



**verily**connect An Australian Government Initiative

# Virtual Dementia Friendly Rural Communities (Verily) Project Final Report



## Authors

Blackberry, I., Wilding, C., Morgan, D., Winbolt, M., Greenhill, J., Perkins, D., O'Connell, M., Bauer, M., Morley, C., Farmer, J., Royals, K., Rasekaba, T., Hamiduzzaman, M., Gottschall, K., Robinson, A., Zaplin, E., Pitman, J., & Davis, H.

## Year

May 2020

## Recommended citation

Blackberry, I., Wilding, C., Morgan, D., Winbolt, M., Greenhill, J., Perkins, D., O'Connell, M., Bauer, M., Morley, C., Farmer, J., Royals, K., Rasekaba, T., Hamiduzzaman, M., Gottschall, K., Robinson, A., Zaplin, E., Pitman, J., & Davis, H. 2020. Virtual Dementia Friendly Rural Communities (Verily) Project Final Report. John Richards Centre for Rural Ageing Research, La Trobe University, Wodonga.

## Contact Details

Professor Irene Blackberry  
Chair and Director, John Richards Centre for Rural Ageing Research  
La Trobe Rural Health School La Trobe University  
PO Box 821 Wodonga VIC 3689 Australia

**T:** 02 6024 9613

**F:** 02 6024 9737

**W:** [latrobe.edu.au/jrc](http://latrobe.edu.au/jrc)

**E:** [verilyconnect@latrobe.edu.au](mailto:verilyconnect@latrobe.edu.au)

DOI: 10.26181/5ed06567d87b2

ISBN: 978-0-6488338-1-9

©2020 John Richards Centre for Rural Ageing Research, La Trobe University

# Acknowledgements

## **Funding**

Funded by an Australian Government Dementia and Aged Care Services Fund: Research and Innovation Grant

## **Project investigators**

Professor Irene Blackberry, La Trobe University

Dr Clare Wilding, La Trobe University

Professor Jennene Greenhill, Flinders University

Professor David Perkins, University of Newcastle

Professor Debra Morgan, University of Saskatchewan

Associate Professor Megan O'Connell, University of Saskatchewan

Dr Margaret Winbolt, La Trobe University

Dr Michael Bauer, La Trobe University

Ms Catherine Morley, Wimmera Health Care Group

Professor Jane Farmer, Swinburne University

## **Project team**

Ms Kayla Royals, La Trobe University

Dr Tshepo Rasekaba, La Trobe University

Dr Ella Zaplin, La Trobe University

Dr Ainsley Robinson, La Trobe University

Dr Hilary Davis, Swinburne University

Dr Mohammad Hamiduzzaman, Flinders University

Dr Kristina Gottschall, University of Newcastle

## **Consultants**

Ms Jennifer Pitman, La Trobe University, Economist

Professor Alan Shiell, La Trobe University, Health economist

Dr Xia Li, La Trobe University, Statistics Consultancy Research Platform

## **Project health service partners**

### **Victoria:**

Cobaw Community Health

Edenhope and District Memorial Hospital

Heathcote Health

Kooweerup Regional Health Service

Mansfield District Hospital

Robinvale District Health Services

Rural Northwest Health

Wimmera Health Care Group

### **South Australia:**

Riverland General Hospital

South Coast District Hospital

### **New South Wales:**

Molong HealthOne General Practice

Nyngan Health Service

## **Project advisory committee**

### **Carers:**

Ann, Wodonga, VIC

Annette, Wedderburn, VIC

Di, Beechworth, VIC

Marg, Bendigo, VIC

Peter, Nyngan, NSW

### **Dementia Australia:**

Simone Hoffman, Bendigo, VIC

### **Carers Australia:**

Alison Wright, Melbourne, VIC

Annie Hayward, Melbourne, VIC

Sue Tucker, Victor Harbor, SA

## **NSW Agency for Clinical Innovation:**

Jenny Preece, Chatswood, NSW

## **Country SA PHN:**

Noelene Cooper, Mile End, SA

## **Project participants**

We gratefully acknowledge and thank all the carers, volunteers, and health and community services staff who participated in the Verily Connect Project. Without their generous participation the project would not have been possible.

## **Production of this report**

We acknowledge Plural Agency for graphic design of this Report, and for creating the illustrations in the Verily Connect app and the behind-the-scenes technical production of the Verily Connect app.

We acknowledge Dutch Media for production of the photos in this Report.

## **Volunteer training resources**

We acknowledge and thank the Centre for Participation who allowed us to modify their volunteer training materials for adaptation to our project.

## **Trial registration and ethical approval**

Australian and New Zealand Clinical Trials Registry Number: ACTRN12618001213235.

Melbourne Health Human Research Ethics Approval Number: HREC 17MH4045

# Contents

## List of abbreviations

## Executive Summary

## Background

## Study aims and objectives

Primary Objective

Secondary Objectives

Hypothesis

## Methods

Research design and implementation strategy

Study sites

Participants

Recruitment

*Open community forums*

*Advertising materials*

*Meetings with community groups*

*Social media, media releases, and paid advertising*

*Online launch*

*Contact Us via [verilyconnect.org.au](http://verilyconnect.org.au)*

Data collection

*Survey data – carers*

*Process and participant feedback data*

*Economic data*

Data analysis methods

*Survey data analysis*

*Process and participant feedback analysis*

*Cost analysis*

## Results

### Quantitative data results

*Carer demographic and background information*

*Demographics and characteristics*

*Social connections*

*Use of services by carers and/or those they cared for*

*Dementia friendly community*

*Social support and carer burden*

### Qualitative data results

*“I only have 5 minutes, life is hectic”*

*“I’m not so good with technology”*

*“I think it has huge potential”*

*Verily increased support, increased flexibility*

*“I’ve learned a lot over the time”*

### Cost analysis results

*Resources required to deliver Verily*

*Cost Estimates and Analysis*

## Learnings from the project

## Next steps

## References

## Appendices

Appendix 1. Initial demographic and background information

Appendix 2. Ongoing demographic and background information

Appendix 3. Perception of social connection

Appendix 4. ZBI survey items

Appendix 5. Publications and conference presentations arising from this project

Appendix 6. Project partners

## List of Abbreviations

<b>AIHW</b>	Australian Institute of Health and Welfare
<b>CFIR</b>	Consolidated Framework for Implementation Research
<b>DOI</b>	Digital Object Identifier
<b>FRRR</b>	Foundation for Rural and Regional Renewal
<b>GP</b>	General Practitioner
<b>IAGG</b>	International Association of Gerontology and Geriatrics
<b>IQR</b>	Interquartile Range
<b>ISBN</b>	International Standard Book Number
<b>MOS-SSS</b>	Medical Outcomes Survey, Social Support Survey
<b>NHMRC</b>	National Health and Medical Research Council
<b>NNIDR</b>	NHMRC National Institute for Dementia Research
<b>NSW</b>	New South Wales
<b>PHN</b>	Primary Healthcare Network
<b>RACV</b>	Royal Automobile Club of Victoria
<b>RSL</b>	Returned and Services League
<b>SD</b>	Standard Deviation
<b>SENDER</b>	Service Navigation and Networking for Dementia in Rural Communities project
<b>TAFE</b>	Technical and Further Education
<b>VIC</b>	Victoria
<b>ZBI</b>	Zarit Burden Interview



# Executive Summary

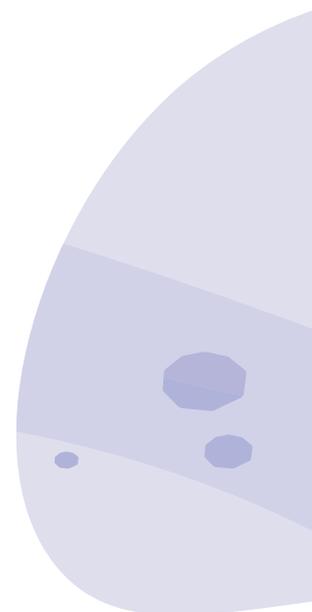
*The Virtual Dementia Friendly Rural Communities (Verily) project trialled a new model of support for carers of people living with dementia and residing in a rural area.*

The Verily model was about using online technologies to build a virtual dementia friendly community and to strengthen communities to become dementia friendly. The model was implemented and evaluated using a randomised stepped-wedge cluster trial design across 12 rural communities in Victoria, South Australia and New South Wales. An aim of the Verily project was to make information and peer support more accessible to rural carers and communities.

A Verily Connect integrated website and mobile application (Verily Connect app) was developed and trialled during the project. Additionally, peer support for carers was facilitated by videoconferencing (using Zoom software). In each of the 12 participating communities, a Technology Learning Hub was established. The hub provided carers access to technology and dementia resources. Also, the hub was established, to provide a venue for volunteers' activities and access to technology and dementia resources. Participants who were unsure or unconfident about using online technology could receive in person assistance through the hub.

Evaluation included a series of surveys, interviews, and focus groups, which were thematically analysed. Additionally, provider interviews were evaluated following the Consolidated Framework for Implementation Research. There were 113 participants involved in the trial across the 12 communities: 37 carers, 39 volunteers, and 37 service providers. Data collected for the evaluation of the trial included 72 surveys, 82 interviews, 283 memos written by researchers, Google analytics for the period August 2018–September 2019, and economic data from the 12 communities.

Findings showed that carers have a strong need for social support and that they experience a high level of burden in caring for a person living with dementia. Carers are very busy, often with multiple caring roles in addition to other life roles such as worker, friend, and community member. Caring was sometimes experienced as being exhausting, overwhelming, and isolating.



Social support was found to increase significantly after Verily was implemented. Furthermore, feedback from carers was that the Verily Connect app and peer support videoconference meetings provided carers with more social and emotional support and the model provided more flexible access to this support. In addition, the model gave carers ready access to a “just right” amount of useful and locally relevant information. Carers appreciated that through the social connection aspects of the Verily model they could give and receive help from other carers. Carers valued being able to connect with other carers who were in similar situations to their own, which was a benefit that was not previously available to some participants.

We recommend that the Verily model could be scaled up to help meet carers’ needs Australia-wide and even globally. Wider implementation of the model would likely result in improved awareness and understanding of dementia and give carers access to vital information and support via a virtual dementia friendly community. However, to achieve this goal, collaboration is needed from an organisation that can implement the Verily model at scale.





**About Verily Connect**

Verily Connect is a project to trial some innovative solutions for providing support for rural carers of people living with dementia and/or other cognitive conditions. We use innovative technology to connect carers to each other and to create virtual support groups. Verily Connect consists of three main components:

1. A digital technology Learning Center powered by online resources who can assist carers and caregiver's needs to help to use Verily Connect technology
2. The Verily Connect website and mobile application that provides information for carers and help them connect with each other
3. Peer support groups for carers that meet via video-conference

A total of 12 rural communities across Victoria, South Australia, and New South Wales are participating in the project. The project runs from July 2017 - December 2018. Local University researchers in collaboration with Cambridge University, Queen's University, University of Waterloo, and University of Saskatchewan, Canada. The project is funded by the Australian Government Department of Health, under the Dementia and Aged Care Services (DACS) funding.

The ethical aspects of this study have been approved by the Human Research Ethics Committee at Melbourne Health. This project will be carried out in conformity with the Australian Government's Ethical Guidelines for Human Research (2007). This statement has been developed to protect the privacy of people who agree to participate in human research studies.

**Contact Us**

08 8344 7070  
verilyconnect@melb.edu.au

# Background

*Dementia places a substantial demand on informal carers, with an estimated 200,000 dementia carers living in the community in 2011 (AIHW, 2012).*

The number of informal caregivers for people with dementia is estimated to be high, and in addition the burden placed upon these caregivers is substantial. Caring for someone with dementia has been shown to be associated with high levels of burden and increased risk of social isolation (Papastavrou, Andreou, Middleton, Tsangari, & Papacostas, 2015; Schulz & Martire, 2004). People caring for someone with dementia are more likely to give up their holidays and hobbies, as well as have less time for their family and friends (Elvish, Cawley, & Keedy, 2014). Carers in general are more likely to have smaller social networks than non-carers, with social support often decreasing over time (Schofield, 1998).



In rural and regional areas, the burden upon caregivers of people with dementia is complicated by challenges specific to living in rural areas. For example, gaining access to services can be difficult for rural older people as they may have to travel long distances to use services (Umstattd Meyer, Janke, & Beaujean, 2014). In addition, rural dementia service users, carers and providers have expressed difficulty and frustration in locating appropriate services within a fragmented health system (Gorska et al., 2013). In Australia, experiencing dementia may attract social stigma (Phillipson et al., 2015) and in small rural communities, in which local residents are often well-known to each other, carers of people with dementia may avoid reaching out for help in an effort to maintain privacy.

The development of information and communication technologies such as apps, video-conferencing, and social media have created new opportunities for fresh solutions to the pressing problems faced by rural communities. For example, use of online technologies can increase support and connection by shrinking the geographical distances that are currently barriers to easy access to services and supports. In the Verily project, these individual technologies were integrated into a whole-of-community approach that connected carers of people living with dementia to service providers and to other community members and groups.

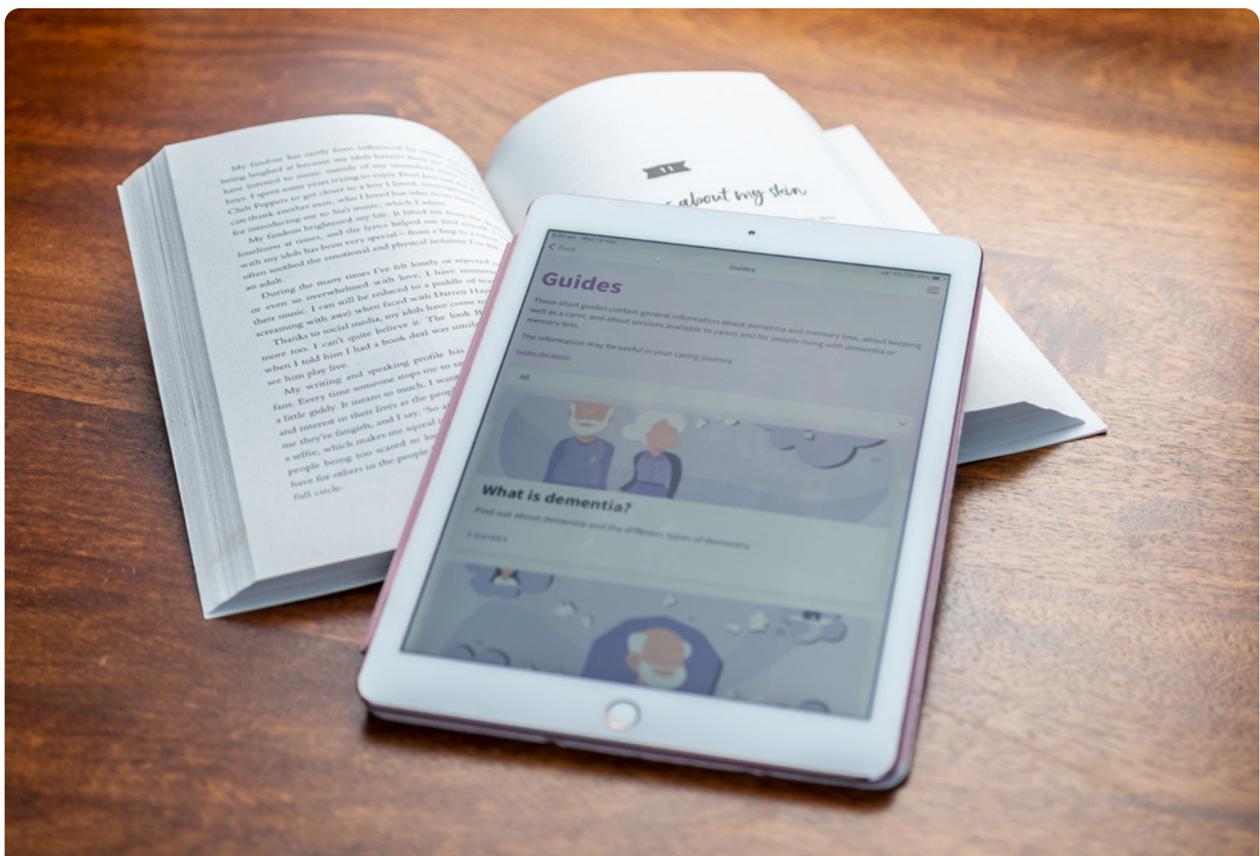
# Study aims and objectives

*The aim of the Verily project was to develop, trial, and evaluate an innovative model for increasing support for carers of people living with dementia in rural communities.*

Three key strategies comprised the Verily model:

1. Development of an integrated website and mobile app
2. Video-conferenced peer support groups for carers
3. Development of Technology Learning Hubs.

