



Royal Commission
into Aged Care Quality and Safety

**THEY LOOK AFTER YOU,
YOU LOOK AFTER THEM:
COMMUNITY ATTITUDES TO
AGEING AND AGED CARE**

RESEARCH PAPER 5

JULY 2020

The Royal Commission into Aged Care Quality and Safety was established by Letters Patent on 8 October 2018. Replacement Letters Patent were issued on 6 December 2018, and amended on 13 September 2019 and 25 June 2020.

The Honourable Tony Pagone QC and Ms Lynelle Briggs AO have been appointed as Royal Commissioners. They are required to provide a final report by 26 February 2021.

The Royal Commission releases consultation, research and background papers. This research paper has been prepared by Ipsos for the information of Commissioners and the public. The views expressed in this paper are not necessarily the views of the Commissioners.

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They look after you, you look after them: Community attitudes to ageing and aged care

A report on focus groups for the Royal Commission into Aged Care Quality and Safety

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Executive summary

Background

This report presents the findings from 35 focus groups and 30 in-depth interviews conducted during July-September 2019 for the Royal Commission into Aged Care Quality and Safety. The research gives attention to three themes: the community's attitudes to older people; their understanding and perceptions of the current aged care system; and their planning, expectations and concerns for their own old age. The qualitative research included the general community and a broad range of targeted diversity groups, resulting in a wide range of views from people aged 18 years or more. The findings affirm and challenge our perceptions of Australian society.

Community views of older people

Age is not seen as being determined by a number, rather it is seen as depending on individuals' attitudes and behaviours. This shaping of our 'age' is, however, impacted by reaching key life milestones, such as retirement and beginning to draw on our superannuation or pension. Significant health and financial events do, for some, increase the speed with which our sense of older age develops, and this loss of physical or economic strength contributes to vulnerability and loss of capacity that is associated with feeling, and being perceived as, old.

Vulnerable, frail and slow are the most frequently used negative descriptors of older people, with them also being seen as close-minded or inflexible, lonely and scared. These perceptions are common to the broad range of participants in this study. However, **personal interactions with older people, be it through family or community, are described positively**, and welcomed as an enriching experience through the sharing of knowledge and culture.

As people age, they tend to focus more on the interrelated concerns of the inevitable deterioration of their health, the financial stress of unknown potential living expenses and unknowable life expectancy, and the slow loss of their independence. Older people are generally aware of the significant impact of loneliness and how this needs to be mitigated through social engagement and both physical and mental stimulation.

Negative perceptions are seen by many as contributing to older people being overlooked or 'invisible' within our society. The absence of older people from the workplace, combined with the limited ways in which many younger adults encounter them in their day-to-day lives, means that **many people have little exposure to older Australians**. The wider population are seen by some as affording older people less respect and value than given to previous generations. In this aspect the Asian community is held up as a positive example of the way in which older people should be venerated and cared for within the immediate family and wider community.

The increasing number of ways technology shapes our lives and interaction with the world are also seen as contributing to the low visibility of older people in society. Older people are seen as placing greater value on in-person interactions than younger generations. Finding the time to maintain relationships with older people is seen as a strain between the generations, with younger people being very time poor, and with insufficient time to support relationships with older people, in the way they would prefer.

Simultaneously, **older people are playing a vital role in supporting family life by providing free babysitting and childcare**, without which many working families acknowledge they would be very financially stretched. Many see older people as **enriching our community through their wisdom and knowledge** and by passing their experience on to younger generations through story-telling.

Our older years are seen as times for relaxation and – assuming our finances and health allow – a time when we can experience greater personal freedom around how we spend our time, such as travelling or developing pastimes, and also how we express ourselves. Older people, particularly women, feel less constrained by societal norms and expectations.

Most people do not think of older people as a ‘burden’ economically, emotionally, or socially. Unsurprisingly, older people have no wish to be, or to be seen to be, a ‘burden’ on their family or wider society. People with experience as a carer do acknowledge the heavy time, financial and emotional demands of the role. For almost all, the **carer role is seen as a positive responsibility that they gladly take on and is the natural cycle of family life**, repaying the care and love that they have received from older family members over the years. There is understanding why this role may be seen as burdensome by society, but few identified this word as accurately describing how they perceived their caring activities for older family and community members.

Community understanding and perceptions of aged care

The **participants knew little about the aged care system** unless they personally had worked in the system or had to find care for themselves, a partner, family member or friend. Those without such experiences had perceptions shaped by hearsay and media reporting. Knowledge of the aged care system increases with age, reflecting the greater experience of the system as people age.

Those who have sought information about the aged care system describe it as being **difficult to find and use to determine your way** through the system. Commonly those with experience of trying to find care used health professionals as a starting place and a valuable guide to help them navigate the key considerations in securing services. The few who had made use of the My Aged Care website found it moderately useful but simultaneously either too simplified to help, or too complicated to fully understand. Information was often described as being generalised and considerable perseverance was necessary to identify and secure care that successfully met an individual’s needs. Some older people recognised that unless they managed the process themselves in a timely fashion, they would be overtaken by events which would likely mean others were making decisions on their behalf.

Among those with some personal experience, access to care was not seen as difficult, however **access to appropriate, affordable and appealing care was challenging**. Those living in regional or rural areas reported having limited choice of aged care facilities. More generally, others felt that their **choice was effectively limited by the prevalence of religiously affiliated organisations** managing aged care facilities. This was particularly salient to people with a negative life experience of organised religion or who felt their lifestyle or choices were criticised by organised religion (e.g. care leavers, parents separated from their children by forced adoption or removal, and Lesbian, Gay Bisexual, Transgender and/or Intersex (LGBTI) people).

Despite knowledge about the aged care system being low, participants viewed finance as a key determinant in the ability to exercise real choice around aged care, and that for most it would limit

the choices available to them. Reflecting on their experience of aged care, many were critical that facilities were **more motivated by profit than by providing high quality care; they saw a clear tension between these two aspects.**

Knowledge is very variable about the bonds in aged care (currently known as Refundable Accommodation Deposits). Those who have engaged with the system have some limited awareness relating to the facilities they investigated; others did not know and were generally surprised at the scale of bonds required. The **level of the bond was daunting** for many, who were fearful that it would significantly reduce their available disposable income during their older age.

Perceptions of aged care – whether based on media reporting or personal experience – are generally negative. The **facilities are seen as depressing, clinical environments and as places to die rather places to live.** The nature of the environment in aged care facilities is seen as contributing to a decline in health and quality of life, and reduction of life expectancy. Criticism of aged care facilities focuses on lack of meaningful mental stimulation and social interaction, lack of agency over basic decisions (such as timing of meals and sleep) and lack of genuine care. Staff are perceived as over-stretched, under-paid and often lacking appropriate training. These factors combine to mean that staff are perceived as lacking the time to engage meaningfully with residents and build positive personal relationships. There is criticism that staff for whom English is not a first language lack sufficient communication skills and have different culturally-based expectations of care that are seen as being lower than those for whom English is a first language.

Most participants had given little thought to the regulation and monitoring of aged care facilities. They presumed that these took place via a government body. The widespread perception that much of aged care was low quality, and that elder abuse was widespread, **led most to assume that the regulatory regime was either failing or not well enforced.**

There is a **clear preference, across all demographics and ages, to remain living independently as long as possible.** For some this involves family support; for others there is an expectation of external support. Older participants already receiving support spoke of delays between registering, assessment and receiving support. **Most people welcomed the idea of family support in their older years, but do not want family involved in the delivery of personal care,** which was seen as inappropriate and burdensome for them.

Planning, expectations and concerns for own older age

Irrespective of age or community, thoughts about older age tended to focus on maintaining independence and control across all aspects of life. **Most people give little thought to the prospect of needing care** – be it in their own home or residential care – until life events force them to deal with it. This reflects a degree of denial and avoidance, and people being caught up in their busy daily lives. Most people are deterred from thinking about planning for these later years by the negative perceptions of aged care facilities and fear of declining health. Middle-aged participants, and older people who had not made plans, were more likely than others to raise the prospect of euthanasia as a way in which they would exert control over their later years and ensure their quality of life did not drop below an acceptable level. A minority of older people had made genuine efforts to put in place realistic plans for where they will be living, and how they will be cared for, in their older years.

Participants were **conscious of maintaining good health and regular physical activity** being necessary to maintain their independence and stave off a serious health 'event'. There was also very widespread understanding of the importance of maintaining good mental health through social interaction and stimulation. This reflected an understanding of the negative impact of loneliness and the importance of maximising good cognitive functioning. Participants spoke of retaining purpose and structuring their older years to ensure each day had a focus and interaction with others.

Financial planning among younger participants was limited; they were aware of paying superannuation but very few had any other form of financial planning or consideration for their older years. In contrast, older participants gave financial planning and security more thought, and for those on lower incomes, it was a worrying topic. The unknown path of each persons' health and associated costs was also a significant cause of worry. **Most people have made plans to self-fund their older years**, and they are doubtful that government support would provide the quality of life they are hoping for. Those receiving the pension are also concerned that this income stream is very limited. They tend to **feel stigmatised for claiming the pension despite feeling it is their right**, after many years of working hard, contributing taxes and being an active member of society.

Participants intend to retire when their finances allow and dependent on the lifestyle choices they wish to make. There was an expectation that employment options will become more limited after the age of 50, but few are able, or wanting, to retire until much older. **Many enjoyed their jobs and acknowledged the clear mental health benefits** they gained from having a daily purpose, being mentally stimulated and interacting with others socially in the workplace. A minority spoke of continuing to work due to financial necessity and needing to add more to their superannuation.

For some, living independently in their own home as they aged would mean **downsizing to a more practical property, that is easier to maintain, and in the process liberating funds to use in retirement**. Some participants planned to re-locate to be nearer to family or for lifestyle reasons, but most wanted to remain living in their existing neighbourhood during their older years to maintain social networks.

Many participants welcome the prospect of living in a multi-generational setting. They do not wish to live with their children – which would be seen as a burden – but would like an independent home where they would interact with a mixture of young and old. The age-limited scope of residents in an aged care facility is one of the aspects that makes them unappealing. Participants **want to be living in a vibrant, stimulating environment that allows them to experience a balance of time with both family and friends and community involvement**.

The views of diversity groups

Many of the diversity groups included in this study shared attitudes and perceptions that were common to the breadth of the community. We have described below where their views were distinct.

Aboriginal and Torres Strait Islander communities

The role of Elders within Aboriginal and Torres Strait Islander communities, and the respect and care with which they generally expect to be treated, were very important aspects for these participants

and a source of pride. They were aware that their communities **valued older people more highly than the wider Australian population**.

Knowing that Aboriginal and Torres Strait Islanders had a shorter life expectancy led to 'old' being perceived to be at a younger age. Participants from this group were more likely than others to spontaneously discuss issues of smoking and drinking and their impact on health in older age.

Aboriginal and Torres Strait Islanders were **more likely to look forward to older age**, seeing it as a time when they would be revered within the community, and could share their knowledge and culture with younger community members. Younger Aboriginal and Torres Strait Islander participants enjoyed this interaction with older people and recognised the value of knowing their traditional culture and stories. However, expectations of intergenerational interaction and care were not always met, with some older participants conscious that younger people are time poor and spend less time with older family members than expected. Some also felt that levels of respect for Elders within the community were falling. Concern around potential lack of support and loneliness in older age led some people to aspire to communal living, rather than feel a burden to their families.

Aboriginal and Torres Strait Islander participants, like others, wish to live independently in their older years. Where they differ from the wider Australian population is their expectations around family support, **care settings that understand and respect Aboriginal culture**, and that this period of life is either spent living on Country, or ensuring they are buried on Country. The cost of being buried on Country was a marked concern for older Aboriginal and Torres Strait Islander people.

Culturally and linguistically diverse communities

Those from culturally and linguistically diverse backgrounds described a **cycle of care within their communities**; living with grandparents in the family home during their childhood, receiving high levels of support from their parents during adult life, and, as a consequence, feeling high expectations to provide care and support to older family members during their later years. This was acknowledged as being different to the wider Australian population – and was held up by those not from culturally and linguistically diverse communities as being an **admirable way in which these communities cared for one another**. Older culturally and linguistically diverse participants were aware that this may be placing a burden on their children, and they spoke of wanting to reduce this sense of burden.

Support and interaction between generations was less likely to be mentioned as a positive means of sharing culture and language, than among Aboriginal and Torres Strait Islander participants. Culturally and linguistically diverse younger people spoke of the tension within families around the older generations' expectations that they behave in a more traditional manner, and that this was often more conservative than the wider Australian culture in which younger people were growing up.

Financially and socially disadvantaged people

People who are financially and socially disadvantaged were more often concerned about having sufficient income during older age, the impact on their health and housing choices, the need to continue working into their older years and being a burden to their children in later years.

These people **believe they would have limited or no choice about aged care facilities**, with private care being beyond their budget. With this expectation of state-provided aged care they tended to have less knowledge and information about age care unless they had previously navigated the system for a partner or family member.

Middle-aged and older financially and socially disadvantaged people were **more likely to have made plans, or moved, to a property or location that was more affordable**. This often meant moving out of a metro setting to a more affordable regional or rural location. By buying or renting more cheaply, these people were able to increase their disposal income, as many spoke of the difficulties of living on the aged pension.

Veterans

Veterans have a **clear, strong and positive perception of ageing and older people**. They see older people as wise, with valuable experience and life lessons to share, and making a strong contribution to the family unit. Veterans were critical that respect for older people has decreased and see this as a consequence of modern parenting, the education system and the widespread use of technology. They have a strong sense of obligation towards older people, and that **society's care for them should be a reflection of the lifetime's contribution that each person makes**. This mirrored the way in which they felt through their own service they had earned the Department of Veterans' Affairs (DVA) support that they received.

When considering care in older age, veterans **want to live with like-minded individuals** who would share their values and understand their lived experience. They were aware that as a community **they had specific physical and health needs that were distinct from the wider community**, and that their culture of independence and self-reliance meant that they were poor at seeking out help. This was recognised as a significant risk for the veteran community.

Gay, lesbian and bisexual communities

The experience of coming out, and the way in which some older family members did not accept younger gay, lesbian or bisexual people, tended to give this community a slightly more critical view of older people. They were more likely to see older people as inflexible, and sometimes bigoted.

Gay, lesbian and bisexual people were clear that they **wanted to spend their older years in an environment of like-minded, non-judgemental people, who respected their sexuality**. Some were wary of aged care facilities run by religiously-affiliated organisations. They had spent their lives navigating prejudice from a range of individuals and institutions and did not perceive these service providers as offering a setting in which they would feel accepted and respected. They were concerned whether their relationships and the rights of their partners would be acknowledged, and whether aged care staff would have the training and experience to provide health care appropriate to their needs.

Intersex and transgender people

The concerns of intersex and transgender people tended to be similar to those of gay, lesbian and bisexual communities, and also to those who are financially and socially disadvantaged. Some had experienced mental health problems that had impacted on their employment prospects. Combining this with gender identity issues, they tended to be more financially insecure and fear social isolation.

They were concerned about their vulnerability during old age, and simultaneously were looking forward to a time when they are happier in themselves or have fully transitioned.

Like the gay, lesbian and bisexual communities, intersex and transgender people **wish to spend their older years in an environment where they are respected and free from prejudice**. They share their concerns of facilities that are run by a religious organisation. Their greater financial insecurity meant that they are more likely to envisage future care being within the public, rather than private, housing or aged care systems.

Intersex and transgender people face ignorance and prurience in their current interactions with health professionals and would want **aged care to be staffed by health professionals who are knowledgeable of their specific health needs**. Given their journey to date, some are loath to move away from the health professionals who currently provide their care.

Care leavers

Most care leavers wish to avoid aged care facilities at all cost; many spoke of preferring to take their own lives, rather than move into an aged care facility. **Aged care facilities trigger traumatic memories of their childhood** in a range of ways; small window-less rooms, locked doors, institutional food and dining rooms, and the noise of footsteps patrolling the corridors at night. Care leavers have a heightened need to control their environments and for their voices to be heard. This led them to actively strive to live independently, making plans and adaptations to maximise their chances (e.g. house modifications, moving closer to family, or living with family).

For many, the **only way in which an aged care facility could be contemplated was if they were designed solely for care leavers**. This would mean a more open physical environment and the staff to be trauma-informed – that is, aged care staff would need to have knowledge of care leavers' history and work with them consistently to build trust. It would also mean sharing an aged care facility with other care leavers who would understand their experience and to whom they would not have to explain themselves or their responses to specific triggering situations.

Parents separated from their children by forced adoption or removal

The trauma of having had their children forcibly adopted or removed presented these women with ongoing health challenges. Some perceived the weight of their grief, combined with the poor physical health suffered as a consequence of treatment during pregnancy and birth, as having led to rapid ageing and premature death. Like care leavers, **memories of their earlier trauma were triggered by specific environments or interactions with health professionals**. As a consequence, they fear loss of control and want an older age where they have agency over all aspects of their lives and an environment where their voices are heard. They would **need aged care staff to be trauma informed and have understanding and experience of the impact of their personal history**.

Many of these women have kept the loss of their child a secret and have felt shamed by society. This has limited their ability to build trusting friendships and lifelong partnerships. They felt unsupported by family, and this has contributed to strained relationships with siblings who had gone on to have children and traditional family lives. These aspects make these women very fearful that they would be lonely and isolated in an aged care facility. For a few, this fear is so intense that they would prefer to take their own life than move to an aged facility.

People who are homeless or at risk of homelessness

People who are homeless or at risk of homelessness had **a very broad range of vulnerabilities; financial, health, housing, employment and social isolation**. This level of uncertainty made the prospect of old age very frightening to consider. Their poor or absent social and family support made this group particularly likely to be fearful of loneliness and social isolation in older age.

These participants were actively striving to secure ongoing stable housing, but their financial insecurity meant that they were dependent on others and had little agency over their outcome. They **tended to be managing complex physical and mental health needs**, and this impacted on their ability to make progress in terms of housing or employment. More so than other groups, they were aware of needing to work into their older age to support themselves, and conscious that they would face prejudice in trying to secure work as an older person.

This group **found it very difficult to consider what their older age would be like** but presumed that they would have no choice other than public aged care facilities. They were concerned about the quality of care, the mixture of other residents and the lack of personal freedom and independence.

Young people living in residential care

Young people living in residential care were the only participants of the study to be currently receiving aged care in a residential facility. As such, they were **very well informed about the process of getting a place in care and were also extremely critical of the care they received**, namely issues of cleanliness, personal hygiene, stimulation for residents and respect and dignity of care.

They highlighted that it was extremely difficult to find an aged-care place that was appropriate, with adequately trained staff with the necessary specialist skills to meet their needs. They were particularly **critical of poor English-proficiency among overseas staff**, and that this negatively impacted communication and building good, positive relationships between staff and residents. They highlighted incidents of **residents being unattended**, and staff operating in ways that suited their convenience, not the residents' best interest, such as residents' being made to wear nappies or be overly medicated. They spoke of the **need for active, daily vigilance by families** to ensure care is appropriate, timely and of high quality.

They had specific concerns about the **inappropriateness of young people living in aged care**. Foremost among these was the lack of appropriate social engagement. Many spoke of withdrawing from social interaction as the friendships they built with older residents became painful as these residents would pass away. The range of stimulation on offer was seen as very limited and not age appropriate. Similarly, the food is soft and mushy and not appropriate for younger people. Rules in aged care facilities were considered very restrictive and impacting on a young person's autonomy and social interaction with friends and family.

Young people living with dementia

Young people living with dementia were well informed about their condition and tended to know more about aged care than other groups. They wanted to maximise their independence and were **actively invested in their health to slow the progress of their dementia** but were aware that aged care would probably be necessary at some point. Given the progression of their condition, they were particularly wary of becoming a burden on their families.

They were **critical of current dementia units**. They perceived them as lacking meaningful and stimulating activities, offering poor quality care, that staff lacked basic dementia training and were frightened by the prospect of being locked in or restrained. They felt dementia places were limited, and that it was very hard to find a place in a high-quality facility with the appropriate skills for the individual resident.

1. Background

1.1. Nature of the research

The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018 by the Governor-General of the Commonwealth of Australia. Its letters patent set out the matters of inquiry which include:

- The quality of aged care services provided to Australians and the extent to which those services meet the needs of the people accessing them
- How best to deliver aged care services to the wide range of people using aged care, including young people with disabilities, and the barriers they face in accessing and receiving high quality services
- How to ensure aged care services are person-centred, including through allowing people to exercise greater choice, control and independence and improving engagement with families and carers

The Royal Commission is to consider the design of Australia's future aged care system. Fundamental to the future design is understanding the community's attitudes to older people, their level of awareness of how the system currently operates, and their future wants and needs for their own old age. This report investigates these three themes.

These themes are explored in the study through 35 focus groups and 30 in-depth interviews conducted during July-September 2019. This qualitative research included 274 people from the general community and targeted diversity groups as shown in the table below. The research was conducted primarily to understand the perspectives of these diversity groups and to complement a national survey for the Royal Commission. More details about the focus groups, including the methodology, discussion guide, and approach letter for individual interviews can be found in the appendices.

AUDIENCE	NUMBER OF FOCUS GROUPS	NUMBER OF PARTICIPANTS
General population		
Aged 18-30	3	20
Aged 31-55	4	30
Aged 56-70	4	30
Aged 70+	4	28
Culturally and linguistically diverse	4	25
Financially and socially disadvantaged	4	30
Veterans	3	13
Gay, lesbian and bisexual communities	3	18
Aboriginal and/or Torres Strait Islander communities	6	50
	NUMBER OF IN-DEPTH INTERVIEWS/PARTICIPANTS	
Intersex and transgender people	5	
Care leavers	5	
Parents separated from their children by forced adoption or removal	5	
People who are homeless or at risk of homelessness	5	
Young people living in residential care	5	
Young people living with dementia	5	

1.2. Interpretation of the findings

This research is qualitative in nature. Qualitative methodologies allow researchers the flexibility to focus on the issues that are most important to participants and to probe in detail on views and experiences. However, qualitative methods do not provide large representative samples upon which to draw conclusions about the population. Instead, they provide a detailed snapshot of the range of attitudes, behaviours and experiences in the population.

Where possible, terms such as ‘a few’, ‘some’, ‘many’ and ‘most’ have been used to give the reader a sense of the proportion of participants who held a certain view or undertook a behaviour. While these are indicative of the relative prevalence of issues among *participants*, readers should be cautious in making assumptions about the *population* based on these descriptions.

Quotes are used throughout the report to enhance readers’ practical understanding of participants’ views and how those views were expressed. Each quote is accompanied by broad demographic category to assist the reader to understand the person’s context.

The report is structured so that sections 2, 3 and 4 outline the key findings from the general population. Subsequent sections provide insight into the distinct views of each of the specific diversity groups, noting their different and similar perspectives to the broader population. Many of the diversity groups make up a vulnerable section of the Australian population and have experienced times of discrimination and hardship either historically or in the present day. These experiences impact on their daily lives now and have shaped how they see their older age.

We would like to thank all of those who participated in the research for their time and for sharing their thoughts, experiences and personal journeys. In addition, we would like to thank the range of charities and support organisations who helped the Ipsos research team to identify and contact participants for the in-depth interviews. We very much appreciate their time and support without which this research would not have been possible.

2. Community views of older people

This section addresses:

- What do we mean when we talk about older people?
- How would we describe someone who is older?
- How, and when, do people have contact and relationships with older people in daily life?
- How do older people contribute to society, community and family?
- Does society have an obligation to older people?

2.1. Summary

Age is seen as a relative concept, with perceptions of old age being determined by a combination of attitude and behavior. Older age is indicated by key milestones such as retirement from the paid workforce and accessing superannuation or the pension. Significant health events speed its onset, and the accompanying sense of vulnerability and consciousness of one's mortality, enhance a person's sense of ageing.

Across the wide demographic of participants in this study, older people were most frequently associated with negative physical descriptors such as being vulnerable, frail and slow, or state-of-mind descriptors such as being scared, close-minded or lonely. Old age raises interrelated concerns regarding deteriorating health, financial stress and the loss of independence. Older people are keen not to be 'a burden' on others, specifically their children. At the same time they are aware that loneliness is a significant issue and they need to remain social engaged, physically active and mentally stimulated.

Widely held positive perceptions of older people are that they are wise, knowledgeable and rich story-tellers who pass on their experience to younger generations. Older age is seen as a time of considerable personal freedom, and assuming health and financial stresses are not too great, one of relaxation and free choice. This freedom includes not just actions (i.e. travel or taking on new pastimes), but also greater freedom about how you express yourself, and feeling less constrained by societal norms.

Older people are seen by many – including some older people – as being overlooked and ignored within our society. This reflects their absence from working life and the limited ways in which many other adults encounter them. This element of invisibility is also seen as a consequence of the faster pace of modern life and the increasing role of technology. Together these are perceived as side-lining older people.

These perceptions are reflected in a view that older people are less valued than they should be and receive less respect than was the case for previous generations – except among Asian communities where greater respect and responsibility for older relatives is perceived as still strong.

Family and social interactions with their older people are generally perceived as positive experiences which share knowledge and culture. These relationships take time and some younger participants

find it difficult to incorporate this in their busy working lives. Many people made the observation that older people place greater value on in-person community interactions, than younger people.

In addition to sharing wisdom, the older generation are seen as providing very valuable family support, babysitting or caring for young grandchildren. Without this free care, many families felt they would be under much greater financial pressure.

People with experience of caring for older family members recognised the heavy demands placed on carers. They understood that this may be perceived as a burden by some people, but almost all of them did not see it in this way. Caring for older family members is seen as a responsibility that they take on positively, as an opportunity to repay the love and care that they, and other family members, have received over their lifetime. Caring for older people is also seen in a wider sense as society giving back to those who have made economic, emotional and social contributions to society over a long lifetime of hard work.

For many, caring for older people is also seen as an obligation that they willingly fulfil for those family members less able to care for themselves; others stress their active wish to care for the older generation and frame it as an active, positive choice, not one they feel obliged to comply with.

2.2. What do we mean when we say ‘old’?

When asked what age was considered ‘old’, most participants were quick to state figures around 60, 60-70 and 80 or over. However, for most, the perception of being ‘older’ was not necessarily attributed to the number itself.

2.2.1. A number or an attitude

Older age was very much seen as a relative concept to all and it related directly to one’s own age. In many instances, individuals reflected on their perceptions of age during different periods of their life and noted that the goalpost for being ‘old’ had shifted through their lifetime. For example, as a child they had perceived being 18 as very old.

You know, when I was younger, I thought 40 and 50 was, ‘Oh my god, that’s old’ ... I’m turning 46 next year, and I’m thinking, ‘Yeah, I’m still pretty young, this is good!’
Financially and socially disadvantaged, aged 31-55, regional New South Wales

I used to think 18 was old, and now I think 100 is very young!
Aged 70+, metro, Northern Territory

I used to think 30 was old, as you get older you realise you don’t feel old!
Gay, Lesbian and Bisexual communities, metro, Western Australia

I have met old people of 35 and young people of 85 ... so I can’t specify ‘age’.
Aged 70+, regional, Western Australia

I consider age immaterial. Old is anybody older than me, and always has been.
Aged 70+, regional, Western Australia

I used to think 50 was old. Now I'm 60, I think 70's old. When I get to 70, I'll be saying 80!
Aged 56-70, metro, Queensland

Because I went to a church boarding school, and had the bible shoved down my throat 24/7 ... (it's) three score years and 10.
Parents separated from their children by forced adoption or removal, New South Wales

Irrespective of a person's physical age, one's behaviour and attitude was perceived as a truer reflection of whether they were 'old'.

I've just turned 60 but I go out once a fortnight for half an hour ... I've lost all the ability now.
Aged 56-70, regional, New South Wales

My grandpa is 70 ... but he does crazy stuff all the time, like he'll get on the roof, with no shirt on, in the middle of the day to fix something ... he's still young at heart ... he's not the kind of person who's sitting in a chair all day or can barely stand.
Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

Their attitude. You can have young people with an old person's attitude – grumpy, pessimistic, complaining, being negative. And you can have some people who are older and active and really motivating.
Gay, Lesbian and Bisexual communities, metro, Western Australia

It's a state of mind though isn't it? My mum's 94 now and a couple of years ago ... there was an advert on TV with an elderly woman aged 65 and she said, 'Poor thing', then realised she was 20 years older.
Aged 56-70, metro, Queensland

A person's mindset determines whether they're old or not, if you think you're old your body will respond and be old ... I don't use hand-rails on the stairs, I don't put my hands on my knees when I stand up. I don't train my mind to think it needs assistance.
People who are homeless, or at risk of homelessness, metro, New South Wales

Many participants commented that age cannot, and should not, be judged quickly, and that it is only by interacting with someone that you could understand both their age, and more importantly, them as a person.

It's very subjective. A lot of my friends are in their sixties. I don't really associate them as being old, we have common interests and common values. They don't spend time moaning about their ageing woes.
Gay, Lesbian and Bisexual communities, metro, New South Wales

Your perception changes as you get older ... and your perception changes when you have a conversation with that person.
Aged 56-70, regional, New South Wales

Certain life events or life stages were also seen as indicative of older age. In particular, the time when we stop working and when we are old enough to access our superannuation or being eligible for, or receiving, an aged pension was linked with being an 'older person'. These events were seen

as well-established landmarks of our ageing process, and clearly identifiable moments in time that can signify that we are older.

I think of their working status... when I think of my parents, I probably thought of them as old when they retired. That was the turning point in my head.

Aged 31-55, metro, New South Wales

I thought 60 was the 'official' age because that's when you can get a senior's card.

Aged 56-70, metro, Queensland

For some, the sense of ageing became suddenly more apparent following a serious health scare. After these events, these individuals began to feel more vulnerable, and significantly more conscious of their mortality and the reality of living into older age with poorer health.

A year ago, I didn't feel my age, I felt invincible but in the last year I was diagnosed with cancer, I lost my bladder, my prostate, and it's a new way of life.

Financially and socially disadvantaged, aged 70+, metro, Victoria

I'm 67, but my 90-year-old mother has become old in the last 12 months since a fall.

Gay, Lesbian and Bisexual communities, metro, Victoria

Older participants (middle-aged or older, particularly those aged 70+) reflected on the fact that, while they knew others viewed them as old, they themselves did not feel old. They spoke at length about the disparity between how they felt and their physical appearance or health. Many were also very aware of the role of physical and mental stimulation in remaining youthful in their outlook and maximising a range of activities in their daily lives.

The only thing that changes is what you see in the mirror. I never get that feeling that I'm getting old. You get a few creaky parts - that comes with age.

Aged 70+, metro, New South Wales

Live your life. You're only as old as you feel.

Veterans, metro, New South Wales

Once you stop learning, that's when you're old ... I don't feel old... I still look out of the same eyes as when I was only 10.

Aged 70+, metro, Northern Territory

2.2.2. Changing views of ageing

Some participants spoke about society's definition of 'old' as having changed in recent years. They attributed this change to shifts in societal values, such as different retirement patterns, older people being more active and with a longer life expectancy. The term 'elderly' was also thought to be different to 'old' and referred to those less able who potentially require assistance.

I think 'old' means something different now, compared to when we were growing up. I feel like 50-year-olds are still pretty young.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

At times, the perceptions held by younger participants were confirmed to an extent by participants in older groups, either consciously or unconsciously; other times, contrasting views were heard. The balance of perceived negative and positive characteristics of older people tended to swing, when moving between discussions among different age groups.

Interestingly, while not a direct research objective, notions of ageism were, at times, heard. These were more often directed at the younger generations, from those older and this is interwoven throughout the report.

2.3.1. 'Story tellers', 'knowledge keepers', 'slow' and 'wrinkly'

While top-of-mind associations were more likely to be negative, and often reinforced stereotype descriptions of older people, responses varied. Many referenced the physical consequences of ageing, using words such as 'frail', 'slow' and 'vulnerable', while other descriptors focused more on the perceived mental state or attitudes of older people, 'being scared', 'close-minded', 'lonely' or 'crotchety'.

Some of them are extremely cranky. The older they get, the crankier they get.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

The fragility of older people was often raised as a key point, both physically and mentally. Beyond descriptors such as 'wrinkles', 'grey hair' and 'glasses', there was widespread acknowledgement of the deteriorating health, loss of mobility and loneliness experienced by people in their older years and how this resulted in a greater need for assistance.

Challenge with movement ... stooped over, with a walker.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

When I was younger, I'd be up in one movement and I'm up but now, I get up, I wait, get my balance and then get up, that's the routine in the morning now.

Financially and socially disadvantaged, aged 70+, metro, Victoria

Moving generally at a slower pace was seen as illustrating that older people had more time available to them, unlike younger generations who were seen as permanently time poor and in a rush. This point was more often raised by those under 55, however those aged 70 and over confirmed this through their self-descriptions. A minority saw this slowness as a reflection that older people had grown up in simpler, and slower times.

Slow, because they haven't been exposed to this mass of incoming data that is technology ... they innately think slower ... with technology, we start thinking faster, getting more impatient ... but they don't have that problem, they're sort of calm.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

2.3.2. Good values, manners, welcoming and warm

All groups countered the negative elements of growing old and older people with more positive views. People of all ages tended to focus on wisdom, knowledge, interesting and rich life experiences, and the ways in which older people passed these on to younger generations through storytelling and empathy. Participants spoke of learning from their parents and grandparents, both

directly and also indirectly by watching their actions and outcomes. Older people more readily identified the positive traits of their age groups, and more easily listed positive adjectives.

Good values, good work ethic – manners, good ol' fashion values.

Aged 31-55, metro, New South Wales

Generally, I find they're not as judgmental with their experience of their life, they're really welcoming and warm, especially to young people.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

If you wanna know, just ask an old person cos they've probably done it.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Some old people are an exception to the rule, they're really more wise than younger people, they've been through places and learnt the hard way that the younger crowd is yet to still do.

Aged 18-30, metro, Queensland

There was recognition across many groups that those who were older were different to the current younger generations; they looked at the world through a different lens and some even felt that they had a higher standard of morals. These attributes were perceived as a product of both their lived experience as well as the way in which society itself had changed over time.

People of a different era, a different way of thinking about things.

Aged 31-55, metro, Victoria

Older people were also perceived as often being more strongly opinionated by those aged under 30 and some of those aged between 30 and 55. This was not necessarily seen as a bad trait – some interpreted it as a sign of an older person being more comfortable within themselves, and others looked forward to being able to do the same in their older age.

I think anyone naturally, probably the older they get, feels more sure about their view and opinion and probably is less concerned with voicing it and letting you know if yours is different.

Aged 31-55, metro, New South Wales

Old people just have no filter. They just say what they like.

Aged 18-30, regional, Victoria

2.3.3. 'Set in their ways'

While often revering older people for their knowledge, many of those aged under 55 also felt that older people were at times inflexible, not necessarily open to new ways of doing things, less able to 'change with the times' and more 'set in their ways'. For the younger groups, this marked people as 'older'. This lack of adaptability was again attributed partially to the way the world had changed around them, but it was also seen as a reflection of the habits people might have developed over time. A minority of younger participants also saw this as representing older people's opposition or resistance to social change.

With society changing, they're not really keeping up with the changes ... technology ... same sex marriage.

Aged 18-30, metro, New South Wales

I think the younger generations are more accepting of differences, but with older generations, they are only used to one kind of landscape.

Aged 18-30, metro, New South Wales

Positively rigid and set in their ways. I'm thinking about a neighbour growing up, who would walk their dog every day, same time by the minute. Go to the pub, same time by the minute ... and this became more extreme as he got older. More intensely by the book, by the clock and it's not the first time I've seen this.

Aged 31-55, metro, New South Wales

Classic conservatism... just not liking change. That's an element that strikes me as an older person's trait.

Aged 31-55, metro, New South Wales

I associate getting older or ageing with being stagnant, less open, things dwindling down.

Gay, Lesbian and Bisexual communities, metro, New South Wales

They're set in their ways ... she's going through a bit of dementia ... they lose a bit of their independence.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

They're set in their ways, always whinging about their aches and pains.

Care leaver, New South Wales

Older people's resistance to change was frequently raised in relation to aspects of technology, or to the workplace, where they were seen as preferring to interact with people rather than computers or automated options.

I'm thinking of older people at work, they're more used to doing things their way and it's harder to change the way they work ... whenever a new thing comes in, they are like, 'Why do we have to change?' ... it's like, 'This has worked for so long, why do we need to change it?'

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

We got a new email system update ... the younger people are like, 'Cool, whatever', we get iOS updates every year. The older people are like freaking out, like, 'Where are my emails gone?'

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Some older people spoke about feeling pressured to keep up with technology and that they could 'feel themselves being left behind'. On the other hand, older people more knowledgeable about technology were frustrated that younger generations were prone to make negative assumptions about their ability to use and manage technology, such as smartphones or computers. It seemed as though either way young people could not get their approach to older people and technology right.

It's just changing too rapidly, they're (younger people) just involved with technology ... I feel that I'm slowly getting left behind.

Veterans, metro, New South Wales

It's always other people, it's their perception of you. Today I went to get my pre-pay internet top-up. The embryo in the shop wanted to know if I needed help ... he perceived me as possibly having trouble.

Aged 56-70, regional, New South Wales

2.3.4. Invisibility

Older people were perceived as being somewhat overlooked and ignored in society. In part, this invisibility was thought to be a reflection of the changing times, the influx of technology and the faster pace of life that had overtaken those in their older age. Some felt that the younger generations no longer had the time nor patience to attend to older people. Others thought part of this invisibility was due to older people's absence from the workforce and as a consequence, opportunities for younger people to interact with older people had genuinely reduced.

Invisible ... it feels like the direction we've been going at least in my lifetime, it feels more youth-orientated ... it feels like more and more, (older people are) being excluded.

Aged 31-55, metro, New South Wales

When I catch the bus to work ... everyone else sits on their phones. Technology has taken over.

Aged 31-55, metro, New South Wales

People don't know their neighbours as much as they used to.

Aged 31-55, metro, New South Wales

I use the train to and from work every day and I've seen multiple times, someone old is struggling somehow and people don't stop to help – could be trying to get on the train, could be trying to use the phone, could be they dropped something and people walk past, oblivious.

Veterans, metro, New South Wales

People under a certain age can be quite dismissive of older people.

Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

Yes, because they're not out there in the workplace making a high-level impact on something. We tend to stay in the background, so add to our own invisibility.

Intersex and Transgender people, New South Wales

Indeed, many of those over the age of 55 felt that as they had aged, they had become less visible to the rest of society. Being invisible was seen as a significant contributing factor to the issue of loneliness among older people.

Definitely invisible. There's a social epidemic of loneliness in older people because they don't have so much social contact.

Gay, Lesbian and Bisexual communities, metro, New South Wales

They ignore them! ... See them as a nuisance.
Aged 70+, metro, Northern Territory

They'll serve that person first, it's as if they don't see me. I pull them up on that now – 'Is my money different?'
Financially and socially disadvantaged, aged 70+, metro, Victoria

Once you get into your fifties, you are sometimes ignored.
Aged 56-70, metro, Western Australia

Many focus group participants over 55 felt leaving the workforce changed their position in society and said that finding work in their fifties was difficult.

The moment you're over 50 ... you find that people who are made redundant in their fifties, struggle to get jobs than people who are younger. ... I think it's changed.
Aged 31-55, metro, New South Wales

In the workplace, the younger guys will push me aside, 'I'll do it, I'll do it'.
Aged 70+, metro, Northern Territory

There's definitely a stage, till they get to know you as a person ... especially if they want your job, they push you out, especially at meetings.
Aged 70+, regional, Western Australia

2.3.5. Older people – benefit and value

Many participants shared that they personally valued older people and were fond of those whom they knew (often reflecting kindly on family members). However, few participants could say with confidence that this sentiment was mirrored more widely by society. They differentiated between their personal stance and that of the broader society.

I think they are a benefit, I don't know if society sees them as a benefit ... I know 100% they are because they help you so much in many aspects of your life. But does society as a whole see older people as a benefit? I don't know.
Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

The employment sector in particular, was referenced on a number of occasions, as an area where ageism was at play and older people felt, and possibly were, less valued. A minority felt that resourcing and care from the government for older people was insufficient and indicative of the value given to older people in society (e.g. the low amount of the pension, and elder abuse reported in aged care facilities).

I think a lot of people view them as (having) a use-by-date ... A lot of people these days, once you're over 50, 55, that's your use-by-date. Employers don't want to know you 'cos they'd rather get a young kid or person and they pay them half the money and they can train them.
Veterans, metro, New South Wales

I don't think it's a part of our population that's valued very highly and I think that's reflected in the sector, the nursing homes, the pay that goes with that. We don't put a lot of our

energy or resources in society into that part of the population.
Aged 31-55, regional, Queensland

Even though they have got a lot of talents, education and wisdom to pass, they think the longevity is not there, that if they employ people over 65, they won't stay for too long. Mentally they are written off.
Culturally and linguistically diverse communities, aged 55+, regional, Queensland

2.3.6. Respect

People often spoke of the change in the level of respect shown towards older people and the value this assigns to them. This ties in with older people being invisible and a community focus on youth culture. This point was particularly noted among the Veterans group.

It's changed ... old people don't get the same level of respect as they did once upon a time.
Aged 31-55, metro, New South Wales

Respect was sometimes mentioned when contrasting Australian cultural approaches with Asian community attitudes to older people. Focus groups often spoke positively of Asian cultures having stronger connections with, and responsibilities for, older generations. Intergenerational support and responsibility was held up as an ideal model to aspire to and learn from.

In certain traditional cultures it's more normal for older people to live with younger generations ... but today in Western cultures, we don't really see that ... because of that separation we can't gain all of those benefits from them that we used to.
Gay, Lesbian and Bisexual communities, metro, New South Wales

When you look at the Chinese people, the Asian people, the respect for their older people is completely different ... the young people are all looking after their elderly just perfectly. I think that for Western societies, that used to be the case, families and grandparents used to live together but Western cultures, they've become just your own little unit ... now also because more people are working within a family so the old people are left to their own devices because the rest of the family are too busy.
Aged 70+, metro, Northern Territory

The Australian way is to live your own life.
Financially and socially disadvantaged, aged 70+, metro, Victoria

See with Asians, the family is very, very important. Out here? No. It's like you put mum and dad in the nursing home, and we'll wait for them to die so we can get the inheritance... and it's like, 'Oh, I don't wanna go visit, because I don't like nursing homes and hospitals, they're never comfortable places' ... the obligation to family in Australia is not the same as it in other parts of the world.
Intersex and Transgender people, New South Wales

Those from culturally and/or linguistically diverse backgrounds tended to confirm this broader perception and described a strong sense of responsibility for older relatives, stronger relationships and a heightened sense of obligation to provide care. Interestingly, Aboriginal and/or Torres Strait Islander groups held very similar views about relationships to family and responsibility and respect

for older people. However, the general population did not recognise this as a positive phenomenon of Aboriginal and Torres Strait Islander societies and cultural practices.

2.3.7. Older people's views of how they are seen

Many participants aged over 55 dislike how they think society perceives them. They believe they are seen as frail or rapidly losing their faculties. They think that others judge them with little knowledge or insight of them as a person, and irrespective of their actual capabilities, see only their age and not their ability. Interestingly, there was a contrast – some older people want to be helped and supported and others found such offers of help as patronising or insulting.

