Wrongly disadvantaged?

Brief report of consumer views on rural and remote care

September 2019

National Seniors AUSTRALIA

Contents

INTRODUCTION

Background

The Aged Care Diversity Framework (1) aims to address the barriers to accessing safe, equitable and quality aged care for those who belong to one or more diverse groups of older people; groups that may experience systemic disadvantage or exclusion compared to the mainstream population.

People living in rural and remote regions constitute one of the diversity groups identified within the framework. The term 'rural and remote' is used commonly to denote the subgroup of the population who live outside the bounds of major metropolitan areas. It encompasses inner and outer regional, and remote or very remote areas.

Rural and remote residents are not a homogenous group in terms of the issues or challenges associated with geographic location, but the category does serve to differentiate the 29% of the population who don't have access to the health and medical services available to the city-dwelling majority (2).

The ageing of Australia's population is more marked in regional areas where higher proportions of people over 65 live compared to major cities (3).On average, older people in rural and remote areas have lower incomes, experience greater levels of disability, have poorer housing, lower education, worse health outcomes and higher per capita need for aged care support (4).

The Government's Diversity Action Plan aims to address the barriers to appropriate aged care for all, regardless of background or circumstances, as well as identifying opportunities for action (5). To this end, the Plan highlights several desired action outcomes including the following:

"*Collect, monitor, analyse and use data about diverse characteristics and life experiences of older people to ensure equitable access and outcomes"* [1]

"*Identify and overcome barriers faced by older people in accessing the aged care system"* [2]

Purpose

The purpose of this report is to document older people's experiences, in their own words, of access and barriers to care when living in rural and remote regions. Doing so provides insight into the specific needs of this subgroup of older Australians, needs that otherwise may be subsumed by those of the majority who live in or around major cities.

The report provides a preliminary snapshot of age care concerns expressed by National Seniors members who identify as belonging to a rural and remote group category. The broader ageing issues for this group are also presented.

[1] Diversity Action Plan: component of Outcome 2: 'Adopting systemic approaches to planning and implementation'
[2] Diversity Action Plan: component of Outcome 3: 'Accessible care and support'

DATA AND METHODS

Data

Data were drawn from the 2019 NSSS-8, an annual online survey conducted by National Seniors of members' behaviours and views across a range of topics relevant to older peoples' lifestyle, health and wellbeing (6).

Participants

Sample recruited

All National Seniors members residing in all states and territories of Australia with an email address were invited to complete the survey. The survey invitation was emailed and contained a link to the survey instrument. This email link was not restricted to National Seniors members but instead accessible to anyone from the general public who was willing to complete the survey.

Sample limitation

As the survey distribution was open and not directed at specific individuals, it is possible that some responses represent duplicates from the same individual. Given the large sample size, this is unlikely to have a large influence on overall percentages.

Sample included in this report

Participants included in this study were those who identified as "people living in a rural or remote area" when asked if they belonged to any of the diversity group listed. All participants were aged 50 or over.

Methods

As part of the NSSS-8, participants provided free text responses to the following questions

- **What age care issues (now or in the future) are the most important ones for you and, if applicable your partner and family?**

- **[Living in a rural or remote area] you may have experienced barriers to the lifestyle and health options available in the broader community. Please feel free to use the text box below to share your thoughts on ageing issues that may be particularly relevant to [living in a rural and remote area].**

Two National Seniors researchers independently evaluated rural and remote participants' free-text responses to these questions with the aim of identifying common underlying themes.

RESULTS

Of approximately 4,500 respondents, 475 people identified as living in a rural or remote region (10.5%). The proportion of rural or remote residents in the NSSS-8 was not representative of the Australian population where 24% of people over 55 live in areas outside major cities or inner regional areas (7). The online administration of the survey contributes to the selectivity of the sample which excludes members who have low digital literacy or live in areas of poor connectivity.

