What Do Older People Want From Their Healthcare?

A survey of older Victorians and their carers

Final report

Table of Contents

List of Figures

List of Tables

Glossary of Abbreviations and Terms

Abbreviation/Term	Description
AFCC	Age-Friendly Cities and Communities
COTA	Council on The Ageing
DH	Department of Health
ECCV	Ethnic Communities Council of Victoria
GP	General Practitioner
HHGL	The WHO Housing and Health Guidelines
HIC	Health Issues Centre
HREC	Human Research Ethics Committee
MAC	My Aged Care
NARI	National Ageing Research Institute
SPSS	Statistical Package for the Social Sciences
TCP	Transition Care Program
U3A	University of the Third Age
WDOPW	What Do Older People Want?
WHO	World Health Organization

Executive Summary

To date, little is known about what older Victorians want or expect from their healthcare as they age or how these priorities may change over time. There is also a need to understand the influence of interactions with the health system at different points throughout the ageing process and across the care continuum. Knowledge about this is important because many of the challenges that confront individual older people as they age can be planned for, predicted and amended.[1]

This report presents the results of consumer consultation that was commissioned by the Older People Policy area within the Victorian Department of Health (DH). It is designed to explore what older people consider important in relation to their health and wellbeing throughout later life by focusing on 6 identified stages of ageing. These stages are in keeping with general trends across the life course for the general population:[2]

1. Healthy and active ageing

2. Managing multi-mobility and/or frailty in the community

3. Healthcare in a crisis for sudden health issues

4. Regaining independence after being unwell

5. Needing specialist aged care support

6. Requiring end of life care

It is important to note that while the above seeks to capture the underlying changes that can occur to some level in all people as they age, there is marked diversity in how the changes are experienced by older people.[2] Losses in capacity that occur through ageing can be compensated for by adaption and are accompanied by gains in knowledge and experience.[2]

Consumer consultation with older Victorians (aged 65 years and over) and their carers was undertaken by the National Ageing Research Institute (NARI) in 3 different formats between April 2019 and February 2020:

1. Face-to-face focus groups with 63 participants from metropolitan and regional Victoria

2. Social media consultation (via a project-specific Facebook page) over a 2-month period

3. State-wide online survey which received 298 eligible responses

Qualitative data obtained from the focus groups and social media consultation, in addition to a review of peer-reviewed and grey literature, was used to inform the development of the state-wide survey that was distributed to older people across Victoria. The survey included 5-point Likert scale, multiple choice and free-form questions with programming to minimise exposure to inappropriate questions.

These components were synthesized to inform this report, which identifies the top 5 health and wellbeing priorities for older people within the above-mentioned stages of later life:

- During periods of **healthy and active ageing** older Victorians prioritised taking an active role in managing their health. A positive outlook on life, healthy eating, access to specialist medical services and meaningful social interactions with family and friends were also thought to be important.

- In **managing multi-morbidity and frailty in the community** older Victorians valued the opportunity to age in place. This goal was assisted by other factors rated as being important including having effective transport in the community, adequate financial resources, age-friendly and safe environments and proximity to healthcare services.

- When requiring **healthcare in a crisis for sudden health issues** often involving hospitalisation, older Victorians appreciated knowing what was going on with their care. They also felt that high quality healthcare, being listened to, being treated with dignity and respect and receiving treatment in a timely manner were important.

- As part of **regaining independence after being unwell** including recovery from an illness or injury, older Victorians thought it was most important to maintain a positive attitude, have a discharge plan when leaving hospital and have a strong support system to assist at home. They also valued both home-based and community-based medical, nursing and allied health services.

- In regards to needing **specialist aged care support** older Victorians expressed a strong desire to remain in their own home for as long as possible and only move to a residential aged care facility when they could no longer be cared for at home. They valued planning the transition to residential aged care ahead of time. Once in residential aged care, older Victorians valued high quality care and the ability to continue to "be myself".

- Finally, when **requiring end of life care** older Victorians valued being treated with empathy and respect, effective pain management and family-centred care which includes, informs and supports bereaved family members. Older Victorians wanted access to appropriate palliative care services as well as written plans and verbal conversations to document their preferences.

WHAT DO OLDER PEOPLE WANT FROM THEIR HEALTH CARE?

Older people told us their top 5 priorities for health & care

WDOPW PROJECT

About the project:

We asked 298 older people in Victoria about their health and care. More than 1 million Victorians are aged over 60.[1] Older people experience 41% of the disease burden[2] Therefore older people's thoughts about their health care matter.

HEALTHY & ACTIVE AGEING

Older people's top 5 priorities:

1. Taking an active role in managing health
2. A positive outlook on life
3. Healthy eating
4. Access to specialist medical services.
5. Social interaction with family & friends

MULTIMORBIDITY & FRAILITY IN THE COMMUNITY

Older people's top 5 priorities:

1. Ageing in place
2. Transport in the community
3. Adequate financial resources
4. Age friendly & safe environments
5. Access to health services

CARE IN A CRISIS & ACUTE HOSPITALISATION

Older people's Top 5 priorities:

1. Knowing what is going on
2. High quality healthcare
3. Being listened to
4. Being treated with dignity & respect
5. Treatment delivered in a timely manner

REGAINING INDEPENDENCE

Older people's top 5 priorities:

1. Maintaining a positive attitude
2. Receiving a discharge plan when leaving hospital
3. Having a strong support system
4. Having medical, nursing or allied health services provided in the home
5. Access to community based health services

SPECIALIST AGED CARE SERVICES

Older people's top 5 priorities:

1. Remaining in my own home
2. Moving into residential aged care only when I cannot be cared for at home
3. High quality care
4. Plan my transition to residential aged care ahead of time
5. Continue to 'be myself' in residential aged care

CARE AT END OF LIFE

Older people's Top 5 priorities:

1. Being treated with empathy & respect
2. Pain management
3. Family centered end of life care
4. Access to palliative care services
5. Written plans & verbal conversations

References 1-2: Department of Health and Human Services VIC (DHHS VIC). 2020.
Ageing. https://www.dhhs.vic.gov.au/ageing

1. Introduction

1.1 Background

1.1.1. Victoria's Ageing Population

Australia's population is ageing, with the number of people aged 65 years and over expected to be 5.7 million, approximately 19% of the population, by 2031.[3] In Victoria there are more than 1 million people over the age of 60 and older people make up more than 15% of the Victorian population.[4] An increase in longevity at the population level is not necessarily accompanied by an increase in health as the population ages.[2] Although older people generally live well as they age, older people experience 41% of the disease burden and have specific health and care requirements that need to be considered in health and aged care settings.[4]

1.1.2. Health and Wellbeing in Older Age

A longer life brings opportunities, not only for older people but also for society.[5] However the opportunities and contributions that longevity affords depends heavily on health[5] and there is likely to be an associated increase in the number of older people accessing health services as they age.[2,6] For many older people, their health and wellbeing will be negatively impacted by events such as acute illness, falls, depression and isolation.

It is possible to build opportunities to intervene and change the ageing trajectory so that older people experience a longer period of independence and less time being ill or hospitalised. A preventive, early intervention focus will better meet the needs of older people and help manage the costs of later life health and aged care, by keeping people safe, healthy and in their homes for longer. This requires a focused government policy and planning approach based on research and evidence.

It is well recognised that health and wellbeing support for older people should be individualised and reflect person-centred practices, as well as be informed by older people's overarching expectations, needs, wants and priorities.[6] Following the second WHO *Global Forum on Innovation for Ageing Populations in 2015*, it was recommended that older people be included and consulted on how best to improve their own lives.[2,6] By making sure that older people are heard, there is an increased likelihood that the environment they are living in, and the care that they receive, is appropriate and effective.[6] In order to support this there is a need to develop robust policies on how older people access care and services across their life trajectory.[2]

As people age, motivational priorities and preferences also appear to change.[2] For example, some older people may find alternative ways to accomplish tasks to compensate for losses in ability as changes may create a shift from being fit and well through to living with multi-morbidity and health and care needs arise at the end of life.[2] There is some evidence that priorities change as people age due to social shifts such as the development of new roles in society and the formation of new viewpoints.[2] Therefore shaping health and wellbeing policies and health settings to be responsive to the dynamic priorities of older people and informed by their expectations is of great benefit.[2]

A review of the existing literature suggests that older people want to 'age in place', or live in their own home safely, independently and comfortably;[6,7] have good health support;[7] timely and accessible services;[7] and be able to remain physically, mentally and socially active.[7] Research has found that when people experience frailty and ill-health they want to be included in discussions and decisions around their health needs,[8] have continuity of care from health professionals and support services[8] and be treated with respect.[5]

While this information provides an over-arching guide as to the perspectives of older people, very little research has been conducted to date, on a local level, to discover specifically what older Victorians want and/or expect from their healthcare and how their priorities change along with changes in health needs. Therefore research into the health and wellbeing priorities of older Victorians is warranted.

1.1.3. Ageing Well Framework

In 2019 the DH undertook development of an 'Ageing Well' framework to maximise the wellbeing and quality of life of older Victorians. This was to be achieved by supporting future policy development and assisting with determining funding priorities in the Ageing and Carers portfolios.

The proposed framework describes a system that responds to keeping older people independent through prevention and early intervention. A number of proactive touchpoints were identified by the DH in establishing the framework. A touchpoint is a point in time where a person may come into contact with the health and care system.

These can be termed 'proactive' when the contact is used as an opportunity to create a positive patient experience, prevent future illness and manage current conditions for future positive health and care outcomes. The following touchpoints were identified:

- Ageing well – universal community-based initiatives that support active ageing, inclusion and participation

- Support in the community – targeted initiatives that help older people to live with long term and complex conditions and respond to the support needs of key population groups

- Care in a crisis – provision of care and support at periods of illness, injury or stress including hospitalisation

- Regaining independence – supporting re-enablement across the service system

- Specialist care (incorporating residential aged care and end of life care) – access to good quality services and supports

In order to ensure that the framework was well-informed by older Victorians stakeholders, DH commissioned a number of agencies and individual projects to seek the views of older Victorians regarding key issues relating to these touchpoints.

1.1.4. Ageing Well in a Changing World

In October 2020, the Commissioner for Senior Victorians released a report titled "Ageing Well in a Changing World" which presented an overview of feedback obtained from Senior Victorians during 2019 about their thoughts on what it means to 'age well'.[9]

The consultation process, which included an online survey and face-to-face consultation, identified eight key attributes of ageing well and presents these in a socio-ecological model (Figure 2).

Figure 2: The eight attributes of ageing well: a socio-ecological model [9]
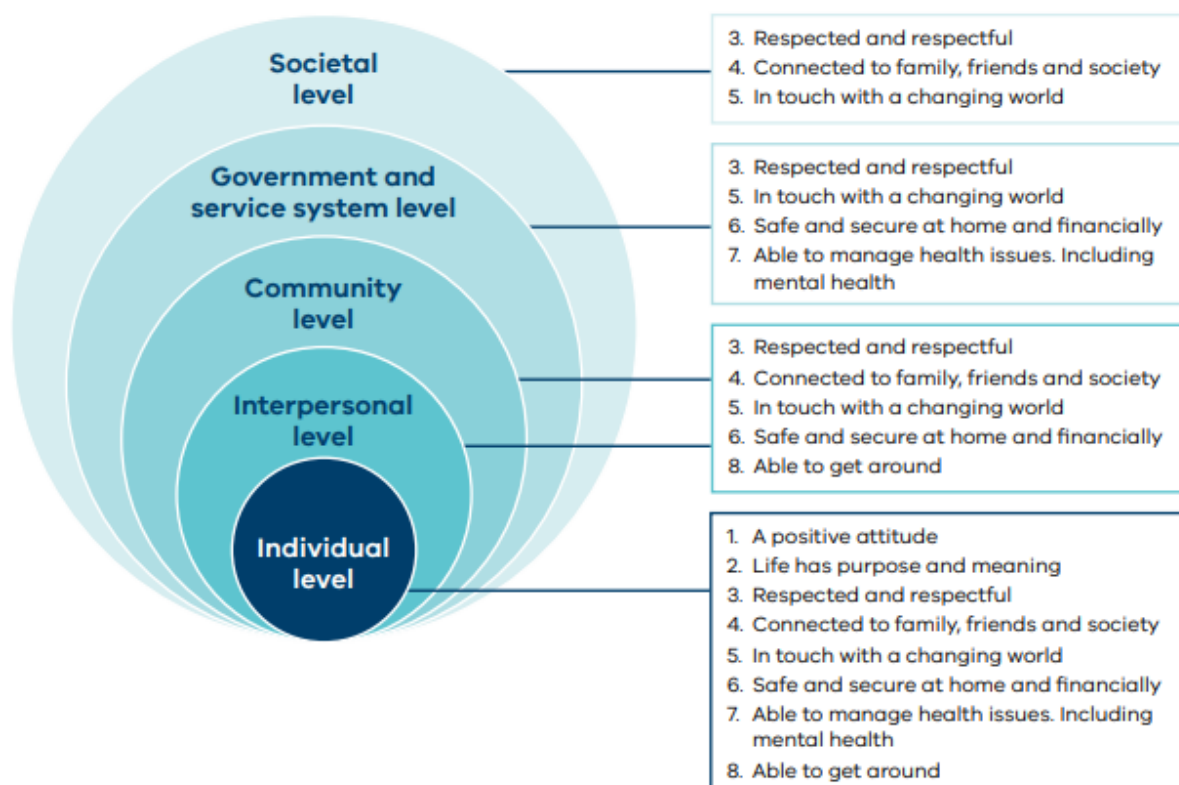
In addition, the report proposed the following five initial priority areas for action at a State Government level as the basis for reform:

1. Senior Victorians desire to have a greater voice
2. Triggering a longevity dividend
3. Respect and recognition of older people
4. Navigation to services and support
5. Online alternatives and support

1.1.5. What Do Older People Want from their Healthcare?

In 2019 the National Ageing Research Institute (NARI) was also commissioned by the DH to consult with older Victorians regarding what they want from their healthcare. Unlike the Ageing Well framework outlined previously, specialist aged care services and care at end of life are separated as listed below. The commissioned work was targeted at the following 6 key stages in later life:

1. Healthy and active ageing
2. Support for multi-morbidity and frailty in the community
3. Care in a crisis and acute hospitalisation
4. Regaining independence
5. Specialist aged care services
6. Care at end of life

These stages are key junctures that align with a typical ageing trajectory. This adheres to the World Health Organization (WHO)'s description of what ageing may involve and the factors connected to ageing that are known to influence people's health and wellbeing, healthcare needs and preferences within a population.[5]

1.2 Aim and Objectives

1.2.1. Aim

The aim of the *What Do Older People Want from their Healthcare?* Project was to develop an evidence base for the DH regarding what older Victorians (aged 65 years and over) and their carers want from healthcare. This will be used to support the development of consumer-driven policy regarding both preventative and responsive healthcare services in Victoria.

1.2.2. Objectives

The objectives of the project were:

1. To explore what older people and their carers want from healthcare across the 6 key stages of later life
2. To identify the needs, expectations and priorities of older Victorians and their carers in response to the following scenarios:

   - Enabling older people to remain healthy and active when ageing
   - Seeking support for managing multi-morbidity and/or frailty when living in the community
   - Seeking healthcare in a crisis for sudden health issues
   - Regaining independence after being unwell
   - Needing specialist aged care support
   - Requiring end of life care

3. To determine the top 5 health and wellbeing priorities for older people for each of these stages

2. Method

2.1 Overview

Semi-structured face-to-face focus groups were conducted with a convenience sample of older Victorians and their carers. The focus groups collected qualitative data concerning the needs, expectations and priorities of participants regarding their healthcare. This data informed the development of a project-specific Facebook page (social media platform) that was used to gather further information from participants who were unable to attend a focus group.

Analysis of the qualitative data obtained from both the focus groups and social media consultation, in addition to a review of peer-reviewed and grey literature, informed the development of an online, mixed-methods survey that was distributed to older people across Victoria. *Appendix 2: Method Further Information* illustrates how project activities lead to the development of the online survey.[10]

Figure 3: Overview of the project method

Face-to-Face Focus Groups	Literature Review
Semi-structured face-to-face focus groups with older Victorians and their carers to determine the structure and content of a state-wide online survey	Extensive review of peer-reviewed and grey literature
Social Media Consultation	
Project-specific Facebook page to collect additional input from those unable to attend focus groups	
Online Survey	
State-wide online survey to collect qualitative and quantitative data from older Victorians and their carers regarding health and wellbeing at key stages of later life	

2.2 Ethics

This project received ethics approval by the Human Research Ethics Committee (HREC) of Austin Health, protocol number HREC/45098/Austin-2020. This project was carried out accordance to the National Statement on Ethical Conduct in Human Research (2007).

2.3 Participant Safety and Confidentiality

A number of safeguards were put in place to minimise the risk of potential harm to project participants:

1. Informed Consent – Informed consent was collected from all focus groups participants prior to the start of the focus group. A disclaimer was fixed at the top of the project Facebook page during the online consultation phase informing users that information posted would be collected for research conducted at NARI in partnership with the DH. A plain language statement was affixed to the introduction to the online survey informing participants of the same.

2. Distress Protocols – Participant distress protocols were drafted and followed by experienced researchers during face-to-face focus groups and monitoring of the online consultation phase.

3. Data Security – To protect the identity of participants, data was de-identified and stored in locked filing cabinets or password protected computer systems. Participant details were kept separate from the collected data in password protected files accessible only to the principal investigators.

2.4 Face-to-Face Focus Groups

Semi-structured face-to-face focus groups were conducted to gain in-depth information to inform the future development of social media consultation and online survey phases of the project.

Recruitment Procedures

Focus groups recruited older people (aged 65 years and over), and carers of older people, living within metropolitan and regional Victoria. Participants were recruited via email from the National Ageing Research Institute's (NARI) volunteer database or through the mailing lists of various organisations and peak bodies willing to arrange onsite focus groups. All advertisement materials were approved by the Austin Health HREC (HREC/45098/Austin-2020). Prior to participation in face-to-face focus groups, participants were provided with a Plain Language Statement and Consent Form to sign. Focus group participants were offered a $40 Coles Myer gift card as reimbursement for travel and parking expenses and as compensation for their time.

Interview Process

Focus groups were semi-structured. Questions and prompts were developed by the research team, and were informed by a literature review of peer-reviewed and grey literature. Focus groups were conducted by 2 researchers; 1 primary facilitator and 1 secondary facilitator to take notes and monitor the participant distress protocol. Focus groups were limited to 15 people, to enable effective discussion and input from all participants. Participants were asked to engage in discussion and respond to questions about what they want and expect from their healthcare at varying stages of later life. With the consent of all participants, focus groups were audio-recorded.

Analysis

Focus group audio recordings were transcribed verbatim. To ensure the confidentiality of participants, overtly identifying information (such as personal names, facility names and geographical locations) were removed and participants were not identified in the transcriptions. The anonymized data was uploaded to NVivo 11,[11] a software package to facilitate the organisation of qualitative analysis.

Three researchers independently used a semi-inductive thematic analysis approach to develop a coding framework, which was then further developed collaboratively. The coding framework was independently applied by 2 researchers to the anonymized data. Differences in coding were discussed by the 2 researchers and mediated by a third researcher where necessary.

2.5 Social Media Consultation

Consultation involving social media (a project-specific Facebook page) was included in this study in an effort to increase the potential for participation in demographics who may have been unwilling or unable to attend face-to-face focus groups, such as people with mobility/transport difficulties or carers employed or otherwise engaged during business hours.

Recruitment Procedures

The project Facebook page was promoted via the social media accounts of NARI and various Victorian based organisations and peak bodies with an interest in ageing and ageing research. Facebook was selected as the social media platform as it is gaining increasing popularity among people over the age of 65, with its adoption rate among older people quadrupling from 13% in 2009 to 56% in 2014.[12] All advertising materials were approved by the Austin Health HREC (HREC/45098/Austin-2020). A disclaimer was pinned to the top of the project Facebook page during the online consultation phase informing users that information posted would be collected for research conducted at NARI in partnership with the DH. The posting of material implied consent for data to be collected. No financial incentive was provided for participants to contribute to the social media consultation phase.

Consultation Approach

Online participants were invited to contribute (at their discretion) to questions, open enquiries and polls, designed to encourage discussion about healthcare preferences and priorities. Content was informed by the analysis of face-to-face focus group data and was uploaded twice a week over a period of 2 months.

Online content and discussion was monitored and facilitated by experienced researchers in observation with the approved participant distress protocols. On completion of the project the project Facebook page was closed.

Analysis

Online data was retrieved verbatim according to The Association of Internet Researchers (2012) guidelines and qualitative data (i.e. online comments from the project Facebook page) were stored on a secure electronic database. To ensure the confidentiality of participants, overtly identifying information (such as personal names, facility names and geographical locations) were removed and participants were not identified in the transcriptions.

The anonymized data was uploaded to NVivo 11. The established coding framework was verified with this new dataset and then independently applied by 2 researchers to the anonymized data. Differences in coding were discussed by the 2 researchers and mediated by a third researcher where necessary.

2.6 Online Survey

The final phase of the project was a comprehensive online survey of older Victorians (and their carers), regarding what they want from their healthcare across the lifespan of ageing. The survey content was informed by findings of the face-to-face focus groups and online consultation.

Recruitment Procedures

The online survey recruited older people (aged 65 years and older), living within metropolitan and regional Victoria and their primary carers to complete a comprehensive online survey. Survey participants were recruited via mailing lists and social media accounts of NARI and various organisation and peak bodies, including, but not limited to: Council on the Ageing (COTA), Carers Victoria, Health Issues Centre (HIC), Office of Senior Victorians, Ethnic Communities Council of Victoria (ECCV), Municipal Association of Victoria, Country Women's Association, Probus Clubs throughout Victoria, Universities of the Third Age (U3A) other community-based service organisations with an interest in older community members. All advertisement materials were approved by the Austin Health HREC (HREC/45098/Austin-2020). Survey participants who provided a valid email address went into the running to win 1 of 3 $40 Coles Myer gift cards.

Survey Design

The survey was a bespoke survey, developed by the research team. Content was informed by an extensive literature review of peer-reviewed and grey literature as well as findings from the face-to-face focus groups and online consultation. For further information on how analysis of literature, focus group data and online consultations informed the survey design, see Appendix 2: Method – Additional Information. The survey collected non-identifiable demographic data (including age, gender, geographical location and carer status) and responses to survey questions about wants, preferences, expectations and priorities with respect to healthcare across different stages of later life. The full survey included 72 questions (Supplementary Figure 26). 5-point Likert scale, multiple choice and free-form questions were developed with programming to minimise exposure to inappropriate questions; no question was mandatory. The survey was administered via REDCap and the estimated completion time was 20-30 minutes based on pilot testing conducted among the research team. The first survey question provided participants with an overview of the project and obtained informed consent from the participant to proceed, implied consent was also obtained on submission of the survey.

Analysis

Survey data (qualitative and quantitative) were exported from REDCap via Excel spreadsheets and stored in a secure electronic database. To ensure the confidentiality of participants, overtly identifying information, (such as personal names, facility names and geographical locations) were removed. Participant email addresses (where provided) were kept separate from the collected data in password protected files accessible only to the principal investigators.

The anonymised qualitative data was uploaded to NVivo 11. The established coding framework was verified with this new dataset and then independently applied by 2 researchers. Differences in coding were discussed by the 2 researchers and mediated by a third researcher where necessary.

The quantitative data from the survey was entered into the Statistical Package for the Social Sciences (SPSS) for summary statistical analysis. Quantitative data was described using numbers and percentages for categorical data and Likert scales. A 2-tailed test of population proportion was used to determine statistically significant differences between categorical data subsets. Statistically significant differences between Likert scale data subsets was determined by a Mann-Whitney U test between 2 independent groups and a Kruskal-Wallis H test between 2 or more independent groups. Differences between subgroups are only reported where they were calculated to be statistically significant ($p < 0.05$).

The top 5 priorities for each domain of ageing were determined by the percentage of "very important" responses within each Likert scale. Likert scale results were expressed as diverging stacked bar graphs where results are aligned to the centre of the neutral response to better visually represent differences in the ranked factors. See Figure 4 below as a demonstration. By aligning the stacked bar graphs from the centre of the neutral response, it is visually clear that Sample 1 (aligned to the right) has more 'positive' responses while Sample 2 (aligned to the left) and has more 'negative' responses.

Figure 4: Example of Likert scale results
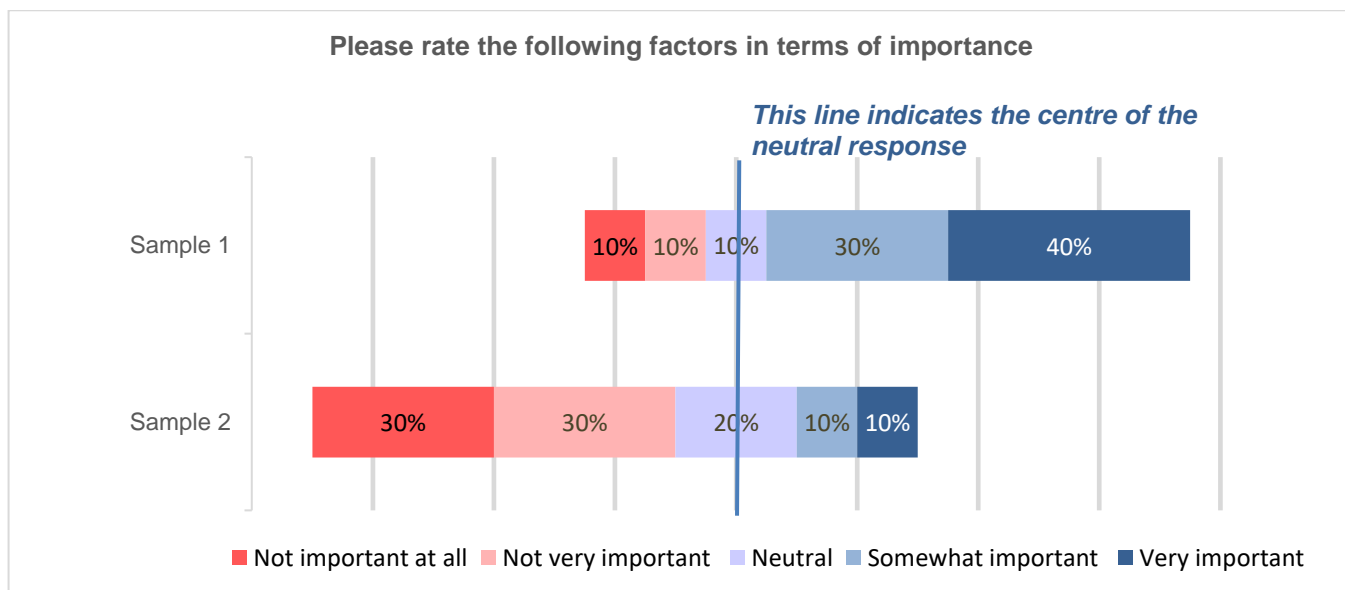
2.7 Limitations

People were excluded from participating in the focus group consultation if they had cognitive impairment, did not have the capacity to provide their own consent or were under the age of 18. Due to resource constraints promotional material, online consultation and the survey were only provided in English, therefore people who were unable to read or converse in English were not able to participate. This resulted in selection bias due to the exclusion of people who speak languages other than English as their primary language.

