engage with apps. For example: *"The calendar for instance...I need my calendar to keep track of what's going on. A reminder list I use extensively on here..."*

A second focus of this workshop was to determine important features within existing apps, particularly ones that drive adoption or abandonment. Unsurprisingly, workshop attendees favoured apps they felt were beneficial (e.g. increasing independence, convenience) and easy to use. This echoes the long-established Technology Adoption Model (TAM: Davis 1989), which identified perceived usefulness and ease of use as significant predictors of technology adoption. The TAM was further developed into the Senior Technology Acceptance Model (STAM: Chen and Chan 2014) to capture additional predictors of technology adoption specifically relevant to older adults, such as age-related cognitive and physical changes and device self-efficacy. Additionally, maintaining or portraying a desired identity also plays a critical



Fig. 11.5 Interacting with DataDay prototype

role in older adult's technology adoption decisions (Astell et al. 2019). This highlights the multidimensional and complex decision-making process that older users of technology undertake when choosing whether to adopt or reject technological devices.

For example, when looking at features within currently available apps and devices that influenced attendees to adopt or start using them, participants preferred apps with an easy setup process, one-time (or no) login, easy navigation, minimal text, limited methods of interaction (e.g. fewer types of touch—tap, swipe, drag, flick—required), adjustable accessibility (e.g. font size, background colours, etc.), limited icons and a clear objective with few steps required to meet the objective. In contrast, features that influenced users to abandon or stop using current apps included complex passwords, navigation difficulties, privacy concerns, complex mechanisms of interaction (i.e. not intuitive), a steep learning curve, cumbersome usage (e.g. too many steps involved in completing a task), lack of age-appropriateness, intrusive and annoying pop-up advertisements, lack of accessibility (e.g. no ability to increase font size or volume), and most importantly, lack of a clear purpose or implications for usefulness.

Workshop 3: Co-designing DataDay Interfaces

DataDay was conceptualised to empower people to self-manage their life with dementia by providing tools for them to keep track of how they are doing, support everyday activities and also detect signs of change. Self-management is an active process, which can be accomplished by equipping individuals with the knowledge, confidence and skills to manage their condition (Bodenheimer et al. 2002). Two further co-design sessions were held with people with dementia and family members (e.g. spouse, parent) of people with dementia to examine the usability, accessibility and functionality of the newly designed DataDay app. Additional co-design sessions

of the app and portal were held with members of the local memory services, but these are not described here.

The third co-design session (March 2018) was held with a new group of people living with dementia plus people providing care for a family member with dementia at home. The session started with each participant independently exploring the DataDay prototype. Participants were given a brief overview of the DataDay prototype (Fig. 5) by a member of the design team, and invited to explore the app independently. We wanted to understand how they ‘organically’ interacted with both the app and the interface so no specific instructions regarding where to go or what activities to complete were provided. The goal was to see what features within the app were capturing participants’ attention, as well as to identify areas where participants were experiencing navigation or interaction difficulties (e.g. where people became stuck or were unsure what to do).

Participants were video recorded over their shoulder to capture the screen and the mechanisms (e.g. touch—tapping, swiping, hesitation, etc.; Astell et al. 2016) with which they interacted with the app. Additionally, video-recorded data can be reviewed thoroughly and repeatedly to pinpoint design flaws (e.g. which button causes an issue), rather than going from memory or relying on field notes. Immediately following participants’ individual interactions with the app, each participant was asked to complete the System Usability Scale (SUS; Brooke 1986) in order to measure their usability perceptions of the DataDay app.

Once all of the participants had interacted with the app independently and completed the SUS, they were invited to share their individual experience with the other attendees, to determine overarching ‘themes’ regarding what they liked and/or did not like about the app, the design of the app (colours, fonts, layouts, etc.), potential usefulness, and whether or not they would use the app in their everyday lives (i.e. what works, and what needs improvement). Participants were asked for feedback on the overall content within each of the four modules by displaying screenshots of each module on a large screen. Additionally, several tablets with the DataDay prototype were placed on the table for participants to pick up and use at any time to facilitate discussion and prompt recollection of their user experience.

After reviewing each module in turn, the discussion was broadened to capture additional feedback. This included the perceived relevance of the DataDay app for their everyday lives, whether they would use an app like this, or how they thought an app like this might be helpful to themselves or others. They were also asked whether there were other elements they would like to see in DataDay. In response to this, the attendees expressed a strong desire for receiving regular feedback regarding the information they entered in the app, such as their scores on the cognition games, to see how they are doing.