People tend to think that as you get older your brain begins to breakdown and fizzle.
Aged 56-70, regional, New South Wales

In my workplace, before I retired, (they were) condescending and patronising to people in my age group ... The younger generation, they think we don't know anything... but then I see they're doing what I told them. It makes you feel insignificant.
Financially and socially disadvantaged, aged 70+, metro, Victoria

Sometimes younger people tend to treat you as if you are senile, just because you are older, even my children ... sometimes he makes me feel this big, the way he talks to me.
Aged 70+, regional, Western Australia

Once you've got grey hair, they think you've got one foot in the grave, especially young men, terribly patronising.
Aged 70+, regional, Western Australia

They think you're doddering, want to help you in and out of cars ... I don't like that.
Care leavers, New South Wales

A lot of them think we're a nuisance.
Parents separated from their children by forced adoption or removal, New South Wales

Older people felt they had insights and intelligence to share but that younger generations weren't interested in learning from them. This was seen to relate to their perceived low skill levels with technology and younger generations being overly enthralled by their smartphones and the internet.

Young people treat you like a halfwit. Usually you know more, but you don't go on about it, unlike them ... With technology, the aged aren't seen to pass on wisdom ... we have (wisdom) in relationships and communicating. (We need) more respect, they discount us and throw us on the rubbish heap.
Aged 70+, metro, Victoria

We are not just old, we are people that have lived. Old people are young people who have lived longer. Grandchildren should respect us as older people.
Aged 70+, metro, Victoria

There's just this assumption ... no-one wanted to talk to you, 'Don't talk to us, just send it on the email or scan it' ... all these sorts of assumptions made constantly that you know how to

do it.

Aged 56-70, metro, Queensland

Disrespect. At about 60 ... young fellas, they're all on their phone. Young ones would give old people a seat on the train or the bus, they'd talk to you nicely. Now, it's like they'd knock you over as much as look at you.

Care leavers, New South Wales

2.4. Interactions and experiences with older people

Exposure to older people was very dependent on age, family dynamics and employment. Among those aged 18 to 55, there tended to be few encounters in daily life, unless they were living near older family members and had strong relationships.

Honestly, I rarely interact with older people now... that's really sad now that I think about it.

Aged 18-30, metro, Queensland

For many people, their career path and environment gave them very limited interactions with older people. In part this narrowing of a social sphere is a product of longer working hours and busy lives. The exceptions to this were those whose chosen career path brought them into contact with older people, working in aged care or in the community.

I live in Darlinghurst and work in Surry Hills, and work is all very 30-somethings.

Gay, Lesbian and Bisexual communities, metro, New South Wales

2.4.1. 'Just at the bus stop'

For those under 55, encounters with older people were often incidental, and took place in public spaces such as on public transport, at cafes, supermarkets, the chemist, the library, church and the beach. For a few, providing support with technology was a specific form of ongoing contact with older relatives.

I'm always really respectful of someone with a walking frame, on public transport, 'cos Mum's had to have one of those.

Gay, Lesbian and Bisexual communities, metro, New South Wales

At the beach, particularly in summer I go nearly every day, and when I go early in the morning, its 70% older people and in winter its 90% - and 100% of those swimming are old!

Gay, Lesbian and Bisexual communities, metro, Western Australia

Help Auntie with mobile 'remote IT support'.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Those living in regional locations tended to encounter older people more often, seeing them at clubs (e.g. RSL) and shopping centres.

(On when they see older people in their day-to-day life) All the time... all the time.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

2.4.2. Community

A few people commented that they had good friendships and supportive relationships with older people. Others commented on the richness of their interactions with older, rather than younger, people.

Spending time with them makes me happy, they're funny, make you slow down, stop watching TV and looking at your phone... I don't know anyone else I do that with.

Aged 31-55, metro, Victoria

I have a grandparent on each side, we're reaping dividends in the family culture because of their hard work, their presence changes the dynamic. (When they're there) it's not just a party, it's a family event.

Veterans, metro, Victoria

I'd rather speak to older people than younger people. My 16-year old nephew always has his face in his phone.

Gay, Lesbian and Bisexual communities, metro, Victoria

Older people were seen as having a strong need for in-person community connections, in contrast to the greater digital connectedness of younger people. Those aged 18 to 30 in particular, discussed how much older people enjoyed talking and that they had a preference for in-person interactions. Some of the younger participants explained they did not always have the time to engage at a level expected of them.

I love talking to them because they're so wise ... and they love chatting with people. They're not gonna sit on their iPads like we do... they're more about that physical interaction.

Aged 18-30, metro, New South Wales

I live in a tiny laneway. Until recently our best neighbour was seventy plus but she had a fall and had to move out. She would keep (the neighbourhood) connected.

Gay, Lesbian and Bisexual communities, metro, Victoria

They usually want to have a short conversation with you, which I don't mind cos I'm used to that in Italy... people here would probably think, 'Why are you talking to me?'

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

They are always looking for others to talk to. They have time to talk. My neighbour, he wants to talk to me, and I really have other things to do today.

Aged 18-30, regional, Victoria

I've unintentionally adopted a grandmother in my street ... she's a bit high energy and anxious and I'm constantly trying to calm her down ... I can direct her in more modern society, help her access things she might not know how to access like community services.

Gay, Lesbian and Bisexual communities, metro, Western Australia

2.4.3. Family

Some participants had grown up with older generations in the same family home. They reflected that this had been, on the whole, a positive experience for them as children. Many participants talked about how much they valued the opportunity to have a close relationship with a grandparent, and for some it was an important chance to better understand their family culture and history.

Whenever she (grandmother) was around, we would look forward to it ...she would tell us her stories, spoil us.

Aged 31-55, metro, New South Wales

I grew up with my grandmother until I was 16. She was involved in the Second World War. Her cooking was marvellous. We were so spoilt.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

I was raised by my grandma for a few years. I loved her. I didn't speak a word of German but I knew what she was saying when she said, 'Get off the couch'.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Having grandparents around was part of my culture. When my parents were not around, my grandparents would be there ... taught me how to be disciplined. She was like a second mum to me. We had a very close relationship ... but when she had dementia it was difficult to cope. We didn't have the knowledge.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Your family unit is always stronger because if someone's called away there's always someone else there. More people in a house gives you a larger pool of resources ... of skills, information, knowledge that you can draw upon when you need it.

Aged 31-55, regional, Queensland

Although growing up with older family members in the house or nearby was not without its challenges, as adults, participants were very much appreciative of the experience.

I learnt a lot of stories from my grandparents and I understand where migrants come from and stuff, so I guess it was a good thing. Back then, I hated it ... looking back now, it was awesome.

Aged 18-30, metro, New South Wales

It's quite common in Asian societies ... I know it's a bit of a burden, but it's quite lovely.

We've gone way too far away from that in our society ... there are challenges ... but they may be contributing to the household in terms of babysitting.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Growing up with older people, sometimes it was frustrating because there were more rules than there otherwise would have been ... but there's also really cool stuff, that's how I learnt to speak the Italian dialect from where I am from.

Aged 18-30, metro, Queensland

Those in the culturally and/or linguistically diverse and Aboriginal and/or Torres Strait Islander communities, in particular, referenced their experiences of growing up with older family members.

For some people in these groups, this history partly contributed to their value and respect for their elders.

2.5. Older people's contribution to society

Regardless of the group the participants belonged to, or their different perceptions and pre-existing stereotypes of older people, they widely acknowledged that older people made contributions to society in many ways. Contribution to society was viewed through an emotional, social and economic lens. Older people's unique input in society was often seen as invaluable and was not necessarily connected to their capacity as part of the paid workforce.

Generally, those who were closest to being 'older' – that is, those aged seventy and over – tended to be quicker to identify the ways in which older people contributed to society. Younger people too, valued the contributions older people made in their lives. Many participants with young children explained how they could not manage without older people in their lives, particularly with helping out with family and looking after grandchildren.

Some participants mentioned how much they appreciated the contribution older people have made in the past. These individuals spoke beyond the day-to-day contributions made by older people, instead citing the deeper value older people had contributed over time.

They laid the foundations on which we are building ... so that's a very big contribution.
Aged 31-55, metro, New South Wales

The lifestyle we live today, we wouldn't be where we are without the older Australians like the war veterans and the people who fought for human rights and the right to vote ... in a way our generation is lucky that we live in the world we live in now.
Financially and socially disadvantaged, aged 31-55, regional New South Wales

They've had to come up hard, they weren't given things, they weren't marched off to Centrelink. The kids today they want to start at the top; we had to start at the bottom.
Care leavers, New South Wales

2.5.1. Knowledge and wisdom

First and foremost, older people were seen as a repository of our collective knowledge and wisdom. Many expressed that older people had lived experiences resulting in valuable lessons to pass onto the younger generation, and they also carried with them interesting stories.

More experience of human nature, and they learn, in time, what's worth getting upset about and what's not.
Aged 56-70, regional, New South Wales

They hold the stories. They're the ones we are relying on to learn about the past. Their job is not to contribute to the economy but to contribute to the history.
Aged 18-30, metro, Queensland

They've given up their lives, taxes to contribute to the society we've got today ... I think morally and culturally they continue to contribute until their last breath.

Gay, Lesbian and Bisexual communities, metro, Western Australia

I think they contribute greatly to society ... They have wisdom to pass on ... I talk to older people, I like listening to older people. They give me insight into how the world was ... I used to listen to my family members talk about what it was like back in their day ... passing on the stories from past eras, passing on from generation to generation.

People who are homeless, or at risk of homelessness, metro, New South Wales

They're living history.

Young people living with dementia, New South Wales

Some participants felt that older people were also there to set examples for others. They brought with them a different set of morals to the current generation, they had a different way of looking at life, different attitudes and a different work ethic. These characteristics meant that some participants viewed them as good role models and a source of good counsel.

The generation has changed a lot in the sense of now everything is so easy and so accessible that we're never happy enough with what we have and we're always looking for something better. Whereas back then, they were really happy to have a job and just do it.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

People like builders and labourers ... they don't cut corners ... they can teach younger people how to go about working ... the old school people will work until the job is done properly, rather than just for money.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

(Their ability in) appreciating life, they endured a lot of hardships, some of us have never seen those dark days.

Aged 31-55, metro, Victoria

2.5.2. Family and support

Within the family structure older people were often identified as providing love and support.

If you took all the grannies and grandpas out of society, I don't think young people could cope ... older people know the way to deal with family problems, social problems, ways to get over it.

Aged 70+, regional, Western Australia

They're the ones that call you up and ask you to come ... they kind of hold the family together.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Love ... they're there. They have so much to give. Very empowering ... they're so authentic ... You can never lose weight around old people. 'Oh, you're so thin, you've got to eat more'.

Gay, Lesbian and Bisexual communities, metro, Western Australia

In addition to providing family with emotional support, there was a recognition, particularly among parents and older people that many families are only able to function and support themselves by relying on the free child care of grandparents and older relatives. Older men were sometimes aware that they were spending more time with grandchildren than they had been able to spend with their own children during their early years.

I can't think of a single friend of mine who's got young kids ... that doesn't rely on their parents or grandparents, for school picks and things like that.

Veterans, metro, New South Wales

Helping, sharing and caring. Helping young families with their children. We've sort of got the experience more, useful babysitters, free babysitters.

Aged 70+, metro, Northern Territory

If the government had to pay for the amount of input that seniors contribute, they couldn't afford it. Because it's out of hours, it's 24 hours, 7 days a week for some people and they're bringing up grandkids.

Veterans, metro, New South Wales

Grandparents sometimes have more time for the kids than the parents.

Aged 56-70, metro, Western Australia

Very good with grandkids as babysitting ... grandkids growing with grandparents can never go wrong! They've got that generosity and consideration to provide.

Gay, Lesbian and Bisexual communities, metro, Western Australia

It's kind of necessary that they don't work in some ways so that they can look after the children of the people who work full time and can't afford childcare.

Aged 18-30, metro, Queensland

It's a major issue the older generation being available to nurture the young. With parents being so busy, that having an adult with more time to focus on the young is a very vital thing.

Young people living with dementia, New South Wales

When thinking about how older people contribute to society, a small minority were slower to recognise the contribution of older people once they are no longer working.

Not sure societally they contribute a great deal. If you break it down, those aged 20-60 are contributing taxes, working bodies. Those 65-plus are draining welfare, or health care or housing ... so, I'm not sure what they're contributing except emotional or personal enrichment to their loved ones?

Gay, Lesbian and Bisexual communities, metro, New South Wales

2.5.3. Volunteering

While there was some awareness among younger people, those over 55 were the most aware of the significant contributions that older generations were making through volunteering. They recognised the benefits of volunteering for themselves in keeping them active and social engaged, and also for their communities. They supported a wide range of charities and services that would otherwise struggle without their free assistance.

You'll find people like us (volunteering) all over the town contributing, making sure this town stays a vibrant and lovely place to be.

Aged 70+, regional, Western Australia

I think they volunteer their time a lot more than young people do.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

One of the areas I help with is peoples' phones and tablets and frequently people ask me something that I don't know so I have to look it up, and I find that really fulfilling. When you do show someone how to do something on their phone that they didn't know, they're so grateful.

Aged 70+, regional, Western Australia

It's a case of constant contribution, you've got to get involved, keep doing things, it never stops until you fall off your twig. The people just sitting in their unit feeling sorry for themselves, they're the ones to be pitied.

Aged 70+, metro, New South Wales

You get far more back, there's a selfish angle to it.

Aged 70+, regional, Western Australia

2.6. Perceptions of ageing

2.6.1. Positive aspects of ageing

The discussion of ageing as a positive experience was a challenge for many participants. While positive aspects of ageing were identified, people were generally slower to list these in comparison to the negative aspects. Some struggled to identify any positive aspects at all. Although as one veteran said:

You don't have a choice! The alternative (not ageing, i.e. dying) isn't very good.

Veterans, metro, New South Wales

Participants looked forward to spending time with family and friends, in leisure, travelling, doing what they want to – free from the responsibilities of work or family.

Time and freedom

The majority of people were able to see that one's older years could be a time of considerable personal freedom and relaxation. Many looked forward to retirement and simply having the time to do the things they wanted to do.

Relaxation – they've got so much time.

Aged 18-30, metro, New South Wales

Time to use as you want and hopefully have money to enjoy life.

Aged 18-30, metro, Queensland

Participants spoke about having fewer concerns or worries in life as you aged. In part, this was due to the cessation of work and reduced family responsibilities, however others spoke about learning to leave the less significant worries of life behind.

You get maximum pleasure out of the smallest of things ... Life is simpler and easier. The peace and quiet, I really embrace that quietness ... it's like a big sigh.

Aged 56-70, regional, New South Wales

I like to wake up and know I don't have to get up and go anywhere. My day is my own.

Aged 70+, regional, Western Australia

All the rubbish goes off, and you know you're not interested at all ... you don't worry about all the hassles ... life becomes simpler.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

You've got more time to focus on family, hobbies, other things in your life. Anything you had on the backburner because of time.

Aged 31-55, regional, Queensland

You're less concerned, for sure, you don't worry so much, and you've got more free time to choose what you want to do. You can live your life more purposively.

People who are homeless or at risk of homelessness, Victoria

Some spoke specifically of the shift from dedicating their time to family, and now to themselves. They looked forward to acquiring new skills or getting involved socially in ways they had not had time for earlier in life when the demands of raising children and earning a living limited free time. Many spoke of using this freedom to travel and explore in ways they had long looked forward to.

We couldn't go overseas till our children had finished school. But since 2009 we can do stuff for ourselves without others (family) being involved in the decision ... we have the choice, and the choice is very important in terms of keeping yourself mentally and physically young.

Aged 70+, metro, New South Wales

Your responsibilities diminish as a family person ... there's a selfishness that's wonderful.

Aged 56-70, regional, New South Wales

It's all live in the south of France, canal boats, bike paths, cheese and crusty bread!

Aged 56-70, metro, Queensland

I was a single mum of a three-month old and seven-year old ... so I had a lot of years of feeding them without any help. But now I have no responsibilities, I can travel ... I've got no responsibility.

Financially and socially disadvantaged, aged 70+, metro, Victoria

We've bought a caravan, I want to do Australia and Tasmania. I look at it as my reward for working.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

It's an opportunity to tick off the bucket list.

Intersex and Transgender people, New South Wales

This freedom and time to slow down meant that some older people could enjoy life. They had time to take pleasure from things they would previously have rushed past in their haste to get to work or take care of family.

I now wonder, how did I ever have time to work.

Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

Sing in the church choir, help a friend going through trouble, be an activist.

Aged 70+, regional, Western Australia

I sit with the Elders, both Aboriginal and white ... and we're building new community gardens and a shed.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Happy in themselves

Another aspect of freedom was the freedom of expression and thought. Many older people described feeling less and less constrained by societal norms, and speaking their mind was a source of happiness and liberation. Some of those who were younger also looked forward to this.

When I'm 80 I won't give a shit who's going for brunch, so I won't get FOMO (fear of missing out).

Gay, Lesbian and Bisexual communities, metro, New South Wales

You have a little bit more leeway in speaking your mind ... because you've kind of been through life and at that stage, people give you a little more leeway.

Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

The freedom to be who you are. What have you got to lose?

Aged 70+, regional, Western Australia

(You) can say what you want without caring about the opinions of others as they will say, 'Don't mind them, they're just old'.

Aged 18-30, metro, Queensland

Some participants, and in particular women, spoke about a greater sense of self, and feeling less pressure to be or act a certain way.

A shift in values to more of the important stuff, less superficial stuff.

Aged 31-55, metro, New South Wales

Care a lot less about what other people think, less judgement, pressure we put on ourselves.

Aged 31-55, metro, Victoria

I'd say you'd have a pretty good sense of yourself, having lived with yourself for 70 years ... it would be nice to know that you knew yourself well.

Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

Care less about what other people think, less important, more self-assured. I'm going to do what I'm going to do and if they don't like it too bad! So, liberating.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Wisdom, family and community

Some people viewed older age as a period of their life where they could share their wisdom with younger generations and relished the prospect of being an elder family member that others would turn to for advice and guidance.

We've got knowledge to guide our young people. They respect us, we respect each other ... The positives of being respected as a resource person within the community.
Aged 70+, metro, Northern Territory

The best thing about getting old is ... all the family comes around and tries to help you and tries to tell you their stories.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

I think any older person that's lived longer has wisdom and life experience to contribute.
Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

2.6.2. Negative aspects of ageing

When asked to consider the negative aspects of ageing three major and interrelated concerns emerged – deteriorating health, financial stress and loss of independence or becoming a 'burden' on family or friends. Health and financial security were always mentioned in one form or another. Loss of independence was often linked to failing health and financial security.

It's not a nice thing, you reach 65, you gotta start thinking about who's gonna look after you if something goes wrong.
Veterans, metro, New South Wales

Everyone says when you retire, it's fantastic ... it's not as glamorous as that, you've got your health to worry about, you've got your finances to worry about ... there's freedom ... but not glamorous at all. I'm not in a hurry to retire.
Gay, Lesbian and Bisexual communities, metro, New South Wales

You look forward to living, but not getting older.
Aged 70+, regional, Western Australia

Younger people tended to find it more difficult to imagine this latter stage of life and the majority were quick to admit they were not looking forward to it. While those middle aged and above had not necessarily looked forward to this stage, they were more likely to have accepted this as they approached the age they deemed as being 'older'.

No ... god no... I want to stay young ... Your body degenerates, and then your mind will degenerate and you can't do anything about it, it's just the way the body is.
Aged 18-30, metro, New South Wales

No ... in fact I would go back in time.
Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

For a minority of older people, the acute awareness of the unavoidable physical and potential mental deterioration overwhelmed their perspective of what ageing would be like.

There's not a lot that appeals to me about being a 70-year-old.

Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

I don't know that there's any great aspects about getting older, other than the fact that you're alive.

Veterans, metro, Western Australia

Opal card for seniors, that's the best thing ... but, you know, there's not much that's positive.

Parents separated from their children by forced adoption or removal, New South Wales

Health concerns

The major negative aspect of ageing is seen firstly as deteriorating health. The most prominent issues associated with declining health were the loss of mobility and consequent loss of independence, followed by pain, the unpredictability of illness and fear of death.

Everything falling apart physically (especially when it impacts on your life and starts to cause restriction, then it's a big issue), transience (those around you dying off), facing the loss of others and your own morbidity, not knowing how much longer you have left, and losing your faculties (e.g. Alzheimer's, mental deterioration).

Gay, Lesbian and Bisexual communities, metro, New South Wales

Your health. Physically wanting to do something but maybe not being able to do it. I hear it from older people that they feel the same as when they were young ... but they now feel tired easily, and they struggle.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Failing health ... if you do a little bit of gardening your back aches. And I'm terrified of a failing mind, that's the worst. You've got to have your onions.

Aged 70+, regional, Western Australia

Health comes to mind because that's the most important thing at this age. You can have all the money in the world, but if you've got no health, it's not worth a cracker.

Aged 56-70, metro, Queensland

I can't get around much. I've got arthritis in both my knees and I just sit in one place and do my paintings. When I get up, my knees just ache ... when it gets cold and winter and that, it gets worse. I just ignore the pain, I just take Panadol.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

Everything becomes harder to do ... shopping, doing house work, cooking.

Parents separated from their children by forced adoption or removal, New South Wales

Some were also concerned that an unpredictable health event would mean that their financial resources would be stretched or insufficient. Given they would have reached an age where income had slowed down, such an event could be catastrophic to their quality of life.

Inability to increase your income if you need to. My employment opportunities are becoming more limited. Opportunities stop the day you turn 50. People are loath to employ old people – which always amazes me because we have so much more to offer than a 30-something.

Aged 56-70, regional, New South Wales

Financial insecurity

The second major negative aspect of ageing is financial insecurity. While the potential of financial freedom was seen as a plus for some, for others, their financial position in later life was a source of considerable stress.

The big thing for me is I don't worry about the future any more. After years of worrying ... money will run out one day ... I used to worry.

Aged 70+, metro, New South Wales

The money thing's a bit of an issue.

Aged 70+, metro, New South Wales

Financially once you've reached those later years, you don't have the money stresses so much.

Aged 56-70, regional, New South Wales

I'm not going to think about travelling because I know I can't afford it.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

There was concern among many people that their financial planning will be insufficient for their future needs. Some were aware that they had not made sufficient provision. Others, particularly those for whom compulsory superannuation was only introduced during the second half of their working life, had not structured their saving or financial planning to provide a steady, sufficient income through a potentially lengthy older age. This generation also reflected the fact that they predominantly raised their families with only one parent working, which exacerbated their financial situation.

The down side is poverty. Poverty is relative ... my wife didn't work ... I was in business on my own, there was no such thing as superannuation ... the value of your business can end up being zero. Finding yourself at the end of your working life, and I'm almost there, with a small pot of money and we've got all these years to stretch it. Fear of being poor is a real definite for me.

Aged 70+, metro, New South Wales

Having to try and live on the pitiful pension that the government pays out, those poor buggers.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Being financially strapped. I've not got much super because I haven't worked much. It scares me.

Gay, Lesbian and Bisexual communities, metro, Victoria

My grandma had not enough money in her super fund ... She wasn't really in the workforce due to childbirth, and so she didn't have enough to spend for her medical bills ... it got me so concerned ... now that I am a mum, I try my best ... I still try to work at least part time or casual.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Most people were aware that they will have limited incomes during their older years, and increasingly limited ways of earning money. Those who are homeless or at risk of being homeless,

unsurprisingly, had heightened concerns around financial insecurity and where they will be living in older age.

Loss of independence

As mentioned above, closely associated with failing health was reduced independence. A major consideration was losing their driving licence and loss of hearing and sight with the flow on effect of limiting day-to-day activities and freedom. Losing independence through loss of sight and hearing would contribute significantly to their sense of vulnerability. Many participants said unprompted that they did not wish to have to rely on others or burden family, in particular, their children.

Needing to rely on other people, that's a bit of a big negative. Not being as independent. It makes you feel bad ... I get into trouble for trying to do things I shouldn't, 'You're not getting up that ladder again'.

Aged 70+, metro, Northern Territory

Euthanasia was a subject that was frequently raised by participants, especially in older focus groups, unprompted when speaking about getting older, fear of deteriorating health and loss of independence. Those who spoke about euthanasia wanted to have an active, positive choice around their end of life. This related to a sense of remaining themselves, being in control and in this way retaining their independence till the very end of their lives.

I don't want to be a burden. When I've lost my quality of life, I want to be able to end it.

Gay, Lesbian and Bisexual communities, metro, Victoria

Loneliness

Aligned with loss of independence was loneliness and living far from family. For some older people, family may not be living nearby and be able to provide love and care, day-to-day support or interaction. The absence of local supportive family was more frequently mentioned by those not living in or near capital cities, with negative comments about family living interstate, who rarely visited. The pressure of busy working lives was highlighted as a reason why many people do not or cannot provide greater support to their older relatives.

We've moved around, we've got no family in town, our children are in Perth, so you're very reliant on places like this (community centre).

Aged 70+, regional, Western Australia

At that stage of your life, you're the one who has all the time and everyone else is busy doing what we're doing ... you're bound to just be alone.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

I worked at (aged care facility) ... when I'd admit them, the family would bring them in, 'We'll come and see them each weekend' ... nowadays people seem to have too much on, mother and father both working, the kids doing their sport, and they don't have time.

Aged 70+, metro, New South Wales

Some of the older people spoke about this from experience and reiterated the need to ensure they had hobbies or interests to fill their time.

Older people are being left out because everyone's so busy, they're not making the time ... my childhood was full of older people ... if any of you have volunteered for meals on wheels ... it really breaks your heart. You see little old ladies, the only one they see on a regular basis is the person delivering the meal ... loneliness is real problem.

Aged 56-70, regional, New South Wales

On maternity leave ... I'm out with my baby son, an older lady was clawing at me (to connect with the baby), it was something she really needed (to engage with other people and the baby).

Aged 31-55, metro, Victoria

I know those who go to the doctors at least once a week, so they've got somebody to talk to.

Aged 70+, regional, Western Australia

Another thing to be worried about is mortality, you have friends and family dropping off around you as you age yourself. You wouldn't necessarily be lonely if you interact with enough people ... but it's the sort of thing you feel the loss of it.

Aged 31-55, regional, Queensland

The topic of loneliness in older age was also one noted particularly by Transgender and Intersex participants, and those homeless or at risk of being homeless.

Loss of respect

The potential of being treated with less respect was raised by some of the younger participants, while some older participants spoke of feeling less able to command authority. These people felt they were considered retired members of society.

(Getting) less respect, a lot less respect.

Aged 31-55, metro, Victoria

The lack of recognition of what we've achieved and what we know ... I found that in the work situation late in life ... the under thirties did not have any recognition of the skills I had ... and that made me feel inadequate.

Aged 70+, metro, New South Wales

Feeling irrelevant and not being allowed to contribute. People don't necessarily want to listen to older people.

Aged 56-70, metro, Western Australia

The area I live in, I get called all sorts of awful names ... they talk back to me as if I don't know anything.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Conversely, some older people made specific mention to the fact that not all young people were necessarily disrespectful towards the older community and gave examples of this in their day-to-day life.

There is quite a bit of respect ... on public transport, often people stand up for me ... that is quite nice.

Financially and socially disadvantaged, aged 70+, metro, Victoria

I don't think we have a right to demand respect, we have to do something to earn that respect ... I don't think the young ones disrespect us, I think they just don't think about things.

Aged 70+, metro, New South Wales

2.7. Society's burden or society's obligation

There was strong acknowledgement among participants that older people made and continue to make considerable contributions to society in a variety of ways. When thinking about older people being a burden, those who thought of older people as a burden on government finances also acknowledged that older people had made economic contributions to society in the past. Many participants spontaneously explained the need to take care of older people and said this was important in our society.

2.7.1. Burden?

The majority of all participants, of all ages, locations and diversity were loath to describe older people as a burden. The concept of what constitutes a burden to society is difficult; are people thinking about time, money, emotions? Here it was very clear that regardless of older peoples' contribution, current or past, economic, emotional, or social, most people did not think of older people as a burden.

The small number of participants who mentioned that older people can be seen as a burden on society mostly did so in the context of older people needing more health care and other social services, such as the pension, which many had paid taxes to receive. Some were of the impression that society did see older people as a burden, despite this not being their personal opinion.

A bit of a burden, on social resources like healthcare ... for some that is definitely the case.
Aged 31-55, regional, Queensland

I can sort of understand from a bigger point of view, like from a purely economic society point of view how they are seen as a burden. We're starting to get older every decade, we're living longer and longer ... I can understand how it's getting harder and harder for taxpayers to support that, so I get that rationally. But in my own life, I wouldn't say they're a burden.
Aged 31-55, metro, New South Wales

A drain on the public purse and medical is the two things.
Aged 56-70, regional, New South Wales

For immediate family, they would be a non-burden. But other people, old people are a burden to society. They are living longer. Society, I wouldn't say that about my own grandparents, but to the whole of society, they are a burden on society.
Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Some older people, yes, they are a burden, but that's generally because of an illness, something that's seriously wrong. People with Alzheimer's that is a burden ... a burden on society. And it's going to become a bigger burden.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

As one participant noted, sometimes the perception of burden simply came down to one's personal attitudes and values.

I think it depends on what sort of person you are. I could think of my grandpa as a burden because my aunty has to go to his house every day and take him to the shops and that sort of stuff, but to me, he's not, because he's my grandfather and I love him and I'd do anything for him ... but I guess if you're not so close to your family and you're being burdened with this person ... then you've got a different view of it.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Older people sensed themselves as a burden when observing the impatience of younger people about their slower pace and slower lives. By contrast, younger people did not equate older people's slowness as them being a burden.

(I feel a burden) every time someone toots their horn at me when I don't move off fast enough.

Aged 70+, metro, New South Wales

People are intolerant, 'Come on, move it, I want to get past you'.

Care leavers, New South Wales

Many others were sensitive to the use of the word 'burden', particularly participants who were currently, or had been, carers of family members. They acknowledged the hard work involved but were loath to imply that they begrudged caring for their loved ones. Almost all participants from the diversity groups were critical of the term.

I don't like the word burden. I wouldn't use the word burden.

Veterans, metro, New South Wales

(Grandparent with dementia) It's not that it was a burden, it's that it was very stressful, because everything in Australia is so expensive ... first she couldn't locate her own key, slowly deteriorating ... when she pretty much forgot everything she became like a different person. She was so afraid ... the cost of caring for grandma, it's not cheap ... my parents and siblings got quite stressed, it's not because she was a burden, it's because of the cost ... If someone's had an older person say, with dementia, it will colour their perception of older people being a burden.

Gay, Lesbian and Bisexual communities, metro, Western Australia

If you're caring for an aged person, in one sense we can't move on with your life ... but we can't say to him, 'Dad, it's time you went into care, or moved over here full time' ... I won't say it's a burden, but sometimes it's a very hard responsibility to be caring for older people especially if they're very adamant about how they want to live their life.

Parents separated from their children by forced adoption or removal, New South Wales

Some participants spoke of the considerable time and cost associated with personally caring for someone. These participants acknowledged and accepted that caring could be a burden on their lives, and that looking after older people had its difficulties. They did or do not, however, have any intentions of shying away from what they see as their caring responsibilities.

But it's also, we say 'yes' and put our hands up straight away, I think 'cos it's in our hearts, but I saw my mother care for my nan in her home and how it aged her, and how physically hard it was and emotionally hard too without support.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

He had dementia, so his last eight years, he was just a vegetable and ... It was a bit of a burden to our family, but at the end of the day, we still did it ... because he is a part of our family.

Aged 18-30, metro, New South Wales

The pressures (of it all). Your own wellbeing, if you work, being able to take time off work to take care of them – you know you can't take that much time off work... you're torn.

Aged 31-55, metro, New South Wales

A small number of people shared experiences where people actively described older relatives as a burden, irrespective of whether or not the younger person was shouldering any caring responsibilities. These younger family members were perceived as not having an interest in the older person's wellbeing but being focused on maximising an inheritance.

I do know quite a few people who view their parents or grandparents as a burden ... they have said they can't wait till they die ... I find that personally very shocking ... they're just quite aggressive about it, it's not like they're actually taking care of them, they're in a nursing home, they're not interacting with them every day, they're actually trying to avoid them.

Gay, Lesbian and Bisexual communities, metro, Western Australia

They don't want to look after you, your family, they want their inheritance.

Aged 70+, regional, Western Australia

2.7.2. Or obligation?

Among the majority of participants, older people were acknowledged as having contributed throughout their working life, both directly in the form of taxation, but also more broadly as active members of society. The 'burden' of care during older years was seen as an acceptable recompense for a lifetime's contribution, and signified a sense of intergenerational solidarity, 'They looked after us, we look after them'. People alluded to the social contract between individuals and the government under which the government needed to ensure there was a minimum standard of care for older people, and those who need help.

The way you care for your older people is a representation of the kind of person you are, it's representative of what you stand for, a representation of your humanity. To abandon that responsibility ... just makes me feel ill.

Young people living with dementia, New South Wales.

They've already contributed to society... they've done it. And now it's time for us to look after them ... it's not just work, it's also family, carers, anything ... it doesn't end just 'cos they're old now. All individuals contribute their individual value.

Financially and socially disadvantaged, aged 18-30, metro, Northern Territory

We owe it to them to take care of them, they made society what it is now.
Aged 18-30, metro, Queensland

They need to be respected and supported, they've given a lot of their life respecting and supporting others ... we have a duty to do the same in return for them.
Intersex and Transgender people, New South Wales

There's no doubt we are a burden in financial terms because we're clogging up the hospital ... our argument is we paid our taxes, we built them.
Aged 70+, metro, New South Wales

I definitely think we do (have an obligation), in terms of they worked really hard, they were always committed to their jobs and society and I do think that they deserve to continue living a decent life. I think they've done enough for us to then give back to them.
Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

We should (feel obligated) because ultimately everybody gets there, sorry, no-one here's special! So surely we should look after each other because we're all going to get there.
Gay, Lesbian and Bisexual communities, metro, New South Wales

It's not an easy thing for the government to do. The government has a responsibility, they're there working for us. There's a transition happening at the moment ... we've done our bit for our life, they have to find ways in this transition, during this peak of old people, they have to find ways to cater for us, we deserve to be looked after.
Aged 56-70, metro, Western Australia

I see older people have walked before me. All of this infrastructure is here at my disposal is because of someone built it before me so, everyone plays their role.
People who are homeless, or at risk of homelessness, metro, New South Wales

A minority were critical of those who relied on the government or were claiming a full pension. Some of those on a pension were also very aware that others viewed them negatively for failing to self-fund their older years.

I believe if you've contributed to society, you've been a taxpayer, you've raised a family, there's a certain amount of care the government should show to you ... We'll take care of you, 'You're one of ours'. I don't think the government should do everything for everyone, I believe the governments done that for too long now, been a little too generous.
People who are homeless, or at risk of homelessness, metro, New South Wales

There's an obsession in a certain part of the elderly community that 'I must qualify for a pension', often disadvantaging yourselves financially ... 'I'm entitled, I've now reached the age, that pension is number one. My investments I'm going to run them down to qualify for that Centrelink benefit'.
Aged 70+, metro, New South Wales

Burden ... if you're on the full pension, you're a burden. It's not that you're sitting back and enjoying the comforts after years and years of working, you're a drain on welfare.
Aged 56-70, regional, New South Wales

Person A: Self-funded retirees are penalised for being prepared! We enable pensioners to have a decent income.

Person B: The pension isn't a decent income!

Person A: We can't afford to pay them anymore.

Aged 70+, metro, Victoria

We don't think we're a burden, but everyone else does.

Financially and socially disadvantaged people, aged 56-70, regional, WA

No, it's up to individual to look after their own life ... and not to be absolutely relying on other people.

Aged 70+, metro, Northern Territory

Many participants expressed that the care extended to older people was kindness and consideration they would hope to show anyone – they felt a sense of obligation to help people, and this was not dependent on age. Among this group, there was a clear sense that looking out for vulnerable members of society people was the morally right thing to do.

Part of a golden rule – you should help people who are disadvantaged.

Gay, Lesbian and Bisexual communities, metro, New South Wales

I think we have an obligation to everybody. As a cohesive society we have an obligation to look after all levels.

Aged 56-70, regional, New South Wales

I don't think obligation is the right word. It's ethically and morally the right thing to do to look after those in need.

Gay, Lesbian and Bisexual communities, metro, Western Australia

I'd like to put it as respect rather than obligation ... they're entitled to respect ... but I don't want people feeling obliged.

Aged 70+, regional, Western Australia

It's a respect for what they've done in their lives, shows we are a caring society when we can care for both the old and young ... and it's a reflection of how we want to be treated when we get older.

Parents separated from their children by forced adoption or removal, New South Wales

For some, this sense of obligation towards older people was also about reciprocating the care they had provided to younger generations.

I think we're all conscious that one day, we'll be in that position one day too so we hope that generations will take care of us too... there has to be something cyclical about it ... there's a moral feeling underlying that too, there's an intrinsic feeling.

Aged 31-55, metro, New South Wales

They cared for us our whole lives, so I think we have to.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

I think we do have an obligation to old people. We should be helping them ... it's an automatic thing ... when we were little they looked after us, so we look after them ... but if

somebody has needs, you do it, you don't think about it.
Aged 70+, metro, Northern Territory

Some older people did not want younger generations to feel obligated. They felt this was a heavy requirement to place on them, but that instead they should simply be treated respectfully.

I don't want my family burdened by me ... I don't want to impact on the family ... (When talking to daughter) It's like, I didn't bring you up to look after me. Go and live your life.
Veterans, metro, Western Australia

I don't think they should feel obligated, but they should treat us normally. Respect.
Care leavers, New South Wales

3. Community understanding and perceptions of aged care

This section addresses:

- Knowledge of the aged care system
- Knowledge or perception of the quality of aged care services
- The experience of accessing aged care

3.1. Summary

People's knowledge of the aged care system reflects their personal experience of finding care for either oneself, a partner or family member, or friend. Among those who have not needed to do this, knowledge is limited and informed by media and secondhand information; this was particularly the case for those under 30.

Information about the aged care system is generally perceived as hard to find and too simplified to be useful or too complex to navigate. Health professionals are a common starting place and valuable guide through the process of securing a place in aged care. A minority of people had used the My Aged Care website which was seen as moderately useful, providing additional information as part of the challenging process of making an informed decision. It was difficult to make an informed decision about the best care for an individual's needs and personal perseverance was necessary to acquire the breadth of information necessary.

Among some older people, aged 70+, there was an awareness that they needed to become better informed and manage the process of finding appropriate aged care because if they didn't, they would be overtaken by events and others would make this decision on their behalf.

People who had been through the process of finding aged care for themselves or others reported that it was not difficult to find a place, but that it was very difficult to find one that offered the appropriate care for the individual, was affordable and was appealing to the prospective resident. For some, the prevalence of religiously affiliated organisations running aged care facilities effectively limited their choice, as they did not want to spend their older years living in an institution run by a religious body. This was particularly the case for people who had experienced abuse as children and did not trust any institution with religious affiliations. Those living in regional areas reported having limited choice of facilities.

Finance was seen as a key aspect in accessing care and having genuine choice in terms of the facility; the built environment, staffing ratios, quality of food and services. There was criticism that aged care facilities are run as businesses and prioritise profit over high quality care.

Those who have navigated the aged care system are aware of the bonds required as part of the process of receiving a place in aged care; though many were not clear on how much this cost or how the sum was decided. For others the scale of the bond was unknown. There was concern among participants that the level of the bond would leave them with little disposal income to fund their ongoing living expenses. Very few people had any depth of knowledge about the regulation of aged

care facilities. They assumed that monitoring and regulation took place via a government body. However, given the widespread perception that many facilities provide low quality care and reports of elder abuse in the media, they also assumed that the regulatory process was not well enforced, and in effect failing to do its job.

Most people described aged care facilities negatively, saying they were depressing, bleak and scary places, that felt clinical and were sometimes overcrowded. Moving to aged care is seen as ‘the beginning of the end’ and precipitates a rapid decline in one’s life expectancy and quality of life.

Facilities are criticised across a range of aspects: a lack of meaningful mental stimulation, social isolation and loneliness, poor quality care, insufficient staffing levels and staff training, and poor-quality nutrition. These factors interrelate, with overstretched staff being unable to spend sufficient time with residents, rushing them through meals and personal care, not having the time to talk and build positive personal relationships, and timetabling care to suit staff rather than residents. Staff were perceived as lacking sufficient training, and, with many staff not having English as a first language, were seen as lacking sufficient communication skills and having different culturally-based expectations of care.

There is a widespread, strong preference across the different age groups and communities to remain living independently as they age and making use of support to do so. Those already accessing support spoke of significant delays between registering for and receiving support. Most people welcome and expect some support from family in their older years, but do not want family providing personal care, which was seen as inappropriate and burdensome.

3.2. Knowledge of the aged care system

Knowledge of the aged care system is very varied. Some people have considerable knowledge based on experience through work or relationships. Others have little or no knowledge. People find out about the aged care system when they need to.

Those people who have been involved in moving a parent or partner to an aged care facility have become relatively well informed, but only when they need to and often this was at a time of crisis. Those who have visited either friends or family in an aged care facility have broad perceptions of the environment and level of care based on their experiences, but lack firm detailed knowledge about the way in which a place is found and what it might cost. Some people also had direct experience working in the industry, or had relatives who had done so, and were therefore relatively familiar with the system.

If you don't seek it out, you don't get to know.
Aged 70+, regional, Western Australia

I know heaps only because I've tried to navigate it for Mum.
Aboriginal and/or Torres Strait Islander communities, older, New South Wales

I really haven't looked into it. I guess it's something I should look into given the age I'm at. I'm relatively ignorant as to what's out there ... I see the commercials ... that's not going to be for me.
People who are homeless, or at risk of homelessness, metro, New South Wales

People who had neither worked in, nor engaged with aged care had limited knowledge and understanding of the aged care system. Many of those aged 18 to 30 had little knowledge of aged care, what they did know was generally based on a combination of stereotype, word of mouth and media reporting. Prior to this research, ABC 'Four Corners' had recently broadcast a program about aged care and elder abuse, and this was spontaneously recalled by a number of people, either influencing or reinforcing existing negative perceptions.

I've heard such bad things from my other friends who have grandparents in homes, and I've heard from the media... I don't think that's a lie.

Aged 18-30, metro, New South Wales

You hear the horror stories all the time.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Dirty. Negative things ... you heard in the news about abuse and the wrong medication that they give. It's quite scary.

Gay, Lesbian and Bisexual communities, metro, Western Australia

The elderly now have seen these reports on TV where the elderly are being abused and Dad says 'You're not putting me in there, you can put your bloody self in there!'.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

While many participants were not confident in articulating the specific differences between a retirement village and a nursing home, they could broadly describe that there is a distinction based on the level of medical and personal care needed for daily living. They also understood that retirement villages provide considerably greater personal freedom and independence. Retirement villages were generally viewed in a much more positive light.

Really different... nursing home is actually where you need help getting clean, eating, getting changed ... retirement home – just a holiday!

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Aged care is about care; retirement village is about leisure and enjoyment.