Participants over the age of 65 were asked to complete the survey in the first-person, considering their own health and wellbeing preferences. Participants under the age of 65 were exclusively carers of an older person and were asked to complete the survey from the point of view of the older person they care for, considering that person's preferences and experiences. We acknowledge that this required some participants to provide answers on behalf of others rather than themselves. This may have influenced the responses as it is difficult to consistently answer on behalf of another person.

3. Results

3.1 Recruitment

3.1.1. Face-to-Face Focus Groups

Sixty-three older Victorians were recruited from metropolitan Melbourne and regional Victoria to participate in 1 of 7 semi-structured, face-to-face focus groups between 15th April 2019 and 14th June 2019. Focus groups were scheduled for 60 minutes and varied in duration between 55 to 90 minutes. Attendance ranged from 5 to 13 participants in a single focus group.

Initial sample size estimations indicated the recruitment of 50 participants across 8 focus groups. As the target recruitment number and saturation of themes was reached after 7 focus groups, an 8th group was not conducted.

3.1.2. Social Media Consultation

An 8-week social media consultation was executed using Facebook between May 31st 2019 and July 26th 2019. Over this time the project Facebook page gathered 1285 views (an average of 86 per post). Of this traffic there were 82 interactions (reactions/shares/comments) and qualitative input was received from 13 participants.

Initial sample size estimations aimed to involve 50-80 participants via the Facebook consultation phase. While this number was achieved in interactions, the Facebook consultation garnered less meaningful data than expected due to low engagement with the platform. However as no additional themes were raised during the online consultation, researchers agreed that data saturation was achieved.

3.1.3. Online Survey

386 online surveys were completed. Of those, 298 were included in the final analysis (Figure 5).

Surveys were discarded if:

- No consent was provided
- They were left blank
- They contained minimal data (limited to age, gender and postcode)
- The participant was non-eligible (under the age of 65 and not a carer of an older person)

Initial sample size estimations called for the recruitment of 384 survey responses with a confidence level of 95% and a 5% margin of error. While 298 responses does not reach this initial target it only reduces the margin of error to 5.68% which still achieves a highly representative sample.

In addition to completing 5-point Likert scale and multiple choice questions, participants submitted 1260 comments in open ended free-form questions.

90% of the surveys were completed online. The remaining 10% were provided in hardcopy on request with a return postage-paid envelope to increase survey availability to participants with low computer literacy and/or access.

Figure 5: Summary of survey responses
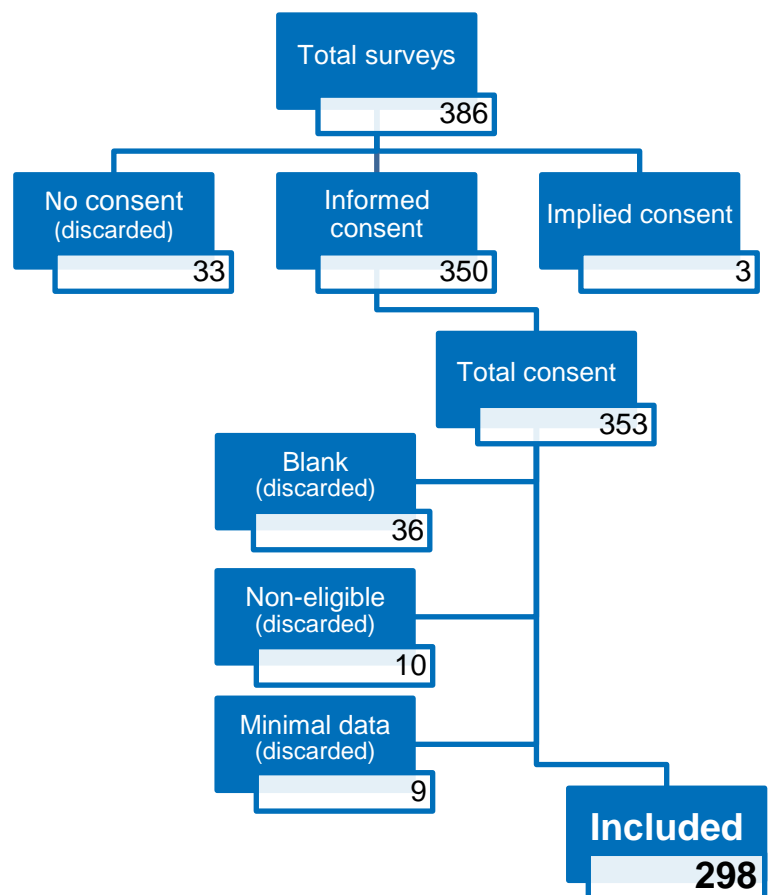
3.2 Demographics

A range of demographic information was collected in order to identify the specific characteristics of respondents relevant to each of the key stages of ageing.

3.2.1. General Characteristics

Table 1 describes the general demographic characteristics of the 298 participants who were included in the survey sample. This includes information such as age, gender, postcode and socio-economic status.

Table 1: General demographic characteristics of survey respondents, n = 298

Characteristic	Number of responses	% of total sample
Gender		
Female	210	70.5%
Male	82	27.5%
Did not describe	6	2.0%
Age (years)		
Under 65	31	10.4%
65 and over	262	87.9%
Did not respond	5	1.7%
Residential Postcode		
Metropolitan Melbourne	170	57.1%
Regional Victoria	100	33.6%
Did not respond	28	9.4%
Living Situation		
I live with someone	201	67.7%
I live on my own	90	30.3%
Did not respond	6	2.0%
Employment Status		
Retired	235	78.9%
Paid Employment	43	14.4%
Unpaid Employment	29	9.7%
Did not respond	5	1.7%
Carer Status		
Non-carer	233	78.2%
Carer	61	20.5%
Did not respond	4	1.3%
Carer Relationships		
Parent/child	26	42.6%
Spouse	17	27.9%
Sibling	10	16.4%
Friend	5	8.2%
Grandparent/child	3	4.9%
Other relative	1	1.6%

21% of participants identified as a carer of a person over the age of 65. Of this subcategory 66% were also over the age of 65, while 34% were under the age of 65. The most common carer relationships were a child caring for a parent (43%), with the next most common being spouses (28%) and siblings (16%).

3.2.2. Health Status

Participant health status, experience accessing aged care services and recent hospitalisation/post-discharge recovery is summarised in Table 2.

Table 2: Health-related characteristics of survey respondents, n = 298

Characteristic	Number of responses	% of total sample
Number of health problems		
I have no health problems	45	15.1%
I have 1 – 2 health problems	158	53.0%
I have 3 or more health problems	76	25.5%
Did not respond	19	6.4%
Rating of current health		
Excellent	26	8.7%
Very good	153	51.3%
Fair	90	30.2%
Poor	11	3.7%
Very poor	2	0.7%
Did not respond	16	5.4%
Currently accessing community aged care services		
Yes	65	21.8%
No	204	68.5%
Did not respond	29	9.7%
Types of community aged care services accessed		
Domestic help services	44	67.7%
Case management	16	24.6%
Transport and/or shopping assistance	15	23.1%
Community-based services	15	23.1%
Personal care assistance	13	20.0%
Occupational therapy home modification	13	20.0%
Home visits from a community health worker, nurse, General Practitioner (GP)/Doctor or social worker	5	7.7%
Meals on Wheels or meal and food assistance	5	7.7%
Social visits and/or a social program	5	7.7%
Other services	7	10.8%
Experience using My Aged Care		
Yes	85	28.5%
No	190	63.8%
Did not respond	23	7.7%
Hospital inpatient within the last 5 years		
Yes	175	58.7%
No	95	31.9%
Did not respond	28	9.4%
Experience receiving short-term in-home services while recovering from an illness or injury		
Yes	48	16.1%
No	207	69.5%
Did not respond	43	14.4%

While over 78% of respondents self-reported having more than 1 health problem, 60% rated their health status as 'very good' or 'excellent'. Around 1 in 5 respondents (21.8%) indicated that they were currently accessing community aged care services; of these, the most common service being utilised was domestic help services (67.7%) followed by case management (24.6%), transport and/or shopping assistance (23.1%) and community-based services (23.1%).The majority of survey participants (59%) had been a patient in hospital within the last 5 years. Hospital attendance correlated with age; of participants aged 65-70, 53% had been admitted to hospital in this timeframe, this increased to 64% in the 70-80 age range and 70% in the 80+ age range.

3.2.3. Specialist Care Status

Survey participant characteristics relating to specialist aged care (e.g. residential aged care) and end of life care are summarised in Table 3.

Table 3: Residential aged care and end of life care characteristics of survey respondents, n = 298

Characteristic	Number of responses	% of total sample
Currently living in residential aged care		
Yes	5	1.7%
No	287	96.3%
Did not respond	6	2.0%
Personal experience with someone who resides in residential aged care		
Yes	204	68.5%
No	57	19.1%
Did not respond	37	12.4%
Previous experience with a spouse/family member or friend receiving end of life care		
Yes	157	52.7%
No	104	34.9%
Did not respond	37	12.4%

The majority of respondents reported currently living in the community (96.3%). Despite this, around two-thirds had personal experience with someone who resides in residential aged care (68.5%).

Approximately half of survey participants had previous experience with a loved one accessing end of life care (53%).

3.3 Healthy and Active Ageing

3.3.1. Physical Health

The highest rated factor within physical health was *taking an active role in managing your health* (82% 'very important'). Participants saw this as taking proactive measures (such as quitting smoking or getting the flu vaccination), being engaged with healthcare professionals (asking questions and keeping a copy of your reports or results) and not ignoring signs of physical or psychological problems.

Figure 6: Percentage of survey responses determining the importance of factors in physical health
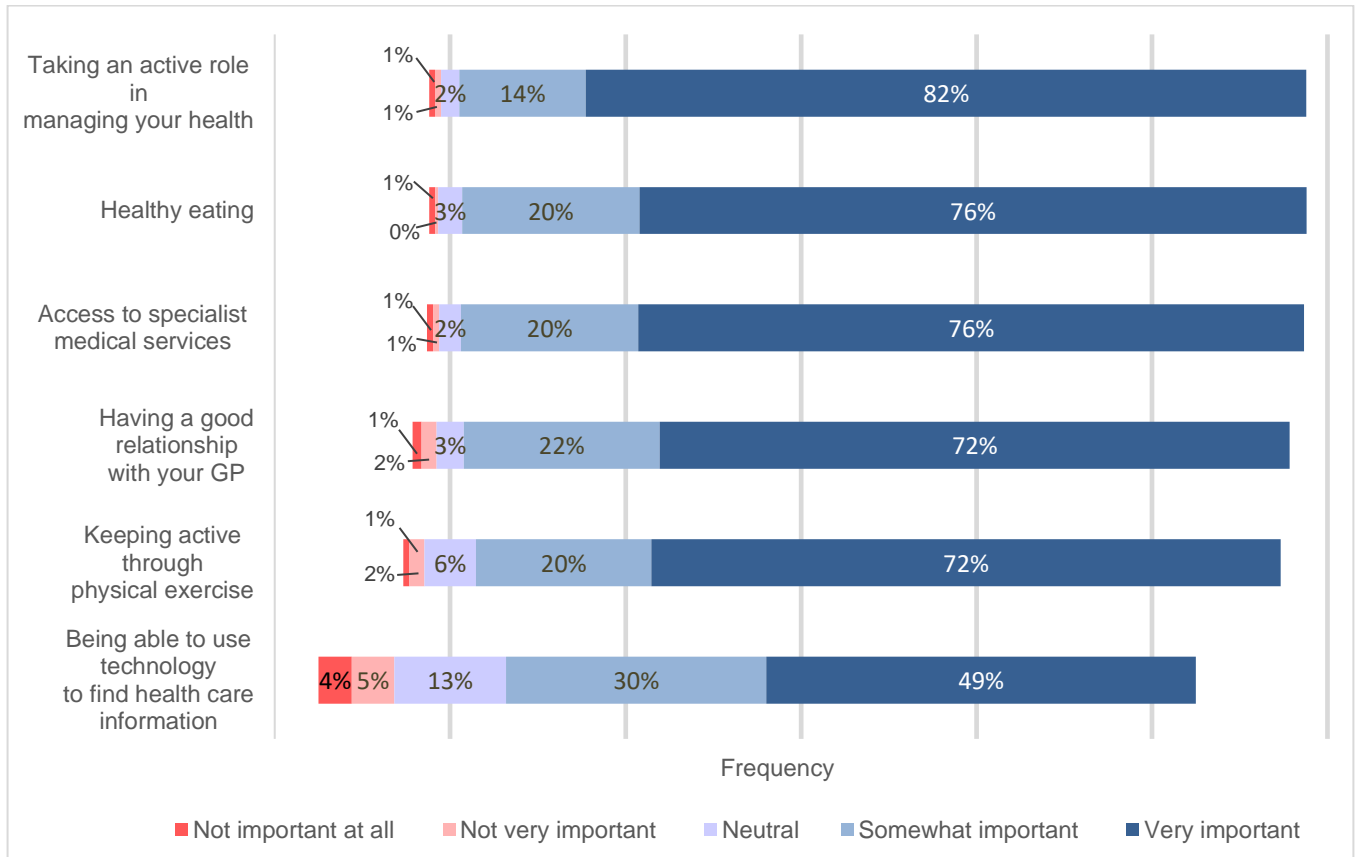
Motivation and awareness were seen as important factors in taking an active role in one's health. This was coupled with the expectation that older people should take responsibility for their health and not abdicate such responsibilities to a GP, spouse or family member. Carers of older people expressed that where an older person did not take responsibility for their own health it may add to the care burden.

Others expressed concern that older Victorians are not often aware of the actions they can take, and initiatives that they can join, which can contribute to healthy ageing. For example, participants mentioned low levels of awareness regarding health promotion and prevention programs aimed at helping older people stay proactively well. Participants were also concerned that such programs were underfunded.

Healthy eating was identified as an important factor for physical health with 76% of respondents rating this as very important in the online survey. In addition, many participants raised concern about the affordability of healthy food.

> *"We need to watch our diet too, and I think that is where governments could help in promoting the right foods. Obesity is supposed to be an epidemic, but all the foods that… older people can afford are the fattening ones."*
>
> *– Focus group participant*

Access to specialist medical services, such as a geriatrician or cardiologist, was considered mildly more important than having a good ongoing relationship with a GP (76% and 72% 'very important', respectively). Despite this, many participants expressed complaints regarding long waiting times for specialist medical services in the public healthcare system.

Keeping active through physical exercise was considered very important by 72% of participants, who described many examples of their personal physical activity preferences and routines. Physical activity was seen as particularly important for weight control, bone health and maintaining movement and flexibility.

Figure 7: Percentage of survey responses agreeing with statements regarding motivation to exercise
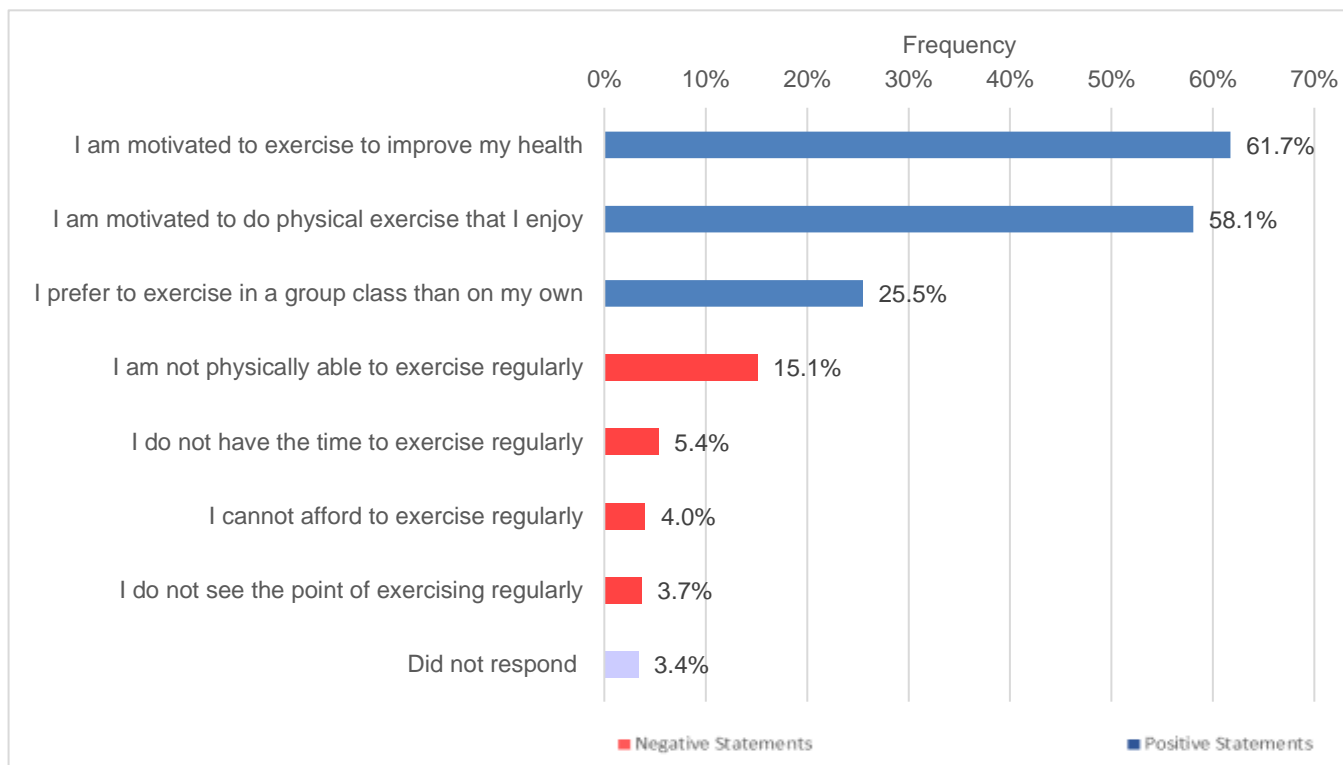
The most popular motivations for exercising were: to improve health (61%), enjoyment (58%) and socialisation from a group class (26%). Comments suggested that the social influence of groups improved attendance and motivation. Despite this, 15% of participants reported they were not physically able to exercise regularly. The data showed 5% cited not having the time to exercise regularly, 4% not having financial resources, and 4% not seeing the point of exercising regularly.

Barriers to physical exercise were also revealed in the survey comments. Several participants commented that the price of gym memberships prohibited their participation and that discounted fees would enhance motivation to attend. Furthermore some participants felt they were not welcome at recreation centres and gyms due to their older age. Some participants also commented that health conditions, such as mobility, pain and/or neurological conditions, prevented them from undertaking regular physical exercise.

The following participant quote illustrates several of the barriers to physical exercise expressed by a number of survey participants in the comments section of the survey. Below the participant identifies that pain, recovery from chronic illness, disability and high costs are barriers preventing them from exercising:

"Exercise is impossible when in constant pain!
Cost of gymnasiums are too high for 65 yo [65 year old] cancer recovering pensioners...
Due to disability I am unable to exercise very much, but I know it is important."

– Survey participant 213

As shown in Figure 6 *being able to use technology to find healthcare information* regarding physical health was considered 'very important' to 49% of participants. The perceived importance of technology varied with age: 55% of 65 – 69 year olds, 52% of 70 – 79 year olds and 42% of the 80+ cohort rated this as 'very important. In addition, access to technology was raised as an important factor.

Several participants also commented that computer literacy may be a double-edged sword when seeking medical information online, and that older people should be cautious of implementing advice from suspect sources.

"Even though I have good computer skills, it is not always a good idea to seek
medical advice from the Internet."

– Survey participant 123

3.3.2. Social Participation

Social interactions with family and friends were considered the most important factors to social wellbeing for older Victorians (76% and 64% of participants respectively rating this as 'very important').

Figure 8: Percentage of survey responses determining the importance of factors in social participation
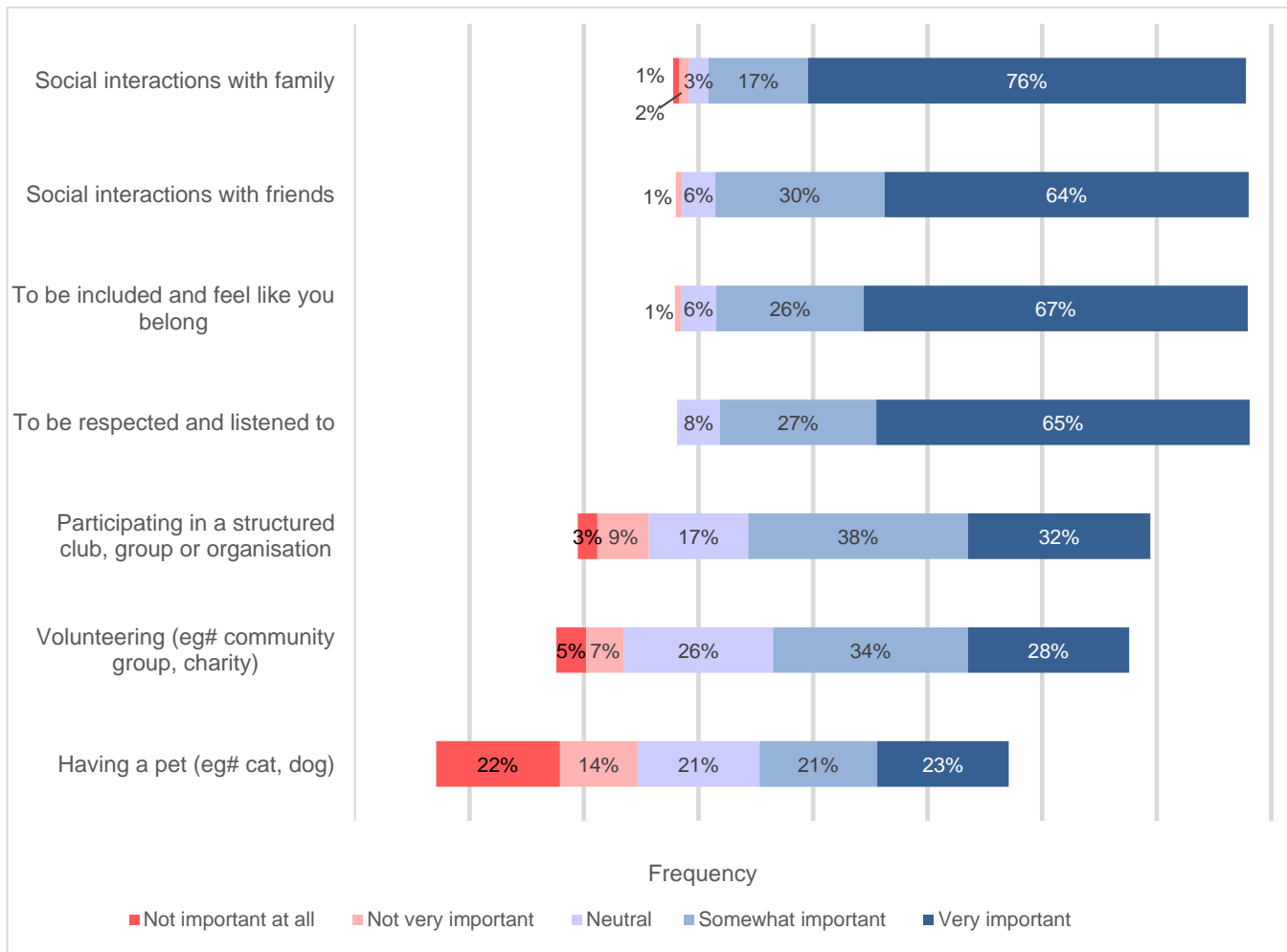
Survey comments revealed that several participants felt family could also be a source of stress, were unavailable if they were located a long distance away or were too busy for social visits and could at times have too many expectations of older family members. This finding demonstrates the heterogeneity of older people and their social preferences with some expressing that friends were most important to them rather than family.

> *"It is not always easy for social interactions with family as often they live far away, interstate or overseas. This is why social interaction with friends is extremely important. Many people are lonely so there is a need for clubs, etc."*
>
> *– Survey participant 19*

Being included and feeling like you belong, are respected and listened to were the next highest rated factors in social wellbeing (67% and 65% of participants respectively rating this as 'very important'). Participants had previously touched on the concepts of ageism and inclusion when discussing gymnasiums and swimming pools in the physical activity section.

