Virtual dementia-friendly rural communities

Irene Blackberry and colleagues introduce the Verily Connect project, which is working to bring together family carers in rural communities across Australia – with the help of co-designed technology

Support for family carers is an area of dementia practice and research that is often overlooked. There are over 200,000 informal carers of people living with dementia in Australia (Dementia Australia). Carers play a critical role in sustaining quality of life of people living with dementia. This is particularly true in rural areas, where the availability of formal care may be minimal. Furthermore, people living in rural, regional, and remote areas of Australia may have trouble accessing services due to the need to travel long distances to be able to use the services (Umstattd Meyer *et al* 2014).

However, online technology provides opportunity for people to connect, interact and build meaningful relationships in the virtual environment and thus bridge geographical distance (Mason *et al* 2017). Analysis of data about internet usage and online access among Australians aged 65 years and over indicates that, although this group of people access the internet in lower numbers than their younger counterparts, an increasing percentage of older people are now getting online (researchacma 2016).

Introducing Verily Connect

Since 2015, our interdisciplinary team has worked closely with rural community members to undertake dementia research that supports family carers. We conducted four focus groups and a modified Delphi survey to identify and prioritise service and support needs of people living with dementia and their carers. Findings from this community consultation

(Bauer *et al* in press) identified the following themes:
- Difficulties with access to and information about services.
- Need for health professionals to have more training to help them better understand the experience of living with dementia and the importance of information sharing.
- Need for more support for carers and access to information about services.
- Need for local community members to better understand dementia and carers' experiences.

These findings were used to develop and pilot a prototype app (SENDER – Service Navigation and Networking for Dementia in Rural Communities) in 2016-2017 and a volunteer-led rural dementia project (HelpDem), which then led to the development of the Virtual Dementia Friendly Rural Communities (Verily Connect) project.

To the best of our knowledge, the Verily Connect project is a world-first trial to

determine the effectiveness of virtual dementia-friendly rural communities. The project uses a newly developed smartphone app, website and videoconferencing to connect carers of people living with dementia and engage whole rural communities, including people with dementia, to achieve the ultimate goal of improving life for people living with dementia locally and nationally.

A total of 12 rural communities across Victoria, South Australia and NSW are participating in the project, which runs from July 2017 to June 2019, with results to be presented by December 2019. La Trobe University in Victoria is leading the project, in partnership with Swinburne University, Flinders University, the University of Newcastle and the University of Saskatchewan, Canada.

We are using a co-design approach to create Verily Connect, drawing upon learnings from the community consultation, the pilot of the SENDER app, and the

HelpDem project. This approach continues as we engage iteratively with community members to develop implementation strategies and to provide us with feedback about Verily Connect technology solutions.

Verily Connect aims to create and trial innovative technology solutions to:
- Increase support for carers of people living with dementia and the rural communities in which people living with dementia age-in-place.
- Increase the capacity of the whole rural community to provide support for and care of local people living with dementia, and their friends and families.

There are three key features of Verily Connect (see Figure 1, next page):
- A purpose-built application (app) available as a website and for mobile devices that provides the opportunity for users to chat to other users and obtain targeted information about dementia, about keeping well, and about local services and supports.
- Peer support groups for carers are available via video-conference, thus enabling rural carers to bridge the geographical distances that divide them.
- In each community, there is a local technology support hub, which is staffed by trained volunteers who are available to provide face-to-face support to Verily Connect users.

Implementation

The Verily Connect Project is currently being implemented

What is a virtual dementia-friendly community?

Alzheimer's Disease International (ADI) defines a dementia-friendly community as "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential" (ADI no date p10).

Key principles of dementia-friendly communities include that people living with dementia need to be supported by people, communities, organisations and partnerships (ADI no date p10).

The various forms of dementia-friendly communities worldwide highlight that this concept is heterogeneous and tailored to each individual community (Williamson 2016). There are resources available for how to create a dementia-friendly community, for example by Dementia Australia (Alzheimer's Australia Vic 2016).

Although there is established understanding about dementia-friendly communities, the concept of a *virtual* dementia-friendly community is new.

