



MAKING THE INVISIBLE VISIBLE

EXPLORING THE EXPERIENCES OF FRAIL HOMEBOUND AND BEDRIDDEN PEOPLE



PRELIMINARY RESEARCH REPORT FOR THE COMMUNITY



Frailty and
Healthy Ageing
Centre of Research Excellence

INDEX

Introduction.....	1
Defining Frail and Homebound and Bedbound People (FHBP) in Australia.....	2
Age.....	3
Gender.....	4
Group identification.....	5
Living alone.....	6
Marital status.....	7
Children and children support.....	8
Education.....	9
Impairments.....	10
Number of chronic conditions.....	11
Diagnosed conditions.....	12
Mobility.....	13-19
Health support.....	20
Living locations.....	21
Occupation and employment.....	22
Help from another person.....	23
Carers employment.....	24
Perceived health status.....	25
Health deterioration.....	26
Hospital admissions.....	27
Prescription drugs.....	28
Experiences with ambulance and hospital services.....	29
Important needs.....	30
Inferences and comments.....	31
Acknowledgement.....	32
Connected research outputs.....	33
References.....	34

INTRODUCTION

This is our preliminary community research report concerning a co-design and co-research investigation of the social and health exclusion factors and lived experiences of Frail and Homebound and Bedbound People (FHBP) in Australia.

This research, and its implementation, respond to health consumers' calls concerning the Medical Access Issues for Homebound/Bedridden Persons, written by Ricky Buchanan: <https://notdoneliving.net/justinvisible/> Her work outlined the lack of access to health services, which seems to be creating disparities, social exclusion, and marginalisation for this population.

To further explore Ricky Buchanan's findings and concerns, [Dr Maria Alejandra Pinero de Plaza](#) and Penelope McMillan, together with several Australian health consumers and academics, co-created a survey to explore the characteristics and experiences of Frail, Homebound and Bedbound Australians, from July to September 2020.

The survey obtained ethical approval from the Flinders University Social and Behavioural Research Ethics Committee (Project No. 8557). This report introduces a preliminary analysis of most of the survey data, to inform the community. It also contains non-identifiable pictures of the surveyed FHBP holding or touching important elements within their life and experiences.

The survey questions and responses are explained in text detailing, when possible, the three largest types of answers for each question. Tables with all response types, counts and percentages are provided for each question, as not everybody surveyed responded to all questions. Graphics that support the written analysis are provided. The graphics present all responses in percentages from the largest to the smallest groups considering all types of responses received.



DEFINING FRAIL AND HOMEBOUND AND BEDBOUND PEOPLE (FHBP)

Frail, Homebound, and Bedridden People (FHBP) are distinct populations that live with a series of complex, incapacitating, and debilitating illnesses, or injuries.^{1,2,3} Members of these populations are unified by shared circumstances: being trapped and unable to leave home.^{1,2,3}

According to the Australian Bureau of Statistics¹⁵ - 2018 Survey of Disability, Ageing and Carers - approximately 596,800 people aged 5 years and over do not leave home as often as they would like due to their disability or condition. Of these people, 383,500 people were aged 5-64 years and 212,800 people were aged 65 years or more.¹⁵ Many Australians from such groups do not receive support to access clinical services, or even have a regular primary care provider, such as a GP.^{1,6,7,8,9}