Aged 56-70, metro, Queensland

Aged care is where you can make that transition from your own little unit (in a retirement village), where a medical person might see you once in a while, into full time care.

Aged 56-70, metro, Queensland

Retirement villages are not so bad because you've got your own space, your own little unit. You can get all the support you need through there. They're pretty good. But that's for people who can live more independently.

People who are homeless or at risk of homelessness, Victoria

Mum got moved to a retirement village ... a housing commission place, a beautiful two-bedroom villa in a gated community ... all government funded ... she done quite well. 'Cos you're a pensioner you get to live in a place like this, sign me up.

People who are homeless, or at risk of homelessness, metro, New South Wales

3.2.1. Finding information about the aged care system

Most people intended to delay finding out about the aged care system until it was an unavoidable necessity. They vaguely understood that their GP was likely to have information on aged care and could be a conduit for accessing a place in aged care. Those with little interaction with the aged care system – generally the younger cohort – would most likely search for information via general streams such as Google, Centrelink or Medicare. Many were also aware of older friends and relatives who, after a sudden health event, had been hospitalized and then transitioned directly from hospital into an aged care setting. As such, they made assumptions that the hospital played a role in facilitating that move.

Most people I know, they had just been to hospital and they weren't allowed home.
Aged 31-55, metro, New South Wales

For older people who had started the process of learning about the aged care system, information was hard to find. If they did find information, it was sometimes too general to be particularly helpful, or alternatively, so complex that it was difficult to interpret and understand.

It doesn't help you, because unless you've got the medical backup ... it doesn't answer straightaway. It's too general, not tailored for your personal needs.
Aged 56-70, metro, Western Australia

A minority of people who had looked for information mentioned the My Aged Care website. While it was considered moderately useful, it was viewed as simply another staging post in the process of gathering the breadth of information they needed, not as a comprehensive destination. Some participants who had accessed the site noted that it was convoluted and difficult to navigate and expressed concern that it would be even more difficult for an older person to use. For the general population however, awareness of the My Aged Care website was low.

Lots of information out there if you can get it. First of all, I researched it online and then I went to My Aged Care. There's not a lot of information there, you've got to chase it up yourself.
Aged 56-70, regional, New South Wales

(My Aged Care) is very confusing! ... and a lot to read through ... it's huge.
Financially and socially disadvantaged, aged 31-55, regional New South Wales

Nothing's set up in modern day for older people. There's no easy way to explain how to get them to fill out forms or anything anymore. It's always do it online ... they tell them to do it online but they have no idea.
Aboriginal and/or Torres Strait Islander communities, younger, New South Wales

My Aged Care website, we looked on that, searched under 'high care facilities' and then just made phone calls. It was ok. My parents were familiar with (the My Aged Care website) from when they were applying for home care.
Intersex and Transgender people, New South Wales

There was awareness among some of those aged over 70 that they needed to take the initiative in managing this stage of life, rather than wait until it was left in their children's hands, when the decision would largely be out of their control.

It's essential that you make the decision, otherwise your children or the system will make the decision and that may not necessarily be in your best interest. You've really got to know what's available.

Aged 70+, metro, New South Wales

Family takes over the financial and illness side ... they take the rights away from the individual ... it's a form of elder abuse. They take control of everything, sell the house, put them in a facility. Even to the point when they can't access a bank account, I've seen that happen quite a lot.

People who are homeless or at risk of homelessness, Victoria

3.2.2. Knowledge of financial costs

People clearly think that finance plays a key role in both accessing aged care and determining the quality of care received. Many were cognisant that different levels of services depended on budget; in terms of the built environment, staffing ratios, quality of food, and range of associated facilities.

You can have what you want as long as you can pay for it.

Aged 56-70, metro, Western Australia

Quite a grim place to walk into... the place, for the most part was pretty clean ... it seemed ok, but you have to understand there are public and private nursing homes (and this was a private one).

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Government also takes away the choice element. The government might have places but they're in not very nice places. If you have financial backing you have more choice.

Aged 31-55, metro, Western Australia

I know there's the ones for people who've just got the pension and no super. They seem to be underfunded by the looks of things, compared to the private ones, there's a huge difference. You need assets to get into the private ones and our family doesn't have that option. I think there's a waiting list as well for the ones that are pension-based. I think we were looking at that and they said it might be a year.

People who are homeless or at risk of homelessness, Victoria

Some spoke of visiting more affluent relatives in very comfortable, attractive expensive facilities that were not dissimilar to golf clubs or hotel resorts. While these experiences made a positive impression, and participants felt they would be pleasant places to live, they were very aware that these facilities were beyond most people's means.

My father was in a very nice place ... he was happy enough, as happy as he could be, he was very short of breath, not able to do a lot ... he certainly never complained and he was a man who would have said if he wasn't happy.

Aged 70+, metro, New South Wales

When you're talking about these places with swimming pools ... You're paying for it, whether you're using it or not.

Aged 70+, metro, New South Wales

They were aware that securing a place at a 'high-end' facility involved a substantial financial investment and that the conditions needed close examination before they should be agreed to.

You need a good lawyer ... you don't want to get trapped in a contract, you need to be able to do a trial for six months.

Aged 70+, metro, Victoria

However, more commonly, people's experiences reflected average, or below average, budget facilities. People traded stories of poor-quality care, such as a small per resident food budget, or residents being heavily sedated to reduce staff workload.

Most of those over 55 understood that providing a bond was part of the process of receiving a place in an aged care facility. Awareness of the level of the bond varied hugely from those who had no idea, to those who had investigated potential facilities and were well aware of the large sums involved. Knowledge was lower, and more variable, among younger people.

They have to make nursing homes more affordable - sometimes it's half a million to get in ... it's ridiculous.

Aged 56-70, metro, Western Australia

I don't know anything about it ... are there free aged care?

Aged 70+, regional, Western Australia

It's a fortune ... those people in there have the money. Other facilities I've seen are run down, they're kept afloat by the government, they're given the minimum that government can give them.

Care leavers, New South Wales

There's a bond for everything... \$20,000? \$30,000?

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

The deposit we paid was \$2,500? \$3,000? From my memory, it's then the pension, and any other extras you wanna pay for.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Some of them, just the cost, the amount you have to put down, \$150,000 so you have to sell your own house and it's very confusing.

Aged 31-55, metro, Western Australia

Among many of those aware of the scale of bond necessary, there was considerable concern that they would be left with very little day-to-day income, after paying the bond.

You've bought your house, it's worth \$1.2m. To buy into (aged care) you have to sell that ... you have a very small pocket of money left, and that's when you go on the pension and you're poor again ... you lose a whole slab of money that sits in the pocket of the aged care facility.

Aged 70+, metro, New South Wales

It's easy if you have money ... if you didn't have a lot of money, I've no idea. As a family we had to ask ourselves could we get \$500,000? If we didn't have that, I can't even begin to

imagine what we'd do.

Young people living with dementia, New South Wales

Some people commented that they had needed to access the services of an advisor to guide them through the process because they had found it so difficult.

It's absolutely crazily confusing and complicated. We had to actually pay for an advisor to advise us on the whole thing. Each room required a bond of \$550,000 ... there's three different fees that they charge you. It's absolutely a nightmare ... all of their assets are going down ... it's not great for people who have a moderate amount of assets. If you had no money, it'd be much better, or a tonne of money ... but if you've got a bit, it's just really sad.

Intersex and Transgender people, New South Wales

3.2.3. Knowledge of regulation

The majority of people make an assumption that there is a regulatory process that has been put in place by government and that is intermittently monitored. Very few people have any real knowledge on which to base this assertion. Some assumed, for example, the ratio of staff to residents was regulated in specific types of facilities.

It's constantly changing and you've really got to be on top of it ... there's state government and federal government legislation.

Aged 70+, metro, New South Wales

I guess with all the deaths and trips and falls and things that have been happening, and the elderly getting bashed ... they've got to (have) accountability.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

The impression for a minority was that the care provided was so poor that the aged care system was unregulated.

Too many bad stories ... we know what's going down, and it's not being regulated.

Veterans, metro, Western Australia

There's no regulation. It's more self-regulation, based on the media report.

Aged 31-55, metro, New South Wales

Many of the people who believed the system is regulated thought, based on personal experiences and media coverage (including well-publicised instances of elder neglect and abuse), that the regulation is poorly enforced, and that facilities are adept at convincing regulators that they abide by the rules.

Lots of safeguards in place but none of the watchdogs do their job properly.

Aged 56-70, regional, New South Wales

There are accreditations, they all have to do it but what is wrong with the system is that they tell you, 'We are coming on the 8th August'.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Bad reputations ... I saw compliance issues, charge nurses and even board members who didn't really understand the nuances of quality assurances and documentation. There's a whole new series of age care standards that aged care facilities are supposed to comply with.

Intersex and Transgender people, Victoria

They're very nervous about audit, and that's good.

Young people living in residential aged care, New South Wales

3.3. Support for independent living

Most people had not given thought to their future support needs when they aged. When prompted many assumed they would slowly supplement their independent living with external service providers, when necessary. For many, family were seen as the ones who would initially provide this type of support.

I don't feel old at the moment, so I'm not going to think about it. (Providing practical help around the house) that's what son-in-laws are for.

Aged 70+, metro, New South Wales

3.3.1. Independence

Many participants felt it was appropriate for family to help with day-to-day practical issues, such as shopping or some basic property maintenance (e.g. mowing the lawn). However, the vast majority of people were clear that they would not want family to provide personal services such as washing, dressing and help with going to the toilet. This was seen as partly a practical consideration that the family member may not be there when needed, but mainly as an issue of dignity and respect.

Even if it is family involvement, they've all got to work and they're not going to be there when you need to go to the toilet!

Aged 70+, regional, Western Australia

I'm on my own ... I'm not sure I want my sons to be my carers ... if you need personal care, it's a bit awkward, I'd feel uncomfortable.

Young people living with dementia, New South Wales

3.3.2. Accessing support

Many older people, aged 70 and over, were already accessing support to continue living at home. They spoke of the delay between registering for support and receiving support. They gave advice to other participants in the focus groups, stressing the need to register in advance, even if they did not foresee needing the support for some years to come.

There's all kinds of services that you can get cheaper than normal ... cleaners, gardeners ... once you register, then you can expand on what services you need. You can get half price taxis if you lose your licence.

Aged 70+, metro, New South Wales

My Aged Care website ... I had a young woman come and I said, 'I'm wasting your time because all I want is the windows cleaned'. But she said, 'It's good now that you're on the system so that if you need more help with the vacuuming, you can ask for it and we don't have to go through that all again'.

Financially and socially disadvantaged, aged 70+, metro, Victoria

It took Mum 12 months to get on an aged care package. And all she got was a level two, which is just one hour a week cleaning.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

As you get older you deteriorate to the situation where you're unable to look after yourself at home ... cleaner comes in once a week ... through the Council (to Homeless Persons) ... they come out, interviewed you, tell 'em what you need, to be done, very slow process ... A lot of things at home that I can't do that I used to. I have trouble keeping up with the washing ... even cleaning out the cat tray is getting harder ... I wouldn't know where to go to get help for that.

People who are homeless or at risk of homelessness, Victoria

Because I've worked in social justice, I knew about in-home care plans. We live in the Melbourne City municipality. They run a good home help service because I know about that. My wife has a bad back, spinal problems and can't do housework.

Care leavers, Victoria

When considering what the experience of receiving support should be like, people stressed the need for respect and personal care. Those with experience of support spoke of the importance to the recipient of consistency, i.e. the same support worker arriving on the same day, at an agreed set time. Older people wanted to be able to plan their time around these commitments. There was also worry about 'strangers' coming into one's home to provide care, and people wanted to be able to build a relationship with the support worker so that it was a more pleasant, trusting personal interaction.

Be respectful ... especially 'cos you're older, you feel like you're entitled to some respect.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

My friend has someone coming in from Anglican Care, but they don't come at the time when they say they will, it'll be a man one day and a woman the next. It's all very irregular.

Parents separated from their children by forced adoption or removal, New South Wales

Consistency, more person-centred way of staffing ... so someone doesn't just have random people come in. People who my mum doesn't know will come in as a casual and not always know what her needs are.

Intersex and Transgender people, New South Wales

I expect some degree of support services to be available at home. Part of my requirement for that is that I vet the people who come, which some providers don't like.

Young people living with dementia, New South Wales

3.4. Accessing residential aged care

People who had investigated finding a place in an aged care facility for themselves, or for a relative, spoke of being largely unaware of, and shocked by, the lengthy waiting lists and financial bonds. Often they had been searching for a place in response to a sudden change in health or personal care needs and finding out about the waitlists and bonds was frequently distressing. Other participants hearing these stories for the first time were generally shocked.

When we went to aged care ... it could have taken six to 12 months, and we needed something from day one.

Aged 70+, metro, New South Wales

Very draining. It does not strike me as an easy process ... If you want something decent, there'll be a big waiting list.

Aged 56-70, metro, Western Australia

Very difficult – the waiting lists. Unless you're very bad, then they always find room for you.

Aged 70+, regional, Western Australia

Navigating it today ... you got to ring this hotline. They bring an assessor out ... it's a real shit fight ... all these old aged providers, they're sly.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

3.4.1. Finding the right place

Among those who had been through the experience of finding an aged care home, many spoke about how difficult and how lengthy a process it had been. Finding a vacancy was moderately easy, but it was difficult finding a place they judged suitably clean, comfortable and appropriate for the care needs of the future resident. They were shocked by the amount of effort required to locate and select an appropriate facility and the persistence required to secure a place in the preferred facility.

Impossible. It's been horrendous, very hard. You have to be very choosy, very direct and blunt with hospital administrators.

Aged 56-70, metro, Western Australia

It's a tough point in your life, you're helping someone through ... You're mentally and emotionally drained, helping this person who is probably giving up their freedom moving into this facility ... education in general for the public as to what's available, how to access it, where to go, what the first step is.

Aged 31-55, regional, Queensland

It's easy, but it may not be the one you want. If you're in a public hospital, the social worker will find a spot for you, but you may wind up in a ward with four beds ... to find one that was suitable ... we rang up about 60 places and visited about 15.

Veterans, metro, New South Wales

It's daunting, a lot of forms to fill in, things like Power of Attorney too ... it takes a long time. (You have to) look at all the places, it's messy stuff, and the forms are massive.

Gay, Lesbian and Bisexual communities, metro, Victoria

The difficulty of locating an appropriate home was recognized by all of those who had been through the process. Those who had a comparably easier experience locating a home often referred to themselves as ‘lucky’, reflecting on the more difficult stories they had heard of. Many also thought that if a person had money, access would generally be easier and they would receive a higher quality of care at the home.

I've seen finances come into the decisions ... the decision-making process can be complicated ... definitely can have a bit more quality if you have a bit of money.
Aged 31-55, metro, New South Wales

3.4.2. Limited choice due to religious affiliation

Some people commented that the number of facilities run by religious organisations effectively limited their choice. Many participants from diversity groups (i.e. care leavers, parents of forced adoption, transgender and intersex and sexuality) had had negative life experiences with institutions run by the Catholic Church and were distressed by the prospect of potentially living in an institution run by a religious body. Others who had been raised in a particular faith had chosen to move away from organised religion as an adult and wanted the choice of whether or not their care in old age was provided by a religiously-based organisation.

I believe it's actually very difficult ... I had a friend, he was trying to get into one for years and couldn't get in ... most of them are run by religious order, which in itself is not the best solution ... a lot of people have turned away from religion and to have to go back into it at that age can be very confronting, but you're not left with any alternative.
Intersex and Transgender people, New South Wales

It would be problematic being in a conservative religious based institution of any sort. Some that might condemn or stigmatise, discriminate.
Gay, Lesbian and Bisexual communities, metro, New South Wales

3.4.3. Limited choice in regional and rural areas

Those living in regional and rural areas were more likely to comment on the limited choice of aged care facilities available, or a lack of facilities. For some of those living in regional areas, this was a source of concern.

There's not one in this neck of the woods. There's not any that provide even the basic needs. When they say they have six dollars a day to feed each person that is absolutely ridiculous.
Aged 70+, metro, Northern Territory

My father-in-law was going to have to go to another place far away but fortunately, or unfortunately, a place opened near us when another resident passed away. It's not uncommon when (there are) no places at the closest, they're not always available.
Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

Melbourne vs. Shepparton – healthcare is there. Here, even with my daughter. She has to go back to Melbourne to see a doctor.
Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

3.5. Perceptions and experiences of residential aged care

Life in a residential aged care facility was perceived as being generally negative. Many people were adamant that they did not want to spend their older age in a residential aged care facility. They tended to use words and phrases such as ‘depressing’, ‘clinical’, ‘drab’, ‘bleak’, ‘scary’, ‘overcrowded’, mentioning that residents were sometimes mistreated and that facilities smelt of urine. Some of these perceptions of residential aged care had derived from the media or through word of mouth. However, across all the focus groups, many people visited family and friends in an aged care facility, and their perceptions were shaped by these encounters.

I’ve only heard negative things. My grandfather was in a nursing home ... and as soon as he got in there, downhill... they fed him mush ... he tripped in the shower, they didn’t care.
Aged 18-30, metro, New South Wales

My experiences have been that the facilities are pretty grim – it feels like a place you go to when there’s nowhere left to go ... just a bit depressing – it’s hospital-like, clinical, grey, quite outdated, smells ... lonely.
Aged 31-55, metro, New South Wales

Depressing. A very distinct smell. Don’t really know what it is.
Gay, Lesbian and Bisexual communities, metro, New South Wales

A lot of healthcare homes are out of touch, like they don’t treat them like human beings.
Financially and socially disadvantaged, aged 31-55, regional New South Wales

Sad, sorrow, misery, grief ... very lonely and very tedious, like vegetables. Like a prison, very mind-numbing.
Gay, Lesbian and Bisexual communities, metro, Western Australia

I was totally appalled ... patients wetting themselves because no-one was coming ... in my mother’s case, in her room, she was dying and the number of blow flies in the room and no-one bothered to spray them. It was pretty horrendous. As we walked in, I was absolutely shocked with the amount of faeces we saw.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

At that home, when you get out of your car, before you even make it to the door, you can smell it. It’s horrible, it’s so bad.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Every place varies. I work in the sector. I’ve seen some that are excellent and some that are shocking.
Aboriginal and/or Torres Strait Islander communities, older, Western Australia

A minority of participants commented positively about their impressions of aged care, but the overwhelming weight of opinion was negative.

The health care provided was great. The facilities had a little bed in there, and a toilet and shower. She was very independent still, couldn’t complain about anything. It was cheap.

She loved it, she made friends there.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

These negative impressions of aged care facilities are summarized in the relatively widespread view that when you enter a home it will reduce your life expectancy and your quality of life. Based on personal experience of family and friends, many people also associated moving to an aged care facility with a rapid depreciation of an individual's capabilities; they see aged care facilities as a place to die, not a place to live. This stark viewpoint strongly motivates people to resist moving to an aged care facility.

Please god don't let me (go to aged care facility), I'll be dead in one week.

Financially and socially disadvantaged, aged 70+, metro, Victoria

Once they go into those institutions ... my grandfather, once he fell and he went into hospital, and he couldn't go home. He just deteriorated rapidly because they're just horrible.

Aged 56-70, metro, Queensland

They come in reasonably alert, after they've been in there a while, they're like a pack of sheep ... not even really talking to each other.

Aged 70+, metro, New South Wales

I just knew that if we put him in (an aged care facility) he'd be dead in a couple of weeks ... it was about quality of life. If we'd put him in there, he'd have had maybe a couple of extra weeks, but his quality of life would have been just dismal.

People who are homeless or at risk of homelessness, Victoria

The overall poor living conditions in residential aged care was attributed to five key aspects: a lack of mostly mental, but also physical stimulation; social isolation and loneliness; poor quality of care which was partially attributable to insufficient staffing; staff levels, quality and training; and a lack of quality nutrition.

3.5.1. A lack of stimulation

A key criticism was that aged care facilities do not provide vibrant or stimulating living environments. Many people felt that when their relatives moved to a facility, their physical and mental health rapidly deteriorated because of the lack of stimulation and independence. The retention of a high degree of control over one's environment was seen as central to retaining self-esteem, alertness and mental acuity.

They looked sad... they were just sitting there ... there were like 20 old people just sitting there ... no one talked.

Aged 31-55, metro, New South Wales

They're basically sitting in their room ... they really have nothing to do ... my mother-in-law's lost her eyesight, so really, it's just a waiting room for when she's gonna go upstairs.

Veterans, metro, New South Wales

Once you go into one of these institutions you have no control, you're at their mercy totally. Having no control over your life any more is a terrifying prospect.

Aged 56-70, regional, New South Wales

Some of them don't even get them out of bed, they lay in bed all day long ... you can see them going downhill.

Aged 70+, metro, Northern Territory

Just depressing ... lack of vitality I guess ... the setting, the people around you. Lack of variation in age groups ... I want something that's variable and interesting and sometimes challenging.

Care leavers, New South Wales

This lack of vibrancy partially reflected the criticism that aged care facilities care solely for older people, and many spoke of wishing to live in a setting, or neighbourhood, which was multi-generational.

The worst things about those places is that they're all full of old people! Institutionalised - a good friend of mine went in and now he doesn't have a life.

Aged 70+, metro, New South Wales

3.5.2. Social isolation and loneliness

Participants with experience of visiting friends and relatives more frequently in residential aged care tended to be critical of both the scope of social interaction that was on offer, and also that social interaction was limited to the confines of the facility.

The friend I went to see didn't even know there was a common room, or that he could leave his room and talk to other people.

Aged 70+, regional, Western Australia

There needs to be more funding for activities and funding for equipment.

People who are homeless or at risk of homelessness, Victoria

Mum was in one for a while ... I wouldn't want to go there, it was depressing. People just sitting around ... there's nothing positive about it.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Some people were concerned about social isolation caused by geographical isolation, i.e. that the facility was located in a quiet, residential area with no easy access to local amenities, such as cafes, shops or cinemas. While some commented that residents may be taken to a shopping centre or the cinema for a time-limited visit, many felt that they were not encouraged, or allowed, to become involved in a social life that took them out of the facility. Others felt that an aged care facility offered a breadth of social opportunities but this was not necessarily sufficient to prevent loneliness because residents' families move on with their busy lives and do not spend sufficient time visiting and continuing to care and give support.

Quite sociable but also very lonely. There's a lot of social activities going on within the home, all chatty, all friends but also a deep sense of loneliness. And also abandoned or passed by, by their family.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Those people who could draw on the experience of visiting friends or family members were more likely to appreciate the social and mental health benefits of moving to a facility within your existing

neighbourhood. This was seen by those who had visited an aged care facility, as well as those who had not, as important in providing a smoother transition. It was perceived as promoting a happier ongoing experience because it was less disruptive, meant existing relationships were more likely to be maintained and was less disorientating for the resident.

You should go into a retirement centre in your immediate area so you can maintain your networks.

Aged 70+, metro, New South Wales

It's very important for people to be in a comfortable environment that they know, with food they're used to eating and not strangers around, but people that they know and care for them and love them. They can feel safe and the freedom to move and potter around. I think that's really important ... I'd like to see more in-home care, to be honest.

People who are homeless or at risk of homelessness, Victoria

I think they have the right to dignity and a lot of the time that right is taken away. I think they have the right to choose ... the right to stay in their own dwelling for as long as possible. I think it's important they stay in their own environment.

People who are homeless or at risk of homelessness, Victoria

3.5.3. Poor quality of care

Participants gave numerous examples of family members or partners providing regular support to ensure basic cleanliness and nutrition was met for an older family member who was now resident in an aged care facility. Some people felt family members had to make additional effort in order to ensure a resident of an aged care facility was receiving satisfactory care.

It wasn't clean ... beds weren't changed ... If you want something done, you have to call the manager of the place in charge to get it done. In our experience, no one's taken the initiative – like, 'Oh this is wrong', no. You have to whinge about it before anything gets attended to.

Aged 31-55, metro, New South Wales

If you live in aged care and you don't have family visiting regularly, unfortunately, it means that things get overlooked.

Aged 31-55, metro, New South Wales

Varied (quality of care) ... its more what we hear than what we see ... it's what we don't see when we're not there that's more the scary part of it ... grandparents that have dementia; it's how they are looked after in the middle of the night and when you're not around.

Gay, Lesbian and Bisexual communities, metro, New South Wales

People I know who are going in (to visit), changing bed linen and changing pads on a daily basis to check parents are being cared for properly.

Aged 56-70, regional, New South Wales

There was also criticism that the level of care received was not sufficiently personal. This lack of attention was another contributing factor to the perceived rapid decline of older people when they move to aged care facilities and to their experiences of loneliness.

I've heard of where someone's clothing ends up on someone else! That's really insulting. I don't want to wear someone else's clothes.
Aged 70+, metro, Victoria

3.5.4. Staff quality and training

People consistently commented that they thought staff were overstretched, underpaid and frequently insufficiently trained for the job at hand. They recognised that the diverse and sensitive needs of residents meant that specialised skills were needed, however the perception was that these skills are often absent.

Need more staff qualified to deal with dementia people. And more trained male staff to deal with troublesome residents.
Aged 70+, regional, Western Australia

Nursing staff, carers and aids ... in my experience, there's a basic carer's package that you do and you get a job ... they do that to pass, they get the job and then it just goes out the door – whatever they've been trained to do.
Care leavers, New South Wales

They do not have enough people on the ground in most (aged care) facilities to deal with the normal people, let alone people with issues. That is my biggest concern ... under-resourced ... people who are trained properly ... As a nurse, I had to do three years training. They stick these kids into aged care facilities with how many months of training?
Parents separated from their children by forced adoption or removal, New South Wales

In addition to an adequate skillset, there was also recognition that the role of caring for older people was a challenging one, and one that also required staff who had the capacity to provide a genuine level of care. Some participants felt that the difficulty of the tasks performed by nurses and care workers were not sufficiently reflected in their remuneration, and that this could contribute to a poor level of care.

It's a job where you need people with a heart.
Aged 31-55, metro, New South Wales

The pay's not good ... I just type all day and I get paid pretty well, compared to nurses to have a harder job and don't get paid as well.
Aged 18-30, metro, New South Wales

It's a crappy industry, it's a shitty job and nobody really wants to do it. It attracts people who aren't very good.
Aged 56-70, regional, New South Wales

The people who work in aged care get paid a pittance ... and they work so hard.
Aged 70+, metro, Victoria

I worry that the pay for the carers isn't what it should be and it's hard to retain staff. They do the best they can, but I don't think the pay matches what they have to do, I just think carers and nurses aren't paid what they should be paid.
Aged 31-55, metro, Western Australia

Some felt that care for their family member would vary markedly depending on which staff members were on duty. Poor staffing ratios were raised by those who had closer encounters with lower quality aged care facilities. Furthermore, it was felt that under staffing meant particular tasks or activities would be undertaken at a time to suit staff members, and not for the convenience or comfort of residents.

Staff being overstretched ... some of the staff start dressing the clients in their pyjamas at 3pm because they have so many people to get through ... that sounds horrific.

Gay, Lesbian and Bisexual communities, metro, New South Wales

The reality of it was that it was well oiled, very scheduled, rigorous and timed, but not particularly fun ... it was efficient ... but whether it suited her or anyone?

Gay, Lesbian and Bisexual communities, metro, New South Wales

My mother, she's down south, she's 'compos mentis' ... she's in a wheelchair, they might put her into her lounge chair but because they're so busy, she doesn't want to disturb them and she can be left in that chair for hours ... it comes down to staffing levels.

Aged 70+, metro, Northern Territory

I think they need more staff because the ratio of staff to residents is crazy. I've known people who've had to be restrained because no-ones around enough to stop them falling off chairs. Especially at that point of ageing where you rely on people to lift you and toilet you, there's not enough staff to do it all in the time that's needed. Some people have to wait too long to go to the toilet, then they soil themselves, then they're shoved into nappies. It's a loss of dignity.

People who are homeless or at risk of homelessness, Victoria

Some participants raised concerns about communication problems between staff and residents, particularly staff for whom English was not a first language.

In the hospitals and nursing homes there's a big thing with the people from other countries communicating. Terrible – they can't speak English half of them.

Care leavers, New South Wales

Some participants used cultural difference to assume that these staff were less well trained or had lower skills levels, overlooking the pressures staff might be under in aged care facilities.

Too many non-English speaking people ... they have no idea how to care.

Aged 56-70, metro, Western Australia

I could see a lot of these overseas people, Indian people, they didn't have the capability of understanding that if a person didn't want it ... they were forcing the food into their mouth. To me, that's abuse.

Care leavers, New South Wales

However, some also recognized that without these carers there would be no one to care for older people.

Monetary ... it's no longer about care ... it's just gainful employment for them ... it's mainly foreigners, Australians don't want to wipe your bum.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

3.5.5. Nutrition

The food and nutrition provided to aged care residents was another issue of concern. Those who had visited family in expensive private aged care facilities recalled food that they consider of 'restaurant-standard'. However, for the vast majority of people with some knowledge of what was provided in more typical facilities, the food was considered unappealing, not particularly nutritious and prepared for people with dietary or eating conditions (i.e. mushy). There was also frustration that facility rules meant that it was sometimes not possible for family and friends to provide food.

I used to work in one when my daughter was three months old. She's now 53 years old and nothing has changed. It was really disgusting how they treated the old people ... their food is disgusting, and if I take (my mother) food, it has to go on the counter for everyone to share, and that's not right ... I wasn't allowed to give it to her ... and they hit them. You don't hit people when they're old!

Aged 70+, metro, Northern Territory

Nutritional level is poor, everyone gets the same meal ... they don't change the menu, they stick to the menu 'cos that's what they can afford to pay out.

Veterans, metro, New South Wales

Food is desperately lacking, they think it's all nutritional. I don't consider party pies sustenance. The food is improving but they're on such a budget they only spend three dollars per person per day instead of the 17 dollars.

Young people living in residential aged care, Victoria

3.6. Areas for improvement

Areas for improvement were far reaching, ranging from the management and culture of aged care facilities, through to the nature and range of activities and services available, and the type and quality of food provided. People who had some level of knowledge of the news reports, or had negative experiences, felt strongly that change was needed within the aged care system. Those with less knowledge, or more positive experiences, were less likely to perceive an urgent need for change.

Many felt that a change in the management of staff was a priority. First and foremost this would involve better training and increased remuneration to attract high quality staff and ensure staff were satisfied. Improved staffing ratios were also seen as crucial.

I feel there has to be some incentive from the government or something to work in the sector ... give those people (aged care facility workers) more.

Aged 18-30, metro, New South Wales

Carer roles are so close to minimum wage. Same as childcare ... but it's one of the lowest paid professions. It's almost like an entry level role and want to get paid instead of people

who care about the role.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Increasing the number of workers as well. Sounds like they're overworked.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

People felt the negative culture of the aged care system needed to be addressed. The system was too business-oriented; aged care providers were interested in making a profit and not really caring of the older people.

Profit-making I think, is what the problem is in this area. It sort of goes against what we're trying to do here – take care of people.

Aged 31-55, metro, New South Wales

They treat the family as the customer, and the person in the aged care is just a number.

Veterans, metro, New South Wales

These places are set up to make a profit – they don't care.

Aged 56-70, regional, New South Wales

It's hard to use the term 'aged care'. I don't see any level of care in there, it's financially driven.

Young people living with dementia, New South Wales

Participants thought perhaps homes needed to be monitored more carefully. Many participants had been shocked by some of the events publicised through the media, and they questioned how this could have taken place.

I don't know how often they come to check but maybe make it once a month that you have a visit from officials. Probably once a month so that the people working there know that they might be monitored.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

The government should definitely monitor more. They shouldn't subsidise those facilities that aren't hitting their KPIs. If there are too many handouts without expectations, they wouldn't keep the standard. The stigma is that aged care facilities are bad, I wouldn't want to put my parents in one.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

There needs to be more transparency in their KPIs.

Aged 31-55, metro, Victoria

It needs to be a place, like a Centrelink. People ordinarily want to talk to someone face-to-face, to ask questions. To try and find that information on a website can be quite tricky. You don't even know what you're trying to look for. You need to talk to someone. Almost have a one-to-one consult with a person about your situation. Someone with your best interests at heart. More customer focus. Almost like a central complaints system so there's an avenue to raise their concerns to. Otherwise, where do they go.

Aged 31-55, metro, Western Australia

Some participants were very keen on supporting people in their own homes for longer. These people felt strongly that older people would benefit greatly if funding priorities were shifted from aged care facilities to maintaining the older person's independence. This was seen as more economical for government, and more in keeping with how many older people want to live.

If the government wants us to stay in our homes, they could reduce the cost of support help coming into our homes.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

There's definitely a shift to have people live in their own homes for as long as long as they can where practical so there's no reliance on care or nursing homes or a retirement facility. Having a smaller abode, so they can still live independently but the parent is still close enough if something goes wrong...

Aged 31-55, metro, Western Australia

Lastly, people felt that care in the current system was inadequately funded and accessible, and this needed to change.

Towards the end of your life At that point that's when the government needs to have a good quality service to look after our people. Something that doesn't kill the family to cost for everything. It just needs to be people who care about older people, looking after our older people that families can afford and the pension will help cover. The same price for everyone whether the government pays out of Centrelink payments or its self-independent as a retiree. It doesn't matter - how about we just look after the people.

Aged 31-55, metro, Western Australia

4. Planning, expectations and concerns for own older age

This section addresses:

- Community planning and expectations for their own older age
- Concerns regarding health, financial planning, housing, employment and social and community engagement

4.1. Summary

Many people have given little thought to their older years, with a mixture of denial, avoidance and being very busy coping with day-to-day demands. They only turn their thoughts to planning their older age when a specific health event or other factors beyond their control makes it unavoidable. Fear of the unknown and financial insecurity deter people from engaging with the issue. Only a few, mostly older, people have proactively engaged with the issue, and made realistic plans about where they will be living and the care they will need.

Planning for older age tended to focus on maintaining independence and control across all aspects of life. This extended to death, with middle-aged people often raising the issue of euthanasia and citing this as a way in which they would want to be control of their final years, determining when their quality of life was no longer sufficient.

There is broad, generalised awareness of the need to maintain good health, and what this means, i.e. regular physical and mental activity, social interaction and stimulation, not smoking and limiting alcohol intake. Older people were very conscious of their older years having purpose and having something meaningful to do each day. They were fearful of losing their cognitive function and spoke about 'using it or losing it'.

The importance of financial planning and security increased with age. For younger people, under 30, older age was sufficiently distant that this was not a front-of-mind concern. Older people, especially those on lower incomes, found financial planning daunting. Uncertainty about the cost of future health events, and not knowing how long their finances would need to last, was a cause of worry and stress. Most people are expecting to self-fund their older years and are sceptical that government support would be sufficient to provide a good quality of life. Among those receiving the pension, or likely to in the future, there was concern that they were stigmatised for doing so, when they saw this as their dues following a lifetime of contribution through taxation and other contributions to society.

There is no longer an expectation that people will stop working at a specific age; timing for retirement is moving in line with financial need and personal choice. Some people intend to continue working due to financial necessity and wish to continue adding to their superannuation. This expectation was tempered by concerns that their employment options would narrow after the age of 50. Many also would continue working because they enjoyed their jobs and recognised the mental health benefits of having a daily purpose, experiencing social interaction and mental

stimulation through their work. People are influenced by their parents' experience of retirement and concluded that a slow transition out of the workforce provided a better balance of work and life.

A primary concern for our older years is continuing to live independently in our homes. This was the goal for all, irrespective of age, community or lived-experience. Many spoke about intending to move to a smaller, practical home, on a single-level with lower maintenance. A few people had intentions of moving to a different location, either for lifestyle reasons or to be nearer to children and grandchildren. However, many recognised the benefits of remaining in their current location, where they had existing social networks. They recognised the challenges, and potential disorientation, of moving to a new setting during their older years.

There was widespread interest in living in a multi-generational setting. The vast majority do not wish to live with their children; they wish to be independent and not be perceived as a burden. Equally, they find the prospect of aged care facilities where everyone is elderly very unappealing. Most people were looking for a balance of family nearby, friends sufficiently close by that they could spend regular social time together, and still encounter all generations of life, so that their environment is vibrant and stimulating.

The idea of a multi-generational setting also contributes to people's goals around community and social engagement. Middle-aged and older people recognise that they will have more time available and want to be able to fill this with meaningful activities (such as volunteering), positive family time, and relaxing social interaction with friends. This is seen as ensuring they are not lonely, and that they are mentally stimulated and still contributing to society.

4.2. Preparation for older age

In a huge variety of ways, many people of all generations were avoiding thinking about their older years, doing little, or only responding when the need to adapt became unavoidable. Some were putting plans in place, or slowly making smaller changes adjusting their life in preparation for older age.

The broad spectrum of responses ranged from those who intentionally refused to engage with the topic, with an attitude of denial, through to those who have engaged and made some preparation but have still not given detailed thought to the reality and requirements of their final years. Those with a clear, realistic plan about their needs in their later years were relatively rare.

There will be a time where I no longer will be able to care for myself ... no matter how much I do ... I have to acknowledge that we will reach a stage when we have to rely on other people.
Aged 56-70, metro, Western Australia

That's starting to go through my head now – organise my funeral ... I've got my plot.
Veterans, metro, Western Australia

I'm not thinking about it, no strategy. I've got enough money to do whatever I have to do ... it's easier not to ... but I did get a 'Vital Call'.
Parents separated from their children by forced adoption or removal, New South Wales

4.2.1. Practising avoidance

The lack of attention given to preparation for older age tended to be driven by a range of factors including financial insecurity, fear of the unknown, and the person having ongoing good health which did not demand that focus shift to times when the individual would have different needs. For some people, it was simply a case of personality type preferring to 'live in the moment'.

I just take one day after the other. I always say to my wife, 'Tomorrow is not guaranteed to anybody'.

Veterans, metro, New South Wales

I live in the moment. Sometimes I look at my super, and think 'Oh, I should be doing something about this', but I take it as it comes.

Aged 31-55, metro, New South Wales

None. I haven't thought anything about it. It's tomorrow's problem.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

I never thought about that, I didn't care. I didn't plan to retire.

Aged 70+, metro, Victoria

I'm practising avoidance. I've not done anything about it. But I know that at the end stage I'll go to Victoria, buy a house and live there for twelve months.

Aged 56-70, metro, Western Australia

When I die, I die.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

I hope I'll always be independent and die in my sleep.

Parents separated from their children by forced adoption or removal, New South Wales

Some of the specific audiences consulted found it particularly difficult to plan further ahead and had few thoughts about their older age. This was particularly the case for people homeless or at risk of being homeless, younger people in residential aged care, and young people living with dementia.

4.2.2. When, why and how planning occurs

Life stage was a key determinant of how much thought an individual had given to their older age, and to a degree, what aspects of ageing were considered. The common aspects people of all ages focused on were:

- Health, including mobility;
- financial security;
- employment;
- housing stability; and
- community and social engagement, including the role of family and volunteering.

The majority of those aged 18-30 and some of those aged 30-55 had given their older age little consideration, some noted that their lives were currently quite busy, older age felt very distant and planning for older age was not a priority. This was somewhat similar to the circumstances of many participants with young children, who felt very busy juggling work life and caring duties. Conversely, some parents with young children had become more likely to make plans for older age as they recognised the greater responsibility they now had.

I think once you have kids, it does change your whole mindset ... me two years ago – I wasn't thinking about that, I wasn't thinking about anything ... having kids ... it's just a whole different perspective.

Aged 18-30, metro, New South Wales

It's right in the middle of the eye of the storm at the moment so I can't say that I'm thinking beyond the next few years at the moment ... we only bought a house five years ago and we had a few kids, they're under five. I can't put myself in that (older age) mindset yet.

Aged 31-55, metro, New South Wales

For the few of those in younger groups who had made plans at all, these tended to focus on their financial position (mainly super contributions) and their day-to-day health.

Unsurprisingly, older people had given more thought to the planning and preparation for older age than younger generations. This was not universally the case, but among those aged over 55 it was more prevalent. Some reflected on their parents' older years and how this had informed their planning, in both a positive and negative way.

I learnt a lot from my parents which is why I have all this put in place so nobody will have to worry about me – because my parents didn't do it.

Aged 56-70, regional, New South Wales

Planning, that's the key ... as I say to my kids if you fail to plan, you plan to fail.

Aged 56-70, metro, Western Australia

There's a bit of guilt there ... we didn't pay enough attention to how my father was travelling ... he lived in the country, we lived in the city. He had to cope with a measure of neglect, as we couldn't get down to see him often enough, he was 85 and he suicided ... I haven't moved away from my own children, so that geographically we are able to be in touch with each other at the drop of a hat.

Aged 56-70, metro, Western Australia

I'm looking at my 70th birthday as the defining moment for when things are going to change ... I want to start putting plans in place now.

Parents separated from their children by forced adoption or removal, New South Wales

The planning process for many was triggered by specific life events. As mentioned above, having children was one of these, but more frequently, it was health-related issues. Adverse health events were a first significant indicator that the individual's previous good health was not a permanent state of affairs. For some younger people, the triggering event had been watching parents or grandparents experience a significant health scare, while for a few it was the sudden death of a friend.

I found the tipping point is when your parents start to lose some of their abilities ... it's a wake-up call ... you don't think about it until you see it.

Gay, Lesbian and Bisexual communities, metro, New South Wales

You can make all the plans you want, but you never know what will happen. Mum and Dad finally settled down to a happy retirement and Mum had a stroke. Dad's life is now taking care of Mum, and Mum's life is sitting watching the TV.

Aged 56-70, regional, New South Wales

My neighbour was slowly venturing into dementia, and there were couples in the little village where I lived who weren't managing ... I'm on my own ... a long way from the facilities in Geraldton and a long way from the facilities in Perth that you'll need ... so I decided to look around at various retirement villages ... I'll change my car to a car that'll last me to the end of my days ... I had to put my house on the market ... I was planning all the time.

Aged 70+, regional, Western Australia

For others, approaching retirement age or circumstances which might bring them to retirement sparked thoughts around planning.

Before I start losing my faculties ... When I saw that 50 was coming, it was like, 'Oh, god, how many more years can I work?', the time's ticking down now.

Aged 31-55, metro, New South Wales

I've put a lot of thought into it recently because I've been told that I can't go back to my previous work, because of my hands... and they're talking about retraining me or I'll possibly never able to go back to work. I'm already thinking about retirement.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

For some, the introduction of compulsory superannuation was a prompt to make greater provision for their older years.

Once they introduced the superannuation the way it is now. I was working for myself, just putting away a bit for a rainy day and now I had to put away more by law.

Aged 70+, metro, New South Wales

Many discussions about ageing focused on maintaining independence and control of their lives. People who were thinking about how they wanted to live their later years appreciated that if they addressed the issue in a timely fashion, they could shape this stage of their lives. They wanted to plan for themselves rather than being reliant on the choices made by family members, and specifically their children. Further, their preparation would ensure they were not being a burden to their children and simultaneously they could retain choice and control.

I've looked at retirement communities and if they have nursing facilities ... I don't want my kids to have to look after me, I just don't want that.

Aged 56-70, metro, Western Australia

Don't leave it too late ... the bottom line is it will be taken out of your hands.