Through the study we aimed to increase support for carers of people living with dementia in rural communities and to increase rural communities' understanding of dementia and their ability to support carers. Additional objectives were to communicate the findings of the evaluation to inform others about learnings obtained from the project.



## Primary Objective

To determine if support perceived by carers and measured using the Medical Outcomes Study Social Support Survey (MOS-SSS) was increased after the implementation of the Verily model in rural communities.

## Secondary Objectives

To determine if the sense of carer burden perceived by carers and measured using the Zarit Burden Interview (ZBI) was reduced after the implementation of the Verily model in rural communities.

To develop a toolkit that could potentially be used by other rural communities in Australia to establish and adapt their own local virtual dementia-friendly rural community.

# Methods

## Research design and implementation strategy

A stepped-wedge randomised cluster trial design (Hemming et al., 2015; Highfield, Rajan, Valerio, Walton, Fernandez & Bartholomew, 2015) was chosen for the implementation of the Verily model and as an overall structure for the research design. Each “cluster” was one rural community. During the implementation period (32 weeks in total), the Verily model was progressively implemented in each of 12 participating rural communities. Thus, at 8-weekly intervals across 2018–2019, 3 clusters (that is, 3 rural communities) received the Verily model. Each 8-week period of implementation is defined as a “wave”; therefore, there were 4 implementation waves, each lasting 8 weeks. By April 2019, all rural communities had implemented the Verily model.

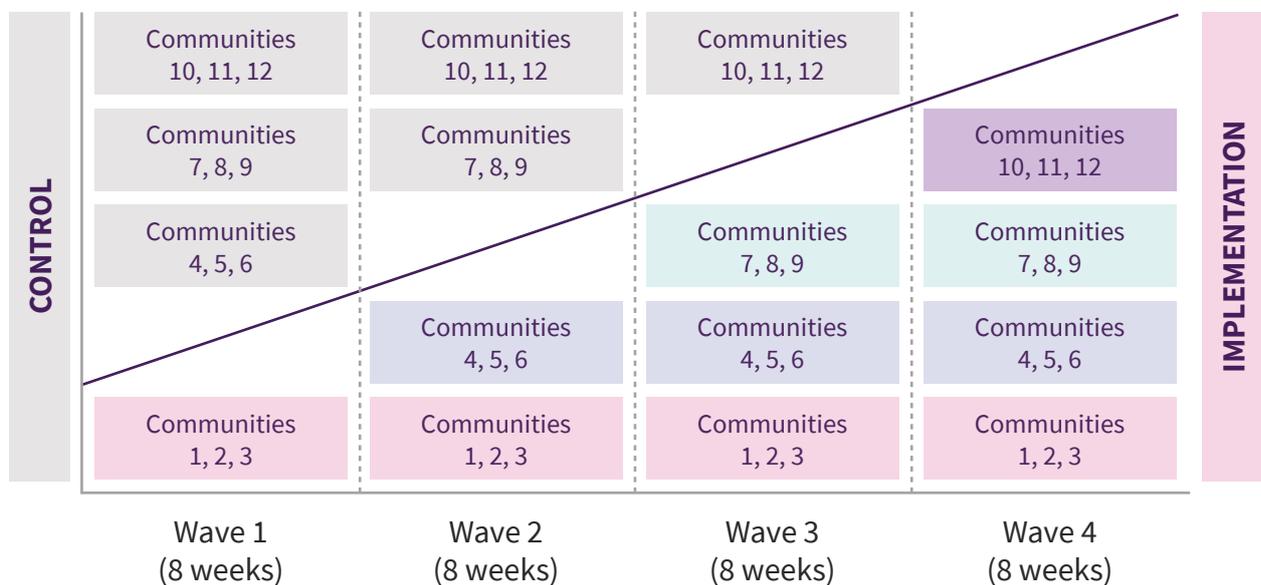


Figure 1. Implementation of the Verily model showing control period and intervention period for each cluster

Each cluster experienced a period of control and a period of intervention; however, the length of control and intervention differed for each cluster (Figure 1). Using an open cohort design of longitudinal and cross-sectional data, measurements from carers were collected for all communities every 8 weeks, beginning in September 2018 and ending in April 2019. A follow-up round of data collection was completed in September 2019. There was a total of 6 rounds of data collection. Thus, in each community, data were collected, compared, and analysed according to whether the cluster was in control or intervention.

## Study sites

Verily was a multi-site study. It was conducted in 12 rural communities (Figure 2): 8 in Victoria, and 2 in each of New South Wales and South Australia. These communities were Edenhope, Warracknabeal, Heathcote, Horsham, Kyneton/Macedon Ranges, Robinvale, Koo Wee Rup, and Mansfield in Victoria; Molong and Nyngan in New South Wales; and, Renmark/Riverland and Victor Harbour in South Australia.

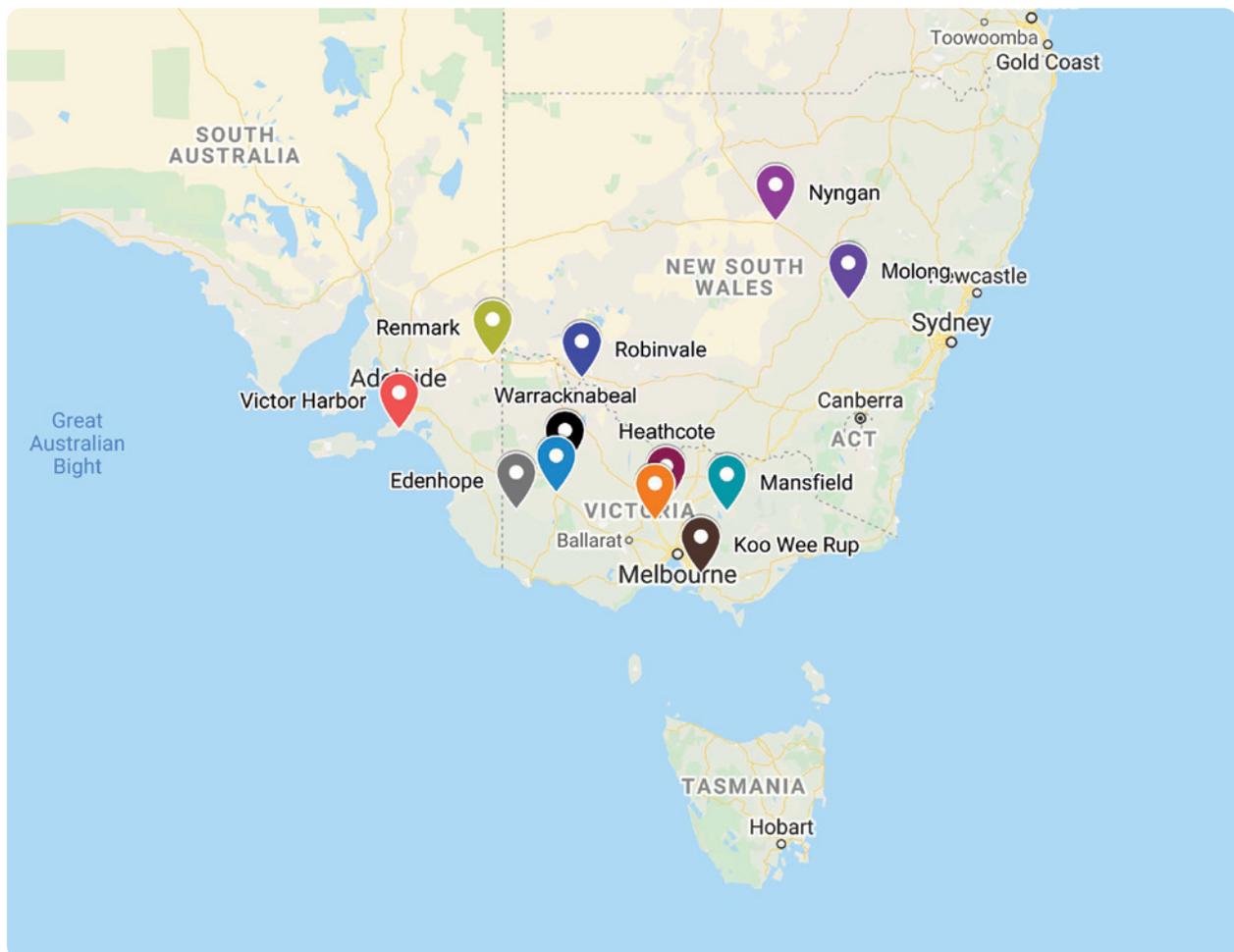


Figure 2. Study sites

## Participants

There was a total of 113 participants in the project. In each rural community, there were participants from three sub-populations:

1. carers of people living with dementia or memory loss
2. service providers (in health, aged care, or community services), and
3. volunteers.

Figure 3 displays the participants according to type of participant and the community in which they lived or worked.

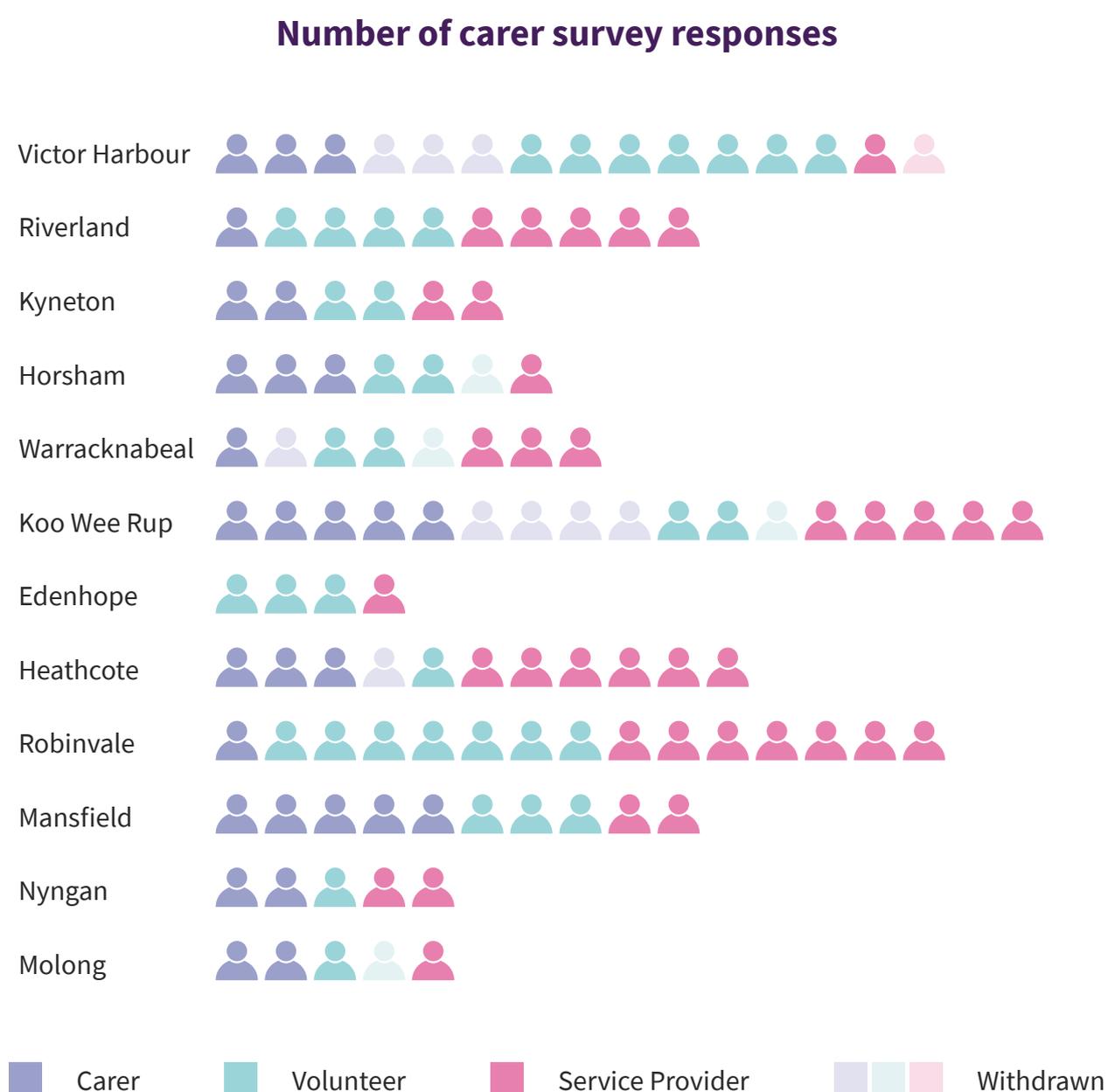


Figure 3. Participants by type and community location

## Recruitment

Through the research team's networks, 12 rural health services were identified that were willing to be partners in the Verily project. These health services are listed in Table 1.

Table 1. Health service partners

State	Partner Health Services
<b>Victoria</b>	Cobaw Community Health Edenhope and District Memorial Hospital Heathcote Health Kooweerup Regional Health Service Mansfield District Hospital Robinvale District Health Services Rural Northwest Health Wimmera Health Care Group
<b>South Australia</b>	Riverland General Hospital South Coast District Hospital
<b>New South Wales</b>	Molong HealthOne General Practice Nyngan Health Service

In collaboration with a representative from each participating health service, a variety of recruitment strategies were undertaken.

### Open community forums

Throughout July–August 2018, an open forum was conducted in each participating community to describe the Verily project, to gather feedback about the project, and to invite people to register as participants (Table 2). At the forums, the research team asked attendees to complete an attendance record that logged their contact details; after the meeting, the research team followed up with attendees to invite further discussion, ask questions, and participate in the project.

Table 2. Recruitment community forums

Community name	Date	Location of meeting
<b>Victor Harbour</b>	17 July 2018	South Coast District Hospital 56 Bay Road Victor Harbor SA
<b>Riverland</b>	19 July 2018	Berri Sim Centre, Flinders University Rural Health 10 Maddern St Berri SA
<b>Koo Wee Rup</b>	26 July 2018	Men's Shed 215 Rossiter Road Koo Wee Rup VIC
	27 July 2018	Senior Citizens Club 1 Icke Road Koo Wee Rup VIC
<b>Kyneton</b>	23 July 2018	Kyneton Mechanics Institute 81 Mollison Street Kyneton VIC
<b>Robinvale</b>	30 July 2018	Robinvale District Health Service 128–132 Latje Rd Robinvale VIC

Table 2 continued

Community name	Date	Location of meeting
<b>Horsham</b>	31 July 2018	Centre for Participation 39 Urquhart Street Horsham VIC
<b>Edenhope</b>	1 August 2018	Elsie Bennet Community Centre 128–134 Elizabeth Street Edenhope VIC
<b>Warracknabeal</b>	2 August 2018	Rural Northwest Health 18 Dimboola Rd Warracknabeal VIC
<b>Heathcote</b>	6 August 2018	Heathcote Health 39 Hospital Street Heathcote Victoria VIC
<b>Nyngan</b>	8 August 2018	Nyngan Multipurpose Health Service Hoskins St Nyngan NSW
<b>Molong</b>	9 August 2018	Molong HealthOne General Practice 103 Bank St Molong NSW
<b>Mansfield</b>	16 August 2018	Mansfield Library Collopy St Mansfield VIC

Figure 4. Example project postcard

### Advertising materials

Physical and digital copies of advertising materials – posters promoting the community meetings, postcards (Figure 4), and expression of interest forms (Figure 5) were distributed widely. For example, physical advertising materials were available at the open community forums, left in waiting rooms at the participating health services and General Practitioner (GP) surgeries, posted on shop windows and community notice boards, and distributed to community groups and individual clients and families. Digital copies of advertising materials were distributed via the networks of the 12 participating health services.

**Verily Connect**  
Expression of Interest Form

Please fill out the form below and return in the reply paid envelope to register your expression of interest for Verily Connect.

