

Empowering Older People

in Accessing Aged Care Services in a Consumer Market

PROJECT FINAL REPORT



FUNDED BY

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YEAR

May 2020

RECOMMENDED CITATION

Blackberry, I., Wilding, C., Chisholm, M., Wishart, D., Keeton, W., Chan, C., Fraser, M., Boak, J., Knight, K., & Horsfall, L. 2020. Empowering older people in accessing aged care services in a consumer market. Project final report. John Richards Centre for Rural Ageing Research, La Trobe University, Wodonga.

ISBN: 978-0-6488338-2-6

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ACKNOWLEDGEMENTS

FUNDING

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We gratefully acknowledge and thank all the older people, carers and health service staff who participated in this project. Without their generous participation this project would not have been possible.

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Executive summary

BACKGROUND

The Australian population is ageing with one third residing outside metropolitan areas. Supporting older people to live independently in their communities is critical. Older people in rural communities have limited choice of services compared to their metropolitan counterparts and exacerbating this further, rural older people can experience barriers due to the “digital divide”. This divide occurs not only because of poor digital infrastructure and internet connectivity, but also results from literacy and socio-economic factors. The interim report from the Royal Commission into Aged Care Quality and Safety, titled Neglect, highlighted issues with My Aged Care and lack of evidence from rural older people. The Empowering Older People in Accessing Aged Care Services in a Consumer Market research project explored the impacts of a Consumer Directed Care model for the provision of aged care home services in rural areas.

There were two main aims:

1. to identify barriers and facilitators experienced by older people when accessing, assessing, and acting on information (particularly online information) and making choices about aged care services provided under the Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP).

2. to recommend strategies at the local and national level to support older people to make informed choices.

This research project brought together an interdisciplinary advisory team from the fields of nursing, allied health, psychology, gerontology, economics, consumer policy, and law, and a rural older person. Semi-structured interviews were conducted with 20 older adults in receipt of either a CHSP or an HCP and living in a rural or regional area of Victoria or New South Wales. The older people were asked about their lived experiences of finding and using information to make choices about aged care home service provision, and about their experiences of accessing and receiving these services. Data collected between November 2019 and April 2020 were analysed thematically from rural older people’s perspectives. A Modified Delphi Method was used with the 20 older adults and 10 rural health service providers to further develop, prioritise and gain consensus about the issues of importance to rural older people when accessing information and services through CHSP and HCP.



KEY FINDINGS

Our findings demonstrate the Consumer Directed Care model has significant limitations in rural areas and in small rural and regional towns. The lived experience of most of the older people in our study was that they lacked a choice of provider in their rural area. The markets in these rural areas are exceedingly “thin”, with often only one service provider available and only basic services available in their area. A lack of the option of an alternative provider also meant that rural older people had to endure poor service. Given that in many rural areas there is insufficient population density to support a viable range of services and service providers, the Consumer Directed Care model may not be appropriate or feasible for rural and regional Australia.

Older rural people were found to experience lengthy waiting times to receive their CHSP or HCP. The reason for these long delays is unknown; it could be due to general funding shortfalls or a lack of service provision in rural areas.

It was sometimes difficult for rural older people to access information. The information currently provided by My Aged Care can be so much as to be overwhelming and much of it may be irrelevant. The participants had trouble accessing online information. Some older people lack knowledge and skill in accessing online information and they reported that the location of online information could change frequently. Online search tools designed to filter information, for example to find services according to geographical location, are woefully inaccurate and include volumes of irrelevant materials. It is difficult for rural older people to compare providers because information is not provided in a format that enables equal comparison.

Older people may be reliant on others to help them identify information and accept the need for services. Not all older people are aware of the existence of aged care home services and they may be in denial of needing services. Therefore, older people depend on family, friends, and health workers to provide them with information about aged care services and service providers. Older people also learn about aged care home services through word of mouth and attending community education.

Some health staff lack knowledge of My Aged Care. This is problematic for older people who count on health workers to give them the information they need.

Rural older people may also experience barriers to accessing aged care home services. Rural older people can experience difficulty in negotiating with service providers. Rural older people perceive that switching providers is costly and difficult. There is a lack of transport options in rural areas and this is especially problematic if older people need to attend larger regional cities or metropolitan areas to receive services (such as specialist medical or allied health services). Many rural older people have reduced financial capacity to source alternative services or fund solutions for access problems (such as hiring taxis to attend appointments).

Some rural older people had a highly competent and caring case manager, who was able to provide them with relevant information, guide them through the process of obtaining services, and advocate for them (for example, in upgrading their package level). Such a case manager greatly facilitated rural older people’s access to aged care home services.

RECOMMENDATIONS

1. Improve equitable access to rural and regional aged care services in thin markets
2. Dedicate funding to establish an independent aged care coordinator who has knowledge of the local context and can dispense comprehensive locally relevant information, within every rural Local Government Area
3. Provide mandatory training and continuing professional development for primary health care teams to promote ageing well and proactively support older people to access aged care services
4. Dedicate funding for proactive follow-up for 75+ health assessments
5. Review information provision and comparison tools on the My Aged Care website to ensure they are fit for purpose in a rural context
6. Review the My Aged Care website and phone call centre to ensure they are easily accessible for rural older people
7. Deliver a targeted awareness raising campaign and education that highlights the importance of timely access to community aged care services

1 Background

Older people can be supported to stay at home for longer and with better quality of life through receiving home support services, such as assistance with domestic cleaning, social support, grocery shopping, meal preparation, and home maintenance. In Australia, the Federal Government provides financial support to obtain home support services through its aged care services programs: the Commonwealth Home Support Programme (CHSP) and the Home Care Packages (HCP) program.

As part of the Living Longer Living Better Aged Care Reform, the Consumer Directed Care (CDC) model was embedded into mainstream aged care program delivery (Commonwealth of Australia, Department of Health, 2012). The Consumer Directed Care model places a person at the centre of decision-making in determining what services they need to support them (Commonwealth of Australia, Department of Health, 2012, 2018). Although Consumer Directed Care provides greater choice and control in service provision, it

simultaneously places a greater responsibility on older people for managing services and decision making (Low et al., 2012). As there are gaps in understanding how Consumer Directed Care has been applied in rural populations (Commonwealth of Australia, 2019; Martin-Hobbs, 2020), it is worthwhile to evaluate its impacts upon older people.

The Consumer Policy Research Centre (CPRC) has previously undertaken research that investigates influences on consumer-driven markets. In 2018, the CPRC published two key reports that investigated the decision-making of consumers within a consumer-driven market: *The Five Preconditions of Effective Consumer Engagement* (Solomon & Martin-Hobbs, 2018) and *“But are they any good?” The value of service quality information in complex markets* (Martin-Hobbs, 2018). The first report illustrated that for consumers to make effective decisions, the following five preconditions ought to be in place (Solomon & Martin-Hobbs, 2018, p. 2):

Precondition 1. Barriers to access for consumers with reduced capacity or vulnerability are removed: Fair access to markets requires outreach interventions and direct assistance mechanisms which address barriers for vulnerable consumers experiencing reduced capacity.

Precondition 2. Key product information is disclosed in a relevant, clear and comprehensible manner: Consumers can easily assess information about different products or services, potentially through comparison tools, to enable simple and accurate comparisons.

Precondition 3. Comparison tools are accurate, simple and effective: Consumers can easily act on key information to switch providers with minimal financial or thinking costs which can create barriers to switching to a product that better suits their needs.

Precondition 4. Switching costs (financial and non-financial) are low: Consumers can easily act on this information, with minimal switching costs or thinking costs that create barriers for consumers to switch from their current provider or product to an alternative that better suits their preferences.

Precondition 5. Consumers are aware of how to access, assess, and act on information: Consumers need to be made aware of how they can access support and key information, compare offers and switch providers. If consumers are unaware of any of these former preconditions, they may disengage regardless of the quality of interventions to address these elements.

The second report highlighted that there is a lack of information about service quality that makes decision-making more difficult for consumers (Martin-Hobbs, 2018). Information imbalances and gaps in information meant that consumers did not have the right information on which to make assessments of service and this in turn resulted in the failure of the market to compete to provide a better quality service, which is a key motivator for having a consumer-directed market (Martin-Hobbs, 2018). These previous studies were used as a starting point for the study described in this report.

The CHSP and HCP program can only be obtained through My Aged Care (Australian Government, 2019), which is an Australian Federal Government program that covers assessments of older people and assigns funding for community aged care service delivery. To access My Aged Care, older people need to have the knowledge, resources, and ability to contact the My Aged Care service by telephone or by the online digital portal (Aged Care Guide, 2017). However, in Australia, people aged 65 years and older are the least likely sub-population to access the Internet; in addition, women, people on



lower incomes, or not living in metropolitan areas are even more unlikely to be digitally included (Malta & Wilding, 2018). According to the Council of the Ageing (COTA, 2018), a third of older people who live outside metropolitan areas experience barriers to online access due to the “digital divide” (Walker, 2017), lack of digital infrastructure, lack of internet connectivity, and socio-economic factors. Despite rural older Australians being among the most disadvantaged group to access online information, there is a lack of research evidence about their experiences of accessing the consumer-directed market. Therefore, we undertook a study to collect information about the lived experiences of older people when accessing, assessing and acting on information. We wanted to find out more about the barriers and facilitators to exercising choice in a consumer-driven

market applied to the aged care system. Our findings will be submitted to the Royal Commission into Aged Care Quality and Safety to inform policy development regarding “allowing people to exercise greater choice” (Commonwealth of Australia, 2018).

The aims of the project were to:

1. identify barriers and facilitators experienced by older people when accessing, assessing, and acting on information (particularly online information) and making choices about services provided under the CHSP and the HCP program; and
2. recommend strategies at the local and national level to empower older people to make informed choices.

2 Methodology

There were two parts to this project: Stage One was interviews with older people who received or had applied for aged care services provided under the CHSP or the HCP program. Stage Two used a Modified Delphi Method (Schneider et al., 2016), in which participants were asked to complete two rounds of surveys and attend a consensus meeting that were used to decide on the highest priority issues.

2.1 Interviews

We conducted 20 semi-structured interviews with older people living in rural Victoria and in the border region of Victoria and New South Wales. The interviews were undertaken in the participants' homes.

The interviews began by asking some general background questions and then proceeded to questions asking about access to aged care services and decision-making about these services (see **Appendix 1**). At the end of the interview, the participants were asked to complete a journal for three months (directly following their interview) that catalogued their interactions with providers, services, and/or My Aged Care. The purpose of the journals was to collect prospective data about accessing, assessing, and acting on information about aged care and support services.

2.2 Modified Delphi Method

Twenty older people who completed interviews, together with 10 health service providers were invited to participate in the second part of the research. In this part, there were three rounds of consultations with participants to rank the highest priority issues and develop consensus recommendations.

Delphi Round One

After thematically analysing the interview data, the research team proposed 15 key statements that distilled the participants' experiences of accessing and assessing information about services and their decision-making

process on service provision. The participants were asked to comment on each statement (for example, expand upon, express agreement or disagreement, suggest changed wording and phrasing of concepts). Next, they were asked to select the 5 statements most important to them (or for service provider participants, the most important statement for older people in their communities) and rank these statements from 1 to 5: with 1 being the most important statement to the participant through to 5 as being of lesser importance than the previous statements.