They elaborated further in the social wellbeing section that ageism should be addressed and that older people wanted respect and to be treated as equal to others as demonstrated by the following survey comments:

> *"Ageism is rife throughout Australia and there needs to be awareness drive to address it."*
>
> *– Survey participant 358*

Older people also commented that they wanted their skills and experience to be valued by others. In particular "keeping in touch with younger people" and "remaining relevant" were mentioned frequently in the survey comments.

Less important factors included: *participating in a structured club, group or organisation* (32% very important), *volunteering* (28% 'very important') and *having a pet* (23% 'very important'). Participation in structured clubs and volunteering were valued for the reliability of their social interactions, as well as their ability to provide a sense of purpose and belonging. The perceived importance of structured social groups correlated with age, 21% of 65-69 year olds rated it 'very important', while this increased to 39% and 56% for the 70-79 and 80+ cohorts respectively.

> *"Families are busy and don't always have the time to offer older family members what a club or community group can. We don't need to be best friends with members but the social interaction from week to week with different group members is a great help."*
>
> *– Survey participant 109*

As indicated previously, Victorians aged over 65 comprise a heterogeneous group. While some survey participants highly valued regular socialisation with a structured group or organisation, others preferred one-on-one social contact, or even their own company. This suggests that older people, like other age groups, prefer to connect socially in their own way, and on their own terms.

> *"I often feel excluded in a group setting which makes me reluctant to be in a group... Some people are quite comfortable with their own company and getting on with their own lives and interests."*
>
> *– Survey participant 125*

3.3.3. Mental Wellbeing

The highest rated factor in mental wellbeing was *having a positive outlook on life* (81% 'very important'). A "positive outlook" meant many things to survey participants, from "inner strength" to "avoiding introspection and low self-esteem" to "being able to articulate and stand up for yourself".

> *"A positive attitude is so important, that if you haven't got a positive attitude to life and to the various things that happen to you – like you're adjusting to widowhood; I've gone through that as well – it's no good if you don't have a positive attitude."*
>
> *– Focus group participant*

Figure 9: Percentage of survey responses determining the importance of factors in mental wellbeing
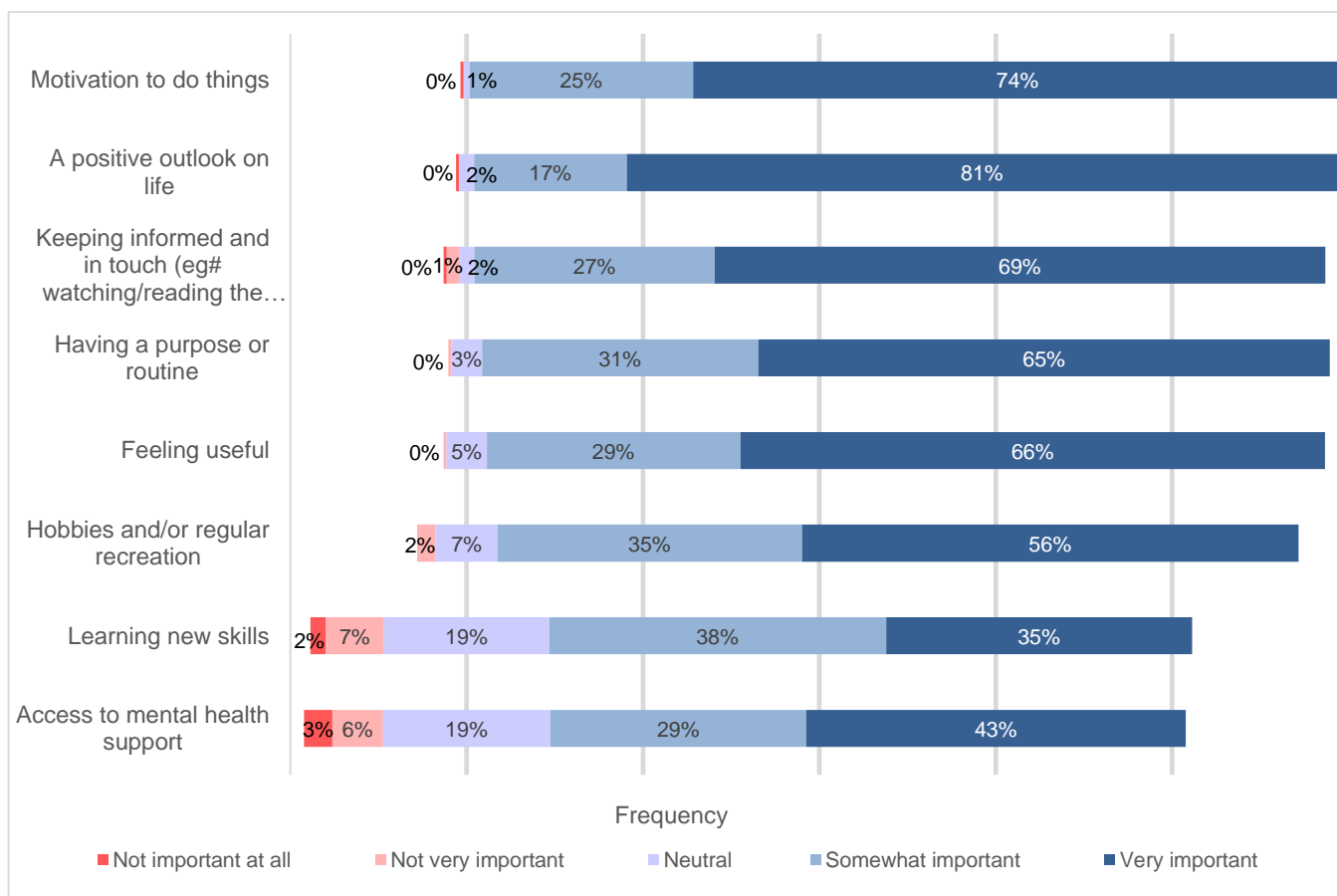
Motivation to do things was rated as 'very important' by 74% of participants in maintaining mental wellbeing. Additionally, *keeping informed and in touch* was also considered by many to be 'very important' (69%). Access to mental health support and learning new skills were ranked the lowest in terms of importance to maintaining mental wellbeing (rated as ''very important' by 43% and 35% of participants respectively). Survey participants provided examples such as "watching the news" and "keeping updated on the lives of your family of friends" and viewed these activities as important steps to "remaining relevant" and taking "an active interest in the world".

Having a purpose or routine (65% 'very important'), *feeling useful* (66% 'very important') and *hobbies or regular recreation* (56% 'very important') were 3 closely related factors under mental wellbeing. Participants outlined a wide range of mental activities, describing regular mental stimulation as "crucial", "so important" and "a reason to get up in the morning". More specifically, one participant lamented the lack of arts based activities available in regional Victoria, commenting that all that is available is "footy". Others mentioned volunteering as a way to connect to community, such as working in an op shop. Several participants mentioned that trusted friendships and a sense of belonging in the community improved their mental wellbeing as did financial security and being physically well.

> *"I belong to a community choir and a creative writing group.*
> *They contribute so much to my mental wellbeing."*
>
> *– Survey participant 164*

Within the survey responses, *learning new skills* (35% 'very important'), included a wide range of examples from computer courses to musical instruments and dance steps. This was most highly valued by the 70 – 79 years cohort (45% 'very important') followed by the 65 – 69 and 80+ age groups (36% and 20% 'very important' respectively).

A*ccess to mental health support* was considered 'very important' by 43% of participants, but 'not important at all' or 'not very important' by nearly 10% of participants. Participants identified several barriers to effective mental health support in Victoria, including financial constraints, stigma and a lack of available services in regional areas.

> *"Five visits through the GP system to see a mental health person is not enough.*
> *Plus mental health practitioners charge over the Medicare benefit so quite often*
> *out of pocket expense is high, so you just don't go."*
>
> *– Survey participant 268*

> *"Mental health carries an enormous weight of fear just to access it and fear that you*
> *will be treated as a lazy nutter instead of respected for seeking help. The stigma is appalling.*
> *The treatment cost is out of reach of the majority or persons who need it. It looks good on*
> *'policy paper' but it just does not translate into easy access for 98% of us."*
>
> *– Survey participant 160*

3.3.4. Role of the GP

Majority of participants (81%) felt that it was *important to have their own personal GP,* with most *feeling confident in seeking information from their GP* (69%) or *receiving appropriate referrals* (68%).

Figure 10: Percentage of survey responses agreeing with statements regarding seeking information from GPs
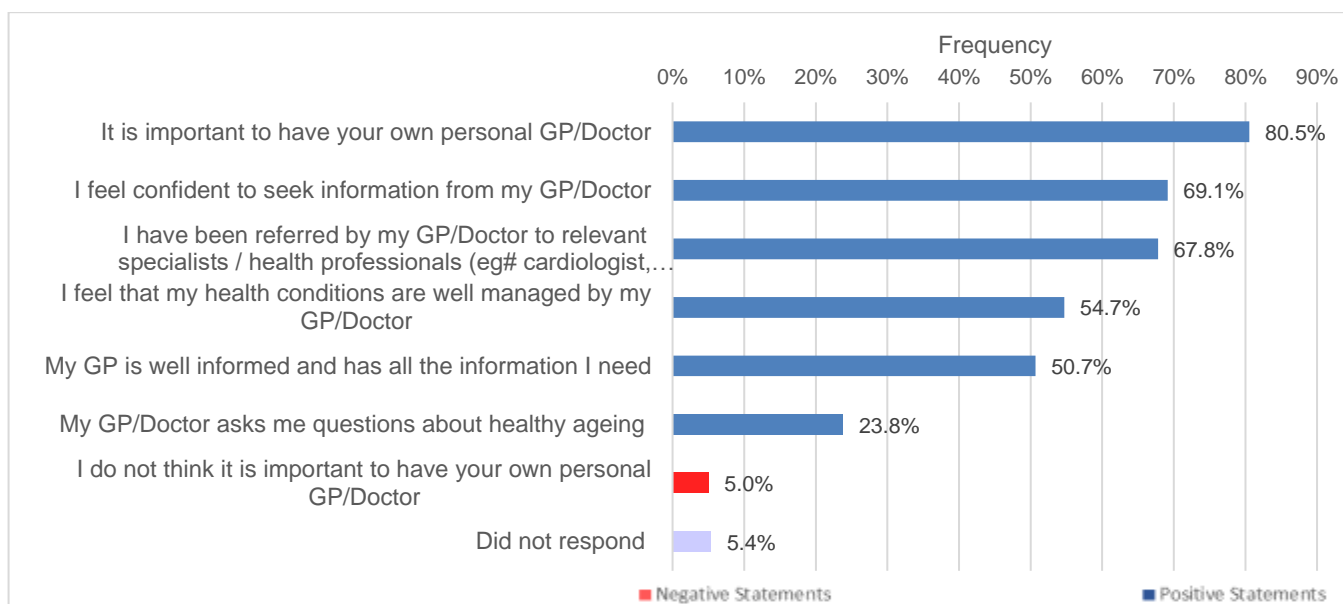
Despite this, just over half of participants *felt that their health was well managed by their GP* (55%) or that their *GP was well informed* (51%). This indicates that although older people value having their own GP, less felt that their GP managed their needs and provided the information that they required. One participant comment (shown below) described the ideal GP relationship as a "partnership" which supports joint decision-making, but suggested that this doesn't tend to occur. This sentiment was reflected across multiple survey comments.

> *"Most Doctors just seem to prescribe something and not give advice.*
> *It should be a partnership."*
>
> *– Survey participant 178*

Less than 24% of participants reported that they been asked by their GP about aspects of healthy ageing. Participants were concerned that their GP did not have the time to enquire about their social or mental health during a standard appointment, and several were concerned that they had never had a healthy ageing assessment. Participants felt that relationship building and the chance to cover off all health questions is often compromised by short appointment times. As one participant commented, "10 minute appointments give you no time to talk".

Other comments included that older Victorians who rely on bulk-billing practices experienced a high turnover of doctors. Overworked GPs and a limited availably of GPs due to their part-time work hours were also mentioned in survey comments as issues effecting access and continuity. In addition to this the large size of some clinics was described as "too big" and "impersonal" and also impacted negatively on survey participant's experiences of GP provided healthcare.

> *"I am not able to see the same doctor regularly as I have to rely on bulk billing clinics,*
> *where doctors change frequently."*
>
> *– Survey participant 283*

Participants in regional Victoria were less likely to feel that their health conditions were well managed by their GP (47% regional compared to 62% metropolitan) or that their GP was well informed (43% to 57%). Regional Victorians also found it particularly difficult to see their preferred GP when required. Barriers described in the comments included high costs, limited choice, long waiting times and a high professional turnover of GPs practicing in a regional or remote area. The following comment reflects this:

> *"In the country you take which doctor you can get and do not have a choice*
> *unless you can wait for a week or more."*
>
> *– Survey participant 80*

3.3.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding healthy and active ageing were:

1. Taking an active role in managing your health
2. A positive outlook on life
3. Healthy eating
4. Access to specialist medical services
5. Social interaction with family and friends

HEALTHY & ACTIVE AGEING

Older people's top 5 priorities:

1. Taking an active role in managing health
2. A positive outlook on life
3. Healthy eating
4. Access to specialist medical services.
5. Social interaction with family & friends

Key Insights:

➢ Older people, and their carers, value taking active measures to maintain and manage their health. Such activity could be encouraged by improving community awareness of healthy ageing practices and building age-friendly environments to promote physical activity and social participation among older Victorians.

➢ Computer literacy to access health information is not considered by older people to be as important as other factors connected to physical health. With more essential health services moving to online service platforms, including telehealth and virtual healthcare, it is important that older Victorians are not left behind. Additional resources to promote and upskill computer and digital technology literacy among older people may be of value. User design that considers older people may be beneficial when planning online health service delivery platforms such as websites and phone apps.

➢ It is important for older people to have their skills and experience recognised and valued by others. Ageism is identified as a potential barrier to inclusion, social interaction and physical engagement in the community. Public awareness of ageism needs to be increased to ensure that all older Victorians feel like they belong and are both respected and listened to.

➢ Older people believe that having both a positive outlook on life and the motivation to do things are key to maintaining mental wellbeing. Being able to access to mental health services was not considered as important as other aspects of mental wellbeing, with survey participants identifying several barriers to effective mental health support including financial constraints, stigma and a lack of available services in general, especially in regional and rural Victoria. Health policy development that promotes awareness and supports older people to access mental health services could be of value.

➢ While older Victorians recognise the importance of having their own GP, many do not feel that their health is well managed by their GP or that their GP is adequately informed. The comments section of the online survey revealed insights into this issue, with participants reporting that access to a consistent GP is hard to achieve. Many older people also felt that they weren't often asked about their healthy ageing goals and that the patient-GP relationship could be improved. These findings support the need to ensure that health policy reinforces the partnership between GPs and their patients over the lifespan, particularly into older age.

3.4 Support for Multi-morbidity and Frailty in the Community

3.4.1. Ageing in Place

Most participants agreed that it was important for them to be able to live independently in their own home for as long as possible (76%), while 15% selected that this was essential.

Figure 11: Percentage of survey responses agreeing with statements regarding living at home with health problems
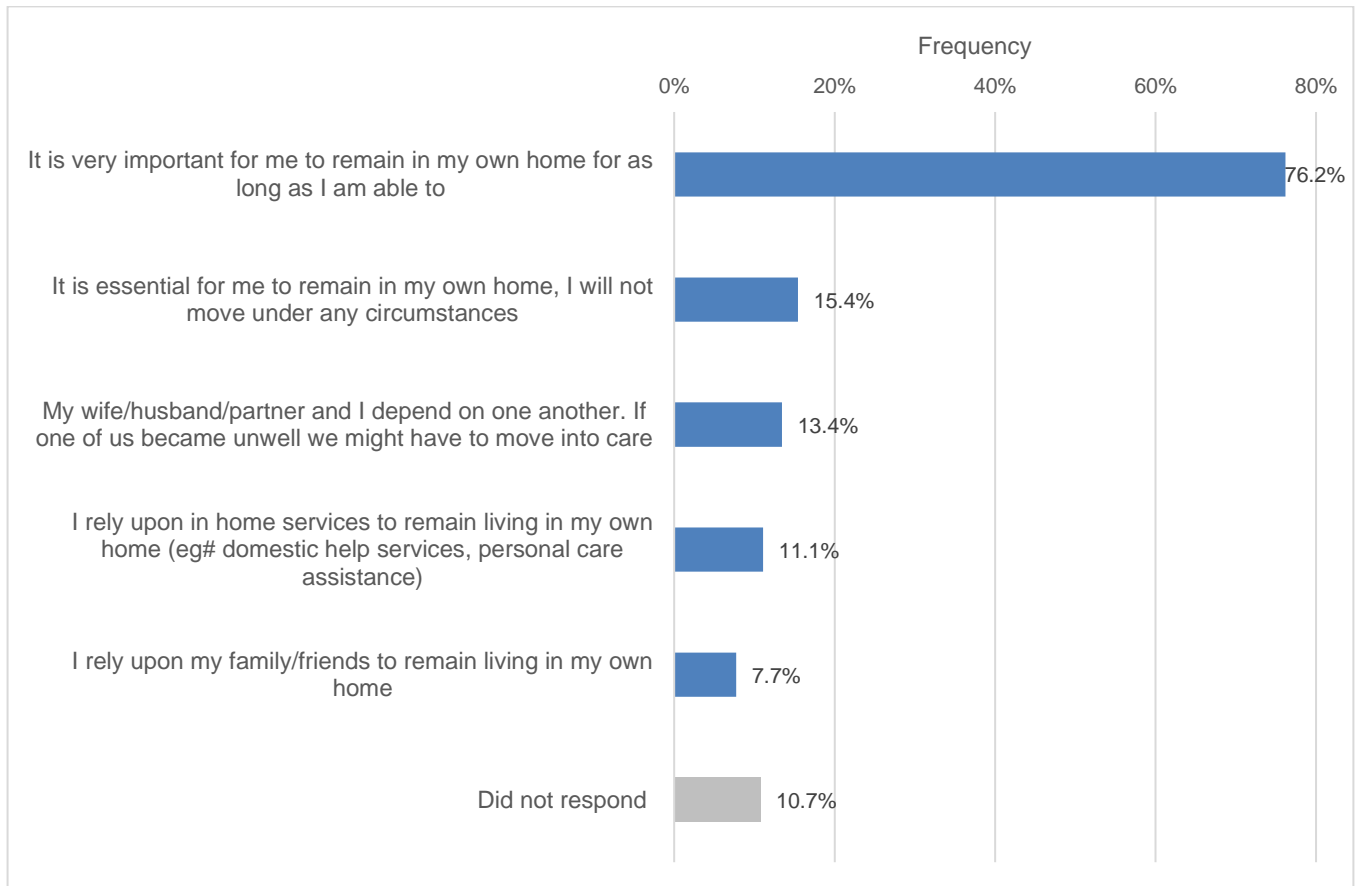
The benefits of remaining in the community, as outlined in the survey comments, included:

- Independence;
- Maintaining a routine, individuality and sense of self;
- Existing friendships with neighbours and other community members;
- Familiarity with the area and available services; and
- Being close to family and friends for support and socialisation.

> *"There is so much connection that comes with the home. You've got your neighbours, you've got your regular routine and…I think you're more likely to stay connected, especially if you've got someone that can help support you in that home."*
> *– Focus group participant*

> *"My wife and I are currently downsizing into a smaller well-insulated home suitable for our next decade. Moving into care would be acceptable if really needed, but I would prefer to be supported at home, especially given community links."*
> *– Survey participant 291*

Participants flagged several enablers to continue living in their own home, including support from family, friends or neighbours (55% 'very important'), in-home services (46% 'very important') and in-home modifications, such as ramps, rails and walk-in showers (42% 'very important').

Figure 12: Percentage of survey responses determining the importance of factors to remaining in the community
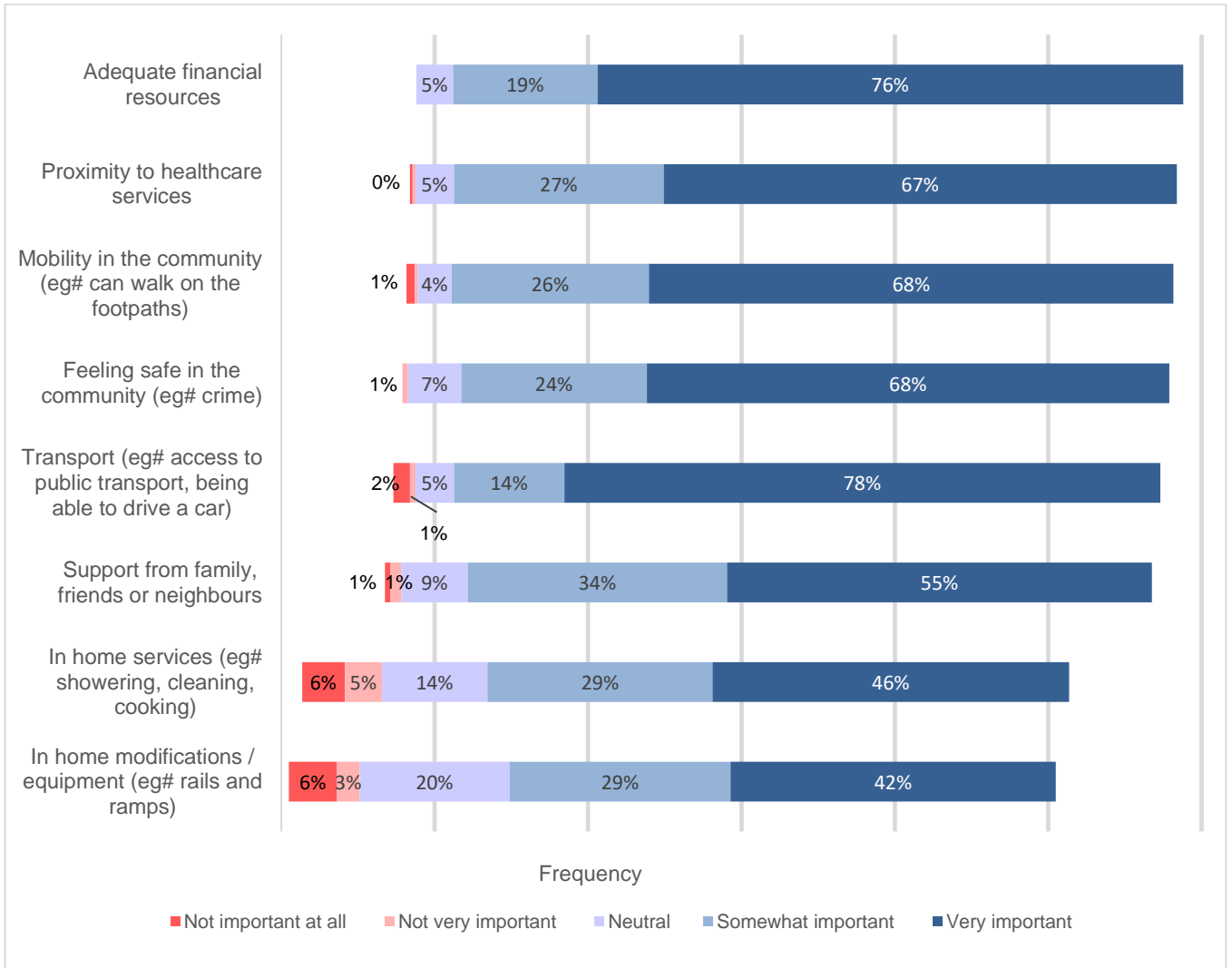
While most survey participants (76%) rated having adequate financial resources as 'very important' to remaining in the community as they age, very few participants elaborated on this further. A few comments reflected on the rising costs of housing upkeep, in-home services, parking and public transportation.

> *"The cost of upkeep in my own home is becoming a concern as rates etc. rise and the cost of labour to get things…done."*
>
> *– Survey participant 143*

In the WHO Housing and Health Guidelines (HHGL), it is strongly recommend that housing stock should be accessible to people with functional impairments.[13] This is based on projected national prevalence of populations with functional impairments and global trends of ageing.[13] In addition to this, the WHO highlight that poor accessibility to their house puts disabled and older people at risk of injury, stress and isolation.[13] Housing that is insecure, sometimes due to affordability issues (as mentioned in the participant quote above) or weak security of tenure, is also stressful and may cause further health harms.[13] Survey comments revealed that affordability of housing/home maintenance and accessibility within the home in the advent of functional impairment were issues that older people themselves considered important.

> *"…We completely renovated our house to make it accessible…Throughout the house & garden there are a maximum of 2 steps & these could be augmented by a low incline ramp. We have a walk-in shower…There are rails to access the toilet which double as a towel rail. We have elevated garden beds"*
>
> *– Survey participant 182*

3.4.2. Accessing Healthcare Services

Access to healthcare services in the community was considered very important by 67% of participants (see Figure 12 above) but only 46% were confident that they were aware of the services available to them (see Figure 13 below). This increased to 73% of those participants who had previous experience accessing My Aged Care (MAC) services.

There was a wide range of responses to the MAC system. As stated in the demographics section, 29% of participants had prior experience accessing MAC however only 6% of participants felt that the system works well.