Aged 70+, regional, Western Australia

4.2.3. End of life

When asked whether or not they had given thought to their older age, some people aged 56-70 tended to discuss death. This spontaneously raised the topic of euthanasia, and those who discussed this tended to be strong supporters. They were vocal about wanting to maintain a good quality of life and when this was no longer the case, to have control over how much longer they lived. This debate was couched as not wishing to be a burden to other family members and wanting to have some control over retaining dignity and maintaining independence in as meaningful a way as possible. Although some people did not necessarily support euthanasia, the general view was that they did not wish to interfere with the choices of others.

You want to have those discussions with your family, it's part of the planning before ... got to have the discussion with family before it's too late. Let them know, you may be vegetative, you may not be able to make that decision.

Aged 56-70, metro, Western Australia

My friend, he had cancer ... I watched him die, he was in nappies, totally undignified, he was in the hospice section ... I vowed when I saw that, that I would take my life before I went into a nursing home.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Do we have to move to Melbourne in order to end it? And we shouldn't have to wait so long.
Care leavers, New South Wales

Many were fearful of becoming unable to care for themselves, or their quality of life becoming so low that they would not wish to remain alive. Participants over 70 who raised the topic of euthanasia were adamant that they should be given the right to choose their fate, though they were also very conscious that it was a personal perspective that might not be appealing to all.

I honestly never think I'm going to die ... and if it looks like I am, I'll move to Victoria where euthanasia is legalised. I'm never going to move into a nursing home, I'll kick and bite and scratch and do what I can not to. Its obscene seeing people in there ... try and keep people in their own homes as long as they can.

Aged 70+, metro, New South Wales

I have a great fear of dementia ... I believe I should have a say in how I go ... if I have dementia and I can't speak for myself, I should just get a little needle. That's my greatest fear. I see people – my dad's cousin has been in a nursing home, in a foetal position for two and half years.

Aged 70+, metro, New South Wales

If you don't want it, you don't have to have it. But don't tell others what they can or can't do.

Aged 70+, metro, Northern Territory

I think all the time about this one, I know it's a bit gory but ... if I ever had the chance, and I was told beforehand, that I'd be incapable of taking care of myself, and my kids get upset about this, but I would suicide. I'm not going to be a burden to my children or my grandchildren. And from my point of view I would be a burden. (Euthanasia) used to be in the Territory ... I think it should be normal ... if I want to die, I want to die in my time ... I'm

not ready ... I really have a good life, but when I come to an end, I want it to be on my terms.
Aged 70+, metro, Northern Territory

A pillow over my face from my son! It's horrific, but not beyond comprehension.
Aged 70+, metro, Northern Territory

As part of their planning, a minority of those aged over 55 mentioned that they had put in place an enduring power of attorney and/or a health directive.

4.3. Health

The high awareness of deteriorating health and the numerous implications of this in older age meant that health was a top priority for most participants, if not all.

Health is a big one for me, because that autonomy thing, that independence, that's huge.
Aged 18-30, metro, Queensland

People were very conscious of the need to engage with their health in order to maximise the period during which they can benefit from good health and retain mobility. Those aged over 55 were particularly aware of the breadth of ways in which they needed to maintain their health, although this did not always translate into action. Nevertheless, they knew that they needed to invest in both their physical and mental health in order to prolong their period of independent living.

I've definitely thought about it since turning 30. The body starts to give way, back aches ... it's made me realise you take your health for granted and made me think about what's ahead.

Gay, Lesbian and Bisexual communities, metro, New South Wales

It's the health issues ... I don't have a partner and I don't have children. As I age and become more infirm, not that you want people to look after you, but I've got no-one.

Aged 56-70, regional, New South Wales

Prolonging the 'well' period, not a corpse.

Aged 56-70, metro, Western Australia

I don't project myself 20 years from here, I take life as it is now, but I invest in practices that are about my financial and physical well-being. Life-long practices.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Everyone my age has several things wrong with them. And a lot of your social life is going to doctors and specialists and blood tests and things like that.

Parents separated from their children by forced adoption or removal, New South Wales

Health risks were also top of mind for some veterans, who noted that underlying conditions or higher risk of poor mental health and loneliness were of particular concern for their cohort.

4.3.1. Healthy ageing – physical and mental health

Very few people aged 55 and under had made any specific plans on how to maintain their physical health in old age, however, they anticipated the broad need to ‘keep fit’ through nutrition and routine physical activity. While not dismissive about physical health, those in younger groups were more likely to speak about the importance of mental health for overall wellbeing. The need for continued mental stimulation via avenues such as social interaction, work or games was viewed as necessary for mental wellbeing. Those over 55 were also aware of this need.

I think if you're physically fit and moving, it definitely affects your mental state.

Aged 18-30, metro, New South Wales

Use it or lose it.

Aged 31-55, metro, New South Wales

Staying social, doing things that you enjoy, keeping your mind active, puzzles!

Financially and socially disadvantaged, aged 31-55, regional New South Wales

On the other hand, older people spoke about keeping active in a very general sense – that is, getting up each day, finding a specific purpose, leaving the house, walking and interacting with society. Some others were actively involved in a range of sports and pastimes. They appreciated the importance of maintaining their mobility and spoke about weaving this type of activity into their day-to-day life or focusing on specific exercise to support ongoing fitness and mobility, essential for maintaining independent living.

Six days a week, I get up before 7am, go to the park, half an hour's walk, half an hour's Chinese exercise and then do some weights when I get home.

Financially and socially disadvantaged, aged 70+, metro, Victoria

Still be able to drive your car, to walk, put your washing on the line, being able to see and hear.

Aged 70+, regional, Western Australia

Just joined a gym. I go three to four times a week. I've never liked the gyms, I'd rather be outdoors, but I found the walking just wasn't doing it.

Care leavers, New South Wales

Another aspect of good health that was raised was nutrition. Older people spoke of the importance of both eating well, but also making homemade food. Good food and nutrition was seen as being beneficial for their health, promoting good mental stimulation and maintaining fine motor skills.

At this stage of life, you've got the time to prepare good food, you've got the time to exercise.

Aged 56-70, regional, New South Wales

I do my own cooking. I think our lifestyle is really good because we do our own cooking. If we went down the shop and got Kentucky Fried, I don't think half of us would be sitting here.

Aged 70+, regional, Western Australia

My parents always complain about the food (in their aged care facility), so something needs to change there ... they don't have choice, it's very restricted. People should be able to do some cooking for themselves, part of maintaining your capacity as an older person.
Intersex and Transgender people, New South Wales

Older people also spoke of the need for maintaining regular check-ups with their GP and being screened for a range of conditions.

Keep active, both mentally and physically ... go for regular check-ups, bowel and breast, diabetes.
Aged 70+, regional, Western Australia

4.4. Financial planning and security

The older the participant the more likely they had some awareness of the importance of financial planning and security. Most people were conscious that a significant amount of funds would be required to support themselves through old age. They understood that this had to be sufficient to cover the possibility of expensive health costs, the need for some support with daily living, and the unknown duration of one's remaining years.

It would be very stressful to retire ... stressful that you have a finite amount of money for the rest of your life
Aged 18-30, metro, New South Wales

Money solves 90% of your problems. Because then you can pay people, get somewhere to go if you need medical expertise ... it all comes down to finance.
Aged 70+, metro, Northern Territory

You need a reasonable degree of financial stability and good health coverage, whether it be a gold card from veteran's affairs, or (being able to) afford the bucks to bring the cleaner (in).
Aged 56-70, metro, Western Australia

I'm worried about my money, there could be a big expense for medical, for a disability.
Aged 70+, regional, Western Australia

For many participants aged under thirty, the prospect of older age and retirement was sufficiently distant that they had not given it significant consideration. Most were content for the time being to continue in this manner and gave little thought to financial planning for those later years beyond the contributions they were making through compulsory superannuation.

While those under 30 were relatively comfortable with their current status, some also expressed underlying concerns around the increasing cost of living, including the pressures of the housing market, particularly in metropolitan areas.

If the hard work is done now, then you can chill when you're older, so I think this is the time to work hard ... have some money on the side, so when you're older, you're safe.
Aged 18-30, metro, New South Wales

I'm not fearful about it, or anxious about it. Generally, people seem to be ok, so I have no reason to think that I won't be fine.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

It depends though ... if the way of living keeps getting more expensive, then it'll be a lot harder for us to get to that point ... Dad found 10c the other day and said, 'Can you believe, this used to buy 10 lollies'?

Aged 18-30, metro, New South Wales

Some people considered relocation as they planned for older age due to the high cost of living and rising property prices in metro areas. Others had already progressed their financial plans by moving into regional areas of Australia in order to enter the property market, after being unable to afford housing in larger cities such as Melbourne and Sydney.

I didn't think we'd be living in Shepparton long term but here we are, looking to buy a house... we just couldn't do it in Melbourne.

Aged 18-30, regional, Victoria

Everyone plans to be a home-owner, for household security. Sometimes it happens and sometimes it doesn't. But that's why a lot of people come to the country.

Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

A minority of older people aged 55 plus had not engaged with the topic of ageing; these tended to be individuals on lower incomes.

I put super in ... and a little bit of salary sacrificing, but I haven't really thought much about it other than super.

Gay, Lesbian and Bisexual communities, metro, Western Australia

I hope my inheritance will cover that, I'm an only child.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Others had watched how their parents did, or did not, make provision for their older age, and made decisions that were influenced by this experience.

I think it'll be property, investing, that's what my parents did. Seeing my parents worry about money going out, they decided to do an investment property, have money coming in ... they saw aunties and uncles having nothing, and they decided to do something ... During my career, god forbid, something happens to me, if I have to stop and don't have an income, at least I'd have something.

Gay, Lesbian and Bisexual communities, metro, Western Australia

On a similar note, some people felt strongly against becoming a financial burden on their children, expressing that avoiding this was a key priority.

I don't want to be a burden on them (children) I want to give them the best opportunity I can to do the stuff that they want to do without having to think about taking care of me, making sure they've got enough money to also support me.

Aged 31-55, regional, Queensland

Somewhat unsurprisingly, those who were financially and socially disadvantaged, were particularly concerned about their financial position in later life and for this group, budgeting was key.

4.4.1. Self-reliance, independence and safety net

The preference and intention of almost all participants was to self-fund their retirement. However, there was an expectation from those not currently receiving financial support that if they could not self-fund their retirement, the government would be able to provide a safety net.

Hopefully they don't have to. That'd be the dream ... I don't want to rely on the government when I retire, 'cos who even knows if that'll be a thing by then.

Aged 18-30, metro, New South Wales

I think it's mostly my responsibility, but I don't think it's unreasonable to expect an aged pension ... 'Here you go, you've worked your whole life'.

Aged 31-55, metro, New South Wales

I think they have a certain amount of responsibility ... you've worked and paid tax all your life ... there is that aspect that they should give back to you in some way ... to a certain degree, maybe not 100% reliance on the government but I'd like to know that if for some reason I make a dumb decision between now and retiring, that I can still retire because the government's got my back so to speak.

Veterans, metro, New South Wales

No one's dream is to be living off the pension, it's not an ideal situation but it's a good back up.

Aged 18-30, metro, Queensland

Many people were however, sceptical that the government would be able to contribute at all, or with an amount deemed sufficient and therefore did not view this as reliable option. A number of participants discussed the uncertainty around the longevity of the Australian pension and in some cases, people had already dismissed the possibility of a pension in their later life. When discussed, the prospect of this being true was a source of concern for some individuals.

I wouldn't rely on the government to support me, I wouldn't think that that was sufficient ... I don't think that the pension is gonna give me much support.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

But the government has changed the goal posts too much. Like in my case, I was entitled to a little bit of partial pension ... but when the change of government came in, they increased the assets test which cut my pension out altogether, so you just can't trust the government.

Veterans, metro, New South Wales

When I retire, will the pension exist? That's why there's all this focus on super and voluntary contributions.

Aged 31-55, metro, Victoria

By the time I reach retirement age, the (pension) will be non-existent. Just with all the ageing population ... The only thing that is certain is your own assets, you can't plan that you'll get a handout, financial assistance from the state or federal government. The only

thing that you can rely on is what you have.
Aged 31-55, metro, Western Australia

In addition to the pension, a minority of participants also expressed concerns around the reliability of superannuation funds. However, it was clear that for many people, these contributions formed a very significant part of their financial plans for older age.

Superannuation, they make changes all the time and all the young people are paying superannuation, but they don't know (what will happen in the future).
Veterans, metro, New South Wales

Speaking for young people, ever since you've been working, you have had superannuation. Superannuation is a new thing in terms of the workforce. Most of our parents didn't have super until it came in. By the time we retire, will the super even be enough.
Aged 31-55, metro, Western Australia

4.4.2. Financial stress

Financial concerns, worries and fears were substantially higher, and more frequently articulated, by those over 55 who are, or had been, earning medium to lower incomes. These individuals were less likely to be homeowners and had also transitioned to compulsory superannuation, before which they had made insufficient provision for their older age. For this group, the pension was more important and if they lacked family support they were very concerned about their financial security in older age. Further, for a few in their mid-fifties and over, life events such a divorce, had led them to be in a position they had not previously planned for.

I'm a bit of an ostrich about my old age. I don't want to think of it. It's scary for me because I can't see myself being in a good financial position to retire. I don't have good super, I didn't have super till quite recently, the pension will be non-existent in a few years, I don't own property, I don't have family ... it all becomes a bit overwhelming.
Aged 56-70, regional, New South Wales

I never really did (make financial plans) because of circumstances. When I lost my wife, I was put on her superannuation ... that sorted me out and selling my house in Perth ... moving to Geraldton for cheaper housing, that left me a little bit of money.
Aged 70+, regional, Western Australia

The situation in my time was we didn't have compulsory superannuation ... none of us have really got a big superannuation.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

There was concern among some of those aged 56-70 regarding how pensioners are perceived and that it was stigmatised. While they felt they had earned the right to a pension through a lifetime of hard work and contributing to Australian society, they felt others were sometimes critical that they had not made greater financial provision for themselves.

There was a lady there from Centrelink ... she said, 'You're on welfare', and I said, 'No, I'm on a pension', and she said, 'No, you're on welfare, it's a government handout' ... you get kicked as you get older.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Because of two knock backs, I thought, I'm never coming back to apply for the pension ... I don't want the embarrassment of going all through that stuff and them saying, 'Look, you're not eligible for this'. I've had a couple of run-ins with Centrelink ... and I'm like, 'Lady, I've worked all my life'.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

I've had government jobs all my life ... I shouldn't have to say those things. They just automatically think you're a bludger.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

A minority of older people voiced the opinion that at a certain age there should be greater, universal provision for old people, irrespective of assets. This view outlined that older people had contributed to society and the economy, over the course of a lifetime and that by 70, this should mean everyone is entitled to a more significant, secure safety net.

Once you get to a certain age you should be given free medical, no matter what your asset is, when you're 70 up. And also you should be entitled to the pension and all the trappings as well. That should be a given. There's a lot of stress happening with people who have a property, a station, and they can't stay there because they haven't got any super ... by that time you're getting pretty low. It should be a given that it's not means tested.

Aged 70+, regional, Western Australia

Everybody should be treated equal at some stage and given the same benefits.

Aged 70+, regional, Western Australia

Those who had made greater personal provision felt they should also benefit for acting responsibly.

You should be rewarded for looking after yourself ... if you're going to be responsible for yourself, and no cost to the government, you should be able to have some relief towards the end of your life.

Aged 70+, regional, Western Australia

If you've been on Centrelink your whole adult life, I'm not sure that society should support you in the same way.

Gay, Lesbian and Bisexual communities, metro, Western Australia

(Older people are) picking up their earnings. They've done the hard yards. I'm talking about myself, I've paid top tax all my life!

Veterans, metro, Western Australia

Among older, more affluent people there was awareness of the need for financial planning and concern about funding an older age of indeterminant length, with unpredictable care needs. However, these people were frequently homeowners and their concern was tempered by the knowledge that they could downsize, or relocate, and largely fund their older years through the proceeds from the sale of their home.

What worries me is the cost of health ... the cost of private health cover, choice and when you have something done being an out-of-pocket expense. That's my main concern for the future ... with everyday things, you just be frugal, you've reached a stage of life where you

don't need a lot of things.

Aged 70+, metro, Northern Territory

A lot of people see their home as the asset that will see them through.

Aged 56-70, metro, Western Australia

We're lucky enough to own our own home and it makes a huge difference.

Aged 70+, regional, Western Australia

Extra contributions to super. And if we need to, we can always downsize.

Care leaver, New South Wales

With the DVA ... Because I own my own home, I have no debts, only bills and I can operate comfortably ... all in all, I'm very happy with my life and the way it's going.

Veterans, metro, Western Australia

Even with this level of financial security, these more affluent older people were still concerned that their funds may not be enough if they needed to enter an aged care facility.

Going into a nursing home costs an absolute fortune ... and look at what you get for it? Stuff all.

Aged 56-70, metro, Western Australia

Participants aged 56-70 spoke about being financially stretched as they were often still supporting children who may not yet be living independently. At the same time, these people were beginning to put in place greater provision and plans for their older years. Others raised how divorces or bad investments had unexpectedly diminished the funds that they expected to have available for their older years.

When we had the global financial crisis, I lost all my superannuation except for \$10,000, so the government has a big responsibility that the superannuation is safe and equitable.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

I'm a pensioner with no home. And I hate that feeling. I've had my own home twice, but two divorces, you have to give up the home and after the mortgage has been settled. I never thought I would end up being a pensioner. I thought I would have my own home and I'd be financially secure, and it doesn't work that way.

Aged 56-70, metro, Queensland

Thought I could retire on my superannuation but then there was the financial crisis and I thought I've got to find ways of augmenting that income.

Care leavers, Victoria

Many of these older people spoke about ways in which they organised their lives so that they could live economically, and within their limited means.

One thing (my father) did teach me was how to live on the smell of an oily rag.

Aged 70+, metro, New South Wales

You cut your cloth to fit your budget.

Aged 70+, metro, New South Wales

The pension will allow you to travel free on the weekend ... but there's still a lot of things a pensioner can't get ... you have to watch every penny when the bills come in. It's not cheap for rates, for electricity or gas, all those expenses. Hooking into concessions for travel and gas and electricity. I know about those things because I made an effort to find out.
Care leavers, Victoria

4.5. Employment

Although not everyone wanted to work into older age, the concept of retiring at a particular age was largely absent. People tended to move this date in line with both their financial needs and their personal preferences for the non-financial aspects of working.

I feel like I'll just decide on the go.
Aged 18-30, metro, New South Wales

A minority of people were clear that they would need to continue working beyond their sixties and seventies because of their financial position.

I plan on going out in a pine box. I fully expect that's going to be the case for my generation ... that's not what I prefer to do, that's what I think will happen. I know my super is quite good for someone my age, so hopefully I can retire, but with the retirement age being pushed back and back and back and the cost of living going up and up and up, I don't see myself retiring till my eighties or maybe my nineties.
Gay, Lesbian and Bisexual communities, metro, Western Australia

Some of these individuals spoke about not making sufficient super contributions earlier in their lives through choice, or because they weren't working, and they were keen to work as long as they can to maximise the funds available to them in their later years. Other participants appeared to have made more provision for their older age but were still aware that they would need to supplement their super in order to live more comfortably.

I just hope for the best and to keep on working for as long as I can. I don't think I'll be 100% retiring, I'll still be doing some cash work, or part-time work.
Gay, Lesbian and Bisexual communities, metro, Western Australia

The advantages of working longer is you get to save more money towards superannuation.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

(I would prefer to) retire but I've still got to do a bit of work here and there. When I'm in Sydney I enjoy doing that work, but I would rather be travelling.
Care leavers, New South Wales

Those people who were still hoping to work beyond their mid-fifties or sixties, were fearful of the narrowing of the employment opportunities that remained available to them as they aged, and the negative assumptions both employers and workmates may make about them because of their older age.

I don't feel I'll be retiring at 60, I don't foresee a long period of time not working (because of needing an income)] but will employers still want me?

Aged 31-55, metro, Victoria

They don't hire older people, but they should realise, they're more reliable, work better, are more knowledgeable. But on the other hand, young people need jobs.

Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

At 56 years old I don't know who would employ me, who would give me any work?

Intersex and Transgender people, New South Wales

Some participants outlined the impact of employment insecurity on future planning for their older age. Working in an industry that functioned mainly on short-term contracts, without any job security, made it difficult to make longer-term financial plans. People without ongoing and secure work could not buy a house or achieve the financial security that they wanted.

I'm on a contract role ... I've no idea of what my career path will be, where I'll end up or how much money I'll be making over the years. And in (the) digital (sector) and you want a job and you're 40 or above it can get a bit difficult, everyone wants to hire the 20-year old ... the redundancies, it's so up and down.

Intersex and Transgender people, New South Wales

4.5.1. Benefits of work

There is a clear understanding across all groups of participants about the multiple benefits of work. Aside from greater financial security, people spoke about wishing to continue working for longer for a variety of reasons: having a purpose, doing something of interest and social interaction.

Good relationships and having friends, pursuing things I'm interested in. I think I'm going to want to work as long as I can. It gives me structure and purpose ... it's got so many good benefits. I don't think I'll want to stop working at all.

Intersex and Transgender people, New South Wales

Many people across all age and population groups spontaneously raised the mental health benefits of working. They valued the purpose it gave each day, and the motivation it gave them to get up, out of the house and interact with the rest of society. They understood that keeping their minds alive and active was fundamental to their wellbeing, and work was seen as an effective way of achieving this. The social interactions experienced at work were also a valuable antidote to the potential isolation and loneliness of their older years.

I think I'd like to keep working, well I might just cut my days down a bit. But I think it's so much more refreshing ... going into work even and interacting with everyone ... Mum is looking for work and she is like, what is she going to do with seven days a week at home? So, I'd like to keep working, even if it was just one day a week. ... just to get out and communicate with other people.

Aged 18-30, metro, New South Wales

Going back to what the benefits are of working longer, I would say that you're mentally stimulated and that helps you keep fit and healthy.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

If you don't have a purpose and stay active ... if you retire and do nothing, they reckon that kills you quicker.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

I really only go to work for the social activity ... it gives me a reason to get up in the morning.

Aged 70+, metro, Northern Territory

For men, it stops them being depressed ... I know they think of suiciding as they think their lives are over when their working life's over.

Aged 70+, regional, Western Australia

We worked since we were 15 ... so retiring is not about age for us. It's about keeping our wellbeing.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Some associated the cessation of work with the termination of their identity and self-sufficiency. They felt that if they stopped working, it would spell the end.

I think that's a big factor for a lot of older people ... take the job away from 'em and they've got nothing, they've got no hobbies or interest, they sit at home and in a few years, they die.

Veterans, metro, New South Wales

Self-sufficiency (is a benefit of working longer), if you can still do it. It will mean you're less reliant. If you can support yourself as long as you can, do it.

Aged 31-55, metro, Western Australia

A minority of those aged over 55 discussed their passion for their work, and how it gave them a sense of purpose and fulfilment. These individuals were keen to continue working as long as they were able.

I can't think of myself as someone who'll stop working, I really like what I do ... it's a really core part of who I am ... if I ever couldn't do those things, I'd feel really crappy ... I don't get fulfilled by just interacting with peers or even my family.

Gay, Lesbian and Bisexual communities, metro, New South Wales

(I'll stop) when I'm no longer physically or mentally capable ... or when the boss says, 'Hey mate'. It keeps me going, it's good for me.

Aged 56-70, regional, New South Wales

I want to keep working till the day I die because I love what I do.

Aged 56-70, metro, Western Australia

I'm in my late sixties, I still want to work a little bit so that I can supplement my income, but when you get to that stage, you're working for fun not because you really have to.

Gay, Lesbian and Bisexual communities, metro, Western Australia

Never, if have to I'll die there, I love it, it's an interest, it's a big thing to take away from people if they've done it all their life.

Aged 70+, regional, Western Australia

4.5.2. Retirement

Only a minority of people mentioned feeling impatient to stop working.

I want to retire early. I keep reading articles about people who planned to retire at 40 or 45. I don't necessarily gain all of my worth through work. I'd feel plenty happy to retire and be a painter, sell the odd canvas, what a life ... if we can't enjoy it because we're 70 and not able physically to enjoy (retirement), why not take it earlier. I wasn't put on this earth just to work.

Gay, Lesbian and Bisexual communities, metro, New South Wales

I am so looking forward to having free time to do things I want to do ... it annoys me I've got to wait another seven years.

Aged 56-70, metro, Western Australia

Others reflected on their parents' experience of retirement. They observed that their parents' physical and mental health had deteriorated rapidly once they stopped work, and this motivated them to manage their retirement differently. Many spoke of transitioning more slowly to retirement, by reducing their working hours to a part-time role or supplementing their daily life with volunteering work, so that they had an alternative motivation to leave the house each day.

I can't just go cold turkey five days a week ... I'll look around and try somethings that I haven't done ... I became an exam supervisor at Sydney University, which is dead easy, meet lots of younger people, meet some interesting people there. It was good, it was the year or two after I finished work and now I'm working full-time four weeks a year and having a holiday 48 weeks a year. I really liked that for a while.

Aged 70+, metro, New South Wales

I'd hate to work my whole life and just stop ... and I think a lot of people deteriorate when they just stop. But I'd like to go to four days, three days.

Gay, Lesbian and Bisexual communities, metro, New South Wales

It gives you purpose in life. I stopped too soon ... all of a sudden work vanishes, you have this energy and need somehow to use it.

Aged 56-70, regional, New South Wales

I'd be happy to work to 70, if part time, think I'd like a purpose (through work). I'd like to slowly dilute my hours until part time then retire into a different lifestyle.

Aged 31-55, metro, Victoria

Some people they retire and they're dead in three months because in Perth, there's nothing to do.

Aged 31-55, metro, Western Australia

Some discussed changing the nature of their work to reflect their changing position. This might mean transitioning to a less physically demanding job for some or moving from a corporate full-time role to a part-time advisory role. Others spoke about not being able to continue working because of the health consequences of a lifetime in a physically demanding job.

I've been doing physical work for almost 50 years, but I don't want to do it anymore ... but if someone's an accountant, sitting at a desk all these years, he's not physically exhausted.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

4.6. Housing

When considering where they want to be living in their older years, the vast majority, irrespective of their age, wish to remain in their own home, living independently for as long as possible. For some, this meant moving to be nearer to children and for others, this meant downsizing to a smaller, more practical property and/or to free-up capital to support their income. The aim of continuing to live in their own home environment was consistent across the breadth of different audiences in this research – even among those aged under 30 who found it particularly difficult to imagine and comment on where they would be living in older age.

What will make me happy? To stay in my house till I die.
Aged 56-70, metro, Western Australia

For many, this desire to remain in their own home was about familiarity with their environment, both within their home and within their local neighbourhood. They spoke of wanting to maintain the living space as they had enjoyed it over the previous years and the comfort of their known surroundings. The idea of being moved to a strange and unfamiliar environment, such as an aged care facility, which would not be set out and decorated as they would choose, was an unwelcome change.

If I could stay in my own home, I would, because it would be safe there. It'd be scary moving out after 30 years.
Aged 70+, metro, Northern Territory

To live in a community where everyone knows everybody else and you look out for everybody ... that would be the ideal.
Aged 70+, metro, Northern Territory

If I'm able to stay in the same house, it'll be easy to get a ramp in there. We've already got rails because of Mum ... some kind of affordable housing that's got good access for somebody who can't climb stairs. And maybe close to the shops so I can get out into the community. I'd like to stay in the same area but I don't think that'll happen. I find moving from one area to another is very disorientating.
People who are homeless or at risk of homelessness, Victoria

Another key reason people want to remain in their own home is to retain independence and freedom of choice in how they live – for example, what they eat, what time they wake each morning, and choosing when and where to go each day.

The other thing for me is freedom. If I want to get up at 5am and go for a walk I want to be able to do it, I want to have breakfast when I want to have breakfast ... I don't want to be told everything.
Aged 56-70, metro, Western Australia

People discussed the need to move to a practical, easy to manage property that took consideration of any mobility issues they might develop in their later years, i.e. a single level property, with low maintenance.

Probably when I was in my sixties, I thought about the stairs here, I've lived here for 47 years ... and I haven't got a walk-in shower, and I've tried to get that put in, but they won't do it ... the only thing they'll do is a different location and I think that'll kill me.

Care leavers, New South Wales

Ideally single level. The house I live in at the moment is lovely but has tiled floors and tiled stairs and I've fallen so many times ... and somewhere near amenities so it's not too far to go to the shops.

Intersex and Transgender people, New South Wales

Irrespective of the setting, many older people spoke of wishing to live in a multi-generational environment. They saw their own home, where they had freedom to come and go from the local neighbourhood, as much better at meeting this need than an aged care facility where they would only be with older people. For many, the lack of younger generations in an aged care environment contributes to its lack vibrancy and interest.

The only thing is about retirement villages is that they're all old people, you want a mix of ages.

Aged 70+, metro, Northern Territory

This interest in a multi-generational environment does not mean that older people want to live with their children. They are interested in living in a setting where they mix with the breadth of age groups, without the perceived restriction and potential burden of living with one of their children. For a few, a granny flat is an appealing compromise.

Even at our age, it would be nice if you could live sometimes with your children, have a granny flat to have access to the grandchildren, but that's not in their minds. If you're financially in need, which we're not, they'll help you but they don't want you in their home.

Financially and socially disadvantaged, aged 70+, metro, Victoria

I love my independence. If I lived with my children, I would go nuts, but I like to feel wanted.

Financially and socially disadvantaged, aged 70+, metro, Victoria

In addition to a multi-generational setting, many of those aged over 55 were keen to live in a location where they had ready access to local facilities, such as a GP surgery, a dentist, a shopping centre, access to community services and ideally, access to broader choices such as cinema, theatre and pubs.

Irrespective of age, people also discussed wanting to live in a community of like-minded individuals, where their values and outlook on life was shared.

My parents, their world has got smaller, but I'd like to live with friends, communal living.

Gay, Lesbian and Bisexual communities, metro, Victoria

A few individuals among those aged 70 and older were in the process of planning a move out of their family home to a new, smaller property. For some this was to live in a preferred environment or

climate, but more frequently it was motivated to be near to children and grandchildren. People spoke about giving support to their working children by helping raise their grandchildren, and simultaneously receiving care and support from their children as they aged.

We chose to move to Brisbane because we think we've got six to seven grandparenting years left ... we've already made friends through our grandkids schools ... we made the decision to move there for our grandchildren and our own long term health because accommodation is cheaper, we'll have more money to play with, and we can grow old together.

Aged 70+, metro, New South Wales

I'm going to look forward to it when I move up to the Gold Coast. That's the long-held dream of living somewhere where I can have a peaceful life ... I want to see sun, surf and sea.

Parents separated from their children by forced adoption or removal, New South Wales

Those making this type of retirement move were conscious of the challenge of making new friends and establishing a new social network once they were settled into their new property.

As human beings, we need to remain connected to the people we're used to being with ... My mother's transition to (location) ... that was not a good move for them, then they were isolated, sure they made new friends, but not as good as the one's they had down here.

Aged 70+, metro, New South Wales

We're going to find that a struggle, losing our connection with friends of over 50 years. We've bought a place on a single level ... we'll have enough money to come back to Sydney on a regular basis ... we want to remain connected.

Aged 70+, metro, New South Wales

These older people were conscious of some other challenges when making this retirement move. While a move out of a capital city immediately provided older people with funds, it potentially also distanced them from medical care that they might need in the future.

The in-laws went to Forster ... they'd always gone there for holidays ... they had a good life there because other members of their family moved up. But when they had to move back to Sydney for medical care, they were locked out ... instead of Peakhurst where they grew up and raised their family, they could only afford Wentworthville ... that sent them downhill, he got dementia, and when she got dementia, he died of a broken heart.

Aged 70+, metro, New South Wales

When contemplating how they would like to live as older people, some thought if a move to an aged care facility is likely, or inevitable, it was preferable if they were proactive and able to make these choices themselves, rather than being overtaken by events, in which case their children were likely to be making the key decisions. This scenario became even worse for those without family support.

The trap is leaving it too late ... if you're physically impaired and no local family, you might end up dependent on people who don't have your best interests at heart.

Aged 70+, metro, Victoria

A minority spontaneously mentioned they thought an early move to an aged care facility could improve the experience rather than waiting until circumstances necessitate a move.

We should have put (Mum) in a nursing home sooner. In the end I had to force her ... she was lying to us about eating, (despite being) financially comfortable. Pride was a huge thing.
Gay, Lesbian and Bisexual communities, metro, Victoria

I know of people who've moved into retirement villages or care homes when they're fit and well and healthy, and they often say that it's better to do it that way than when you're forced to.
Aged 56-70, metro, Western Australia

A few of the people were contemplating the idea of moving abroad to live more cost-effectively, and, if needs be, receive cheaper care and support. These people expected to be living on lower incomes during older age and some were without family ties.

As someone without immediate family, it's something I've entertained. Why be in rainy Melbourne when I could be in a warmer place, cheaper ... it's definitely an option, in my plans.
Gay, Lesbian and Bisexual communities, metro, Victoria

I might do a 'Marigold Hotel' and head off to India!
Aged 56-70, metro, Western Australia

4.6.1. Housing stability and security

There was some discussion among those who were not homeowners about the challenges of paying private rent, and the time and difficulty of accessing social housing. Some thought their difficulty being accepted as tenants was due to their low income and reliance on the pension.

Those in renting have less certainty about their housing, less control, are more vulnerable, less able to remain independent. (There's) government responsibility to help here.
Aged 70+, metro, New South Wales

Person A: I pay \$82 a week rent for a beautiful two-bedroom unit.

Person B: I pay \$650 a fortnight!

Person A: I don't know how people exist. My pension is \$800 something a fortnight. I couldn't (live) if I had to pay full rent. No waiting list, if you have to wait a few weeks or months, but 15 years to get a house or a unit, public housing ... it's crazy ... where we are, someone has to die before a vacancy. It's wrong. I know old people who are sleeping on the street in Darwin ... they call them 'long grass' here, because they sleep in the grass. It's not just black fellas.

Aged 70+, metro, Northern Territory

Recently I've been trying to pay off my mortgage a bit quicker. I see my mum struggle, she doesn't own a home. I want to make sure I'm comfortable (when I reach that age).
Gay, Lesbian and Bisexual communities, metro, Victoria

Everyone plans to be a homeowner, for household security. Sometimes it happens and sometimes it doesn't. But that's why a lot of people come to the country.
Culturally and linguistically diverse communities, aged 56-70, regional, Victoria

People who don't own their own unit, pay rent, they find it so costly to keep a roof over their own heads.

Aged 70+, regional, Western Australia

4.7. Community and social engagement

While health and finances were seen as the top priorities in later life, there was an understanding across the breadth of age groups that a healthy level of social engagement was key to a good older age. In a variety of ways, people were able to articulate the range of benefits, from maintaining mobility, to mental stimulation, to protecting against the negative impact of loneliness and to one's general enjoyment of life.

It's really important when you get older, that sense of community. You're not relying on your children. They're not going to be there for me every day. They have their own lives.

Financially and socially disadvantaged, aged 70+, metro, Victoria

I think it's important because that's what will help you live longer or enjoy your quality of life ... if you're so lonely, I don't think you would last long.

Aged 31-55, metro, New South Wales

Friday night on the train to Mandurah, (the older people are) so funny. They're all tanked up, maybe two glasses of wine and having a laugh.

Gay, Lesbian and Bisexual communities, metro, Western Australia

People are still dying and months later they find out ... the neighbours don't know each other ... loneliness.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

For me, it would just be making sure you had something to do ... to keep you occupied and fill the rest of the things that you miss.

Aged 18-30, metro, Queensland

Dance and shake the leg with me and my wife.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

To keep moving, keep going. Not to just sit there ... I can't walk too far these days. But I go to the garden group, painting, ten-pin bowling ... we have BBQs.

Care leavers, New South Wales

Remaining busy socially and mentally was a particularly dominant theme with participants aged over 55. This manifested in many ways such as arranging activities with friends, family life across the generations, and continuing to engage with the 'outside' world through part-time work or volunteering. Common to all of these was the importance of having a purpose to leave the house and interact with others each day. Through such activities they were better able to enjoy life, maintain a positive outlook and avoid feeling 'old'.

Tomorrow I've got a group of friends aged 74 to 84 going up to Newcastle just to ride on that new train thing up there, have a few beers and come home. Have lunch. Tell the 84-year old that he's old and he'll get cranky with you. But another friend of ours, he's just in his

eighties, he dawdles around the place, can't remember a thing, and he's old.

Aged 70+, metro, New South Wales

Once you stop work you slow down a bit, but you still have the choice of what to do. You could sit at home but get out with the kids and do all sorts of things. You have to get out or you go crazy. I look after people's pets, people's kids, it's something to do, I never get bored.

Aged 70+, metro, Northern Territory

What keeps you young is your children and grandchildren ... they don't see you as old, so you don't feel old.

Aged 70+, metro, New South Wales

What you going to do all day long – sit around and look at each other? You still must have a life and communicate with other people to give your life longevity. If you sit in your home your life becomes shorter.

Financially and socially disadvantaged people, aged 56-70, regionally, Western Australia

Mental stimulation keeps dementia and everything at bay.

Aged 56-70, metro, Queensland

Keep challenging your brain, it keeps making new synapses or something, it keeps you going. That's what the Mah-jong's for – it keeps you going.

Veterans, metro, Western Australia

Older participants, particularly those aged over 70, were aware of the potential distress of loneliness and that by actively engaging in life, they were defending themselves from the negative impact of loneliness.

On your own for a few days and you can easily feel down.

Aged 70+, metro, New South Wales

Some reflected on lessons learnt from their parents and grandparents, and the different levels of social interaction witnessed. They shared examples of those who were more socially active and the benefits that came with this. Others described times when they had watched family members deteriorate at a more rapid pace when they had little engagement with others or with the wider community.

I've got one grandmother ... not outgoing, even with us grandchildren, not really interested, doesn't really know what's happening in the world, doesn't really care – just in her own room, behind closed doors. Then I've got my other grandparents, who are still outgoing, every charity thing possible, they're travelling all the time, they're constantly meeting new people and interacting with us ... I see that and I wanna be just like that ... The one who's with it – she does volunteering at the hospital ... she has lots of people. Whereas, my other Nan, she doesn't want to do that, so I feel like she's losing it quicker ... use it or lose it.

Aged 18-30, metro, New South Wales

My grandmother is 90 and her sister had very few social connections and after her husband passed away, next to none. And she passed away in a far less able state. My grandma is extremely social, she's been single since she was 40, she does all these extra-curricular

activities, calls people every day, and you just see the benefits. ... to me, it seems very key.
Aged 31-55, metro, New South Wales

4.7.1. Family

For a significant proportion of people, the priority for their older years is maintaining functioning, positive relationships with family members, and for some this means being geographically close to those family members. They want to continue their role as active parents and grandparents, irrespective of their health or location. They are seeking balance between supporting children and grandchildren, by helping care or babysit, whilst ensuring they have sufficient freedom to pursue their own lives.

Society's completely changed. We never had the luxury of grandparents, and we had five kids, I was the breadwinner, my wife ran the house. That's how we battled through ... but now, if I wasn't around to babysit, I don't know what my kids would do. I spend more time with my grandkids than I ever spent with my kids.

Aged 70+, metro, New South Wales

I try to maintain good connections with my daughters and grandkids. The best way to get benefit from life is to be involved with them as much as I can ... that to me is very, very important. That gives me a sense of achievement that they're all on track.

Aged 56-70, regional, New South Wales

We'll probably be looking after the grandchildren more than our children will be looking after us.

Financially and socially disadvantaged people, aged 56-70, regional, WA

Cheap childminding. I've love to see how much grandparents are worth in Australia ... because families can't afford to have time off work.

Aged 56-70, metro, Queensland

People shared how they had observed the joy that family brings to older people.

At family gatherings, when we all get together, I just see how happy it makes them to have us all around.

Aged 18-30, regional, Victoria

Grandchildren ... they light up your life.

Aged 70+, metro, Victoria

Older people whose families had moved away felt a sadness that family were not a local, regular part of their day-to-day life. Some felt concerned that their families did not make more effort to see them.

Having caring family around you ... a lot of Australian families are away from their immediate family. Your children seem to grow up, marry, find jobs and go anywhere, a lot of them are not in Australia, they're overseas. A system where elderly parents could visit at not these exorbitant rates. I can fly to Adelaide and return, cheaper than I can get a ticket to visit my daughter up in the Pilbara.

Aged 70+, regional, Western Australia

The only time I get to see my family is when we go to Perth because they never come here. Our family can fly to England, Greece but they never fly here.
Aged 70+, regional, Western Australia

In this day and age, family are all over the world.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

The majority of people want an ongoing relationship with their family, but do not wish to live with them. This may be despite having had a positive experience of older family members living with them when they were children. The reticence to live with family members relates to the very strong desire to retain independence and control over their life and living environment and avoid becoming a burden on their children. Some felt so strongly against this that they admitted preferring to live in an aged care facility. In part, older people reflected on their own experiences as carers and did not want their children to have to undergo the same experience.

It's not a good atmosphere, too many clashes 'cos you've got two different generations, you don't agree on the same thing. It doesn't work ... family's everything though.
Veterans, metro, New South Wales

I don't want to do that to my kids. I don't want to stop their life. I don't want to be, 'Oh, gotta go home, I can't go out to dinner, mum needs to be put to bed, mum needs a nappy change'.
Financially and socially disadvantaged, aged 31-55, regional New South Wales

I wouldn't mind if I lived near family, but not with them ... that's like being in purgatory.
Aged 70+, metro, Northern Territory

I would rather go to a home than be a burden on my kids.
Aged 31-55, metro, Victoria

I've never liked the thought of living in a retirement village or nursing home and would want to live on my own in my own home or with my family but when I think of the reality of it, when you do become dependent... I thought my worst nightmare is being in a nursing home or retirement village but then my worst nightmare is also being dependent on my children. I might go live with my girlfriends.
Aged 31-55, metro, Western Australia

I don't think they should be in the family structure. You are asking that person to put their time on hold for this person. This is a Western society and we don't have these traditions being handed down. If you want to implement that I think there'll be more violence on the older person.
Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

For others, they welcomed the involvement of family in their care during their later years but wanted to ensure that external support is involved so that children do not feel burdened and are not involved in personal care. The vast majority of people find the prospect of their children undertaking personal care as a significant loss of dignity for them.

No, you don't want to be cared for by family ... that's when the word burden comes in ... I don't want to be dependent on them ... We don't want the last years of our relationship with

our children to be marred with them having to clean up after us and all that yucky stuff.
Aged 56-70, metro, Western Australia

We've decided ... have family and helpers combined. We've got a big family ... and we've all agreed, that we will stay where we want to stay and they'll get in help, till the end.
Aged 56-70, metro, Western Australia

I don't want (kids) to feel obligated to take care of me ... I don't believe in the idea that your relatives are bound, obligated to you ... you have to treat them with respect and love, but not this expectation that I don't really believe in.
Intersex and Transgender people, New South Wales

Some people commented that they did not have children or family that would be involved in their lives as older people, and this presented a greater responsibility for them to plan and prepare for their later years. It also raised fears as to who would safeguard their care when they were very old.