Delphi Round Two

After analysing the Delphi Round One data, the research team proposed 9 key statements that were the aggregate top ranked statements from Delphi Round One and which had also been modified according to the comments made by participants during round one. In Delphi Round Two, participants were asked to select the 3 most important statements to them (or to older people in their communities) and then rank these statements from 1 to 3: with 1 being the most important statement to the participant and 2 and 3 being important but of lesser importance than the statement ranked number 1.

Delphi Round Three

After analysing the Delphi Round Two data, the research team proposed 4 key statements that were the aggregate top ranked statements from Delphi Round Two. The research team reflected on findings from both stages of the research and proposed 4 preliminary recommendations. The final Delphi statements and the preliminary recommendations were circulated to the participants and then a meeting was conducted to gain consensus and discuss the recommendations. Participants and research team members attended the meeting, which was held by Zoom video-conference.

More details about ethics, recruitment, and data analysis can be found in **Appendix 2**.

3 Participants

Of 20 older people recruited into the study, there were 16 (80%) in rural and regional Victoria, one (5%) in outer metropolitan Melbourne, Victoria, and three (15%) in city of Albury, NSW (a city adjacent to Wodonga, Victoria). There were 15 female (75%) and five male (25%) participants. The ages of participants ranged from 66 to 96 years with an average age of 81 years.

Sixteen (80%) participants reported having a person to support them at home and four (20%) did not receive direct support from family or friends. Ten (50%) participants were supported by their spouse/partner, six (30%) were supported by their child/children. Ten (50%) participants received supports under CHSP. Eight (40%) participants received an HCP; two (10%) participants were approved for, but had not yet received, an HCP. For more detail see **Appendix 3**.

See **Figure 1** for a map that details how many participants were interviewed according to Local Government Areas. More detail about participant locations according to the Modified Monash Model (MMM) and Urban Centres and Localities (UCL) population data is located in **Appendix 4**. The MMM is a geographical classification system (numbered 1-7). The higher the MMM number, the more rural or remote the area is classified (<https://www.health.gov.au/health-workforce/health-workforce-classifications/modified-monash-model>). Of the 20 participants, 8 (40%) resided in MMM Level 2 communities, three (15%) in MMM Level 3 communities, one (5%) in an MMM Level 4 community, and 8 (40%) in MMM Level 5 communities. According to UCL population data (see **Appendix 4**), there were five participants (25%) living in populations of fewer than 500, five participants (25%) living in populations of 500-9,999 persons, and ten participants (50%) living in populations of 10,000-49,999 persons.



Figure 1. Geographical locations of participants

For the second part of the research, 26 participants completed a Delphi Round One survey. These participants were 19 older people (95% response rate) and 7 service providers (70% response rate). There were 21 completions of the Delphi Round Two survey: 18 older people (90% response rate) and three service providers (30% response rate). For Delphi Round Three, there were 16 attendees at the meeting: eight older people, three service providers, and five research team members.

Table 1. Participant numbers and types for Delphi phase

Delphi Round	Older people	Staff	Researchers
One (n=26)	19	7	
Two (n=21)	18	3	
Three (n=16)	8	3	5

4 Findings

The purpose of this research was to identify the barriers and enablers that older rural people experienced when accessing, assessing, and acting on information and making choices about aged care service packages. Some older rural people were satisfied with access to information and making choices about obtaining the services they needed to support them at home. In general, the older people who were content with the process were those people living in larger regional cities and who felt they received a good quality and supportive service from their service provider. However, there were other older rural people who identified a range of barriers that significantly impeded them in accessing, assessing, and acting on information and making choices about aged care service packages. These barriers included that:

- some rural older people and some health service providers were unaware of the availability of home-based aged care services and/or how to access these services.
- some rural older people found it difficult to access information about locally available services.
- in some rural areas there was a lack of choice of community aged care service providers; in some rural areas there was only one provider, and access to even this provider could be difficult with long waiting times, lack of quality service provision, and gaps in service provision.
- The Consumer Directed Care model, on which the provision of community aged care service packages is predicated, could possibly be made to work for older rural people living in larger regional cities and in which there is more than one viable aged care service provider. However, the following changes would still be required:
 - clearer, simpler, more transparent, and more user-friendly provision of information about services, service providers, service inclusions and exclusions, costs, and especially local service providers.
 - removal of irrelevant service provision information, especially information about service providers who do not actively provide services within an older person's postcode.
 - provision of information by an independent person with good knowledge of local service providers and service provision mechanisms.
 - provision of information about and support from an independent advocacy service (for example, to assist if there are problems with service quality or supply).

For older rural people living in smaller regional and rural towns and areas, the Consumer Directed Care model does not appear to be viable given the lack of choice of aged care service providers. In these areas, there is significant likelihood that older people may not receive a service, may have to wait a very lengthy period of time for service delivery (commonly months, sometimes years), and/or may have no recourse but to accept poor quality service (or go without services altogether).

Another key finding of this study is that some older rural people depend on others – family, friends, health providers – to assist them at one or more stages of the process of accessing, assessing, and acting on information and making choices about aged care service packages.

4.1 Others help older people identify the need for services

Although some older people could see that they required assistance, many of the participants in this study relied on health care providers or family members to tell them or confirm for them that they needed help. There were several reasons why older rural people tended to wait to seek services until prompted by another person:

- Older rural people did not always know that support was available.
- Older rural people considered there were other people who needed services more than they did.
- Health staff could visualise an older person's need for services before the older person was able to notice this need themselves.

Although consumers might identify their own need for help, in this study, we found that older rural people who needed home support services tended to rely upon a family member or health care provider to identify that help was required; for example: "I was in ... Hospital ... and the social worker there said I needed help when I went home, which was quite right... so the social worker said I needed this care package". Sometimes an older person suspects that they may need help and then they seek the advice of a health care provider to confirm that help is needed:

Older person We decided that we didn't need it because there were people far worse off than us

Older person We put it off for a long time

Older person And they convinced us that we should have it for reasons known only to [Health Service]. I could understand where they're coming from, but it's one of those things you very slowly take up because you think "oh not for me"



Older person When you've been self-sufficient in a way – there's always just been us two, so we've always just relied on us two. When it was – it's been mooted a couple of times. We thought "no, there's a lot more people who are far more needy than we are who deserve it". Then when I got to this point where I was shuffling around and I couldn't even go up and down the steps, that was when we said we'll go and see [Health Care Service]. According to the people who assessed us "yes, we were well and truly needing it".

A support person noted that the health service took responsibility for connecting the older person to My Aged Care and to receiving services: "it was [Health Service] that pushed the barrow and they got My Aged Care here to come and assess [older person] ... They pushed me into making contact with My Aged Care... pestered me to get on to My Aged Care". Similarly, a general practitioner recommended seeking help from aged care services:

I spoke with my GP and I said, what services do you think I need to get this right? We had a general discussion about it and then he encouraged me to put in an application to My Aged Care and it came about through that, through discussion with others that are consuming the service. The GP, who's now preparing quite a comprehensive medical care plan for us... Our GP ... I think he referred us to the – for the assessment.

Older people tend to trust health service providers. When health services say that an older person needs help, the older person tends to listen. A support person felt that the health service "convinced us to go with it [a package] ... because they could see where we would be in 10 years' time – we couldn't". An older person relied on her general practitioner's encouragement, before she agreed to accept services: "her backing up that it was necessary, I guess helped make my decision that I should go ahead with it".

4.2 Older people may not be aware that services exist

Although some rural older people knew about the assistance of My Aged Care or its precursor versions of home help and community support, there were also several participants who were unaware of the availability of support services. An older person had heard about the availability of services through her community service work: "you've got to hear about these things from somewhere to know that they're available and actually, I've been a pastoral care visitor with our church and therefore I've learnt a lot about older people and I probably learnt how to access this from that, actually". Another older person was unaware that there were services for older people living in the community.



Interviewer What sort of services were you aware of that were available to you here?

Older person We, well before that, we weren't aware of anything. It was only because they [health service] alerted us to it. I wouldn't have known such a thing existed.

Even though an older person in receipt of an HCP, she was unsure what a "package" actually was; she relied on the researcher to provide an explanation:

Interviewer Do you understand what a package is?

Older person Not really, no. It's to do with the travelling, I must say, this package they were talking about.

Interviewer Your package would actually cover all the services that you get. It would cover your gardening, your home maintenance, as well as your transport. It would cover everything.

Older person Oh, I see. Okay, right.

Another older person was receiving services but was unaware that she might be eligible for a higher level of service provision until a service provider suggested that she could apply.

What prompted me? Well I had been getting help from [service provider] with somebody coming in just doing the floors and things like that for a few years and one of the ladies who had worked at [service provider] was now at this [home care provider] and she said "have you

applied for this?" I said, "I don't know anything about it." I think this was the problem. She said, "well there's money there waiting for everybody that is over 65 if they apply." So, I thought well, I better apply.

There was at least one older person who had heard that there were services available for older people as he had heard advertisements for My Aged Care on the radio:

Interviewer Prior to sort of needing services, were you aware of the My Aged Care website or call centre?

Older person Well, it's advertised all the time. You know it's always on the radio...and everywhere you go to, they say - recommend you contact My Aged Care.

4.3 Others help older rural people find needed information

When seeking information, rural older people tended to rely on others. They found information through service providers, family members, and friends. Sometimes they found information through happenstance.

Rural older people relied on others to help them access information because:

- Some people did not know that services existed.
- Some people encountered challenges in accessing information from My Aged Care.
- Some health services were very proactive in providing information, which meant that older people did not think there was need for further information gathering.

4.3.1 Family, friends and staff help older people find information

Older rural people tend not to seek information by searching for it online; rather, they will seek it by speaking to their general practitioner or other health service provider, or they may ask a peer, a family member or a friend for assistance: “[We found out about services by] talking with friends and colleagues out there ... you sort of share your experiences or knowledge... we got talking to our neighbour, actually, about care in the home.” Similarly, another interviewee found out about services through talking with her neighbour: “The only reason I know there’s somebody who will take you, say, to hospital, and bring you home from hospital, because next door has used it and she goes through the same health [service]. So, it’s word of mouth”.

An older person reported that she did not need to try and seek information because “it was all given to me... It was done for me” by the social worker who identified that she needed an HCP, and who organised a referral for her to My Aged Care. Later, other service provider staff, including her current case manager, assisted her to find information.

Other participants were informed about services by health care providers:

My doctor at the time was pretty good with letting me know different things. Then once I started going to oncology, of course they link you into certain things as well.

I found out via the district nurses that you could obtain meals from ... a community-based food place and they cook up food and they put it in the freezers and mainly provide food.....at [regional centre] Hospital they were wonderful. They were telling me all the services that I could receive from home help to district nursing to Meals on Wheels, and all that. They were great.

Older people may ask a family member to assist them with seeking information. For example, an interviewee recognised that her family member had superior computer skills to her and that it was easier for her to search for information rather than for the interviewee to struggle to do it.

Older person *Well, I don’t research anything. She does. She’s the researcher in the family. She’s the scientist.*

Support person *She knows how to use the very basics on the computer, but she’s not really very good at Google and stuff*

Older person *No.*

Support person *So if she needs anything like that, she just tells me to find it.*

Older person *If I need any research, I just ask her to find out about it.*

Similarly, another older person relied on her family member to source information and coordinate services: “I leave it to [my family member] ... She organises most of it.”

Sometimes friends of older people talked about the availability of services, as they interacted with each other:

I found out because a friend ...told me about it. ... I knew I had to try and do something so I did a bit of phoning around and a couple of friends found out what was going on and they were obtaining already home help themselves for various reasons. So, they gave me a number.