Figure 13: Percentage of survey responses agreeing with statements regarding aged care services
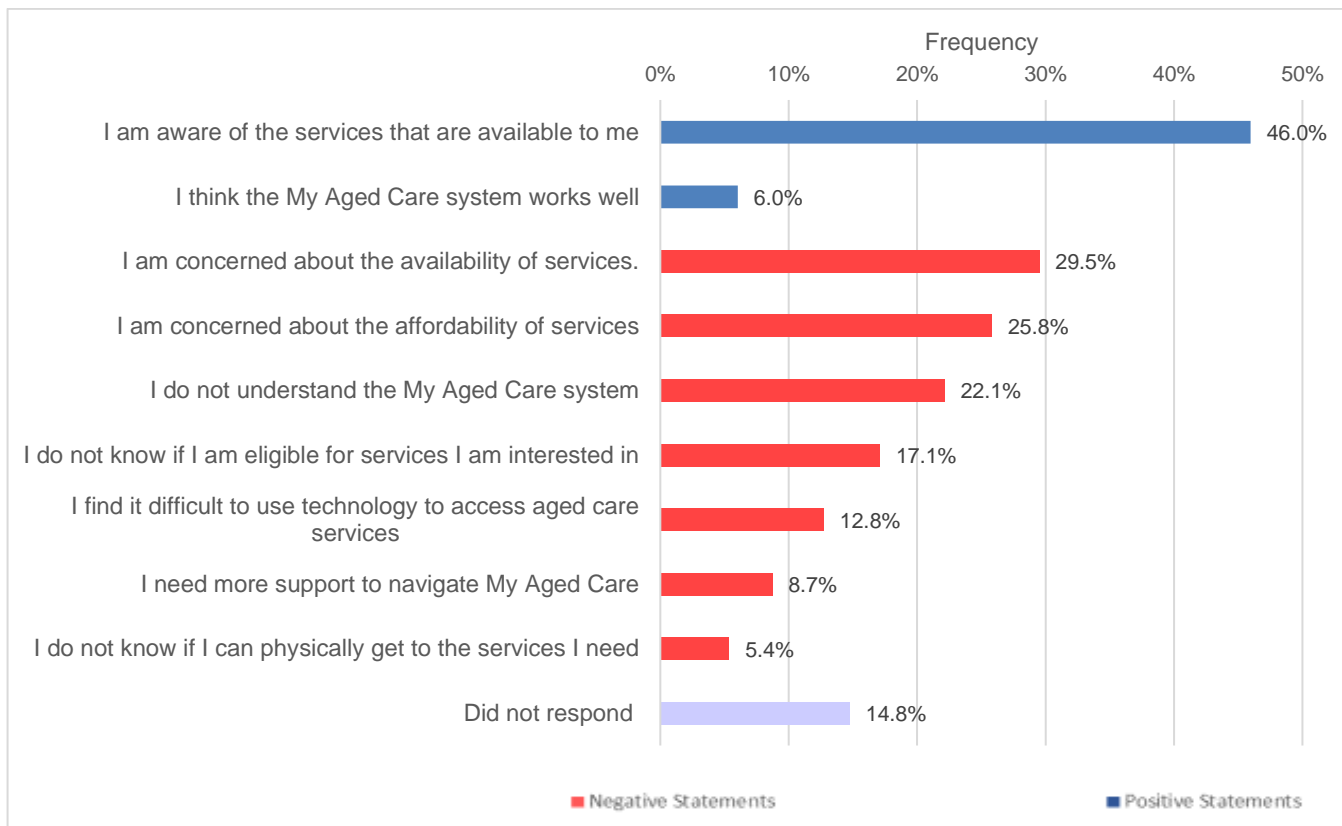
Concerns about accessing MAC services could largely be broken down into issues with; the useability of the system; affordable access; and waiting times for assistance and packages. Some of the survey comments shed light on these issues as many mentioned the MAC system being difficult to use. Six areas (usability, awareness, eligibility, availability, affordability and access) are relevant to issues that older people identified as barriers to using and accessing the MAC system. The most common concern expressed in the survey data was the availability of services (30% see Figure 13 above). Participants described long waiting times, a shortage of service providers and a perceived underfunding of aged care services which all contribute to older Victorians not receiving the care they need in a timely manner.

> *"…Access to Aged Care is extremely difficult with LONG waits, phone call cut off, frustrating interactions with staff."*
>
> *– Survey participant 365*

> *"[The aged care system] needs better funding urgently. People die waiting for help...Access to home care packages need drastic improvement now."*
>
> *– Survey participant 274*

The next highest concern was the affordability of aged care services (26%). Participants described aged care services as "pricey", the "cost is out of reach" and "fees are a problem". It was perceived that affordability/funding came at the price of consumer choice and quality of services.

> *"There are very large disparities in providers and the type of care someone can receive if they are government vs private funded."*
>
> *— Survey participant 42*

Of lesser concern were the eligibility requirements (17%) and physical access of aged care services (5%). Confusion regarding the navigation of the MAC system was a concern for 23% of participants. Participants used phrases such as "non-user friendly", "excessive paperwork", "very confusing" and "difficult". Many of these concerns were also linked to difficulties in using technology to access MAC (13%) with 9% of participants feeling that they needed more support to navigate MAC.

> *"Having used MAC [My Aged Care] for others I found it an absolutely appalling service. Poorly trained staff, slow or no responses. Great way to save money for the government by making the system too hard to navigate and use. It is a misnomer to call it a service. The service delivery people are fantastic but severely constrained by the MAC system."*
>
> *– Survey participant 176*

3.4.3. Personal and Domestic Care Services

As stated in the demographics section, 21% of participants were currently receiving in-home services. Of those, the majority were happy with the choice of providers in their area (71% positive). When it came to their aged care services, participants valued personnel that were friendly and respectful (73% very important), achieved the tasks they were meant to do (70% very important), were competent (67%) and punctual (66%).

Figure 14: Percentage of survey responses determining the importance of factors to use of in-home services
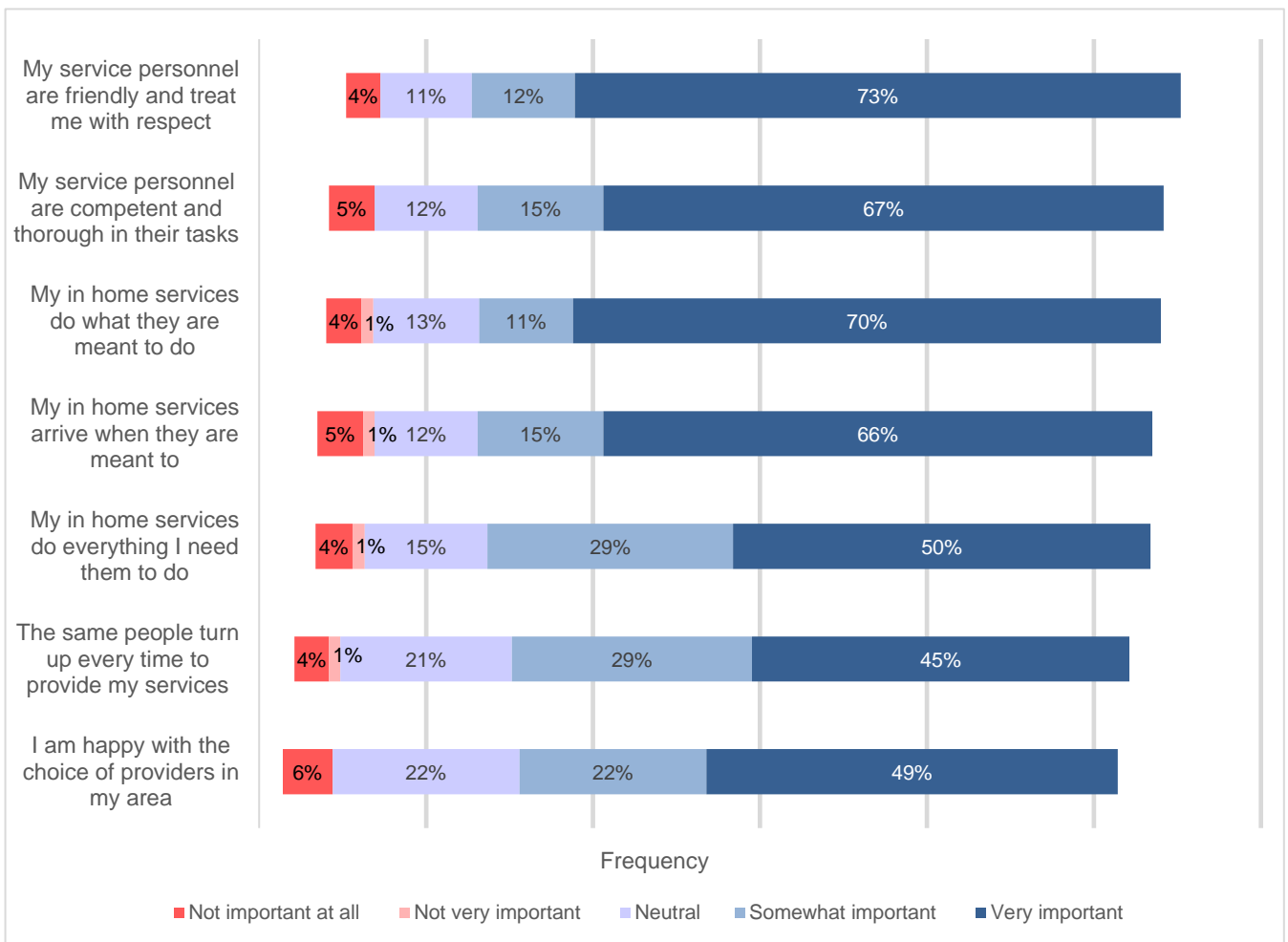
The most common criticisms in the comments were that cleaning staff did not meet some people's standards of cleanliness, could improve communication skills and the services themselves could not be tailored to meet the requirements of the older person.

> *"I have contacted My Aged Care and the Home Assessor was terrible. I have to pay half the hourly rate to have my windows cleaned (no problem) BUT I can't have all my windows cleaned, I have to pick out the windows I look out of the most and have them cleaned…"*
>
> *– Survey participant 72*

3.4.4. Age-Friendly and Safe Environments and Transport

As illustrated previously in Figure 12, *Access to public and private transport* to support living in the community with multi-morbidity and frailty was considered 'very important' by 78% of participants. Barriers to this that were identified by survey participants, included the availability and cost of public transport as well as transport alternatives required to access essential services, such as grocery deliveries. Lack of wheelchair accessible public transport options was also raised as a significant concern.

"(Our) nearby town has no taxi, no bus, no community transport. Hopeless."

– Survey participant 291

Participants also valued *effective mobility in the community* (68% 'very important'). Comments regarding mobility were focused largely on the quality and safety of community footpaths, which were at times absent and when present were described as being overgrown, crowded or in disrepair by both metropolitan and regional Victorians. There were also comments about safety in regards to experiencing illness and injury while being alone and the need for personal alarms and looking out for hazards to avoid falling.

"My residential area does not have many footpaths, and tree roots are a great problem if walking along the nature strips."

– Survey participant 50

"I worry about being alone if I should fall or have a stroke"

– Survey participant 367

Participants also valued feeling safe in the community (68% very important). Factors that contributed to this included the safety of paths and illness and injury when alone, as mentioned above. Other comments, like the one below, described feeling unsafe in certain places due to things like lighting and the perceived presence of crime.

"In certain suburbs, (such as) Melbourne CBD, I do not feel safe especially at night."

– Survey participant 14

There was also mention in the survey comments of age-friendly spaces, for example:

"Local government services and facilities need to be age-friendly"

– Survey participant 94

As outlined by the WHO, Age-Friendly Cities and Communities (AFCC) encompass the social and built environment.[14] AFCC can have the effect of increasing the inclusivity of older people in community life, fostering connections, access to housing and healthcare and increasing the physical accessibility of community spaces and built infrastructure and transport for older people.[2,14]

3.4.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding support for multi-morbidity and frailty in the community were:

1. Ageing in place
2. Transport in the community
3. Adequate financial resources
4. Age-friendly and safe environments
5. Proximity to healthcare services

SUPPORT FOR MULTIMORBIDITY & FRAILITY IN THE COMMUNITY

Older people's top 5 priorities:

1. Ageing in place
2. Transport in the community
3. Adequate financial resources
4. Age-friendly & safe environments
5. Proximity to healthcare services

Key Insights:

➤ Older people highly value living independently in their own home for as long as possible. Given this, future health policy should prioritise actions and resources that enable ageing in place, such as in-home services, in-home modifications and resources to enable spouses, family, friends and neighbours to foster connection and continue supplying critical support to older Victorians.

➤ The availability and cost of public transport, grocery delivery and wheelchair accessibility is a concern for older people. Community footpaths, described as "overgrown", "crowded" and "in disrepair" by both metropolitan and regional Victorians also pose a significant health risk. In future, local communities should be built and modernised according to age-friendly principles, identifying and addressing infrastructure and safety concerns.

➤ Adequate financial resources are considered a very important factor to remaining in the community as people age. This finding is important as recent evidence supports that lower socio-economic status is connected to the development of mental and physical health conditions in adulthood.[14]

➤ Many older people are unaware of the community-based health services available to them and how they can access these. Public awareness of the MAC system needs to be increased.

➤ In addition, the vast majority of survey participants who were familiar with the MAC system feel that it does not currently function well. Concerns could largely be broken down into issues with the useability of the system, eligibility, affordability, and waiting times for assistance and care packages. Action should be taken to improve the overall accessibility of this system for older Victorians and their carers.

3.5 Care in a Crisis and Acute Hospitalisation

3.5.1. Communication

The most important factor in hospital care (94% 'very important') identified in the survey was *knowing what's going on with your care*. This is reflective of the high importance participants placed on effective communication between patients and hospital staff.

Figure 15: Percentage of survey responses determining the importance of factors to communication in hospitals
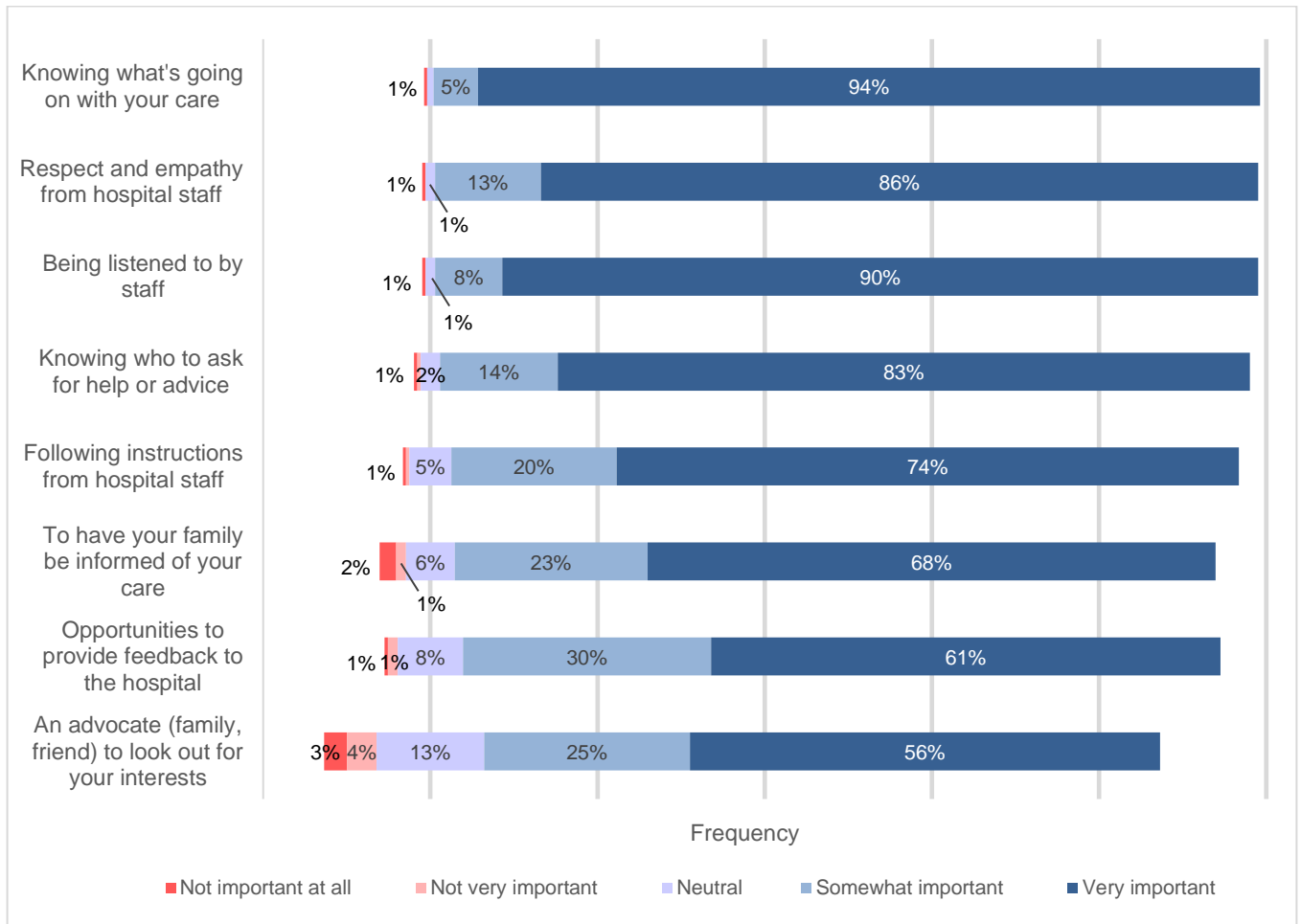
Being listened to (90% 'very important') and *knowing who to ask for help or advice* (83% 'very important') were also identified as key features of effective communication. Survey participants expressed a desire to be routinely updated regarding their management plan as well as informed of the reasons supporting decision-making, particularly regarding key points of transition such as discharge.

> *"To be kept informed of what to expect, what tests were being done and why,*
> *the results because at 99yrs of age, the changes are confusing."*
>
> *– Survey participant 335*

> *"No-one asked me if I felt ready to go home on the third day after a hip replacement.*
> *They told me I was going."*
>
> *– Survey participant 254*

Additionally, most participants wanted their *family to be informed of their care* (68% 'very important'). Communication with family members was viewed as important for psychological wellbeing and as a means of optimising both acute care and discharge planning.

> *"It was a battle to get a family meeting.*
> *Staff seemed unprepared and left us with unanswered questions."*
>
> *– Survey participant 150*

Many participants valued the idea of an *advocate* (a family member, friend, or officially appointed) to look out for your interests while in hospital (56% 'very important'). Several participants believed that patients with an advocate would receive more attentive care from hospital staff and were apprehensive for older people who did not have someone to fill this role for them.

> *"Personally I believe it imperative to have a relative /friend to be beside your bed 24/7,*
> *especially in a public hospital, to look after your welfare.*
> *Otherwise with the lack of staff you can be neglected."*
>
> *– Survey participant 348*

Of less importance to survey participants, but still significant, was the *opportunity to provide feedback to the hospital* (61% 'very important'). Participants expressed frustration at feedback not being followed up but conceded that hospitals often lack the required funding to enact meaningful change.

> *"(I) have given constructive feedback regarding food quality and quantity*
> *in the past and got a letter back saying they are trying to improve.*
> *(It) does not help if you don't see any improvement."*
>
> *– Survey participant 81*

Majority of survey participants expressed a strong desire to be treated with *respect and empathy* (86% 'very important') when in hospital. In addition, participants acknowledged that the need for empathy and respect extends beyond clinical roles to all hospital staff. Specific comments regarding the importance of empathy and respect during acute hospitalisation related to being actively involved in discussions regarding care provision, including having the opportunity to ask questions and voice opinions.

> *"Being listened to with my opinions/questions treated with more respect by medical staff.*
> *Not being discussed in my presence as though I am not there."*
>
> *– Survey participant 376*

While many participants felt that staff were inclined to be empathetic and accommodating, they acknowledged that organisational level barriers often made this impossible. Chief among these were *inadequate staffing levels* and *rigid care protocols* that fail to facilitate person-centred care.

> *"It is essential that hospital staff treat each patient with dignity and respect as sometimes*
> *patients are treated as a hospital number rather than as a person."*
>
> *– Survey participant 156*

> *"Whilst it seems that many acute centres espouse the mantra 'person-centred care',*
> *I am not entirely sure that staff walk the walk."*
>
> *– Survey participant 183*

3.5.2. Quality of Care

Survey participants had high expectations of receiving *safe, quality healthcare* in hospital. In addition to being treated with dignity and respect, a*ppropriate healthcare* (90% 'very important'), *provided competently* (91% 'very important') and *delivered in a timely manner* (87% 'very important') were identified as critical factors.

Most survey comments regarding the quality of hospital care were positive. Complaints about care provision were often centred on nursing shortages, limited time with doctors, lack of empathy and the hospital environment.

> *"I was very pleased with the service and treatment I received.*
> *Staff were very courteous and competent."*
>
> *– Survey participant 268*

Figure 16: Percentage of survey responses determining the importance of factors to quality of care in hospital
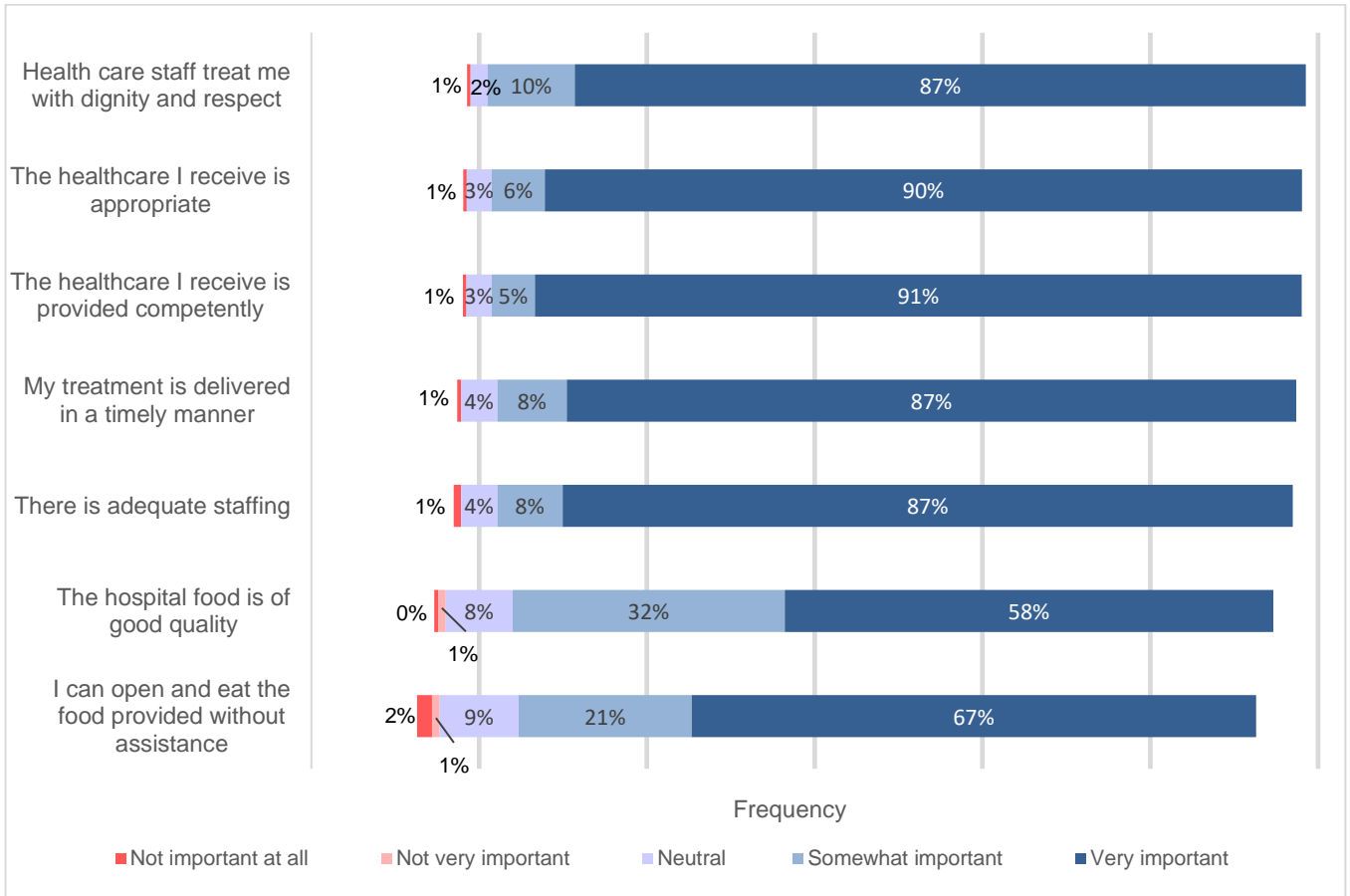
The need for a *dequate staffing* in ensuring quality care was considered 'very important' by 87% of participants, with a number of comments referring to the impact of insufficient staff on hospital experience.

"Not enough staff.
Everyone is rushed promising to come back and help you, but (they) never do."
– Survey participant 348

"More nursing staff to enable more focus on connecting with me rather than
with the computerised checking system."
– Survey participant 277

"The staff's shifts and workloads were challenging. The nurses knocked off at 10pm and were back
in the wards about 8am. The pressure on their time reflected the care they were able to provide.
For example, a nurse left me on the toilet unable to walk un-assisted or reach the bell, and forgot to
return before knocking off… I don't blame the individuals…"
– Survey participant 254

Of less importance was *good quality hospital food* (58% 'very important'). Complaints of food quality in public hospitals were one of the most common survey comments. Hospital food was described by some participants as "inedible", "appalling" and "lacks enough nutrition".

"Food is inedible and I lost 5kg in 11 days.
Try the scrambled eggs that had a green juice and foul smell or the rubber steamed chicken."
– Survey participant 275

"Food is generally of a very poor quality and worse, not contemporary - it's the stuff
my grandparents used to make! … Insufficient vegetables, not fresh anyway. Instant coffee.
Butter on junky white bread. All 1920's stuff… Hospitals should be setting a healthy eating standard,
not supporting the junk food industry and adding to the health problems of our society."
– Survey participant 229

Food service was even more important to survey participants who rated the need to provide food that could be *opened and eaten without assistance* (67% 'very important'). Participants expressed their concern where the food service did not include meal assistance such as; enquiries about why food was not eaten, offering alternative food or offering help with eating. Survey participants requested that more attention be payed to food packaging that can be easily opened (hard seals on plastic fruit cups were mentioned several times) and physical assistance provided to patients as needed.

"They don't think, they just bring the meal and plonk it down.
I had a broken arm and they brought me an orange, just left it there!
Were you supposed to use your teeth to peel it?"