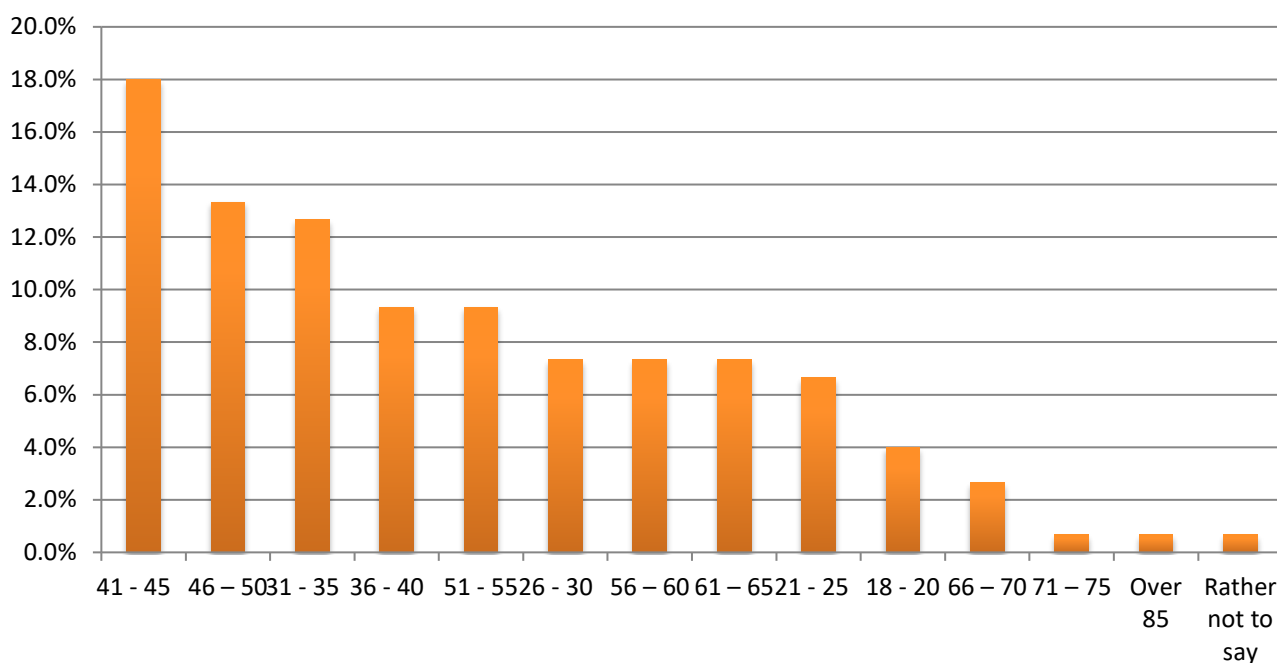
AGE

What is your age?

Most FHBP surveyed were younger adults. For instance, the respondents with ages between 41-45 years old were largest the group identified (18%). They were followed by the 46-50 years old, and the 31-35 years old which represented 13% of the responses for each group.



Answer	%	Count
18 - 20	4%	6
21 - 25	7%	10
26 - 30	7%	11
31 - 35	13%	19
36 - 40	9%	14
41 - 45	18%	27
46 - 50	13%	20
51 - 55	9%	14
56 - 60	7%	11
61 - 65	7%	11
66 - 70	3%	4
71 - 75	1%	1
76 - 80	0%	0
81 - 85	0%	0
Over 85	1%	1
Rather not to say	1%	1
Total	100%	150