Table 1 presents the demographic characteristics of the rural and remote subsample of the NSSS-8 in comparison to the main sample:

Participant characteristics	Rural & remote subsample n=475	% of rural & remote subsample	% of main sample
National Seniors membership			
Yes	436	**92.0**	**94.0**
No	38	**8.0**	**6.0**
Free text response: Care issues	299	**62.9**	—
Free text response: Ageing issues	175	**36.8**	—
Age group			
50-54	6	**1.2**	**2.0**
55-64	108	**23.1**	**20.9**
65-74	225	**48.2**	**46.2**
75-84	109	**23.3**	**29.7**
85+	18	**3.9**	**3.8**
Gender			
Man	265	**56.0**	**42.8**
Woman	204	**43.1**	**56.7**
Non-binary/other identity	0	**0.0**	**0.2**
Prefer not to say	4	**0.8**	**0.3**
Education (highest level)			
High school certificate	93	**20.8**	**17.2**
Other certificate or diploma	175	**39.1**	**32.2**
Bachelor's degree or above	167	**37.4**	**40.8**
Other	39	**8.7**	**9.1**
State			
NSW	126	**26.5**	**21.9**
QLD	171	**36.0**	**41.2**
WA	42	**8.8**	**9.5**
VIC	72	**15.2**	**17.5**
SA	27	**5.7**	**4.9**
TAS	13	**2.7**	**3.2**
NT	24	**5.1**	**1.4**
ACT	0	**0.0**	**0.3**
Relationship status			
Married	290	**64.4**	**54.1**
De facto	27	**6.0**	**5.1**
Divorced/separated	40	**8.9**	**12.8**
Widowed	51	**11.3**	**16.0**
Single	38	**8.4**	**10.7**
In relationship living apart	4	**0.9**	**2.0**

SECTION 1: CARE ISSUES FOR RURAL AND REMOTE RESIDENTS

1. The financial burden of age care

Rural and remote residents experience higher costs of living and are on average less financially secure than those in metropolitan areas (4). Results from the NSSS-8 show that compared to the main sample, 15.6% of people in rural and remote locations have a mortgage compared with 11.2% of the main sample (Figure 1). A higher proportion of rural and remote residents receive a full pension (19.8% versus 14.2%), so have limited, if any income from superannuation or savings and investments (Figure 2).

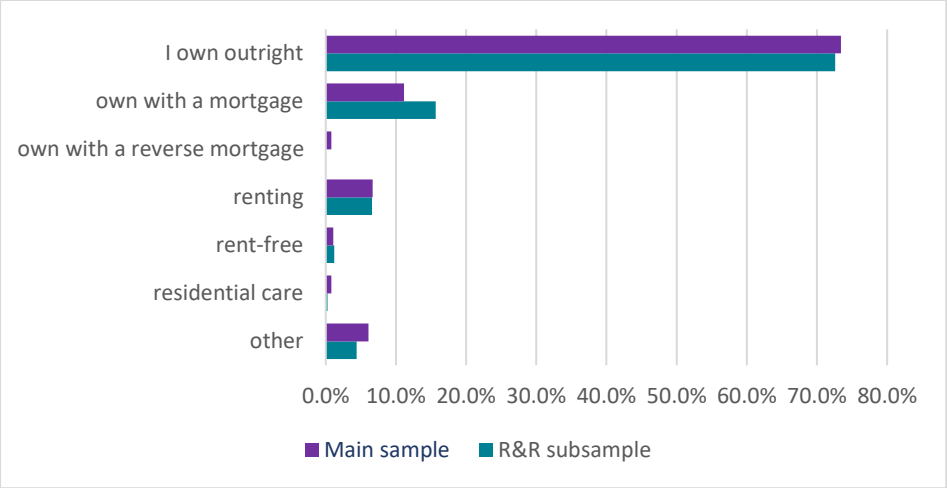

Figure 1: Housing situation of rural and remote residents (n= 409) compared to the main sample (n=3905) of the NSSS-8, 2019