**I am:**

- A carer or family member of a person living with dementia or memory problems
- A volunteer
- A service provider
- An interested community member

**I am interested in:**

- User testing the website or app
- Joining an online peer group
- Learning digital and online skills
- Helping others learn digital and online skills

**Name:** \_\_\_\_\_

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

**Postcode:** \_\_\_\_\_

To receive more information about Verily Connect (Melbourne Health HREC 17/MH/404), and/or to find out how your information will be used, please contact (00) 0000 0000 or [verilyconnect@latrobe.edu.au](mailto:verilyconnect@latrobe.edu.au)

**LA TROBE UNIVERSITY** **verilyconnect**

Melbourne Health HREC 17/MH/404 Version 3 07.05.2018  
Verily Connect: An Australian Government initiative

Figure 5. Expression of interest form

### **Meetings with community groups**

In each of the 12 participating communities, service clubs and community groups, such as Lions club, Probus, Country Women's Association, Returned and Services League (RSL), Senior Citizen's clubs, Men's Shed, were identified. Research staff contacted these groups and clubs and spoke to organisation officials, offered to speak at club/group meetings, and distributed advertising materials. Special effort was made to inform any existing carers' groups (dementia-specific and broader carers' groups) about the Verily project.

### **Social media, media releases, and paid advertising**

The participating health services that had active social media profiles (such as Facebook, Twitter) posted about the Verily project. Social media messages were also posted by members of the research team.

La Trobe University, the Centre for Rural and Remote Mental Health (University of Newcastle), and Flinders University issued press releases about the study. Press releases were also issued by each of the 12 participating health services.

### **Online launch**

An online launch of the Verily implementation was held on 18 October 2018. It was attended by potential participants, partner health service staff, and members of the project team. In addition, Honorable Ken Wyatt AM, MP provided a video message for the launch meeting (Figure 6) and Professor John Dewar, Vice Chancellor of La Trobe University, spoke about the value of the project for rural communities. A recording of the meeting can be accessed on YouTube: [youtube.com/watch?v=pJhGOR0idnU&t=630s](https://www.youtube.com/watch?v=pJhGOR0idnU&t=630s)



Figure 6. Hon. Ken Wyatt AM delivered a video message at the online launch

### Contact Us via [verilyconnect.org.au](https://verilyconnect.org.au)

On the Verily Connect app there is an “About” page/button that has information about the project and also a “Get in touch” form (Figure 7). The About button does not require a login to be used. Therefore, potential participants and other interested persons were able to directly approach the research team and express interest in participating.

## Get in touch

 (02) 6024 9718

 [verilyconnect@latrobe.edu.au](mailto:verilyconnect@latrobe.edu.au)

Please fill out the enquiry form below to contact us.  
We'll get in touch with you as soon as possible.

Name 

Phone number

Email

Message

**Submit**



Figure 7. Get in touch form available in the About section of the Verily Connect app

## Data collection

### Survey data – carers

All carers were asked to complete surveys at 6 time points (Table 3). The first collection time was when the participant was first recruited. Survey rounds 2–5 corresponded with the end of each implementation wave and the final survey was collected in the follow-up period.

Table 3. Carer survey collection periods and survey content detail

Survey round	Collection period	Survey content
1	Prior to the start of the trial or when the participant first joined the trial	Initial demographic and background information Perception of social connection ZBI MOS-SSS
2	15–26 October 2018	MOS-SSS
3	10–21 December 2018	Ongoing demographic and background information Perception of social connection ZBI MOS-SSS
4	4–15 February 2019	MOS-SSS
5	1–12 April 2019	Ongoing demographic and background information Perception of social connection ZBI MOS-SSS
6	7–18 October 2019	Ongoing demographic and background information Perception of social connection ZBI MOS-SSS

Details of the questions asked about initial demographic and background information are listed in Appendix 1. Particulars of ongoing demographic and background information are itemised in Appendix 2. Questions about perception of social connection are recorded in Appendix 3.

A total of 72 carer surveys were collected across the 6 rounds of surveys. Details are shown in Table 4.

Table 4. Number of carer surveys collected for each survey round

Survey Round	n
Survey round 1	26
Survey round 2	8
Survey round 3	12
Survey round 4	12
Survey round 5	9
Survey round 6	5

### Process and participant feedback data

Large amounts of qualitative feedback data were collected. Details of these data are shown in Table 5.

Table 5. Numbers of qualitative data collected by participant type and data type

Participant type	Interviews (end of implementation)	Interviews (follow-up period)	Memos
Carers	18	10	118
Service providers	25	7	45
Volunteers	18	4	55

In addition to the planned data collection reported in Table 5, the following incidental qualitative data were collected:

- 51 memos about the recruitment process
- 8 memos giving feedback about the Verily Connect app
- 6 memos about a variety of incidents.

Interviews and focus group data (focus groups were used to collect data from volunteers) were transcribed verbatim. Memos were brief written accounts and thus the verbatim memos themselves were collected as data.

## Economic data

### Economic data collection

A data collection template was developed to collect and collate resource utilisation information according to input cost classifications. The development of the template drew from the cost classification scheme outlined by the World Health Organisation (Creese & Parker, 1992). Table 6 illustrates the cost classification scheme used for the data collection from each community.

The template was produced for each of the 12 communities. Research project staff populated the template with available data and information. Data was only collected for Verily implementation activities, not for research-related activities. Thus, the scope of the analysis was to estimate the resources that would be required to implement the Verily model in a non-research environment.

Table 6. Cost classification scheme for Verily data collection

Cost Category	Description / definition
<b>Recurrent costs</b>	Relate to inputs that are used up in the course of one year and are purchased/employed regularly
<b>Personnel time</b>	Time spent by individuals delivering or engaging with the intervention
<b>Materials</b>	Supplies used to deliver the intervention, such as stationary, that have a unit cost under \$100
<b>Vehicles – operation and maintenance</b>	Petrol, diesel, registration, insurance, servicing costs of private vehicles* used to deliver the intervention
<b>Buildings – operation and maintenance</b>	Electricity, water, heating, cooling, cleaning, telephone, internet, repairs
<b>Other travel related costs (other than vehicles)</b>	Meals, accommodation, flights, other transport (taxis, bus, train etc.)
<b>Other recurrent costs</b>	Any operating inputs not captured above
<b>Capital costs</b>	Relate to inputs that last longer than one year
<b>Equipment</b>	Equipment with unit cost above \$100
<b>Furniture</b>	Desks, tables, chairs etc.
<b>Vehicles</b>	Cars
<b>Buildings – space</b>	Offices, health centres, training rooms etc. used to deliver the intervention
<b>Start-up costs</b>	Relate to inputs that last indefinitely

\*The term “private vehicle” refers to any vehicle that is not hired.



In addition to the data collected for each community, overhead data were collected from the project manager. These data represent activities that were performed once for all communities, and include things such as:

- Verily Connect app development
- promotion of the overarching program (not community specific)
- training development
- overarching communications

Any materials, travel and capital inputs associated with these overhead activities were also collected.

## Data analysis methods

### *Survey data analysis*

Demographic and background information and perception of social connection were analysed descriptively. Pre- and post-intervention data for social support (collected by MOS-SSS) and caregiver burden (collected by ZBI) were analysed separately. Only those participants who completed both pre and post tests were included in the comparison analysis (N=18 for MOS-SSS and N=16 for ZBI). The difference between pre- and post-intervention results was tested for statistical significance with a paired t test.

### *Process and participant feedback analysis*

Interview data were transcribed verbatim and the transcripts entered into a *QSR International NVivo* project. Memos were already in written form and so were also imported into NVivo. Data were analysed by participant type; therefore, there were three NVivo projects, one each for carers' data, volunteers' data, and service providers' (staff) data.

Qualitative data for carers and volunteers were analysed using a framework of structured feedback about the Verily model and the implementation of the model including what worked well, what was not effective or useful, and what could be improved about the Verily Connect app, about the Verily model, and about the implementation process. Carers' data were also inductively analysed to yield a thematic analysis of the experience of being a carer for a person living with dementia in a rural environment and the experience of participating in the Verily project. Qualitative data for service providers were analysed using the structure of the Consolidated Framework for Implementation Research (CFIR).

### *Cost analysis*

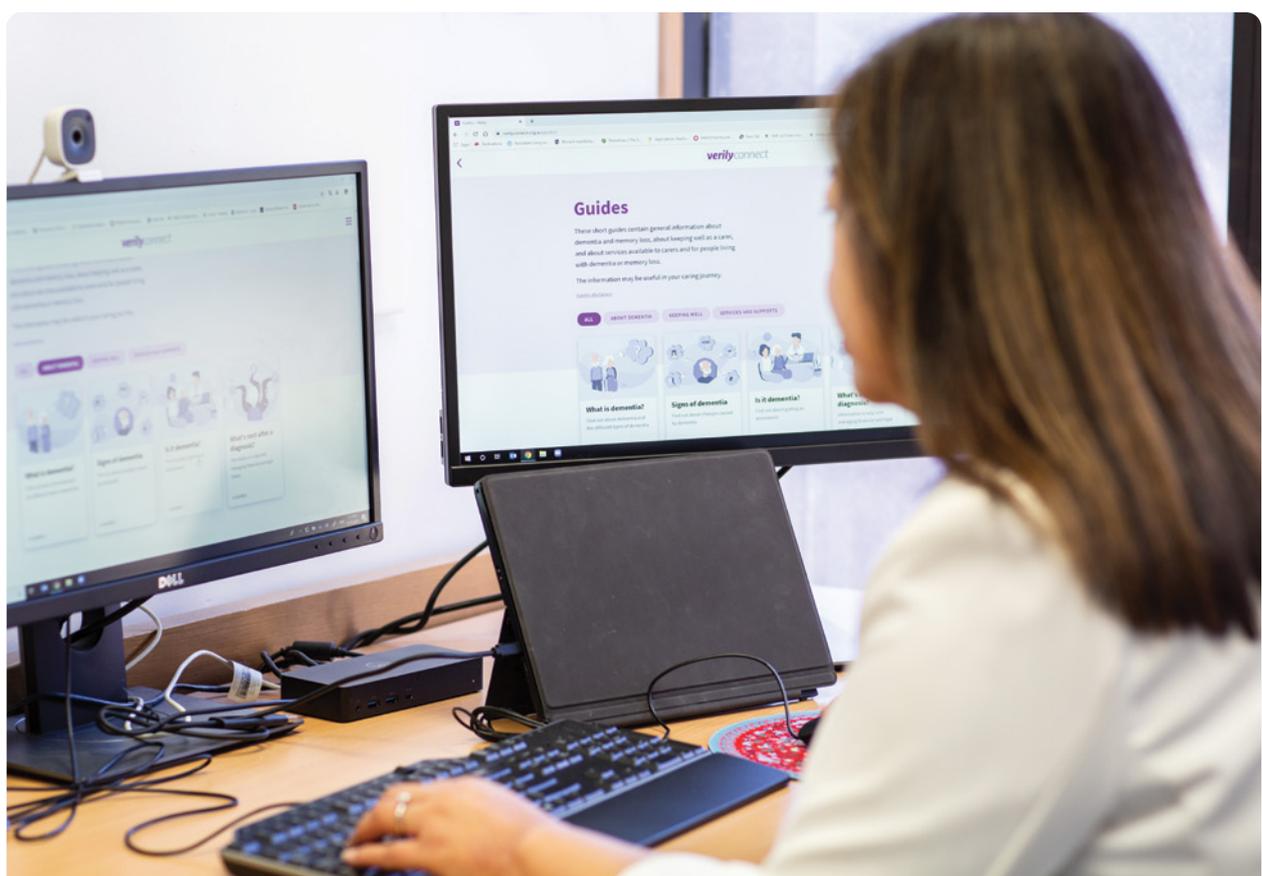
Economic data were insufficient to conduct an economic evaluation and therefore an analysis of the provision costs of the Verily intervention, focusing on the project management costs and the health service costs, was completed. The aim of the cost analysis was to provide insight into the cost of implementing the Verily model and joining the online virtual dementia friendly community and the factors which drive these costs.

# Results

## Quantitative data results

### *Carer demographic and background information*

Participant demographic characteristics are presented in Table 7 and Figure 10 to 16. A total of  $n=37$  carers were enrolled during the Verily project implementation period from 3 September 2018 to 12 April 2019 (Figure 8). However, there were  $n=8$  participants who did not complete a baseline survey and were therefore deemed as having withdrawn from the study. The remaining  $n=29$  completed the baseline (round 1) carer survey (Figure 9). Completion rates declined for subsequent survey rounds as 15 participants were lost to follow up or withdrew during the implementation period. In addition, survey completion for subsequent survey rounds was impacted by the time at which carers enrolled (because carers were able to join the study throughout the implementation period). For example, if a participant enrolled during the data collection period for survey round 2, the participant completed the baseline survey rather than the round 2 survey and then their second survey completion would be during survey round 3.