In our view, a virtual dementia-friendly community adheres to the key principles of dementia-friendly communities, but it adds a virtual dimension. That is, not only is there face-to-face interaction with environments, people, communities, organisations and partnerships, there is also an interaction in the virtual space of the internet.

We propose that sharing information and facilitating communication online is another way in which the goals of "reducing stigma and increasing understanding of dementia and empowering people with dementia" (ADI no date p10) can be achieved.
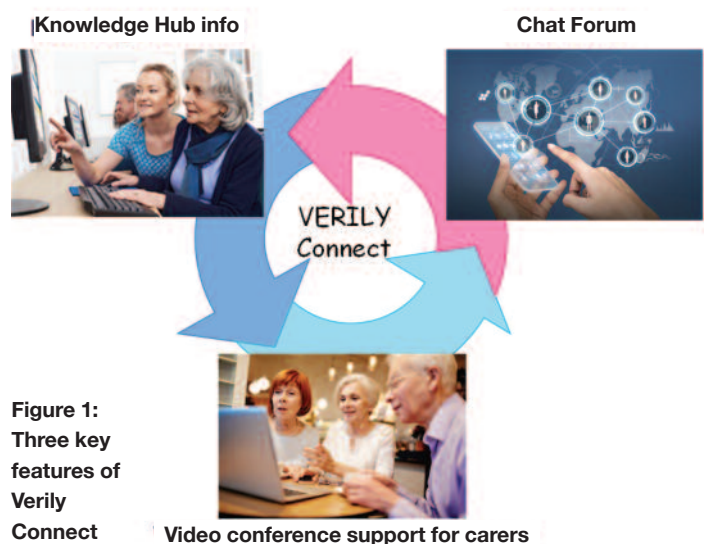
How will it help?

Social isolation in rural areas is a significant problem (ReachOut 2018). Through using technology, our project aims to reduce social isolation among carers of people living with dementia. Technology offers carers the opportunity to be connected to a wider network of carers and service providers. The use of technology may also alleviate stigma and privacy issues that can occur in small rural communities. The Verily Connect Project will examine how tailored use of technology may increase support among carers and lessen the more stressful impacts of caring.

How to get involved

Recruitment for the Verily Connect project is well underway in all our participating communities: Victoria (Koo Wee Rup, Mansfield, Warracknabeal, Horsham, Kyneton, Robinvale, Heathcote, Edenhope), NSW (Molong, Nyngan) and South Australia (Victor Harbor, Riverland).

We encourage carers, volunteers, service providers and all community members of our participating communities to be involved and help their community become more dementia friendly. Please visit www.verilyconnect.org.au or call (03) 5444 7676 for further information. We welcome all feedback to help us further support carers in rural communities. ■

---

across 12 rural communities in Victoria, NSW and South Australia. We will evaluate the project using a stepped wedge cluster randomised controlled trial. (In this type of trial, each of the 12 communities is classified as a 'cluster', and the time that each community starts using Verily Connect strategies is staggered. At each 'step', three communities have access to the online technologies. Each step is eight weeks' long. Effects of Verily Connect are compared for each community according to when they are waiting for Verily Connect to start in their community and when they are actively using the online technologies.) Our primary outcome is an increased level of support among rural carers as measured by the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart 1991).

At the end of the project, a toolkit will be developed to share learnings from the project and to assist in the development of a global network of virtual dementia-friendly communities.

A virtual network gap

A review of models of dementia-friendly communities was recently published (Blood *et al* & Innovations in Dementia 2017). However, current evidence for the effectiveness and cost effectiveness of dementia-friendly communities is lacking, as the evaluation primarily used qualitative methods (Lin 2017). In addition, the role of digital technology in supporting dementia-friendly communities is not well understood. Although digital technology may be used as part of the implementation of a dementia-friendly community, to date there have been no attempts to set up a virtual network of dementia-friendly communities.

Linking carers and services

Verily Connect is an adjunct to existing services; it does not replace current services. Through providing clear and accessible information about services, we anticipate that Verily Connect will assist members of the public to identify and more readily approach service providers. Over time, users of Verily Connect might also provide each other with user-friendly advice and tips about which services are most helpful in particular situations, for example, where it is best to go to receive emergency respite care.