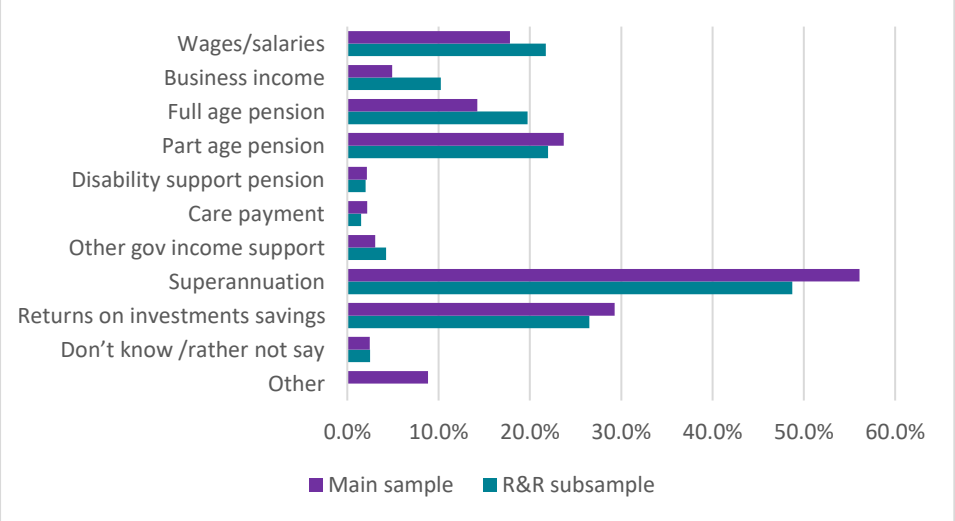

Figure 2: Income sources of rural and remote residents (n=400) compared to the main sample (n=3550) of the NSSS-8; 2019

Despite being accessible to people on the age pension, the cost and affordability of aged care were dominant issues for rural and remote participants. The financial burden of residential care was particularly concerning:

"Aged care homes are way too expensive for most people."

"Don't know how we will ever afford aged care if needed."

"Being able to afford to go into aged care when and if the occasion arises."

"High cost of admission to aged care facilities will preclude many from obtaining care."

This was quite explicit for those with assets who were worried about the impact of aged care costs on their finances:

"Self-funded retirees are most affected as they are not eligible for subsidised aged care beds."

"Affordable aged care without dipping into capital reserves."

"We have always been careful and saved to be self-funded retirees. We are by no means rich, but we are disappointed that aged care costs will come out of our savings."

"We will each have to sell an investment property in order to fund an aged-care placement. Aged care in the home with the provision of services has got to be the best option, if at all possible due to health."

2. Age care quality and desirability

Amongst rural and remote residents, aged care quality was perceived as being compromised by providers who prioritise profit over care without benevolent or community-minded motivations:

"Age care is becoming unaffordable and care is less patient-centred; rather it is becoming more about profit."

"Authentic care is needed!!!, we are still living beings, these business are not for profit, it's about CARE."

"Aged care centres are only there to see how much profit they can make like the banks. They don't care about their patients only about the money. They are understaffed by less qualified people than should be and they don't care."

"I am hoping these facilities become safer for the residents as well as the staff as it appears that both are affected by bad corporate management focussed on profit as primary consideration."

Given that it was affordable, the quality of residential aged care was of concern - encompassing issues of respect and dignity:

"All issues are important - but being treated with respect, and carers having time to attend to their client without masses of paper work being their priority instead."

"Affordable age care in a residential situation, where you have your own dignity and independence."

"Good care with dignity. Aged care seems to be more like palliative care when people are treated like they have nothing to look forward to or no future."

"As a minimum - affordable high quality person-centred care both at home (primary care support) and in aged care facilities - care needs to reflect research and evidence based practice whilst inclusive and consultative of the resident's needs, individuality, equality, respectful etc."

With a background of general community negativity to 'nursing homes', some people vehemently rejected residential facilities as a care option:

"I refuse to go into care. I have seen what they are like."

"I will never ever go into an aged care facility!"

"Personally, my wife and I would not go into an aged care facility."

"(I fear) that we will end up in Aged Care due to infirmity. After working in it - not happy."