## Enrolments and drop-outs, total n=37

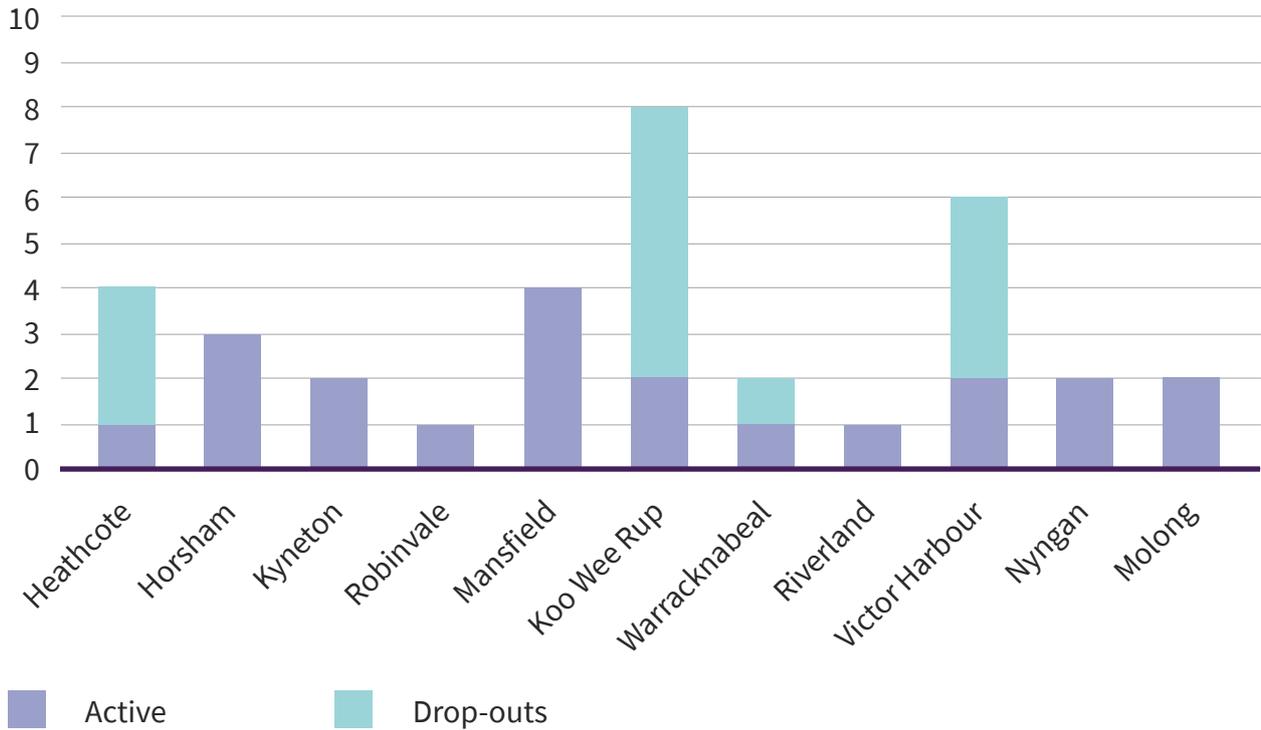


Figure 8. Carer enrolments showing active participant and dropouts

## Number of carer survey responses

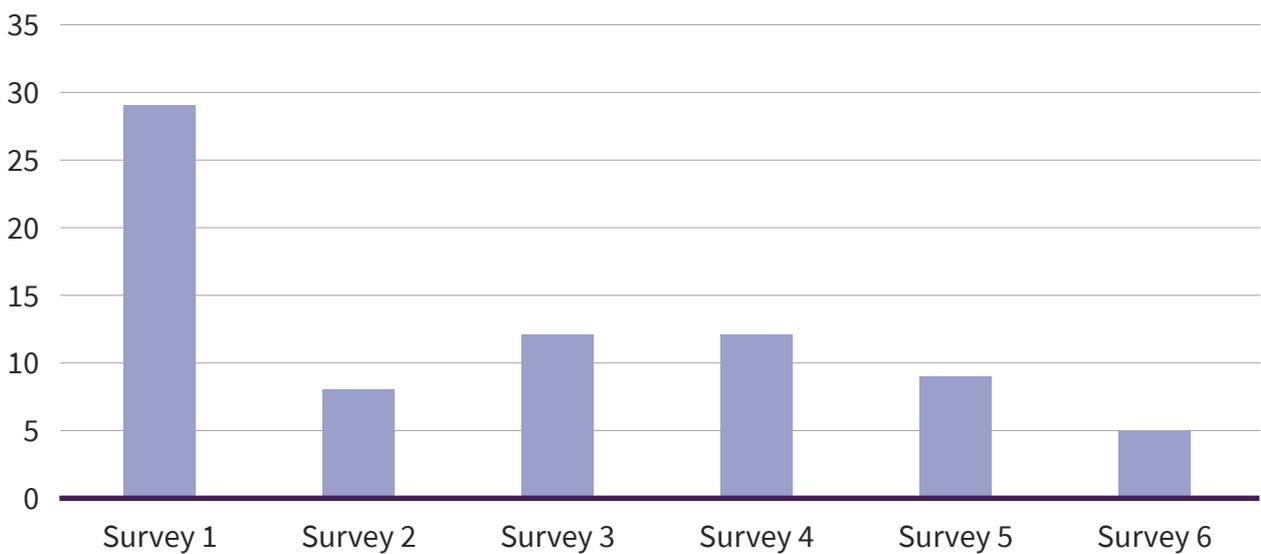


Figure 9. Number of carers who completed the survey in each round

Table 7. Carer characteristics data

Carer characteristics	n=29
Age, mean (SD) years	60 (12)
Female	86%
<b>Years in caring role</b>	
<2 years	35%
2–6 years	35%
>6 years	30%
<b>Person cared for (relationship)</b>	
Spouse	38%
Sibling	10%
Friend	3%
Parent	48%
<b>Diagnosis for person cared for</b>	
Dementia	72%
Cognitive impairment	10%
<b>Years diagnosed with dementia</b>	
Less than 2 years	34%
2–4 years	14%
More than 4 years	24%
<b>Residence of person cared for</b>	
Lives with carer	45%
Lives in the same postcode as carer	45%
Lives 50–100 km from carer	10%
<b>Healthcare</b>	
Healthcare card holder	48%
Has private health insurance	66%
Has home care package	14%
<b>Highest level of education attained</b>	
Secondary school (Year 7–Year 11)	34%
Completed secondary school / TAFE / College	41%
Undergraduate tertiary education	10%
Postgraduate tertiary education	14%



**4 out of 5 carers were female**  
**Carers' age ranged from 34–79 years**

Figure 10. Gender and age range of carers

### Length of time in caring role

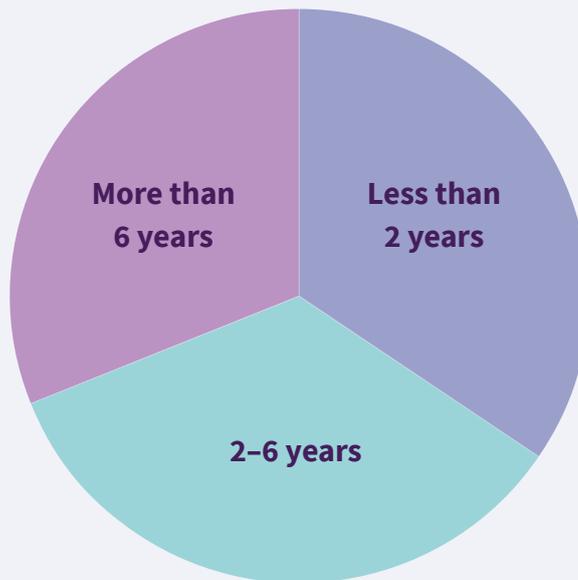


Figure 11. Length of time in caring role



## Who did the carers look after?

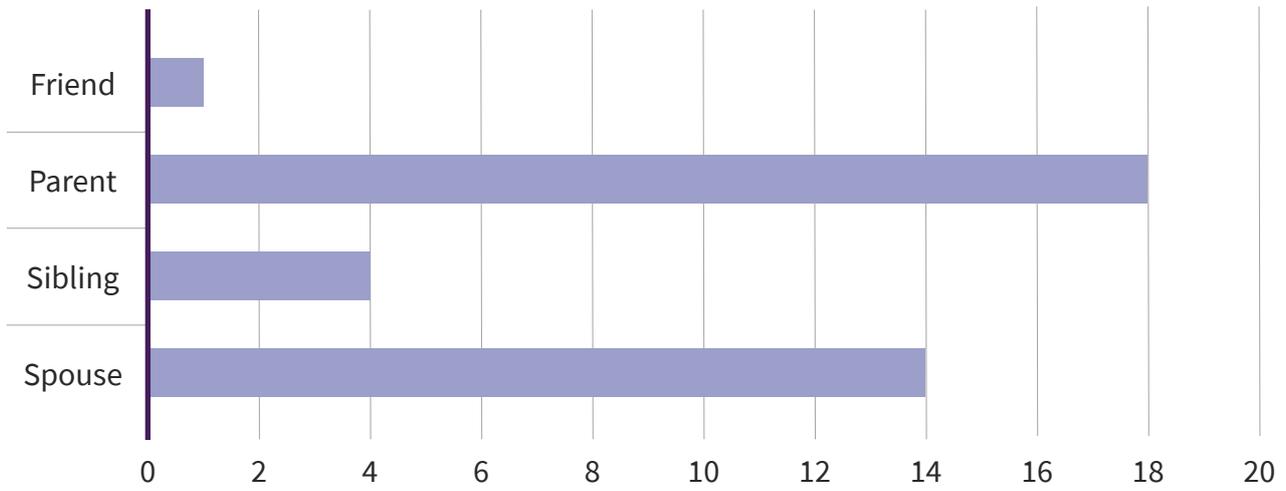


Figure 12. Relationships of carers to person being cared for

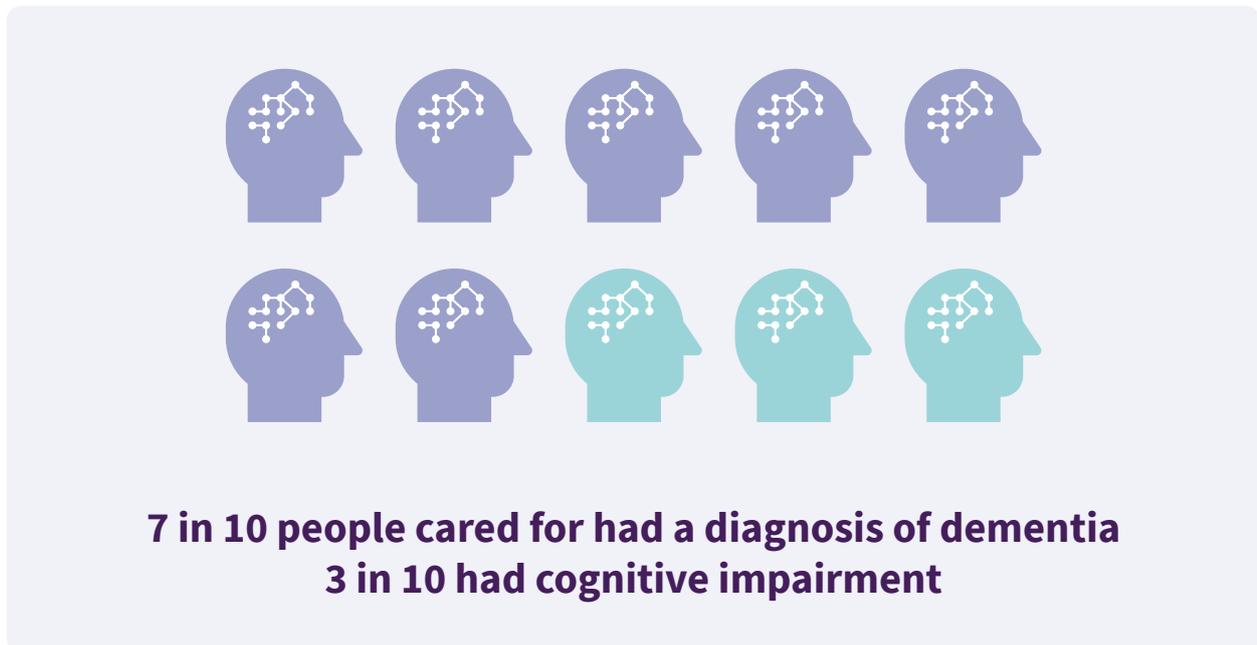


Figure 13. Diagnosis of people being cared for

## For people with a diagnosis of dementia, years since diagnosis

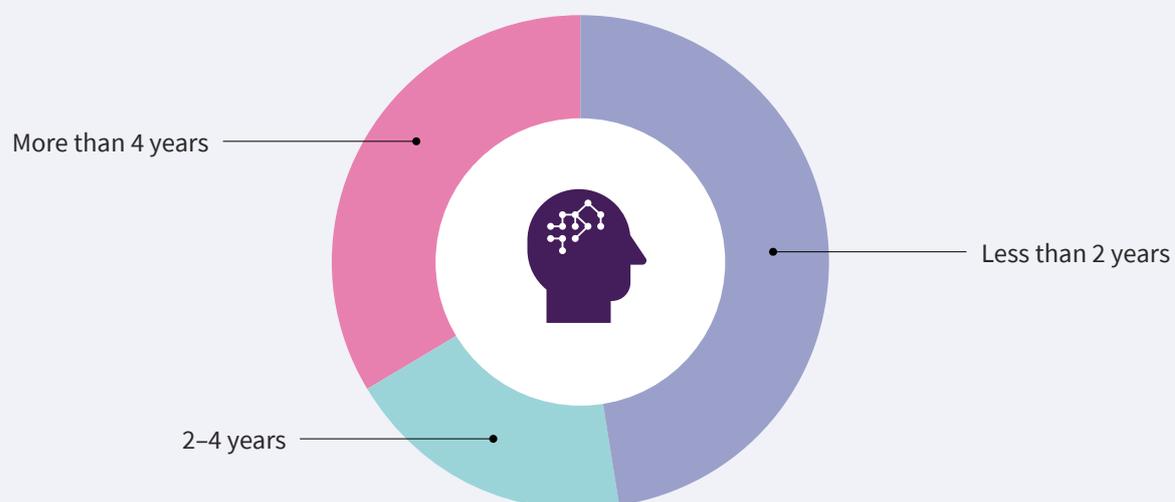


Figure 14. Years since diagnosis of dementia



### Where did the carers live?

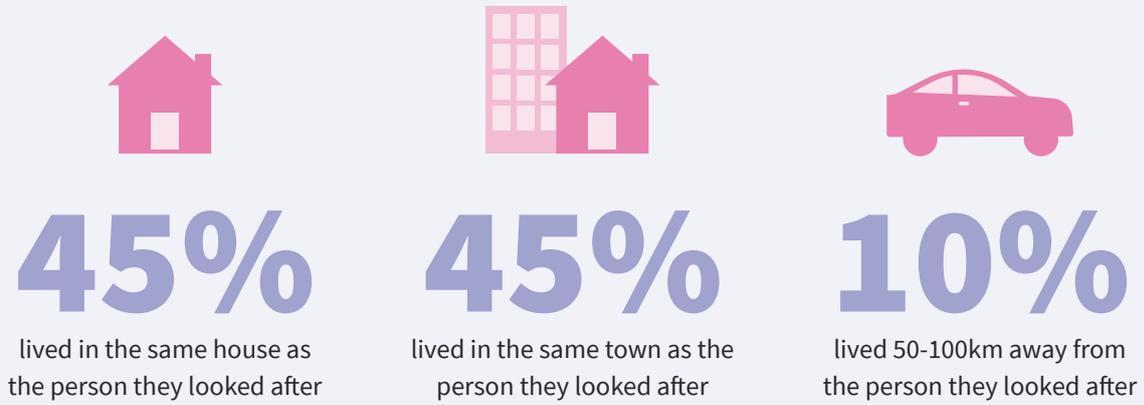


Figure 15. Geographical locations of carers in relation to person being cared for

### Carers' highest level of education attained

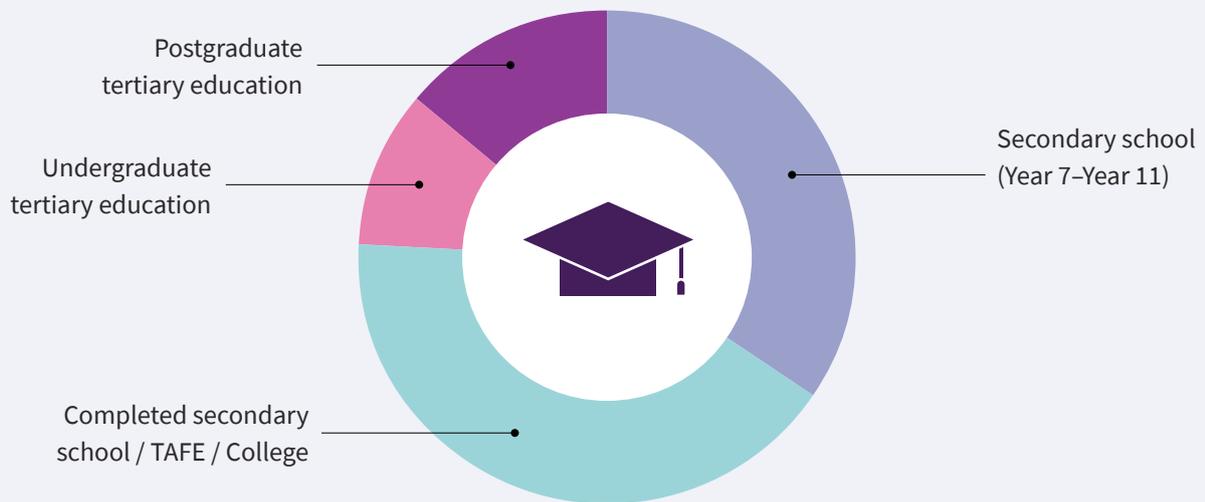


Figure 16. Carers' highest level of education attained

## Social connections

As seen in Figure 17, carers did not feel a close sense of connection to other carers either at the beginning of the study, nor as the study progressed. However, as indicated in Figure 18, carers felt a closer sense of connection to service providers than to other carers throughout the study.