Well, see, I don't have any kids, so I have to think, 'Who's gonna take care of me?' ... so, I worry about financial security as well, making sure I have enough money ... I gotta try and plan to be somewhere, like a retirement village.
Aged 31-55, metro, New South Wales

I don't want children, I don't have a partner. How will I be treated in aged care? (Will I have to settle) for the bare minimum?
Gay, Lesbian and Bisexual communities, metro, Victoria

4.7.2. Friends

Beyond the immediate realm of family, older people are keen to be able to spend time with friends, and see this as a very positive, enriching experience that will bring them happiness, mental stimulation and ensure they are not lonely.

He's in his mid to late seventies, he has been one of the most positive role models for post-retirement ... he's taken up woodworking, he's joined the MG club, he's heavily involved with the grandchildren, he's with the bush regeneration group ... It is about filling your day with meaningful activities that gives you interaction with different communities.
Aged 56-70, metro, Western Australia

For some, these are lifelong friends and friendships that are tantamount to family, described by some as 'chosen families'. Maintaining these friendships is essential and a vital consideration in any potential relocation, whether as a process of downsizing or entering an aged care facility. There is a strong appreciation of the importance of these relationships and this forms a further aspect of why most people do not wish to live in an aged care facility.

Yes, like-minded people ... you can get distracted... shared interests and do things together ... it would keep me healthy and young.
Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Not having kids, I think about that, I won't have my kids around - no one to look after me, so living close to friends that I grew up with (will be important).
Aged 31-55, metro, Victoria

Friends are your lifeline.

Aged 70+, regional, Western Australia

Definitely my friends, as well as my family. Sometimes I think your friends can be closer than your family.

Aged 18-30, metro, Queensland

4.7.3. Volunteering

A large number of participants aged over 55 were already actively involved in volunteering. Some people were combining this with part-time work as they transitioned from their working life to retirement. Those volunteering were very positive about the benefits gained from their experiences. They appreciated the companionship and social interaction of being part of the volunteering organisation and mixing with the other volunteers and people they were helping. Volunteers felt they benefited from the mental stimulation and challenges of the new situation. Many also commented that their volunteering sometimes brought them into contact with younger people, which they enjoyed and thought helped to keep them feeling young.

I don't want to be sitting around, you can't be holidaying all the time, so you'd have to do something. I'd still want to be doing something, whether it's working or helping.

Gay, Lesbian and Bisexual communities, metro, New South Wales

We joined the Lions Club when we moved to Geraldton in 2001 ... mainly to help my husband have an outlook on life.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

I enjoy it! You meet people ... there's some young people, there's people my age, you interact. There's a bit of a social aspect to it.

Veterans, metro, Western Australia

I'd like to still be part of the community and do something worthwhile, but I certainly look forward to the freedom to pursue the activities that I enjoy, like art and music. Wouldn't mind doing some volunteering without restriction on the kind of time that you have at my age.

People who are homeless or at risk of homelessness, Victoria

In addition to these personal benefits, most also gained considerable satisfaction from a sense of 'giving back' to their communities.

If you look at charity organisations and volunteers, they're mostly run by older people. They set a good example and set the culture.

Gay, Lesbian and Bisexual communities, metro, Western Australia

You'll find people like us all over the town contributing, making sure this town stays a vibrant and lovely place to be ... You get far more back, there's a selfish angle to it.

Aged 70+, regional, Western Australia

While younger people were much less likely to be currently volunteering, many were open to the idea and a minority had already considered it as a positive aspect of older age.

Mum's involved in a charity, mixing with lots of different people. If I can contribute ... that'd be great, giving back and being part of something.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Not far from where I live ... I see a group of older people there once a week planting trees, weeding, I'd absolutely love to do that... contribute back ... it's doing something that is a long-term contribution.

Aged 31-55, metro, New South Wales

I enjoy work. I'm probably the kind of person that if wasn't working, I'd be volunteering. But to be blunt I haven't really thought about it.

Gay, Lesbian and Bisexual communities, metro, New South Wales

5. Aboriginal and Torres Strait Islander communities

This section highlights the distinct views of Aboriginal and Torres Strait Islander participants. This includes those taking part in the six dedicated groups for Aboriginal and Torres Strait Islander communities and also Aboriginal and/or Torres Strait Islander participants who attended groups with the wider population.

5.1. Summary

Respect and care for Elders is an important and distinct aspect of Aboriginal and/or Torres Strait Islander communities, which is markedly different from the wider Australian population and a source of pride for Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander people tended to be aware of their community's shorter life expectancy, which impacted on their understanding of when people were considered old. They were more likely than others to discuss ways to maintain their health in older age, specifically talking about quitting, or limiting, smoking and drinking.

People had an expectation of family care and support in older age which did not always match the reality of older Aboriginal and Torres Strait Islander people's experience. They believed they were better cared for than other communities, but often felt that the younger generation did not make sufficient time to spend with them, were too busy working and did not always show them the level of respect warranted. The community expectations about caring for Elders is sometimes acknowledged as a burden but was one that many were happy to undertake for their direct family. Some older people spoke of wishing to live communally to ward against potential lack of support and loneliness.

Aboriginal and Torres Strait Islander people were marginally more likely to look forward to older age as a time when they would be revered within their community, enjoying their role as a source of wisdom and teacher of Aboriginal culture. Younger Aboriginal and Torres Strait Islander people spoke of valuing time they had to spend with Elders. They enjoyed the opportunity for a yarn, hearing traditional stories and learning traditional culture. This was an important aspect for these younger people of understanding who they were and where they were from.

As in the wider population, Aboriginal and Torres Strait Islander people aspire to live independently in their older age. This aspiration is supported by their higher expectations of family support. However, irrespective of their situation, the paramount concern is that they are cared for by those who understand and respect Aboriginal culture, and that they are in a culturally safe environment, be that their own home or an aged care facility. Most aged care facilities were seen as being staffed by people who were not knowledgeable about Aboriginal culture and unable to speak traditional languages, as such, would not understand key considerations such as the number of family who would want to visit, how long they might want to stay, and that personal care should only be undertaken by someone of the same gender.

As with other communities, people were broadly aware of the costs associated with aged care and were concerned that it may be beyond the family's budget, and that very little would be left from an individual's pension to cover any other day-to-day expenses.

Part of their planning for older age was consideration of either living on Country or ensuring they were buried on Country. The associated expense of these aims was a marked concern for older people.

5.2. Community views of older people

Respect and care

Aboriginal and/or Torres Strait Islander participants had a distinct perception of ageing, older people, and how they should be cared for. They were far more likely to actively articulate the need to respect older people. This aspect of behaviour within their communities was highlighted with real pride and was seen as a significant difference from the way in which the rest of Australian society treats older people.

I'm lucky to be Aboriginal, to have those cultural connections to know someone will look after me and hopefully not put me in a home.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

As I was growing up, I was made to respect older people. Just respect.

Aged 31-55, metro, New South Wales

You pay more respect to old people, this is our way, the Indigenous way. A different way of thinking.

Aged 70+, metro, Northern Territory

I've had good treatment in Western Australia, I think it's the Aboriginal culture of respecting your elders.

Aged 70+, regional, Western Australia

Aboriginal people, you wouldn't really see (older people) as a burden. The Elders, you respect (them).

Aboriginal and/or Torres Strait Islander communities, younger, New South Wales

For Aboriginal and/or Torres Strait Islander people, a key positive aspect of ageing is being an Elder, a person who is afforded respect and recognition for knowledge and responsibility within your community. This was something participants looked forward to as an appealing aspect of ageing. Across the age groups and the country there appears to be an implicit intergenerational social pact with younger people taking care of older people within their community as part of life.

They look after you, you look after them.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Many Aboriginal and/or Torres Strait Islander participants were very aware that there is a shorter life expectancy for their community. This impacted on their perception of being 'old' and for many this meant that 'old' started at 50 or 60.

I say 60 because... my family don't live much longer than that. Both my parents were gone by 60. That's about average for Aboriginal people.

Aged 31-55, metro, New South Wales

A lot of our old people didn't even get old. They died before that ... if you got to be old, then it's a real privilege for our people ... old was 56.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Both my kids' fathers died at a young age, so I worry about still being here for my boys.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

60 plus because a lot of our elders don't live to a ripe old age.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Overall, Aboriginal and/or Torres Strait Islander groups described their Elders with high esteem, marking them out as revered members of the community from whom there is much to learn. Older members of the community would provide guidance and knowledge to younger community members. This largely relates to learning about Aboriginal history and culture, learning Aboriginal ways and caring for country. This knowledge passed from Elders to younger members of the community was considered highly valuable, and the time spent with Elders in this way was prized by most younger participants.

I love running into the Elders. Having a yarn and stuff. It kind of soothes my soul ... you can yarn to them for hours.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

They are regarded as the highest people in our family ... bowing down to them, whatever they want.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

They lived with us, so they were always there until they passed away. We don't put our people in old people homes, we look after them. It was good, 'cos they'd tell us stories, take us out, out in the bush.

Aged 31-55, metro, New South Wales

Older people can tell you who your family are.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

Stand out stories from generation to generation.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

I contribute in teaching the younger generation about our culture. Their paintings and stuff that I make. Boomerangs, clapsticks and paintings all the time and didgeridoos ... use them in ceremonies and dances.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

Old people like to talk about their past and how they were brought up ... we should really keep them closer and tell our little ones from the younger generation.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

They're an Elder, their role is to teach us ... we still have our culture in our family because of our Elders. My daughter knows bush medicine because of our Elders.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Grandma taught me to be proud of who I am and where I come from.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Participants highlighted that this respect was extended beyond Elders in one's immediate family to all Elders you met.

Every day, you treat them the way you'd want your grandparents to be treated.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

However, for some, respect was also something that needed to be earned; it was not an automatic consequence of age.

There are some Elders that I don't have time for ... my way of thinking is they need to earn that respect too.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Among people who were supporting Elders, or had done so, there was common recognition that caring for older people was often demanding, could be a burden but was always accepted as part of being a member of your community.

There is a burden if you're looking after an older person ... it is a burden that I'm happy to do because of what I've been taught ... I do get reward out of that.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

I used to live with my grandparents ... had to take my grandpa to the toilet, help him with his medication ... bit hard, (but I) just helped.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

I had to look after my brother ... he had emphysema real bad and he was on an oxygen tank. I took good care of him right in my own house right up until he passed one morning.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

Similar to the broader Australian population, the obligation to care did not necessarily extend beyond one's own family.

You have an obligation to your grandmother but not the old person on the street.

Aboriginal and/or Torres Strait Islander communities, younger, New South Wales

Some participants thought there has been negative influence from the broader Australian population and a change in the degree of respect afforded to Elders, and some felt that they were not regarded with as high a level of respect as in the past. This point was raised by other participants – particularly among veterans – but it was most strongly felt among Aboriginal and/or Torres Strait Islander participants.

White, black, yellow all these kids these days, even the adults, are disrespectful to the Elders. Elders are meant to come first. No-one does this these days.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

The perceived reduction in respect for older people was seen as manifesting in a number of ways. The most notable was in day-to-day interactions and communications between the generations, with older people commenting on tone, language and swearing used by younger people. But it was also seen as contributing to more significant problems, such as abuse and neglect.

Seeing the younger mob just destroying their lives and they don't want to learn and be strong ... young kids are turning to all this violence, drugs, alcohol, homeless. Parents are not there to even help the children.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

As an older person, I don't want to get old in a community where you're not respected ... you're in danger of being neglected, abused, robbed. Where we are now with our Indigenous families are bashing our old people for money to buy the next whatever.
Aboriginal and/or Torres Strait Islander communities, older, Western Australia

5.3. Community understanding and perceptions of aged care

Several of the Aboriginal and/or Torres Strait Islander participants had worked in an aged care facility. This experience, combined with their expectations around caring for Elders within their community, meant these participants were very aware of the need for family to remain actively involved in care for an Elder. They valued family involvement in the care of Elders and were very proud that this was an accepted and encouraged cultural norm within their community.

If you're not there to keep the people accountable for taking care with your family, you've failed them. Interact with them more, be there, make sure you can pull the nurses into gear ... dying on your own, that's not our culture ... because now our young people have something better to do, so they say.
Aboriginal and/or Torres Strait Islander communities, older, Western Australia

I worked in aged care. You wash 'em, you clean 'em, you feed 'em, daily activities. I know the outcome when you don't have someone there to care for you ... I wouldn't want to be in that position. I was only 18, it was a rude awakening.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

They're convenient, someone to look after somebody when somebody else doesn't want to. You're never going to find someone who'll love your grandparents the way you do ... basically it's a place they go to die.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Among those aware of the potential costs associated with aged care, there was concern that it was beyond the financial resources of their family. There was simultaneously greater concern regarding the cost and an expectation of government support. Due to institutional, historic and current discrimination, Aboriginal and/or Torres Strait Islander communities have increased financial and social disadvantage, when compared to their non-Indigenous counterparts. Many were concerned

that services were paid for through the pension, and that this meant very little financial support would be available for day-to-day living.

'Cos my family member won't have any money ... No family members going to bring up 10 grand.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

I don't know if we have to pay to get in there. Why do we have to pay if they take it out of your Centrelink money?

Aboriginal and/or Torres Strait Islander communities, older, Queensland

When they put (female friend) in there the first thing they wanted to know is does she have super?

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Cultural safety and respect in residential aged care facilities

There was strong interest in having access to aged care facilities that could provide a culturally safe space and, ideally, are located on the older person's Country.¹ Cultural safety could be done in different ways. Like all participants there were diverse and at times conflicting views about what kind of services would be good for communities. Some participants thought it would be good to have a choice, with a few facilities designed with Aboriginal and/or Torres Strait Islander people's cultural practices at the centre, or at least have an area that planned for and accommodated their needs.

There need to be more Aboriginal aged care places everywhere for our mob ... this is not about segregation, it's about being culturally appropriate.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Aboriginal people should have their own nursing homes. No-one understands our culture.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Knowledge and experience of visiting aged care facilities led many participants to be critical of current provision. In addition to the broader criticism raised by the wider population, Aboriginal and/or Torres Strait Islander people felt that aged care facilities did not understand their needs and culture. In particular, this related to issues of privacy and that it was not acceptable for the opposite sex to undertake personal care for a resident.

¹ *Cultural Safety* is defined in the National Aged Care Standards as: Care and services that are planned and delivered in a way that is spiritually, socially, emotionally and physically safe and respectful for consumers. Culturally safe care and services also ensure that a person's identity is respected so that who they are and what they need is not questioned or denied (<https://www.agedcarequality.gov.au/providers/standards/glossary>). *Country* is a term that has special meaning for Aboriginal and Torres Strait Islander people; it is more than a geographical location, it indicates a spiritual connection and evokes interlinked concepts of people, community, culture, nature, history, tradition, law and land. *On Country* is a term used to refer to Aboriginal and Torres Strait Islander people being physically present on, or near to, the *Country* that is of significance to each individual or their community.

In a mainstream nursing home an old woman, if it was a male nurse they could come in and change her. Whereas a black fella wouldn't even be in that room.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Whether we like it or not some of the people who are caring for our mob aren't culturally sensitised to the needs of our mob ... a man can't be in a room with a woman ... the nursing staff will do all sorts of stuff to them.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Further, the need for family to have access to an Elder, and not to be restrained by visiting times, or numbers of visitors allowed, was also raised. This was seen as an issue of cultural understanding and was fundamental to an Elder feeling well supported in aged care.

Our own leaders have gone to old people's home ... there's nobody there to sit down and yarn with them. Their grandchildren aren't around to run around and make noise where they can listen to them.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

We entrust our old people to the care of the state because we haven't got the financial ability to have them in a private facility. We can't guarantee adequate care for our people in the public system, we don't trust the public system ... there's no cultural sensitivity unless those aged care facilities allow us to come in and interact with our old people, and that's very rare.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Culturally safe aged care facilities would have Aboriginal and/or Torres Strait Islander staff, who would understand their culture, and specific needs such as including family and speaking traditional language.

Some of the older Indigenous people don't understand English ... that's why some of the old people fight with their nurse ... it's good to have some Indigenous workers ... some of (the Elders) are a long way from home ... (they) miss their languages and the people that speak it.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

It's the best facility, they've got their own Aboriginal section, they've their own little art groups. And all the workers are Aboriginal too.

Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Home care

There was a view that access to in-home support services was somewhat unsystematic – participants were not fully aware of exactly how to access these services.

A lot of it's by word of mouth from extended family members in the community ... so you'll tap into that service. Other than that, you'll be lucky to hear ... meanwhile there are others that miss the boat.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

5.4. Planning, expectations and concerns for own older age

When contemplating their older years, Aboriginal and/or Torres Strait Islander people talked about their shorter life expectancy, specific health concerns within their communities, and the importance of having access to support near to family and on Country.

I want to be in my community, on Country ... or the Country that I feel at peace with.
Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Family and community

While Aboriginal and/or Torres Strait Islander participants were mostly confident that family and community would be present in their older age to support them, there was discussion as to where they would want to live at this life stage. Some spoke of returning to Country, and the importance and happiness of being on Country during this stage of life.

(Older people) are in (aged care) that they don't want to be because their family don't want them ... (they) want to go back to their own Country.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

Stay home with my niece and live at her house, looking after great-grannies and going out bush and doing things out bush. Going fishing or camping.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

Some older people like to pass away in their old place, in their own Country and their own community. That's how we lose our culture when they start taking old people away from home.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

(Where would you want to live?) Out bush.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Others spoke of the need to be near both good health facilities and family and were realistic that these were both likely to be in larger towns or capital cities.

They all live in the city now, 'cos if you're in the country they don't have all the medications, like diabetes, only one hospital ... nearly all the family now live in Perth, not in the country where they used to be.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

Like many participants, Aboriginal and Torres Strait Islander communities' value ongoing interaction with family members, whether in an aged care facility or preferably in one's own home. They felt these relationships were critical in maintaining culture and also enhancing the quality of life of Elders and contributing to their resilience and health.

I have an older friend that's of a very old age. I'm glad he's not in an old people's home because it's better for their wellbeing being around family members I reckon.
Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

While there was an expectation to remain living independently – hopefully with some family support – there was also a wish to live within the Aboriginal community, and with friends. There was also an interest in some level of communal living so that older people could support one another.

I prefer Indigenous Australians not to go into aged care. They'd be better off left off staying with family and getting looked after by families.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

I used to look after my grandmother a few years back. She was on dialysis. It was good to have her close at home instead of out at an old people's home. We'd rather have her at home because we knew she would be safe around us.

Aboriginal and/or Torres Strait Islander communities, mixed age, Queensland

Some older Aboriginal and/or Torres Strait Island participants were concerned that younger generations were less willing to take on the expected caring commitments for Elders. Given this potential lack of support, some older participants stressed the hope of living near friends where they can provide care to one another.

We need cluster housing for us oldies so that we can look out for each other, have (security) gates to stop family humbugging the oldies.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Many older Aboriginal and/or Torres Strait Islander participants, like all older people who participated in the focus groups or interviews, felt that loneliness was a very real danger. Despite family and community being important to their culture, the day-to-day lived experience was that contact with family was not as frequent as many older Aboriginal and/or Torres Strait Islander people would like. Company and support from friends was particularly important.

I don't go out ... I sit at home. I'd like my family to come and visit more often. Sometimes they come past the house and just blow the horn and say they'll come back later.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

I never thought at this elderly stage of my life that I would be living on my own ... if I'm having a bad down day, the whole world closes in on me.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Mum's at the stage where she wants me to be there 24/7, because she's feeling fragile.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

I'm 95% of time on my own ... but my immediate family live in the suburbs ... no-one comes near me. The love I get from them is when I'm giving them something ... there's a lot of them isolated with no-one to talk to.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Isolation ... it's a dangerous thing ... I've had five kids, 16 grandchildren, seven great-grandchildren, (but) where are they?

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

The hardest thing about being old is the loneliness. If it wasn't for these couple of ladies here, I would have no-one.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Shorter older age and financial vulnerability

The Aboriginal and/or Torres Strait Islander participants were particularly concerned about access to the pension, the age at which it is provided and its level of financial support. There was concern that as the pension age is pushed back, it disadvantages their community who have shorter life expectancy. There was also concern that by the age of 50, or 55, health concerns among Aboriginal and/or Torres Strait Islander people are such that it is very difficult for them to work full-time and support themselves.

I think Aboriginal persons should stop working when they're 50 years of age ... Aboriginals have a shorter life span than non-Aboriginal.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

(The pension) was 55 but it's been pushed back ... the government knows that we only reach a certain age. We can't win.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Our people, older than we are, are dying in poverty.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

A primary concern for Aboriginal and/or Torres Strait Islander people was the financial responsibility for ensuring a proper funeral and burial, and that funds may not be available because aged care has used up any savings or assets. This was a heightened concern for these communities.

We know when our people go into care, they're pensioners ... when they die, we've got to pay to bury these people because they reckon all their money has been used up in their care in the facility ... we've been running out of money and our people get paupers' funerals.

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Why can't funerals be covered under 'Closing the Gap'. This is our land, why should we have to pay to be buried in it?

Aboriginal and/or Torres Strait Islander communities, older, Western Australia

Sometimes they pass away a long way from family. The family have to come up with money to take the body back home.

Aboriginal and/or Torres Strait Islander communities, older, Queensland

Not having that money and the family is stressing me out and trying to gather money and bury our people.

Aboriginal and/or Torres Strait Islander communities, older, New South Wales

Maintaining health

Aboriginal and/or Torres Strait Islander participants were more likely to talk about maintaining their health in an active way, by quitting smoking and drinking. Many were aware of the increased health needs of older people in communities, with issues of diabetes and kidney disease.

A lot of us Indigenous people have health problems from drinking and smoking.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

Used to go camping with our granny and our sister ... used to mostly live off the land, go fishing for turtle and fish ... sit down by the campfire. We really enjoyed it back in them days. These days you can't do it anymore because in our community, alcohol is the biggest problem with our younger generation these days. I don't know, we can't help them much.
Aboriginal and/or Torres Strait Islander communities, older, Queensland

Stop drinking ... otherwise you die sooner from drinking too much, having alcohol early in the morning from the fridge when they wake up. I've seen them die ... gotta stop the alcohol.
Aboriginal and/or Torres Strait Islander communities, younger, Western Australia

6. Culturally and linguistically diverse communities

This section highlights the distinct views of Culturally and Linguistically Diverse (CALD) participants, that is, those who speak a language other than English at home. This includes those taking part in the four dedicated CALD groups and some who took part in the broader population focus groups.

6.1. Summary

Those from culturally and linguistically diverse backgrounds tended to receive more support from their parents in adult life, and this related to the higher expectations they had to support older family members in their later years. This was recognised as being different to wider Australian society. This distinct expectation of care tended to be raised as a positive example by the wider population, who were less likely to understand the similar expectations within the Aboriginal and Torres Strait Islander communities.

Like the Aboriginal and Torres Strait Islander communities, those from culturally and linguistically diverse backgrounds tended to express greater respect for older people, although they placed less emphasis on the passing down of cultural history, practices or language. Younger culturally and linguistically diverse people raised the inter-family tensions of growing up with older family members whose expectations of behaviour were more traditional and were sometimes more conservative than wider Australian culture.

Those from culturally and linguistically diverse backgrounds were more likely to have grown up with a grandparent living in their family home, and this was almost universally seen as a good aspect of their childhood and contributed to their stronger expectation of providing care to their parents as they aged. That said, older culturally and linguistically diverse people were conscious of the burden of caring for their parents and wanted to lessen this burden for their children.

6.2. Community views of older people

Respect and empathy

Participants were from diverse cultural backgrounds but the theme of living with and taking care of older family members was consistently raised, often in contrast to Australian culture. There was recognition that family living arrangements and level of involvement differed. They felt there was a higher tendency for parents in their community to help children throughout their adult lives; be it with housework, caring for children or general support. In turn, this equated to higher expectations around caring for your family in their older age.

I think it goes back to the culture as well... if I was in need, my family would never let me down.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

I remember when I was younger, my grandmother ... would come over every single day to help my mum with housework ... look after us... now my parents are doing the same ... I think different cultures do it differently, like in Australia it's more like independent ... each family is their independent circle and have to figure things out on their own, whereas for Italians, grandparents would never leave their kids without support or anything.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

I think Australians are more independent, in the sense that they just live with their own family, not extended family or other generations ... I think coming from a European background, we're more focused on doing as much as you can for the family and be there for them all the time and then if you just focused on your life outside, then you'd be considered selfish.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

It's very much the case of once the kids grow up (in Australia), it's out the door kind of thing, so the parents can go and do their own thing ... in European culture, it's definitely more expected that when they reach an older age where they might need help with day to day stuff, it's expected that the kids take them in.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

It's both ways – the expectation here is that when you're eighteen, you run your own life, and similarly, the parents also don't expect that you're there for them in their old age – the culture of putting your parents into a nursing home is very much accepted. Whereas, in Indian culture, the parents would be more than happy to spend months at a time looking after their grandkids ... but the culture is with the expectation that the children will look after their parents in old age as well.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Participants in the culturally and linguistically diverse focus groups, like the Aboriginal and or Torres Strait Islander participants, tended to express a great level of respect for older people. The respect shown was not confined to simple descriptions and was demonstrated through attitudes and empathy felt towards older people.

We're all going to be old someday. I'd hate to think they thought of me as a burden. I'd like them to pay the respect to me that I've given to older people. They've done their time.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

You need to respect them. That's how you want to be treated. They're still a member of society, it's discrimination against age otherwise.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Like others in the broader population, younger people from culturally and linguistically diverse communities identified ways in which they felt older people were more conservative or set in their ways. They described specific challenges they had experienced with older family members adjusting to Australian culture.

I think the people who immigrated here kept their culture more than they did back home ... when I think of Italians in Italy and Italians here, I would say Italians here are more traditional.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

My cultural background ... my parents are very regimented and they're very stuck in stone – you can't shift them – you can't just say, 'This is the way things are done now' – they're just so resistant ... the inflexibility of shifting to Australian culture ... it's very, 'There's only one way to do things, and the Croatian way is the right way'.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

However, they were particularly quick to defend older people, empathising with them to explain these behaviours.

Probably they've only worked one job in their life... and they've been in the same role, with the same people and they always felt comfortable in that role ... they haven't tried anything else ... so one, they're resistant to change and two, it's hard for them to adapt to new situations.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

I think you have to have a lot of respect for your elders. As much as my Dad is stubborn ... you still have respect them, no matter what happens... for them, and what they've done.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Older people are more conservative. They're more sensible, don't take risks.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

In contrast, a minority of participants who had more recently migrated to Australia, spoke about some of their more negative experiences with older people being more inflexible.

I had some experience with some people when I first came to Australia. I couldn't speak English and my friend said that she was saying that I should be speaking English, not my language. And my friend had to say to the lady, 'She's new to Australia', but the lady kept saying, I should speak English.

Culturally and linguistically diverse communities, aged 18-30, regional, Victoria

Some culturally and/or linguistically diverse participants made specific reference to their strong appreciation of older family members. They perceived them as a benefit, particularly in how they would share their culture. This was similar to the Aboriginal and/or Torres Strait Islander participants.

I think that's how culture is passed on from generation to generation ... what I know about my culture has come from my parents and my grandparents. And my mum would look to her mum or her grand mum to learn about the culture. ... so, the most elderly people are the ones that are in the position of passing on that knowledge to the next generation 'cos otherwise you just lose it.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Why would they be seen as a burden?! I don't think they are seen as burden. More a benefit more than anything else. The culture, the language. Things they can pass down to us ... It's not about literacy or computer skills but it's the other stuff.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Responsibility towards older people

Many people from diverse cultural communities had grown up with grandparents or older family in the household looking after them. For some, this experience had left them feeling an even stronger sense of respect and responsibility to look after them.

At one stage, I had both sets of grandparents with us. My grandparents pretty much raised us. Four-bedroom house... that was for most of primary school, then when my brother and I grew too old to share, one set moved out. It was normal.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

I lived two years with my grandmother and a couple of uncles. It wasn't that big a house.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Somewhat similar to the broader community focus groups, culturally and/or linguistically diverse participants were particularly uncomfortable with the word 'burden'. Some acknowledged the work required in looking after an older person but were more likely than the wider population to see this as a responsibility that needed to be taken on by the family.

I have a soft spot for them. My parents were working full time and I was raised by my grandparents. It's like I owe them. So, I have a soft spot for them. Even if they are a burden ... I feel that you still should do your bit to help them out.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Granddad is 94 but he's pretty mobile. Grandmother is a bit senile. I like to check in more often with her. We have the same conversations over and over again. I can see why people might see her as a burden, she's on Centrelink and someone from the family needs to take her to appointments. I don't see it as a hardship, you just do it.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

Caring for an older family member was commonly accepted, but people worried about being a burden to their own children.

It won't be family for me– they'll be busy, they'll have things to do. I don't want to be a burden too.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

When it comes to the point when I can't look after myself, I'd go to a facility.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

6.3. Community understanding and perceptions of aged care

In line with the culture of looking after older family members in home, culturally and linguistically diverse participants opposed the relocation of older people to nursing homes. Younger groups who might have expressed the wish to live independently and who were perhaps more culturally acclimatised to Australian culture, were still reluctant to move their parents to an aged care facility and expected to eventually have their parents live with them.

We (Australian community) disregard older people, we put them in homes, they have no value to society anymore ... as you get older you become more of a reject in society in a sense when I would like to see them contribute more in wisdom, experience.

Culturally and linguistically diverse communities, aged 55+, regional, Queensland

(If a parent could not care for themselves) Easiest thing would be to have help come over, but my parents wouldn't feel that comfortable with that, they would come and live with me.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Participants did not have distinct knowledge of views on aged care facilities. However, a minority raised the complication of culturally appropriate care for older people.

I am a Christian, but my family is not Christian, I am born in a Hindu family ... In our culture ... my mother would not allow me to undress her, change her nappies, she will not, she will kill herself rather than allow her son to do it. Daughter can, but son cannot. So, what do you do when your parents are resisting?

Culturally and linguistically diverse communities, aged 55+, regional, Queensland

6.4. Planning, preparation and expectations of own older age

Culturally and linguistically diverse participants talked about the role of family in planning for their older age, discussing where they would live and having family members care for them. For most, if not all in this group, their upbringing influenced their expectations of older age in some shape or form.

Living or not living near family

Many participants from diverse cultural backgrounds expected to maintain their family traditions; they spoke about their intentions of living and caring for children, as well as being cared for by their children in older age. In particular, those who had migrated more recently appeared more likely to hold these attitudes. One participant explained how back at home, the absence of social security meant that it was usual to invest in children so that they would look after parents in their old age.

I hope to be able to help my children when they're grown and stay with them to help them look after their children so they can work ... I hope to be able look after the grand kids so that my children can spend their time in a useful way.

Culturally and linguistically diverse communities, aged 18-30, regional, Victoria,

We're going to move back to Hong Kong because the Asian culture is very much about family and looking after family and we've been told that we're very welcome to move back to Hong Kong and all our nieces and nephews have said they'll take care of us.

Culturally and linguistically diverse communities, aged 56-70, metro, Western Australia

Some of the younger people from diverse cultural communities reflected on their upbringing, living with or nearby an older family member, they idealised the closeness of this arrangement. They could see the advantages and disadvantages of living together and the compromises that might need to be made.

There's a certain level of obligation to help out ... my personal preference, I'd do all I can, but I would like to have my own independence.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

We don't want to feel like a burden to them (future kids) ... the same way we don't want to give up our lives for our parents, we wouldn't want that from them either.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

Interestingly, those who had moved to Australia with younger children also acknowledged the impact that Australian culture would likely have on their children, and what that meant for them. These culturally and linguistically diverse participants, while at times liking the prospect of their children taking care of them, did not have strong expectations that this would happen given the environment their children were being raised in. Younger and older people viewed life in Australia as more 'independent' from family, although many still expected and hoped that they would be part of their children's lives.

I'd probably want to live with my children, before I live with strangers... I'll be like, 'I'll support you and your kids! I'll take them to school'. I feel like that would be more natural for me, culturally, than go into assisted living facility.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

I think the solution that my parents had was really good, how my grandma was across the road, I would like something like that.

Culturally and linguistically diverse communities, aged 18-30, metro, New South Wales

(On benefits of being cared for by family) You know that there's someone that knows you ... It would be nice but I don't count on it.

Culturally and linguistically diverse communities, aged 31-55, metro, Western Australia

7. Financially and socially disadvantaged people

This section highlights the distinct views of participants who were financially and socially disadvantaged, that is those with a weekly household income before tax of less than \$800.² This includes those taking part in the four dedicated groups for financially and socially disadvantaged people.

7.1. Summary

People in the financially and socially disadvantaged focus groups more frequently discussed income and financial planning than those in the broader community. Key concerns in these groups included income uncertainty and how this might impact on their health and housing.

These people were either planning to receive the pension, or currently receiving the pension and were grateful for this. Many people explained how challenging it is to live on the aged pension. Their financial insecurity meant that they were more likely to be concerned about being a burden to their children in later years.

Financially and socially disadvantaged people tend to know less about aged care. Their understanding is that they will have limited choice of, or not be able to afford, private aged care. They have an expectation of state-provided aged care, but unless they have navigated this process for a partner or family member, they are not knowledgeable about how to access this care.

Those who were financially and socially disadvantaged were more likely to have already moved to a location with more affordable housing or were planning to do so as they aged. By moving to a regional or rural setting they felt more able to buy or rent a property, and have sufficient funds left over to support themselves.

These people were more likely to expect to continue working into older age to improve financial security and to bolster what they perceived as their insufficient superannuation funds.

7.2. Community views of older people

Those on lower incomes tended to be slightly more apprehensive about ageing and less likely to be looking forward to their older age, given the personal insecurity they had regarding their income than their wealthier counterparts. This meant they were more likely to feel vulnerable and aware of the restricted choices they would face in older years due to their financial insecurity.

² 25% of households in the 2016 Census of Population and Housing had weekly income less than \$800 (Australian Bureau of Statistics, General Community Profile, table G29 Total Household income (Weekly), Catalogue 2001.0).

7.3. Community understanding and perceptions of aged care

Financially and socially disadvantaged people were broadly aware of the cost implications of aged care, and generally felt that private aged care was beyond their budget. Given this belief, they tended to be slightly less well informed about aged care than the wider population.

I don't really want to know about (aged care facilities).

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

But is there private and public?

Financially and socially disadvantaged, aged 31-55, regional New South Wales

There was an awareness that their financial insecurity would reduce choices available to them and may impact on the quality of care they received. These lower income participants had a vague understanding that there would be some level of state provision for them, if they required aged care, but were not knowledgeable of how this would be arranged, and the detail of the care available to them.

7.4. Planning, preparation and expectations of own older age

People who were financially and socially disadvantaged were more likely to engage in longer discussions around financial planning or financial concerns. Financial security was often raised as a priority for older age and a concern since they were uncertain as to what their future stream of income would be. They also saw their limited finances as impacting on housing and health.

Have I got enough money? Is it going to last?

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

If you're on top of the heap, you're fine but if you're not, it's a worry.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

I hope I'll have enough money to travel.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Because things are starting to get more expensive, like housing prices, electricity, gas and food.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Budgeting

Many of the older people who were financially and socially disadvantaged were living on some government support, such as an aged or disability support pension. People approaching older age felt they would likely be reliant on government support to some degree. Those already on the pension were grateful for its existence.

As long as I'm getting the pension, I'll be happy.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

I feel more control with the pension than when my husband looked after our own business. I don't know how we lived, but I'm thankful for the pension, and you worry about the future but you have to take a month, a day, a year at a time and do the best with what you got.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

Many in these groups also discussed the value in budgeting and being financially cautious. This was in contrast to those across the breadth of the other groups who had some ability to self-fund their older age and retirement. The general sentiment was that the aged pension was too small a sum of money to live on.

Trying to teach kids these days to save and what saving is, to learn about that, putting it away for later on in life ... I'm 45, I've gotta start saving now, it's gonna be way too late.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

In our situation, we are living pension to pension.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

I'm on the aged pension, I live basically, you don't save much when you're raising two kids on your own and there was no super then. But I feel I live carefully and comfortably on the pension and when I work, I save up, I can go overseas.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

(On financial planning) I can't be bothered with it ... so long as I've got food on the table, a roof over my head, rags on my bony body, then I'll be happy.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

Some older participants, who were of an age to be eligible for a pension, raised concerns about the fairness of the pension. From these discussions it was apparent that few understood how the pension system worked including the means testing arrangements.

They work their ass off to pay off their house, yet they're not entitled because they have too many assets.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

There are friends who don't get the pension, and they tell us it's not fair that they didn't get the pension and they worked hard. But we worked hard, we spent and sent our children to private school, so we don't have as much wealth, so we need the pension. But why do I have to say this, this is between me and the government.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

They say they're paying for our pension, but I say, no, we worked, we paid taxes. They say that those taxes are for infrastructure, but I say, no, that is for my pension.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

In addition to the concerns about financial security in their older age, the potential of being a financial burden on their children was a source of stress for some. Instead, they wanted to have the resources to financially support their children, if necessary.

I don't want to live to my eighties and nineties and I worry about my funeral. My children, say live your life, don't worry about your funeral, but it's so expensive.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

I'd like to be in a position to help my kids, the way my parents have given me support ... it's made a big difference in my life, especially when you've hit rock bottom and your head's all over the place and your parents are there to pick you back up. I'd like to know I can do that for my kids.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Moving somewhere cheaper

In planning for older age, some people had relocated or were considering relocating specifically for financial reasons.

I suppose having enough money to be comfortable ... that's another reason why I wanted to move here ... because here you can buy a unit for \$100,000. In (location), the cheapest you could get was \$300,000-\$400,000.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

I'm not confident. We're actually considering moving to Vietnam. It's a Buddhist country, they're very peaceful. And cost of living is 10 times less than here. Medically, you have to weigh it up, but they are as good as they are in Australia.

Financially and socially disadvantaged, aged 70+, metro, Victoria

Retiring was a difficult option for participants who were financially and socially disadvantaged. Whereas many participants in other groups wanted to stay in the workforce for mental stimulation, this group were more likely to say that they were doing so out of financial necessity.

It'll probably be hard to afford to stop working.

Financially and socially disadvantaged, aged 31-55, regional New South Wales

Options in older age were somewhat limited for this group and more often than not, dictated by available budgets. Among those aged over 70, social engagement plans were very much dependent on budgetary constraints.

Most councils have activities for older people to meet and do things.

Financially and socially disadvantaged people, aged 56-70, metro, Victoria

I'd like to live somewhere different, but, financially, I can't. I've got to live where I am.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

I'm not going to think about travelling because I know I can't afford it.

Financially and socially disadvantaged people, aged 56-70, regional, Western Australia

8. Veterans

This section highlights the distinct views of veterans, that is, those who have worked for one of the Australian armed services and experienced active service. This includes those taking part in the three dedicated groups with veterans.

8.1. Summary

Perceptions of ageing and older people were very distinct among veterans, who universally, hold older people in high esteem and respect. Veterans were more likely to describe older people positively – seeing them as wise, having a wealth of experience and providing valuable support to the family unit (e.g. childcare and babysitting). Veterans perceived society as having changed over recent years and that it no longer afforded older people the respect they deserved. Modern parenting, the pervasive use of technology and the current education system were all identified as contributing to this loss of respect for older generations.

Veterans believed that society should have a strong sense of obligation to older people, thanking them for the contributions they've made over their lifetime. In contrast, they tended to see younger generations as a burden, being unwilling to work as hard as their forefathers. Reflecting their period of service, veterans felt that they had earned the financial support they receive from the government and appreciated Department of Veterans' Affairs support.

Similar to other audiences, such as care leavers and LGBTI communities, veterans were specifically interested in living in aged care facilities, or communities, of like-minded individuals who would share their values, and understand their lived experience.

Planning for older age included addressing ongoing health issues that were a consequence of their active service, in addition to mental health issues including post-traumatic stress disorder. As individuals they valued independence and self-reliance, but they recognised that their health needs required external support that they found difficult to ask for. This unwillingness to ask for help meant that veterans were aware that loneliness was a particular risk for them as a community. They were aware of higher levels of dependency on drugs and alcohol among veterans, and their risk was higher because of the greater prevalence of family breakdown.

8.2. Community views of older people

The notion of respect resonated particularly deeply with veterans and it was clear that this had been reinforced by both their upbringing and their disciplined service training. The high esteem in which they held people older than themselves was reflected in many of their personal attitudes, and the obligations that they felt society had towards older people.

I respect my elders and I think that's the only way it should be, otherwise the system falls apart.

Veterans, metro, New South Wales

The older people I talk to are good at putting things into perspective, a huge contribution to me, they have really valuable skillsets, a wealth of knowledge.

Veterans, metro, Victoria

As a group (having worked in the military) we were taught respect, we admire and respect (older people).

Veterans, metro, Victoria

For this group, a characteristic of an older person today was their own respect for those around them. Veterans were quick to articulate that older people were knowledgeable, had a wealth of experience and were great care takers of children. They also recognised that not all members of society viewed older people in the same way, leading veterans to be critical of younger people. Veterans discussed at length how they felt society had changed and that the respect in which older people are held by society has changed markedly over recent years.

It's got to do a lot with how the person is brought up. Unfortunately, I have some serious reservations about some in the younger generations ...

Veterans, metro, Western Australia

I live in a high rise in the city. And you walk in the foyer, and there's a bunch of young people in there and they look over their shoulder, but would they hold open the lift for ya? Hell no. But the older guys in there, they'll stick their hand out and check, 'Oh no one's coming, I can let the door shut.' It's just a respect thing. It's a generational shift and a mindset shift in the way that people behave and the way they live their life now.

Veterans, metro, New South Wales

Social values have been lost.

Veterans, metro, New South Wales

This group felt strongly that the pervasive use of technology, the education system and parenting in current culture were some of the factors responsible for these changes in social values. All of these changes, including the change in the level of respect shown to the elderly, contributed to perceptions that growing older today was different or more difficult. Some compared this to what they had been taught and lamented the days of their youth where they had paid a greater level of respect to older people. Many expressed stereotypical views that are somewhat challenged by what the broader sections of the community said in their discussions.

There is no moral substance anymore. The values that we had are gone because we've let it slip and what we now have is a generation of people jumping on technology and using it for social media advantage for themselves and that's it.

Veterans, metro, New South Wales

Many kids at school don't learn the things we learnt – the flag, the country and respect. What they learn is Facebook, a computer and text, that's what they do all day ... they're losing their values.

Veterans, metro, New South Wales

Being courteous is not that hard – just say, 'Yes, please' and, 'No, sir' ... I still say, 'Thank you, maam' or, 'Yes, maam'.

Veterans, metro, New South Wales

They're (young people) connected and entitled.
Veterans, metro, New South Wales

The profound appreciation for older people translated to a strong sense of obligation towards them. The term 'burden' was rejected and on the contrary, veterans felt that younger people were sometimes the burden. Older people were perceived as having 'done their time' and the sentiment was very much that they had earned the right to rest and receive care from wider society. These quotes represent the views of many participants.