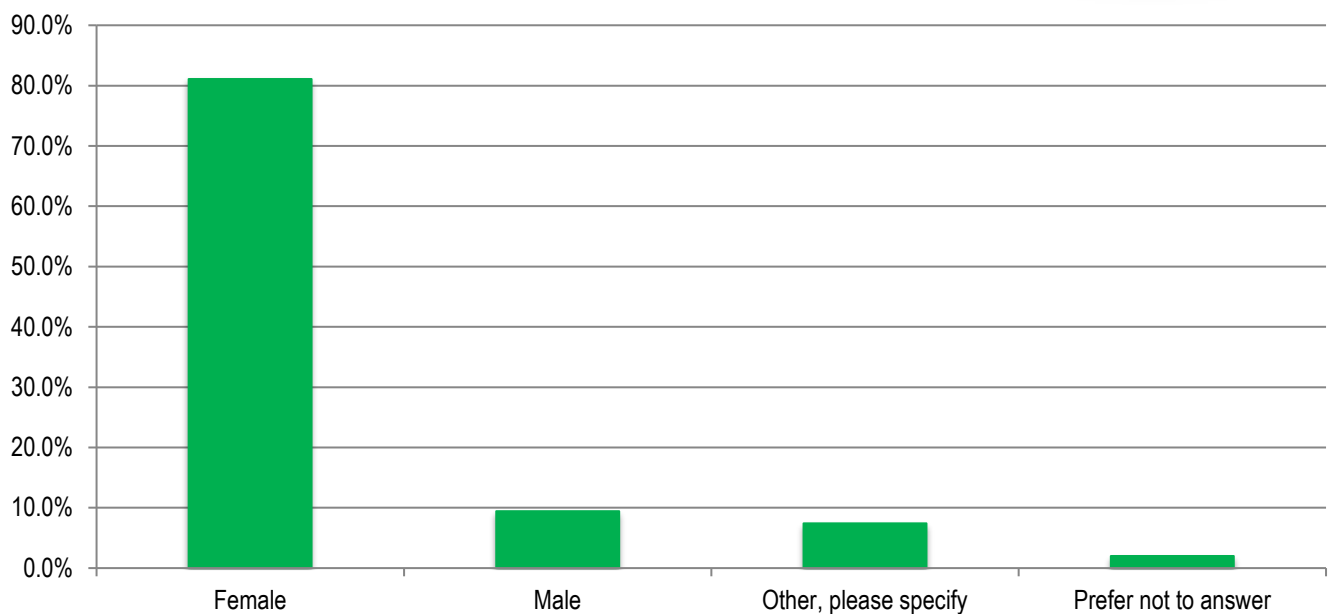


GENDER

What gender do you identify as?

Most respondents were self-identified as female, 81%, and only 9% as male.

Answer	%	Count
Male	9%	14
Female	81%	120
Other	7%	11
Prefer not to answer	2%	3
Total	100%	148