### Rating of carer to carer connections

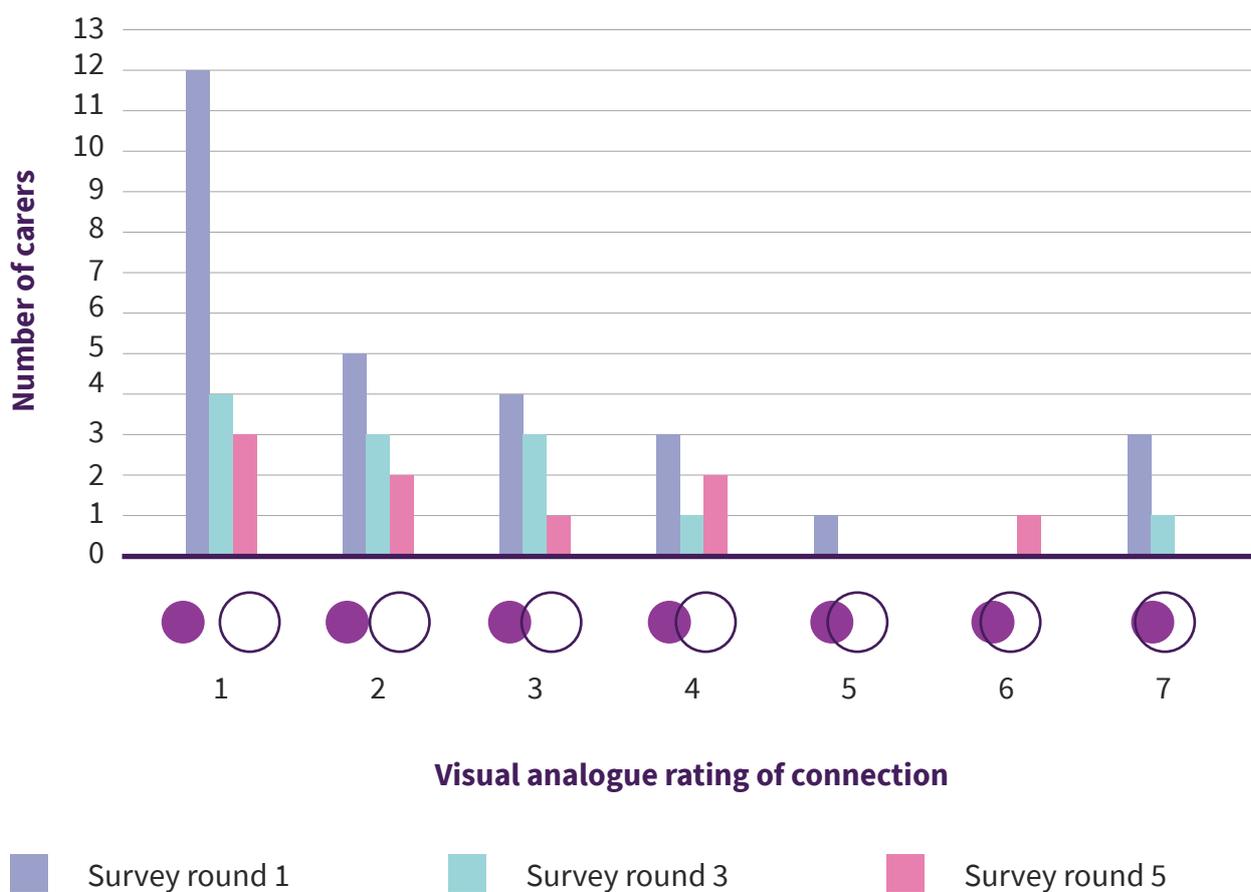


Figure 17. Carers ratings of their sense of connection to other carers using the visual analogue scale

## Rating of carer to service provider connections

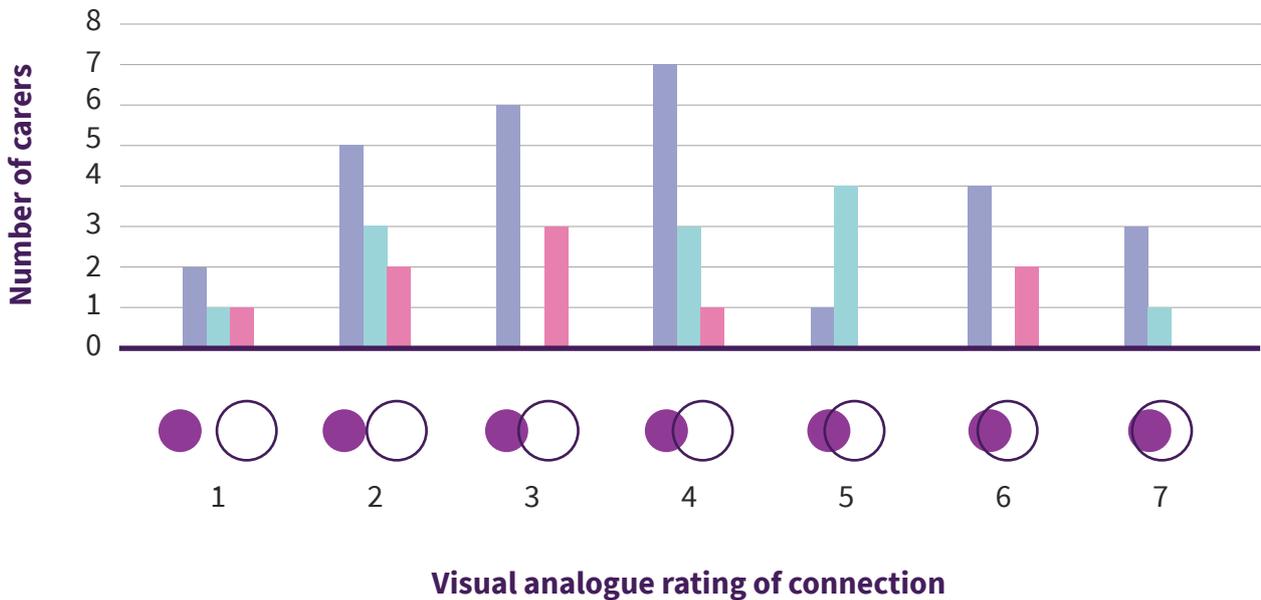


Figure 18. Carers ratings of their sense of connection to service providers using the visual analogue scale

### Use of services by carers and/or those they cared for

Carers and/or the people they cared for used a range of services at all stages of the study, as indicated in Figure 19. Three different people each experienced an occasion to use emergency care services (one each during Survey round 1, Survey round 3, and Survey round 5). The reason for these presentations were for a broken elbow, a bowel obstruction, and a laceration to the leg.

## What services have you and/or the person you care for used in the past 2 months?

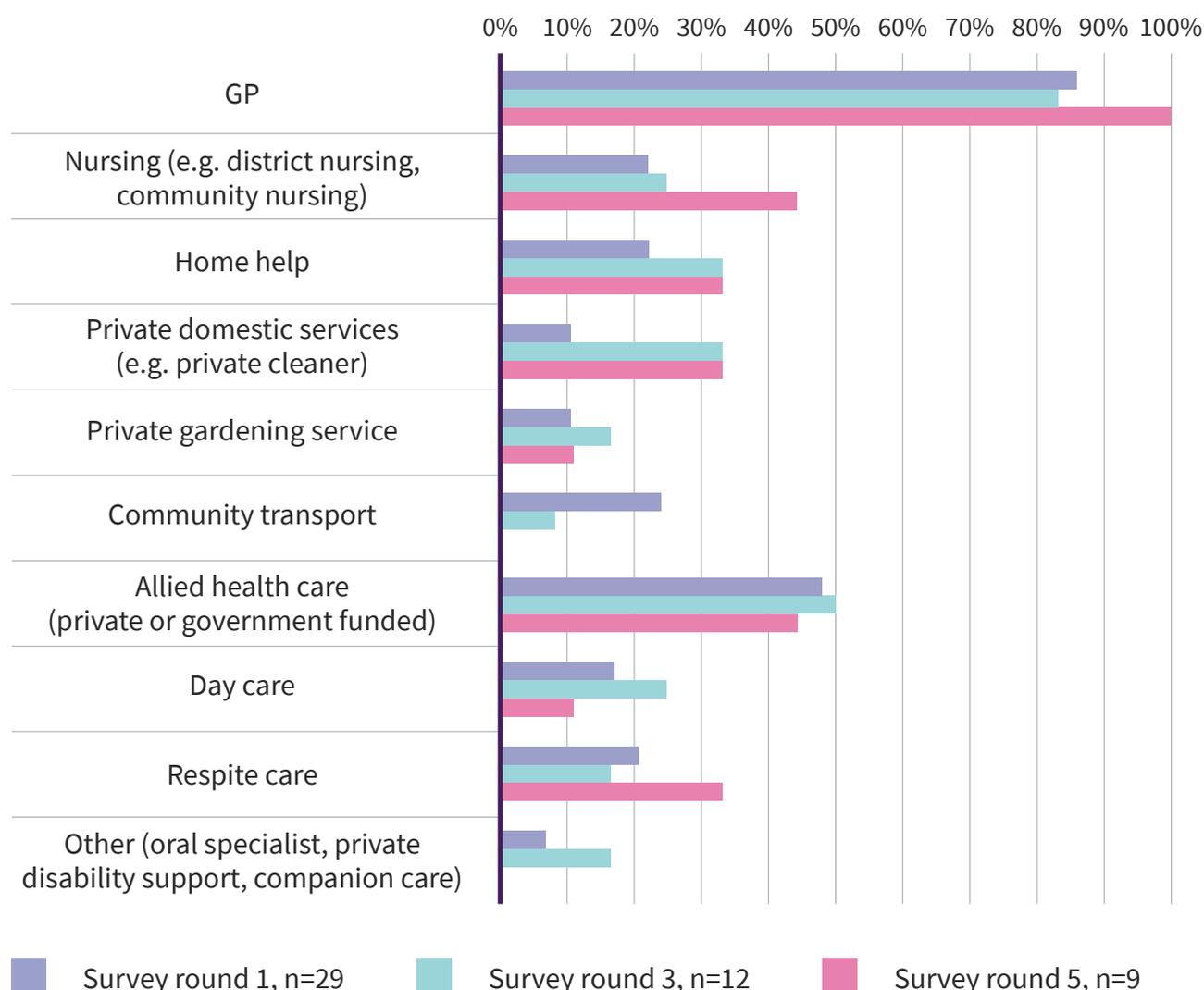


Figure 19. Services received in the previous 2 months

Carers were asked if they received any other kind of support (in addition to those listed in Figure 19). There were 16 responses indicating that additional support was received, as illustrated in Figure 20. The “Other sources of support” were the pension (n=2), Dementia Australia (n=1), the local health network (n=1), and the National Disability Insurance Scheme (n=1).

## Sources of other support received

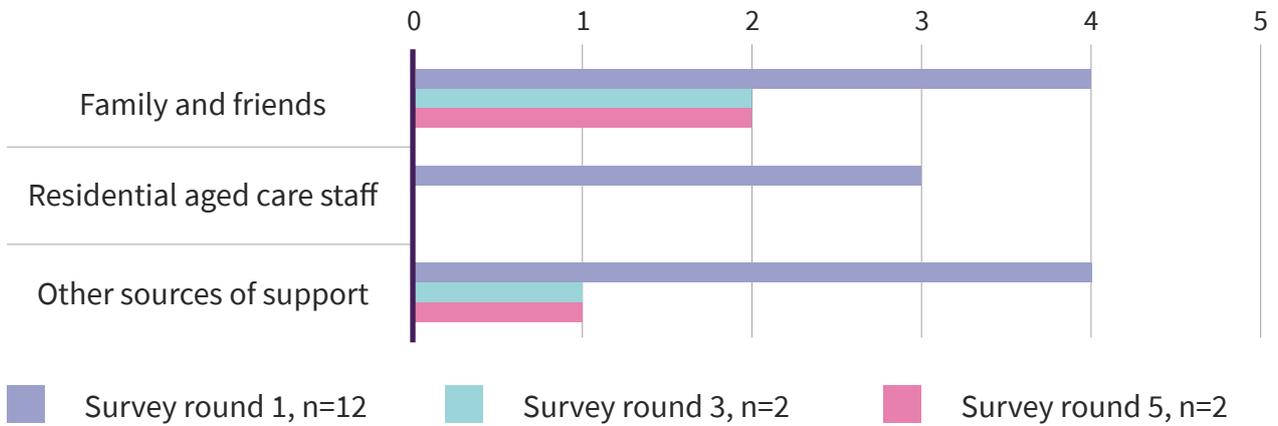


Figure 20. Sources of other support received

Figure 21 illustrates who organised or referred the participants or the people they cared for to services. It may be seen that a variety of different people, including the carers and people living with dementia/cognitive impairment, arranged appointments for services.

## Who organised or referred you and/or the person you care for to this service in the past 2 months?

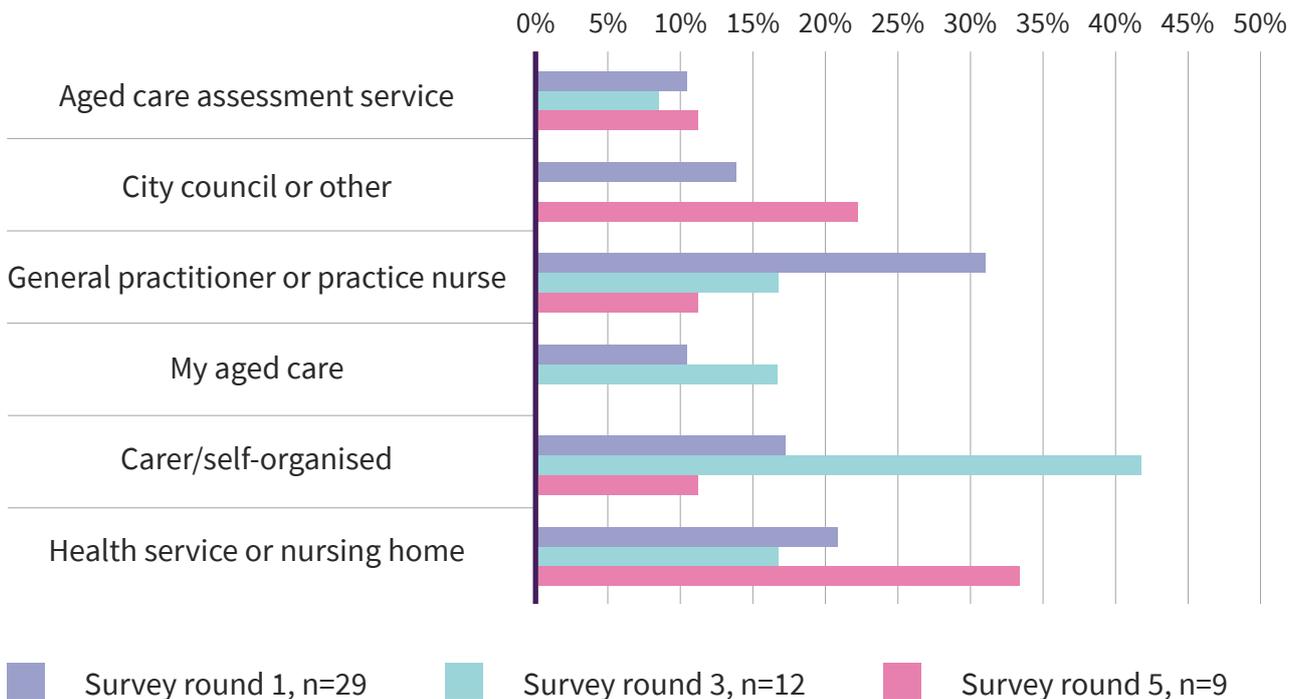


Figure 21. Sources of referrals for services used in the past 2 months

In addition to services that carers and/or those that they cared for accessed, carers were asked about the services that they needed but were not in place. There were 20 responses indicating that there were unmet needs: survey round 1 (n=10), survey round 2 (n=6), and survey round 3 (n=4). Figure 22 shows the types of services that participants needed but did not receive; the frequencies of these services have been aggregated across survey rounds 1, 3 and 5 (Figure 22). The specific services needed were reported as being: social activities, an easily accessible peer support group, extended respite care, transport for the person being cared for, gardening and home maintenance services, a higher level aged care package, assistance with shopping, testing/diagnostic services, bulk billed dental and emergency visits, and access to better management of comorbid conditions.