[I] had no idea where to go. No idea. It was word of mouth. It might have been me whingeing one day, which I do a lot of, and somebody said, what about [service provider]? I’d never heard of [service provider] and coming from the country that we came from and an area that was lucky to have a post office ... It was just word of mouth; people that we knew told us about [service provider] and we, and me being, finding everything a problem sometimes, from a depressive point of view, I suppose because I just can’t handle that, trying to search for that. Anyway, it came around and we were able to make - and made - a friend here come one day and he actually, [to] cut a long story short, gave me a number. I rang the number and the rest is history.

4.3.2 Older people find information by happenstance

Older rural people may obtain or hear about potentially applicable services for them by happenstance: that is, they know about available services by having previous experiences of caring for an older relative, through voluntary work, through attending presentations delivered at service clubs (for example, Returned Services League (RSL), Country Women’s Association, Probus, Senior Citizens), or through engagement in community activities (for example, attending a Neighbourhood House): “Well I’ve always known that there’s services available because my mother went through the system”. Similarly, another older person knew services were provided because her mother had received them and in addition the older person had interacted with the aged care support system through paid and voluntary work roles:

Yes, I was aware because way back my mother used to have them... So, I’ve been aware of them for a long while. I’ve worked in aged care. I’ve worked as activities coordinator ... in an adult day centre ... because of my pastoral visiting that I did. I had to ring My Aged Care for a lady who was a friend and desperately needed it and hadn’t done anything about providing for herself. I thought then, you need to do this before you have to have somebody else doing it for you [laughs].

An older person heard about (and subsequently registered for) My Aged Care as part of community activities she and her husband were involved in:

Older person That was because of the work from the hospital they'd sent to us, I think I can't remember what group, but at some time they'd given a talk to older people, to say "hey, this is My Aged Care, and this is what you're going to have to do".

Older person This actually happened at the meeting of the Ladies Auxiliary, someone came in and gave us a talk and said, "you must get this done".

Older person That's right, and the Men's Shed as well, that's right, and said this is how you do it and this is what you do...

Older person They are outgoing, they really come on to you rather than wait for you to ask them... If they think you need it, then they'll suggest it.

Older person They have lots of lectures within those groups, like they give to the Ladies Auxiliary, lectures on health promotion and things, and also to the Men's Shed, they come in and talk to us about all sorts of things...

Older person If there's anything we don't know or want to know we can go along and ask.

4.4 It can be difficult to access information

For the small number of people who tried searching for information online, they experienced that finding the information they needed was challenging: "I tried Googling some of the government websites, which are atrocious to try and find your way through". Another interviewee also reported having problems with searching for information on the Internet.

It was really the stuff on the computer was so just absolutely - well it was horrendous really in that it was just - if you were used to it all the time, it might be all right but I do a lot of things on the computer but I just couldn't find out all the information that I wanted to know... I found it very, very difficult. It was all these links and things again... it wasn't user friendly, that's about the word for it, I think. All the time, I thought to myself, good God, if I were a person that wasn't well, how the heck would you do it?

A family member of an interviewee reported that she had experienced difficulty with receiving consistent information and advice from My Aged Care. Thus, she felt confused about how to advise her older relative.

Support person Well, part of the problem was I could then never find, again, who I had called that time to ring that area again, because I've tried again to find who I had called in My Aged Care and I cannot find that section.

Interviewer Okay. So, it's sort of hard to get back to the same person or department?

Older person Yes.

Support person Yeah, because I've had - I can't remember what information I was looking for the next time - and yeah, I cannot find - because they keep changing the format of how things look.

Older person It must be terribly bamboozling for somebody that hasn't got somebody like you to look after them. I mean, I wouldn't have a hope of doing it.

Support person Well, this is how I wonder. This is My Aged Care, they're dealing with old people. I'm not that young anymore, but

Older person But at least she's with it enough to know what she's doing.

Support person If I can't follow it, how is someone in their 70s or 80s going to follow it?

Older people considered that information provision was lacking: "Well I found it very hard. As I say, this woman had come from [location] and she just sort of assessed me and ta-ta, sort of thing". After the older person was assessed she did not receive any further information or advice about the next stage of the process. Rural older people reported lacking information about what providers and what services were available in their locations.

Older person We just know about [provider name]. If there's anybody else out there, we don't know about it.

Older person No, we don't know about it. Nobody's ever told us.

Another older person read that choices of providers ought to be available, but she lacked information about options:

Older person We don't have much knowledge with that.

Interviewer You don't know?

Older person Yes, what the options are because they're not listed over there.

An older person wanted to find out more information about administration costs; however, he was unable to locate this material.



The one that I was concerned about was the administrative charge. I said, now, what are you actually doing for that? I wasn't quite satisfied, but I was asking because they weren't very much different to [another service provider] in particular, but I don't know how they arrived at that charge. What I was looking for and didn't get was a breakdown. They must have charges against that administrative fee somewhere... [but] I wasn't privy to that.

Older people can have trouble accessing information because they are in pain, feeling unwell, or because they are experiencing illness that impacts their cognitive abilities.

Older person In that last three years we've been here, I've had a stroke, which affects my, me a little bit, because, sometimes ... I get sometimes lawnmowers mixed up with vacuum cleaners and vice versa. I've had a few problems. It's not bad but I have a few problems in that department, where [my wife] – she looks after me pretty well. Here I am now, poking along the bottom... I really do need help around me, like [my wife]. Because I'm very forgetful and vague at times, aren't I?

Older person He's a bit insecure at times.

Older person Yeah. Sometimes, I'm, I get giddy, turn around in the kitchen because I don't know what I've got to do next.

Older person You've lost a little bit of confidence I think since your stroke.

Some older people may lack experience with interacting with Government services and therefore they do not know how or where to obtain information: "I think a lot of your trouble is not knowing where you go for some of this information, is probably the truth of the matter". Similarly, another older person did not know where to start to look for information; she knew that she was required to find a service provider but she did not know how to source data about her available options: "that actually makes it hard because they ask you to find your own provider, but they don't give you the information as to who".

For older people who lacked experience with and knowledge of Government services, a more proactive approach of providing information in an easy to understand format would have been welcomed. One couple proposed that a short leaflet detailing available services would be useful:

Interviewer You're aware of the other types of services and support available through that package?

Older person Not really.

Older person If we ask, we find out that it's available.

Older person Yes, because we've never had anything that says they do that, that, that and that. ... Well, we've got what we need. We don't know what else is available. That's the problem. ... We've never had a

Older person A leaflet to say what we

Older person A leaflet from [service provider] saying we offer these services.

Older person A, B, C and D.

Another older person suggested that because older people may not know about services or have the skills and experience to search online for information, then primary care health workers ought to take a more proactive role in providing them with information and support in learning about and accessing services:

I would also like to say, I think that the people are not ... people don't even know it exists and that has to be doctors or people who come in contact with older people. They're the ones that should be - I feel really strongly about that because even my little gardening girl that comes, she said that she goes to all these old people who have to pay for their assistance and they get nothing and they don't know - they can't go online. They don't know anything about things like that. So the people that they come in contact with, like a doctor or when they go for that [assessment] they have to after they're 75 [the 75+ years health assessment], that's when it should be picked up.

4.4.1 Too much information can be overwhelming

In some instances, the participants had been able to access information but then the information provided was too much and therefore the information was overwhelming. It was very difficult for the older people to sift through the voluminous materials, much of which they considered irrelevant. Therefore, the exercise of information seeking was not ultimately helpful.

I sent to their main office in Melbourne and asked for them to send me up the names of all these different places. I got a stack about this - it turned out there was well over about 100 different kind of ones. Some of them didn't even service [my town] when it was all said and done, when I looked at it... I selected about half a dozen and by the time they sent their packages, I had such a wad of stuff that I used to hide it behind the couch there because it was so much of it... They'd tell you so much and then they'd sort of run out and then this business of got to get on the computer. Well that was absolutely hopeless again. It didn't tell you enough and it was sort of written in their kind of style that it occurred to me that so many people just wouldn't know what they were getting at... it was an overload of information. It was just too much ... Really, it took me a couple of months where I did very little in the evening beside trying to work these packages out. I felt quite stupid, actually.

Even at different stages of the process, the information provided could be so much that was overpowering. In the following excerpt, the interviewees are discussing the Service Provider Agreement:

Support person Oh, it's very - you know that package, that big wad of material that you had to read through and sign?

Older person Oh, right.

Support person It was a lot of jargon...

Older person A lot of jargon, but it did have

Support person A lot of repetitive information.

Older person all these ABCs and ...

Support person It's just too much.

Older person It's just too hard for my age to understand it. You wonder, what's that for? Cut that down to three letters, and I just would

Support person I think it was about 44 pages.

The large volume of information was not helpful but rather it was off-putting. People simply did not have the time or inclination to read pages of information, whether that information was in print or online: "they refer you to their site but you're that busy, you don't really look at it".

4.5 Lack of options for service provision

In some rural areas there is only one (or even no) provider of services. Of the 20 interviewees, 12 (60%) reported that they had no choice of service provider as there was only one provider of services for their rural location. As there may only be one provider available, rural older adults are unable to compare providers and services and they have very few choices about the service provision options available to them: they either use the available provider, seek a privately funded provider, or go without a service.

Interviewer Have you ever changed providers?

Older person Just the [current provider].

Interviewer Is there a reason why you haven't changed?

Older person Who else would do it?

Older person I would imagine there would be only one service provider ... They are the provider for this area and I would imagine it would be them.

Interviewer That's an interesting point. So, you may not get a choice?

Older person I don't think so. I think all the services in [local] area are [service provider], as far as I know. There might be some private ones, but that would be the one that would cater for most.

When asked if she had choice of a provider, one older person reported, "No, you take what's given [laughs] and then pay up, happy or not [laughs]." Overall, this older person was not unhappy about the service she received, but she could not switch to another service provider because none was available. The older person had experienced one instance of being dissatisfied about the service and when asked if she gave feedback about the



bad experience, she said, “Oh, I don’t think I bothered. You either take them or you’ve got nobody up there you see ... I think you either take it or lump it [laughs].”

Given that there was often a lack of options about service providers, some participants saw no value in complaining about poor service. They considered that making a complaint or providing feedback was unnecessarily vexatious and with no tangible benefit:

Interviewer Of course at that time, it was the only service available anyway?

Older person Yes, but that has always been [the case] – I don’t complain about them. The district nurse, they’ve always been very good. It was the girl doing the floors and sitting down reading anything she could find [laughs]. I shouldn’t have let her get away with it you see. I should have said, “excuse me, you better do that work” [laughs].

One older person was in the situation of waiting for an assessment for an HCP and in the meantime felt “locked in” to accepting the CHSP service, which was only delivered by one service provider in his location. The older person was dissatisfied with the service delivery – and made a complaint – however, although the service provider listened to the complaint, the provider reported that they were unable to give the participant the service he was looking for. (The story was reported as an email trail as part of the older person’s returned journal. In the following excerpt, the older person’s and service provider’s actual words are written in italics. Plain text has been added by the researcher to assist with providing additional context, to de-identify details, and increase cogency.)

Older person I ought to receive domestic assistance services for 90 minutes every fortnight. My last service was on 13 December 2019 and yesterday I was informed that my next one will not be until the 24 January 2020. No one came on 27 December or 10 January. Reasons given – staff holidays and bushfire smoke health issues. Why aren’t any make up days offered? I find your service very unsettling.