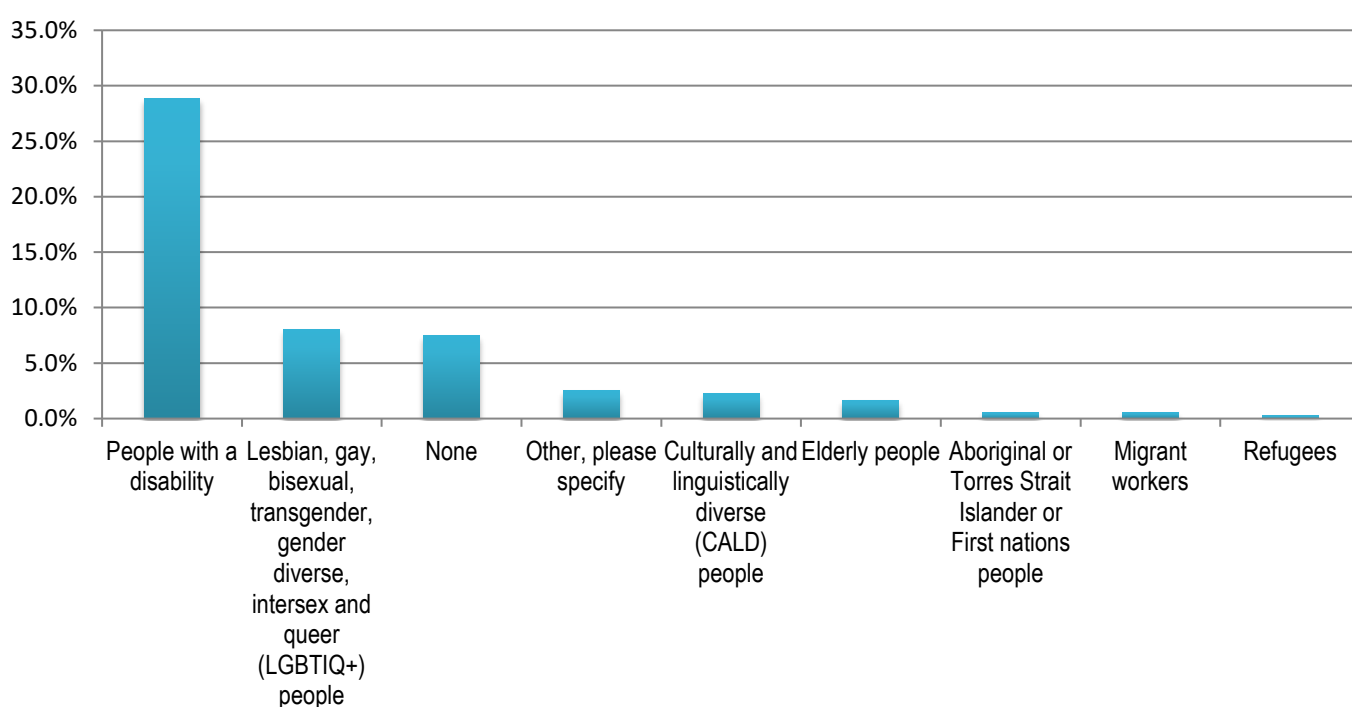
GROUP IDENTIFICATION

Do you identify as a member of any of these groups?

Most FHBP surveyed were self-identified as people with disability, 72%. They were followed by the lesbian, gay, bisexual, transgender, gender diverse, intersex and queer (LGBTIQ+) people, which represented 20% of the respondents.



Answer	%	Count
Aboriginal or Torres Strait Islander or First nations people	1%	2
Culturally and linguistically diverse (CALD) people	6%	8
People with a disability	72%	104
Elderly people	4%	6
Lesbian, gay, bisexual, transgender, gender diverse, intersex and queer (LGBTIQ+) people	20%	29
Migrant workers	1%	2
Refugees	1%	1
Other, please specify	6%	9
None	19%	27
Total	100%	144

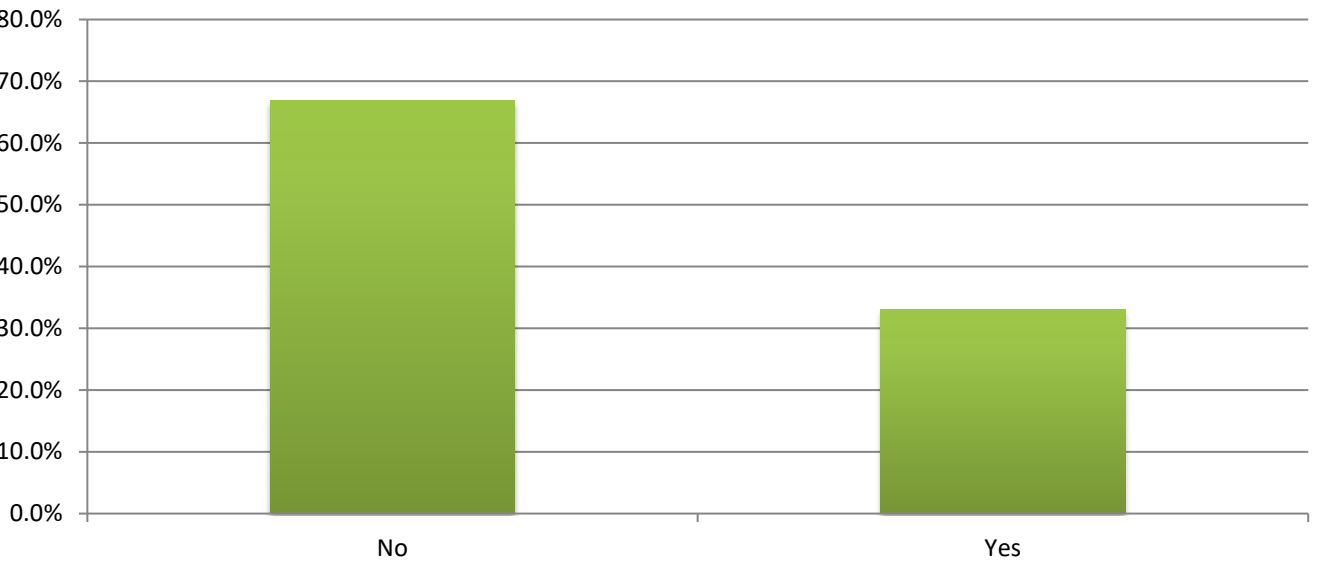


LIVING ALONE

Do you live alone?