You can use the word burden for those in their twenties and thirties who are taking welfare who are fully able to go to work but are choosing not to ... as opposed to the elderly people who would work if they could but they can't cos they're old.
Veterans, metro, New South Wales

I wouldn't use the word burden, I'd say more or less reliant on assistance.
Veterans, metro, New South Wales

They've done their bit, it's time for them to have some time off and have their break, so it's time for us younger blokes to do the work.
Veterans, metro, New South Wales

The older generation have paid their dues, worked all their lives, sometimes they need to put their hands out (and they should be supported when this happens).
Veterans, metro, Victoria

8.3. Community understanding and perceptions of aged care

The heightened respect that veterans have for older people translated into greater concern regarding the quality of care provided to older people. Like the wider population, veterans were aware of reports of elder abuse and poor care in aged care facilities and felt that the care for older people should reflect the lifetime contribution they have made to Australian society.

They built it, the foundations. It's disgraceful – (the bad stories you hear about) aged homes, pensions (meaning older people live) below the poverty line. We need to be able to say, 'If you've made it to 80, you'll be right mate'."
Veterans, metro, Victoria

As with other specific audiences, such as care leavers and those in the LGBTI communities, veterans were interested in living in communities, or facilities, with like-minded people, with similar life experiences who may be able to understand and support each other in their older years.

I think I'd enjoy living in a group of Vets basically, 'cos we understand. Like a retirement village, but Vets, that understand each other. I think that would be good. If I can't live independent, that's where I'd like to live ... so that you're not running around explaining yourself, people understand you, you understand them. It is a niche ... Yes, it's good to have comradery.
Veterans, metro, Western Australia

They were appreciative of the support they received from the Department of Veterans Affairs. This was specifically raised in relation to the availability of in-home support and care, to help them remain living independently. However, it was noted that this level of contact and support fell away if they moved into an aged care facility.

With the DVA system, you're on the DVA pension, you're a DVA client whether you're on the white card, gold card, whatever. When you need in-home care, they will look after you 100% ... as long as you can manage your own affairs, you need a ramp or whatever ... they will do it. No problems ... once you move from your own home or retirement village, as soon as you go into an aged care facility, you virtually drop off the radar with the DVA ... once you're there, it's sort of, 'You are their problem, not our problem'.

Veterans, metro, Western Australia

8.4. Planning, preparation and expectations of own older age

When thinking about their own older age, some veterans dealt with the added concern that underlying health complications as a result of their service could surface as they aged. For example, traumatic brain injuries, trauma-induced dementia and Post-Traumatic Stress Disorder (PTSD). They were conscious of this risk, having witnessed fellow veterans experience emerging physical and mental issues later in life.

Different people age at different rates ... (they take them away for service), 12 months later, they bring 'em back here to Australia – they reckon they could see a 5-10 year ageing pattern in those blokes in 12 months!

Veterans, metro, Western Australia

The unknowns are scary. I look healthy but I had lots of injuries that I ignored for a long time so I could keep getting deployed. Even in the (office-based) workplace I can't move a box if I'm having a bad day.

Veterans, metro, Victoria

Unfortunately, now with the early onset dementia and that, too many veterans in particular – they grow older before their time.

Veterans, metro, Western Australia

Similar to the wider population, self-sufficiency, a level of independence and having a purpose were traits very much valued by veterans.

Staying in my castle as long as possible ... I expect to be there the rest of my life.

Veterans, metro, Victoria

Even though I've retired, you still have to have an interest, a reason to get up in the morning and do something.

Veterans, metro, New South Wales

Something that would keep you active and safe and keep you in that home environment as long as possible.

Veterans, metro, New South Wales

We (veterans) don't ask for help... we want to do it ourselves. My house, my garage, (I want to have those) as long as I want it, do my homebrew, my woodwork. (It's important to have) a sense of, 'Hey! I made that!'

Veterans, metro, Victoria

I think once you've lost your independence, you flick a switch in your head. You go from 'I'm fine, I'm fine', to 'I'm a burden'.

Veterans, metro, Western Australia

Veterans spoke about not needing much to get by, they also talked about the downside of this attitude, which was that some were unwilling to reach out for help. As such, it was felt that loneliness was an acute risk for veterans, and the risk of alcoholism and drug dependency (including cigarettes) was higher among this group. Participants felt that this group could benefit from a greater level of attention.

An issue might be, for (veterans like us, we're) people who are bad at saying they have a problem, if we keep bullshitting people and saying we're fine we might fall to the side as a group - we need a voice (to advocate).

Veterans, metro, Victoria

Adding to the risk for veterans was when they no longer had ongoing family relationships, which increased the likelihood of loneliness and mental health issues, and in combination with health risks, left this group more vulnerable as older people. They were more likely to lack day-to-day support as older people, be that living independently or when they enter an aged care facility.

Aged care when there is no known family (is no good) ... he passed away with no known family ... they rang me ... 'Are you sure there's no one out there anywhere?' ... (he) enlisted in the army, went over in '65 ... got married just before he went over, by the time he came back, his missus had done a runner ... fortunately they rang me ... I got a few veterans together, flagged his casket.

Veterans, metro, Western Australia

Another bloke, he's ex-SAS, he's got Parkinson's now ... he's in a wheelchair and where he is, they're worried about him falling, more than they're worried about his wellbeing and they tell him, 'Don't get out of the wheelchair'. ... he said, 'The doctor has come to give me some tablets, but he's never come back to see whether they've worked or not'.

Veterans, metro, Western Australia

Veterans felt unambiguously that they had earned the right to financial support from government in their older years.

DVA? Gold cap ... I'm not gonna say a single bad thing about them, they've been good to me ... They're paying my pension, my medical ... we did our service overseas, I think we've been there and done it. I think this our just reward, for what we've done.

Veterans, metro, Western Australia

At the end of the day, you've been a good, nice worker and you've paid taxes – and that's a big one. And you're standing at the door of retirement, I think you should be looked after.

Veterans, metro, Western Australia

9. Gay, lesbian and bisexual communities

This section highlights the distinct views of gay, lesbian and bisexual participants. This includes those taking part in the three dedicated groups with these communities.

9.1. Summary

People in the gay, lesbian and bisexual communities largely shared the same views of the older population as the rest of society. They were, however, distinct if they had experienced rejection or stigma from older generations in relation to their coming out. These individuals were more likely to see older people as bigoted or, at best, inflexible.

This community was very clear that they wanted to spend their older years in an environment that respected their sexuality and was nonjudgmental. They had encountered a range of individuals and institutions where they faced prejudice, such as schools or religious organisations. Their overriding focus for their older years was to live in a supportive setting, with like-minded individuals. This did not necessarily mean a segregated facility for the LGBTI+ community; it did mean a facility where they felt accepted and respected.

Gay, lesbian and bisexual people want aged care facilities to acknowledge, accept and support their relationships, and the rights of their partners, in the same way as heterosexual relationships would be respected. They also wanted facilities staffed by health professionals with experience of providing health care for the LGBTI+ community, so that their specific needs could be met.

9.2. Community views of older people

The prospect of ageing, and what being older meant, was distinct among some of the gay men who attended the group in Sydney. They discussed the greater emphasis placed on physical appearance and fitness. Gay culture was described as youth-centric and gay men were often perceived as old once they had passed the age of 30. This was not raised in the lesbian or bisexual groups.

I've just turned 32 and there were a lot of jokes about me gay-dying because I'm no longer seen as young. It's to do with the glorification of looking young ... it's deemed to fall apart at 30.

Gay, Lesbian and Bisexual communities, metro, New South Wales

People say to me that I don't look my age and that makes me feel really good.

Gay, Lesbian and Bisexual communities, metro, New South Wales

The alternative view put forward by some was that the traditional landmarks of ageing did not necessarily apply to gay men (e.g. children and 'settling down'), which meant that ageing was also recalibrated for them.

I think the opposite. In the gay world old it's a bit older than the straight world ... sometimes you associate old with settling down, having kids, or following the norm whereas actually in gay society it's maybe more acceptable not to fall into the norms.

Gay, Lesbian and Bisexual communities, metro, New South Wales

For a few participants in the gay, lesbian and bisexual groups their perceptions of older people had been shaped by their 'coming out' experience. When older family members reacted negatively to the individual's sexuality, they were seen as bigoted and inflexible, and these reactions were seen as representing older people in general.

(Why describe older people as narrow minded?) My grandparents around my being gay, what it entails, (they) assume HIV.

Gay, Lesbian and Bisexual communities, metro, New South Wales

For some, the inability of other generations to accept their sexuality was linked to less ongoing involvement with family.

I don't really talk too much to my grandparents on either side.

Gay, Lesbian and Bisexual communities, metro, New South Wales

When asked to consider how older people contribute to society, some participants describe the current lesbian, gay and bisexual older generation through their ground-breaking work in progressing rights for the community and contributing to the improvements experienced today.

I work in the LGBTI community health sector and when we're framing LGBTI elders, there's almost a different framing, they're almost like trailblazers, they form the legacy of activism. Yes, they're aged, but they've gone through the HIV epidemic.

Gay, Lesbian and Bisexual communities, metro, New South Wales

9.3. Community understanding and perceptions of aged care

Gay, lesbian and bisexual participants' understanding and perception of aged care were in keeping with the wider population. Like others, their perceptions had been formed through media coverage and personal experience, and they had similar levels of knowledge about the aged care system, how to access care, and the quality of care provided.

9.4. Planning, preparation and expectations of own older age

Gay, lesbian and bisexual people talked about having spent their lives navigating a society that was at best not supportive, and more frequently was critical and bigoted regarding their sexuality. They spoke of transitioning through many institutions or life experiences where they faced prejudice, for example school or religiously-influenced organisations. There was a clear consistent voice that they wanted to spend their older years in a positive, non-judgemental environment where they did not have to explain or justify their sexuality or lives to others.

I've never felt welcome anywhere, and that would be a concern for aged care too.

Gay, Lesbian and Bisexual communities, metro, Victoria

I know of LGBT-only aged care in Germany ... I kind of thought that's the kind of idea I'd like when I'm older ... it's about still having things in common with your peers. And spending the

start of your life being in institutions which aren't necessarily the same as you, like schools and university, and it'd be nice to end your life in institutions that are like you.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Not sure I want to retire to a straight people's facility and hang around them ... I've had to work around (a hetero-normative society), I don't want to be old and frail and have to think about these things.

Gay, Lesbian and Bisexual communities, metro, Victoria

Like many participants in other groups outside the general population, most did not necessarily want to live in an aged care facility that was segregated along sexuality lines. They did, however, want to spend their later years surrounded by peers, and staff, with whom they felt accepted, respected and understood. At a minimum, they were looking for residential aged care where staff were happy to be there, and to be caring for gay, lesbian and bisexual residents without prejudice.

We shouldn't segregate ourselves.

Gay, Lesbian and Bisexual communities, metro, Victoria

Staff don't have to be gay men ... but staff need to be happy to work there and enjoy being there.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Just decorate ... the rainbow flag ... celebrate Pride and all that surrounds that.

Gay, Lesbian and Bisexual communities, metro, New South Wales

In addition to this, an appropriate aged care facility would need to acknowledge and support the residents' partners, ensuring that they can share a bedroom and have the right to make care decisions for each other.

When I'm older and I need care, what if my partner can't stay in the same room?

Gay, Lesbian and Bisexual communities, metro, Victoria

You'd want acknowledgement of unmarried partners as equivalent to married partners to be able to sign off on medical things ... recognition that friends or carers are formed not necessarily of your biological family.

Gay, Lesbian and Bisexual communities, metro, New South Wales

Staff would also need to be aware and trained to address any specific health needs that may relate to residents' sexuality.

Aged care services, that there aren't any services that are LGBT specific, that offer HIV care ... discrimination that can come from within the environment ... for example, a gay man going into a general aged care facility and having no peers, or facilities that stigmatise HIV care which is a very real thing.

Gay, Lesbian and Bisexual communities, metro, New South Wales

10. Intersex and transgender people

This section highlights the distinct views of intersex and transgender participants. This includes those taking part in the five in-depth interviews with intersex and transgender people.

10.1. Summary

The intersex and transgender people were more likely than others to be concerned about their vulnerability during old age. They tended to be more financially insecure and more likely to fear social isolation in older age due to their personal history: their gender identity, the mental health problems many of them had experienced and the consequent impacts these issues had had on their employment prospects. Still, many were enjoying, or looking forward to their older years, as a time when they are happier in themselves or have fully transitioned and can live the life they've always wanted to live.

As with the gay, lesbian and bisexual community, intersex and transgender people were concerned about having sufficient choice regarding aged care facilities and avoiding those run by a religious organisation. Intersex and transgender people, like all participants, want to spend their older age in environments in which they feel respected, understood and supported, and previous experience of prejudice from these organisations mean they are unlikely to feel safe in these places. They were not advocating for segregated care facilities but suggested that an LGBTI+ community would be likely to provide appropriate care and support.

Intersex and transgender people were keen that aged care staff be well trained in understanding their specific health needs. Many had experienced ignorance and prurience among health professionals and felt strongly that they would want to be supported by both care staff and medical staff who were knowledgeable and experienced in the health challenges they faced. For some, this issue was sufficiently important that they were unlikely to move away from the health professionals who currently care for them.

Given their greater financial insecurity, many of their broader concerns mirrored those raised by financially and socially disadvantaged people. They had faced prejudice in the workplace and were apprehensive of their ability to accrue a sufficient superannuation fund to support themselves in older age. Given this, they were more likely to see their future in public, rather than private, housing or aged care.

10.2. Community views of older people

The views of transgender and intersex people were very much in keeping with the wider population, however there was a greater concern about vulnerability in older age. These concerns tended to focus on the fear of social isolation, financial insecurity and lack of resources, reflecting their experience of mental health problems and periods of unemployment or poorly paid employment. These participants did not necessarily cite personal experience of loneliness, but they were more likely than other audiences to raise concerns around this issue for older people.

Loneliness is a big factor too, when all the children have left the home, that speeds up the ageing process. The older you get, the more anxiety you get, people are afraid to go out, their friends have died, a lot of people let themselves go.

Intersex and Transgender people, New South Wales

Because these folks are isolated and invisible, they are disempowered, disenfranchised. They feel they are a load on society. They probably feel they've nowhere to go ... that isolation eats away at people. The isolation is a cancer that creates stress and mental illness.

Intersex and Transgender people, Victoria

I've thought about it occasionally, and I've worried that I'll be on my own ... I don't want to be in that situation. I'm a bit worried that when I get to the age when I need more help, I'll be on my own and won't have the help.

Intersex and Transgender people, New South Wales

I think just having people that I love in my life; friends and family. Being lonely would suck.

Intersex and Transgender people, New South Wales

Despite this, many were enjoying or looking forward to their older years as a time when they are happier in themselves or have fully transitioned and can live the life they've always wanted to live.

When I was growing up, I had depression and anxiety, and I didn't really see myself getting to a certain age anyway, so I'm just happy to be here and be happy.

Intersex and Transgender people, New South Wales

As a late transitioning trans woman ... I had a lot of pressure in my head to transition, I wanted to have at least a few years as the perceived 'me'. I'd already put in a lifetime as a traditional heterosexual, marriage, four kids. There was pressure to achieve '(new identity)' for a few years before I passed.

Intersex and Transgender people, Victoria

10.3. Community understanding and perceptions of aged care

As with the wider population, transgender and intersex people would prefer to remain living independently in their own homes.

The best facility is to live in your own home and have care or support workers to drop in and see how you're going.

Intersex and Transgender people, New South Wales

Transgender and intersex people were marginally more likely than others to be concerned that many aged care facilities are run by religiously-based organisations. This added to their concern that these may be environments in which they are not respected or understood. As such, this was seen as limiting their choice of facility.

They need to open it up and take it away from the churches ... put it out to public tender, people who can offer it and do it in different ways.

Intersex and Transgender people, New South Wales

When asked to think about the possibility of moving to an aged care facility, transgender and intersex people raised concerns about the training of the staff. There was concern that aged care staff and related health professionals have little exposure to the transgender and intersex communities. As such, these participants were concerned about facing ignorance and prejudice, similar to experiences they had in their past, in an aged care facility.

Training medical professionals ... so many of them need to be exposed to so much, so they can understand better.

Intersex and Transgender people, New South Wales

I think if it comes to point where I'd have to be in care, I think it's important that the people who are looking after you understand what your body is like, how it works and how it connects with other intersex people. Having that education and awareness is very important for anyone who's helping me with my day to day needs.

Intersex and Transgender people, New South Wales

LGBTI awareness as part of their basic training.

Intersex and Transgender people, New South Wales

From an intersex perspective, it's important that with these facilities, that staff could be trained in what to expect from people who are intersex. Most people don't understand what intersex is and confuse it with being transgender ... a lot of intersex people are living in the gender that they were born in, they haven't changed. But they have bodily issues or psychological issues ... facilities need to be aware of issues that intersex people most probably will have, and the best people to do that are intersex people themselves.

Intersex and Transgender people, New South Wales

It's neither efficient or practical to have screaming big banners or over the top symbols – the rainbow icon (to welcome the rainbow community) but there needs to be understanding that gender and sexuality are not binary, people need to understand pronoun use, and be accepting.

Intersex and Transgender people, Victoria

While it is not the top priority, transgender and intersex people wanted to be among peers. In terms of their happiness within an aged care setting, it was important that they would be living with others who understood and accepted them and were respectful. A facility that catered solely for the LGBT+ community was seen as offering a setting where they would feel welcome and safe.

Even if it wasn't just specifically trans, if it was LGBTQ community, that'd be cool. I've heard of some gay people who when they go into aged care have to go back in the closet.

Intersex and Transgender people, New South Wales

I'd like to be in an environment where I'm respected. I'd feel a lot safer in a woman's environment than a male environment.

Intersex and Transgender people, New South Wales

If forced into an aged care home, the rainbow community need to be confident that they'll be respected and cared for in as sensitive manner as possible. (They need to be confident that they're) not bullied by either residents or staff, or physically abused.

Intersex and Transgender people, Victoria

10.4. Planning, preparation and expectations of own older age

The transgender and intersex participants were no more or less likely to have given thought to their older age than other members of the wider population. Like other specific audiences, when prompted they expressed a need for cultural safety and had concerns around health care. Several of these participants recalled negative interactions with health care professionals and significant medical procedures.

Being trans so much can impact how you are treated medically, how people including doctors will view me, and how it can skew things with how diagnosing works ... it overshadows how people should just look at the symptoms ... If you go in for one thing ... doctors who don't have a speciality in trans healthcare will think it's odd you're taking hormones. It's completely unrelated. With getting older, medical stuff does come up and I'm conscious of how that will impact.

Intersex and Transgender people, New South Wales

Intersex people have often been through a lot of trauma with medical profession, so it's important to ask that nurses and doctors are aware that sometimes medical procedures can bring up trauma from the past ... it would be good for nursing staff to know about trauma-informed care ... giving you control and choice when medical things are involved so that there's communication, as sometimes we weren't communicated with very openly or honestly.

Intersex and Transgender people, New South Wales

Participants spoke of a lack of knowledge among health professionals about transgender and intersex people. This ignorance manifested in inappropriate communication and inability to provide relevant health information. They spoke of sometimes knowing more than the health professionals they were interacting with and also being asked inappropriate questions due to the health professional's curiosity or lack of knowledge. Many participants continued to encounter health professionals who were not well informed about how to use pronouns and appropriate language.

Even if people are aware of the concept, some people still get very uncomfortable about it. Some doctors can be socially awkward and don't understand how invasive some questions are because they're seeing you not as a person but something they haven't encountered ... I know someone who went in for an eye test, mentioned they were trans and had this optometrist ask about their genitals ... they don't know how to temper their curiosity.

Intersex and Transgender people, New South Wales

Language with intersex and LGBTI is important so you don't make assumptions about gender and the pronouns they use ... some people prefer 'they' rather than 'he' and 'she'. You can't assume what their physical body is going to look like, they might have a female gender identity but their body might be different to the standard female.

Intersex and Transgender people, New South Wales

Others were conscious of those in their community who were ageing and encountering specific health challenges as a result of their transgender or intersex status. This was a source of considerable worry.

I do worry about getting old. Being XXY, it's not just about hormones, it's about your biology, your body, the older you get ... the more issues you have. I've been fortunate to this point, but I know people in their sixties and seventies who are really struggling ... the odds are stacked against us.

Intersex and Transgender people, New South Wales

Mental health is pretty high up because I've had so many problems with that ... I imagine that'll continue for the rest of my life ... but I also have physical health issues because of the intersex thing, I have to have external hormones that I have to use all the time. I don't know what'll happen with that.

Intersex and Transgender people, New South Wales

These concerns resulted in a desire to be living in later life near the relevant doctors and specialists who they knew well, who understood their medical history and were trusted.

I will need to be near doctors who can manage my hormones. I have had surgery, but that's all fine now. I guess it's more just if something else comes up how that will impact me getting treated.

Intersex and Transgender people, New South Wales

(Where do I want to live?) In a small place that is super easy to take care of, just a small space. At the same time, I think I'll be sick of the city, but then you've got to think am I close enough to good doctors and hospitals?

Intersex and Transgender people, New South Wales

Transgender and intersex participants were slightly more likely than the general community participants to describe feeling financially insecure and worried that they would not have the funds necessary to provide for their older age. This tended to reflect a life where mental health had affected their employment prospects, and that they had not had the opportunity to save or contribute as much to their superannuation. Some transgender participants also spoke of encountering ageism and prejudice from potential employers because of their appearance.

How am I going to cope in the future if I don't have very much money to live on? That concerns me, the financial aspects of the future.

Intersex and Transgender people, New South Wales

I just think about getting by day to day, I don't have a nest egg put by.

Intersex and Transgender people, New South Wales

When I ring up and I say I'm 72 and I wanna do this ... they say, 'Yeah, come in and we'll have a talk'. But then, when I walk in, I can see that they were expecting their idea of a 72-year-old woman, not me, so society has got a lot to do with it.

Intersex and Transgender people, New South Wales

Transgender and intersex participants with fewer financial resources saw government housing as their most likely option for their older years.

It's too late, 'cos I can't buy a house, I can't get finance on a house even though I'm getting government money in, so I'm going to be in shared accommodation until the government

can find me a place ... peace and quiet.

Intersex and Transgender people, New South Wales

I don't own a home, so I guess I'll be dependent on government housing, but I don't really want to move into government housing because it will be like another sign of giving up. I've applied for community housing through LGBTI co-ops and they're a completely different concept to housing ... more like a normal home.

Intersex and Transgender people, New South Wales

Transgender and intersex participants were keen to spend their older age in an environment with like-minded people, where they would be accepted. This group were likely to talk actively about friends within the LGBTI community as family members. They did not necessarily feel the need for residential care to be with an LGBTI community – it only needed to be LGBTI-friendly.

People who have similar interests or values ... which could be hard to find because I'm a bit off centre ... maybe a community up on the north coast, hippies ... I could see myself doing that when I'm older when I'm less focussed on my career.

Intersex and Transgender people, New South Wales

To be in a community that gets you ... doesn't have to be, but ideally (with LGBTI) ... to be in an LGBTIQA environment where people would just be wise to your needs.

Intersex and Transgender people, New South Wales

11. Care leavers

This section highlights the distinct views of care leavers including those taking part in the five in-depth interviews. These people were placed in institutional and other forms of out-of-home 'care' as children through the last century. Many suffered abuse and neglect from their carers.³ They often are referred to as 'Forgotten Australians'.

11.1. Summary

Care leavers have very distinct views regarding their older years and how they wish to live. Most care leavers said they are traumatised by the prospect of re-entering an institution, triggered by memories from their childhoods in institutional 'care'. There were a range of aspects of an aged care facility that would bring back the trauma of their youth; small window-less rooms, locked doors, communal dining rooms, institutional food, and the sound of staff walking the corridors at night.

Their experience in 'care' left all of the care leavers with an intense need for control over their environment and needing their voice to be heard and respected. They also struggled in situations with strict rules and regulations. This heightened their need to remain living independently. Some care leavers spoke about how their personal history had negatively impacted on their education, employment opportunities and financial security.

Many spoke about taking their own lives rather than move into an aged care facility. They had made plans for their older age to maximise their chances of avoiding aged care; moving closer to family, moving in with family, and undertaking adaptations to their houses to make them more suitable to their changing needs as they aged. For those care leavers who could contemplate the possibility of living in an aged care facility, a key priority was ensuring that staff are fully trauma-informed and had an understanding of care leavers' history. They also felt strongly that they would need consistent staff who could understand their specific needs; stating personal care from a stranger would trigger a traumatic response. Care leavers aspired to an aged care facility solely for care leavers so that they could live in an understanding and supportive environment.

Many care leavers have ongoing health conditions due to the harsh way in which they were treated as young people. Most also found it very distressing interacting with health professionals due to abusive experiences in their childhood, and that health professionals lack knowledge of care leavers experience and how best to support them.

Care leavers often had very close, supportive friendships with other care leavers, and spending time with these friends was highly valued. More of these times were an enjoyable prospect for their older years. While some had built successful families of their own, with supportive partners and children, others had struggled to and could not necessarily turn to family to support them as they aged.

³ For details, see the 2014 report by the Senate Community Affairs References Committee, *Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/inst_care/report/index. Many care leavers reject the term 'care' as the term does not express their experience in childhood.

11.2. Community views of older people

Care leavers did not have distinct view of ageing or older people; their perceptions were in line with the opinions of the wider population.

11.3. Community understanding and perceptions of aged care

Childhood experiences and residential aged care

The prospect of entering an aged care facility was a traumatising thought for all care leavers who participated in this research. It raised direct parallels with their experience of being institutionalised as a child and triggered much worry for them. The parallels were manifest in a number of ways, both in the echoes of the built environment, the nature of the care and the way in which life would be controlled.

(My feelings towards aged care facilities) It all stemmed from the orphanage and my independence.

Care leavers, Victoria

It can be the most little thing that will trigger off something ... a word, the way it's said. They have to understand that if I get annoyed, it's not them.

Care leavers, New South Wales

Moving to an age care facility is in essence asking care leavers to repeat the traumatic experience of their childhood; to repeat the sense of abandonment and loss of family and community.

There's the sense of abandonment in childhood. That's what I remember. Abandoned and taken out. Lost connection with my parents and that carries over. If they were to go into aged care, you're just in there to rot and die. Left to die. And that's a strong driver to keep out of that situation. That's the sense of a lot of care leavers and foster care placements.

Care leavers, Victoria

Care leavers spoke of their childhood experience causing an intense need to have control over their environment.

I don't have concerns about (the aged care system) personally. My children wouldn't put me in a home like my mother did. It's more a question of pride, having a sense of agency, that I'm in control, no one is going to control me. They haven't controlled me since I left the orphanage. I won't let anyone control my life.

Care leavers, Victoria

They were fearful of being placed in relatively small or window-less rooms, and specifically frightened of the thought that staff may be able to lock them in, that there would be a lack of privacy, or that they were vulnerable to the trauma they experienced as children.

We've got a lot of windows and there's a reason for that ... and also whether the doors are locked or not. I wouldn't want to go to a communal dining room in an aged care facility.

Care leavers, New South Wales

In a dormitory with 20 or 30 beds. Of course, there's not that scale of things in an aged care facility, but there's the feeling they won't have privacy. We all shared and bathed communally and dressed communally. Toilets were all without doors. There's that feeling of if you go into aged care, you won't have the personal privacy or care.

Care leavers, Victoria

The idea of being 'checked on' at night by staff, or even the sound of footsteps in a corridor, was deeply distressing for these care leavers.

Footsteps ... because that's what you'd hear at nighttime.

Care leavers, New South Wales

The thought of communal dining in an aged care facility brought a direct comparison with their negative childhood experiences, as did the thought of institutionally produced food. In order to avoid this distress, care leavers spoke of needing the freedom to eat meals in their rooms or elsewhere in the facility. There were also certain foods that strongly reminded them of their childhood in care and the thought of being served these foods in an institutional setting was deeply upsetting.

What type of food they serve ... most of us grew up with frogs' eyes, sago, tripe or porridge. That would be a big big turn off.

Care leavers, New South Wales

My brother (also a care leaver) has just moved into an aged care facility ... He did not go to the dining room for meals ... (he) convinced them that because he's a Forgotten Australian he can't go to the dining room because it brings back memories. They've accepted that. He didn't want them coming and checking on him between 7pm and 7am. Other little things. They give him sandwiches that he can come up and get and take to his room. People have various reasons for doing or not doing things. Mentally he's never recuperated from being a Forgotten Australian.

Care leavers, New South Wales

There's the poor food. We had masses of children, 200 children, three meals. They don't want that mass-produced food (again) ... There have been recent stories of poor quality of food in old folks' home and that would trigger (them to say) I don't want that food again.

Care leavers, Victoria

The regimented nature of their childhood experience meant that care leavers spoke of struggling with environments with strict rules and regulations. In order to feel at ease and manage any trauma triggers, they needed freedom of movement and the ability to exert control over their personal space. Care leavers need their voices to be heard and respected, something that was absent from the care they received as children.

We don't like authority.

Care leavers, New South Wales

I was institutionalised from 6 to 18. I didn't have a voice, I didn't have care and control, it was all abuse from the word go.

Care leavers, New South Wales

I think there would be mixed reactions to this ...some don't want people to know. They think ... "Treat me as a person, not as a charitable object". They don't want that stigma. But on the other hand, they want you to know why I object to having a lock on the door. I don't want to be locked in because that's what happened when we were children. I don't want strangers touching me, it's not because I'm crazy, that it's my fears of childhood returning. They might have nightmares not from being in that aged care facility but from memories, triggers from memory from when they were children.

Care leavers, Victoria

If we don't want to have a shower, that's our prerogative. But we shouldn't be forced to have a shower. Apparently in some of these facilities they still do this because of the hygiene side of it ... what right have they got to force you to have a shower? They will have issues with Forgotten Australians because they will become violent.

Care leavers, New South Wales

You can't stand face-to-face with a Forgotten Australian and raise your voice because you're stirring up a hornet's nest. You're going to get a gun barrel down your throat. They're just so angry.

Care leavers, New South Wales

Maintaining independence in older age

All care leavers spoke of avoiding aged care at any cost. They were striving to remain independent and continuing to live in their own homes till they died. For some this meant planning ahead to undertake renovations, make adaptations, or simply to move, so that their home was better suited to them as an older person. This also meant engaging with support services to help with the more practical aspects of independent living, such as household maintenance and cleaning. However, help might mean strangers entering their homes and the idea of an unknown support worker entering their home was challenging. Several care leavers described how they struggled to build trusting relationships.

Personally, we're adamant about this. My wife, she has an arts studio that backs onto our garage and I'm saying, we only have one car ... If we knock down the wall, we can put in an ensuite. We won't have to go upstairs. We can live in the studio, have the toilet and shower there. That's in my plan. It's absolutely out of the question I would go into a home.

Care leavers, Victoria

I don't want to go into a home. I think I'd try and struggle on, probably get a nurse, some home help to come. I'm very independent.

Care leavers, Victoria

We had some people help here cleaning, but they'd move stuff, remove stuff and not put it back. There are people who go through people's draws, go through cupboards – that's what I distrust.

Care leavers, Victoria

Several care leavers spoke of stockpiling pain medication so that, if the need arose, they could take their own life rather than move to an aged care facility.

I'm not going in a nursing home, I'd rather kill myself ... I know people who are stockpiling pills. Because it's like going into another institution. We started our lives in an institution and I don't want to end my life in an institution.

Care leavers, New South Wales

Getting old is scary ... a lot of people would rather die ... we feel (health professionals) aren't trauma-informed.

Care leavers, New South Wales

Trauma informed care

For the few people who could contemplate life in an aged care facility, the priority was ensuring the staff were fully trauma-informed. It was essential for staff to have an understanding of the likely life experiences of care leavers, the impacts of those experiences, and the way in which they need to be supported and cared for.

If I'm put in a facility, I'd like to know that the staff there are trauma-educated on what a Forgotten Australian has been through. The trauma of being raped, the trauma of not being able to talk to people about the situation, the trauma of being forced to eat food when you don't like that food and because you've done it wrong, being slapped across the earhole.

Care leavers, New South Wales

In addition to being suitably trauma-informed and trained, the consistency of staff was also a significant issue for care leavers. This was about stability, having meaningful connections with people who care for them, and not receiving personal care from a stranger. Many of the care leavers were also raised in foster families, as well as in care homes, and the thought of entering an aged care facility triggers the trauma of being passed from foster family to foster family and adapting to a new environment.

Never having a set of adults that you're connected with. Rostered staff and that I won't see the same staff. Strangers dressing and undressing me, I don't want that. That sense of stability. They would like to know the people (at the facility) ... and being known as person.

Care leavers, Victoria

The preference would be for dedicated aged care facilities for care leavers which could fully accommodate their support needs. As well as having appropriately trained staff, this would allow care leavers to live together. For most care leavers this was an appealing prospect as they understood each other's trauma, and, unlike residents who were not care leavers, they wouldn't have to repeatedly explain why they had specific needs, and what the source of their trauma was.

One of the good things about (Forgotten Australian's support) is we've all been there, done that, so we don't have to talk about it ... you can just get on and do things. If you're stuck in a place with other people, they're going to ask, 'What was your childhood like?'

Care leavers, New South Wales

Nursing homes for Forgotten Australians ... we'd all have each other ... they'd have to get the sort of people who are trained and understand us ... understanding and caring people, so kind, nothing's a problem ... you'd need flexibility, not have it run like a regiment. People who understand us, (that) we've been bashed and locked in cells and all that kind of stuff.

Care leavers, New South Wales

Open up an aged facility for Forgotten Australians, because what better scenario could it be ... these people know my trauma, I'm going to be open arms, take me and look after me till I die. That would be gold to hear there is a facility like that.

Care leavers, New South Wales

11.4. Planning, preparation and expectations of own older age

The experience of growing up in 'care' and the harsh physical treatment that many care leavers had received left some with long term health conditions that were becoming more apparent and problematic as they aged.

My health ... hard labour and conditions imposed in those homes.

Care leavers, New South Wales

Care leavers often say that they're not in good health because their early life, no visits to the dentist and no regular medical attention and that kind of neglect.

Care leavers, Victoria

Interacting with health professionals and hospital settings was very distressing for many care leavers. The institutional nature of a hospital setting brought back echoes of their childhood experience in care. For some this related to the physical environment, for example being kept in an enclosed space, potentially with limited access to daylight. For others it was about the presence of health professionals wearing uniforms and behaving in ways that were similar to those of the staff in the care homes.

They didn't know what a Forgotten Australian was, they didn't know why I needed a private room, but jeez didn't I educate them over four days. I got what I wanted but it was with a big fight. Getting them to understand that I've always been institutionalised and that being in a hospital ... not a happy place ... I was listened to, I got a private room ... 'cos I didn't want any male doctors, they had to be female. I had a whole new cancer team.

Care leavers, New South Wales

Care leavers commented that the vast majority of health professionals they have met are unaware of their situation as 'Forgotten Australians' and what this means in terms of the nature of the care they need. It was very difficult for care leavers to repeatedly educate these health professionals and persuade them to take account of their requirements. For many the prospect of greater interaction with hospitals and health professionals was a daunting aspect of older age.

As with the wider public, care leavers often reported that they first engaged with the topic of their approaching older age following a significant health event. For some this raised the realisation of how they might struggle to cope with the potential need to move to an aged care facility. They mostly did not have parental role models to follow, and their fears and trauma had deterred them from engaging in any form of planning or preparation of how they would be cared for in their older age.

There was nothing in place for my two children ... they didn't know what to do either ... I didn't have anything ... I've never been able to be that adult ... Getting old for me is scary.
Care leavers, New South Wales

I'm 58 ... me getting cancer and the big scare that I've recently had, has made me think that I've got nothing in place. As Forgotten Australians we've not thought ahead. We've been stuck dealing with our childhood trauma.
Care leavers, New South Wales

Some of the care leavers referred to having limited education and training due to their childhood in care, leaving them with limited employment opportunities. While this was not universally the case, many commented on earning lower income during their working life, leaving them with less financial security than might otherwise be the case.

We could only do jobs like housecleaning and nursing homes ... to have financial security, very important when you're older ... because we'd been in homes, we didn't have good jobs, the chance to go to Uni, I could've been something ... we didn't have the same chances as other people.
Care leavers, New South Wales

Like others, care leavers were keen to remain living independently in their homes for as long as possible, due to their personal history. They spoke of finding new environments challenging, of needing to be in control of their environment to a greater degree than most and of struggling to interact with wider society.

I don't particularly want to live here but I don't see that I've got any alternative ... I like it here and I'm well known around the place. There's only four units here and I know this sounds awful, but I control this place, and I've had to because of drug addicts that have moved in.
Care leavers, New South Wales

It's a lonely life for Forgotten Australians as a lot of us don't like mixing ... we can talk amongst ourselves, but we don't know how to interact with the rest of the community. It's a big eye opener for us going into a facility.
Care leavers, New South Wales

Many care leavers stated that, rather than leave their home, they would stockpile pain medication and use this to take their own lives in the event that they have no choice but to move to an aged care facility.

Family, friends and relationships

The impact of their childhood experiences has been that many care leavers are hesitant to trust others and family relationships can be hard. Community and social interaction was important for care leavers as they age, and it was also very challenging. They reported finding it difficult to build relationships with those who do not know their history and the damage it has caused, while simultaneously not wishing to be burdened with explaining this to all new friends they meet. Many care leavers spoke of true friendships really only being possible with other care leavers who understood the depth of their trauma and appreciated the way in which their care and environment needs to be moderated for them to be at ease.

I've kept in touch with a lot of the people I was in the institutions with ... a lot of them have died, I've been and sat with them ... they're my family.

Care leavers, New South Wales

Some care leavers still have relationships with older and peer family members, but these were not always reliable relationships in which they could place much trust. As such, interaction with, and support from, parents, uncles, aunts and siblings did not necessarily form part of how they envisaged their older years.

My sister rang me the other day for my birthday, she only lives in (location) and that's not far, and she hasn't seen me in 24 years, I just can't be bothered. I think more of that table (than I do of her).

Care leavers, New South Wales

If you've got family, you've got family who might look after you, or they might just shut the door on you ... What if you've got no-one?

Care leavers, New South Wales

That's s a common feature of care leavers. They don't have a close-knit family. They can't rely on siblings. Parents are well dead. They are left with no close-knit support.

Care leavers, Victoria

One of the reasons is my family. When I came home from the orphanage, I did a lot of things for them, money wise, and did a lot for their kids and was treated badly. The kids would steal from me ... and it wasn't just a cigarette ... so there would be distrust.

Care leavers, Victoria

Many had gone on to have successful families of their own, and their partners and children were supportive of their needs and very important in how they saw their older age. For others, they had struggled to parent given their own childhood experience, and these care leavers did not have functional relationships with their children.

Many of the care leavers say, I've never been a good parent. I didn't know how to be. I was too tough on them. Because I didn't want things that happen to me. They don't talk to me and now I've alienated them.

Care leavers, Victoria

12. Parents separated from their children by forced adoption or removal

This section highlights the distinct views of parents who were separated from their children by forced adoption or removal. Separation was common in Australia in the post-war period because the parents, particularly mothers, were forced to relinquish their children or faced circumstances in which they were left with no other choice.⁴ The views in this section include those taking part in five in-depth interviews.

12.1. Summary

Those separated from their children by forced adoption or removal were likely to be suffering ongoing mental health challenges due to the lifelong distress of the loss of their child. This ongoing grief was seen as having a heavy mental and physical toll, leading to more rapid ageing or premature death. Like care leavers, some parents separated from their children by forced adoption or removal also suffered poorer physical health as a consequence of the treatment they received during their pregnancy and the birth of their child. Several had attempted suicide over the years, and the pain of their loss had not diminished. All of these women had sought to connect with their lost child and to establish an ongoing relationship. These were all challenging relationships and most had not been successfully sustained.

Many parents separated from their children by forced adoption or removal were fearful of the idea of moving to aged care. A few – like care leavers – would prefer to take their own lives rather than live in an aged care facility. Their fear of this prospect was triggered by the loss of control and thought of being in an environment where their voices might not be heard. These women needed to maintain agency over all aspects of their lives.

Similar to care leavers, parents separated from their children by forced adoption or removal found interacting with health professionals triggered their past trauma, and they had significant fears around being restrained or held in confined spaces.

Many women have kept the loss of their child as a ‘shameful’ secret. This has negatively impacted on their ability to build trusting friendships and lifelong partnerships. For those who did not go on to have other children, their relationships with siblings are also strained as they witness these family members enjoy the pleasures of being a parent or grandparent. This lack of social and family support made some fearful that they would be very lonely and isolated within an aged care facility.

⁴ For detail, see the 2012 report by the Senate Community Affairs References Committee report, *Commonwealth Contribution to Former Forced Adoption Policies and Practices*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2010-13/commcontribformerforcedadoption/report/c01

12.2. Community views of older people

Greater mental and physical support

Parents separated from their children by forced adoption or removal shared the breadth of views of ageing and older people expressed by the wider population. To this, they also added their distinct experience of having suffered ongoing mental health challenges as a consequence of having their child forcibly removed, and this had taken a toll on their physical well-being. These parents believed the experience of having their child forcibly adopted led to more rapid ageing and premature death due to the pressure of their loss and ongoing grief.

If a person's in a state where they're not able to feel comfortable, powerful, in control, which a lot of these mothers can't, they're going to have more psychological problems, more physical problems ... it all goes hand in hand.

Parents separated from their children by forced adoption or removal, New South Wales

When they start losing their memory, thinking about the past, getting physically weaker.

Parents separated from their children by forced adoption or removal, New South Wales

Grief and loss remain with these women throughout their lives. The distance in time from the loss of their child in no way alleviates their pain, and grief and loss were intense in every aspect of these women's lives. For these women suffering was perceived to likely continue into their older age.

The older I get, the more I'm impacted by what happened in Crown Street in 1967.⁵ It's to do with social justice, it's to do with mental health, and the fact that we were judged by society to be unfit to raise our own children.

Parents separated from their children by forced adoption or removal, New South Wales

I don't know if I'm going to last ten years, I've got very maudlin. I've seen a lot of women like myself just die ... they just fade away ... a lot of them didn't see their sixties out ... they grieved themselves to death. It's a slow form of suicide ... unable to engage with the rest of the world and she just slowly slid away.

Parents separated from their children by forced adoption or removal, New South Wales

Those who had not gone on to have other children also felt the loss as they watched others around them enjoy the pleasures of family life and the ongoing support of children, grandchildren and great-grandchildren.

I have three older sisters, the oldest has two children, the next has two children ... they have a support system ... I feel there's no support for me.

Parents separated from their children by forced adoption or removal, New South Wales

⁵ Crown Street Women's Hospital operated between 1897-1983. Many women had their baby forcibly removed by authorities and adopted to couples wanting to have children. In 1971-72 there were 10,000 adoptions across Australia. Crown Street Women's Hospital cared for many unmarried mothers, including state wards and Aboriginal girls who were in the wardship of the Aborigines Protection and Welfare Boards. Crown Street Women's Hospital developed a major adoption service, arranging a high proportion of the state's adoptions.

<https://www.findandconnect.gov.au/guide/nsw/NE00446>

They spoke about the challenges of attempting or maintaining a relationship with their forcibly adopted child later in life. For many, this had not led to a permanent, ongoing and functional relationship. For those that did have a relationship with the adult child, it tended to add to their physical and mental strain.