Users of the Verily Connect app might also help service users identify a wider range of services that are available, but which may be unknown to all carers.

Likewise, our community consultation also revealed that many rural service providers do not have comprehensive knowledge of the services available for people living with dementia and for family carers (Bauer *et al* in press). It is widely acknowledged that rural services experience high staff turnover and have a high proportion of overseas-trained staff, both of which may limit understanding of local services and access to specialist services. The Verily Connect app enables rural service providers to promote their service to people living with dementia, family carers and other service providers.

Knowledge Hub info

Chat Forum

VERILY Connect

Figure 1: Three key features of Verily Connect

Video conference support for carers

■ Authors: Professor Irene Blackberry is the Principal Investigator of the Verily Connect project and Chair and Director of the John Richards Centre for Rural Ageing Research, La Trobe University; Dr Clare Wilding is a Research Fellow at the John Richards Centre; Professor David Perkins is Director of the Rural Health Research Centre for Rural and Remote Mental Health, University of Newcastle; Professor Jennene Greenhill is Director of Flinders University Rural Health SA, Flinders University; Professor Jane Farmer is Director of the Social Innovation Research Institute, Swinburne University of Technology; Dr Michael Bauer and Dr Margaret Winbolt are Senior Research Fellows at the Australian Centre for Evidence Based Aged Care, La Trobe University; Catherine Morley is CEO of Wimmera Health Care Group; Megan O'Connell is Associate Professor of Psychology, University of Saskatchewan, Canada; and Debra Morgan is Professor and College of Medicine Chair in Rural Health Delivery at the University of Saskatchewan.

References
Alzheimer's Australia Vic (now Dementia Australia) (2016) *Creating dementia-friendly communities: a toolkit for local government* Available at: https://bit.ly/2OrkfE3 (Accessed 20/09/2018).
Alzheimer's Disease International (no date) *Dementia friendly communities: key principles.* Available at: www.alz.co.uk/adi/pdf/dfc-principles.pdf (Accessed 20/09/2018).
Bauer M, Farmer J, Fetherstonhaugh D, Wilding C, Blackberry I (in press) Identifying support needs to improve rural dementia services for people with dementia and their carers: a consultation study in Victoria, Australia. *Australian Journal of Rural Health.*
Blood I & Associates and Innovations in Dementia (2017) *Evidence review of dementia friendly communities. European Union Joint Action on Dementia.* Available at: https://bit.ly/2PEpLI8 (Accessed 20/09/2018).
Dementia Australia (no date) *Support, information and services for carers, family and friends.* Available at: www.dementia.org.au/ (Accessed 20/09/2018).
Gorska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, Reid J (2013) Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *International Psychogeriatrics* 25(7) 1107-1114.
Lin S-Y (2017) 'Dementia-friendly communities' and being dementia friendly in healthcare settings. *Current Opinion In Psychiatry* 30(2) 145-150.
Mason C, Fleming A, Paxton G, Singh J (2017) *Lifelong participation through digital technology.* CSIRO EP165189, Brisbane.
ReachOut (2018) *How to deal with isolation if you live in a rural or remote area.* Available at: https://bit.ly/2quUDg5 (Accessed 24/09/2018).
researchacma (Australian Communications and Media Authority) (4 August 2016) *Digital lives of older Australians.* Available at: https://bit.ly/2buCqrj (Accessed 20/09/2018).
Sherbourne CD, Stewart AL (1991) The MOS Social Support Survey. *Social Science & Medicine* 32(6) 705-714.
Umstattd Meyer MR, Janke MC, Beaujean AA (2014) Predictors of older adults' personal and community mobility: using a comprehensive theoretical mobility framework. *The Gerontologist* 54(3) 398-408.
Williamson T (2016) *Mapping dementia-friendly communities across Europe: a study commissioned by the European Foundations' Initiative on Dementia (EFID)* European Foundations' Initiative on Dementia. Available at: https://bit.ly/2RAOeLS (Accessed 20/09/2018).