Two thirds of the people surveyed do not live alone, 67%.
However, about 33% of the FHBP surveyed live alone.

Answer	%	Count
Yes	33%	50
No	67%	101
Total	100%	151

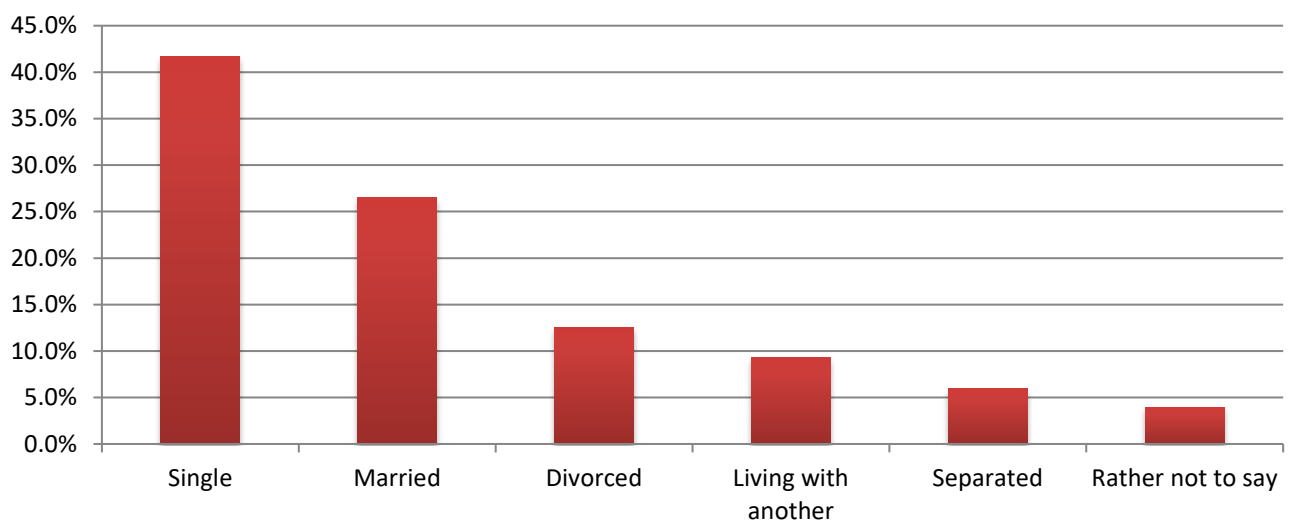


MARITAL STATUS

What is your current marital status?

Most FHBP surveyed were single, 42%. The second-largest group of respondents were married, 26%. The third-largest group was constituted by divorced people, 13%.

Answer	%	Count
Rather not to say	4%	6
Divorced	13%	19
Living with another	9%	14
Married	26%	40
Separated	6%	9
Single	42%	63
Widowed	0%	0
Total	100%	151