Service provider Thank you for your email. In preparing this response I have looked at all the Domestic Assistance Services being provided to your residence for your wife and yourself from December 2019 to today. Of the 7 services that were scheduled, 5 of these have been provided as per the roster and a Domestic Assistance service has been provided fortnightly.



The service on 27 December was cancelled as the staff member rostered for that day was absent due to illness. There were no other staff available to replace them as it is a period of high staff leave because of the Christmas/New Year period. In these situations we prioritise clients' personal care/hygiene to ensure clients receive this service.

The service on 10 January 20 coincided with the Victorian Government declaring a 'declared State of Disaster' due to the significant dangerous bushfires. On this day our services were restricted to personal care only due to the risk of fire and the impact of smoke on staff health. This action was in accordance with the Emergency Management Plan and our service delivery arrangements for Extreme and Code Red Fire Danger Ratings.

In reviewing these cancellations I am satisfied that we have done all that we could do to try and provide services in what has been a very difficult period. I will now provide response to your direct question: "Why aren't any make up days offered?" – For clients who receive a fortnightly Domestic Assistance service we will endeavor to make that service up in the days following. Where a weekly Domestic Assistance service is being provided to a residence, such as [your] residence receives, it is generally not possible to provide a 'make up' service due to the short time between services.

Older person Thank you for your reply. Some points that you raised need to be addressed: You have put the dates that home care services were delivered to our home, it is a combined list of services for me and my wife who currently received 60 minutes a fortnight. She is a My Aged care client in her own right and is a separate client to me. She is not responsible for services that you haven't delivered to me but unfortunately, she has to do the home care services when you don't. I had surgery last year which hasn't been successful and am now very limited in performing many tasks. My wife has her own health issues. She is not in the position to take on your workload.

Clearly, the situation was complex for both the older person and the service provider and there was no satisfactory resolution for either party. This case story illustrates some of the pressures that exist for older people and service providers in rural areas: providing quality and safe care is clearly impacted by external events (such as bushfires), shortages of staff, and "thin" markets (there is only one provider for the area).

In another journal entry, another older person reported poor quality service in an area in which there was only one service provider.

Friday 31st Jan 2020

Called [service provider] - no reply. Left message to ensure gardener brings hedge trimmer on visit 4/2.

Tuesday 4th Feb 2020

Gardener normally arrives 7.30am - did not arrive. At 9am rang [service provider] and was told gardener should arrive around 10am. Lack of communication, could have made medical appt and would have had to cancel not being informed gardener arrival time changed.

Gardener arrived 9am, did lawns but forgot to bring hedge trimmer.

I rang [service provider] and asked for hedge trimmer to come with gardener on 18th Feb to do hedge.

Tuesday 18th February 2020

Gardener came to cut lawns and hedge - did not check before left office so missed note advising to take hedge cutter to do our hedge. We supplied our own personal hedge cutter, small version of industrial type - did some work on hedge but really need large unit on next visit to do job properly - poor service!

4.6 Comparing providers is not easy

It was difficult for the older people to compare providers. Some of the difficulties related to having to go online to find the information, some were about having too much irrelevant information but not being able to find the relevant information, but most importantly, there was no easy and brief way to compare like with like information about service providers or services.

They didn't compare properly for one another. They'd tell you so much and then they'd sort of run out and then this business of got to get on the computer. Well that was absolutely hopeless again... As I say, one might have told you something then another one told you something in a different department. Everything was correct but they weren't - it wasn't coordinated. I think that was it. A lack of coordination all the way through

There just wasn't the coordination and when they talk about these packages ... You might have to pay so much a week yourself and we'll let you know, kind of thing but you don't know what the devil you've got to pay and whether that applies to you or somebody else... and you sort of think now, is it going to be worth it or am I better just to stick with [current provider] with the cleaning?

Well it was a lot of work. A lot of people wouldn't have been well enough to put up with it... It wasn't compatible insomuch that they didn't all have the same information... It doesn't work out that you can go right through a list and think now, this one will do it and this one won't and all this sort of stuff... Well I think I've said it several times now that it was confusing.

It wasn't all aligned so that you could do a comparison or anything like that. By the time I got this great big package, it really - I suppose it floored me in a way because I thought how the heck can I work all this out? Then when I found that again, they didn't compare, that you couldn't add them up and see the similarities. That they all had their own thing about it, that they - some left out the important bits that you wanted to know and others put it in and all that sort of thing. There was no conformity. Comparisons and conformities and confusion.

4.6.1 It is easiest to follow the path of least resistance

One support person noted that there was only one provider available in her area when her older relative "came out from the hospital, so we just stuck with them". Later, when there were more providers available, the older person and the support person decided not to worry about doing further comparisons: "we chose not to make it a challenge, we just went with the flow... with the organisation we'd become familiar with and the carers".

Older rural people may not feel confident or are unable to compare providers so they decide to use a provider that they already know, a provider who employs people they know or are related to, or a provider who is recommended to them by a friend, peer, or family member. For example, one interviewee relied on "feedback from others who've had the services" to help her choose a provider. Rural older people tend to trust their general practitioner or local health service and are therefore happy to use providers recommended to them.

I think the most helpful thing was that the lady [support worker] that had been at [Home and Community Care (HACC) provider] had transferred over to [Provider 1] and I asked her a few times different things that she knew and in the end, as I said, I spoke to the [Provider 2] lady ... and she thoroughly recommended it but I thought to myself, in the long run well I know this other lady [employed by Provider 1]. She was a wonderful worker and if I could get her, I'd do that and that's what they've done.

4.7 Switching providers happened very seldom

There was only one participant who switched providers, and the only reason that she changed was because she physically moved locations, from one area to another, so she changed providers to the one that serviced the new area that she moved to. It is rare for older rural people to switch providers because there is frequently limited, or no, choice about providers. For example, one older person laughed when asked if she had considered changing service providers; she explained: "Well, I haven't got no option [laughs]... No option."

Switching providers was perceived to be bothersome, annoying, and expensive. There was one older person, who although she had not switched providers, she had been reading about exit fees and had learned that hers

would be \$250.00 if she decided to change providers. She said, "I was just wondering if I could find anything about the exit fees anywhere there but I was quite amazed about that alone. That just seemed to be far too much." Similarly, other interviewees thought that changing providers would be difficult and expensive.

Support person I can remember reading through the costs and being horrified at the exit costs [laughs].

Older person Yes.

Support person Because the amount of costs at the exit that they got to keep, I looked at it and went, wow, you really don't want to [change] businesses at any point.

Older person It's like banks. Once you're there, you're there.

Support person No, banks you can change a lot easier than you can these things.

Older person Ah, yes

Support person ... the time and effort it would take. It's a hassle to go through the changes. So, they would have to do something fairly major to make us want to change.

4.8 Barriers to accessing care

4.8.1 Lack of transport options

Although it is not a barrier to receiving many of the services provided by HCP and CHSP (because these services by their nature tend to be delivered within older people's homes and thus there is no need to travel), a lack of transport options in rural areas can limit an older person's ability to access services. For example, services that enable a person to be involved in community activities may be less accessible to rural older people.

I just find that if I want to go to things, like for instance there's something going on, on Sunday down at the hospital which I'd like to go to, I can't get to... because [local town] doesn't seem to have a taxi driver... there was one when I first came here and when I needed him I couldn't ever get through on the phone. So, and I think for me to go from here to the shops would hardly be worth a taxi coming from [regional centre] really. So, there is a difficulty, if there was a little bus that would be lovely.

Our buses only run until five o'clock. On Saturdays, they only run until lunchtime. We have none on Sundays or public holidays. Taxis are very hard to get at times and expensive. We do have community accessibility. That's a fairly recent innovation. But again, that's very expensive I find. Some people may not. I try to walk as much as possible but my back is not good. I've had multiple laminectomies... We're very dependent on trains. Our train system is dismal. We're into our tenth year now of track

works and upgrades and a lot of times, you'll get to the station and there will be a bus. I find it extremely hard to access a bus... particularly those with coaches with all the steps. I've had to actually be manhandled. Again, they've got no idea. I just - I hate it. I know people are very kind. But when you've got someone behind you and one up the top. I think "God, we shouldn't have to do this!" ... Community transport, like we've only got one car and that's always in demand. I actually, when I had [treatment], I had a month of [treatment] in [regional centre]. I actually had to live up there because my doctor didn't want me to be trying to get up and back every day, because I was having it daily, on the train. I was very lucky because the [Philanthropic Organisation] subsidised my accommodation. I was so grateful. I was living within walking distance of my treatment.

There's only one driver available for community transport vehicle ... you have to book away ahead because you're lucky to get in. Particularly places like - if you need to go [to regional centre] or anywhere for check-ups. Closer [in local small town] it's a lot easier you can - if you haven't got a friend to take you, well, there is the taxi but after a time that can add up... Then you have to sing out to friends and hopefully that they're available at the time. Otherwise you've just got to cancel your appointments.

But it's not a case of them, you being able to freely go anywhere because as I say, there's no bus. We have plenty of taxis but not everybody can afford a taxi. There's the half fare taxi but you just about need to have lost an arm and a leg before they want to give you a ticket.

I've got to rely on the [charity organisation] for medical appointments and once a month you can get a car from up here [a local service provider]. You pay for it, of course for four hours which gives you three hours shopping.

I would say we can't live here if we can't drive because without family right here, we couldn't expect neighbours to do that all the time.

Reliance on public transport means that older rural people have to fit in with the transport organisation's timetables and this can be inconvenient for older people.

There is a bus service from here ... and they do have bus services to places like... [regional centre] and places like that... So, there's always somewhere you can get to, but I mean it's not always at the times you need it, this is the problem. There are bus services but not regularly, so you have to go to suit the timing.

These older users of public transport, who also have medical conditions that limit their ability to move around easily, experience increased vulnerability through using public transport. For example, using public transport exposes them to adverse weather conditions (exposure to rain and cold weather, prolonged sun exposure). The need to coordinate using the public transport system with other appointments can make journeys very fatiguing. "Apparently for shopping you can get the bus to [regional centre], but it returns in about 20 minutes, so you don't have time to do anything, then you've got to wait two hours before the next one".

Well we've got very poor transport options, extremely poor. We don't even have a decent bus service... When we got onto the train in Melbourne [to return home to rural area], we only went a few yards and they decided - they told us it was the switches but in truth it was the train and they had to take it back and change it again. We were an hour late getting home. At night-time, it's not funny and there's not enough services. First thing in the morning and then last thing at night but there's nothing in between.

Due to the lack of accessible public transport some older people are reliant on family or friends to get around. One older person reported that she relies on her family member for transport: "She takes me everywhere. A couple of times when I was at the [hospital], they came and picked me up in the bus, but I didn't like that. Otherwise, if she can't take me, I don't go."