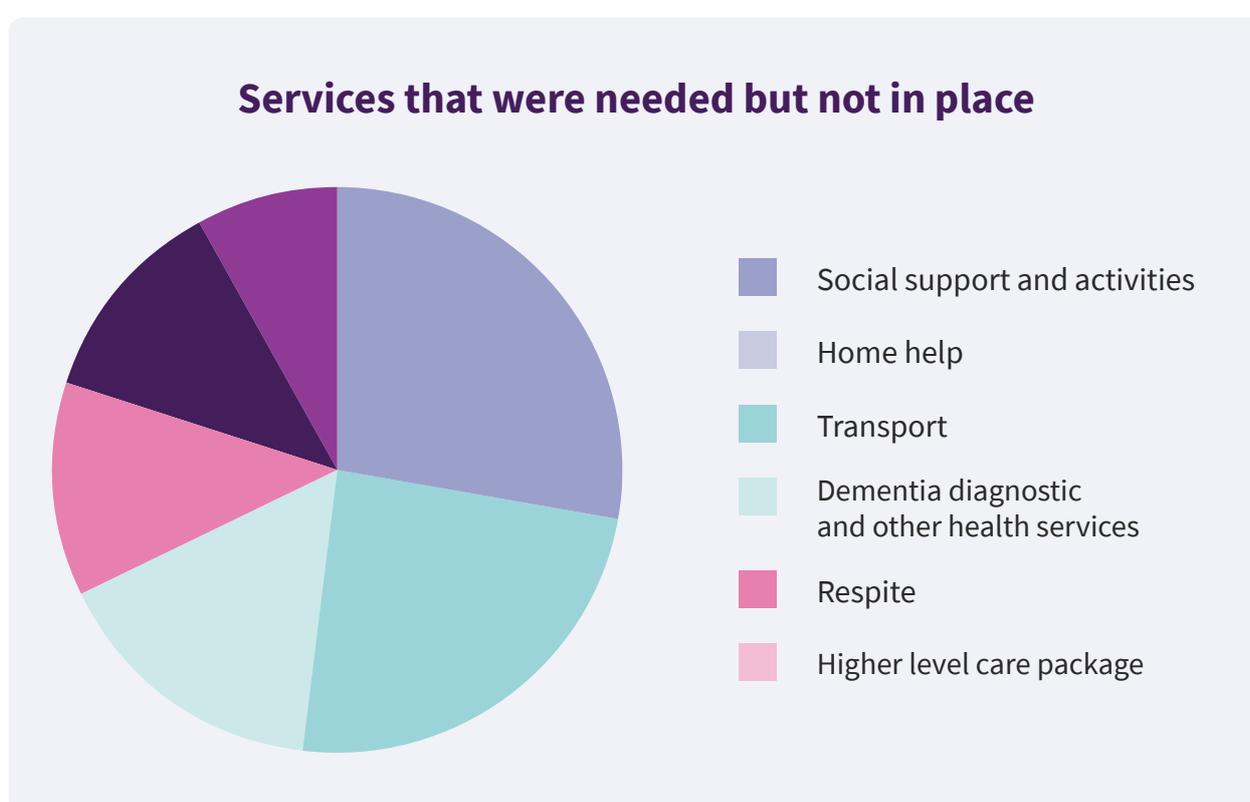


Figure 22. Frequency distribution of services that were needed but were not in place

It appears that for most carers it was neither difficult nor easy to access the services they needed (see Figure 23). However, it is still concerning that there were 12 responses indicating that services were difficult to access and 4 responses reporting that service access was very difficult.

## In general, how difficult or easy has it been to access services to support you and the person you care for?

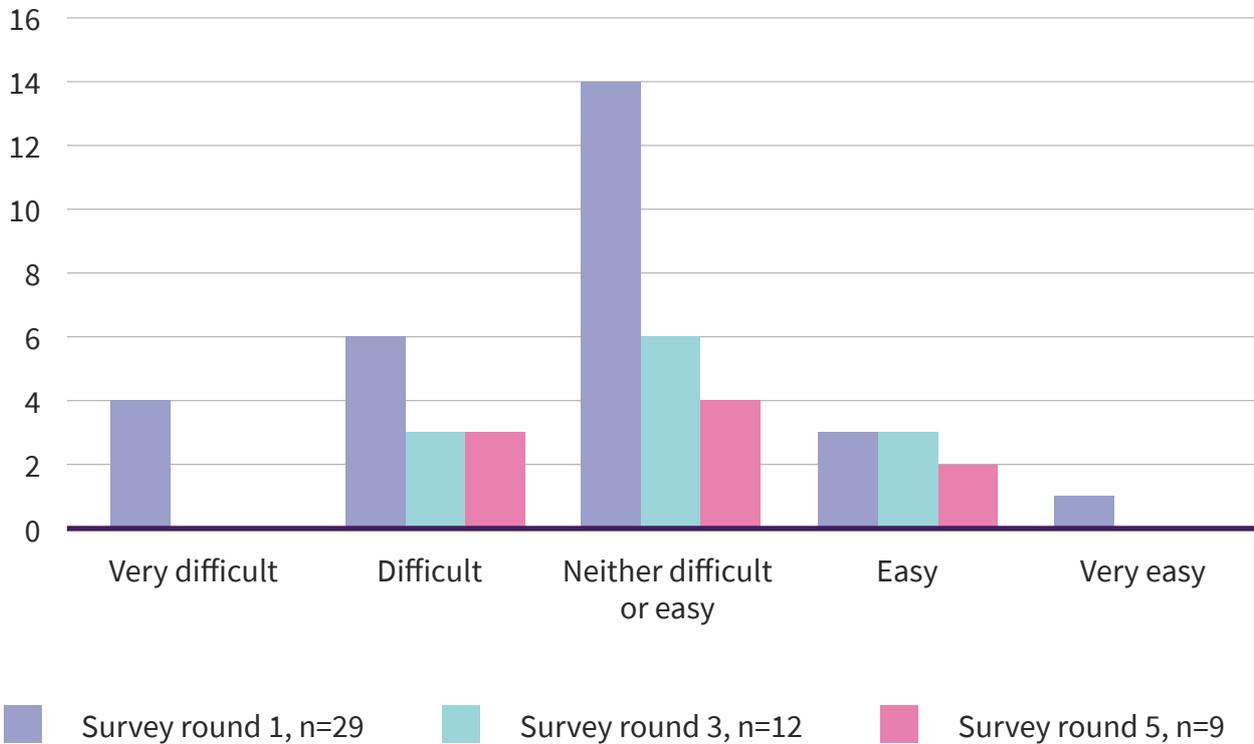


Figure 23. Level of difficulty with accessing services

### **Dementia friendly community**

The carers were asked what they considered a dementia friendly community to look like. A content analysis of their responses (n=26) indicated that the most common responses were that a dementia friendly community is understanding, people in the community have an awareness of dementia and the needs of carers and people living with dementia, and that the community is supportive and patient. Figure 24 is a word cloud of the content analysis: the size of the word corresponds to the frequency with which the word appeared in the carers' responses. That is, the bigger the word, the greater the frequency that it was mentioned.



Figure 24. Word cloud: what is a dementia friendly community?

### Social support and carer burden

Carer perception of social support data (measured using the MOS-SSS) are presented in Table 8. Possible scores for the MOS-SSS range from 0 (lowest social support) to 100 (greater social support) (Sherbourne & Stewart, 1991). The scores showed a trend towards improvement in social support by survey round 3 (week 16) but decreased over the next survey rounds, however remained above baseline scores. Baseline (survey round 1) MOS-SSS scores lower than 50 (the halfway mark from low to higher social support) demonstrate that carers of people living with dementia need social support.

Table 8. Social support (MOS-SSS) total scores

Survey round	n	Mean (SD)	Median (IQR)
Survey round 1	27	40.9 (27.9)	47.0 (24.4, 61.8)
Survey round 2	8	52.0 (25.4)	53.3 (34.2, 78.5)
Survey round 3	12	61.2 (24.1)	72.3 (42.4, 87.2)
Survey round 4	12	69.5 (24.3)	80.6 (57.0, 93.6)
Survey round 5	9	55.7 (34.5)	66.7 (41.1, 94.9)

Caregiver burden as measured by the ZBI is presented in Table 9. Scores on the ZBI can range from 0 (no burden) to 88 (severe burden) (Zarit, Reever & Bach-Peterson, 198). Participants' total ZBI scores were collapsed into levels of burden (Figure 25). Other studies have similarly shown that levels of carer burden are reported to be high for carers of people living with dementia.

Table 9. Carer burden scores

Survey round	Carer Burden (ZBI) Score	
	Mean (SD)*	Median (IQR)#
Survey round 1, n=28	62.8 (12.0)	64.0 (59.0, 69.8)
Survey round 3, n=12	64.7 (6.7)	65.0 (58.8, 70.1)
Survey round 5, n=9	59.2 (9.1)	58.0 (53.5, 66.0)

\*SD – Standard Deviation; #IQR – Inter-Quartile Range

### Carer burden

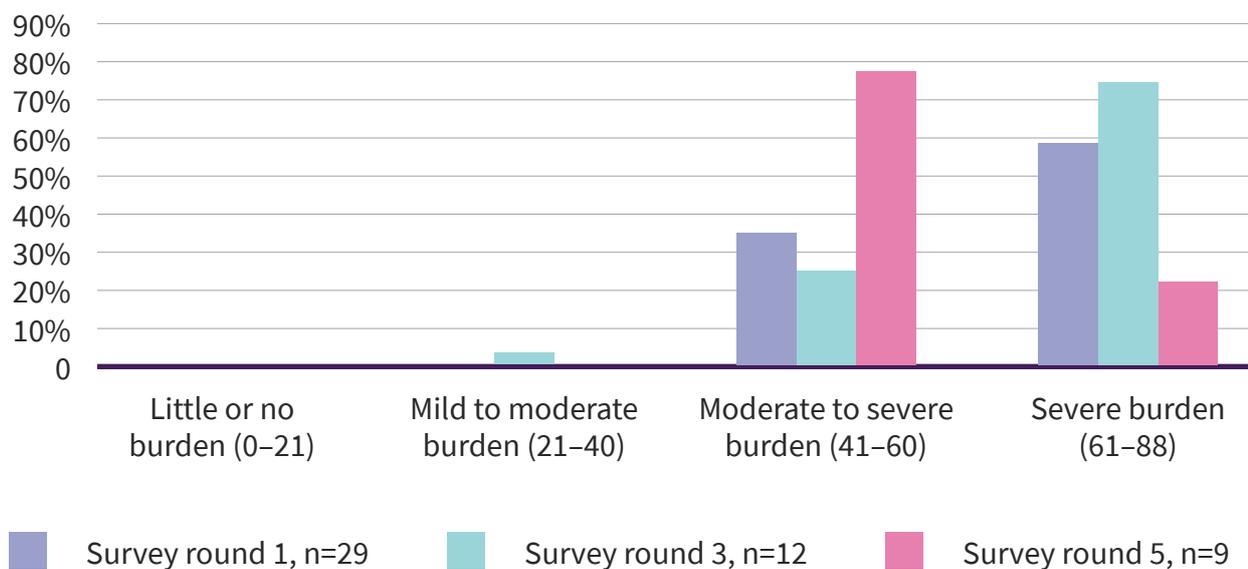


Figure 25. Levels of carer burden

When examining a more nuanced breakdown of the ZBI findings, there were three issues that carers reported as being the most burdensome, that is, those items rated as occurring “quite frequently” or “nearly always”:

- Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
- Are you afraid about what the future holds for your relative?
- Do you feel that your relative is dependent upon you?

These responses are perhaps unsurprising given that dementia can cause very significant loss of functional abilities, dementia is a progressively worsening illness, it has no cure or treatment, and it shortens lifespan.

Statistical analysis of social support (measured using MOS-SSS) and carer burden (measured using ZBI) was completed for pre- and post-intervention scores using a paired t test. Table 10 shows the results of this analysis. Prior to the intervention there is generally a lower level of overall social support and higher level of carer burden. After the intervention, results for overall social support increased significantly with p-value of 0.001 and large effect size of 0.906, whereas carer burden did not change significantly.

Table 10. Pre and post comparisons for social support and carer burden

		Social support (MOS-SSS)	Caregiver burden (ZBI)
<b>Pre</b>	<b>N</b>	27	28
	<b>Mean (SD)*</b>	40.9 (27.9)	62.8 (12.0)
<b>Post</b>	<b>N</b>	19	16
	<b>Mean (SD)</b>	58.4 (29.7)	67.3 (8.2)
<b>Difference</b>	<b>N (pair)</b>	18	16
	<b>Mean (SD)*</b>	15.1 (16.7)	5.3 (12.3)
	<b>95% CI#</b>	(6.8, 23.4)	(-1.3, 11.8)
	<b>Effect Size</b>	0.906	0.428

\*SD – Standard Deviation; #CI – Confidence Interval



## Qualitative data results

### ***“I only have 5 minutes, life is hectic”***

It was clear from discussions with carers that they faced considerable challenge in their caring role. Carers were very busy. Many of the carers had caring roles in addition to a caring role for a person living with dementia or memory loss. They cared for children and grandchildren, for other older relatives, and for other unwell family members and friends. Their industriousness was compounded by employment, domestic work, home maintenance, and volunteer work. Caring was also experienced as being exhausting and overwhelming. Carers could feel isolated (especially prior to their involvement in Verily) and carers sometimes experienced conflict with other family members about caring for a family member with dementia.

*I am under the pump big time... My brother is causing trouble again. He wants to document stuff and he thinks I am wasting the money. He is just a pest... It is a strain on Mum and Mum doesn't want to meet him. I have tried to organise a family meeting I have said you don't want to come to a family meeting because you don't care. I've got a lot of things on my mind but I am chipping through it... After mum broke [a bone] she no longer helps with the housework... I am trying to get her on a level three. I will have to wait 18 months to get it approved. The council come and shower. They just shower. Shower and then leave. If they have cleaning and shower it is a bit better. When she stands up in the shower, she gets dizzy. I have to say, are you alright in the shower and keep asking her how she is going... See what I'm up against. When your family is against you too. It is a struggle with me. (carer participant)*

### ***“I'm not so good with technology”***

Although it was clear that using technology could overcome some of the challenges faced by carers, use of technology itself was a barrier that some of the carers did not feel they could overcome. Potential participants were put off from being involved in the Verily project because of fear, distrust, lack of desire, and lack of willingness to try to use technology. Even though there were volunteers available in each community to provide face-to-face technical support to Verily participants, for some carers even this support was insufficient. In combination with the burden carers already felt through the physical and emotional challenges of caring for a person living with dementia, the requirement to learn to use technology as well was sometimes too great a step for carers to take.

### ***“I think it has huge potential”***

For the carers who participated in the Verily project, there was a greater quantity of positive feedback about their involvement than negative feedback. Staff and volunteers also praised many aspects of the project. The Verily Connect app and Zoom technology was reported to be easy to use, intuitive, and user-friendly. Content on the app was readily understandable. The information located in the guides and the services directory was considered to be helpful and just the right amount of detail.

*I certainly think it's something that's needed and I think it's particularly needed in rural areas. There's a lot of stigma associated with dementia and... if you've got people that are a little bit disconnected from the community, if they're geographically isolated, if they've not got a lot of money to get to facilities and to find out what's going on, and if they're worried about letting everyone know their circumstance, then what Verily Connect could offer with volunteer support and access with dignity and privacy, so information with health pathways and networking and so on, I think that would have worked well for them. (staff participant)*

### ***Verily increased support, increased flexibility***

The social and emotional support afforded by Verily was highly valued by carers. The carers appreciated the ability to give and receive help and support from other carers.

*Somebody always knows something different that you don't know, so I'm quite happy to look at those things. You'd read, oh yeah, I know that, oh, that's a good idea. So there will always be something that you hadn't come across or you hadn't thought of. The same like I could tell somebody that and they'll think, “oh, that's a good idea”, you know? Whereas their input might be something different as well that I hadn't thought of or I don't know. (carer participant)*

Carers considered that Verily resulted in more access to support than they had previously received. Verily provided access to information and support more flexibly and more constantly than other types of information and support provision.

*It's just a really great support to have when you're in a small community and you don't have access to a lot of different services; that you can use these online services to get support. (carer participant)*

*I think it gives a new type of support ... that support is not there in exactly the same way with other organisations. The information might be, but the way it's provided is not. The same, if you've got a face to face group ... they send you newsletters and they have information sessions. They're all things I can't necessarily get to face to face ... because you're working and you're caring, you don't necessarily have time to get out to be face to face. So, anything that brings it in to you is much better.  
(carer participant)*

*I like things [online] like that, that you can keep going back to, like it's still there... not so much that you're learning but I like repetition. Like I like things there that you can go back to... I don't know if it's because I'm tired or whatever but I often forget things... I am one to refer to websites for different things for that reason, that you can go back and read over it again or whatever.  
(carer participant)*

### **“I've learned a lot over the time”**

The information provided on the Verily Connect app was deemed to be helpful, useful, and just the right amount.