– Focus group participant

"Many times (I) saw food left, an attempt at eating, or unable,
and just taken away without questions. Pathetic."

– Survey participant 375

3.5.3. Optimising Outcomes

The majority of participants thought that it was more important for recovering patients to "*get up and moving*" (66%) rather than "*rest and recuperate*" (16%) following an illness or injury, although many clarified that their answer would depend on the specific nature of the illness or injury and individual circumstance.

Older age cohorts were less likely to prioritise "get up and get moving" over "rest and recuperation"." Among the 65-70 and 70-80 age groups 72% and 68% prioritised "get up and moving" respectively, this number dropped as low as 52% for the 80+ age group. While "rest and recuperation" increased from 14% and 15% in the 65-70 and 70-80 cohorts respectively up to 24% for the 80+ age group.

"There needs to be a balance between rest and get up and moving.
Both are very important."

– Survey participant 236

Figure 17: Percentage of survey responses agreeing with statements regarding recovery in hospital
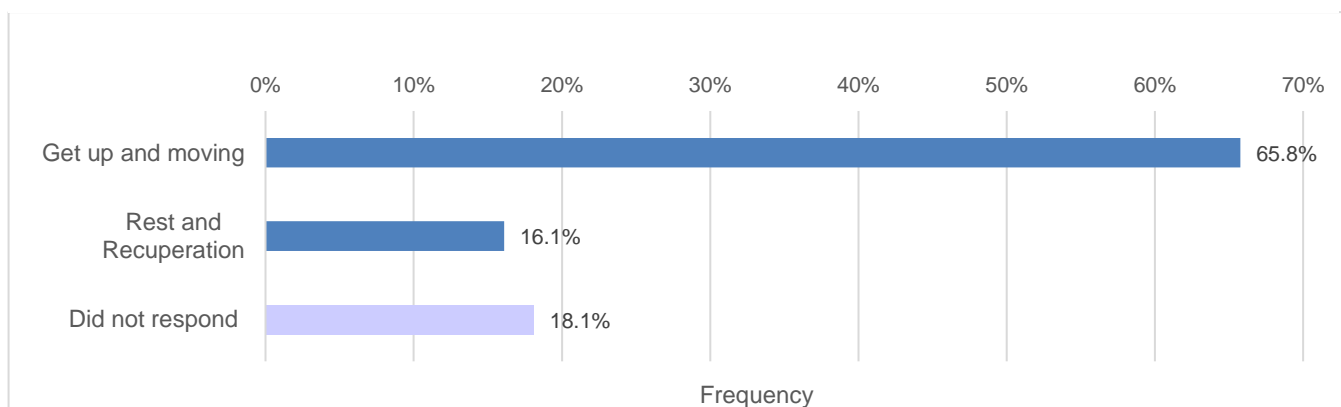
A range of opinions were expressed by survey participants regarding *length of stay* for older people in hospital, reflecting on both expected recovery time and concerns regarding hospital acquired complications.

"Older people take longer to recover from illness or injury,
short stay hospitalisation is not appropriate."

– Survey participant 252

"Infection risk in hospital is huge, it's important to get my granddad
out of there as soon as possible."

– Survey participant 351

Although regular contact with friends and family is generally considered valuable for the mental wellbeing of patients in hospital, it was the opinion of many survey participants that "you can have too many visitors" and "a hospital with a visitor free hour in the afternoon (is) a bit more peaceful for everyone". Approximately half (53%) of participants agreed it was 'very important' for *family and friends to be able to visit anytime*.
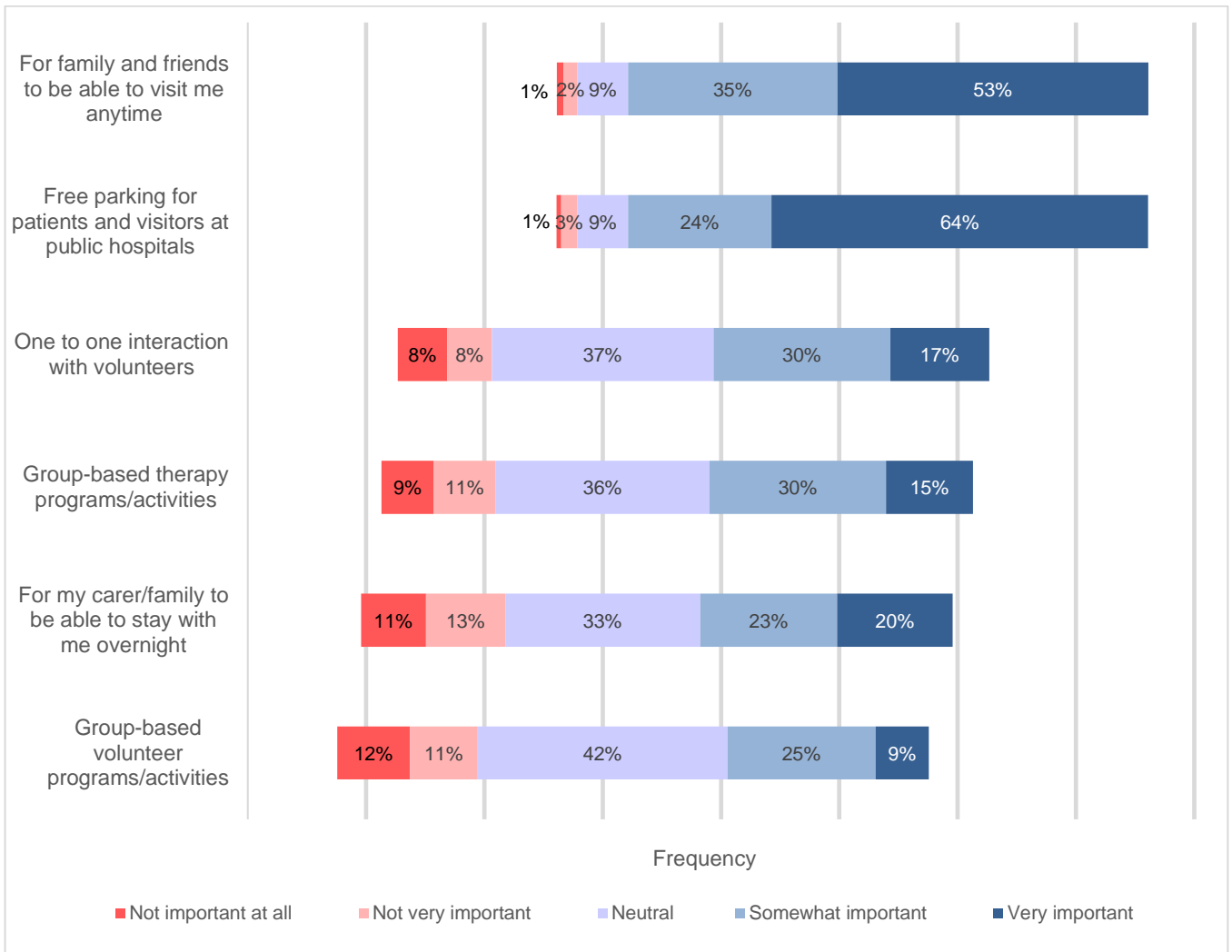
Participants were largely ambivalent about *carers and family members being able to stay overnight* (20% 'very important'), with the exception of palliative care situations.

"Keep visitors to set hours, so other patients can get peacefully rest time."

– Survey participant 348

*"When in hospital, I am sick so (I) want excellent medical treatment and good sustainable food.
I am not there for a good time so visitors are unimportant, especially other patient's unruly kids and
their visitor's loud voices as they talk amongst themselves."*

– Survey participant 72

3.5.4. Hospital Environment

After the perceived lack of staffing and the poor quality of hospital food, the most common participant grievance regarding hospital admission involved the *physical environment*. Complaints included high noise levels (particularly at night) and cold air conditioning.

*"There is no peace and quiet. Staff talk loudly to each other in middle of night.
Modern technology machines beep 24/7.
A sick person no longer gets rest in hospital. It's hell."*

– Survey participant 348

*"(My) only problem was feeling cold. (I) want to be allowed to wear warm clothing
or have warm blankets, not just (a) cold sheet."*

– Survey participant 40

Free parking for patients and visitors at public hospitals was considered 'very 'important' by 64% of survey participants. Complaints regarding the cost of hospital parking were one of the most frequent comments of this section. This was felt to be compounded by the associated stress of a loved one being acutely unwell.

"Free parking for visitors would ease the strain and worry
they are already undergoing."

– Survey participant 12

3.5.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding care in a crisis and acute hospitalisation were:

1. Knowing what's going on
2. High quality healthcare
3. Being listened to
4. Being treated with dignity and respect
5. Treatment being delivered in a timely manner

CARE IN A CRISIS & ACUTE HOSPITALISATION

Older people's Top 5 priorities:

1. **Knowing what is going on**
2. **High quality healthcare**
3. **Being listened to**
4. **Being treated with dignity & respect**
5. **Treatment delivered in a timely manner**

Key Insights:

➢ Older people want to know what's going on with their care when they are in hospital and ensure that their opinions and preferences are heard. This requires staff to provide opportunities for consumers to partner in their healthcare and must be supported by effective communication and shared decision-making.

➢ Systemic barriers are perceived to exist regarding the provision of quality and empathetic healthcare. These include inadequate staffing ratios, care needs not being identified and/or met, not being listened to, lack of flexibility in protocols, and a failure to facilitate patient-centred care.

➢ The quality of public hospital food is generally considered inadequate by older people, both in meeting nutritional needs and being palatable. Additional suggestions to improve food consumption include the provision of mealtime assistance and food packaging that can be easily opened.

➢ Older people expect to receive safe, quality healthcare from hospitals including care that is provided competently and delivered in a timely manner. Policy development should support models of care and workforce capacity/capability that ensures patients are able to receive the individual care that they require to meet their needs and preferences.

➢ Access to free parking for patients and visitors at public hospitals is another significant issue for older people, with complaints regarding the cost of hospital parking one of the most frequent comments relating to hospital care. Hospital parking is an access issue globally that has been a point of discussion in countries such as the U.K and Canada.[15,16]
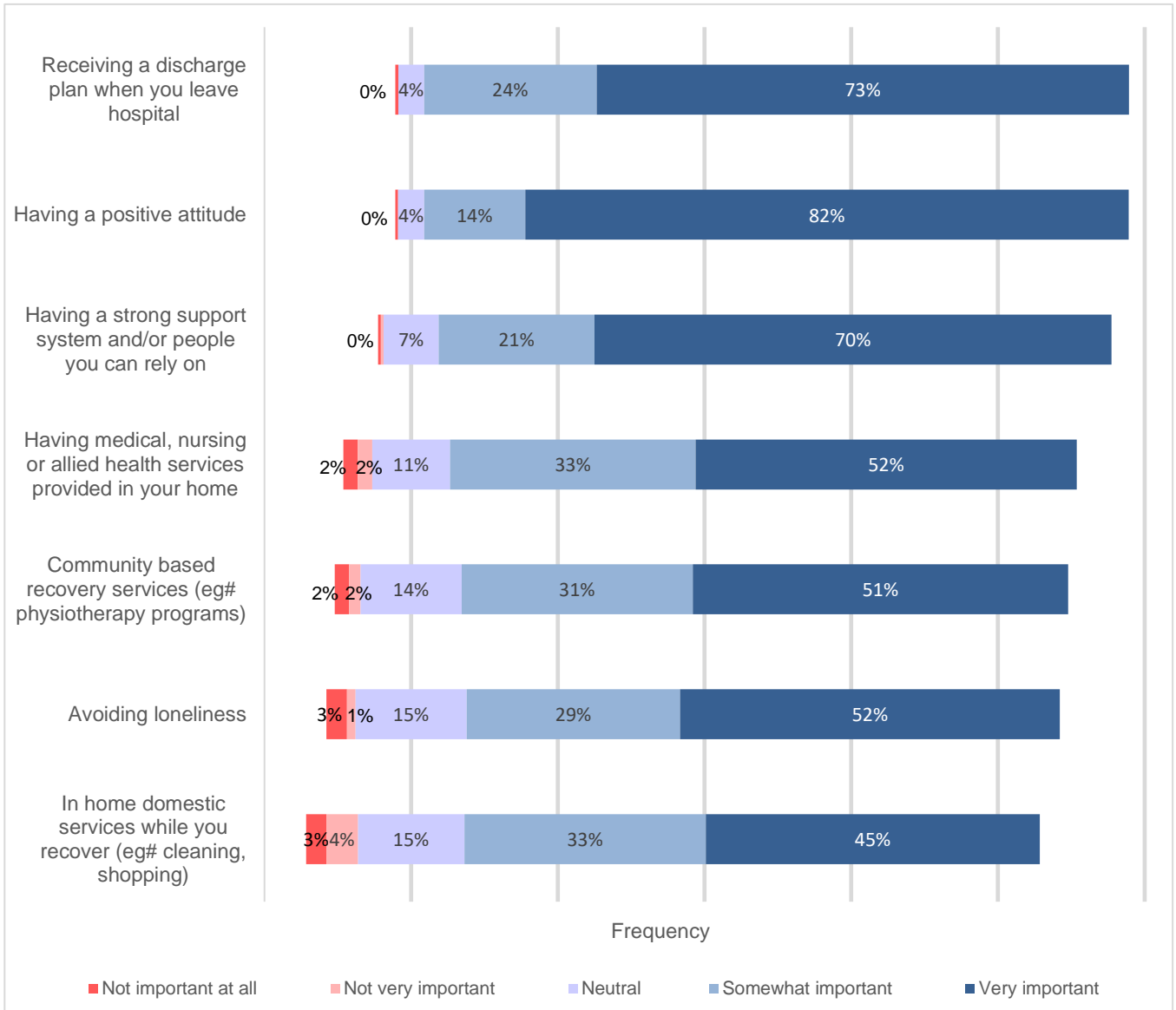
3.6 Regaining Independence

3.6.1. Maximising Recovery

When recovering from illness or injury a factor ranked as very important (82%) was maintaining a positive attitude, as seen in Figure 19.

Figure 19: Percentage of survey responses determining the importance of factors to recovering from an illness or injury

Participants did not elaborate in the comments section as to what having a 'positive attitude' meant to them in terms of their recovery. However they did suggest that other factors assisted them in regaining independence, including *having a discharge plan* and support systems within the community including *social support, in-home services and community-based medical, nursing and allied health services*. *Avoiding loneliness* was also rated as important (52% 'very important').

Participants were also asked to describe their biggest obstacles to recovery. Common responses included: stubbornness, impatience, exhaustion, low energy, pain, limited mobility, living on your own, fear and anxiety, and depression and loneliness.

3.6.2. Discharge Planning

Participants emphasised the importance of an *appropriate and well thought out discharge* plan in regaining independence after an illness or injury (73% 'very important'), as seen in Figure 19.

Approximately half of participants (47%) who had been a patient in hospital within the last 5 years remembered receiving a discharge plan.

Figure 20: Percentage of participants (who had been a patient in hospital within the last 5 years) who recalled receiving a discharge plan.
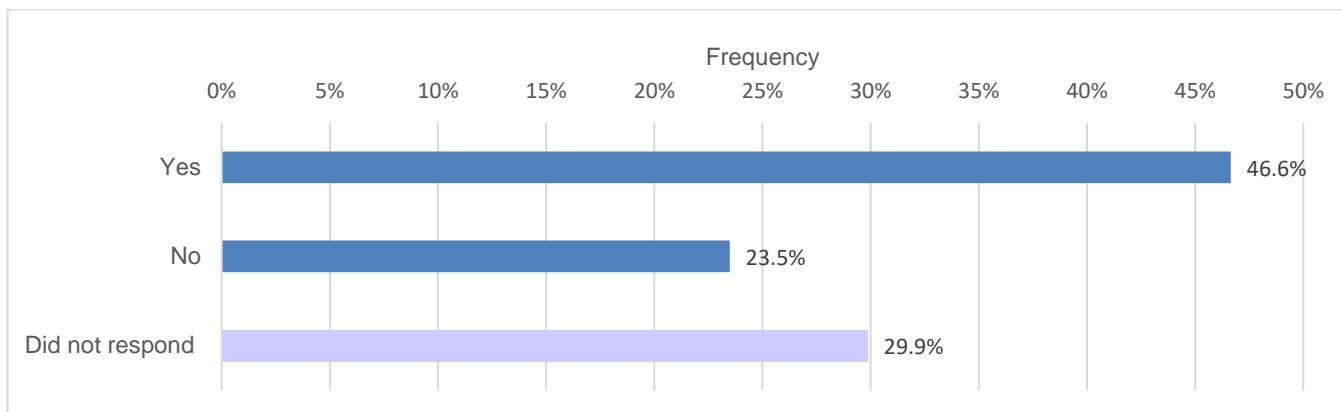
Some participants had good experiences with comprehensive discharge plans, describing them as "organised", "co-ordinated" and bordering on "ultra-cautious".

> *"The plan put in place…worked well. I knew it was necessary to be able to get walking again and so did them religiously and thus I recovered pretty quickly. At about 14 weeks I was able to get back to walking 9 holes of golf so the exercises paid off!"*
> *– Survey participant 83*

Other participants felt bewildered by *the lack of support* they, or someone they knew, experienced when discharged from hospital. Participants described experiences where they received no advice at all upon discharge, inadequate or inappropriate advice or, in one participant's experience, advice she was not capable of reading.

> *"I did not feel supported the weekend after discharge. I had problems with my blood pressure and was told to go to (another hospital)…which I found daunting. My concern is there (is not) sufficient follow-up after hospital discharge."*
> *– Survey participant 342*

> *"Take home instructions after EYE surgery were impossible to read because they were printed in font size 6, presumably to save paper. I could not read the plan even with my good eye. It was ridiculous."*
> *– Survey participant 264*

Participants reflected that current *discharge procedures* could be better co-ordinated to provide the right balance between timeliness and thoroughness. In particular, participants commented that discharge planning should include more effective communication with the patient's family and GP to ensure that the discharge plan is appropriate, implemented and followed up.

> *"Sometimes it takes hours for hospital to obtain all paperwork for discharge. Some better systems need to be in place."*
> *– Survey participant 348*

> *"Not well co-ordinated as there was no one central role within hospital responsible for this including the communication with family about plans, changes etc. This resulted in a quick rebound back into hospital due to an error in handing over medication changes."*
> *– Survey participant 122*

Discharge planning is an opportunity to encourage older people to participate in their care in hospital and involve both them and their families and carers, as appropriate, in the process of discharge planning.[17]

In order to facilitate this, a person's biological and psychosocial needs as they interact with their environment should be considered, as well as any chronic conditions that will need ongoing maintenance.[17] In addition to this, meaningful discharge plans often centre on a person's particular values, preferences and social supports.[17]

"The letters back to my GP were late & frankly pathetically lacking in clinical detail."

– Survey participant 182

"It is one thing to supply a plan - it is another completely to actually ensure implementation and follow up. Of course there is a cost, but there is also a cost for repeat presentations and slower recovery"

– Survey participant 229

3.6.3. Social Support Systems

Survey participants ranked social support as important (70% very important as seen in Figure 18). Survey comments suggested that having other people to help; including family, friends and neighbours invested in your welfare could help with recovery. Living alone was identified as a factor that could make recovery more difficult. This suggests that some older people may need social support assistance when recovering from illness and injury. For example encouraging participation in social activities of interest and equipping people with realistic strategies that can be implemented once discharged from hospital to keep well.[17] Below are some comments expressing a need for more social support and people to help with tasks in recovering from an illness or injury:

"It is hard when [you're on your own], living alone, no family, no friends, no car, limited income, ill, in pain…I am still a vital person - just stuck!"

– Survey participant 213

"Zero assistance or advice was given, even though they knew I lived alone..."

– Survey participant 213

3.6.4. Short-Term Home-based Services

Short-term in-home healthcare, including medical, nursing and allied health services were highly valued by approximately half of participants (52% 'very important'), closely followed by community-based health services (51% very important). For the most part participants described positive experiences with district nurses and allied health such as physiotherapists when recovering from an illness or injury at home. Participants particularly valued comprehensive services adapted to their circumstances and clarity regarding who is coming and when.

"It was a while back and for a very specific major situation. Mainly just district nurses. They were exceptional."

– Survey participant 375

"Someone came in and stayed outside the bathroom door while I showered, (I) felt secure."

– Survey participant 204

Short-term domestic services, including cleaning and shopping, was the lowest ranked factor in terms of importance to recovery, yet still received a highly positive result (45% very important). Participants valued short-term in-home services for their ability to allow them to return home faster. Some participants described their domestic help as "helpful and ongoing", or "wonderful while required". Others found the choice of providers limited (particularly in outer metropolitan and regional Victoria) and some reported competency and training of their domestic service providers was somewhat lacking.
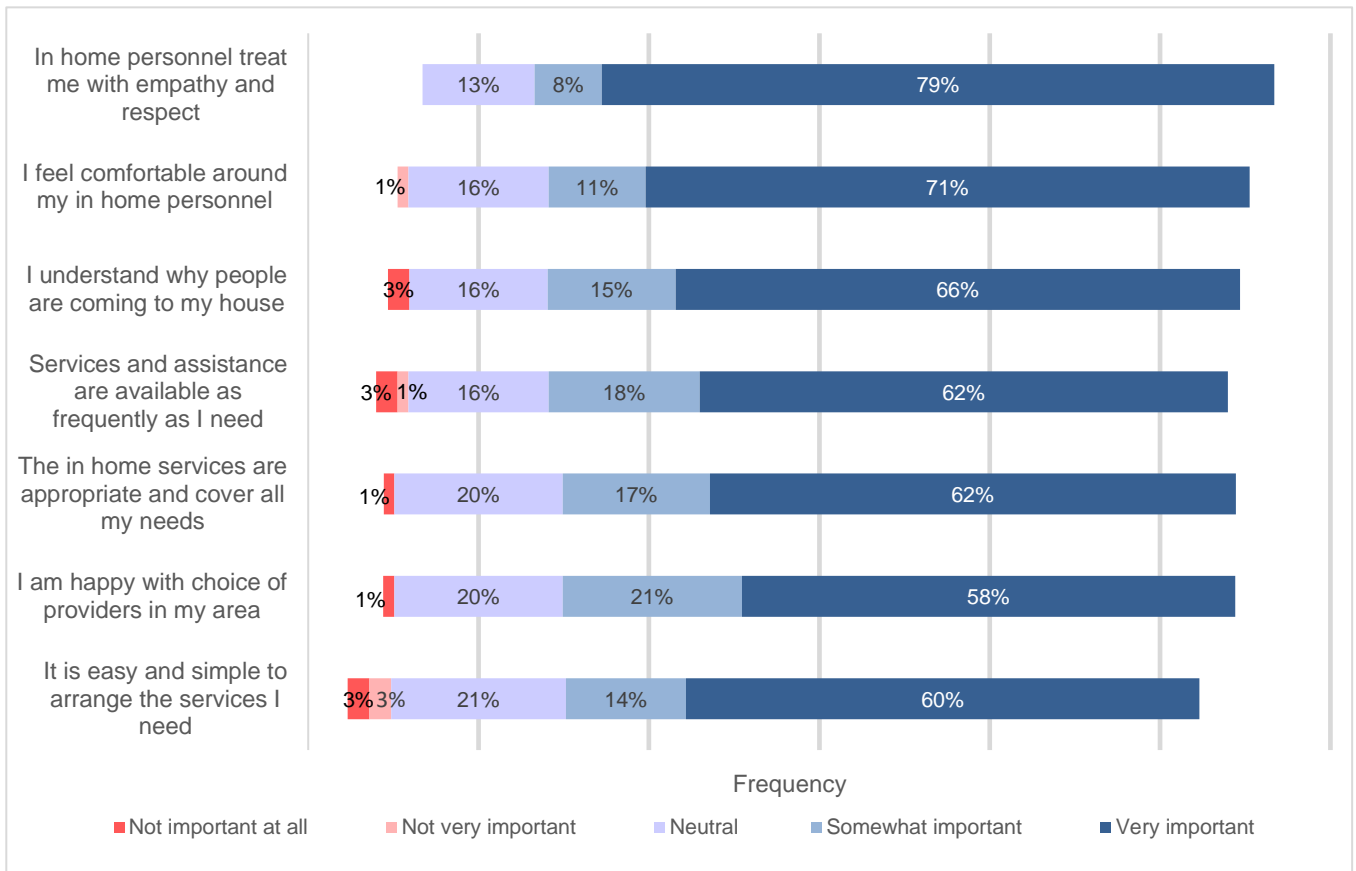
"Mostly great people, but in great need of training and understanding of patient experience."

– Survey participant 313

"Limited providers in the outer east so not much choice and no choice of care staff."

– Survey participant 167

16% of survey participants had received short-term domestic and healthcare in-home services in the past. The most important factor when receiving short-term in-home services (both domestic and healthcare services) was to be treated with *empathy and respect* from service personnel (79% very important), followed by *feeling comfortable around personnel* (71% very important) and *clear communication* over why they are coming and what they are there to do (66% very important). Participants felt that post-acute care was important but domestic help in the home was not something they regularly used outside of recovering from an injury or ill health.

> *"Post-acute care after hospital admissions are very important.*
> *If I'm not injured, I don't use regular domestic help as I find it too intrusive."*
>
> *– Survey participant 283*

Other factors included *services being available as frequently as needed* (62% very important), and services being *appropriate and covering all needs* (62% very important). It appeared as though some participants in receiving home care were expecting domestic help that fitted more under the social supports as discussed earlier in this report. In addition to this some participants were concerned by the waiting times experienced when trying to access in-home support after injury or ill health and perceived a disconnection between hospital healthcare, community healthcare and home care providers.