My neurologist said to me, 'Honestly, I think that a lot of what's happened to you is because of what's happening with you and your son at the moment' ... he never saw me ... he was so angry, he wasn't talking to me.

Parents separated from their children by forced adoption or removal, New South Wales

My son says I cannot have contact with my granddaughters and, I suspect, great-grandchildren, because they would get close to me and I would abandon them, like I've abandoned him.

Parents separated from their children by forced adoption or removal, New South Wales

Some also raised how their physical health had been negatively impacted. This tended to be due to painful, harsh treatment by health professionals during the later stages of pregnancy or during the birth of their child.

They almost broke my back when they delivered my son, the way they had me tied up, it's affected me since my twenties ... they had me tied down, leg up in stirrups ... I've had back problems ... the pain depresses me a lot.

Parents separated from their children by forced adoption or removal, New South Wales

The most eminent gynaecologist in New South Wales ... I'm in the labour ward ... he puts his head in the door and the sister says to him 'Oh, Professor ... what should we do?' He looked around and said, 'Where's the family? Oh, she's one of the single mothers, well then, do what you bloody well like', and he walked off.

Parents separated from their children by forced adoption or removal, New South Wales

Several women also spoke of being given a range of medication to subdue them during the birth and obscure their memory of the event. They understood that these medications had raised their risk of having cancer.

We were given a whole lot of drugs, psycho-tropic drugs during the labour, that's why we have lots of fragmented memory about what's happened to us ... to make the experience unreal ... carcinogenic drugs ... and a lot of the women have some sort of cancer.

Parents separated from their children by forced adoption or removal, New South Wales

12.3. Community understanding and perceptions of aged care

The prospect of entering an aged care facility was a fearful one for many parents separated from their children by forced adoption or removal. It does not directly trigger negative recollections of their experience of institutionalisation during hospitalisation in the same way as it does for care leavers. Rather, it is associated with the fundamental aspect of control and how this was wholly absent during their pregnancy and birth of their child that was forcibly adopted. They clearly articulated that they need agency over their choices in life and specifically during their older years.

When I came out of the home, I was fearful of the outside world. It doesn't overly concern me that I may end up in an institution in my old age – my fear is what they'll do when I get there. And you don't have anyone to cry out to, to rescue you, to keep you safe.

Parents separated from their children by forced adoption or removal, New South Wales

These women spoke of how the experience of the loss of their child, and the environment in which it took place, left them with significant trauma and fear when they interacted with health professionals or were in a health or care environment. For some, this lack of control related directly to ways in which they had been restrained or examined during their hospitalisation. Despite significant psychological support over the years, this trauma was undiminished for many of these parents.

I don't like people holding me down ... people getting too close to me physically ... I don't know if I could stand being physically touched.

Parents separated from their children by forced adoption or removal, New South Wales

My major concern is my fear of being restrained ... it creates that panic. I don't like people getting too close to me physically. That's my biggest fear in terms of nursing homes.

Parents separated from their children by forced adoption or removal, New South Wales

About seven years ago my GP wanted to send me for a colonoscopy In hospital ... they came at me and I lost it, I ended up in the foetal position in the corner of the ward in tears. I cannot stand it for anybody to touch me ... I can't do it ... I actually ran away.

Parents separated from their children by forced adoption or removal, New South Wales

For other women, the experience of restraint was imposed by their families, being kept in their bedrooms for months, and being banned from leaving the house or appearing in public during their pregnancy because of the 'shame' it would bring on their family. As a consequence, these women had trauma about being held in confined spaces.

I have very intense spatial issues from being in that room ... being confined in anything. I can't bear the thought of leaving this place ... I like my own space, I trust my own space. I don't trust other people's spaces so well.

Parents separated from their children by forced adoption or removal, New South Wales

They held me hostage in one sense ... I have to get out (of this house) every day, otherwise I feel anxiety ... so I can still feel that I've got control, that I can get away if it's upsetting me.

Parents separated from their children by forced adoption or removal, New South Wales

However, for several, an aged care facility could be acceptable, given certain conditions. These women felt they were not listened to in relation to the forced adoption, so recognition of their needs and their wishes is vital for an environment to be welcoming and comfortable. They said this would mean the facility would have staff who understood their history and did not judge them. Importantly, it meant facilities that were better resourced so that staff had more time to listen, talk and support these women.

There's a level of understanding among women that can be broken down ... the biggest problem is women being silenced.

Parents separated from their children by forced adoption or removal, New South Wales

They don't have time to sit and talk to some of these people and that's what they need to do.
Parents separated from their children by forced adoption or removal, New South Wales

There was also concern that many parents of forced adoption have never talked about, or sought psychological support for, the impact of forced adoption. They fear this unresolved trauma would manifest itself in how these women behaved in aged care, and this is another reason there needed to be appropriate resources including trained trauma-informed staff.

There are hundreds and thousands (of mothers of forced adoption) who haven't come out of the closet yet. When it comes to the end of their lives, everything that they've suppressed as they face whatever they're facing, it's going to come out. They're going to be sitting there in silence, in tears, with no mental health history and suddenly this blob in the corner who's crying, who's in a foetal position and staff (won't understand) ... it will come out, it can't not come out.

Parents separated from their children by forced adoption or removal, New South Wales

12.4. Planning, preparation and expectations of own older age

Trauma and loneliness

The parents separated from their children by forced adoption or removal were very aware of having carried a lifelong secret. They felt judged by society as having done something 'wrong', and, as such, this led to most of these women feeling they could not be open with their friendships, and how they related to others. Throughout their lives this had led to isolation, and older age was thought likely to exacerbate this situation.

I've cut myself off from everyone I've loved, in some respect.

Parents separated from their children by forced adoption or removal, New South Wales

It's a life sentence, punished by society, punished by everyone we were in contact with.

Parents separated from their children by forced adoption or removal, New South Wales

I've found it very hard to make friends because when you've got all the secrets I've got, nobody really knows you. You don't get close to people ... and I can't tell them now, I'm too old.

Parents separated from their children by forced adoption or removal, New South Wales

There's an unresolved sense of injustice ... we're still scorned by society ... women that never got over the stigma of saying you lost a child to adoption. Very little sympathy from society and the government for our issue. They still looked down on us as immoral women who bought those children into the world ... women have carried that guilt and that stigma all of their lives ... women that have never found true acceptance in the world. In one sense we are still social outcasts.

Parents separated from their children by forced adoption or removal, New South Wales

Furthermore, there was ongoing distress in seeing siblings enjoying family life, when their family life was limited and often fraught with pain.

Her family don't support her ... they've ostracised her.

Parents separated from their children by forced adoption or removal, New South Wales

I will do everything I can do to avoid Christmas with my sisters and their children ... a sense of they're all included with one another, they have that common bond of having their children and grandchildren ... I don't have any of that.

Parents separated from their children by forced adoption or removal, New South Wales

(Friends have) got other children. When you don't have children, you have nothing. All your conversation is about children when you're young, when you're older, its grandchildren. All these groups, it's what they talk about, and I'm on the fringe.

Parents separated from their children by forced adoption or removal, New South Wales

Financial insecurity

For some of these women, their employment opportunities had been impacted by their experience of losing their child. As a consequence, they were not as financially secure as they might otherwise have been. When compared to how their family members' lives had developed and prospered, this was another source of distress.

My sister's husband died this year, left her with a waterfront house in (location) and probably close to \$4 million in the bank, and I live in housing commission. There's a social divide as well as a sense of exclusion ... I guess I'm a failure all round.

Parents separated from their children by forced adoption or removal, New South Wales

The need for control

For all of the above reasons, in looking forward to their later years, the **issue of control** remained key for parents separated from their children by forced adoption or removal. They were very clear how they wanted their older years to be spent: living independently in a manner of their own choosing.

If the focus could be on providing support in your own home for these mothers ... the biggest problem for these women is that they had no choice. It's giving them a choice, and I think there's an enormous amount of healing in that choice. If these women want to stay in their own homes, then there should be a major focus on letting that happen for these women, they deserve it. They deserve to have that power given back to them.

Parents separated from their children by forced adoption or removal, New South Wales

These women were fearful of entering aged care partly due to their lack of social support, be it from family or friends. Due to the impact of 'carrying' the secret of the forced adoption all their lives, they struggled with trust, which limited the scope of friendships. Furthermore, due to the way their family had responded to their pregnancy, and birth of the child, they either did not have, or could not rely on, family to provide the support they would need in such a facility.

I will do everything in my power to keep out of it. Yes, I would prefer to be dead than to go into (aged care) ... that is going to be total isolation for me, I don't have any children, my sisters are all older than me, I'll be on my own ... there won't be anybody to come and visit me.

Parents separated from their children by forced adoption or removal, New South Wales

Isolation; a lot of women never married, never had other children. They've lost a lot of family support, people to take care of them. They estimate that 50% of women never had a relationship, never had another child. That's a major thing ... they still don't forget their child, they still grieve over a baby. It's the thing about ending up somewhere where you're alone ... when you've lost a child you never get over that grief, you feel alone all your life.

Parents separated from their children by forced adoption or removal, New South Wales

As with the care leavers, there are some parents separated from their children by forced adoption or removal for whom the prospect of an aged care facility is sufficiently frightening that they would prefer to end their life.

I've got 300 odd (painkillers) and a whole lot of Endone ... the last time I tried I got it wrong by one tablet.

Parents separated from their children by forced adoption or removal, New South Wales

13. People who are homeless or at risk of homelessness

This section highlights the distinct views of people who are homeless or at risk of homelessness. This includes those taking part in the five in-depth interviews.

13.1. Summary

People who are homeless or at risk of homelessness tended to be aware that their situation – lack of consistent housing, minimal health care, stress and social isolation – contributed to their premature ageing. The uncertainty surrounding their lives left them vulnerable and it was very frightening for them to consider their old age and what it might be like.

For these participants, their lack of housing, or uncertainty about future housing, overshadowed all other considerations. All were actively striving to secure more stable housing but due to their financial vulnerability this was not something they had agency over. Access to a bed was conditional on other's decisions and on their complying with behavioural rules for specific accommodation.

Given their financial insecurity, they tended to presume they would have little choice about the public aged care facility they might be offered in the future. This raised concerns regarding the quality of these facilities and the nature of the other residents. They tended to view aged care facilities as restrictive environments, akin to prisons.

Many of the people homeless or at risk of homelessness were simultaneously managing ongoing mental and physical health problems. This impacted on their quality of life and their ability to make progress in housing or employment. Some people were trying to secure jobs but, as they aged, were aware that they faced prejudice and had diminishing opportunities. However, their financial insecurity was such that they discussed needing to work into their seventies and beyond.

Family relationships for these people were either absent, limited or strained. Some had supportive friendships; others spoke about not being able to trust the people they came into contact with. This meant that they lacked reliable ongoing family and social support and were more concerned than other groups by the fear of loneliness and social isolation in their older age.

13.2. Community views of older people

Among the people who were homeless, or at risk of homelessness, there was some recognition that the nature of their lives exacerbates the ageing process. Lack of housing and support, sometimes untreated physical and mental health, stress and loneliness, were all mentioned as aspects of their situation which contributed towards premature ageing, compared to the wider population.

If the person is sick, if the person has nobody around her, nobody listen to her, she become older quicker. I think because I had a bigger problem and nobody want to listen me and that make me very unhappy. Maybe because I am stranger, because I am sick ... they see you as

older lady. They did not want to help me.

People who are homeless or at risk of homelessness, New South Wales

Many of society's life stage expectations – those things that mark maturity or mid-life, such as a steady employment, a settled family life or permanent housing – have not occurred for these participants. These people feel such uncertainty and vulnerability about their current situation that looking forward to an older age was extremely frightening. Unsurprisingly, this group of people were very concerned about their housing situation as they aged, more than other groups. This factor obscured all other considerations about their future.

Depends which day you ask me. I did think 60 was old ... whereas now, I don't know. I sure as hell don't feel happy, comfortable or young. It's the fear of the unknown. Its day by day, will I get government housing?

People who are homeless or at risk of homelessness, New South Wales

Housing, definitely housing is something I'm always worried about ... I don't have any super or anything, so housing is a real concern. And my disabilities will just get worse.

People who are homeless or at risk of homelessness, Victoria

Loneliness was a greater concern among those who were homeless, or at risk of homelessness, than for the wider population. While some of these individuals had limited social support, others felt more isolated and many had no or limited contact and interaction with family. The emotional support together with mental, physical and social stimulation provided by organisations working with this community were vital in maintaining their wellbeing.

Finding things to do. I live in the city and there's nothing to do ... I hang out where the meals are, and for the company as well ... If I don't work with (name of organisation working with people at risk), I sit at home and do nothing. I isolate myself.

People who are homeless or at risk of homelessness, Victoria

We get treated like we're invisible. That's the idea for the tattoos – that stops that ... no-one wants to know me, so I thought, 'Bugger', I did the whole lot. People come up and talk to me, people smile at me ... so people can take notice of who I am and what I am.

People who are homeless or at risk of homelessness, Victoria

13.3. Community understanding and perceptions of aged care

People who are homeless, or at risk of homelessness were very much focused on tackling the housing and health issues that they currently faced and none had given much thought to their care in later years. They were mostly frightened to think that far into the future and had very little knowledge of what their options might be. Their fear was fuelled by their lack of agency over their future.

Housing security

For some people currently in permanent housing, the change inherent in moving to a different institutional setting was a significant worry. They had built strong, trusting relationships with housing officers and were fearful of losing these supportive connections.

(What do you know about the aged care system?) Being honest, bugger all. I know with winter coming there's a package I can claim, but I don't want to claim it ... 'cos I'll lose my housing officer ... I've built the trust up with them. And I don't like changes.

People who are homeless or at risk of homelessness, Victoria

There was concern that their financial insecurity, and consequent limited choice, would mean that they spent their older years in a low-quality aged care facility. This was seen as similar to some of the shelters that they had previously lived in and this was a significant worry, both in terms of the quality of their care and also the other residents.

Not good ... the conditions ... that's scary, that I'll be left alone in what seems to me, unhygienic. It's another version of here (homeless shelter), down-and-out completely. The private one's are fantabulous ... but if we get down to the basic levels, that would terrify me, the people I'd be with, incontinence ... you come to terms with where you're at. Seeing it happen to my dad, this is what lies ahead.

People who are homeless, or at risk of homelessness, New South Wales

One aspect of their life was that they had a lot of physical freedom and an aged care facility was viewed as being a very restrictive way of life.

(Being asked to move to a nursing home) It'd be a fight, I can tell you ... all the memories that I'd lose. Touch wood I'll stay (in current accommodation) till the day I die. For me a nursing home would feel like a prison. You've got to rely on other people to feed you ... to me that's a prison. You haven't got the freedom to come and go as you want.

People who are homeless or at risk of homelessness, Victoria

13.4. Planning, preparation and expectations of own older age

It was extremely challenging for people who were homeless, or at risk of becoming homeless, to think about what their later years might be like. For each of them, their current situation had multiple challenges around achieving and retaining permanent housing, improving their financial security, and managing ongoing physical and mental health conditions.

Those who were currently homeless were focused on improving their current situation, and the aim of permanent housing overshadowed most other considerations. Given the precarious nature of their situation, they found it frightening to think about their older age.

I don't really think about it too much because I get a bit of fear. Where am I going to end up? ... so, I guess I tend to focus on the moment, how am I going to go right here, right now?

People who are homeless, or at risk of homelessness, New South Wales

Participants who were currently housed, but remained at risk of homelessness, were marginally more able to consider the longer term. However, the future was still daunting for them to think about and without resources they had not made, and were not in the process of making, plans about their older age.

Support in older age

Most, if not all, of the people who were homeless, or at risk of homelessness, were managing ongoing physical and mental health conditions, that impacted on their current quality of life to a greater extent than other people in this research. The management of these conditions consumed significant amounts of their time and limited their scope to make change in other areas of their lives.

Mental health aspect, I haven't been able to move on from the marriage. Working as hard as I can in that way.

People who are homeless, or at risk of homelessness, New South Wales

The disabilities I have restrict what I can and can't do.

People who are homeless or at risk of homelessness, Victoria

I have to do exercises, specific ones. There's things that I can't do ... also I have to go to the chiropractor, acupuncture, physiotherapy, psychologist, psychiatrist – it's all about maintenance.

People who are homeless or at risk of homelessness, Victoria

These people were very aware of the need to improve their health and were actively engaged in dealing with current health challenges and adopting positive changes that would improve their condition.

I've thought long and hard about (health) in the last two years and I've given up cigarettes, I've turned vegan, and I exercise. I want to try and get as far ahead in the race as possible. ... At 52, I got diagnosed with emphysema.

People who are homeless, or at risk of homelessness, New South Wales

Financial vulnerability and work

Financial security was a very significant issue for people who are homeless, or at risk of homelessness. Regaining employment was a fundamental part of their plans to improve both their housing position and financial security as they moved forward. They were motivated to remain employed into their later years so that they had both a better income and were also contributing to their superfund.

Where am I going to end up? Will I have enough money to bury myself?

People who are homeless, or at risk of homelessness, New South Wales

I'm one of those foolish people that lived their life in reverse, I partied when I was young, I didn't think about the future, superannuation or anything like that, so now, at this stage of my life when I should be winding down and getting ready to retire, I have to work. I'm looking at working to 75 or 80, just to get a little bit of super together.

People who are homeless, or at risk of homelessness, New South Wales

Participants were very aware that in the sectors where they were looking for work, they may face prejudice based on their age, appearance, strength or stamina. While they were relatively confident that they had strong skills and experience to offer an employer, they did not think these would necessarily be valued over the appeal of a younger candidate.

I feel I'm just about hitting my 'use by date' ... if I go for a job ... I'm from (location), a very youth orientated town and I found it increasingly more and more difficult to secure employment because I don't have what's considered to be a front of house look. I'm not beautiful, I'm not young, I'm not fresh. I got stuck in the back of the kitchen washing dishes.
People who are homeless, or at risk of homelessness, New South Wales

If there's me and a 22-year old sitting at the table asking for the same job, I'm more likely going to bring rationality and maturity and stability to the workplace more so than the young person ... I'm getting a little confused sometimes as to why everyone isn't treated equally, why there's an imbalance in society.
People who are homeless, or at risk of homelessness, New South Wales

Several of those who were homeless or at risk of becoming homeless were in the process of either retraining or enhancing their skills. This was primarily to improve their employment prospects, but for some it was also a source of pride, and to illustrate to their families that they were focused on getting their lives back to a more stable position.

A part-time job, or a naughty job (cash) ... I've been slapped around enough ... along with that, I want to continue on with a Bachelor of Arts in property valuation ... I want that as a piece of paper. I want that for the kids. With that sort of scenario, you can almost get a job.
People who are homeless, or at risk of homelessness, New South Wales

Future housing

Looking forward to where they might be living in later years was extremely challenging for people who were homeless, or at risk of homelessness. They were mostly focused on complying with the current conditions that accompanied their temporary housing and receiving permanent social housing.

Apparently, it's a three month (waiting list). And if you're fulfilling your obligations, we all have to cook for each other, clean... they're not going to kick you out ... particularly at my age ... if you get into the drugs and alcohol, you're straight out the door.
People who are homeless, or at risk of homelessness, New South Wales

Some were optimistic that by working into their later years, they may accrue enough money to purchase a modest home.

I'm never going to own a home, that opportunity has passed me by, I accept that. If I can accumulate enough money by my late seventies, hopefully I can buy a houseboat or a camper van.
People who are homeless, or at risk of homelessness, New South Wales

Permanent housing was also seen as a key enabler for people who are homeless or at risk of homelessness in maintaining and progressing family relationships.

Hope the case worker here will get me priority because of my age and the children. The utopia is to have my own house, have the children over on Sundays and cooking ... that's the sort of stuff that grounds you.

People who are homeless, or at risk of homelessness, New South Wales

For some people who currently had permanent housing, but were still at risk of homelessness, their ongoing mental health condition meant that they struggled to maintain their tenancy. This vulnerability created instability and reduced their capacity to consider their home as a longer-term housing option.

For me, I am not welcome for the public housing ... if they give me places with bad situation like Waterloo, like Redfern ... they don't have another place ... people who drink too much ... smoking, drinking, drugs etc. ... if I have a problem I go to public housing and they resolve them ... they didn't want to help me, and me, I was screaming ... The social worker sent me to (name of service) for women and girl, but they didn't want me because my character is rebellious.

People who are homeless, or at risk of homelessness, New South Wales

Family support

A minority of people who were homeless, or at risk of homelessness, had ongoing and highly valued relationships with family members. Maintaining and enabling these relationships in a positive and supportive manner were crucial to how these people saw their future and were key considerations in any plans they made.

Concern for my children and their future – and my worries are multiplied because I'm not there.

People who are homeless, or at risk of homelessness, New South Wales

It would be ideal if I could stay near family, particularly my daughter ... we'd support each other.

People who are homeless or at risk of homelessness, Victoria

However, most no longer had contact with family members. Many people were socially isolated and described themselves as having few, or no, friends. Some talked about seeking out activities and volunteering roles to provide social interaction, but family and friends did not form part of their plans when contemplating their older age.

I don't have friends, I don't have family ... I didn't know where to go, I didn't know what to do.

People who are homeless, or at risk of homelessness, New South Wales

(My kids) they don't want much to do with me, mostly because of my addiction ... I've had occasional contact with them now and then, but they're not really interested ... that's the price I pay for the choices I made ... they don't want me in their life, they don't need me in their lives, I just love them from a distance and wish them well.

People who are homeless, or at risk of homelessness, New South Wales

14. Young people living in residential care

This section highlights the distinct views of young people (those aged under 65 years) living in residential aged care and includes those taking part in five in-depth interviews. Some of these interviews were conducted directly with the young people living in residential care; others were conducted with a family member as the young person's representative, due to the limitations of verbal interviews.

14.1. Summary

Young people living in residential care were the only audience currently receiving aged care in a residential facility. As such, they were very well informed about the process of getting a place in care and were also extremely critical of the care they received.

Young people or their carers described how it was not difficult finding a place in aged care, but it was extremely difficult finding a place that was an appropriate environment that provided adequately trained staff to care for their needs. Several reported that the reality of living in the facility and the quality of care was markedly different from their expectations. Their criticisms focused on personal hygiene, cleanliness of the premises, activities and stimulation for residents and respect and dignity of care.

Some were living in facilities where staff did not have the specialist training to appropriately undertake their care. They also expressed frustration that overseas staff had lower levels of training and that their English-proficiency was poor, hindering communication and the building of positive relationships between young residents and staff. They perceived the facilities as being understaffed; staff were generally rushed, and not able – or motivated – to provide personal attention.

As the only audience with current experience in residential aged care, these participants were more likely to highlight the need for family to be vigilante and actively engaged in their care. Even with daily visits by family, young people in residential aged care (or their representatives) highlighted incidents of residents being unattended for long periods of time and put in nappies or medicated for the staff's convenience, not the residents' benefit.

A lack of appropriate social engagement is a substantial concern as these young people are surrounded by people who are significantly older. They talked about withdrawing from forming friendships as they found it difficult to repeatedly get to know other residents, only for them to die. They recognised that the rules and regulations that supported safe care for older residents were frequently very restrictive for them as younger residents. Young aged care residents were also critical of the food. They understood that the food was very soft to accommodate older residents, but this was not always necessary for them, and was an unpleasant aspect of their living conditions.

Like the rest of the population, young people living in residential care were aiming to maximise their independence. Given their care needs, and limited housing options, maintaining independence was a frustrating challenge.

14.2. Community views of older people

The views of ageing and older people among young people living in residential care were not distinct from the wider population.

14.3. Community understanding and perceptions of aged care

Most participants who were younger people living in residential aged care had experienced a particularly difficult time finding appropriate accommodation to suit their care needs. Their specific medical and physical requirements meant that the number of facilities with appropriately trained staff and environment were very limited. Even if an appropriate facility was identified, this did not necessarily mean a place was available.

For several participants, the challenge in finding an appropriate care setting meant that they had repeatedly moved from one setting to another. In some cases, this meant bouncing back and forward between a hospital intensive care setting and an aged care facility.

She was in hospital for three months, and they said, 'This is it, she can't stay here anymore, she'll have to move to a nursing home'. I said, 'Why? Nursing home can't take care of intense care like that' ... they don't want to know. The hospital picked the nursing home for her because I refused to – and within three months, she ended up in ICU eight times.

Young people living in residential aged care, New South Wales

Participants spoke of finding what they considered an appropriate and appealing aged care facility but having their applications refused when the facility recognised the high level of care that would be required.

I went to 25 nursing homes. Every time I put the application form in, they walked away. These nursing homes that I knew and liked were too smart, they won't take her, too much responsibility, 'We don't do trachea care'. And the one that took her, they don't care. Now she's in care with one-on-one nurse, this is a miracle.

Young people living in residential aged care, New South Wales

One young person had transitioned through a capital city rehabilitation centre and subsequently sought ongoing residential care to be nearer to their regionally-based family. The lack of choice of regional facilities meant that, although they had moved nearer to family, they were not sufficiently close to enable regular interaction with and support from family and friends. They also missed the busier, more stimulating environment of the rehabilitation centre, and felt isolated and lonely in the aged care facility that was overwhelmingly populated by residents who were so much older than them.

The reality of residential aged care for young people

Many of the participants commented that while they were initially impressed by well-presented reception areas or communal spaces in aged care facilities, this did not represent the actual quality of care being provided. Having lived in the facility for a period of time, they became starkly aware that the facility was run as a business and corners were being cut to maximise profits.

Aged care strips you of your autonomy, your dignity, it's all about money. There's a chandelier when you walk in (reception of the aged care home) – I want to smash it down. It looks like a hotel, but you're treated like dirt.

Young people living in residential aged care, Victoria

Two years ago (when looking around care homes for my daughter) I would have said they look beautiful, but behind closed doors (it's very different) ... I called around a few different ones, had a tour, the one she went into sounded good, looked beautiful. They sold it to you, they said she'd have this and that... she was meant to go to the dementia part but then actually went to the high care part and was sharing a room with a 90-year old – I cracked it! But I was told no private room was available. Once they got her in and you'd signed documents, it was different (to how it was sold).

Young people living in residential aged care, Victoria

When I first saw the aged care home, I thought, look at the home, look at the fountain! Isn't it beautiful! Look at the furniture! The outdoor space... (but then) why don't you use it? They're too busy to supervise out there so the door's always locked.

Young people living in residential aged care, Victoria

I realised I was a dollar figure to them. And the finance person didn't even change expressions when, I asked, 'Can I stay here (in another safer room) for my mental health, and safety?' and she said, 'It's three dollars different a day' ... the other room had a view of a court yard. It's all about size and viewing vantages. The rooms are exactly the same size room but in a different area. One's more safe and secure, more staff on that side. No staff on the whole corridor, where I am now.

Young people living in residential aged care, Victoria

Most of the young people in residential aged care, or their carers, were extremely critical of the care they were receiving. This ranged across aspects of basic personal hygiene, cleanliness of the premises, activities and stimulation, and respect and dignity. The lack of appropriate care meant that some people felt their condition had deteriorated since entering residential aged care.

The cleaners are a joke, they use the same mop bucket for every room, including areas where people have their accidents or in the bathroom.

Young people living in residential aged care, Victoria

Living in aged care is one of the cruellest things, you can lie cold and wet in your own bed... Thank goodness I have my voice (and can call out to staff).

Young people living in residential aged care, Victoria

Here there is zero brain stimulation, perhaps bingo at best. If you don't eat at 12pm (lunch) or 5pm (dinner) you go hungry. It's an institution.

Young people living in residential aged care, Victoria

On day one they had her in a nappy, but she could go to the toilet. They put her in a wheelchair, but she had a walking frame. She needed to use it or lose it. She forgot how to walk and go to the toilet (as a result of being there). It took her too long for her to feed herself so they shoved it down her throat to get her to bed by 6pm.

Young people living in residential aged care, Victoria

With the old people (in my daughter's facility) I would notice they'd come in a wheelchair, then (progress to) a princess chair, then die! They walk in healthy but go downhill because it's depressing.

Young people living in residential aged care, Victoria

Living in an environment where people around you are significantly older also presents a number of challenges for young people in residential aged care. Some spoke of initially building relationships with other residents but as, over time, these people would die, they chose to engage less so that they did not repeatedly go through the distress of seeing a friend pass away.

One woman (a fellow resident) said to me, 'My soul is gone, all I see is death' ... I try to get out of here as much as possible.

Young people living in residential aged care, Victoria

But I also isolated myself, I was worried a lot of people would die, I would meet good people I would admire and respect and I didn't want them to die ... you think, 'How many people am I going to have to watch die?'

Young people living in residential aged care, Victoria

The needs of the younger people in residential care are not easily accommodated by the rules and regulations in place for older aged care residents. The young people recognised these rules were for older residents' safety and at the same time considered them very restrictive. These restrictions impacted on a young person's autonomy and social interaction with friends and family.

I feel like I'm in a cell in my room.

Young people living in residential aged care, Victoria

Staffing and staff training

Staffing and staff training was a key concern for young people living in residential aged care. Several participants reported there were not enough staff and that aged care staff lacked the specialised skills necessary to take care of them. Some people, or their family or carers, found themselves instructing lesser-trained staff on how to undertake relatively complex procedures, rather than wait lengthy periods for appropriately trained staff to attend to their needs.

The trachea in her throat, she coughs a lot, you need a tractioning machine and the only person who can do that is a registered nurse, the normal nurse is not qualified. And the ratio is one staff for 30 patients. Mostly it's at nighttime, after five.

Young people living in residential aged care, New South Wales

Every time I need the right staff for (patient), they have to run to another building to get someone.

Young people living in residential aged care, New South Wales

The staff know nothing about my care, nothing about being paralysed. I kept my own carers. I was originally told I couldn't, but then they realised they couldn't (provide that level of care for me).

Young people living in residential aged care, Victoria

It's not all bad, 10%-15% of staff genuinely care but the others, it's just a job, just have to do a six-month course.

Young people living in residential aged care, Victoria

Some attributed a lack of skill to overseas-trained staff, who often had lower levels of competence in English.

They only hire overseas nurses. I don't think they're qualified enough, not skilled enough ... the way they're handling patients. They speak broken English ... sometimes when they come to suction her, I have to show them how.

Young people living in residential aged care, New South Wales

Young people in residential aged care, and their carers, were critical that low staffing ratios also add significantly to the risks posed to residents. They felt sometimes staff were rushed because the facility was short staffed. By not spending sufficient time to get to know the young people's needs, the staff were not able to provide appropriate care to them. They also thought some staff were not motivated to provide personal attention.

Staff had no idea, they told me she had aggressive behaviour – not at all! They don't understand her disease, she was wriggling, but that was because she needed the toilet (and they didn't know) ... They didn't take the time to know (my daughter) or her triggers, they just put a nappy on her. They didn't bother showering her every day until I made them. I said, 'Why aren't her teeth being cleaned?!' and they said they thought she had false teeth!

Young people living in residential aged care, Victoria

They're not enough staff, they get tired, so what do they do? There's less attention for everyone, so someone will die because the care will be less. The risk of injury will be higher.

Young people living in residential aged care, New South Wales

They hurry you ... (you get) half an hour to eat, I have throat issues so I can't hurry and I (end up saying) 'Take it away'.

Young people living in residential aged care, Victoria

The staff were lovely, but not enough staff at all, they've got no time, it's a business. They've got five minutes to shower (a resident) and put in a chair and on to the next person. They're (left) sat looking out the window all day. There's no time (for staff) to sit and massage hands, spend time. There's no stimulation whatsoever.

Young people living in residential aged care, Victoria

With the nursing staff at a hospital vs. nursing home staff, it seems that anyone can get a job (in aged care). 70% shouldn't be there. They're so used to hearing the babble, that when I speak, I say, 'Didn't you hear me?' And they would say, 'I'm sorry, I heard but I wasn't paying attention'.

Young people living in residential aged care, Victoria

The younger people in residential aged care were particularly critical of the staffing levels over night, which would frequently leave them unattended for lengthy periods of time when they needed help.

I can't hold a cup or brush my teeth, I have a carer, she comes in, but once she's gone for the night I can't drink (unaided). I call and ask for water ... (I'm often) told they're too busy.
Young people living in residential aged care, Victoria

Me being in my bed, I'm trapped, I can't get out.
Young people living in residential aged care, Victoria

Family support for young people in residential aged care

Younger people in residential aged care spoke of the need for families to be actively engaged in their care. Having family members present as frequently as possible ensured basic standards of care are met. They also said it was vital for family and carers to be constantly advocating on behalf of the younger person in residential aged care in order to ensure that the facility took appropriate care of them.

You can't just throw your relative (in the nursing home). You have to be there at least once a day, four times a week, to get things better. You need the cooperation between the family and the nursing home.

Young people living in residential aged care, New South Wales

This vigilance extended to engaging regularly with the aged care facility management to ensure care was being provided in the way, and to the standards, that the individual and family expected.

(The management) were never honest, got secrets ... like medication ... a few times (I caught them) prescribing Valium but not calling (to consult me). I only found out because I was billed. But when I'd asked, they said, 'No, no, we're not drugging her!'

Young people living in residential aged care, Victoria

Some were also critical of the food which was generally mushy for the ease of older residents but was not suitable for younger people who were able to chew.

14.4. Planning, preparation and expectations of own older age

Young people in residential aged care had generally given limited thought to ageing. Some were aware that they were vulnerable to infection or injury which meant they were cautious of thinking of life too far ahead; they were mostly aware that they had a shorter life expectancy than their counterparts.

The considerations they had made about their future focused on their health and housing. Depending on the nature of their condition, they were either working to stabilise or maintain their condition, or for some, to make progress so that they could achieve a greater degree of independence.

It depends on how her health improves and the support around her. For the next five years, if she still has that support ... it's simple, she needs one-on-one, a nurse with her 24 hours a day.

Young people living in residential aged care, New South Wales

Some were keen to find a supported care facility to move into that would allow them to live in a more stimulating environment, with other residents of similar ages.

There needs to be more residential care for young people. We do not belong there. It's like we don't exist. We get treated like they treat the dementia patients. They don't know how to interact with us. There needs to more housing for young people ... It's not a place for young people. It's very depressing ... I can't walk, I'm trapped ... Don't treat me as a dollar sign and treat me as someone that has feelings.

Young people living in residential aged care, Victoria

A few of the young people had attempted to find private rental housing but found it too difficult to accommodate their needs.

I tried to rent but people don't want to put the new equipment in and then have to take it out. Private rental is not existent.

Young people living in residential aged care, Victoria

15. Young people living with dementia

This section highlights the distinct views of young people (aged under 65 years) living with dementia and includes those taking part in the five in-depth interviews.

15.1. Summary

Young people living with dementia were fearful of ageing. They were well informed about their condition and the uncertainty about how their dementia would progress and manifest as they aged was frightening. They were conscious of needing care as the disease impacted on their lives and articulated more concern than others about the prospect of being a burden to their families.

Like the wider population, young people living with dementia wished to remain as independent as possible, for as long as possible. To this end, they were more actively engaged than others in pursuing activities that provided them with mental stimulation, in an attempt to prolong their cognitive health.

Most of these people were familiar with what was offered by dementia units within aged care facilities and were extremely critical of the quality of care. They saw them as lacking meaningful and stimulating activities for residents and were frightened by the prospect of being locked in or restrained.

Many had investigated the process of finding a place in aged care. They felt that dementia places were limited, and it was very hard to find a place in a high-quality facility with the appropriate skills for the individual resident.

As with other audiences, young people living with dementia were critical of the quality and level of staffing and felt that basic dementia training was lacking in many facilities. They also commented that specialist dementia centres were lacking.

15.2. Community views of older people

Fear of the future

Young people with dementia were particularly apprehensive about getting older because of the uncertainty of how their dementia would progress and the way in which society views people with impaired cognitive function (which some identified as discriminatory). They felt the unpredictability of their prognosis overshadowed any future freedom from paid unemployment and opportunity to spend more time with friends and family that older years might offer.

As soon as someone starts to show some sort of cognitive difficulty, then people start wanting to avoid them.

Young people living with dementia, New South Wales

Now I'm diagnosed with dementia, (older age is) not appealing any more.

Young people living with dementia, New South Wales

Young people living with dementia were very engaged with the issue of whether or not society saw older people as a burden. In their responses, they were highly cognisant of the diagnosis of dementia and the impact the illness would have on their lives, the fundamental change to their closest relationships, and the level of care that they might require. They were also well aware that the responsibility for their care would fall to their close loved ones. Some knew what changes to expect associated with their diagnosis and were aware this could include behaviour and attitude changes, meaning that beyond memory loss, they could become very difficult to live with.

They can be a burden to a family if they have some sort of disability ... but it's a burden if you've got a bad attitude towards them. If you resent it. If you say, 'This is still the person I decided to marry', 'This is still my parent' ... then as a person, they're valued. And I imagine someone with a heavy care burden could go through both feelings in the same day.

Young people living with dementia, New South Wales

The kind of dementia I have is much worse for carers, worse than Alzheimer's, because its known for changing your personality. I don't want Mum to go from caring for Dad to me straight away ... she's in her eighties, she deserves to have a bit of time for herself.

Young people living with dementia, New South Wales

While they all aspired to continue living at home and remaining as independent as possible, there was a widespread acceptance that a diagnosis of dementia meant that the level of care required would likely become too much for their families. These participants believed that this type of care needed to be reframed so that it was not seen as a burden. However, they did recognise that the pressure of time and earning a living made it very challenging for some families to care for older people in person, in the way they might prefer.

Before I would have said 'Farm me out the minute I don't recognise you, don't worry about me, have a happy life', and that seems to be the Western way, not to burden your children. You come across that time and time again when they talk about their advanced care directives ... I joined that bandwagon readily until I got involved with this supported decision-making project ... helping older people with dementia to make their own decisions ... why are we consigning people who no longer have utility to nothingness, to a vacuum, when they can still be part of society. Scaffolding them up rather than shunting them away.

Young people living with dementia, New South Wales

The inability of families to care for their own ... deep down it's a genuine inability because of time and finances to care, so that you know you're going to be vulnerable because your family can't wrap you up.

Young people living with dementia, New South Wales

One of the participants felt strongly that more can be done to ensure people with dementia are able to continue living with family, or in the wider community, for longer than is currently typical.

Of course, we have an obligation ... and meeting that obligation we can do a lot better. It doesn't have to cost more, it's not about throwing more money at it ... we need to facilitate families to be able to care for their older family members if they want to. That's where the money should be going.

Young people living with dementia, New South Wales

15.3. Community understanding and perceptions of aged care

These younger people living with dementia were more critical than the wider population about the nature of care provided in aged care facilities. As people who are currently living active, engaged lives they were very concerned with what they saw as the lack of stimulation and appropriate activities on offer in these facilities.

An aged care facility is like a box, a prison, corridors to get lost in, there's no stimulation, complete lack of activity, there might be bingo ... Nothing to do, just sat in a chair 12 hours a day.

Young people living with dementia, New South Wales

Appropriate facilities for young people living with dementia

Some young people living with dementia were aware that dementia units in aged care facilities were locked and their criticism was also focused on that fact. The prospect of living in such a unit was very frightening for them.

There is no choice, I'm going to live at home till I die. If I go into a care facility – I haven't seen one that I find acceptable – particularly, all the dementia units being locked. It's interesting that in some parts of the world, that's illegal, e.g. Germany. Visiting people in locked wards like that, there's no ability to maintain outside contacts.

Young people living with dementia, New South Wales

Like many of the broader population, people who had researched aged care facilities either for themselves, or for a parent, found the process difficult. Young people living with dementia commented that much of the information is online and that older people may not have the skills to interrogate the internet to find what they need.

The assumption is that everyone has web skills and can navigate the site.

Young people living with dementia, New South Wales

Young people living with dementia spoke about places in residential aged care being limited and hard to find. Additionally, they were aware that finding a place with the appropriate type of care for specific individual needs added significantly to the difficulty.

Extremely difficult in terms of the time it takes to do all your research, to find one, and then if you can actually get into the one that you'll prefer. And have the money to go into one.

Young people living with dementia, New South Wales

It can be extremely difficult to get the right care. Getting care is not easy but getting the right care can be very awkward. Finding a place that'll take someone with particular needs ... the higher your needs and the more unusual your needs, the harder it is.

Young people living with dementia, New South Wales

It's very difficult ... literally you have to wait for someone to die till you can get in there ... none of them offer an environment which I would consider to be home-ish ... and the dementia facility is always out the back. The front of the building has views of the bay, the

back has trees and views of the public dump. To me it illustrates the way in which they treat (dementia) people.

Young people living with dementia, New South Wales

This group also highlighted the need for a greater number of specialist dementia aged care centres. They spoke of the increasing number of younger people receiving dementia diagnoses and that additional dedicated facilities with specialist staff were needed to care for them.

More facilities for people who are younger ... there are enough people who get diagnosed younger than 65 that it means we need dedicated facilities in each capital city.

Young people living with dementia, New South Wales

Staff training and restraints

Similar to the views of other audiences, young people living with dementia have considerable concern about adequate staff training. This concern focused on all staff having at least a basic level of training in care for people with dementia and having more time to interact in a meaningful way with people.

Because the old age care system has a lot of people with dementia, I'd like to see all staff to have minimal training in dementia. There's very limited training for a lot of people. They have to know what it is, having sensitivity, there's certain things you can learn. That is the first step.

Young people living with dementia, New South Wales

It's as simple as giving staff the freedom to have conversations that they don't have at the moment ... they all say, 'I was scolded for talking so long to Mrs So-and-So' ... their KPIs are task and process orientated. And that's what needs to change.

Young people living with dementia, New South Wales

Young people living with dementia worried about the use of physical and chemical restraints. Restraints were seen as being over-used, and implemented mainly to make it easier for staff, because of inappropriate resident to staff ratios, rather than being in the interest of people with dementia.

I'm very strong against chemical restraints and physical restraints in high care need. It's dehumanising. Put someone in a restraint just because someone can't explain their needs. It's wrong. A lot of time when they use restraints it's because they don't have to use so many staff.

Young people living with dementia, New South Wales

15.4. Planning, preparation and expectations of own older age

Some young people living with dementia said they had not given thought to their older years and had made few plans. These participants were more financially secure, with close family relationships, and had strong support structures and networks in place. Those young people living with dementia who had fewer support structures – for example, being single or less financially

secure – were more likely to have given thought to their older years and what plans might be necessary.

Because I'm single, I don't have people who could help me when I get beyond where I can do things myself. I can see I'll probably be needing more care than can happen at home much earlier than if I'd had a spouse. My Dad has the same condition. I can see that my Mum will be in her eighties and it's not fair me expecting care from her.

Young people living with dementia, New South Wales

There's very little that's available for people who are younger and need that kind of care. My biggest fear is that it's going to happen quicker because I don't have someone who can be a family carer.

Young people living with dementia, New South Wales

Some of the young people living with dementia had family members who also had diagnoses with dementia or had a high risk of dementia. As such, they were very aware that they could not necessarily rely on these family members to provide care in the future.

I can't rely on a sibling because they've got a 50-50 chance of getting what I've got.

Young people living with dementia, New South Wales

Retaining quality of life

In terms of priorities for their later years, young people living with dementia were very focused on their health and taking steps to prolong their cognitive functioning; this was through remaining active members of society, engaging positively with the wider community and intentionally engaging their brains in educational activities. The aim was to retain as high a quality of life for as long as possible.