Relying on others for transport means that older people have less flexibility if plans change at the last minute. One participant had to rely on the kindness of a [community transport] driver who went beyond his duty to help her when her appointment was changed at short notice:

Just recently, I've been having all these tests ... and thought I was booked for the tests to do them all in the one day. That's what they told me so I booked the [community transport] car for that day. Then I get in there, oh no, the day before, they ring and say, "No you'll have such and such test, but you can't have the last one on the same day. You'll have to come in the next day." They like a week's notice naturally. I rang them - no hope. I rang up here - no hope. Anyhow, one of the [community transport] drivers... he gave me his private number. He said "whenever you're stuck". Anyhow, I rang and just left a message. I was starting to panic so I rang and ordered a taxi. I had no other option. That would have cost me \$110 or something, just the one way and then I'd have to pay the same coming back. Anyhow, he [the community transport driver] finally rang and he said, "Oh no!" I said, "No I can't do that." "No", he said, "cancel that taxi, oh well you fill my ute up. You don't mind putting petrol in the ute?" I said "no, look come on I come from a farm" [she laughed]. That was very good of him. Yes.

4.8.2 Health care staff lack knowledge about My Aged Care

As stated previously, rural older people tend to rely on their general practitioners or other health care providers to identify that they need services and to assist them in finding out about, and ultimately receiving services. However, in some communities, the older person's first point of contact lacked knowledge of My Aged Care services and processes. For example, one older person stated, "interestingly, the doctor doesn't know much about it."

One older person relied on her general practitioner to help her access services, however she did not receive the needed services until another general practitioner stepped in to assist her.

About three months ago, I tweaked my knee a bit more and it became quite painful. I stopped being able to go for walks with [my husband] and it just became a problem... It was at that stage that I started to talk to my doctor about whether I would be able to get into the system to get some help. Now, nothing happened ... Nothing happened and then I've asked again. This was before it was acute. Nothing happened. Now, I don't know whether he submitted that or whether the girls at the office were supposed to do it, but nothing happened until I injured my knee further... I rang the clinic because I needed to see a doctor. I couldn't walk ... I couldn't get in with my

normal doctor, so I saw [a different doctor] and she, I told her what had happened, that I'd asked [my usual doctor] for this. She said, "I will send another one and it will go tomorrow". She wrote that letter out in front of us and gave me a copy of it and I was rung, well, that was to get into the physio, at that stage... But I also asked for a referral for My Aged Care to get the cleaning and I received contact with the relevant people within the week.

4.8.3 Negotiating for services can be difficult

The support person of a participant reported an instance in which there was lack of clarity about whether her older relative was entitled to receive glasses as part of her HCP. The support person needed to exercise determination and perseverance as she advocated for her older relative's needs:

She needed new glasses and I had asked our service provider at the time, "Could I get glasses through her funds?" And I was told "No". I was told there was other government funding for glasses, and of course, when I investigated that, the glasses Mum needed weren't available through that. I said, "no, I can't use the other funding", and she [case manager] says, "Well, you can't use this". So, I contacted My Aged Care to kind of go, "So what am I supposed to do?" They said, "why can't you use your funding for that?" I said, "I don't know, the service provider won't let me". So, we had discussions and eventually she got her new glasses through her package, but it took a bit of arguing to get it... There was nothing written anywhere in any of the information online of what you can access and what is available through it. As ... our service provider was saying, they had used it in the past and got into trouble for using it in the past by My Aged Care, which is why they were saying "No". I'm kind of going, "Well, she can get a walker to get around, why can't she have glasses to see to get around?" [laughs]

Although much younger than her relative, the support person still found it troublesome to find the information she needed. Thus, it may be seen how much more difficult it can be for older people, who may have more health problems and less energy, resilience, and problem-solving capacity, to be able to negotiate with government and service organisations in order to obtain the needed service.

One participant had two very different experiences of accessing home help services after being in hospital. After the first hospital visit, the hospital advised what services she would need, and the hospital staff organized these services. The participant found this experience to be very easy, seamless, and beneficial. However, after her second hospital visit, she needed a similar level of care and support but on this occasion she was required

to utilize My Aged Care (due to being older than 65 years) and to negotiate directly for her service delivery; the participant reported that the second experience was frustrating, unsatisfying, and even humiliating.

Both operations were done in [regional centre]. But the second time I had the operation they wouldn't give me a referral to home help. They said, "Oh, you probably won't be able to get it" ... I had some fun and games trying to get hold of home care because I knew I wasn't allowed to do anything for six weeks. The first time was easy. The second time there was a hiccup with obtaining home care ... We basically had a bit of an argument in the hospital.

I said, "I had it for my first [operation]. I was told I'm not allowed to do anything. Surgeons said make sure you don't, make sure you obtain some services", I said – and they just kept saying "No". Whoever interviewed me in the hospital kept saying "you probably won't get it. You're too far out" ... I said, "Well, I can't go home" ... and they said, just basically shrugged their shoulders and they said, "Well, you'll have to do what you can".

So, I had to call out to some friends. Luckily, I had a friend ... who said she could stay with me for four days. Then my son came across for four days. But after that I knew I had to try and do something, so I did a bit of phoning around and a couple of friends found out what was going on and they were obtaining



already home help themselves for various reasons. So they gave me a number and I rang a person ... who in turn said, "Well, we can't do much for you because you haven't got a referral" – and I said, "well, what can I do?" They said, "well, ring [regional health service] ... So, I rang and they took over and then they sent someone out. But all that process, paperwork, interviews, phoning, all took three weeks before the, nearly four, before they could start. By that time, I'm more than halfway through my recovery.... [The response time the] first time was quite quick... because I remember they came second week I was there... [But the second time] there was a big gap ... nearly four weeks actually... it was a heck of a lot slower.

4.8.4 Needed services are not available in a community

One older person liked to attend a gym and receive individualised help with the exercises; however, this type of facility was unavailable in her local community and she needed to travel to a nearby larger town.

I would like a little bit more help with exercise. I did go to the crowd ... up here for a while ... But, the only trouble that I found with that, the first day you turn up, they show you the machines and everything and they're wandering around keeping an eye on you to a certain extent but I feel I need more personal one-to-one exercise because at times my legs get very stiff and I find I'm not walking as well as I can... I do feel that I need one-to-one exercise. I'd have a lot more if I could get that... Well I did mention to them [package service provider], there was something at [name of larger town], but that's 20 miles away for a start... I wondered if they could bring it up here as well because there'd be a lot of other people with stiff legs too.

Several participants discussed difficulties accessing gardening and home maintenance services such as having gutters cleaned and windows washed.

Interviewer *Are there any services you need but that you know are not available in your community?*

Older person *Gardening. The windows. I'd love to have a windows wash. I try to do it myself with the broom. I'm not very good at it. Because there is a lot of windows and hard to get to it. I try to do what I can but luckily, we have Jim's Mowing does the lawns for all the units. I do have a little electric mower that I try to use sometimes. But again, I have a lot of back problems.*

I asked them to do the gutters and windows or can we get someone to do the windows and the gutters? And they said, the government's cut back the funding. [The participant had to go without this service.]

Some participants noted that the service providers placed restrictions on the activities that were acceptable to be performed by home care workers. When services could not be performed due to restrictions, the participants sometimes asked friends or family to help, or they went without having the task completed.

Older person *There's a lot of stuff they're [home care workers] not allowed to do so – and I thought, well – I just did what I could and – without bending to the ground and then I – if there was any further needed, well, then there was friends and some family members. ...*

Interviewer *What are the things that they're not allowed to do that you'd like them to do?*

Older person *Well, they're not allowed to clean windows at all. They're not allowed to dust unless you remove everything off the benches. Absolutely. [Laughs] ... I was told they can't sweep porches or anything like that.*

Sometimes services were needed but there were insufficient funds in the package to cover the service delivery.

Support person *We need more [help]... since this last fall, since this last hospitalisation...*

Interviewer *So, in terms of things that aren't covered by your package, or not available in your community, you would purchase those privately?*

Support person *Yes ... except the ramps. We can't afford the ramp... We need a ramp [for egress via the front door] ... We got a quote in May for \$9750 and then we went and got another quote for \$6500. That's the best we could do but we haven't been – can't afford that.*

Participants sought help from family and friends if extra help was needed but not provided or available: "My son is [nearby]. If I need anything, he'll come and do it for me... all the family will do things for me if they have to... I've got a church family that do things for us as well." Even though participants called upon family and friends to assist, there might still be tasks that could not be completed.

While we were out on the farm, I was able to mow because I was using a ride-on. When we came in here, because I had an injury and we had a different type of grass in here, which is much more difficult to put a push-mower through, so I was having troubles mowing the lawn in here. So, then I started trying to find out if there was any mowing assistance, and of course, we were told, "No there isn't any mowing assistance available through what's around".

So, our lawn just got very unkempt and all that sort of stuff. So, that was the main thing we were after and a lot of the other stuff you just did in very short – like pruning of bushes, you can do in five- or ten-minute stints... we just let it get unkempt. Although we did actually end up paying a friend to do it which meant it came out of our pocket. We found somebody who was doing it at a good price, but it was costing us.

4.8.5 Limited economic resources

Many participants needed to carefully manage their funds because their financial resources were small. Some interviewees utilised a mix of package-funded and privately-funded services so that they could afford to pay for all of the services needed.

Older person *I think I can probably do all those things, providing that the money is there for them, but I keep my own gardeners because I think they're probably better priced. I do think their charges [package service providers] are very high for all that sort of thing. So, it's the same with - if you were going to go to an event, you could have your carer more or less take you but again, it costs so much. If you can afford a taxi or if you can drive yourself is better still, but if you can afford a taxi, you're better to just go and come back, rather than*

Interviewer *Tapping into your money that's in the package.*

Older person *Yeah, that's right.*

The participants expressed concern about the administration costs for packages. One older person thought the administration costs were too high and she was not entirely satisfied with the amount of her package funds that needed to be spent on package administration.

Older person *If I ring up [case manager] to speak to her, even that costs money. Yeah, I'm not joking. ... Yep. If I was to ring up [case manager], well she'd have the clock on me and*

Interviewer *That comes out of your money that you've got?*

Older person *Yeah, even though they've already got an amount every month that they take any rate... I didn't really know very much about that and I just wondered why they needed so much. I feel that they are getting quite a - quite a lump out of it.*

Interviewer *Out of the package?*

Older person *More than possibly I would have paid them but on the other hand, there must be a lot of work involved but I do think*

it's going a bit far that even if I talk to her on the phone, well I can expect to pay something for it. .. if they have some of their services on the weekend, such as from a district nurse type of person and things like that. Well then it - for the weekend, it goes up considerably and all that sort of thing. It's much more expensive if you need help on the weekend than through the week. ... their charges do seem to be pretty high ... They talk about your monthly statement and management of your package funds... I suppose it's all there, truth be told, but I just simply haven't read all that. ... They say well, if you'd like to sit down and read that book, you'll find out yourself. Well, how many of us do sit down and read? How many pages is in it, even?

Other older people wanted a bit more transparency from service providers about the costs of service provision.

I'd like a bit more clarity in their accounting... they always - they're a month behind all the time, so current months. Some things for us, they're reimbursed. We evaluated the cost of my incontinence pads and we could get them cheaper with the Chemist Warehouse than what they were getting them for... The one that I was concerned about was the administrative charge. I said, "Now, what are you actually doing for that?" I wasn't quite satisfied, but I was asking because they weren't very much different to [another service provider], but I don't know how they arrived at that charge. What I was looking for and didn't get, was a breakdown. They must have charges against that administrative fee somewhere, and they wouldn't - I wasn't privy to that.

They give us a statement every month... I've had a few issues with that. Their set-out isn't very clear... Last month, when she went from level one to level two, they didn't show the extra level - the extra money that was available. They told me that they'd produced another statement, but we haven't received it to date.