3.6.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding regaining independence were:

1. Maintaining a positive attitude

2. Receiving a discharge plan when you leave hospital

3. Having a strong support system

4. Having medical, nursing or allied health services provided in your home

5. Access to community-based health services

REGAINING INDEPENDENCE

Older people's top 5 priorities:

1. **Maintaining a positive attitude**
2. **Receiving a discharge plan when leaving hospital**
3. **Having a strong support system**
4. **Having medical, nursing or allied health services provided in the home**
5. **Access to community based health services**

Key Insights:

➢ About half of older Victorians surveyed who had been admitted to hospital within the last 5 years remembered receiving a discharge plan. Supporting transitions of care from hospital to the community is a critical component of service delivery and could be enhanced by ensuring that all older people receive a detailed and meaningful discharge plan, incorporating discharge planning into e-health record systems at hospital level, and (with the consent of older people) ensuring copies of discharge plans are communicated to older people's carers, key supports and healthcare providers such as GPs.

➢ A strong support system was identified as a key factor when recovering from illness or injury. Performing routine screening on admission to identify older people who are at risk of experiencing social isolation, and/or who are living alone without anyone to assist with everyday tasks following discharge, may help to improve health-related outcomes. In this case, allied health workers such as social workers could enhance the social support system of isolated older people by linking them with support groups in-home, welfare payments to supplement low-income, affordable or free transport, domestic help and community-based services upon discharge from hospital.

➢ Some participants suggested that it was difficult to access community-based and in-home services and sometimes hard to access follow-up care when recovering from illness and injury. There was also confusion over which services are provided and who provides them. This could mean that plans after acute illness or injury need to be communicated in a different way to help older people access the services that will assist them to regain their independence.

3.7 Specialist Aged Care Services

The vast majority of survey respondents were community-dwelling older people (96%); only 5 survey participants identified as living in a residential aged care home (1.7% of total survey respondents). As such it was not possible to collect first-hand data regarding wellbeing and the healthcare expectations in residential aged care homes.

Despite this, 68% of survey respondents had personal experience with someone who resides or has resided in residential aged care, and all participants were able to answer questions about their own opinions and plans to eventually transition to residential aged care.

Previous experiences of moving loved ones into residential care were overall reported to be negative. Concerns about residential aged care generally fell into 1 of 3 categories: poor care, isolation and loss of independence.

3.7.1. Attitudes towards Residential Aged Care

Most participants expressed a reluctance to ever move into a residential aged care facility, in fact 0% of participants were eager to move into residential aged care and 17% declared they would never live in residential aged care.

> *"Situations change with health which may lead to not being able to stay in my own home.*
> *I won't like it at all if I have to move into care"*
>
> *– Survey participant 364*

> *"I dread the thought of ever moving in to aged care. I have seen some of the horror stories*
> *on the news and feel that it would be an absolute last resort".*
>
> *– Survey participant 268*

Figure 22: Percentage of survey responses agreeing with statements regarding attitudes towards residential aged care
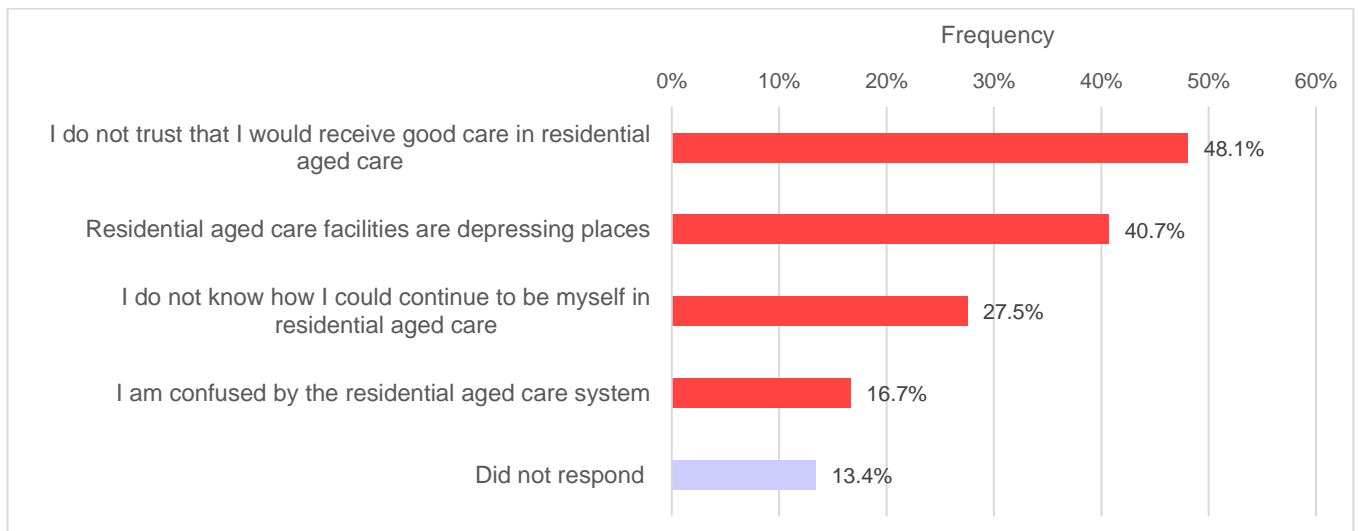
48% of participants did not trust that they would receive good care in a residential aged care home. Comments revealed that these fears were often linked to perceptions of *understaffing*, as well as *inadequate training* and lack of *empathy* from residential aged care staff. Participants suggested that, "not all people are suited to personal care," and so greater emphasis needs to be placed on recruiting staff who can deliver quality care. Participants also perceived low wages for aged care staff and high staff turnover/insecure work for aged care staff as barriers to adequate care and suggested increases in aged care funding.

> *"Increase staff ratio, better pay, psychology test to make sure carers have the*
> *right mental attitude to caring for the aged."*
>
> *– Survey participant 344*

> *"…Ratios are currently inadequate in my opinion. A resident should not have to wait over an hour*
> *in the day time for a response to a call button for a toilet visit."*
>
> *– Survey participant 278*

> *"Not enough staff, some carers don't have the empathy to care for the elderly,*
> *they don't adhere to the training… It is hard to watch your loved ones not being cared for properly."*
>
> *– Survey participant 81*

40% of participants thought that residential aged care homes were depressing places. This began with the *physical environment*, which was described by various participants as "cold" and "clinical", but also extended to perceptions of social isolation and loss of independence/sense-of-self in residential aged care homes. Participants feared being *separated from their spouse* and *losing social connections* with their family, friends and community. There was a general fear that one would be "forgotten" or "totally isolated".

> *"It was a cold formal looking place with residents seated in such a way that there could be no interaction. It was a dreadful place to end up."*
>
> *– Survey participant 330*

28% of participants did not know how they could continue to "be themselves" in residential aged care. This concept had many facets, including a perceived loss of independence, individuality, routine, and ability to engage in the activities you love. Participants described their fear of being "institutionalised."

> *"I am only in my own home because I have pets and aged care do not accept them. I live on my own so they are my companions."*
>
> *– Survey participant 383*

> *"While I'm able to, I want to be able to make my own cup of tea when I want. I don't want someone to say that you can't use the kitchen or you can't have a power point here… or you've got to wait for someone to come to take you to the toilet or you can't do this or do that."*
>
> *– Focus group participant*

Some participants mentioned taking proactive steps to avoid needing to live in residential aged care such as:

- Moving closer to family/other support people;

- Establishing a share house with other older friends;

- Employing a carer (formally or informally);

- Accessing home care packages;

- Moving closer to amenities and services such as public transport;

- Downsizing to smaller housing;

- Home modifications to make an existing home safer and/or more accessible;

- Moving into a retirement village; and

- Moving from rural/remote locations to more populous locations.

Participants suggested the motivation for undertaking these actions was to only move to residential aged care at need as a last resort or to avoid it altogether and remain in the community.

> *"I have already downsized to an apartment close to facilities and public transport. I view residential aged care as a last resort to be avoided at all cost!"*
>
> *– Survey participant 197*

> *"I have recently moved into my daughter's home instead of going into aged care."*
>
> *– Survey participant 115*

3.7.2. Predicted Catalysts for Moving Into Residential Aged Care

Many participants predicted that they would move into residential aged care only when they could *no longer be cared for at home* (46%) or felt they had become *a burden to their family* (41%). Reasons for moving someone they have cared for into residential care, or a trigger they would consider for themselves, included:

- Being unable to attend to their own needs (e.g. showering, getting out of bed, administering insulin); and

- Being unable to be discharged home from hospital following an illness or injury.
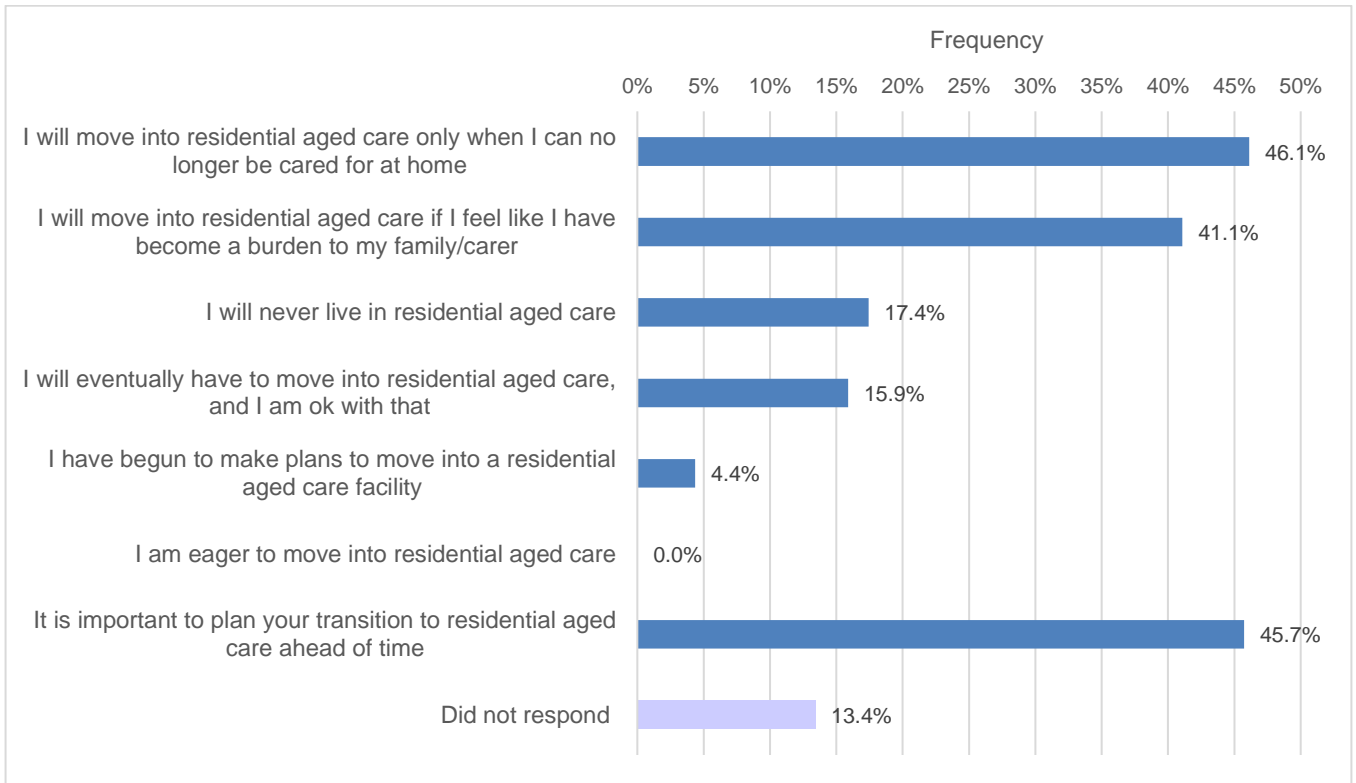
> *"I may have to go into residential care/nursing home when I cannot care for myself. I don't want to because being in my own home motivates me to be more active. I like to be independent and care for my dog."*
>
> *– Survey participant 195*

Figure 23: Percentage of survey responses agreeing with statements regarding transitions to residential aged care

3.7.3. Planning for Residential Aged Care

Participants felt it was important to plan their transition to residential aged care ahead of time (45.7%) and it was therefore one of the top 5 priorities identified in the survey data. However only 4.4% had begun to make plans to move into a residential aged care facilities. Some of the survey comments revealed the reasons for this. Many participants considered their eventual transition to residential aged care as an event in the distant future that did not require attention or planning at present. This could be of interest to policy makers as it can be problematic if the need for residential care arises after capacity losses impair decision-making or because of an unexpected medical emergency. Some participants mentioned that it is difficult in younger older age to imagine living in residential aged care, and so they did not feel the need to plan for it.

"I have started to enquire about residential aged care, but consider it a long way off."

– Survey participant 345

"At 66 it is truly hard to imagine moving from my home into care."

– Survey participant 359

3.7.4. Transitional Care and the Hospital – Residential Aged Care Interface

Participants' mentioned that transitional care facilities and services, including but not limited to the Transition Care Program (TCP), were sub-standard and could be improved. They also mentioned that moving a loved-one from hospital to residential aged care when they were unable to return home after an illness or injury felt like a rushed, burdensome, emotionally taxing and/or stressful experience.

There were also reports that once an older person was in residential aged care and needed to be in hospital for healthcare the communication between the residential aged care facility and the hospital was poor.

*"The transition from hospital to RAC was APPALLING - communication was poor,
(my) mother was left without a walking aid and the hospital expected the RAC to provide everything
from when she was dropped off, while the information the hospital
provided was incorrect as they didn't know her needs."*

– Survey participant 319

3.7.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding specialist aged care services were:

1. Remaining in your own home

2. Moving into residential aged care only when you cannot be cared for at home

3. High quality care

4. Plan your transition to residential aged care ahead of time

5. Continue to 'be myself' in residential aged care

SPECIALIST AGED CARE SERVICES

Older people's top 5 priorities:

1. Remaining in my own home
2. Moving into residential aged care only when I cannot be cared for at home
3. High quality care
4. Plan my transition to residential aged care ahead of time
5. Continue to 'be myself' in residential aged care

Key Insights:

➢ Older Victorians indicate a strong desire to age in place. Future health policy should prioritise maintaining older people in their own homes and communities for as long as possible if this is their preference. Within the survey, older people identified actions that they had undertaken to facilitate remaining in the community and, where appropriate, many of these could be supported by both health and housing policies.

➢ While planning regarding a potential move to residential aged care was noted as one of the top 5 priorities for older people, few survey participants had made plans for a potential future move. In light of this, promotion of the importance of planning for future care requirements before a loss of capacity to make decisions or before an emergency could be beneficial.

➢ Survey participants expressed a lack of trust that they would receive adequate care and experience a good quality of life while in residential aged care. Improving the standard of residential aged care, and communicating this to older people and their carers, would therefore be of significant value.

➢ Particular concerns raised by older people regarding residential aged care include poor care, isolation and loss of independence. This is often linked to perceptions of understaffing, inadequate training, lack of empathy and fears of being socially isolated and dependent. These opinions appear to be felt across the community which suggests that a comprehensive, wide-ranging approach will need to be adopted to improve public confidence.

➢ Moving to residential aged care from hospital when it was found an older person could not return to their home in the community was reported by older people and their carers to be difficult. This was also the case with accessing hospital care when living in residential aged care. Identifying, exploring and addressing systemic issues relating to the interface between hospitals and residential aged care is essential.

3.8 Care at End of Life

Of the respondents, 53% of participants had prior experience with a loved one receiving end of life care. This cohort was asked to reflect upon the care their loved one received at end of life. Most participants felt that their loved one was *treated with empathy and respect* (80%) and that they were provided with *appropriate palliative care services* (70%) and were ultimately *happy with the care their loved one received* (70%). Less participants felt that their *loved one's choices were heard and respected* (59%) or that the end of life care was *family-centred* (55%).

Figure 24: Percentage of survey responses answering true, false or unsure to statements regarding the care received by a love one at end of life
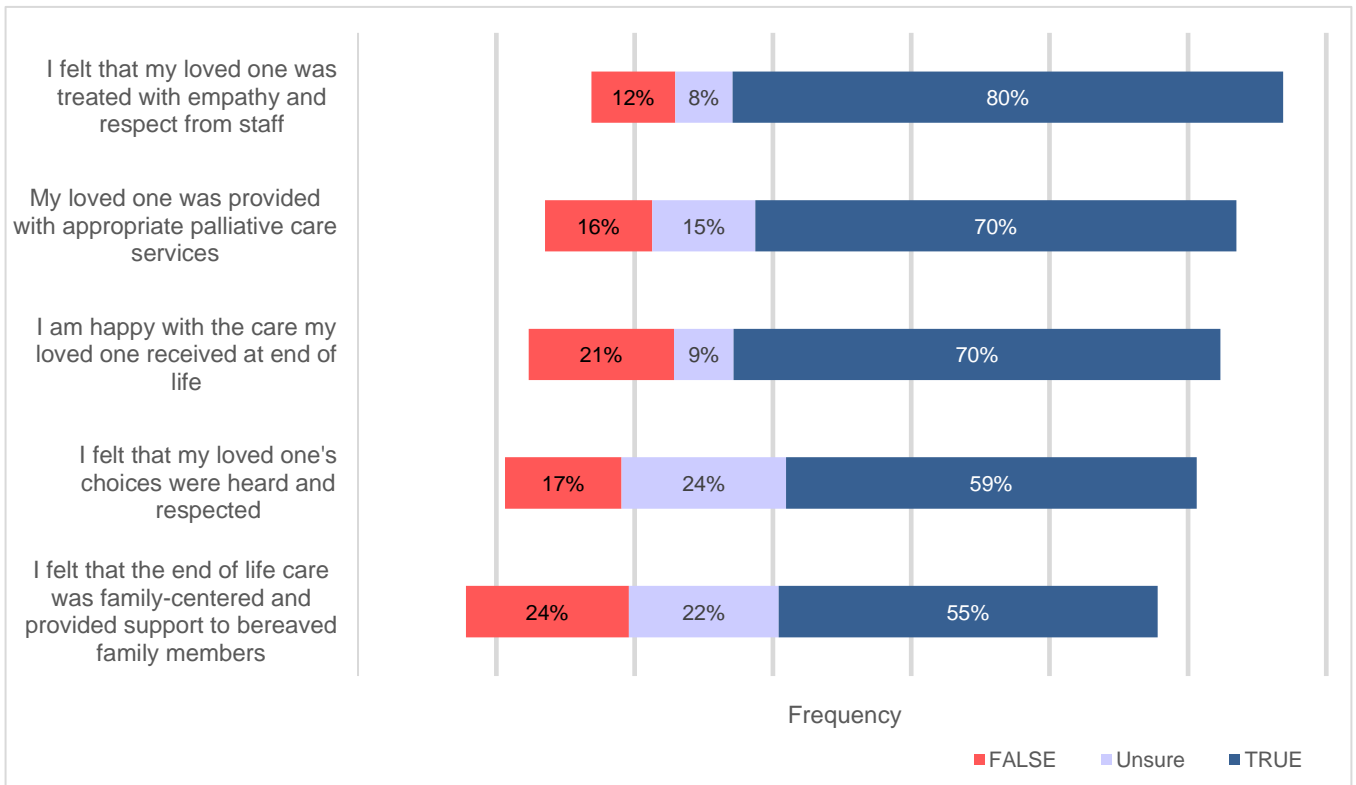
The concept of *choice* in end of life care emerged strongly from participant comments and the prior consultation that shaped the online survey. Choice was identified as a key factor applicable to all aspects of end of life care. Participants wanted their choices, and those of their loved ones, to be heard and respected, whether it was their choice of pain management, family involvement, location, religious support or specific palliative care services. As such 'choice' was not included as an independent factor to be rated on its own within the survey.

3.8.1. Empathy and Respect

Participants identified the most important aspect of end of life care as being treated with *empathy and respect* (92% very important); these concepts were used to refer to many things. One of the most common expectations of empathy was "empathetic, understanding and caring" healthcare staff, but also referred to empathy from family members, auxiliary staff and other residents or patients (depending on the location of end of life care). Specifics as to what constituted empathetic care were not clearly elucidated in participant comments, however a few participants outlined what they considered to be poor examples of empathetic care.

*"The registrar was very rude and abrupt and told us (my husband) was doing ok
but we knew he wasn't. We as a family were not happy with the care
my husband received at his end of life."*

– Focus group participant

*"My partner was called by the wrong name until the last minutes of her life,
while she continued to try to tell the staff politely that that was not her name.
It sounds ridiculous and it was actually very upsetting to her family."*

– Survey participant 205

Figure 25: Percentage of survey responses determining the importance of factors to end of life care
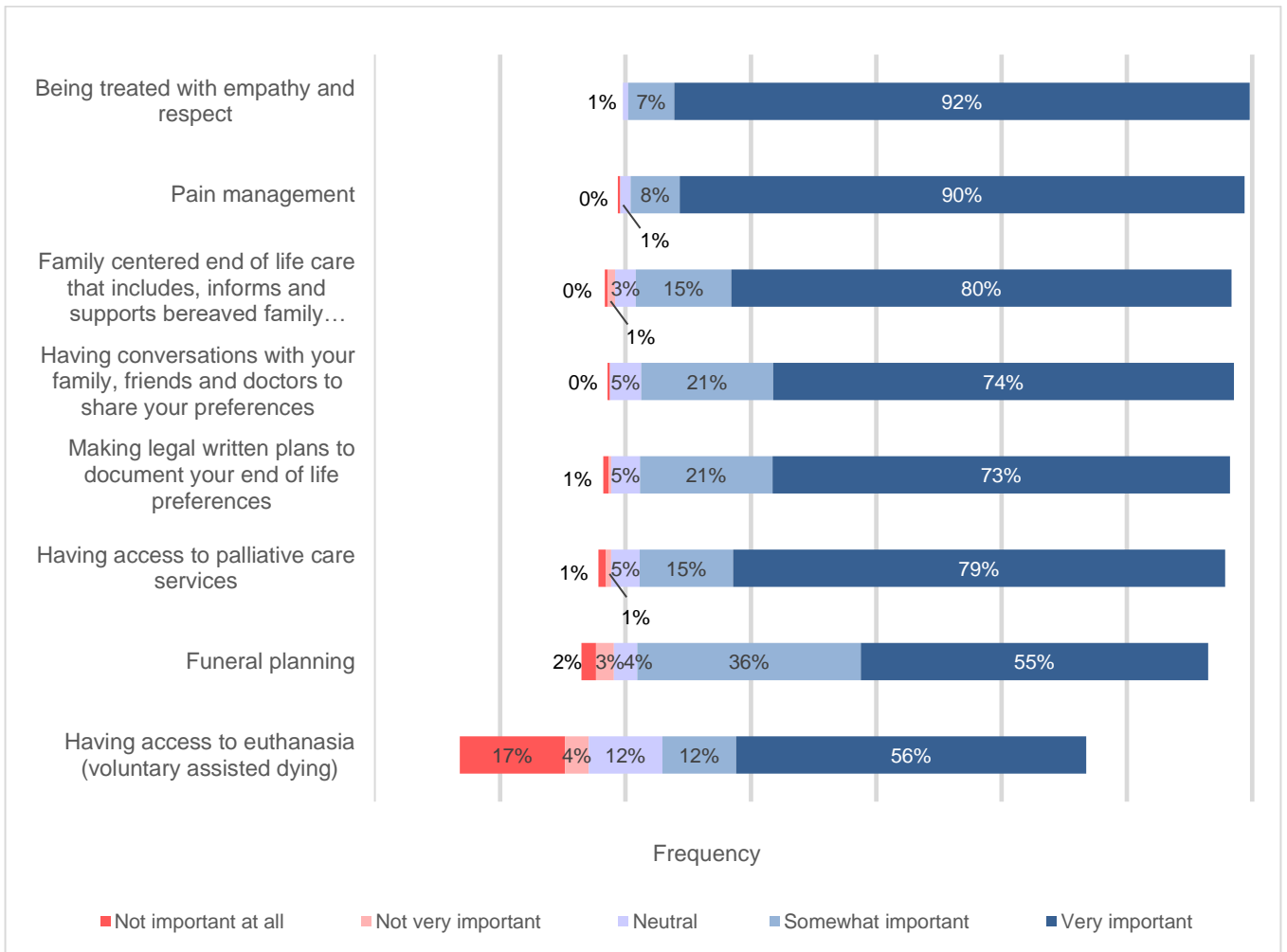
When referring to respect, participants were largely concerned with the *acceptance and execution of ones' choices*, even when those choices conflicted with the personal beliefs of staff or family.

"Respect (is) listening to and acting on my preferences."

– Survey participant 73

"That my wishes are respected and acted upon and not overturned by other family members."

– Survey participant 127

Respect was also used to refer to the needs of bereaved family members, particularly their need to physically be with their loved one and to be informed of changes in their condition or care.

"My family will be well informed, have access to the doctors/medical staff and treated with respect and empathy."

– Survey participant 38

3.8.2. Pain Management

The need for effective pain management strategies were identified as 'very important' by 90% of respondents. While pain management was a very popular topic within the survey, comments often lacked additional context or clarification. Those that did elaborate considered pain management to be essential to maintaining dignity and protecting both the individual and their family from additional distress.

"Pain relief maintain(s) dignity."

– Survey participant 124

One participant also suggested that pain management should be of particular importance to people with dementia, acknowledging that cognitive impairment often results in an inability to communicate the presence or source of pain.

3.8.3. Palliative Care Services

Participants highly valued access to *appropriate palliative care services* (79% very important). Of the 46 comments related to previous experience with end of life, 19 contained very positive reflections of palliative care services, 17 were negative and 10 described neutral experiences. The most common complaints were that palliative care services took too long to be implemented, that families did not feel well enough informed and that palliative care units were understaffed and inattentive.

Despite this, from the survey responses provided it was evident that not all participants *understood the meaning or purpose* of palliative care services. Some self-reported that they were "unaware of what palliative care means", others thought that palliative care included only highly invasive procedures where people were "maintained by life-support machines in a vegetative state". However many participants had previous experience or a good understanding of palliative care and described it as "comfort without cure" and "compassionate care". Participants thought that palliative care services needed to be well funded and provided in a timely manner by appropriately trained staff.