On the extreme end of views, death was preferable to residential care:

"I nor my spouse want to go to a nursing home. I'd rather euthanise."

"I will never consider a nursing home facility after the sickening scenes that have been covertly filmed. I would rather die than enter one."

In rural and remote regions, moving to residential care may mean isolation from a partner, family and home by very significant distances:

"It is very traumatic for rural people to have to move to big towns, far from their homes and family to live in aged care homes. This move often signals the end of their lives."

"I want to be able to access it (care) where you spent most of all of your life (in my case 75 years so far)."

"There currently is not enough senior housing nor dementia care facilities, so it may mean I have to move interstate."

"In our area, if the nursing home or hospital in town has no vacancy, then the elderly person is accommodated in another town/village which may be anything from 30 to 50 km away. There is no public transport connecting the towns which means no or limited visits from an elderly partner which is upsetting for both patient and partner."

It should also be noted that the loss of a few people from small villages and towns can cause shops and facilities to close down leading to further departures.

3. Assisted dying

In the context of an active, contemporary discussion of types of euthanasia, some were in favour of assisted dying to ensure they had control over their quality of life:

"I would like to have the opportunity for voluntary euthanasia if I became very ill. I don't like the idea of ending up in an age care facility."

"…..having assisted dying legally available when quality of life doesn't exist."

"Assisted dying. When it's my time I want to go on my own terms, not like my father who took 15 years to die of MND."

"Acceptance of voluntary euthanasia would seem to be both humane and intelligent."

"Being able to exit stage left when quality of life becomes unacceptable."

4. Care at home

Generally, receiving care at home was the preferred option for the future which is accentuated by isolation and distances to other forms of care:

"I want to be able to stay in my own home as long as possible."

"I want in home support as I age."

"I want to stay in my own home and make my own decisions."

"My husband and I do not want to enter an aged care facility unless absolutely 100% necessary. We want to try to stay at home, with assistance as long as we can."

"I have asked my son NOT to ever put me in a care home as I would like to stay in my own home, surrounded with the things I love and care about."

"The facility to age gracefully in one's own home."

But participants expressed doubt about the availability and adequacy of home care when needed:

"How to stay at home - the system seems to be slow to sort out issues for folk to stay at home."

"The availability of in-home care when needed. Decrease the wait time for packages."

"There must be greater and quicker provision of home care."

"I need more than one service of 6 hours from Aged Care services per year. It only scratches the [surface] and I have to wait months for a service. There never seems to be enough personnel to help aged people. I would also like to have occasional house help and maintenance."

These concerns are amplified by the sparse services in the bush and the distances required to deliver them.

The difficulty in accessing information about assistance was also highlighted:

"Being able to find out what is available easily. There seems to be a lot of choice/things available, but you never hear about them until in a crisis, and then it is mind-boggling!"

"Knowing who to contact to find out about services as we get older; changing the way of dealing with Human services departments eg Centrelink - not being able to talk to anyone changing technology and not being able to keep up."

While these experiences have been reported generally, including in our report ‘The Centrelink Experience’(8), they add another dimension of disadvantage experienced by those in rural and remote areas.

SECTION 2: OTHER AGEING ISSUES FOR RURAL AND REMOTE RESIDENTS

5. Access to health and medical care

The aged care sentiments expressed by rural and remote residents are in accord with those of the senior population more generally who have a strong preference to remain in their own home (7). Ageing at home, however, requires access to appropriate health, medical and community services to optimise health, thereby preventing early entry into residential care (9). In the rural and remote subsample, only 13% rated their health as excellent compared to 18.5% of the main sample, with higher proportions in the 'Fair' and 'Poor' health categories (Figure 3).