4.9 Facilitators to accessing care

One of the most important facilitators for the rural older people in accessing, assessing, and acting on information was the assistance of health professionals and service provider staff.

I didn't have any problems, because as I said they asked me to fill a form in across at the [service provider] and they arranged for the lady to come and see me ... She rang me up and said could she come and see me on a certain day. So, I didn't have any problems there whatsoever. ... It was all done through the [service provider] across the road.

I had problems ... I was barely able to walk and a friend's husband said you should go and see my wife; she works at [service provider]. So we got in touch with [service provider] ... and that's the end of the story, because from then on it's just been brilliant. Somebody came out and interviewed both of us and we've had the services ever since. For me for having the floors and the bathroom cleaned - what a difference it's made!

4.9.1 A caring and competent case manager is invaluable

For the older rural people who had an aged care package case manager there could be considerable variation in the support and quality of care provided by the case manager. However, there were clearly some case managers who provided excellent and compassionate care; these case managers facilitated the processes of deciding how to spend funds, finding out about important information, and interacting with My Aged Care. In a journal entry, an older person wrote about the support that was provided by her case manager:

Just wanted to report that my ACPCM [aged care package case manager] has been continually

in touch with me throughout the fire [bushfire] problems. She has arranged all the thoughtful details about getting my husband out of hospital, providing and arranging for accommodation in town for both of us. I can't believe her thoughtfulness and kindness... the empathy and wisdom of our ACPCM is outstanding. She understands our needs and is good at knowing how to meet those needs.

Case managers often also played a role in facilitating communication between My Aged Care and the package recipients. For example, one interviewee noted that his local service provider acted "as an intermediary between ourselves and Aged Care". His wife added, "So, if we have a question, we just ring up [telephone health service]. They've always been very obliging, very helpful, can't do enough for you". Another interviewee also reported that "it was the case manager who did all that" interacting with My Aged Care.

I have a good thing going with [case manager] ... She won't come unless I need something and if I need something, I'll call her to see if I can get it under the package or if it's feasible... She's good because she knows your needs and she knows, yeah, she keeps her finger on the pulse very nicely, which is good.

When we first started to think that we might need some services, we didn't really know what was available. I knew of people who got Meals on Wheels which is around the countryside and I was quite aware that plenty of people are getting assistance. You also get to talking with friends and colleagues out there and you sort of share your experiences or knowledge.

We thought we should have home services because of just general problems - well they all, you know, age and all that sort of thing and because of the fall, she had a bit of difficulty with walking and movement things of that nature. Well I think it was because the health service were you know treating my wife for her walking and they were the ones who were concerned. So that's when we triggered the whole thing and they suggested it. One of the women in that was part of it and she pestered me to get on to My Aged Care.

I spoke with my GP and I said, "what services do you think I need to get this right?" We had a general discussion about it and then he encouraged me to put in an application to My Aged Care and the local health service encouraged us to join up with My Aged Care and it was the health service that pushed the barrow and they got My Aged Care here to come and assess my wife. Our local health service sort of referred us to My Aged Care. They suggested and in fact I contacted My Aged Care. They pushed me into making contact with My Aged Care.

It was pretty easy to get an assessment. They just said, we'll get somebody to come down and assess. I just rang up My Aged Care and they first of all sent somebody down who did the original assessment. However, what we needed and what we could have straight away, wasn't the same. Even though she was eligible for Level 3, they gave her Level 1. They could only supply Level 1 and there'd be a six month wait for a Level 2. We're on Level 2 at the moment but we were eligible for Level 3 but with the delay and everything, it's months and months go by.

We had a choice of providers, but we went to Service Provider because one of the persons that was part of it was in the Club with me. We didn't compare Service Provider with other aged care providers because they are just over the back of the hills, we can see them all the time there and we've been pleased to hear what other people are saying, that they're pleased with their care. I had contact with the people; they were locals and other people who'd used Service Provider and were very happy with their service. So, we relied on the recommendations and experience of friends of ours.

We got lots of information about the package. There's a book in there with it all in. There are many pages. We have a case manager for the package. We didn't negotiate the terms of our Home Care Agreement. We were just so happy that they would come and it seemed to fit in with us. We didn't know anything about negotiating it.

She [case manager] drops in every so often, make sure everything's up to scratch and give us any updates of you know agreements and they've had two different agreements they seem to update every time she drops in [visits]... She's been here, well it could be once a month. I've spoken to her several times about various things.

Older person *You get maintenance, but if we want anything, we usually just ring [case manager]. "Can we get this, can we get that?"*

Support person *She has suggested a couple of things that you wouldn't actually think about as being normal. As in, Mum got a DVD and a stereo for her room, because she doesn't get out a lot. Mum's stereo had died, so she gets to listen to some music. Her phone died, so she's replaced her phone with a new one...*

Older person *Yeah, anything that I need, we usually check with [case manager] first [laughs]... We had trouble with the gardener.*

Support person *Yeah, but we changed who was providing the garden service.*

Older person *That's right, but that was no problem at all. We were a bit worried and [case manager] says, "Oh no, I'll just tell him that he's not needed to go there anymore, and we'll give you a new gardener" ... Then she organised it all. It was good.*

I'd been away and when I came back, [husband] was in a really bad state... when I came home, he was - I don't know, he was being very, very cross and not like himself at all. He was being very male about what services he'd allowed to be coming in because he would say he could do those things but in actual fact, he wasn't doing them and I had to do them. I was really upset ... my friend said, you need to phone the - his case manager and tell her what's going on. She came straight here and was very sensitive and wise about how she went about it ... she phoned the government and said that I'd been on the waiting list apparently longer than the time that you're supposed to be... She rang them and they said first of all, well we'll give her a level one and ... our case manager, she said "I won't accept that because that wouldn't even pay for somebody to come to this house". After a lot of toing and froing, they suddenly said "Oh give her a level two". So, from that point on, stuff could be allocated for my needs

Our case manager is fantastic. Her profession is occupational therapist so she knows things that - she's come up with eating utensils that - so I could get stuff in my mouth and for picking up gadgets. She got the thing in to raise the toilet ... It's emotional support as well. Like when [husband] went [to] hospital, at first he was very, very sick and I was in there every day and he wanted me there all the time. I was just so... I was exhausted and I rang her on my way home one afternoon, I just had had enough. I burst into tears on the phone. She was in at the hospital the next day and she's talked to [husband] about how if this is the long haul ... it's unsustainable to expect me to do what he was expecting me to do. ... he's much, much better. But she's been in to visit and now she's been liaising with the physio about our house. So, she's coming next week in her - with her OT [occupational therapist] hat on, to check what needs to be done before he can come home.

I suppose we take notice of what [case manager] says. She's very wise... Yeah and she asks what we want but she's always - she knows what's available and she also understands our needs as well... She knows what we need.

Some people did not have easy experiences of receiving services, rather they had to keep asking and following-up to ensure that the services they needed were delivered. Some older people have the tenacity of mind and spirit to be able to be persistent, however having a case manager who can provide advocacy was also a solution.

So it's flying through now because we've got to the point of where we're funded to deliver what we were assessed at, so that was a little bit of persistence ... after we were assessed, there was a bit pursuing and making the point, even with my GP [general practitioner]... I can't clearly recall whether I had any real difficulty. It's a matter of patience, I think, and trying to - from what communication you're having is to appreciate how to progress it. I think that's worked pretty well... Yeah, kept at them, and that's where the case manager was brilliant.

4.10 Case story: Relying on others to access My Aged Care

A theme that was echoed throughout the interviews was the rural older people's reliance upon other people for assistance at all stages of the process of accessing, assessing, and acting on information, making a decision, and receiving services. The following case story portrays some of the ways in which rural older people rely on others to assist them in accessing home based aged care services. (Words in italics are actual words used by participants. Words in normal font are researchers' words.)



5 Priority issues

5.1 Delphi Round One results

After analysing the findings from the interviews, the researchers distilled these findings into 15 statements that they thought captured many of the themes that were discussed in the interviews. The participants were given these statements and asked to pick the 5 most important statements to them (or for service provider participants, the most important statement for older

people in their communities) and then rank these statements from 1 to 5: with 1 being the most important statement to the participant through to 5 as being of lesser importance than the previous statements. The participants were also given the opportunity to make comments about the statements. A detailed description of the results is listed in **Appendix 5**. In summary, the ranked statements are listed in **Table 2**.

Table 2. Delphi Round One results

Ranking	Statement
1	Rural older people desire to be independent for as long as possible and only seek services when they feel a very strong need for help.
2	Rural older people prefer to receive advice about aged care services by talking to health professionals, friends, peers, and family.
3	There is a lack of awareness of community aged care services among rural older people and rural communities.
4	There is a lack of clear and detailed information about what services will and will not be delivered and the costs.
5	Rural older people prefer to use a known, local provider recommended by family, friends, or health providers.
6	Trusted health professionals or family members usually need to encourage rural older people to seek community aged care services.
7	It is not easy to compare services and service providers.
8	In some rural areas there is only one, and sometimes no, choice of aged care service provider.
9	The information about services provided by My Aged Care is overwhelming and often not relevant.
10	Rural older people are reluctant to switch providers; they worry that switching is inconvenient or costs extra.
11	There is a lack of clear and consistent communication from My Aged Care both online and over the phone.
12	Rural older people find out about available services through “word of mouth” (for example, through caring for others, going to a community talk, doing volunteer work).
13	Rural older people are very grateful for services and so they avoid making complaints.
14	Most health professionals and service providers have enough knowledge to help rural older people to navigate My Aged Care.
15	With an older person’s permission, it is okay for family (or trusted other people) to make decisions about community aged care services on the older person’s behalf.

5.2 Delphi Round Two results

The top 9 ranked statements from Delphi Round One were modified according to comments made by participants and the 9 statements were sent to participants as the Delphi Round Two. The participants were asked to select the 3 most important statements to them (or to older people in their communities) and then rank these statements from 1 to 3, with 1 being the most important statement to the participant and 2 and 3 being important but of lesser importance than the statement ranked number 1. The statements circulated are listed in **Table 3**.

Table 3. Delphi Round Two statements

Statement
Some rural older people, families, and rural communities lack awareness of community aged care services.
Comparing types of services and service providers is not easy.
In some, not all, rural areas there is only one, and sometimes no, choice of aged care service provider.
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.
Communication with and navigating My Aged Care can sometimes be challenging.
Rural older people prefer to use a known, local provider recommended by family, friends, or health providers.
For some people information provided by My Aged Care is overwhelming and difficult to follow.
Rural older people rely on getting advice about aged care services from health professionals, friends, peers, or family.
Rural older people tend to access services when they are in crisis, after a fall or hospitalisation, or if they are in dire need.

A detailed description of the results is listed in **Appendix 6**. The 4 statements that were ranked as most important to rural older people are reported in **Table 4**.

Table 4. Top four ranked statements in Delphi Round Two

Statement	Top responses older people	Top responses staff	Top responses combined
Rural older people tend to access services when they are in crisis, after a fall or hospitalisation, or if they are in dire need.	2	2	1
Some rural older people, families, and rural communities lack awareness of community aged care services.	1		2
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.	3		3
Rural older people rely on getting advice about aged care services from health professionals, friends, peers, or family.	4	1	4

* 1 is the highest ranked through to 4 as the lowest ranking

6 Recommendations

6.1 Improve equitable access to rural and regional aged care services in thin markets

The Consumer Directed Care model is feasible for older people living in larger regional cities where there are more than one viable aged care service providers. However, for rural older people living in smaller regional towns and rural communities, this model does not appear to be workable, as there is a lack of options for aged care service provision.