> *"The staff did all they could with their limited time and resources.*
> *There were not enough staff or staff communication between each other on the needs*
> *of each individual person. Too many relief staff not knowing the client's needs, likes, dislikes.*
> *Staff not bringing themselves up to date with individual client records.*
> *Not having time to care for their clients properly."*
>
> *– Survey participant 109*

When there was a perception that the need for palliative care services was *not identified soon enough* (or not at all) participants described the experience as highly distressing to both the individual and their family.

> *"(She died) in the middle of the night…due to septicaemia from an untreated pressure sore.*
> *(It was) a shocking end with no palliative care."*
>
> *– Survey participant 68*

> *"Palliative care took too long to be instituted. He was in five different hospitals*
> *in two years with no existing treatments available to treat his condition, just morphine.*
> *A place came up in palliative care (and) he passed away eleven days later."*
>
> *– Survey participant 177*

Participants also wanted their families to be included in their end of life care, including regular updates, unlimited visiting hours and bereavement support where required. 80% of participants thought it was very important to have access to *family-centred end of life care* that includes, informs and supports bereaved family members.

> *"I received Palliative care visits for 12 months after the loss of my wife which was*
> *a continuation from the palliative care she received in hospital."*
>
> *– Survey participant 71*

Access to *voluntary assisted dying programs* (euthanasia) was highly contentious, with large swings towards to the 'very important' (56%) and 'not important at all' (17%) categories. Comments that approved of euthanasia considered it to be an issue of choice, dignity and quality of life. Participants wanted their choices to be respected and for voluntary assisted dying procedures to be simple and compassionate rather than dominated by bureaucracy.

> *"Euthanasia is an important choice for me - without the red tape and complications that exist now."*
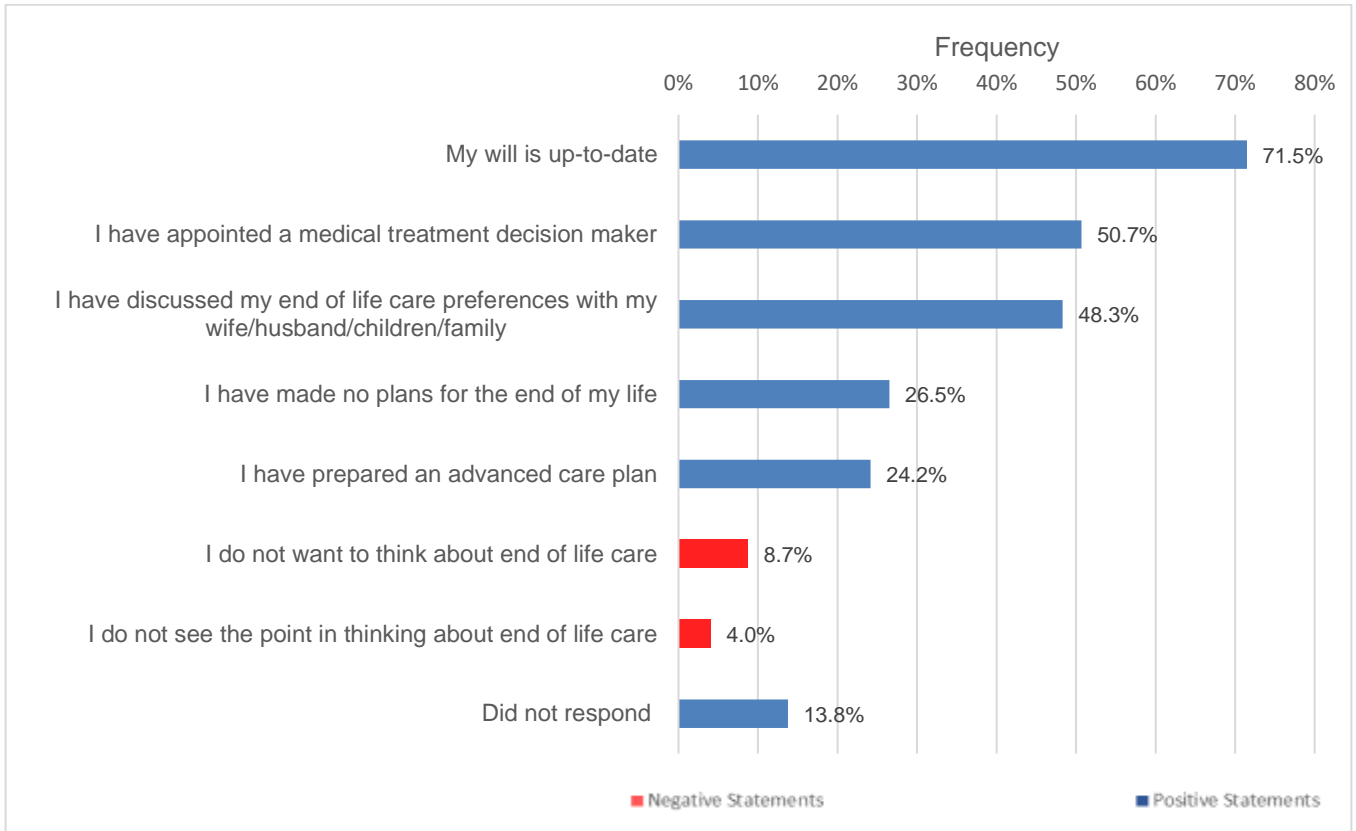> *– Survey participant 171*

Disapproval of voluntary assisted dying programs correlated strongly with age, with the 80+ cohort being most likely to rate it as 'not important at all' (28%) followed by the 70-79 cohort (18%) and 65-69 cohort (12%), while only 7% of carers under the age of 65 thought it was 'not important at all'.

3.8.4. Planning for End of Life Care

The majority of participants valued end of life care planning, with only 4% stating that they do not see the point in thinking about end of life care, and 9% stating that they do not want to think about end of life care. Interestingly neither point of view correlated with age, carer status or prior experience with a loved one receiving end of life care.

Most participants (71%) had an up-to-date will, 51% had appointed a medical treatment decision maker, 48% had discussed end of life care preferences with their families and 24% had prepared a formal advance care plan. However, 27% of participants had made no plans regarding their end of life care.

Throughout the survey, participants acknowledged that, in order to respect and act upon one's choices, it is essential that healthcare staff, families and advocates know what they are. As one participant stated:

> *"To advocate adequately for someone at the end of life, it is important to be well informed of the person's needs and wishes."*
>
> *– Survey participant 70*

Participants agreed that *conversations with family, friends and your GP* (74%) regarding end of life care, as well as *legal written plans* (73%) and *funeral planning* (55%), were all very important aspects of end of life care, particularly for the >80 years cohort as compared to the younger 65-69 and 70-79 groups.

Legal written plans, such as advance care plans, were considered particularly important in cases where there were no close immediate family. Most participants agreed that conversations around end of life care need to be held prior to medical emergencies, although several flagged that the awkwardness of the subject matter was a barrier to honest conversations and careful timing should be considered.

> *"It looks like I haven't chosen to discuss my end of life with my children, but I have tried; they are the ones who don't want to think about it."*
>
> *– Survey participant 30*

> *"Questions around (death) are confronting. Both my parents were confronted in admission (with questions about an advance care plan, this) added all sorts of stress and upset to a difficult situation. (It) wasn't good timing."*
>
> *– Survey participant 291*

Regarding the location of end of life care, 38% of participants would like to receive end of life care in their own home while 14% would like to receive end of life care in a hospital. Participants elaborated in comments that location was less important than feeling comfortable and having unlimited access to family and loved ones.

> *"(I would like) to be cared for in a supportive environment. To die in a place where I (and my family) are very comfortable."*
>
> *– Survey participant 279*

Figure 27: Percentage of survey responses agreeing with statements regarding planning end of life care
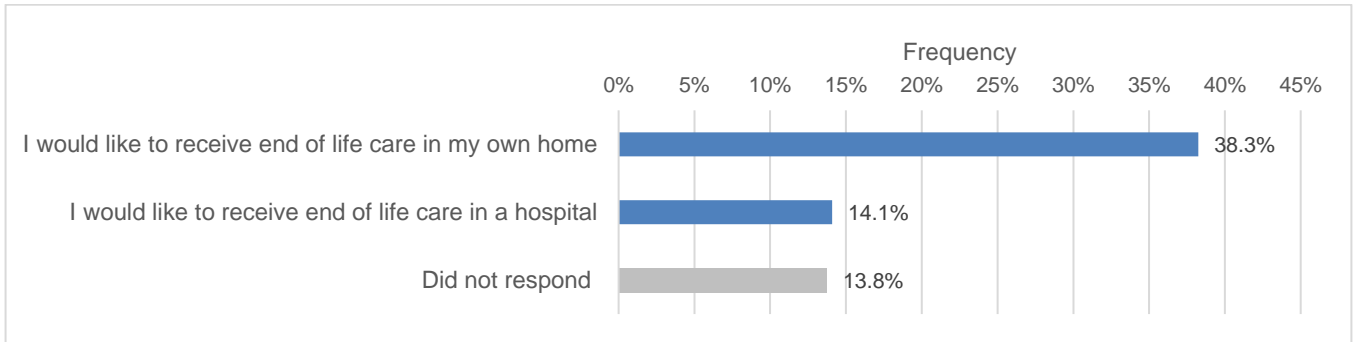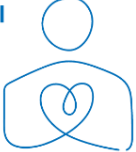

3.8.5. Top 5 Priorities

Overall, the top 5 priorities identified by survey participants regarding care at end of life were:

1. Being treated with empathy and respect

2. Pain management

3. Family-centred end of life care

4. Access to palliative care services

5. Written plans and verbal conversations

CARE AT END OF LIFE

Older people's Top 5 priorities:

1. **Being treated with empathy & respect**
2. **Pain management**
3. **Family centered end of life care**
4. **Access to palliative care services**
5. **Written plans & verbal conversations**

Key Insights:

➢ Older Victorians seek access to appropriate and timely palliative care services that are empathetic, family-centred and both respect and honour the choices of the individual. For many, this is strongly linked to effective pain management in ensuring that care provision is compassionate and dignified.

➢ Majority of older people agree that conversations around end of life care need to be held prior to medical emergencies however the awkwardness of the subject matter is a barrier. Honest but sensitive conversations and careful timing should be encouraged.

➢ While survey participants report valuing palliative care services, it is uncertain whether they actually understand the meaning or purpose of these, with majority indicating they had made no plans regarding their end of life care.

➢ Greater public awareness is required to encourage older Victorians to have the necessary conversations and make the necessary legal plans required for them to receive the care they desire at end of life.

3.9 Carer experience, opinions and attitudes

Within these relationships the most common form of care provided was comfort (87%, Table 4), often in tandem with another form of care. 'Comfort' was described in the comments as "psychological care", "friendship" and "love". Other common forms of care included; assistance managing healthcare (70%), transport (62%), housework (including cooking, home repairs and gardening) (51%) and advocacy (59%).

Survey comments elaborated that advocacy may take the form of financial management, helping purchase items, or as one participant looking after a friend in aged care phrased it, "just helping him with his business". Personal care, such as showering and dressing, and 24-hour nursing care were less common (20% and 3% respectively).

Table 4: Self-reported carer experience, opinions and attitudes

Variable	Number of responses	% of total sample
Types of Care Provided		
Comfort	53	86.9%
Health care	43	70.5%
Transport	38	62.3%
Advocacy	36	59.0%
Housework	31	50.8%
Personal Care	12	19.7%
24-hour nursing care	2	3.3%
Did not respond	4	6.6%
Enablers for Carers		
I can advocate well on their behalf	40	65.6%
I know what the person I care for wants	38	62.3%
Caring is a fulfilling experience that brings me great satisfaction	19	31.2%
I am well supported by other carers and/or services that help share the load	10	16.4%
Barriers for Carers		
I find caring can be emotionally taxing	39	63.9%
I find caring to be physically demanding	22	36.1%
I find caring to be very time consuming	19	31.2%
I find caring to be a significant financial hardship	12	19.7%
I feel alone and unsupported	8	13.1%

More than half of carers felt they knew what the person they cared for wanted (62%) and could advocate well on their behalf (65%). But a great deal of uncertainty and stress was also expressed in the survey comments, with many describing feeling alone (especially when important decisions needed to be made), anxiety over having to interpret a person's needs and feeling burdened by an overwhelming sense of responsibility. Less than half of carers felt that caring was a fulfilling experience (31%) and a very low 16% felt well supported by other carers and/or services.

> *"Caring for someone living with dementia…is a real concern as the disease has changed my mother's wants and needs. Many times I am concerned that I really don't know that the decisions I am making on her behalf are right for her - yet she has an unshakable faith that I will take care of her. The responsibility is great - and as such, incredibly stressful."*
> *– Survey participant 243*

Many participants described their caring responsibilities as a significant burden. One of the most common complaints was the lack of respite care opportunities, which lead to emotional exhaustion and poor health and wellbeing outcomes for the carer.

Similar comments were made regarding transitional care. Participants described feeling a high level of care burden; they used phrases like "I find it's very hard for me to get away for any period of time" and "I have no time or thoughts even to think about myself." This was reflected in the data, where 64% of carers said they found caring to be emotionally taxing. Other difficulties included care was physically demanding (36%), time consuming (31%) and a significant financial hardship (20%).

"I work (caring for my husband) 24 hours a day…it's very isolating, it's very difficult at times, it's scary. I've just had the doctor visit and (tell) me again if I don't look after me I'm not going to be looking after him."

– Focus group participant

"I am very happy to be able to care for my mother but as a single parent of a teenage girl as well I am finding making time for myself to be very hard."

– Survey participant 115

It is important to remember that 66% of carers were over the age of 65, which could increase the likelihood of them experiencing their own health and wellbeing needs related to older age. Participants suggested that the health and wellbeing needs of older carers can be overlooked and postponed in the course of their responsibilities. Carers over the age of 80 were considerably less likely to feel that they know what the person they cared for wanted (25%, compared to 62% for all carers) or feel they could advocate well on their behalf (25%, compared to 65% for all carers). They were also vastly more likely to find caring time consuming (75%, compared to 31% for all carers). But carers aged 70-80 and over the age of 80 also found caring to be a more fulfilling experience that brought them great satisfaction (59% and 50% respectively, compared to 31% for all carers).

"I'm caring for (my partner) and I need care myself. I could do with someone to care for me. It would be nice."

– Focus group participant

"I know to give (my parents) help is very rewarding…The satisfaction of being able to give my time and support and know it makes a great difference to their lives, it eases the burden for them and the happiness and contentment and relief when jobs are done is second to none. Both appreciate that someone is there for them."

– Survey participant 81

A common theme in comments was the significance of co-dependant situations where two older people, often spouses, acted as each other's principle care giver, "we are co-carers, we care for each other". These arrangements were reported to be meaningful and essential to the everyday wellbeing of the participants. However participants also flagged caring for each other to be dependent on both keeping well and worried over what would happen if one person became unable to care for the other.

"Alice and I depend on one another - like, if either of us gets to the stage where we can't help one another, then we need someone to help to come in, and even in the time they come one or both might have to go to a home, into care."

– Focus group participant

"We are in a situation of mutual support. There are some things only I can do and some things that only (he) can do."

– Survey participant 182

THE CARER EXPERIENCE

What did carers say?

1. **Caring can be emotionally taxing**
2. **Commonly provided care included: assistance with healthcare, providing comfort & transport**
3. **Carers did not feel well supported by services to help share the load**
4. **Carers felt that they knew what the older person they cared for wanted & could advocate for them**
5. **Most carers surveyed were older (aged 65+)**

Key Insights:

➢ Many carers of older people view their caring responsibilities as a burden, feeling overwhelmed by the level of advocacy and decision-making required and unsupported by other carers and/or services. Emotional exhaustion is common, compounded by the physical demands and time consuming nature of the caring role. Greater investment into carer support, including appropriate and accessible respite and transitional care options, could help reduce carer burden, improve the health and wellbeing of carers and, ultimately, keep older Victorians ageing in place for longer.

➢ Victorian carers of older people, many of whom are older themselves, may be in danger of delaying or overlooking their own health needs. Health policy could consider targeting a range of preventative and proactive health management measures for this group and promoting carer health and support.

➢ Co-caring arrangements where two older people care for each other seem common. Older people who are dependent on each other worry about what would happen if one, or both, of them became ill. Some ideas to alleviate this could involve increasing support services for carers, tailoring home-care packages and improving the standard (and subsequent reputation) of care provision in residential aged care. Work could also be done on developing residential aged care models where couples and those caring for each other can continue to live together and support one another.

4. Discussion and Future Implications

This report outlines the expectations, preferences and priorities of older Victorians for their health and wellbeing across the ageing spectrum, identifying the areas of greatest importance and, by extension, the areas where improvement may be needed. The findings of this research should be used to inform the development of future healthcare policy in Victoria, ensuring that it is receptive to the changing needs of older Victorians.

In addition to ascertaining the top 5 priorities in each of the 6 domains of ageing, this study identified several overarching themes that demonstrate the core priorities of older Victorians.

1.   Older Victorians want their opinions regarding health and wellbeing to be heard

Over the course of the study, participants regularly expressed their appreciation for the opportunity to provide feedback regarding issues relating to ageing. This suggests that older Victorians want to have greater and more regular input into healthcare policy development, as they are well aware that these policies and frameworks will have a profound impact on their ability to age well. Incorporating the knowledge and expertise of older people and their carers in this decision-making process will therefore allow the Victorian Government to create future healthcare policies are reflective of the needs of this growing demographic. However, as our community moves through the recovery phases of COVID-19 it is clear that healthcare preferences and priorities will naturally be shaped by community context. As such, a long-term commitment from policy makers is required to ensure that older Victorians are regularly consulted about their changing opinions regarding the healthcare system. It is therefore recommended that this report is updated periodically to reflect the changing wants, needs and preferences of our ageing population.

In addition, advocacy was a theme that came to the fore across a number of stages of later life. Many older people indicated that they wanted someone to help them and speak up for them during hospital stays, in recovering after hospitalisation and/or injury or illness. They also mentioned the usefulness of assistance and advocacy when managing multi-morbidity and living in the community and to help them navigate all aspects of aged care including staying in their own home with services provided to the home and living well in residential aged care. While advocacy was also acknowledged as a common feature of the carer role, many carers reported feeling isolated, overwhelmed and burdened by this significant responsibility. As such, it is critical that informal and formal opportunities for both individual and systemic advocacy regarding the healthcare needs of older Victorians are encouraged and supported. Promoting the availability of independent services that deliver free advocacy, information and education to older people and their carers, many of which also provide valuable input into policy reform, should be prioritised to ensure that the voices of all older Victorians are able to be heard at all levels.

2.   Older Victorians want choices built into their healthcare

The older Victorians who took part in this research valued options, alternatives and preferences when it came to accessing and selecting healthcare services and management approaches, whether it was a choice of GP, in-home service providers, treatment methods for acute/chronic medical conditions, residential aged care facilities or specialist palliative care services such as voluntary assisted dying programs. Participants wanted to be able to make informed decisions regarding their health and opportunities for care provision, then have those decisions respected and acted upon. Regional and rural Victorians, in particular, require a greater degree of choice due to their geographical isolation, which may be improved by the further development of telehealth and other technology-based healthcare services.

3.   Older Victorians want support to identify, navigate, access and use healthcare services

The aged care system is renowned for being complex and often difficult to navigate. Study participants complained of long waiting periods for in-home support services and complex eligibility criteria, with most finding the MAC system difficult to use. When faced with care in a crisis, many older people reported feeling rushed to be discharged and left without support following admission in a hospital setting. It was reported that particular improvement was needed in facilitating the transition between hospital and residential aged care.

Participants also identified the need to evaluate and reset health and care settings to meet the needs of older people. In particular, they cited barriers to healthy and active ageing in locating age-friendly spaces, from gyms to social spaces to public transport systems. Improvements are needed to not only ensure that older Victorians are able to find the information and practical support they require, but that the environment they live in is as accessible as possible. This could include strategies to accommodate varying degrees of computer literacy and personalised alternatives to current online practices as well as promoting age-friendly local environments.

4. Older Victorians want effective communication with service providers

Throughout the research activities it was clear that not all participants had a comprehensive understanding of the scope and purpose of many common healthcare services and supports. There was confusion as to what to expect from in-home services, GP services, hospitals, residential aged care and palliative care services as well as concerns regarding the way in which service providers deliver information and the extent to which they involve older people and their family/carers in shared decision-making about their care. In order to recognise and appreciate quality healthcare, older Victorians require more effective communication strategies to inform them as to what constitutes quality care and establish appropriate expectations of care. This includes, but is not limited to, factors such as the scope of personal care services versus domestic in-home services, what to expect in hospital (particularly the length of stay and rehabilitation aspects) and how to ask for help and advocate for yourself, or find an advocate in a hospital setting. Awareness of quality care could be improved through targeted public education programs and more effective communication from heath care service providers to accurately establish consumer expectations.

5. Older Victorians want healthcare that is integrated and responsive to their needs

Some of the frustrations expressed by older people in regards to their own care experiences, and the experiences of their older family and friends, related to not getting care where they expected it to be and at the time of need. There was also an impression that there was a lack of integration between the facets of health and care services including; health promotion, mental healthcare and management, chronic disease care and management, hospital care, in-home care for health, personal care, domestic assistance, social care services, welfare/income assistance, housing assistance, residential aged care, and palliative care. It was expressed that these services sat separately, were disparate from each other, were not well provided to older people and where they were accessed were not delivered at a high standard. There was a general confusion among participants as to who provided services for older people, who was responsible for the health and care of older people, the circumstances in which older people are eligible for health and care assistance and what the purpose of the services available were.

Overall, the findings of this project support a case for more integrated care for older people to create a system-wide approach that works to address the demands arising from an ageing population and better supports people with multi-morbidity, functional impairment and other long-term conditions. There is evidence of benefits when health and care organisations and services work together and co-ordinate the care they provide around the needs of older people.[18] Developing integrated services can result in overcoming barriers between different health and care services and levels of care, as well as types of care and providers.[18] This improves the effectiveness and impact of services that exist separately from each other but are often all relevant to an individual older person, their health or care needs and/or an acute health event. Reducing barriers between physical and mental health, primary healthcare and the broader healthcare system, hospital and community care, hospital and residential aged care, community and residential aged care and, finally, health and social care overall supports the delivery of the right care, at the right time and in the right place for older people.[18]

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5. Conclusion

While health and wellbeing support for older people and their carers should be informed by overarching consumer expectations, needs and priorities, and adapted on a case by case basis to reflect person-centred practice, these appear to vary over the ageing spectrum.

The findings of this project were separated into 6 domains of ageing to draw attention to how the needs and priorities of older Victorians are likely to change over the course of their lifetime. For example, during healthy and active ageing, participants prioritised taking an active role in their wellbeing but communication became most important when receiving care in hospital. A positive attitude was most highly valued when recovering from an illness or injury. It is also important to acknowledge this changing spectrum of needs and priorities when shaping future healthcare policy. An older person is likely to pass through several health and care domains during their ageing journey and better co-ordination of policies and services is needed to streamline access and delivery across these domains

The 'What Do Older People Want from their Healthcare?' Project, conducted by NARI on behalf of the Victorian DH, provides valuable insights into what older people in Victoria want, need or expect when they seek support for their health and wellbeing, as well as how these priorities change at different points in the care continuum. This evidence base will guide future policy development on ageing throughout the life course for older Victorians; supporting them to age well for longer, providing targeted interventions during times of acute health and/or care crisis, facilitating re-enablement across the service system, maintaining optimal independence through greater access to specialist care services and integrated care (including the transition to residential aged care) and providing timely, planned and co-ordinated end of life care when needed.