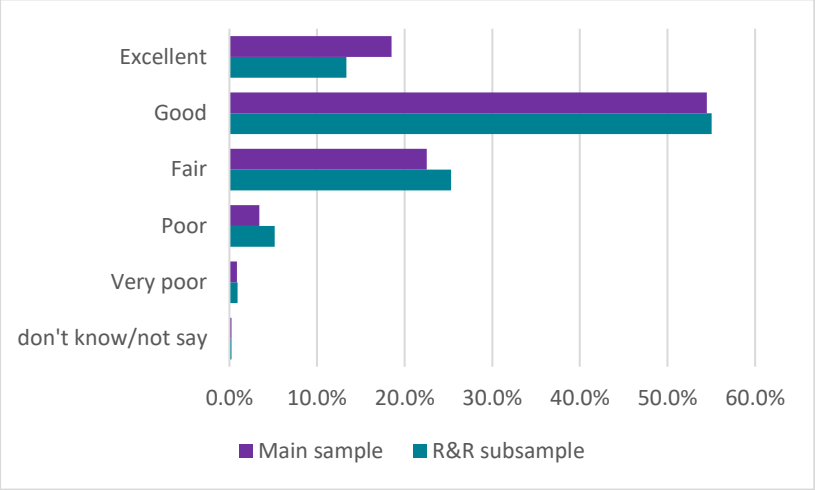

Figure 3: Self-rated health of rural and remote subsample (n=427) compared to the main sample (n=3706) of the NSSS-8; 2019

Inadequate access to health and medical facilities was the overarching theme of rural and remote participants' free-text responses when asked about general ageing issues:

> *"Most significant health facilities are located in major cities so to access adequate health care and specialist services often requires a 6-hour round trip. As we age, we'll all need these services but they just aren't available unless you live in or close to a capital city."*

> *"Difficult (financial/work/family) to leave home and family to go to a capital city to get adequate health care even for the basics. If unable to drive, then having to pay extortionate money to get a flight to a capital city if you can get a direct flight and not have to fly all over Australia to get where you are going. When unwell I fully understand why people just give up and put up with health issues that eventually lead to major problems and death."*

Poorer health care was reflected in the relative proportions of ratings for Australia's public health care system on a scale from 'Very poor' to 'Excellent'. Higher proportions of rural and remote residents selected 'Average', 'Poor' and 'Very poor' ratings (Figure 4).

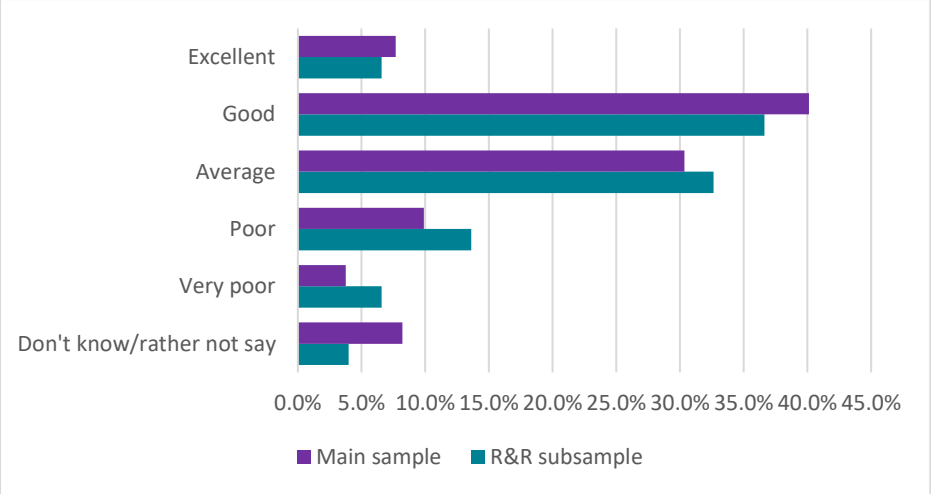

Figure 4: Public health ratings (n=426) compared to the main sample (n=4124) of the NSSS-8; 2019

Participants' text comments, consistent with care responses, documented their struggle to access all levels of the health system, beginning with GPs:

> *"Currently there isn't a permanent doctor in our town. No public daily bus services to access Drs & other paramedics in near-by town."*

> *"Hard to access medical appointments when we have only one very hard-working doctor."*