In rural areas, the aged care market is different from that in urban areas. The consumer-based market model fails in rural areas because markets are thin, often with no choice (only one provider) or only limited choice (no more than two or three providers). Delivering aged care services across small rural communities will continue to be a challenge in a consumer market, as the current funding mechanism and incentives fall short of the actual costs to deliver the service and thus it is not deemed sustainable by aged care service providers. The lack of competition in rural communities warrants an alternative model with more equitable access to aged care services in thin markets.

6.2 Dedicate funding to establish an independent aged care coordinator who has knowledge of the local context and can dispense comprehensive locally relevant information, within every rural Local Government Area.

The role of the independent local aged care coordinator would be to assist and support older people to navigate the process of interacting with My Aged Care, of arranging services with local service providers, and negotiating any problems with service delivery. A coordinator is needed because some participants found the My Aged Care website to be daunting, irrelevant, difficult to navigate or confusing. There is too much information, which can be overwhelming to digest. Information about locally available aged care services particularly in small rural communities is not evident. Comparing options and making informed decisions is challenging.

Rural areas are heterogenous. Compounded by a mix of Federal and State Government funding, each rural area has its own distinctive model of service provision, workforce profile, and its own operational idiosyncrasies. Rural areas operate differently from urban areas and from each other.

As a centralised information-provision service, the My Aged Care website and telephone call centre have no comprehensive ability and no access to localised service information in rural communities. In addition, the My Aged Care website perpetuates a false idea of choice in rural areas, when in reality there is no choice available locally. Only a person with specific local knowledge of

a particular rural area would be able to field enquiries to provide the correct, specific information required by rural older people. For these reasons, a local information provider is needed in each Local Government Area.

It is important that the local aged care coordinator has independence from service providers, even in areas where there is only one service provider available. The independent aged care coordinator needs the trust of rural older people that they are working in the best interests of the rural older person and do not have any conflict of interest.

Dedicated funding for the independent local aged care coordinator is needed because there can be challenges in sourcing a local information provider who is impartial. In rural areas there can be significant overlap between aged care and health care providers; due to the thin markets, one organisation (and sometimes also individual staff members) can take on multiple roles within a rural community. An example is the Australian Government Multi-Purpose Services (MPS) program that offers integrated health and aged care services in rural and regional areas (<https://www.health.gov.au/initiatives-and-programs/multi-purpose-services-mps-program/about-the-multi-purpose-services-mps-program>). There are also higher chances of personal connections occurring within such small rural communities.

The Australian Government is currently trialing 62 different Aged Care Navigator programs across Australia, led by COTA, with results due late 2020 (<https://www.cota.org.au/information/aged-care-navigators/>), to address challenges for older people in accessing aged care services. The Aged Care Navigators have the potential to act as a reliable source of information for older people however the challenge will be to sustain this program if there is no further dedicated funding for the program and/or the navigators' role beyond June 2020. Another challenge of the navigators' program is that there is a heavy reliance on volunteers to undertake the bulk of the role, which can affect the sustainability of the program and could cause threats to supply and local accessibility (for example, if there was a lack of volunteer availability in communities that are already small in number). In addition, due to concerns about privacy, some rural older people may avoid seeking information about services from a local volunteer. Thus, although the navigator program might meet some of the challenges, it is still likely that a local independent aged care coordinator will also be required.

To ensure the success of the independent aged care coordinator role, the incumbent ought to be located in a prominent and easily accessible location in their Local Government Area. The coordinator will need to have the resources and capacity to undertake home visits and/or the resources to facilitate older people to attend a



central office. The role will need to be well promoted within the community. The independent local aged care coordinators, community members or health care staff may refer older people to advocacy services, such as Older Person's Advocacy Network (OPAN) (<https://opan.com.au/>), Council on the Ageing (COTA) for Older Australians (<https://www.cota.org.au/>) or Senior Rights Victoria (<https://seniorsrights.org.au/>). Funding is also required for these organisations to offer outreach advocacy services in rural and regional areas.

6.3 Provide mandatory training and continuing professional development for primary health care teams to promote ageing well and proactively support older people to access aged care services

Primary health care is the initial point of care for older people to access the health system. A comprehensive primary health care tackles a range of social and environmental factors that cause ill-health as well as those that sustain and create good health. Primary health care has a critical role in protecting and promoting the health of people in communities and addressing challenges of poor health and dysfunction in a preventative manner. It is also the setting in which health issues are commonly identified, managed, or referred, in the context of early intervention. With appropriate training and professional development, the primary health care team should and can play a larger role in promoting ageing well and preventive health.

There is provision within My Aged Care for health workers to refer older people for a My Aged Care assessment, with the older person's consent. In addition, health workers can refer a person directly to a service provider if there is an urgent need for a service which, if not met immediately, may place the patient at risk. (More information about this process is available at <https://www.myagedcare.gov.au/health-professionals>). Our

findings indicate that this option of referral by health workers is not well known by older people or health care staff.

Given the increasing ageing population, all primary health care multidisciplinary team members, including general practitioners, practice nurses, pharmacists, and allied health staff, need to receive mandatory training and ongoing professional development about caring for older people and the My Aged Care program. (This training and professional development support could potentially be delivered by Primary Health Networks.)

In addition, in each Local Government Area, the community health staff who work with older people should be made known to the primary health care team for the purpose of networking and information-sharing. This is particularly pertinent in rural and regional areas where there is a high workforce turnover, or an overseas trained workforce, or both, resulting in a workforce that has limited knowledge and understanding of the health and aged care systems, local services, and the rural context in which older people live. Primary health care staff ought to regularly discuss with their older clients that My Aged Care is available to provide home support services for older people and encourage older people to proactively seek help to maintain their quality of life and independent living. Primary health care can distribute pamphlets about My Aged Care in their waiting rooms and give these to older people attending primary health care services.

6.4 Dedicate funding for proactive follow-up for 75+ health assessments

There is opportunity for rural older people to be more proactively encouraged to access home based aged care services through providing funding to enable follow-up and referral for people who have received a 75+ health assessment. The Australian Government provides a Medicare funded initiative for people aged 75 years



and older to receive an annual 75+ health assessment in general practice (https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_75andolder). It is usually Practice Nurses who, as an integral part of the general practice, undertake early screening, comprehensive assessment and management of the 75+ health assessment. Although Practice Nurses could coordinate aged care services for older people in the community, this rarely occurs due to funding constraints. However, given our findings that rural older people depend upon health workers to inform them the availability of and the need for services, we contend that these 75+ health assessments provide an ideal opportunity for this type of proactive information provision and reinforcement to access services.

6.5 Review information provision and comparison tools on the My Aged Care website to ensure they are fit for purpose in a rural context

We found that the information provided on the My Aged Care website was not sufficiently tailored to differentiate actual service availability in rural areas. When a rural location is entered in the My Aged Care website services search, “national” providers who are located more than 100km away and who do not actually provide services in the rural area can be listed as “available”. In addition, the information listed about service providers is not consistent and thus it cannot be easily compared. Therefore, at a minimum, it is suggested that there be information about aged care service providers that:

- is standardised, using the same template for all providers, so that like-with-like details can be easily compared
- providers that do not have offices and/or staff located in the same Local Government Area are not listed as available for that area.

6.6 Review the My Aged Care website and phone call centre to ensure they are easily accessible for rural older people

Despite previous efforts to make the My Aged Care service easier to use, our findings indicate that it is still not user-friendly for older people. Some rural older people do not have access to the internet and online devices, or they are not able to use technology. When older people contact My Aged Care by phone, the information provided is not always consistent as there are various staff responding at different times. Furthermore, older people may experience sensory deficits such as reduced hearing or vision that can impair communication. An older person’s ability to comprehend information is affected by their literacy level and other medical conditions that may impact cognition. Therefore, testing of services for fitness of use for rural older people is recommended.

6.7 Deliver a targeted awareness raising campaign and education that highlights the importance of timely access to community aged care services

Rural older people value their independence and rarely seek help as they believe there are many other people who are worse off and in more urgent need of aged care services. Their introduction to community aged care services is often precipitated by major crisis such as falls, stroke, hospital admission, or bereavement. Following discharge from hospitals, older people may access post-acute care, sub-acute care, or rehabilitation programs for their health care needs. Unlike health care, that is equipped to act and treat older people when ailment occurs, access to appropriate aged care services may not always be readily available when and where it is required. This is particularly true in rural and regional areas that commonly experience workforce shortages.

Education and greater awareness of available services and their waiting lists enables better planning for aged care support and services. It is vital that older people access aged care services in a timely manner when they first notice difficulty coping at home, or a decline in their functional level, so that the likelihood of developing further injury or impairment can be avoided. Transition to retirement is a potential time to review the available aged care support and services. Older people also need to consider information about options for future respite care and/or residential aged care options. Timely adoption enables older people to have the time to consider the best aged care service options for them in the short and longer term, and to make informed decisions.

An awareness raising campaign ought to be delivered to older people and their families, service providers, and the broader community. However, there would necessarily need to be variations to key messages and foci for each of these three groups of people:

- a. For **older people and their families**, the key message should be that accepting services early is likely to result in a longer period of living independently (albeit with services) rather than that the acceptance of services indicates waning independence and that they may soon need residential care. Preserving quality of life and function early is essential to ageing well in the community.
- b. Older people rely on **health service providers** to indicate that aged care services are required. Hence the key message for health service providers is their important role in proactively encouraging early adoption of services and that they also have a fundamental role in suggesting what types of services would be valuable to older people.
- c. For the **broader community**, the spotlight should be that services are available that enable older people to live independently in the community for longer and that these services are provided because they can help to prevent costly hospital and residential care admissions. The awareness campaign needs to address stigma associated with reduced independence when receiving aged care support and services.

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8 Appendices

8.1 Appendix 1: Interview schedule

General information

- Please tell me a bit about yourself
- Do you have anyone supporting you at home?
- Please describe anything that limits your ability to access information or care and support services?
- Please tell me how you access online technology
- Please tell me about your community

Accessing care and support services

- What care and support services are you aware of in your community?

- What prompted you to seek care and support services?
- What services did you need?
- What were your experiences when seeking information about care and support services?
- How easy or difficult was it to arrange and assessment for care and support services? What made it easy/difficult?
- Please tell me about your experiences with My Aged Care
- Are you receiving support services through the Commonwealth Home Support Program (CHSP) or Home Care Packages (HCP)?

- Are there any services you need but are not available in your community? If yes, how do you manage this?
- Do you need to travel to access any services?
- Are you waiting for any approved services to begin?

Making choices about care and support services

- Please tell me about your experiences choosing care and support services
- If you had a choice, what aspects were most important to you when choosing your service provider?
- What was the most important source of information that you relied on when choosing your provider?
- Did you compare different providers before choosing one? Did someone help you compare providers? Did you use any comparison tools when choosing between services?
- When accessing care and support services, what do you want to have choices about? If there anything you do not want to have to make a choice about?
- What was the biggest challenge for you in deciding which provider to go with?
- What is the most important to you when deciding on services or a provider?
- Was cost important to you when choosing a provider? How was information about costs provided?
- Is quality an important factor to you when choosing care and support services? Did you choose services based on quality? Was information about the quality of the service provided?
- Did you find that information provided was clear and understandable?
- (For people with HCP) Is the written Home Care Agreement with your provider easy to understand?
- Have you ever changed providers?