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Supplementary Data

Demographic age distribution

Figure 28: Supplementary demographic age distribution
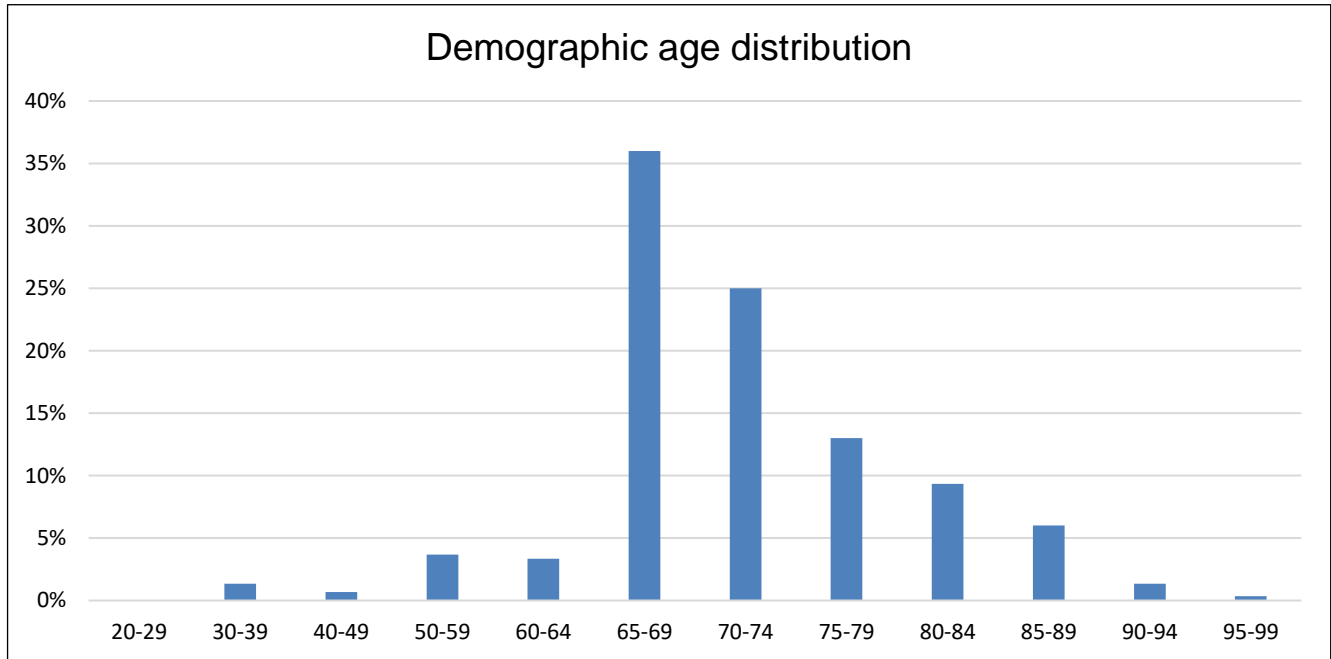
Demographic regional distribution

Figure 29: Supplementary demographic regional distribution
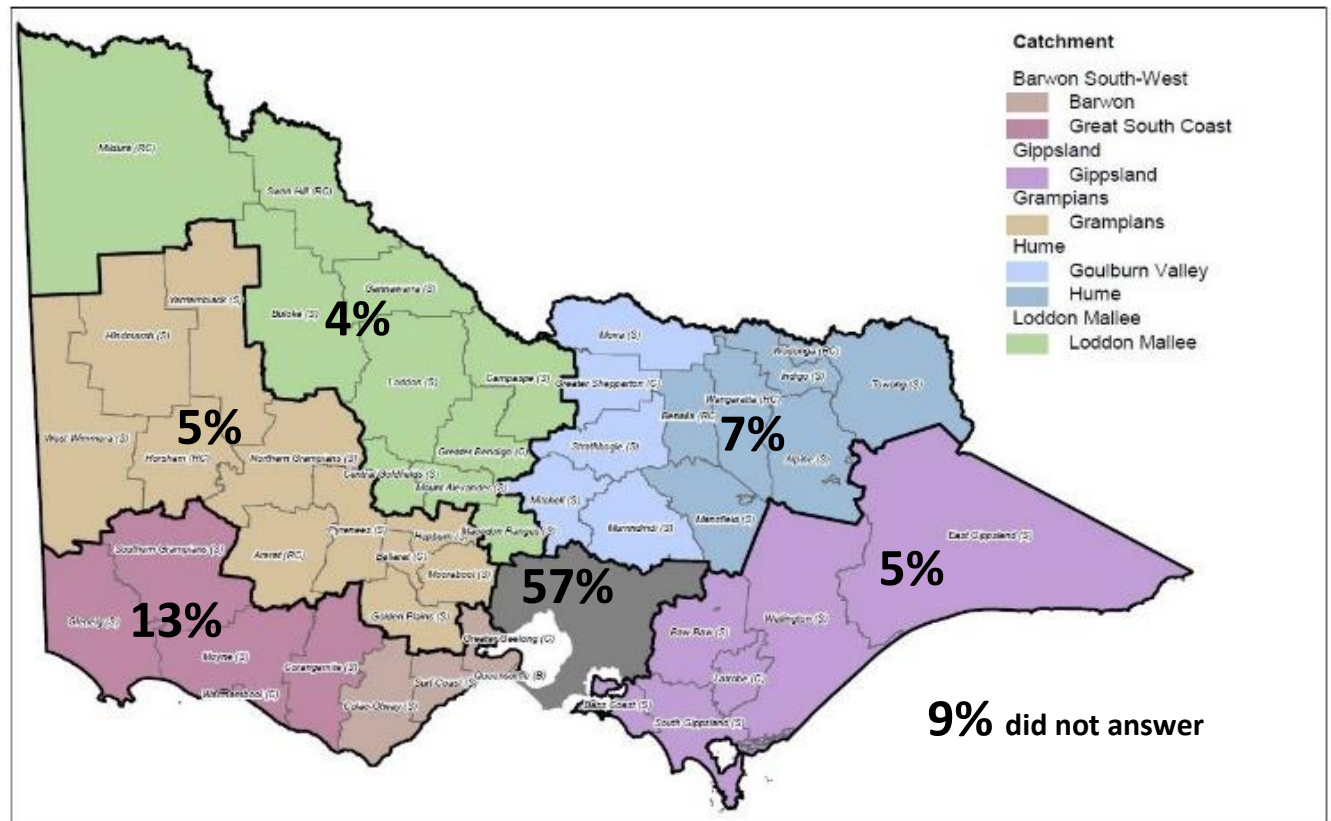
Table 5: Supplementary demographics living situation

Characteristic	Number of responses	% of total sample
Living Situation		
I live on my own	91	30.54%
I live with my partner	177	59.40%
I live with family/friends	17	5.70%
I live in a retirement village	8	2.68%
I live in communal living (e.g. share house, boarding house etc.)	3	1.01%
I live in residential aged care	4	1.34%
Did not respond	6	2.01%

Appendix 1: Method – Additional Information

Creswell and Poth (2017) conceptualised the process of data collection, analysis and creation of narrative as a 'Data Analysis Spiral'.[10] As seen in Figure 30, this model can be used to explain how preliminary activities undertaken in the WDOPW project generated data that was then analysed and used to inform further project activities including the development of the online survey.

Figure 30: Creswell and Poth's Data Analysis Spiral

Researchers working on the project gathered audio recordings/notes and relevant literature, with this collection occurring at the top of the spiral; the data collection phase.[10] It allowed the researchers to leave the 'spiral' as illustrated in the above figure with an account of findings (the final report).[10] Note that this process is not linear.[10] It is represented as a spiral because, in-between project activities, researchers touch on facets of analysis and circle around and around to identify themes, codes and nodes.[10] Within each spiral the researcher uses analytic strategies with the goal of generating specific outcomes.[10]

In the case of the WDOPW project, a literature review allowed for the analysis of focus group data with reference to sources such as the WHO AFCC[14] and the WHO World Report on Ageing and Health.[2] Codes and nodes were created through the analysis of the focus group data and online consultation data. These were then described and classified while researchers 'spiralled', brainstormed and developed key themes from circling around ideas, checking coding within the team and re-reading key literature.

The literature review and analysis of focus group data could be seen as a development phase where looking at key words, similarities and differences within the responses from each focus group facilitated the development of a coding framework. This phase aligns with the idea that initial coding can be done by looking for general patterns within data.[19] After the initial literature review, literature was consulted throughout the project to help further define the coding framework and themes. When conducting the focus groups, researchers started with general questions which resulted in 'scattered' responses. With the aid of consulting the literature, the responses were then organised into identified themes/codes. This created a framework which allowed for more specific questions about those themes to be asked during the social media consultation and for priorities to be identified during the online survey. See Figure 31 below for an overview of the way in which project activities connected to each other in generating data, as well as an explanation of how data analysis occurred.

Literature review: Initial literature review to assist in defining research question and project aims. Literature is consulted throughout the project to help define patterns in the data to form rudimentary codes/themes. This step informs the focus group design and occurs across and throughout the project

Face-to-face Focus Groups

Activities 1-3

1. Focus Groups: semi-structured, face-to-face focus groups carried out with older people.

2. Data analysis: Connecting threads and patterns, cross coding of data to hone codes/themes into nodes for NVivo analysis.

3. End of focus group phase: Saturation of codes/patterns/themes emerges in focus group

Findings from social media consultation shape coding framework

Data from online survey builds on coding framework

Data from focus groups used to design social media consultation.

Coding framework influences survey design and data analysis.

Data from social media influences online survey design.

Social Media Consultation

Activities 4-6

Online Survey

Activities 7-9

9. Survey Data: Survey data exported from REDCaps and collated in Excel. Analysed using NVivo and SPSS.

4. Social Media Content: Developed to convey evidence, spark engagement & discover older people's health priorities

5. Social Media Contact List: A list of organisations to tag and follow developed to create reach

6. Social Media Consultation: Participants engage with content uploaded twice a week over a period of 2 months

7. Survey Design: Shaped by literature review, findings from face-to-face focus groups and social media consultation. Recruitment via NARI mailing lists, social media, peak bodies and organisations. Designed in REDCap.

8. Survey: Included 72 questions using 5-point Likert scale, multiple choice and free-form questions. Total responses received **n298.**

Appendix 2: Online Survey

What do older people want from their health care?

The National Ageing Research Institute (NARI) is working with the Victorian Department of Health and Human Services (DHHS) to develop an understanding of what is important to older people in Victoria in relation to their health and wellbeing needs, at key points in their later life.

We would like to invite you to participate in this survey to discuss your health care preferences, priorities and expectations. Your ideas and input will be used by the DHHS to assist in developing health policy initiatives that are responsive to older people's priorities.

The survey involves you completing 35 questions and will take approximately 15-20 minutes. You do not have to complete this survey if you don't want to. Your participation is completely voluntary.

By completing the survey, you agree to the collection and use of the information for research conducted at NARI. Your answers will be treated confidentially and you will not be identified in any way. The information will be used to generally inform a report to the Victoria DHHS about what older people want from their health care.

We greatly value your input into this project and appreciate the time you are taking to complete the survey.

Do you agree to participate in this study?

○ Yes
○ No

This survey PDF can be printed, completed and returned to...

National Ageing Research Institute
PO Box 2127
Royal Melbourne Hospital
VIC 3050

Section 0: Demographic information

Are you...?	○ Male
	○ Female
	○ Prefer not to describe
	○ Self describe (please specify)

Self-describe (please specify)	_____

Are you 65 years or older?	○ Yes
	○ No
Or (for Aboriginal and Torres Strait Islanders only) are you 50 years or older?	

What is your age? (optional)	_____

Are you currently employed?	☐ Paid employment
	☐ Unpaid (volunteer) employment
	☐ Retired
	☐ Other (please specify)

Other employment (please specify)	_____

Do you identify as the carer of an older person?	○ Yes
	○ No
A carer is someone who provides unpaid care and/or support to a family member or friend with a disability, illness, chronic health issue or age-related concern.	
Every care situation is different. Some carers provide 24-hour nursing aid to a family member with high needs. Other carers support a person who is fairly independent but may need help with some tasks like banking, transport, shopping, or housework. Carers may give comfort, encouragement and reassurance to the person they care for, oversee their health and wellbeing or monitor their safety, regardless of where they currently live.	

You have selected that you are under the age of 65 and not a carer of an older person. If this is the case please do not proceed further with this survey.	☐ End survey

What is your relationship to the person you care for? (eg# Spouse, sibling, child, friend)	_____

How do you care for an older person?	☐ 24-hour nursing aid ☐ Personal care (help with showering, grooming, mobility) ☐ Transport ☐ Advocacy (help with banking, shopping, talking to services) ☐ Housework (help with cleaning and cooking) ☐ Healthcare (help overseeing medical problems, talking to the doctor) ☐ Comfort, encouragement and reassurance ☐ Other (Please provide any details you believe relevant)
Other (Please provide any details you believe relevant)	....
Please select the following statements that are relevant to your experience as a carer	☐ Caring is a fulfilling experience that brings me great satisfaction ☐ I know what the person I care for wants ☐ I can advocate well on their behalf ☐ I am well supported by other carers and/or services that help share the load ☐ I find caring to be very time consuming ☐ I find caring to be a significant financial hardship ☐ I find caring can be emotionally taxing ☐ I find caring to be physically demanding ☐ I feel alone and unsupported
Other comments (on your experience as a carer)	....

As you are a person under the age of 65 we are interested in capturing your perspective and experience as the carer of an older person. For the rest of the survey please answer questions on behalf of the older person you care for, considering their needs and wants. You do not have to answer all questions if they are not relevant to your experience as a carer.

This survey is for people living in Victoria. If you do not currently reside in Victoria please do not proceed any further with this survey. What is your postcode?	....
Which statement best describes your living arrangement?	☐ I live on my own ☐ I live with my partner/spouse/wife/husband ☐ I live with family/adult children/friends ☐ I live in a retirement village ☐ I live in communal living (eg# share house, boarding house etc.) ☐ I live in residential aged care ☐ Other (please specify)
Other living arrangements (please specify)	....

Section 1: Healthy and active ageing

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Please rate the following factors in terms of importance to your physical health as you age?

	Not important at all	Not very important	Neutral	Somewhat important	Very Important
Keeping active through physical exercise	O	O	O	O	O
Taking an active role in managing your health	O	O	O	O	O
Healthy eating	O	O	O	O	O
Having a good relationship with your GP	O	O	O	O	O
Access to specialist medical services (eg# geriatrician, cardiologist)	O	O	O	O	O
Being able to use technology to find health care information	O	O	O	O	O

Other comments (on physical health)

Please select the following statements about exercise and motivation that are relevant to you	☐ I am motivated to do physical exercise that I enjoy ☐ I prefer to exercise in a group class than on my own ☐ I am motivated to exercise to improve my health (eg# decrease my chance of falls, osteoporosis, cardiovascular disease, obesity etc.) ☐ I do not have the time to exercise regularly ☐ I am not physically able to exercise regularly ☐ I cannot afford to exercise regularly ☐ I do not see the point of exercising regularly

Section 1: Healthy and active ageing (continued)

Please rate the following factors in terms of importance to your social well-being as you age?

	Not important at all	Not very important	Neutral	Somewhat important	Very important
Social interactions with family	O	O	O	O	O
Social interactions with friends	O	O	O	O	O
Participating in a structured club, group or organisation	O	O	O	O	O
Volunteering (eg# community group, charity)	O	O	O	O	O
Having a pet (eg# cat, dog)	O	O	O	O	O
To be respected and listened to	O	O	O	O	O
To be included and feel like you belong	O	O	O	O	O

Other comments (on social well being)

Section 1: Healthy and active ageing (continued)

Please rate the following factors in terms of importance to your mental well-being as you age?

	Not important at all	Not very important	Neutral	Somewhat important	Very important
A positive outlook on life	O	O	O	O	O
Motivation to do things	O	O	O	O	O
Having a purpose or routine	O	O	O	O	O
Feeling useful	O	O	O	O	O
Hobbies and/or regular recreation	O	O	O	O	O
Learning new skills	O	O	O	O	O
Keeping informed and in touch (eg# watching/reading the news, knowing what's happening with your family/friends)	O	O	O	O	O
Access to mental health support	O	O	O	O	O

Other comments (on mental well being)

Section 2: Managing health problems

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Do you have any health problems?	○ I have no health problems ○ I have 1-2 health problems ○ I have 3 or more health problems
How would you describe your health?	○ Excellent ○ Very good ○ Fair ○ Poor ○ Very poor
Please select the following statements about seeking information from your GP/Doctor that are relevant to you.	☐ It is important to have your own personal GP/Doctor ☐ I feel confident to seek information from my GP/Doctor ☐ My GP is well informed and has all the information I need ☐ My GP/Doctor asks me questions about healthy ageing (eg# exercise, memory loss, loneliness) ☐ I feel that my health conditions are well managed by my GP/Doctor ☐ I have been referred by my GP/Doctor to relevant specialists / health professionals (eg# cardiologist, oncologist) ☐ I do not think it is important to have your own personal GP/Doctor
Other comments (on your GP/Doctor)	---
Please select the following statements about living in your own home with health problems that are relevant to you. If you currently live in residential aged care please skip this question.	☐ It is essential for me to remain in my own home, I will not move under any circumstances ☐ It is very important for me to remain in my own home for as long as I am able to ☐ I rely upon in home services to remain living in my own home (eg# domestic help services, personal care assistance) ☐ I rely upon my family/friends to remain living in my own home ☐ My wife/husband/partner and I depend on one another. If one of us became unwell we might have to move into care ☐ I have begun to make plans to move into a residential aged care facility ☐ I am eager to move into residential aged care
Other comments (on living in your own home)	---

Section 2: Managing health problems (continued)

Please rate the following factors in terms of importance to remaining in your community as you age?

	Not Important at all	Not very important	Neutral	Somewhat Important	Very important
Support from family, friends or neighbours	O	O	O	O	O
In home services (eg# showering, cleaning, cooking)	O	O	O	O	O
In home modifications / equipment (eg# rails and ramps)	O	O	O	O	O
Transport (eg# access to public transport, being able to drive a car)	O	O	O	O	O
Proximity to healthcare services	O	O	O	O	O
Mobility in the community (eg# can walk on the footpaths)	O	O	O	O	O
Feeling safe in the community (eg# crime)	O	O	O	O	O
Adequate financial resources	O	O	O	O	O

Other comments (on remaining in your community)

_____

Have you ever used My Aged Care? My Aged Care is the Australian Government's online website for finding and accessing government funded aged care services, such as in home services, short-term care or aged care homes.	○ Yes ○ No

Please select the following statements about aged care services that are relevant to you	☐ I am aware of the services that are available to me. ☐ I am concerned about the affordability of services. ☐ I am concerned about the availability of services. ☐ I do not know if I am eligible for services I am interested in. ☐ I do not know if I can physically get to the services I need ☐ I find it difficult to use technology to access aged care services ☐ I think the My Aged Care system works well ☐ I need more support to navigate My Aged Care ☐ I do not understand the My Aged Care system

Other comments (on aged care services)

_____

There are many aged care services that can help you remain in your own home for longer.

Please select any services you currently access

- ☐ Case management (eg# a professional who helps to manage your services)
- ☐ Meals on Wheels or meal and food assistance
- ☐ Transport and/or shopping assistance
- ☐ Home visits from a community health worker, nurse, GP/Doctor or social worker
- ☐ Domestic help services (eg# cleaning)
- ☐ Personal care assistance (eg# showering)
- ☐ Social visits and/or a social program
- ☐ Occupational therapy home modification (eg# ramps and rails)
- ☐ Community based services (eg# community health center, activity groups)
- ☐ Other services
- ☐ I don't use any aged care services

List other relevant services

_____

There are many ways aged care services can be financially supported. How do you pay for your aged care services?

- ☐ Commonwealth Home Support Programme (CHSP)
- ☐ Home Care Packages
- ☐ I pay for the services myself
- ☐ I don't know
- ☐ Other
- ☐ I don't use any aged care services

Other (please provide details)

_____

Section 2: Managing health problems (continued)

Please rate the following factors in terms of importance to using in home services

If you do not receive any in home services please skip this question.

	Not important at all	Not very important	Neutral	Somewhat important	Very important
My in home services arrive when they are meant to	O	O	O	O	O
The same people turn up every time to provide my services	O	O	O	O	O
My service personnel are friendly and treat me with respect	O	O	O	O	O
My service personnel are competent and thorough in their tasks	O	O	O	O	O
My in home services do what they are meant to do	O	O	O	O	O
My in home services do everything I need them to do	O	O	O	O	O
I am happy with the choice of providers in my area	O	O	O	O	O

Other comments (on using in home services)

....

Section 3: Hospital Care

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Please rate the following factors in terms of importance to quality of care in hospital

	Not important at all	Not very important	Neutral	Somewhat important	Very important
Health care staff treat me with dignity and respect	O	O	O	O	O
The healthcare I receive is appropriate	O	O	O	O	O
The healthcare I receive is provided competently	O	O	O	O	O
My treatment is delivered in a timely manner	O	O	O	O	O
There is adequate staffing	O	O	O	O	O
The hospital food is of good quality	O	O	O	O	O
I can open and eat the food provided without assistance	O	O	O	O	O

Other comments (on quality of care in hospital)

Have you been a patient in hospital within the last 5 years?

O Yes
O No

How could your recent stay in hospital have been improved?

Section 3: Hospital Care (continued)

Please rate the following factors in terms of importance to communication in hospitals

	Not important at all	Not very important	Neutral	Somewhat important	Very important
An advocate (family, friend) to look out for your interests	○	○	○	○	○
Respect and empathy from hospital staff	○	○	○	○	○
Knowing what's going on with your care	○	○	○	○	○
Being listened to by staff	○	○	○	○	○
Following instructions from hospital staff	○	○	○	○	○
To have your family be informed of your care	○	○	○	○	○
Knowing who to ask for help or advice	○	○	○	○	○
Opportunities to provide feedback to the hospital	○	○	○	○	○

Other comments (about communication in hospitals)

Section 3: Hospital Care (continued)

Please rate the following factors in terms of importance to receiving visitors/socialisation in hospital.

	Not important at all	Not very important	Neutral	Somewhat important	Very important
For family and friends to be able to visit me anytime	O	O	O	O	O
For my carer/family to be able to stay with me overnight	O	O	O	O	O
Free parking for patients and visitors at public hospitals	O	O	O	O	O
One to one interaction with volunteers	O	O	O	O	O
Group-based volunteer programs/activities	O	O	O	O	O
Group-based therapy programs/activities	O	O	O	O	O

Other comments (about receiving visitors/socialisation in hospital)

When recovering in hospital do you think it's more important to have rest and recuperation or get up and get moving?	O Rest and recuperation O Get up and moving
When you were discharged from hospital did staff ask you questions about how you would manage at home (eg# showering, cleaning, shopping, physiotherapy) and help construct a plan for you?	O Yes O No

Other comments (on making a discharge plan)

Section 4: Recovering after being unwell

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Please rate the following factors in terms of importance to recovering from an illness or injury

	Not important at all	Not very important	Neutral	Somewhat important	Very important
Remaining in hospital until you are completely recovered	O	O	O	O	O
Getting home as soon as possible	O	O	O	O	O
Receiving a discharge plan when you leave hospital	O	O	O	O	O
Having medical, nursing or allied health services provided in your home	O	O	O	O	O
In home domestic services while you recover (eg# cleaning, shopping)	O	O	O	O	O
Community based recovery services (eg# physiotherapy programs)	O	O	O	O	O
Having a strong support system and/or people you can rely on	O	O	O	O	O
Avoiding loneliness	O	O	O	O	O
Having a positive attitude	O	O	O	O	O

Other comments (on recovering from an illness or injury)

Have you ever received short term in home services (eg# help with cleaning, shopping, cooking) while recovering from an illness or injury?

O Yes
O No

Confidential

Section 4: Recovering after being unwell (continued)

Please rate the following factors in terms of importance to receiving short term in home services

If you have never received short term in home services please skip this question.

	Not important at all	Not very important	Neutral	Somewhat important	Very important
The in home services are appropriate and cover all my needs	○	○	○	○	○
I understand why people are coming to my house	○	○	○	○	○
It is easy and simple to arrange the services I need	○	○	○	○	○
Services and assistance are available as frequently as I need	○	○	○	○	○
In home personnel treat me with empathy and respect	○	○	○	○	○
I feel comfortable around my in home personnel	○	○	○	○	○
I am happy with choice of providers in my area	○	○	○	○	○

Other comments (about your short term in home services)

....

When recovering from an illness or injury what has been your greatest obstacle to recovery?

....

Section 5: Residential Aged Care

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Do you currently reside in residential aged care?	○ Yes ○ No
Do you have personal experience with someone who resides/or has ever resided in residential aged care?	○ Yes ○ No
How could the residential aged care facility you are familiar with be improved?	....
Please select the following statements about accessing healthcare services in residential aged care that are relevant to you If you do not reside in residential aged care please skip this question	☐ My health is well managed in my residential aged care facility ☐ My health is not well managed in my residential aged care facility ☐ My health has declined considerably since moving into residential aged care ☐ I find it difficult to see a GP/Doctor when I need one ☐ I find it difficult to be transferred to or from hospital when I have been ill or injured ☐ I was transferred from hospital to residential aged care because I was too unwell to return home
Other comments (on accessing health care in residential aged care)	....
Please select the following statements about transitions to residential aged care that are relevant to you. Please answer this question even if you do not currently reside in residential aged care	☐ I will eventually have to move into residential aged care, and I am ok with that ☐ I will move into residential aged care only when I can no longer be cared for at home ☐ I will move into residential aged care if I feel like I have become a burden to my family/carer ☐ It is important to plan your transition to residential aged care ahead of time ☐ I do not know how I could continue to "be myself" in residential aged care ☐ I am confused by the residential aged care system ☐ I do not trust that I would receive good care in residential aged care ☐ Residential aged care facilities are depressing places ☐ I will never live in residential aged care

Section 6: End of life care

REMINDER (for carers under the age of 65): please answer all questions on behalf of the older person you care for, considering their needs and wants.

Please select the following statements about planning your end of life care that are important and/or relevant to you

- ☐ My will is up-to-date
- ☐ I have prepared an advanced care plan
- ☐ I have appointed a medical treatment decision maker
- ☐ I have discussed my end of life care preferences with my wife/husband/children/family
- ☐ I would like to receive end of life care in my own home
- ☐ I would like to receive end of life care in a hospital
- ☐ I have made no plans for the end of my life
- ☐ I do not want to think about end of life care
- ☐ I do not see the point in thinking about end of life care

Have you had previous experience with a spouse/family member/friend receiving end of life care?

- ○ Yes
- ○ No

Section 6: End of life care (continued)

Please select True, False or Unsure for the following statements about the care your loved one received at end of life

If you have no experience with a loved one receiving end of life care please skip this question

	True	False	Unsure
My loved one was provided with appropriate palliative care services	O	O	O
I am happy with the care my loved one received at end of life	O	O	O
I felt that my loved one's choices were heard and respected	O	O	O
I felt that my loved one was treated with empathy and respect from staff	O	O	O
I felt that the end of life care was family-centered and provided support to bereaved family members	O	O	O

Other comments (on the care your loved one received at end of life)

Section 6: End of life care (continued)

Please rate the following factors in terms of importance during end of life care

	Not important at all	Not very important	Neutral	Somewhat important	Very important
Making legal written plans to document your end of life preferences	O	O	O	O	O
Having conversations with your family, friends and doctors to share your preferences	O	O	O	O	O
Having access to palliative care services	O	O	O	O	O
Having access to euthanasia (voluntary assisted dying)	O	O	O	O	O
Pain management	O	O	O	O	O
Being treated with empathy and respect	O	O	O	O	O
Family centered end of life care that includes, informs and supports bereaved family members	O	O	O	O	O
Funeral planning	O	O	O	O	O

Other comments (on end of life care)

What will be most important to you when receiving end of life care?

Thank you for participating in our survey

I would like to receive a copy of the research
outcomes

○ Yes
○ No

If you would like to go in the running to win one of
five $40 Coles Myer gift cards and/or receive a copy
of the research outcomes please supply your email or
postal address (optional)