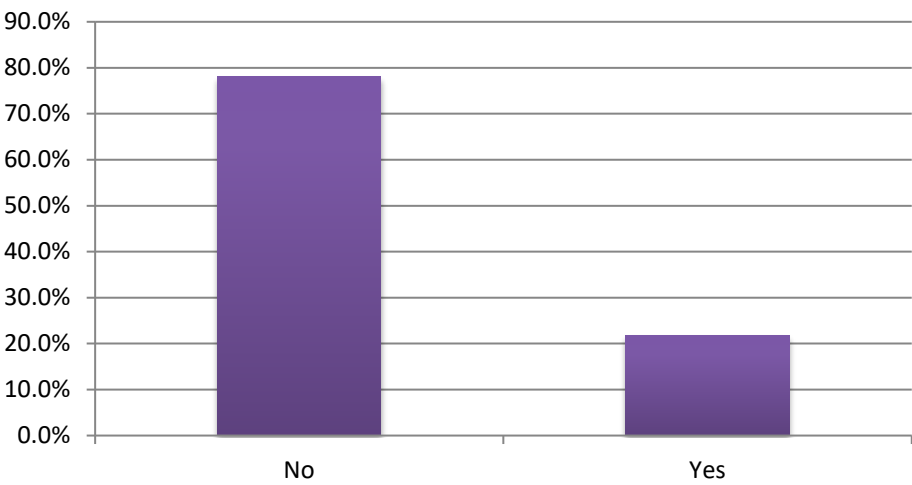
CHILDREN AND CHILD SUPPORT

Do you have children/stepchildren aged 18 and younger who do live with you?

Most FHBP respondents indicated that they do not have children living with them, 78%. However, 22% indicated that they have children aged 18 and younger living with them



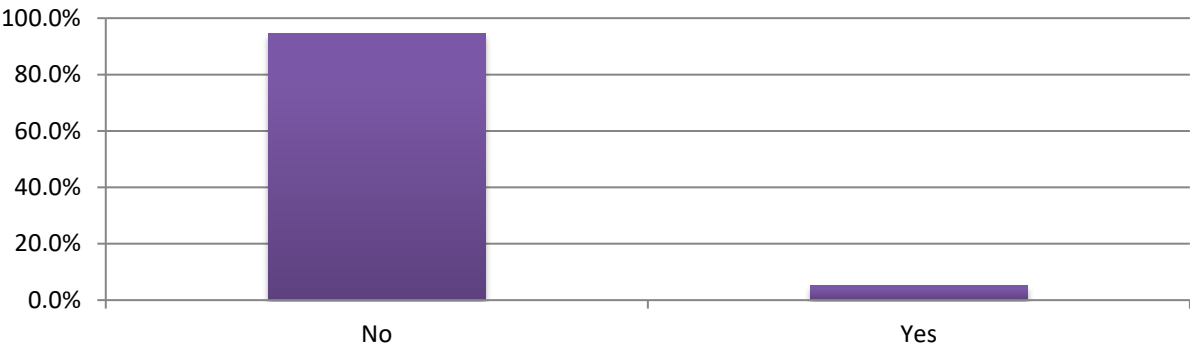
Answer	%	Count
Yes	22%	33
No	78%	118
Total	100%	151



Do you have children or stepchildren living outside the home for whom you provide financial support?

Five per cent of the surveyed FHBP indicated that they provide financial support for their children living outside their home. The majority of respondents 95% revealed that they do not have or support children living outside their home.