8.2 Appendix 2: Methodology in detail

Ethical approval

- This project received ethical approval from the La Trobe University Human Ethics Committee, reference ID: HEC19333. Approval from also received from all Boards of the participating health services.

Participant Inclusion Criteria

Stage One:

- People aged 65 years or older, who were in receipt of or who had tried to access services under CHSP or HCP program
- Live in remote, rural, or regional areas within Victoria or within 20kms of the border of Victoria/NSW

Stage Two:

- Older people who participated in Stage One
- Staff who work for one of the 10 Project Partner health services (Cobaw Community Health, Edenhope and District Memorial Hospital, Heathcote Health, Kilmore and District Hospital, Kooweerup Regional Health Service, Mallee Track Health and Community Service, Rural Northwest Health, Robinvale District Health Services, West Wimmera Health Service, Wimmera Health Care Group)

Participant recruitment

Flyers (see **Figure 2**) were distributed by the 10 Project Partner health services to older people living in their catchment areas. When older people contacted the research team to express interest in participating in the project they were given a written Participant Information Statement and Consent Form (PICF) and an interview time was scheduled. A PICF was sent to the ten liaison staff representatives, one from each Project Partner health service, who had been appointed at the commencement of the project. These staff were invited to participate in Stage Two or forward the invitation to another staff member in their organisation.

Data collection

The interviews were conducted November – December 2019.

Delphi Round One data were collected in February 2020.

Delphi Round Two data were collected in March 2020.

Delphi Round Three (consensus meeting) was conducted on 28 April 2020.

Data analysis

Stage One:

The interviews were digitally audio recorded and transcribed verbatim by a professional transcription service. The transcripts were imported into an NVivo Project and analysed inductively and using the structure of the interview questions and considering the “Five preconditions of effective consumer engagement” (Solomon & Martin-Hobbs, 2018) to yield a thematic analysis. Journal data were analysed inductively to yield a descriptive analysis.

Stage Two:

The data for the statement rankings for Delphi Round One and Delphi Round Two were imported into an Excel file and then analysed by frequency and mode of ranking by participant type (older person or staff) and by whole sample. Comments collected as data for Delphi Round One were qualitatively analysed to yield a descriptive analysis.

Empowering older people in accessing aged care services in a consumer market

Researchers at the John Richards Centre for Rural Ageing Research, La Trobe University are seeking older people living in rural communities to be involved in a study to share their experiences about accessing services.

Would the research study be a good fit for me?

The study might be a good fit for you if:

- You are an older person living in a rural community of Victoria
- You receive services or have tried to access aged care services under the Commonwealth Home Support Programme (CHSP) and the Home Care Packages (HCP) program.

What would happen if I took part in the research study?

There are two stages to the research study. If you decide to take part in the research study, you would:

Stage 1

- Participate in an interview with a researcher about your experiences accessing, accessing and acting on information to access aged care services in your community.
- Keep a journal for three months about your interactions when accessing information about aged care services.

Stage 2

- Following Stage 1, you will have the opportunity to participate in Stage 2 of the research which will involve the completion of two questionnaires and attending a community meeting if convenient.

Will I be paid to take part in the research study?

You will be provided with a \$100.00 gift voucher to thank you for your time to participate in this research.

Who do I contact if I want more information or want to take part in the study?

If you would like more information or are interested in being part of the study, please contact:

Name:	Marita Chisholm, Research Officer
School/Department	John Richards Centre for Rural Ageing Research, La Trobe Rural Health School, La Trobe University
Email:	m.chisholm2@labtrobe.edu.au
Phone:	03 5444 7277
Ethics Approval Number	HEC19333

Version dated: 20 August 2019

Figure 2. Recruitment flyer

8.3 Appendix 3: Demographic details for older person participants

Int. No.	Age	Gender	Support person	Package type
1	89	Female	None	HCP Level 2 waiting for Level 3
2	70	Female	None	CHSP
3	83	Female	Husband (87)	HCP Level 2 waiting for Level 3
4	66	Female	None	CHSP
5	86	Male	Wife	CHSP waiting for HCP Level 2
6	83	Female	2 local children	CHSP
7	96	Female	3 children	CHSP
8	75	Male	Wife	Transition Care Program (TCP) for post-acute care, approved and waiting for HCP Level 2
9	88	Female	Husband (87)	CHSP
10	91	Female	Daughter (66)	HCP Level 1 waiting for Level 2
11	79	Male	Wife (78)	HCP Level 3
12	72	Male	Wife (70)	CHSP
13	71	Female	Husband (82)	CHSP
14	82	Male	Wife (71)	CHSP
15	91	Female	Daughter (67)	HCP Level 2 waiting for Level 3
16	73	Female	Husband (78)	Approved and waiting for HCP Level 1
17	83	Female	Daughter (49)	HCP Level 2
18	80	Female	None	CHSP
19	74	Female	Husband (89)	HCP Level 3
20	88	Female	Daughter	HCP Level 2

8.4 Appendix 4. Detailed information about participants' locations

Local Government Area (LGA)	Modified Monash Model (MMM) Classification Level	Urban Centres and Localities (UCL) population data
Alpine Shire	5	935
Alpine Shire	5	99
City of Albury	2	47,974
City of Albury	2	47,974
City of Albury	2	47,974
East Gippsland Shire	4	12,952
Indigo Shire	5	2,929
Indigo Shire	5	2,929
Shire of Cardinia	2	2,281
Shire of Cardinia	2	2,281
Swan Hill Shire	5	238
Swan Hill Shire	5	238
Towong Shire	5	242
Towong Shire	5	242
Wangaratta Rural City	3	18,566
Wangaratta Rural City	3	18,566
Wangaratta Rural City	3	18,566
Wodonga Rural City	2	35,130
Wodonga Rural City	2	35,130
Wodonga Rural City	2	35,130

8.5 Appendix 5: Delphi Round One detailed results

Results (reported in **Table 5** and **Table 6**) were derived using a two part process:

- Frequency of selection (Freq): the number of times a statement was selected regardless of its ranking
- Rankings: the mode ranking for each statement.

For example, consider the statement "Rural older people desire to be independent for as long as possible and only seek services when they feel a very strong need for help".

- Freq=20: this was the most frequently selected statement, regardless of ranking. Of the 26 participants, 20 picked this statement as important.
- Mode=Rank 1: of the 20 who selected the statement, 14 ranked it as being of most importance, Rank 1.

Table 5. Delphi Round One combined rankings

Statement	Freq	Ranking (shaded cell is mode rank)					Final ranking
		Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	
Rural older people desire to be independent for as long as possible and only seek services when they feel a very strong need for help.	20	14	2	1	1	2	1
Rural older people prefer to receive advice about aged care services by talking to health professionals, friends, peers, and family.	12	0	5	2	4	1	2
There is a lack of awareness of community aged care services among rural older people and rural communities.	12	2	3	4	2	1	3
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.	11	1	4	2	3	1	4
Rural older people prefer to use a known, local provider recommended by family, friends, or health providers.	11	3	2	1	1	4	5
Trusted health professionals or family members usually need to encourage rural older people to seek community aged care services.	10	3	4	0	1	2	6
It is not easy to compare services and service providers.	8	2	2	1	2	1	7
In some rural areas there is only one, and sometimes no, choice of aged care service provider.	7	3		2	1	1	8
The information about services provided by My Aged Care is overwhelming and often not relevant.	7	1	2	1	3		9
Rural older people are reluctant to switch providers; they worry that switching is inconvenient or costs extra.	7	1			2	4	10
There is a lack of clear and consistent communication from My Aged Care both online and over the phone.	6	1	1	2	1	1	11
Rural older people find out about available services through “word of mouth” (for example, through caring for others, going to a community talk, doing volunteer work).	6	2		2		2	12
Rural older people are very grateful for services and so they avoid making complaints.	6	1	1	2	1	1	13
Most health professionals and service providers have enough knowledge to help rural older people to navigate My Aged Care.	5		1	3	1		14
With an older person’s permission, it is okay for family (or trusted other people) to make decisions about community aged care services on the older person’s behalf.	3	1				2	15

Table 6. Delphi Round One rankings by participant type

Statement	Older persons ranked responses	Staff ranked responses	Combined rankings
Rural older people desire to be independent for as long as possible and only seek services when they feel a very strong need for help.	1	1	1
Rural older people prefer to receive advice about aged care services by talking to health professionals, friends, peers, and family.	4	2	2
There is a lack of awareness of community aged care services among rural older people and rural communities.	3	7	3
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.	2	10	4
Rural older people prefer to use a known, local provider recommended by family, friends, or health providers.	5	3	5
Trusted health professionals or family members usually need to encourage rural older people to seek community aged care services.	7	4	6
It is not easy to compare services and service providers.	6	6	7
In some rural areas there is only one, and sometimes no, choice of aged care service provider.	8	8	8
The information about services provided by My Aged Care is overwhelming and often not relevant.	11	9	9
Rural older people are reluctant to switch providers; they worry that switching is inconvenient or costs extra.	13	5	10
There is a lack of clear and consistent communication from My Aged Care both online and over the phone.	10	11	11
Rural older people find out about available services through “word of mouth” (for example, through caring for others, going to a community talk, doing volunteer work).	12	13	12
Rural older people are very grateful for services and so they avoid making complaints.	9	12	13
Most health professionals and service providers have enough knowledge to help rural older people to navigate My Aged Care.	14	14	14
With an older person’s permission, it is okay for family (or trusted other people) to make decisions about community aged care services on the older person’s behalf.	15	15	15

* 1 is the highest ranked through to 6 as the lowest ranking

8.6 Appendix 6: Delphi Round Two detailed results

Results (reported in **Table 7** and **Table 8**) were derived using the same two part process as for Delphi Round One:

- c. Frequency of selection (Freq): the number of times a statement was selected regardless of its ranking
- d. Rankings: the mode ranking for each statement.

Table 7. Delphi Round Two combined rankings

Statement	Freq	Ranking (shaded cell is mode rank)			Final ranking
		Rank 1	Rank 2	Rank 3	
Rural older people tend to access services when they are in crisis, after a fall or hospitalisation, or if they are in dire need.	13	4	4	5	1
Some rural older people, families, and rural communities lack awareness of community aged care services.	9	6	1	2	2
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.	9	0	5	4	3
Rural older people rely on getting advice about aged care services from health professionals, friends, peers, or family.	8	2	5	1	4
In some, not all, rural areas there is only one, and sometimes no, choice of aged care service provider.	5	2		3	5
For some people information provided by My Aged Care is overwhelming and difficult to follow.	5	2		3	5
Rural older people prefer to use a known, local provider recommended by family, friends, or health providers.	5	3	1	1	6
Communication with and navigating My Aged Care can sometimes be challenging.	5	1	2	2	7
Comparing types of services and service providers is not easy.	4	1		3	8

Table 8. Delphi Round Two rankings by participant type

Statement	Older persons ranked responses	Staff ranked responses	Combined rankings
Rural older people tend to access services when they are in crisis, after a fall or hospitalisation, or if they are in dire need.	2	2	1
Some rural older people, families, and rural communities lack awareness of community aged care services.	1		2
There is a lack of clear and detailed information about what services will and will not be delivered and the costs.	3		3
Rural older people rely on getting advice about aged care services from health professionals, friends, peers, or family.		1	4

* 1 is the highest ranked through to 4 as the lowest ranking



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