GP shortages and subsequent extended wait times were common experiences:

> *"Shortage of GPs in rural areas. Even though we are patients of a regular health practice, you rarely get to see the same GP as they are here on short term contracts or you have to wait several days, sometimes up to a week, to see the doctor. There is no bulk billing service."*

> *"Most options are none existing in rural community here. We have a hopeless medical/health option as we are down to 2 doctors, at all times, to aid the population here, so waiting time is 2 weeks."*

> *"After waiting five months once relocated here, we were finally able to find a new local GP to become our family Dr. Large shortage of available GPs in this [region]."*

Although local emergency services were available, they were not necessarily adequate:

> *"I am concerned that although we can attend our local hospital for any emergency, unless it is within certain hours, we will be sent to Wodonga Hospital, 1.5 hours away by ambulance. Not good in certain situations."*

But the fly-in fly-out services were appreciated:

> *"It is not always possible to get special or specialist health care without considerable travel, but the various Care-Flight and similar emergency services are particularly wonderful in many ways."*

The travel distance required to access specialists and specialist medical care was a major concern:

> *"As with everyone in my community, we have to travel 400 plus kms for specialist medical treatment."*

"Local hospital does not have a surgeon, anaesthetist, or obstetrician. Nearest alternative is Wagga Wagga RR Hospital 100 km."

Travel may be particularly difficult for those with a disability or older residents:

"I have to go to Toowoomba - 4.5hrs away to see specialists. Becomes harder as people get older."

"Because of my disability travel is very difficult. I cannot use buses or even the airline in my town. The only option for obtaining specialist care is by private vehicle. When/if my husband is sick I cannot leave the town. In emergencies the flying doctor takes patients to the nearest large town but does not return them to their home. This creates a lot of difficulties."

"To access specialist health care, it is necessary to travel up to two hours, which is fine IF you can drive or have family to transport you. I have neither."

"Health care is a very big issue especially when having to travel away from the region for specialist or emergency health. Often we do not have any choice about where we are sent (often alone without family members) and then we are faced with how to get back home."

The burden of additional cost was also an issue highlighted by rural and remote residents who had to travel to receive care:

"Carers pension means tested and not compensating for cost of taking a relative to medical visits 100km drive each way."

"We fly to Brisbane for specialist treatment and the air fares are exorbitant compared with larger towns."

"My wife has a chronic illness which requires us to travel to see a specialist in Sydney at least once a year and this means the cost of flights and accommodation which adds to our household budget in a way that would not apply if we were in a capital city. This also impacts on our ability to connect with our extended family for support. Simply, in this country, if you live outside a capital city and you are ageing, there are additional costs."

6. Sense of injustice

Some rural and remote residents felt wrongly disadvantaged compared to city dwellers:

"A lot of the medical services available to our city folk are not available to us, even though we have to pay the same level for private health cover, & even if we are able to get access to needed health services, we have to be on an often unacceptable list of preference. It's not only health services we suffer loss of in rural regions, the cost of living & general services are often dearer as we have no other options available to us & the providers know it & charge accordingly."

"Anyone not in a city is unseen by the policy makers."

"Our area is known as Far North Qld. It would be better described as FORGOTTEN North Qld as everything is available if you live in a major centre. Not so in the country"

"…not a lot of votes in rural/remote areas but we like the resources that are mined and exported from these areas but dollars are spent in capital and regional cities where the most votes are."

7. Other ageing concerns cumulating disadvantage

Access to health and medical care were the dominant ageing concerns identified by rural and remote participants, but many highlighted the lack of services generally, particularly the lack of public transport when driving is not possible:

"There is a lack of transport options available in our area which means reliance on your car to get places."

"Public transport does not exist in our area. If I was unable to drive, life would be quite challenging for me."

"My main difficulties will arise when I can no longer have a driving licence and use my car."

"Zero public transport for older citizens unable to drive."

