SENDER: a smartphone app for carers and service providers of people with dementia

Irene Blackberry
La Trobe University
Wodonga VIC 3689
i.blackberry@latrobe.edu.au
Clare Wilding
La Trobe University
Wodonga VIC 3690
c.wilding@latrobe.edu.au
Jane Farmer
Swinburne University
Melbourne, Australia
jcfarmer@swin.edu.au
On behalf of SENDER team

ABSTRACT
One in three older Australians live in rural regions and have poorer health outcomes than their urban counterparts. Accessing appropriate dementia services can be challenging and frustrating for rural people with dementia, and their carers and providers, due to lack of knowledge about available local services, including eligibility and service location. We are piloting and evaluating the feasibility, acceptability and impact of a service navigation and networking app for rural people with dementia, their families, and service providers. This trial is currently limited to the regions in Victoria covered by Rural Northwest Health and Healthcote Health. As people tend to be particularly socially isolated and disadvantaged in rural areas, we hypothesised that the use of a tailored app will ease service navigation challenges and connect dementia service providers and users with each other. By co-designing and co-producing this app with dementia service users and providers we propose that it provides an innovative solution to bridging the significant gaps in current health services.

Author Keywords
Dementia, app, navigation, networking, health access

ACM Classification Keywords
HCI design and evaluation methods

INTRODUCTION
Dementia is a significant health concern in Australia with 298,000 Australians living with dementia in 2011 and up to 400,000 by 2020 (Australian Institute of Health and Welfare, 2012). People living in rural areas face significant problems in obtaining the services they need. Gorska et al. (2013) found that it can be challenging and frustrating for rural dementia service users, carers, and providers to locate appropriate and needed services as the health system is fragmented. In addition, rural older people are required to travel long distances to access services (Umstatt Meyer, Janke, & Beaujean, 2014).

In response to these needs, a group of health service providers and researchers have collaborated to develop a prototype smartphone app. The Service Navigation and Networking for Dementia in Rural Communities (SENDER) app aims to provide accurate and up-to-date information about relevant and local services for rural older people with dementia, including information relevant to travelling to the service. The SENDER app also facilitates sharing of feedback about services between service users and service providers. It is anticipated that this ability for users and providers to share their experiences may enable additional support for service users and may assist service providers to improve the visibility of and access to their services.

CHALLENGES ACCESSING INFORMATION AND SUPPORT IN RURAL COMMUNITIES
Rural older people are often faced with difficulties accessing good quality information about what is provided or whether the service might be appropriate. People with dementia and their carers experience difficulties in locating appropriate services, from the moment of diagnosis and as their condition progresses (Górsk et al., 2013). Similarly service providers are also challenged to provide services due to inconsistent funding rules between states and even within the same state or region (Downs, Clibbens, Rae, Cook, & Woods, 2002). These challenges are more pronounced in rural areas as local specialist services, knowledge amongst service providers of local services, continuous care and communication between health professionals and rural Australians are lacking (Innes, Morgan, & Kostineuk, 2011; Szymbczynska, Innes, Mason, & Stark, 2011). Mobility issues impair rural older people’s ability to travel long distances to access services (Szymbczynska et al., 2011; Umstatt Meyer et al., 2014). Uncertainty about what services to access may deter people from using services that could be beneficial.

Although information and communications technologies (ICTs) are increasingly being used in healthcare, their role in dementia is only just beginning to be considered. In Australia, the National Health Services Directory has a mapping tool to locate general practices, hospitals and emergency departments (National Health Services Directory, 2014). Outside health, navigation apps have become part of everyday life, for example TripAdvisor, Booking.com and UrbanSpoon. SENDER utilises the concepts of such apps, and applies them to the area of dementia care. For example, SENDER assists in...
identifying the locations of services and enables users to build information about service experiences, availability, and quality, and other information that users and providers define as useful.

To date, online information and resources have little capacity to create a virtual community network (Lauriks et al., 2007). SENDER aims to facilitate the development of a supportive network of carers and service providers who are assisting people with dementia. Through providing information about services and chat forums in which app users can freely discuss a range of issues they are most interested in, SENDER aims to assist, support, and build knowledge of, and between, service providers and carers. SENDER advances people’s objective (e.g. which service is available) and qualitative (e.g. reviews and reflections about services) knowledge; it is not a replacement for discussion with health and other support practitioners. However, it facilitates empowerment as it enables carers to learn from each other and from service providers.