Living as healthy as long as possible. Keeping cognition, knowing as much as possible. It's a hard one because I don't know where I'm going. It's highly unlikely I'll make it to my parents age.

Young people living with dementia, New South Wales

My mind is the most important thing ... as an advocate, that helps to look after it.

Young people living with dementia, New South Wales

These participants were also very aware that the quality of life as they now know it may be short-lived and that they wanted to enjoy social and family life while they can.

I've got quite a few dementia mates, they're very important to me ... it's supportive for all of us, being able to discuss, 'Have you had that problem?'.

Young people living with dementia, New South Wales

I have to get my two cents out of life now, 'cos I might not get it later.

Young people living with dementia, New South Wales

Something that's functionally good is social engagement. It's not a curative but it delays progression. Doesn't prevent it but delays it.

Young people living with dementia, New South Wales

I'm riding my horses and that's pretty much all I need ... it stimulates my brain, it's physically and mentally challenging.

Young people living with dementia, New South Wales

To us our health is good except for a little bit of forgetfulness ... rust on the brain. Apart from that we're doing everything we want to do.

Young people living with dementia, Victoria

There was some concern among young people living with dementia that when you engaged with some of the relevant dementia health services, they made automatic assumptions about the course your life would take, and that your children would acquiesce with professional advice because there was no alternative available.

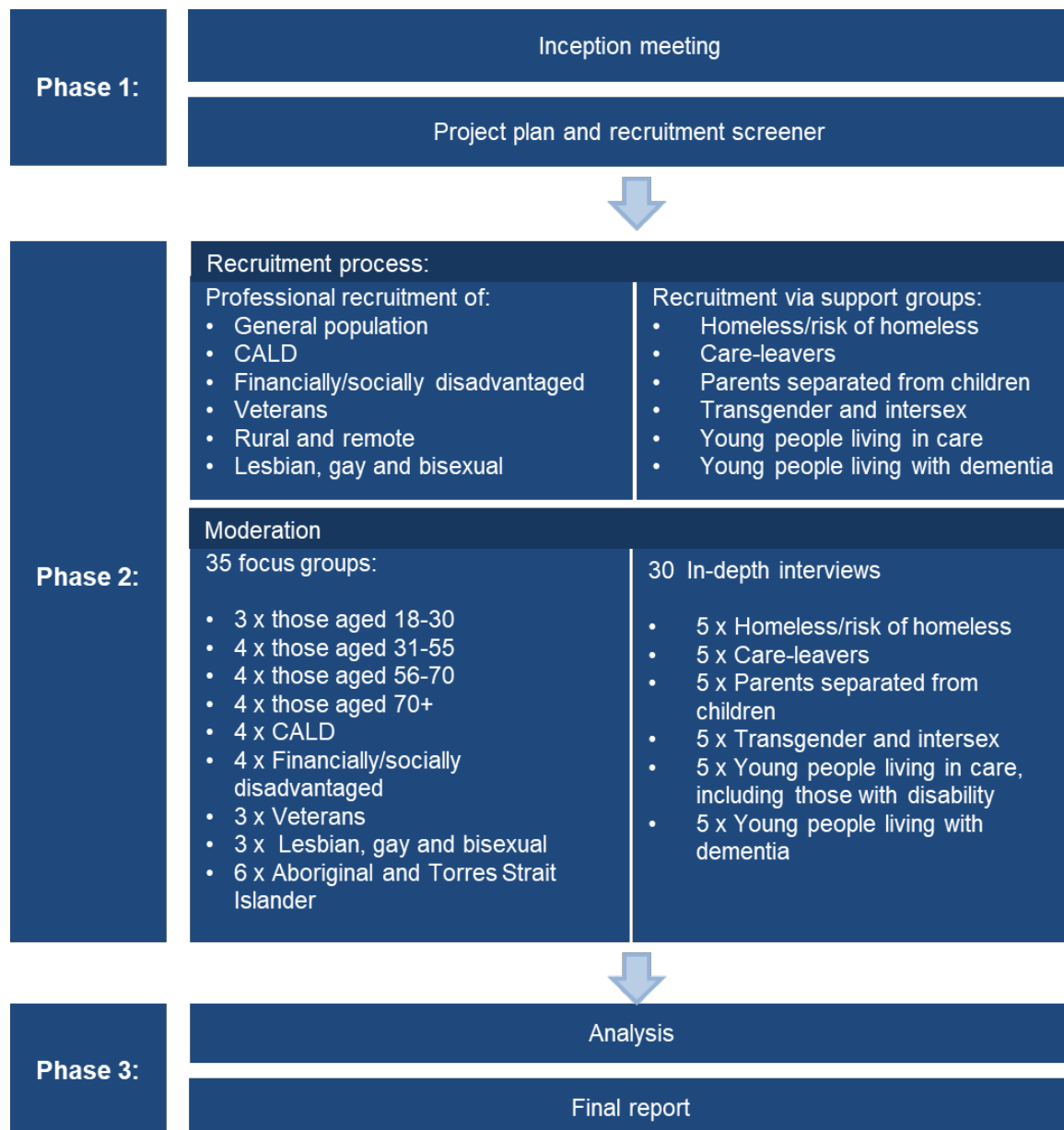
Once I start going to a memory clinic they will push me to residential clinic, and my children would just say 'Yes', as all children do, because someone from authority is telling you that's what you should do for your parents benefit ... just being lead to externalised care because that's expected.

Young people living with dementia, New South Wales

16. Appendix

16.1. Methodology

The diagram below outlines the methodology for this qualitative research.



The qualitative fieldwork was divided into three parts:

- Phase one
 - Project plan and recruitment screener
- Phase two
 - Recruitment of 35 focus groups across the Australian population - general population to include age groupings (18-30, 31-55, 56-70, 70+) and diversity of people from Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, financially and socially disadvantaged communities, rural and regional areas, veterans, and lesbian, gay and bisexual communities
 - Recruitment of 30 in-depth or paired interviews with diversity groups - people homeless or at risk of homelessness, care leavers, parents separated from their children by forced adoption or removal, transgender and intersex communities, young people living in residential aged care, young people with dementia
- Phase three
 - Analysis and writing the report

Focus groups

The focus groups were undertaken among the adult (18+) population, covering a broad range of project objectives. Across all 35 focus groups, a total of 244 people were consulted in the research.

The focus groups were designed to be nationally representative in both metro and regional locations. The design matrix was agreed to provide insight into the views of specific population groups, namely:

- By age, with groups specifically among those aged 18-30, 31-55, 56-70, and over 70.
- Among culturally and linguistically diverse communities, defined as those speaking a language other than English at home.
- Among those financially and socially disadvantaged, which was defined as people with a weekly household income of less than \$800 per week.⁶
- Among Aboriginal and/or Torres Strait Islander communities.
- Among veterans, defined as those who had seen active service.
- Among those who identified as gay, lesbian or bisexual.

The design matrix is shown overleaf.

⁶ 25% of households in the 2016 Census of Population and Housing had weekly income less than \$800 (Australian Bureau of Statistics, General Community Profile, table G29 Total Household income (Weekly), Catalogue 2001.0).

Focus group design matrix

AUDIENCE		NSW Sydney	NSW Regional/	VIC Melbourne	VIC Regional/	WA Perth	WA Regional/	QLD Brisbane	QLD Regional	NT Darwin	TOTAL
General Popn	Aged 18-30	1			1			1			3
	Aged 31-55	1		1		1			1		4
	Aged 56-70		1	1		1		1			4
	Aged 70+	1		1			1			1	4
CALD		1 (18-30)			1 (56-70)	1 (31-55)			1 (55+)		4
Financially and socially disadvantaged			1 (31-55)	1 (70+)			1 (56-70)			1 (18-30)	4
Aboriginal and/or Torres Strait Islander			2			2			2		6
Veteran		1		1		1					3
Sexuality		1 x Gay		1 x Lesbian		1 x Bi- sexual					3
SUB-TOTAL		6	4	6	2	7	2	2	4	2	35

Recruitment for the majority of focus groups was undertaken by The Human Network (THN). The recruitment screener is in the appendix (see 16.2).

The recruitment for the 6 groups among Aboriginal and Torres Strait Islander communities was undertaken by the Ipsos Aboriginal and Torres Strait Islander Research Unit. Two groups were

conducted in Perth, two in Coffs Harbour and two in Mount Isa. Due to community issues in Mount Isa these were eventually conducted as a larger number of smaller consultations.

A discussion guide was developed in consultation with the Royal Commission into Aged Care Quality and Safety. The final focus group discussion guide can be found in the appendix (see 16.3). The general population discussion guide was reviewed and amended by the Ipsos Aboriginal and Torres Strait Islander Research Unit to ensure it was appropriate for the Aboriginal and/or Torres Strait Islander community.

Moderation was conducted in English, in person, by the Ipsos project team. Members of the Ipsos Aboriginal and Torres Strait Islander Research Unit moderated the groups with the Aboriginal and Torres Strait Islander communities.

Discussion groups were between 90-120 minutes in duration. All participants received an incentive of \$100 to thank them for their time.

All discussion groups were video and/or audio-recorded with the participants' permission.

In-depth interviews with specific diversity groups

A total of 30 face-to-face in-depth interviews were conducted with members of six specific diversity groups. These were:

- Transgender and intersex people
- Care leavers
- Parents separated from children by forced adoption or removal
- People who are homeless or at risk of becoming homeless
- Younger people (aged under 65 years) living in residential aged care
- Young people (aged under 65 years) living with dementia

Five interviews were conducted with members of each audience.

These participants were recruited through a variety of charities and support organisations that work with each of these target audiences. A number of organisations were initially contacted by the Royal Commission into Aged Care Quality and Safety by letter (see appendix 16.4), which explained the purpose of this research project and asked for their help in identifying individuals willing to take part. The Ipsos project team subsequently made contact with these organisations and was able to recruit participants to the study. We would like to thank these charities and support organisations for their help and time throughout the project in connecting us with these participants.

The discussion guide for the in-depth interviews was adapted from the general population focus group discussion guide. It was changed to reflect the different nature of the interview – that it was a one-on-one interview, with a likely duration of 45 minutes. This final in-depth interview discussion guide can be found in the appendix (see 16.5).

In practice the in-depth interviews ranged from 35 minutes to two hours in duration. Moderation was conducted in English, in person, by the Ipsos project team, and all participants received an incentive of \$80 to thank them for their time. The interviews were audio-recorded with the participants' permission.

16.2. Focus group recruitment screener

Name of project	Aged care
Topic	Exploratory qualitative research to understand community attitudes towards ageing and aged care.
Duration of focus groups:	Approximately 1½ -1¾ hours
Date:	Fieldwork planned for 4th July – 8th August 2019.
Number of participants:	8 participants for focus groups with general population, CALD, and financially and socially disadvantaged. 6 participants for focus groups with veterans and sexuality.
Recruitment criteria	Gender = Q1 Age = Q4 CALD = culturally and linguistically diverse, code 'Yes' at Q5. FSD = financially and socially disadvantaged, code 'Less than \$400' at Q10 OR code 'Less than \$800 per week' at Q10 Veteran = served in armed services (ADF) (codes 'army', 'navy', 'airforce' and 'other specify' at Q8) and seen active service (code 'yes' at Q9) Sexuality = 'gay', 'lesbian' or 'bisexual' at Q12
Incentive:	\$100
Should I send out a written confirmation:	Yes, via post, fax or e-mail. Must use the confirmation letter attached.
Contact person:	Jess Elgood: (02) 9900 5100

Venues:	Listed overleaf.
Other:	<p>Screeners and confirmation letter attached.</p> <p>Recruiters to record responses to all screener questions – to be compiled into a spreadsheet and sent to Ipsos, along with the signature forms, by no later than 4.30pm the day before each interview is scheduled.</p> <p>Participants should be told that the interview is about Australian society. Please do not tell them it is about aged care.</p> <p>If the participant asks who the study is on behalf of, please reassure them that they will be told the client name at the end of the interview.</p>

Focus group matrix New South Wales:

Metro - Sydney

	Group 1	Group 2	Group 3	Group 4	Group 5	Group6
Location	South Sydney	CBD	South Sydney	West Sydney	West Sydney	CBD
Venues	CGR South, Shop 5 438/452 Forest Road, Hurstville (02) 9191 7870	CGR, Level 11/60 York Street, Sydney CBD (02) 9299 8907	CGR South, Shop 5 438/452 Forest Road, Hurstville (02) 9191 7870	CGR West, Level 4, 85 George Street, Parramatta (02) 9635 9024	CGR West, Level 4, 85 George Street, Parramatta (02) 9635 9024	CGR, Level 11/60 York Street, Sydney CBD (02) 9299 8907
Date	Tues 23rd July	Thurs 4th July	Tues 23rd July	Tues 6th Aug	Tues 6th Aug	Thurs 4th July
Time	6pm	6pm	4pm	8pm	6pm	8pm
Number of participants	8	8	8	8	6	6
Incentive	\$100	\$100	\$100	\$100	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Male
Age	18-30	31-55	70+			
CALD				18-30		
FSD						
Veteran					1	
Sexuality						Gay

Regional – Wagga Wagga

	Group 7	Group 8
Location	Wagga Wagga	Wagga Wagga
Venues	1-15 Morgan Street, Wagga Wagga (02) 6921 6444	1-15 Morgan Street, Wagga Wagga (02) 6921 6444
Date	1st August	1st August
Time	6pm	8pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	56-70	
CALD		
FSD		31-55
Veteran		
Sexuality		

Focus group matrix Northern Territory:

Metro - Darwin

	Group 9	Group 10
Location	Darwin	Darwin
Venues	Mantra on the Esplanade, 88 The Esplanade, Darwin 08 8943 4333	Mantra on the Esplanade, 88 The Esplanade, Darwin 08 8943 4333
Date	Mon 29th Jul	Mon 29th Jul
Time	4pm	6pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	70+	
CALD		
FSD		18-30
Veteran		
Sexuality		

Focus group matrix Victoria:

Metro - Melbourne

	Group 11	Group 12	Group 13	Group 14	Group 15	Group 16
Location	Richmond	Coburg	Richmond	Coburg	Richmond	Richmond
Venues	Group Focus, 140 Coppin Street, Richmond, (03) 9421 1827	JB Market Research, 9 Glencairn Avenue, Coburg 0416 034025	Group Focus, 140 Coppin Street, Richmond, (03) 9421 1827	JB Market Research, 9 Glencairn Avenue, Coburg 0416 034025	Group Focus, 140 Coppin Street, Richmond, (03) 9421 1827	Group Focus, 140 Coppin Street, Richmond, (03) 9421 1827
Date	Tues 16 July	Thurs 18 July	Tues 16 July	Thurs 18 July	Weds 17 July	Weds 17 July
Time	6.30pm	6.30pm	4pm	4pm	6pm	8pm
Number of participants	8	8	8	8	6	6
Incentive	\$100	\$100	\$100	\$100	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Female
Age	31-50		70+			
CALD		56-70				
FSD				70+		
Veteran					1	
Sexuality						Lesbian

Regional - Shepparton

	Group 17	Group 18
Location	Shepparton	Shepparton
Venues	Parklake Hotel 481 Wyndham St, Shepparton, VIC (03) 5821 5822	Parklake Hotel 481 Wyndham St, Shepparton, VIC (03) 5821 5822
Date	Tues 23 July	Tues 23 July
Time	8pm	6pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	18-30	56-70
CALD		
FSD		
Veterans		
Sexuality		

Focus group matrix Western Australia:

Metro - Perth

	Group 19	Group 20	Group 21	Group 22	Group 23
Location	Subiaco	Subiaco	Subiaco	Subiaco	Subiaco
Venues	Ipsos 338 Barker Road, Subiaco	Ipsos 338 Barker Road, Subiaco	Ipsos 338 Barker Road, Subiaco	Ipsos 338 Barker Road, Subiaco	Ipsos 338 Barker Road, Subiaco
Date	Wed 17 July	Tues 23 July	Tues 23 July	Wed 24 July	Wed 24 July
Time	6:30pm	6pm	8pm	6pm	8pm
Number of participants	8	8	8	6	6
Incentive	\$100	\$100	\$100	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	31-55	56-70			
CALD			31-55		
FSD					
Veteran				1	
Sexuality					Bisexual

Regional – Geraldton

	Group 24	Group 25
Location	Geraldton	Geraldton
Venues	Queen Elizabeth II Community Centre 88 Durlacher St, Geraldton WA 6530 (08) 9956 6636	Queen Elizabeth II Community Centre 88 Durlacher St, Geraldton WA 6530 (08) 9956 6636
Date	Thurs 25 July	Thurs 25 July
Time	4pm	6pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	70+	
CALD		
FSD		56-70
Veterans		
Sexuality		

Focus group matrix Queensland:

Metro - Brisbane

	Group 26	Group 27
Location	Brisbane	Brisbane
Venues	River City Research, 11 Wicklow Street Kangaroo Point 0400 164057	River City Research, 11 Wicklow Street Kangaroo Point 0400 164057
Date	Wed 10th July	Wed 10th July
Time	8pm	6pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	18-30	56-70
CALD		
FSD		
Veteran		
Sexuality		

Regional - Toowoomba

	Group 28	Group 29
Location	Toowoomba	Toowoomba
Venues	Platinum International 326 James Street Toowoomba (07) 4634 0400	Platinum International 326 James Street Toowoomba (07) 4634 0400
Date	Thurs 11th July	Thurs 11th July
Time	8pm	6pm
Number of participants	8	8
Incentive	\$100	\$100
Gender	Mixed, min n=2 of each gender	Mixed, min n=2 of each gender
Age	31-55	
CALD		55+
FSD		
Veteran		
Sexuality		

Recruitment script

Introduction

Good evening. My name is _____, calling on behalf of Ipsos, a social research company.

We are conducting research about Australian society. The research involves an informal discussion with around 6-8 people for approximately 1½ - 1¾ hours. We hope you will find it interesting.

Light refreshments will be provided during the discussion.

The discussion is confidential and your responses will remain anonymous.

Those who take part will be reimbursed \$100 for any out of pocket costs associated with attending the discussion. Are you interested in participating?

IF YES, CONTINUE: I just have some questions for you, to make sure that you qualify, as we need to speak to a good cross section of people as part of the research.

[ONLY IF NECESSARY: This is strictly SOCIAL research for an Australian government agency. Your responses will remain completely confidential. We are not promoting or selling anything. If you would like to verify the validity of this research you can call the Australian Market and Social Research Society's survey line on 1300 364 830).

1. Are you:
 - a) Male - CONTINUE
 - b) Female - CONTINUE

2. Have you taken part in an in-depth interview or discussion group within the last six months?
 - a) Yes - TERMINATE
 - b) No - CONTINUE

3. In which town or suburb do you currently live?

PLEASE RECORD TOWN OR SUBURB:

POSTCODE:

4. How old are you? [DO NOT READ RANGES, UNLESS PARTICIPANT DOES NOT WANT TO PROVIDE EXACT AGE]

1	Under 18	TERMINATE
2	18-24	RECRUIT TO QUOTA
3	24-30	
4	31-34	RECRUIT TO QUOTA
5	35-39	
6	40-44	
7	45-49	
8	50-55	RECRUIT TO QUOTA
9	56-59	
10	60-64	
11	65-70	RECRUIT TO QUOTA
12	71-74	
13	75+	

PLEASE ALSO RECORD EXACT AGE (UNLESS REFUSE TO PROVIDE) ____ years

5. Is any language other than English spoken in your household?

1	Yes	ASK Q6
2	No	CONTINUE

6. ASK IF CODE 1 AT Q5. What other languages are spoken in your household? MR.

1	Arabic	21	Korean
2	Australian Indigenous languages	22	Khmer
3	Assyrian	23	Lao
4	Bosnian	24	Macedonian
5	Burmese	25	Mandarin
6	Cantonese	26	Maltese
7	Creole	27	Persian
8	Croatian	28	Polish
9	Dari	29	Portuguese
10	Farsi	30	Russian
11	French	31	Serbian
12	Dinka	32	Spanish
13	Dutch	33	Sudanese
14	German	34	Tagalog
15	Greek	35	Tamil
16	Hindi	36	Thai
17	Hungarian	37	Torres Strait Islander
18	Indonesian	38	Turkish
19	Italian	39	Vietnamese
20	Japanese	40	Other [SPECIFY]

7. ASK ALL. Are you of Aboriginal and/or Torres Strait Islander origin?

1	Aboriginal
2	Torres Strait Islander
3	Both Aboriginal and/or Torres Strait Islander
4	None of these
98	Prefer not to say
99	Don't know [DNRO]

8. Have you ever worked for one of the Australian armed services (the Australian Defence Force) – that is the army, navy or airforce?

1	Army	CONTINUE
2	Navy	CONTINUE
3	Airforce	CONTINUE
4	Other (SPECIFY)	CONTINUE
6	No, none of these	CONTINUE TO Q10
98	Prefer not to say	CONTINUE TO Q10

9. And did you ever experience active service?

1	Yes	RECRUIT FOR VETERANS
2	No	CONTINUE
98	Prefer not to say	CONTINUE

10. ASK ALL. What is your approximate weekly personal income before tax?

1	Less than \$400 per week	RECRUIT FOR FSD
2	Between \$400-\$1,749 per week	CONTINUE
3	Over \$1,750 per week	CONTINUE
99	Prefer not to say	CONTINUE

11. ASK IF Q10=2-99. What is your approximate weekly household income before tax? That is, the combined income of all members of your household each week.

1	Less than \$800 per week	RECRUIT FOR FSD
2	Between \$800-\$3,500 per week	CONTINUE
3	Over \$3,500 per week	CONTINUE
99	Prefer not to say	CONTINUE

12. Would you describe yourself as ...?

1	Heterosexual	CONTINUE
2	Gay	RECRUIT TO SEXUALITY
3	Lesbian	RECRUIT TO SEXUALITY
4	Bisexual	RECRUIT TO SEXUALITY
5	Other	CONTINUE
98	Prefer not to say	CONTINUE

IF QUALIFY READ:

The discussion will be audio taped and may also be video recorded, to help the researchers prepare their report. As I mentioned earlier though, your responses will remain anonymous and confidential. Is this okay with you?

IF YES, CONTINUE. IF NO, DISCONTINUE WITH THANKS.

Would you be able to attend the discussion to be held ... [SAY DATE/TIME/VENUE]?

EXPLAIN IT IS IMPORTANT TO CALL IF ANY ISSUES OR UNABLE TO PARTICIPATE.

We would like to send you a confirmation of this appointment to your email or other preferred address. Do you have an email address or mail address where we can send it? [IF YES, WRITE IN ADDRESS]

THANK YOU VERY MUCH FOR YOUR ASSISTANCE WITH THIS PROJECT

Just to remind you, I'm [INSERT NAME], on behalf of Ipsos. In accordance with Privacy Principles, your responses in the discussion will remain anonymous. In case I need to check something with you, can I just confirm your name, telephone number, etc.?

RESPONDENT NAME:

TELEPHONE NO.: ()

POSTAL ADDRESS:

POSTCODE:

DATE & TIME OF INTERVIEW:

I certify that this is a true, accurate and complete interview, conducted in accordance with IQCA standards and the ICC/ESOMAR International Code of conduct. I will not disclose to any other person the content of this questionnaire or any other information relating to this project. Signed as a true and accurate interview in accordance with all briefing instructions:

INTERVIEWER NUMBER:

NAME:

SIGNED:

DATE:

Confirmation letter script

[INSERT DATE]

Dear [INSERT NAME]

Thank you for agreeing to take part in the discussion group about Australian society.

The discussion will take place on [INSERT DATE] at [INSERT TIME] at the [INSERT VENUE]. It will run for approximately 1½-1¾ hours. This research is being conducted by Ipsos, an independent social research company that operates under the market and social research code of professional conduct and the Privacy Act.

If, for whatever reason, you can no longer attend, please call [INSERT CONTACT] on [INSERT NUMBER] straight away.

You will be given \$100 to cover any out-of-pocket expenses you may incur for taking part in the discussion. This will be given to you at the end of the discussion.

If you require reading glasses, please remember to have these with you as you may need to read some materials during the discussion.

Thanks again - and please do not hesitate to call if you have any questions and concerns.

Kind Regards,

[INSERT CONTACT]

16.3. Discussion guide – focus groups

INTRODUCTION

5 MINS

- Thank for taking the time to participate in this project.
- This is an informal discussion and will take about 1½ to 1¾ hours.
- We'll be talking about a broad issue about Australian Society. There is a more specific area that we will get into a little later in the interview, but I'd like to start by asking a few more general questions.
- There are no right or wrong answers.
- Ipsos is an independent social research company. You can tell us exactly what you think.
- It's a confidential discussion - the final report will show the combined responses of the people we speak with.
- EXPLICIT PERMISSION FOR AUDIO/VIDEO TAPING.
 - The recordings will be watched/listened to by members of the Ipsos project team;
 - And may be watched/listened to by the client team;
 - The recordings will be stored securely for up to two years and then destroyed.
- Mobile phones off/refreshments/toilets/exits
- To start off, let's go around the table and introduce ourselves. If you could tell me your first name, where you live, are you working, do you have children/grandchildren?

WARM-UP

40 MINS

Objectives: establish a broad perception of how older people are perceived, explore knowledge/exposure and insight into ageism.

- In today's discussion, we're going to be talking about a range of different aspects of getting older.
 - Firstly, when I mention older people, what age do you think of?
 - And what determines whether or not you think of someone as old? PROBE appearance, behaviour, lifestyle, relative age
 - And what words spring to mind when you think of older people? LIST SPONTANEOUS ASSOCIATIONS. PROBE REASONS FOR EACH WORD (i.e. evidence-based or stereotype).
 - And in what, if any, ways do you think older people contribute to our society? PROBE FAMILY, COMMUNITY, CULTURAL KNOWLEDGE.
 - And how do you think older people are seen in our society? PROBE BURDEN/BENEFIT/INVISIBLE and why?
- Thinking about your day-to-day life, when do you encounter older people – that is, people aged 70 and over? PROBE FOR RANGE OF SETTINGS – family, workplace, socially etc.
- What range of interactions do you have with older people?

- PROBE FOR LEVEL OF INTERACTION WITH ELDERLY PARENTS/GRANDPARENTS/ELDERS
- PROBE FOR POSITIVE/NEGATIVE MIXTURE OF INTERACTIONS
- What roles do older people have in your life?
- What do you think are the more appealing aspects of becoming an older person? Why are those aspects appealing? LIST
- And what do you think are the less appealing aspects of becoming an older person? Why is that? LIST
- Do you see it as a stage of life that you look forward to, or not? Why is that?
- ALTERNATE ORDER OF ASKING BURDEN/OBLIGATION:
 - Some people see older people as a burden; others don't. What do you think? Why do you say that? PROBE TO ESTABLISH VALUE OF OLDER PEOPLE IN SOCIETY
 - Do you think we have an obligation to older people – due to the various contributions they may have made to our society over the course of their lifetime?
- Did any of you grow up with older members of the family living with you? e.g. a grandparent living with the family.
 - IF SO, what was that experience like?
 - What are your thoughts on older people being cared for within the family?
 - What are the benefits? Drawbacks/Challenges? Limitations?

PREPARATION FOR OLDER AGE

20-30 MINS

Objectives: understand expectations of older age across range of domains.

- How much, if any, thought have you given to your older age? In what ways have you started thinking about your older age?
- What has prompted you to start thinking about these aspects of older age?
- Looking at your parents, or grandparents, what lessons have you learnt about retiring and getting older? PROBE
- Thinking about your older age, what are your priorities? What are the things that will really matter to you in terms of what you want for your older age, and will make you happy? PROBE FOR PRIORITIES/PREFERRED LIFESTYLE AND LIST.
- EMPLOYMENT
 - At what age do you expect to stop working?
 - Is that your preferred age – or earlier/later than you would like?
 - What might be the advantages to you of working longer?
 - How likely is it that you might become involved in volunteering when you are older? Why/why not?

- FINANCIAL PLANNING/SECURITY
 - [ASK FOR FINANCIALLY/SOCIALLY DISADVANTAGED GROUPS]:
 - Are you worried about your financial security in older age? PROBE In what ways? What have you thought about?
 - What do you think your main income source/s will be when you're older?
 - And what role do you think the government has in supporting you when you're older?
 - [ASK ALL OTHER GROUPS]:
 - In what ways have you made financial plans for your older age?
 - How confident do you feel that you'll be able to support yourself financially when you're old?
 - How do you see the balance of responsibility for supporting ourselves vs support from government?
- HEALTH
 - Which aspects of your health do you think will be most important to you as an older person?
 - In what ways do you think you'll need to actively maintain your health?
 - PROBE physical and mental health, regular exercise, consumption of alcohol/cigarettes, need for social interaction/loneliness.
- HOUSING
 - Where do you think you would like to be living as an older person? PROBE independently, with family, supported accommodation. Why do you say that?
 - What are the different things you'll be taking into account when you decide where you'll want to live at that stage of life?
 - PROBE cost/mortgage, location, structure (e.g. single-level), proximity to family/friends, independence services, green spaces/nature.
 - Would you like to be living/cared for by family? PROBE pros/cons/concerns
- COMMUNITY AND SOCIAL ENGAGEMENT
 - What are your hopes/expectations around spending time/being involved with family?
 - And with friends? Do friends 'count' as family for you?
 - What are your hopes/expectations around being involved in community events?
 - [ASK FOR CALD GROUPS] Do you think you have expectations around growing older and how you will live and be cared for that are distinct for your community/background? PROBE
- And do you have hopes/expectations around getting to travel when you are older?
- [ASK FOR GAY, LESBIAN AND BISEXUAL COMMUNITIES, METRO, NSW] As a gay man, are there any additional considerations that you think about when planning your older age? Are there things that are specific concerns or worries for you?

- [ASK FOR GAY, LESBIAN AND BISEXUAL COMMUNITIES, METRO, VICTORIA] As a lesbian woman, are there any additional considerations that you think about when planning your older age? Are there things that are specific concerns or worries for you?
- [ASK FOR BISEXUALITY GROUP] As a bisexual person, are there any additional considerations that you think about when planning your older age? Are there things that are specific concerns or worries for you?
- [ASK FOR VETERANS GROUP] As a veteran, are there any additional considerations that you think about when planning your older age? Are there things that are specific concerns or worries for you?

AGED CARE SYSTEM AND SERVICES

10-15 MINS

Objectives: People's knowledge and perceptions of aged care system and services

- How much would you say you know about the aged care system and services that are available for older people? PROBE for understanding of difference between aged care facility or home (e.g. nursing homes) and retirement homes/villages
- And how have you heard about the aged care system? PROBE FOR INFORMATION SOURCES, PERSONAL EXPERIENCE
- [MODERATOR READ OUT] The aged care system and services are for people aged 65 and over (and or 50 and over for Indigenous Australians), and includes care provided in people's homes, in the community and in aged care homes.
- Aged care homes (sometimes known as a nursing home or residential aged care facility) are for older people who can no longer live alone and need ongoing personal help with everyday tasks or health care.
- Have you ever visited an aged care home/facility? Why was that? PROBE What words would you use to describe the aged care home/facility?
 - IF YES:
 - How often have you visited?
 - From what you know, what's your perception of the care that older people receive?
 - And, what's your perception of the food?
 - And, what's your perception of the activities and social interaction available to them?
- And do you know someone who's receiving aged care in their own home? PROBE
 - What is your impression of the care that that person is receiving? Good/bad aspects?
 - How satisfactory is the quality of care that person is receiving in their home?
- [ASK FOR GROUPS AGED 18-30]. ALTERNATE STARTING WITH SCENARIOS 1 AND 2.
 - SCENARIO 1: Imagine your parents are now in their late-seventies and they are diagnosed with a condition which means they'll lose some of their sight. They'll no longer have a driving licence, and over time will find day-to-day tasks like cooking more challenging.

- What are your thoughts on what kind of care they will need?
- What sort of care would you want for them?
- Who do you think will care for them?
- SCENARIO 2: Imagine your parents are now in their late-seventies and they are diagnosed with a condition that means they find it hard to get out of bed and dressed on their own, their mobility is limited, and they are sometimes need help with going to the bathroom.
 - What are your thoughts on what kind of care they will need?
 - What sort of care would you want for them?
 - Who do you think will care for them?
- From your experience, how easy or difficult is it to get access to aged care services if you, or a family member, needed them?
- From what you know, how do you go about accessing aged care services? PROBE via hospital referral, GP, My Aged Care website. What are the challenges?
 - How easy do you think it will be for you to get a place in an aged care home/facility when you need one? PROBE: awareness of waiting lists
 - Are you aware of any bonds that need to be put down to secure your place in an aged care home/facility?
 - IF YES: From what you know, how much, if any, bond do you have to put down?
- And from what you know, what's your understanding of how the quality of care is regulated or monitored? PROBE
- And from what you know, what do you think needs to change to improve the aged care system and service for older people?
- [ASK FOR GAY, LESBIAN AND BISEXUAL COMMUNITIES, METRO, NSW] Would it be important to be in an aged care home/facility that was provided solely for gay men? IF YES/NO, why is that?
- [ASK FOR GAY, LESBIAN AND BISEXUAL COMMUNITIES, METRO, VICTORIA] Would it be important to be in an aged care home/facility that was provided solely for lesbian women? IF YES/NO, why is that?
- [ASK FOR BISEXUALITY GROUP] Would it be important to be in an aged care home/facility that was provided solely for bisexual people? IF YES/NO, why is that?
- Most of us will eventually reach a point when we need some support with our day-to-day living.
 - Who would you expect to provide you with that kind of help?
 - And who would you prefer to provide you with that kind of help? Why is that?
- And what will be the most important aspects of that care? Why?
- Who do you think will be responsible for any care you might need? PROBE self, family, government
- And who do you think will pay for any care you might need? PROBE self, family, government

- Thank you very much for talking with me today; it's been really helpful.
- We've discussed this topic in a lot of detail, do you have anything else you would like to add?
- Do you have any questions that you'd like to ask? Or anything else you'd like to say before we finish the interview?
- The client for this project is the Royal Commission into Aged Care Quality and Safety, who are keen to better understand views around ageing and aged care.
- THANK AND HAND OUT INCENTIVE.

16.4. In-depth interviews primary approach letter

Dear [Name],

Research into Aged Care Quality and Safety

The Royal Commission has commissioned Ipsos, an independent social research agency, to conduct research into the needs and expectations of the Australian community into ageing and aged care. The information collected may form part of the report to the Federal Parliament.

As part of this consultation, the Royal Commission seeks to hear the views of the breadth of Australian society, including [INSERT TARGET AUDIENCE NAME]. As a group working with, and supporting members of this community, we would very much appreciate your assistance in helping the Ipsos research team identify potential participants for this research.

The research will involve a short interview of between 30-45 minutes, at a time and place convenient to the participant. Our aim is that the interview is conducted in a way that best supports participants and as such, if it is helpful for a carer or friend to be present, we would welcome their involvement. Interviews will be entirely confidential – only generalised, anonymous findings from the research will be reported to the Royal Commission.

Over the next few days, Ipsos will contact you to discuss whether your organisation can help with this research. If you have any queries or would like to respond beforehand, please do not hesitate to contact Kathrina Phan at Ipsos on (02) 9900 5100 or by emailing kathrina.phan@ipsos.com.

We thank you in advance, and we very much appreciate any assistance you can give us with this important project.

[Signatory]

Official Secretary to the Royal Commission into Aged Care Quality and Safety

16.5. Discussion guide – in-depth interviews

INTRODUCTION

5 MINS

- Thank you for taking the time to participate in this project.
- My name is and I work for Ipsos, which is a social research agency. We have been commissioned by the Royal Commission for Aged Care Quality and Safety to research what Australian thinking about ageing and aged care. We are talking to a broad range of people, trying to understand the topic from a diversity of people's different life experiences.
- This is an informal discussion and will take about 30-45 minutes.
- The discussion is confidential. While (NAME OF SUPPORT ORGANISATION) has put us in contact with you, no-one else will know you have been interviewed so your participation in this research is anonymous. The final report we will be writing and will show the combined responses of the people we speak with.
- PROVIDE PARTICIPANT INFORMATION AND CONSENT FORM.
- SEEK EXPLICIT PERMISSION FOR AUDIO TAPING.
 - The recordings will be listened to by members of the Ipsos project team;
 - And may be listened to by the Royal Commission for Aged Care Quality and Safety;
 - The recordings will be stored securely for up to two years and then destroyed.
- To start, could you tell me a little bit about yourself? (e.g. health, work, home, relationships)

PERCEPTIONS OF AGEING

10-15 MINS

Objectives: establish a broad perception of how older people are perceived, explore knowledge/exposure and insight into ageism.

- I'd like to start by talking about a range of different aspects of getting older.
 - Firstly, when I mention 'older people', what age do you think of?
 - And what determines whether or not you think of someone as old? PROBE appearance, behaviour, lifestyle, relative age
 - And what words spring to mind when you think of older people?
 - And in what, if any, ways do you think older people contribute to our society? PROBE FAMILY, COMMUNITY, CULTURAL KNOWLEDGE.
 - And how do you think older people are seen in our society? PROBE BURDEN/BENEFIT/INVISIBLE and why?
- ALTERNATE ORDER OF ASKING BURDEN/OBLIGATION:
 - Some people see older people as a burden; others don't. What do you think? Why do you say that? PROBE TO ESTABLISH VALUE OF OLDER PEOPLE IN SOCIETY

- Do you think we have an obligation to older people – due to the various contributions they may have made to our society over the course of their lifetime?
- Thinking about your day-to-day life, when do you encounter older people – that is, people aged 70 and over? PROBE FOR RANGE OF SETTINGS – family, workplace, socially etc. What roles do older people have in your life?
- What do you think are the more appealing aspects of becoming an older person? Why are those aspects appealing?
- And what do you think are the less appealing aspects of becoming an older person? Why is that?
- Do you see it as a stage of life that you look forward to, or not? Why is that?
- Did any of you grow up with older members of the family living with you? e.g. a grandparent living with the family. IF SO, what was that experience like?

PREPARATION FOR OLDER AGE

10-15 MINS

Objectives: understand expectations of older age across range of domains.

- In what ways have you started thinking about your older age? What has prompted you to start thinking about these aspects of older age?
- Looking at your parents, or grandparents, have you learnt any lessons about getting older? PROBE
- Thinking about your older age, what are your priorities? What are the things that will really matter to you in terms of what you want for your older age, and will make you happy? PROBE FOR PRIORITIES/PREFERRED LIFESTYLE.
- (ASK ONLY IF PARTICIPANT CURRENTLY WORKING) EMPLOYMENT
 - At what age do you expect to stop working?
 - Is that your preferred age – or earlier/later than you would like?
 - What might be the advantages to you of working longer?
 - How likely is it that you might become involved in volunteering when you are older? Why/why not?
- (ASK ONLY CARE LEAVERS, PARENTS, TRANSGENDER/INTERSEX) FINANCIAL PLANNING/SECURITY. INTERVIEW NOTE: VERY SENSITIVE SECTION, PLEASE COVER WITH PARTICULAR CARE AND SENSITIVITY
 - In what, if any, ways have you made financial plans for your older age?
 - Are you worried about your financial security in older age? PROBE In what ways? What have you thought about?
 - What do you think your main income source/s will be when you're older?
 - How confident do you feel that you'll be able to support yourself financially when you're old?
 - And what role do you think the government has in supporting you when you're older?

- (ASK ALL) HEALTH
 - Which aspects of your health do you think will be most important to you as an older person?
 - What about your health worries you most, when you think about getting older?
 - And what do you think you need to focus on to maintain the best health for you, as you get older?
 - PROBE physical and mental health, regular exercise, consumption of alcohol/cigarettes/drugs, need for social interaction/loneliness.
- (ASK ALL) HOUSING. INTERVIEW NOTE: VERY SENSITIVE SECTION FOR CARE LEAVERS AND PEOPLE WHO ARE HOMELESS, PLEASE COVER WITH PARTICULAR CARE AND SENSITIVITY
 - Where would you like to be living as an older person? PROBE independently, with family (ASK ALL EXCEPT PARENTS SEPARATED FROM CHILDREN), supported accommodation. Why do you say that?
 - What are the different things you'll be taking into account when you decide where you'll want to live at that stage of life?
 - PROBE cost/mortgage, location, structure (e.g. single-level), proximity to family/friends, independence services, green spaces/nature
 - Would you like to be living/cared for by family? PROBE pros/cons/concerns
 - [ASK TRANSGENDER/INTERSEX] As a [TRANSGENDER/INTERSEX] person, are there any additional considerations that you think about when planning your older age? Are there things that are specific concerns or worries for you?
- (ASK ALL) COMMUNITY AND SOCIAL ENGAGEMENT. INTERVIEW NOTE: VERY SENSITIVE SECTION FOR PARENTS SEPARATED FROM CHILDREN, PLEASE COVER WITH PARTICULAR CARE AND SENSITIVITY
 - When you are older, what are your hopes/expectations around spending time/being involved with any of your family?
 - And with friends? Do friends 'count' as family for you?
 - What are your hopes/expectations around being involved in community events?

AGED CARE SYSTEM AND SERVICES

10 MINS

Objectives: People's knowledge and perceptions of aged care system and services

- (ASK HOMELESS, CARE LEAVERS, PARENTS, TRANSGENDER/INTERSEX) How much would you say you know about the aged care system and services that are available for older people? PROBE for understanding of difference between aged care facility or home (e.g. nursing homes) and retirement homes/villages
 - [IF NECESSARY, MODERATOR READ OUT] The aged care system and services are for people aged 65 and over (and or 50 and over for Indigenous Australians), and includes care provided in people's homes, in the community and in aged care homes.

- Aged care homes (sometimes known as a nursing home or residential aged care facility) are for older people who can no longer live alone and need ongoing personal help with everyday tasks or health care.
- And how have you heard about the aged care system? PROBE FOR INFORMATION SOURCES, PERSONAL EXPERIENCE
- Have you ever visited an aged care home/facility? Why was that? PROBE What words would you use to describe the aged care home/facility?
- From your experience, how easy or difficult is it to get access to aged care services if you, or a family member, needed them?
- From what you know, how do you go about accessing aged care services? PROBE via hospital referral, GP, My Aged Care website. What are the challenges?
 - How easy do you think it will be for you to get a place in an aged care home/facility when you need one? PROBE: awareness of waiting lists
 - Are you aware of any bonds that need to be put down to secure your place in an aged care home/facility?
 - IF YES: From what you know, how much, if any, bond do you have to put down?
- And from what you know, what do you think needs to change to improve the aged care system and service for older people?
- [ASK FOR TRANSGENDER/INTERSEX] If, as an older person you needed to be in an aged care facility, who would you like to live with? And are there people, or types of people, that you wouldn't want to live with? PROBE.

THANK AND FINISH

5 MINS

- Thank you very much for talking with me today; it's been really helpful.
- We've discussed this topic in a lot of detail, do you have anything else you would like to add?
- Do you have any questions that you'd like to ask? Or anything else you'd like to say before we finish the interview?
- The client for this project is the Royal Commission into Aged Care Quality and Safety, who are keen to better understand views around ageing and aged care.
- THANK AND HAND OUT INCENTIVE.