"There is next to no public transport. Getting to the local doctor can be difficult if you don't have a partner, family or friends that can drive. Getting to a specialist is extremely difficult. We had a community car available, driven by 2 locals who volunteer their time. The car is booked up most of the time."

Lack of connectivity was another source of frustration:

"Mobile connection, it's always dropping out. NBN, well that's a complete joke. Telstra seem to be constantly working on it and we are always checking the home phone to see if it actually works."

"I live 12 kilometres from Highway 1 yet have very limited Mobile reception and often landline receptions is dodgy as well. Not only does this create communication issues as everyone uses mobile phones to text etc nowadays, it is an added expense to continue needing a landline. I also have aged relatives that need to be easily contactable and again this communication limitation is a worry."

"If you do not have internet there is next to no medical information available in the community. Communication is very slack."

As was the general lack of community resources:

"To far to go to anything or place on spur of moment. Need to plan weeks in advance to go anywhere. No resources/community involvement for ageing people."

"It is much harder to access services e.g. Garden maintenance, house repairs, housework help, health services including x-rays, physiotherapists etc."

SECTION 3: SUMMARY AND IMPLICATIONS

Compared to the main survey sample, higher proportions of rural and remote participants in the NSSS-8 were men, were aged between 55 and 74, and were married. Higher proportions also still had a mortgage, were receiving a wage or were on the full pension compared to the main sample. Rural and remote participants rated their own health and the standard of Australia's public health system more poorly.

Approximately two-thirds of the 475 people who identified as rural or remote contributed free text responses when invited to share their concerns about age care, with one-third commenting on general ageing issues. This is a general indication of their felt disadvantage as consumers.

The following themes were evident from the responses given:

1. The financial burden of age care
2. Concerns about the quality and desirability of age care
3. The importance of assisted dying being available to ensure quality of life
4. The desire to age at home
5. Difficulties accessing health and medical care due to location
6. The injustice of poor health care for rural and remote residents
7. Lack of general services, including connectivity difficulties

Under the Aged Care Diversity Framework, there have been action plans developed specifically to support older Aboriginal and Torres Strait Islander people, CALD and actions to support LGBTI elders. The themes identified from rural and remote participants' comments to the NSSS-8 align with Australian Association of Gerontology's call for the development of an action plan for older peoples' care in rural and remote regions (10). Many actions are already in progress, including the Rural and Remote Accord overseen by the Aged Care Workforce Industry Council.

The predominance of comments on access to health care as the major issue, indicates that this is a significant 'pain point' for rural and remote consumers. Given the lack of services or distance to them, health events are more critical than care needs since these may have to be dealt with at home or with community support in small towns. In the bush, it is very clear that health and aged care are inseparable. Despite the fact that both are 'stretched' in these areas, strengthening age care and primary health care links comes through as a clear priority. It is not surprising then that this is a priority in the overall diversity plan for Aboriginal and Torres Strait Islander people, CALD communities and LGBTI elders. Managing health concerns is critical and essential for rural and remote residents to stay in communities and homes.

Living rural and remotely also creates issues of equity of access to specialist care, for example, the travel cost to receive specialist care. However, we had no comments from participants on the adequacy or otherwise of the patient-assisted travel schemes available across all jurisdictions. It is a fact that people living in these areas expect to travel long distances routinely and accept the costs of this. This expectation doesn't mean they are being fairly treated.

It remains an open question from this evidence how well the availability of support services is being communicated. Some comments suggest people know there are additional systems/supports out there but don't know how to get the information they need.

With the inevitable difficulties of distance and remoteness, digital difficulties reported here are an obvious direction for improvement. The Digital Transformation Agency and other units are engaged in supporting such change. An immediate need is being addressed, presumably partially, in the 'Black Spots' initiative. Without reception, any digital initiative will be irrelevant.

The funding of a Rural and Remote Age Care Accord will focus on getting a sufficiently skilled workforce in rural and remote areas to improve the levels of available, quality care. In conclusion, difficulties in accessing medical care plus desire to age in place suggests even greater need for effective joint preventive health and home care initiatives in rural and remote areas to support future generations in these areas.

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