*The website information is useful. There's a whole heap of info on there. (carer participant)*

*I've been on the site. It was quite good... I liked that you could click on and 6–8 different steps – one was signs of dementia. It was quite helpful the section about speaking to people with memory loss and issues. I went through all of them [the guides].  
(carer participant)*

*Sometimes we've got the information, but there is too much information. The simplicity of this probably is a positive, because you're not getting bombarded with too much information. (carer participant)*

## Cost analysis results

### *Resources required to deliver Verily*

#### *Personnel*

##### **Project staff**

The project staff team included project officers and a project manager. A project officer was assigned to each community. A single project officer could manage multiple communities.

The project officers engaged in the following types of tasks:

- Organising community forums and events to advertise the project
- Engaging and liaising with local health and community services
- Administration.

The project manager oversaw all communities and engaged at a higher level in the implementation. Activities that were performed once for all communities, such as higher-level promotion of the Verily project, have been called “overhead activities”.

##### **Health and community service staff**

Staff from local health and community services engaged in the following types of tasks:

- Flyer distribution
- Attending project events
- Speaking with carers about the project
- Attending meetings and trainings
- Engaging with the app and website.

Figure 26 shows the contribution of project staff time and health service staff time to the intervention in each community. Project staff time is further divided into community-specific hours and overhead hours. Project staff time accounts for the majority of hours in all communities, at around 85 percent on average.

## Personnel hours by staff type and community

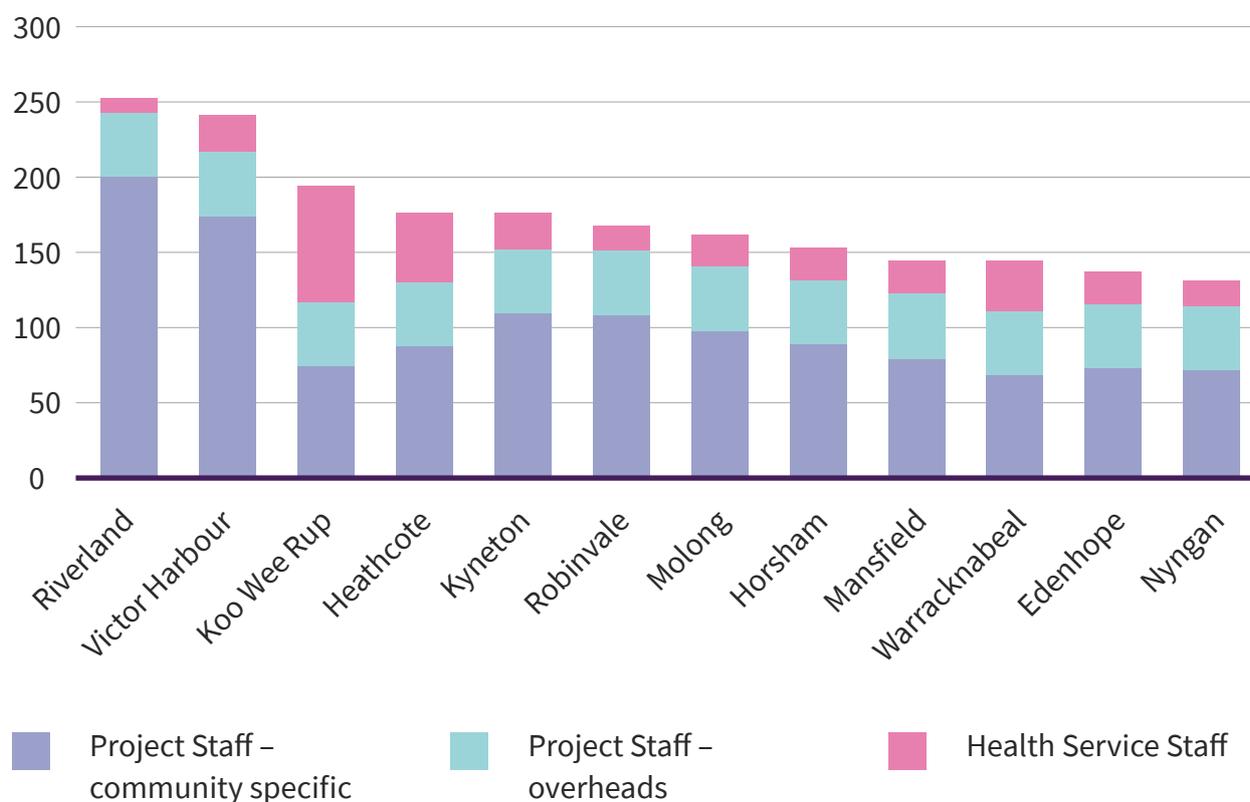


Figure 26. Personnel hours by staff type and community

### Volunteers

The main role for volunteers was to assist carers with using the Verily Connect app and Zoom technology. Volunteers were available in each community to provide face-to-face support for people who had not used or felt unconfident using mobile or online technologies. The average number of hours provided by volunteers in each community ranged from three in Heathcote to 18 in Kyneton. The average number of volunteers in each community ranged from one in Nyngan to six in Victor Harbour.

### Materials

Materials that were needed included advertising materials such as posters and postcards (including graphic design and printing) and general office supplies. Cost of annual app/website maintenance and updates was also included.

### Travel

The project team travelled to the 12 communities for meetings, trainings and inception activities such as recruitment and advertising. Trips were made using several modes including hire cars, university-owned (private) vehicles, flights and taxis. Accommodation was required for many overnight stays, as were meals and other incidentals.

### *Other operating inputs*

Other operating inputs included newspaper and radio advertising in each community and catering at some events.

### *Equipment*

Equipment required for the Verily implementation included:

- **Laptops** – each member of the project team had a Dell laptop which was used for the project. The share of total time it was used for this project was estimated by each project team member.
- **iPads** – an Apple iPad Pro 10.5 inch 64GB was purchased for the Technology Learning Hub in each community.
- **Mobile phones** – a Samsung Galaxy S4 was provided to the Technology Learning Hub in each community.

### *Furniture*

The only furniture required were the tables and chairs in the project team members' offices and the Technology Learning Hubs.

### *Vehicles – capital*

Three private/university-owned vehicles were used for travel. However, most travel was made with hire cars.

### *Buildings – space*

The buildings used were:

- **Project team offices** – for any administrative and project management activities. Offices were located in Wodonga, Bendigo, Orange and Renmark.
- **Health service staff offices** – for liaison with the project team and any administrative activities.
- **Technology Learning Hub** – each community had a Technology Learning Hub in which carers and volunteers could meet. This space was also sometimes used for community meetings and volunteer training.

### *Start-up activities*

Start-up activities were those relating to the app and website development, including meetings. The content development for the guides and collection of information for service directories was completed by project staff. The development of the app software was outsourced.

### *Shared resources*

Many of the resources used for the Verily intervention were shared resources and therefore only a portion of these resources' time was used for the project. Shared resources were allocated to the project based on estimates of the proportion of total time each was used for the project.

## Cost Estimates and Analysis

It is estimated that the Verily model would cost approximately \$27,000 per community per annum on average to run, excluding start-up costs. The two South Australian communities recorded the highest costs (Victor Harbour at \$31,258 per annum and Riverland at \$29,772). The lowest cost community was Nyngan, at \$25,266 per annum (Figure 27).

### Total costs by community

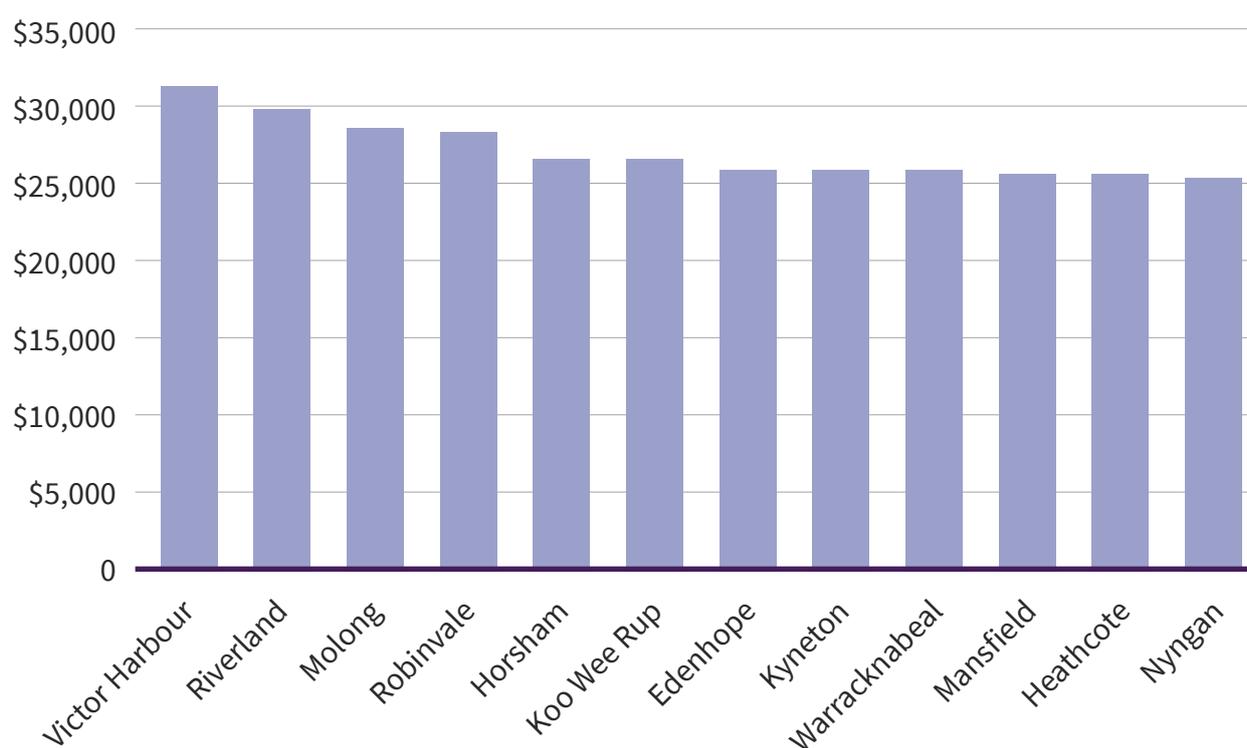


Figure 27: Total costs by community

Personnel time was the largest cost component in all communities, accounting for three-quarters of total costs on average (Figure 28). Most of the cost to run this program is driven by the project staff's time to organise, promote and develop the program in each community. Salaries, wages and other expenses associated with personnel are typically the largest cost item in health programs (Creese & Parker, 1992).

The second largest cost category is travel costs, accounting for 11 percent of costs on average. This includes expenditure on hire cars, estimated operating costs of private vehicles and other travel-related expenditure such as flights, taxis, meals and accommodation. This travel relates to travel by the project team to the communities for meetings, trainings and liaison.

Capital costs account for less than 10 percent of the cost of the Verily project on average, owing to the fact that it is largely an online, virtual service with little capital requirement (and that website and app development costs are reported separately).

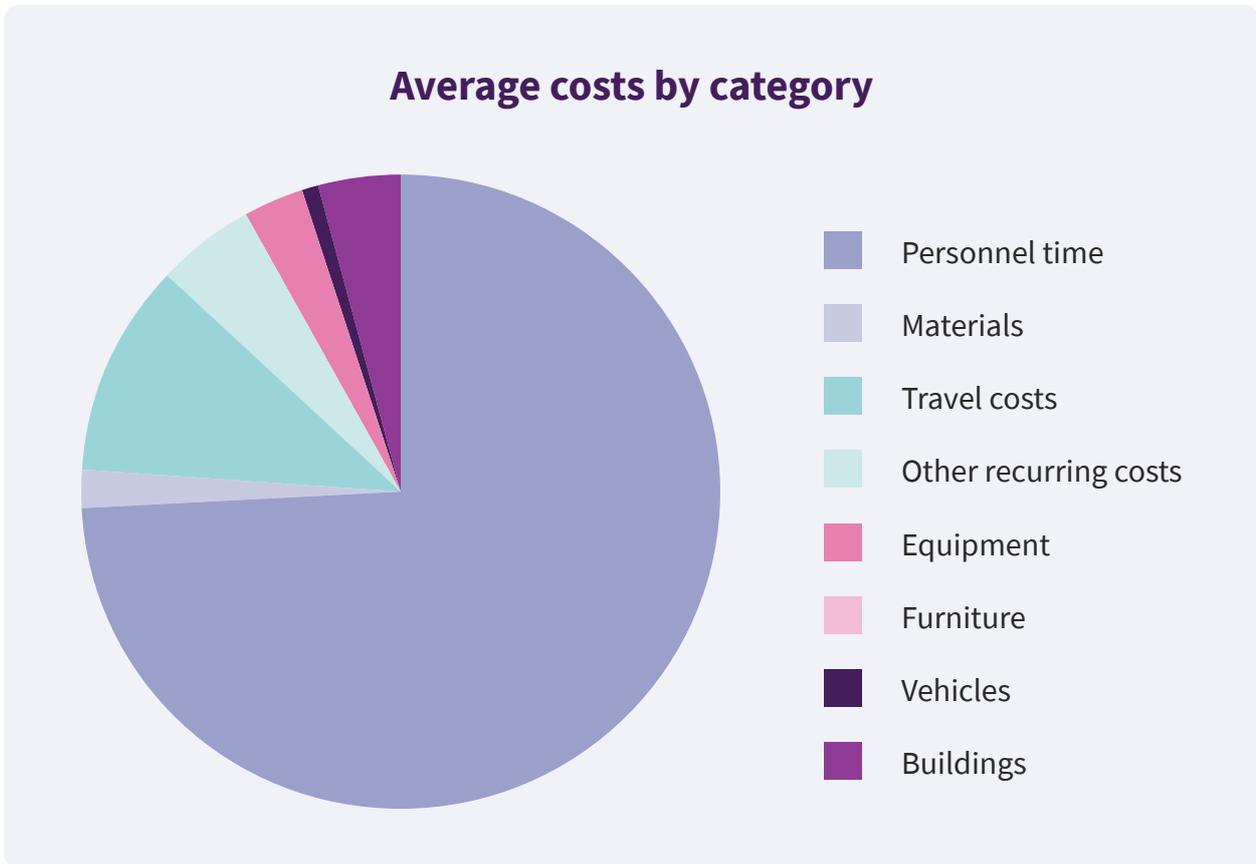


Figure 28. Average costs by category

# Learnings from the project

*The Verily model was well received, and all features were thought to be helpful and contributed to increasing the knowledge and support available to carers.*



All types of participants valued the information provided by the Verily Connect app. The carers appreciated opportunities for videoconference peer support groups, and the local face-to-face support provided by volunteers and the Technology Learning Hub. The Verily model increased access, amount, and flexible options for obtaining information and support. Feedback about the Verily Connect app indicated that it was very easy to use, informative, and aesthetically pleasing, which added to its accessibility and helped to motivate people to use it.

The focus on involving whole communities also worked well. It meant that different stakeholder perspectives could be heard and considered in the project design and implementation. A whole community perspective meant that increasing community dementia-friendliness was more likely because a range of different community members could improve their understanding of dementia, of living with dementia, and of caring for and including persons living with dementia. Through shared endeavours, relationships between researchers and health service partners and other community representatives were also strengthened.

Plans for future improvements to the Verily Connect app include adding images created by Aboriginal and Torres Strait Islander artists, adding a glossary of commonly used terms, and adding a guide about how to reduce the risk of developing dementia. The video-conference support group meetings could be improved by providing training for carers to take on a leadership and organisational role for the meetings. By preparing carers for such roles, it is anticipated that more peer support meetings could be offered, which would further increase volume of and accessibility to support if the Verily model was to be implemented at a larger scale.



# Next steps

*The Verily model has potential to be scaled up by making the Verily Connect app and project artefacts available across Australia and potentially across the world.*

The project team has already taken steps to facilitate this outcome:

- Access to the app is currently available for free and from any location. New users need to register to gain access
- *A Toolkit to develop a Virtual Dementia Friendly Community* is available for download from [verilyconnect.org.au](https://www.verilyconnect.org.au)
- Training materials are available on request.

In order for the project to be adopted more widely, collaboration is needed from an organisation that can implement the Verily model at scale (for example, Dementia Australia or Alzheimer's Disease International). Such collaboration would enable backing and governance for an ongoing project manager and /or project officer, who has a primary role for implementing Verily. Securing ongoing sponsorship will improve sustainability of implementing the Verily model and increase buy-in from stakeholders (carers, health and community staff, and volunteers).