DESIGNING, DEVELOPING, AND UTILISING TECHNOLOGY FOR DIGITAL INCLUSION

Evidence suggests rural people experience stigma when discussing dementia within their community, potentially cutting them off from social activities, usual community life, and even long-term living at home (Szymczynska et al., 2011). These factors can affect people’s capacity to seek services at a time when they are also very vulnerable and when they really need support. For example, carers have been shown to benefit from support to avoid anxiety and depression (Thompson et al., 2007). Rural service providers may also be challenged by a lack of knowledge and connection with and about different services. Health professionals are often invoked to be the gatekeepers to assisting those with dementia and their carers to find appropriate services, but they may lack knowledge and time to spend with individual patients (Szymczynska et al., 2011).

SENDER is being developed as an innovative ICT that can facilitate people living with dementia and their families to gain the information and support they need to live well in their communities. At this stage of the project, the app has the following features:

- **Service Identification:** A person can search for services in SENDER by proximity, service name, and service type. Service types include: health professionals, counselling, social support and activities, transport, home help, personal care, respite and accommodation, carer services, physical activity, and financial assistance. The services include community, peer support, and primary, secondary and tertiary care. Each service has a “page” that links to the service’s phone number, email, website, and address. This page has basic information about the service and from here a user can also write a review about the service and read reviews that other users have written.

- **Navigation:** Using global positional system (GPS) technology and links to Google Maps, the app produces a map that highlights the location of the service and provides navigation to the service by private vehicle, public transport, walking, or bicycle. The app produces a proposed route from a user’s current position and an estimate of the time needed to travel according to the chosen mode of transport.

- **Social networking:** People using SENDER can participate in sharing information, advice, and support with each other via chat forums and via the service review system. A chat forum can be created by any SENDER user about any topic that is of interest to the user. Any other user can join a forum and then “chat” with other users. User chat messages are identified by the “display name” that users create when they sign up to the app. Chat messages are also time-stamped. In another networking feature, users can write a review about a service. The review includes the opportunity to give the service a rating out of 5 stars and to add free text. Reviews are posted anonymously. These networking functions enable users to share information with others, to ask questions, and to receive support from other users.

STRATEGIES FOR FACILITATING UPTAKE AND EVALUATION OF DIGITAL INCLUSION AND PARTICIPATION

We designed a whole-of-community-based participatory action research methodology to engage dementia service users, carers, families, and a range of health and social service providers. As described by Baum, MacDougall and Smith (2006) this method uses reflective and iterative processes and facilitates participants to partner with researchers. In this instance participants and researchers are collaborating together to develop an app and reduce health inequity. The project covers the following stages:

**Stage 1: Co-designing SENDER prototype and mapping services**

During the initial development of SENDER, we gathered locational and objective information about a range of services and community networks through discussion with health providers, consumer representatives, and other key stakeholders in the region. As we pilot the app it will be co-designed with key stakeholders by incorporating their feedback into future iterations of the app.

During the project we will be collecting qualitative data to build additional useful information into the app. For example, app users may discuss the transport mode they used to reach the service, its ease of use, what the journey was like, whether there are important amenities nearby the service if people have to wait (for example, cafés, accessible toilets, quiet space). Feedback on experience of using a service and useful tips for future users will also be encouraged.

It is expected that the list of services described within the app will be expanded over the project duration, with input from participants. For example, users may suggest that services be added or advise of changes to service offerings. Services will be contacted to determine if they are satisfied with the information listed about their service or if they wish any alterations made to the information about them.
Stage 2: Pilot testing SENDER
Ethics approval for pilot testing was obtained from the Human Research Ethics Committee at La Trobe University. The SENDER research team consists of two participating health services, and multidisciplinary national and international researchers. The team meets monthly by video/teleconferencing.

We sought two key groups of participants to pilot test SENDER: carers of people who have a diagnosis of dementia, and service providers of services for older people and for people who have dementia. In addition, participants needed to live or work in the catchment areas of Rural Northwest Health (Warracknabeal) or Heathcote Health (Heathcote). We focused on recruiting carers and service providers of community-dwelling people with dementia, as SENDER is particularly designed to assist people with dementia who are living in the community, rather than in residential care. Participants also needed to have access to an Android smartphone or tablet and have internet access. (It is only currently available using the Android platform.)

Multiple recruitment approaches were used, including via health services, community networks, local media, and social media (Facebook). The research officer for the project determined eligibility, obtained consent, and collected baseline data. Currently, there are 15 participants: six carers and nine service providers across the two regions. Recruitment is still ongoing.