Workshop 4. Finalising the Interface

The fourth and final co-design session (July 2018) focused on specific concepts including granular usability, the number and complexity of steps involved in each data entry activity (e.g. completing the cognition games, entering a meal, etc.), the onboarding process (e.g. setting up an account), and the way in which the requested

user feedback was provided through the app (e.g. statistical and graphical feedback). Some of the participants had attended the first co-design session and provided feedback on the initial app prototype, while others were new to DataDay. Blending new with previous participants was helpful for gaining additional insights regarding the app as a whole, as well as assessing how successfully the participant's feedback had been incorporated into the revised design of DataDay.

As in Workshops 1 and 2, the co-design participants completed the Technology Interaction step first to stimulate group discussions regarding the reasons why they do or do not adopt specific technologies, services or products. Also similar to the Workshop 3, attendees were excused one by one during the group activity and invited to interact independently with the revised DataDay app in a separate area of the room. This time around we asked our co-design partners to complete a list of standardised tasks (e.g. complete the cognition games, enter a meal) found within the DataDay app, rather than exploring the app organically. The goal of this structured interaction was to evaluate how different individuals interacted with the same components of the app (e.g. how many steps it took on average to complete a task; Fig. 5). As before these interactions were video recorded over their shoulder to capture accessibility and usability issues.

In the subsequent group discussion many attendees reported that they found all modules easy to use except for the nutrition module, given that it contained more steps to complete (i.e. enter a meal) than the other three modules. After reviewing each of the screens and steps within the DataDay app, the discussion was broadened for further feedback unrelated to the specific tasks. For example, attendees were asked about the aesthetics of the app (e.g. colours, fonts, layouts, etc.), as well as the way feedback was provided (e.g. bar graphs), the onboarding process (e.g. signing up and creating an account), and whether there were other elements missing from the revised design. The discussion, feedback and videos were used to further iteratively revise DataDay into a version deemed suitable for pilot testing with people living with dementia in the community.

Feasibility Testing DataDay

DataDay is similar to the NANA toolkit in featuring four core modules—cognition, nutrition, activity, and mood—which users complete each day. Information can be easily and instantly logged when users play cognition games, enter meals, and answer questions about their mood and physical activity. The aim is to empower people to stay informed about their well-being by providing scores and feedback about their performance in each of the modules, as well as keeping reminders about daily activities. DataDay can be used independently or connected to health and social care providers through a corresponding memory services portal co-designed with members of local memory clinic teams.

DataDay is currently being tested 'in the wild' by individuals living with dementia. The purpose is to test the feasibility of people living with dementia adopting DataDay and incorporating it into their everyday lives to support self-management. The hope is for DataDay to be offered to individuals receiving a diagnosis of dementia from a

memory clinic, in order to provide them with additional support between follow-up appointments, and the ability to self-manage their condition.

11.5 Conclusions: Co-designing Future Direction with People Living with Dementia

This chapter focused on the experience of co-designing DataDay, a self-management application, with people living with dementia and family caregivers. In considering what worked well, the interactive workshop format provided a supportive environment for everyone's voice to be heard. This is especially important for people living with dementia who have traditionally been excluded from the co-design process, with caregivers being used—mistakenly—as proxies (Astell 2006). In DataDay, people living with dementia were full participants at all stages of development and informed all interface and interaction decisions. This is an extremely important message firstly for innovators seeking to work in this space who may have little or no experience of people who have dementia. Secondly, this finding adds to the growing examples of co-design with people living with dementia on a wide range of topics (e.g. Favilla and Pedell 2014; Lazar et al 2016; Rodgers 2018). This evidence is crucial for challenging the negative perceptions and low expectations people living with dementia constantly face (Astell 2019) and ensure they are involved as full partners in all projects and decision making.

Whilst the TUNGSTEN tools were successful in fully engaging people living with dementia in the DataDay project, timing can be a challenge with interactive activities—once the sharing begins, everyone must be given time and space to have their say—which means building flexibility into the schedule. It is also extremely important that the individuals living with dementia set the pace of the sessions so that everything they want to cover is given adequate time and space. Successful participation may also require accommodation of additional needs, such as hearing or mobility challenges.

Organising successful co-design projects with people living with dementia is both rewarding and vitally important. A few simple steps can help to ensure maximum benefit to everyone. First is to consider the environment where the sessions will be held to ensure that seating and movement in the space are optimal. Second is to establish house rules for co-design sessions relating to respect, confidentiality and valuing everyone's contribution. Third is to clarify what you aim to achieve in each session. Fourth is to identify the activities that you will use during each session to achieve this and prepare any necessary materials. Estimate how much time each activity will take, bearing in mind the number of attendees, and also consider how demanding or tiring each activity can be. Try to balance high-demand activities with resting or more relaxing activities to allow people to recharge. Finally, don't forget to have fun.

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