# References

Australian Bureau of Statistics. (2019). Survey of Motor Vehicle Use, Australia, 2018 (cat. no. 9208.0). Retrieved from [abs.gov.au/AUSSTATS/abs@.nsf/Lookup/9208.0Main+Features112%20months%20ended%2030%20June%202018?OpenDocument](https://abs.gov.au/AUSSTATS/abs@.nsf/Lookup/9208.0Main+Features112%20months%20ended%2030%20June%202018?OpenDocument)

Australian Bureau of Statistics. (2020). Average Weekly Earnings, Australia, Nov 2019 (cat. no. 6302.0).

Australian Government, Australian Taxation Office. (2019a). Income Tax: Effective Life of Depreciating Assets (applicable from 1 July 2019).

Australian Government, Australian Taxation Office. (2019b). Income Tax: what are the reasonable travel and overtime meal allowance expense amounts for the 2019–20 income year?

Australian Government, Fair Work Ombudsman. (2019c). Pay Guide – Health Professionals and Support Services Award 2010.

Australian Government, Fair Work Ombudsman. (2019d). Pay Guide – Higher Education Industry – Academic Staff – Award 2010.

Australian Government, Fair Work Ombudsman. (2019e). Pay Guide – Local Government Industry Award 2010.

Australian Government, Fair Work Ombudsman. (2019f). Pay Guide – Nurses Award 2010.

Australian Government, Fair Work Ombudsman. (2019g). Pay Guide – Social, Community, Home Care and Disability Services Industry Award 2010.

Bauer, M., Fetherstonhaugh, D., Blackberry, I., Farmer, J., Morley, C. & Morgan, D. (2015). Identifying support needs to improve rural dementia services: A Delphi consultation study. Building Healthy Communities Research Focus Area, La Trobe University.

Blackberry, I., Farmer, J., Morley, C., Mahoney, A. M., Douglass, D., Torabi, T., Wilding, C., Babak, M., Morgan, D. (2017). Evaluation of Service Navigation and Networking for Dementia care in Rural Communities (SENDER) app. 21st IAGG World Congress of Gerontology and Geriatrics (IAGG), 23–27 July 2017, San Francisco, California.

- Budget Direct. (2020). Car Running Costs in Australia 2019. Retrieved from [budgetdirect.com.au/car-insurance/research/car-owner-cost-statistics.html](https://budgetdirect.com.au/car-insurance/research/car-owner-cost-statistics.html)
- Creese, A., & Parker, D. (1992). Cost analysis in primary health care: A training manual for programme managers. Geneva: Geneva: Division of Strengthening Health Services, World Health Organization.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation science : IS*, 4(1), 50. doi:10.1186/1748-5908-4-50
- Elvish, R., Cawley, R., & Keady, J. (2014). The experiences of therapy from the perspectives of carers of people with dementia: An exploratory study. *Counselling and Psychotherapy Research*, 14(1), 56–63.
- 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.
- Hemming, K., Haines, T. P., Chilton, P. J., Girling, A. J., & Lilford, R. J. (2015). The stepped wedge cluster randomised trial: rationale, design, analysis, and reporting. *BMJ : British Medical Journal*, 350(feb06 1). doi:10.1136/bmj.h391
- Hemming, K., Taljaard, M., & Forbes, A. (2017). Analysis of cluster randomised stepped wedge trials with repeated cross-sectional samples. *Trials*, 18: 101–101.
- Highfield, L., Rajan, S. S., Valerio, M. A., Walton, G., Fernandez, M. E., & Bartholomew, L. K. (2015). A non-randomized controlled stepped wedge trial to evaluate the effectiveness of a multi-level mammography intervention in improving appointment adherence in underserved women. *Implementation Science*, 10(1), 143. doi:10.1186/s13012-015-0334-x
- Hussey, M.A. & Hughes, J.P. (2007). Design and analysis of stepped wedge cluster randomized trials. *Contemp Clin Trials*, 28(2):182–191.
- Mills, K (2017). HelpDem: Skilled Volunteers for Dementia. FRRR – Foundation for Rural and Regional Renewal grant awarded 2017
- O’Connell, M. E., Crossley, M., Cammer, A., & Morgan, D. (2014). Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias. *Dementia*, 13(3), 382–395.

- Papastavrou, E., Andreou, P., Middleton, N., Tsangari, H., & Papacostas, S. (2015). Dementia caregiver burden association with community participation aspect of social capital. *Journal of Advanced Nursing*, 71(12), 2898–2910.
- Phillipson, L., Magee, C., Jones, S., Reis, S., & Skaldzein, E. (2015). Dementia attitudes and help-seeking intentions: an investigation of responses to two scenarios of an experience of early signs of dementia. *Aging & Mental Health*, 19(11).
- RACV. (2020). Car running costs 2019. Retrieved from [racv.com.au/on-the-road/buying-a-car/car-running-costs.html](http://racv.com.au/on-the-road/buying-a-car/car-running-costs.html)
- Schofield, H. (1998). Family caregivers: Disability, illness and aging. St Leonards, N.S.W: Allen & Unwin in association with the Victorian Health Promotion Foundation (VicHealth).
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240–249.
- Sherbourne, C. D. & Stewart, A. L. 1991. The MOS social support survey. *Soc Sci Med*, 32, 705-14.
- Uleman, J. S., Rhee, E., Bardoliwalla, N., Semin, G., & Toyama, M. (2000). The relational self: Closeness to ingroups depends on who they are, culture, and the type of closeness. *Asian Journal of Social Psychology*, 3(1), 1–17. doi:10.1111/1467-839X.00052
- Umstattd Meyer, M. R., Janke, M. C., & Beaujean, A. A. (2014). Predictors of older adults' personal and community mobility: Using a comprehensive theoretical mobility framework. *The Gerontologist*, 54(3), 398–408.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden<sup>1</sup>. *The Gerontologist*, 20(6), 649–655. doi:10.1093/geront/20.6.649



# Appendices

## Appendix 1. Initial demographic and background information

In the first survey, carers were asked for the following demographic information:

- Age
- Gender
- Identification as Aboriginal or Torres Strait Islander
- Speak a language other than English at home
- Postcode
- Highest level of education completed
- Have a health care card
- Have private health insurance
- Receive a home care package

Carers were asked about their caring relationship and use of services:

- Relationship to the person with dementia or cognitive impairment
- Confirmed diagnosis of dementia or cognitive impairment (If yes, length of time)
- Length of time in caring role
- Location of person being cared for (Options: lives with carer, lives in same postcode as carer, lives 50–100km from carer, lives more than 100km from carer)
- Had unexpected visit to hospital in previous 2 months
- Services used in previous 2 months:
  - GP
  - Nursing
  - Home help
  - Private domestic services
  - Private gardening service
  - Community transport

- Allied health care
- Day care
- Respite care
- Meals on wheels
- Other
- Person who organised or referred for these services
- Receipt of any other kind of support? (If yes, what kind of support and from whom?)
- Services/support needed but not currently received? (If yes, what other services or support is needed?)
- Level of difficulty/ease in accessing services (Options: Very difficult, Difficult, Neither difficult or easy, Easy, Very easy)
- Description of a dementia friendly community
- Dementia friendliness of community? Agreement/disagreement with following statements (Options: Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree):
  - There is awareness of dementia in my community
  - Information about dementia is available in my community
  - Social activities for people with dementia are available in my community
  - The physical environment allows people with dementia to move about safely and easily
  - Affordable, accessible transport is available in my community
  - Healthcare is easily accessible in my community
  - Our community has support groups for people with dementia and cognitive impairment
  - Our community has support groups for carers in the community
  - Our community has groups and activities for people with dementia and cognitive impairment and the people who care or them to attend together

Carers were asked about their usage of and familiarity with technology:

- Have a landline telephone
- Have a mobile phone (If yes, standard or smartphone)
- Have a tablet device (If yes, iPad, Android, Windows/other)
- Used a computer in the previous month (If yes, home computer or public computer)

- Sent messages by email or text in previous month (Options: Never, Rarely, Some day, Most days)
- Used social media in previous month (Options: I have not used social media, Facebook, Twitter, Skype, Instagram, Linked In, Google Hangouts, Other)
- Completed the following online in the previous month
  - Shop for groceries or personal items
  - Pay bills or do banking
  - Contact or find any health care provider
  - Manage Medicare or health insurance
  - Get information about health conditions
  - Use the My Aged Care website
  - Communicate with others (e.g. by Skype or social media)
- Have Internet access at home (If yes, wi-fi, broadband, other)
- Have problems with lack of mobile phone service at home



## Appendix 2. Ongoing demographic and background information

The following information was asked for in surveys 3, 5, and 6. The purpose of asking these questions was to ascertain changes to demographic and background information across the 12 months of the project.

Demographic information:

- Have a health care card
- Have private health insurance
- Receive a home care package

Use of dementia services:

- Received a diagnosis of dementia or cognitive impairment since last completed a Verily questionnaire
- Location of person cared for (Options: lives with carer, lives in same postcode as carer, lives 50–100km from carer, lives more than 100km from carer)
- Had unexpected visit to hospital in previous 2 months (If yes, provide details)
- Services used in previous 2 months:
  - GP
  - Nursing
  - Home help
  - Private domestic services
  - Private gardening service
  - Community transport
  - Allied health care
  - Day care
  - Respite care
  - Meals on wheels
  - Other
- Person who organised or referred for these services
- Receipt of any other kind of support (If yes, what kind of support and from whom?)
- Services/support needed but not currently received (If yes, what other services or support is needed?)
- Level of difficulty/ease in accessing services (Options: Very difficult, Difficult, Neither difficult or easy, Easy, Very easy)

- Dementia friendliness of community. Agreement/disagreement with following statements (Options: Strongly disagree, Disagree, Neither agree nor disagree, Agree, Strongly agree):
  - There is awareness of dementia in my community
  - Information about dementia is available in my community
  - Social activities for people with dementia are available in my community
  - The physical environment allows people with dementia to move about safely and easily
  - Affordable, accessible transport is available in my community
  - Healthcare is easily accessible in my community
  - Our community has support groups for people with dementia and cognitive impairment
  - Our community has support groups for carers in the community
  - Our community has groups and activities for people with dementia and cognitive impairment and the people who care for them to attend together

Usage of and familiarity with technology:

- Have a landline telephone
- Have a mobile phone (If yes, standard or smartphone)
- Have a tablet device (If yes, iPad, Android, Windows/other)
- Used a computer in the previous month (If yes, home computer or public computer)
- Sent messages by email or text in previous month (Options: Never, Rarely, Some day, Most days)
- Used social media in previous month (Options: I have not used social media, Facebook, Twitter, Skype, Instagram, Linked In, Google Hangouts, Other)
- Completed the following online in the previous month
  - Shop for groceries or personal items
  - Pay bills or do banking
  - Contact or find any health care provider
  - Manage Medicare or health insurance
  - Get information about health conditions
  - Use the My Aged Care website
  - Communicate with others (e.g. by Skype or social media)
- Have Internet access at home (If yes, wi-fi, broadband, other)
- Have problems with lack of mobile phone service at home

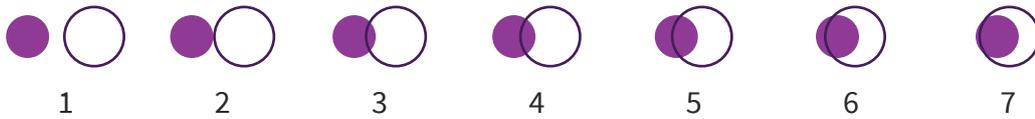
## Appendix 3. Perception of social connection

A visual social connection scale that was adapted from Uleman et al. (2000) and used to obtain the carers' perception of social connection to other carers of people living with dementia and service providers. Carers were asked two questions:

1. Which image best represents how close or connected you feel to other carers of people living with dementia? (Dark circle is you and light circle is other carers of people with dementia) (Options: check image 1, image 2, image 3, image 4, image 5, image 6, image 7)



2. Which image best represents how close or connected you feel to service providers? (Dark circle is you and light circle is service providers) (Options: check image 1, image 2, image 3, image 4, image 5, image 6, image 7)



## Appendix 4. ZBI survey items

No.	Question
1	Do you feel that your relative asks for more help than he or she needs?
2	Do you feel that because of the time you spend with your relative you don't have enough time for yourself?
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
4	Do you feel embarrassed about your relative's behaviour?
5	Do you feel angry when you are around your relative?
6	Do you feel that your relative currently affects your relationship with other family members?
7	Are you afraid about what the future holds for your relative?
8	Do you feel that your relative is dependent upon you?
9	Do you feel strained when you are around your relative?
10	Do you feel that your health has suffered because of your involvement with your relative?
11	Do you feel that you don't have as much privacy as you would like, because of your relative?
12	Do you feel that your social life has suffered because you are caring for your relative?
13	Do you feel uncomfortable having your friends over because of your relative?
14	Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?
15	Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
16	Do you feel that you will be unable to take care of your relative much longer?
17	Do you feel that you have lost control of your life since your relative's illness?
18	Do you wish that you could just leave the care of your relative to someone else?
19	Do you feel uncertain about what to do about your relative?
20	Do you feel that you should be doing more for your relative?
21	Do you feel that you could do a better job in caring for your relative?

## Appendix 5. Publications and conference presentations arising from this project

### Publications

Blackberry I, Wilding C, Perkins D, Greenhill J, Farmer J, Bauer M, Winbolt M, Morley C, O'Connell M, Morgan D (December 2018/January 2019). Virtual dementia-friendly rural communities. *Australian Journal of Dementia Care*, 7(6), pp. 11–13.

### Conference presentations

Blackberry I, Wilding C, Farmer J, Morgan D, O'Connell M, Bauer M, Winbolt M, Greenhill J, Perkins D (2018). Verily Project on Virtual, Dementia-friendly Rural Communities: Perspectives from Australia. *Ageing and Society: Eighth Interdisciplinary Conference*, 18–19 September 2018, Tokyo, Japan

Wilding C (2018). Developing virtual dementia friendly rural communities: challenges and opportunities. *51st Australian Association of Gerontology Conference*, 21–23 November 2018, Melbourne, Australia

Blackberry I, Wilding C, Perkins D, Greenhill J, Farmer J, O'Connell M, Winbolt M, Bauer M, Morley C, Morgan D (2019). Building a virtual online community to support rural carers: Verily Connect project. *15th National Rural Health Conference*, 24–27 March 2019, Hobart, Australia

Blackberry I, Wilding C, Greenhill J, Perkins D, Morley C, Winbolt M, Bauer M, Morgan D, O'Connell M, Davis H, Farmer J, Royals K, Rasekaba T, Gottshall K, Hamiduzzaman M (2019). Creating virtual dementia-friendly rural communities: Are we ready yet? *International Association of Gerontology and Geriatrics European Region Congress 2019*, 23–25 May 2019, Gothenburg, Sweden

Blackberry I, Wilding C, Chisholm M, Winterton R, Davis H, MacDermott S, Rae M, Poynton D (2019). Living well with dementia: What does the future look like for dementia research and knowledge exchange in rural and regional Australia. *NHMRC National Institute for Dementia Research (NNIDR) Australian Dementia Forum 2019*, 13–14 June 2019, Hobart, Australia

Wilding C, Blackberry I (2019). Verily Connect model: virtual support for rural dementia care. *52nd Australian Association of Gerontology Conference*, 5–8 November 2019, Sydney, Australia

Blackberry I, Wilding C, Greenhill J, Perkins D, Morgan D, O'Connell M, Davis H, Winbolt M, Bauer M, Morley C, Farmer J, Royals K, Rasekaba T, Gottschall K, Hamiduzzaman M, Robinson A (2020). Lessons from a pragmatic trial of virtual dementia friendly rural communities in Australia. *34th International Conference of Alzheimer's Disease International*, 19–21 March 2020, Singapore, Malaysia (Abstract was accepted: Conference was deferred due to the Covid-19 global pandemic)

## Appendix 6. Project partners



**Molong HealthOne  
General Practice**

**Riverland  
General Hospital**

**Nyngan  
Health Service**



**verilyconnect**

An Australian Government Initiative

 [verilyconnect.org.au](https://verilyconnect.org.au)

 02 6024 9718

 [verilyconnect@latrobe.edu.au](mailto:verilyconnect@latrobe.edu.au)