Stage 3: Evaluating SENDER
At the point of recruitment to the pilot, carers were interviewed and using a specifically-designed survey, the research officer asked them about basic demographic information, their knowledge of dementia services and support networks, their recent use of ICT, and their self-perceived feelings of connectivity to other carers of people with dementia and to service providers. The research officer also administered the Zarit Carer Burden Index (Zarit, Reever & Bach-Peterson, 1980) and the brief Older Persons Quality of Life Questionnaire (Bowler, Hankins, Windle, Bilotta & Grant, 2013). Service providers were asked to complete a specifically-designed survey similar to the carer’s survey, which asked about basic demographic information, their knowledge of dementia services and support networks, recent use of ICT, and self-perceived feelings of connectivity to carers of people with dementia and to other service providers. These same surveys will be re-administered to participants at the conclusion of the pilot.

As the pilot progresses, the research officer regularly follows up with participants by email and telephone. She collects feedback about the app and its functioning and provides technical support as required. Regular meetings are conducted between the research officer, the chief investigator and the technical team; these meetings address problem-solving in relation to arising technical issues and ideas for further development of the app. During the pilot, carer participants and the people they care for continue to receive usual care from their health care providers.

At the conclusion of the pilot, carers and service providers will be asked to participate in focus groups. During these focus groups further feedback will be collected from the SENDER users about their experiences of using the app. For example, participants will be asked about: frequency, time and ease of use of the app; input and output of information (what did people use and what did they contribute in feedback); social connectedness using the app; and general satisfaction with use and useability. We will also track and monitor the use of SENDER using Google Analytics.

LESSONS LEARNED ABOUT EMBEDDING DIGITAL LEARNING IN A REAL-WORLD CONTEXT
One of the key challenges that has been experienced already during the pilot is that the older people who are participating have frequently never used smartphone technology before and using an app is a new experience. Challenges for adopting new technology among older people are well documented. There is fear and reluctance to trial new ways of connecting and accessing information. We have found that principles of adult learning that incorporate timely assistance and support are crucial to enhance adoption of digital technology among older people. However, this is particularly challenging in rural regions as it is less available outside of metropolitan centres and regional cities.

In this study, we have experienced that mentoring, hands-on learning and feedback mechanisms can facilitate adoption of digital technology; and in the current project, the research officer is playing this role. In the long term, partnerships with family members, health service providers, and volunteers in community and social organisations are likely to be important to sustain and develop older people’s engagement with digital technology.

Enabling easy access to technology
Many older people often lack the financial resources and capacity to own technological equipment. In this project to facilitate access to Android devices, La Trobe University loaned a tablet to Rural Northwest Health and to Heathcote Health. These tablets are accessible for use within the health service by any member of staff, or the public, who request to use them. Carers were loaned Samsung Galaxy S4 handsets that were donated to the study by Telstra Australia, as part of their Digital Inclusion Program. Some of the project funding was used to purchase pre-paid SIM cards and to pay for monthly recharges for data downloads and phone usage. The ability to provide these materials to new smartphone users was essential.

When the SENDER pilot was launched, it received considerable interest from service providers, older people, the media, and the general public. There is clearly a need for people caring for someone with dementia to receive more help and assistance. We believe that projects like the SENDER pilot are vital for enabling older people to be included in technological advancements and for assisting older people to develop digital skills. The SENDER pilot
project is facilitating multiple outcomes for the older people who are participating:

- It is enabling them to learn about and practice their digital skills in a relevant, real-world context.
- Older people’s perspectives are informing the app design, development, and adaptations.
- Use of the app is assisting older persons to gain much-needed assistance and support in managing a serious chronic illness.

CONCLUSIONS
Large geographical areas and limited specialist services are extra challenges faced by rural Australians in a fragmented health system. We propose that our innovative app will help rural people with dementia and their families, and service providers, to locate needed services and to feel more connected to the community of dementia carers and service providers. Timely access to services may assist people with dementia to receive support and live independently longer in the community. Carers’ and health systems’ costs are likely to be reduced as people with dementia and their families will be able to undertake greater self-management and be more actively engaged and empowered in decision-making. Providers are also likely to develop more knowledge of each other and to better collaborate to provide patient-centred care.

ACKNOWLEDGMENTS
The SENDER project received a Research Focus Area Building Healthy Communities grant from La Trobe University Australia. Telstra Australia supported SENDER by donating 12 Samsung Galaxy S4 mobile handsets as part of their Digital Inclusion Program. The SENDER team include A/Prof Irene Blackberry, Prof Jane Farmer, Dr Clare Wilding, Catherine Morley, Dr Torab Torabi, Dr Dan Douglass, Dr Anne-Marie Mahoney, and Prof Debra Morgan. Mr Babak Danyal undertook his MSc research project by participating in the technical development of SENDER.

REFERENCES