Answer	%	Count
Yes	5%	8
No	95%	142
Total	100%	150

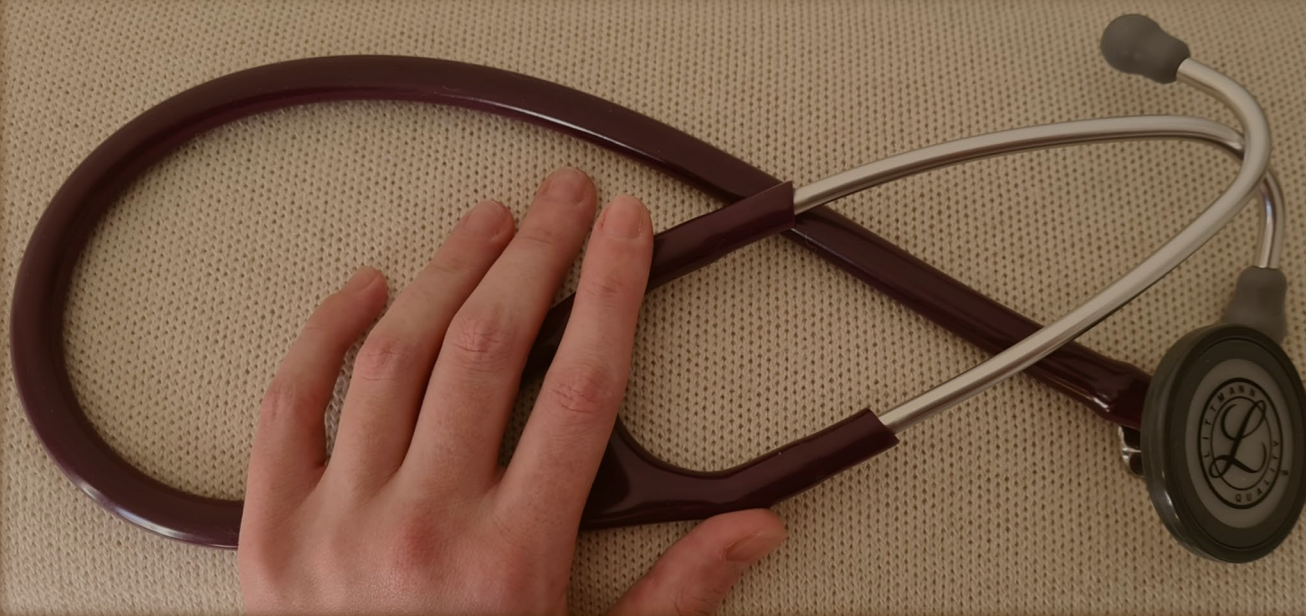
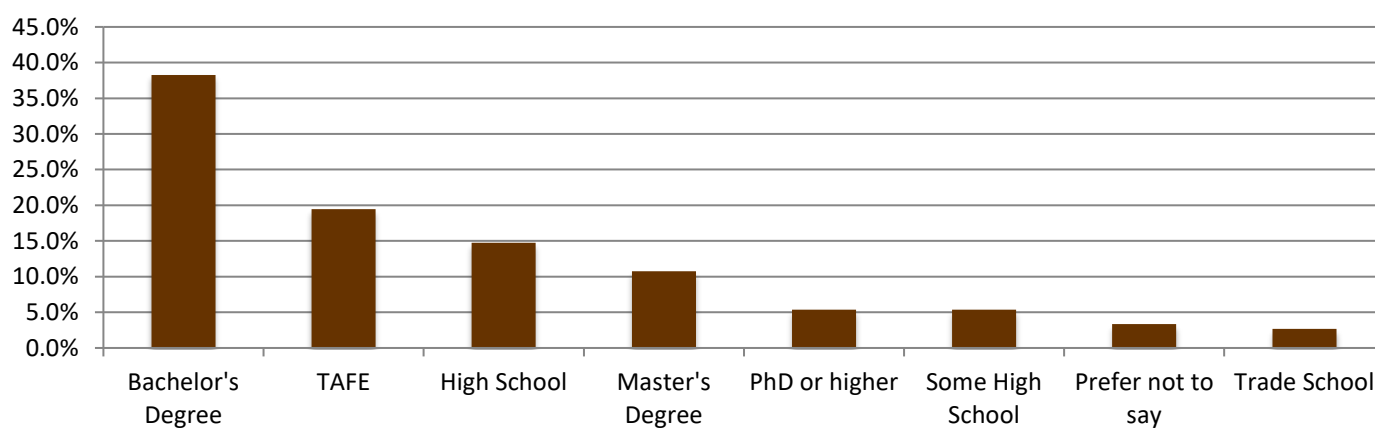


EDUCATION

What is the highest degree or level of education you have completed?

Most FHBP were highly educated. The largest group of respondents for this question indicated that have completed a bachelor's degree, 38%. This group was followed by those who completed a TAFE education, 19% and a High School, 15%.

Answer	%	Count
Some High School	5%	8
High School	15%	22
Trade School	3%	4
TAFE	19%	29
Bachelor's Degree	38%	57
Master's Degree	11%	16
PhD or higher	5%	8
Prefer not to say	3%	5
Total	100%	149



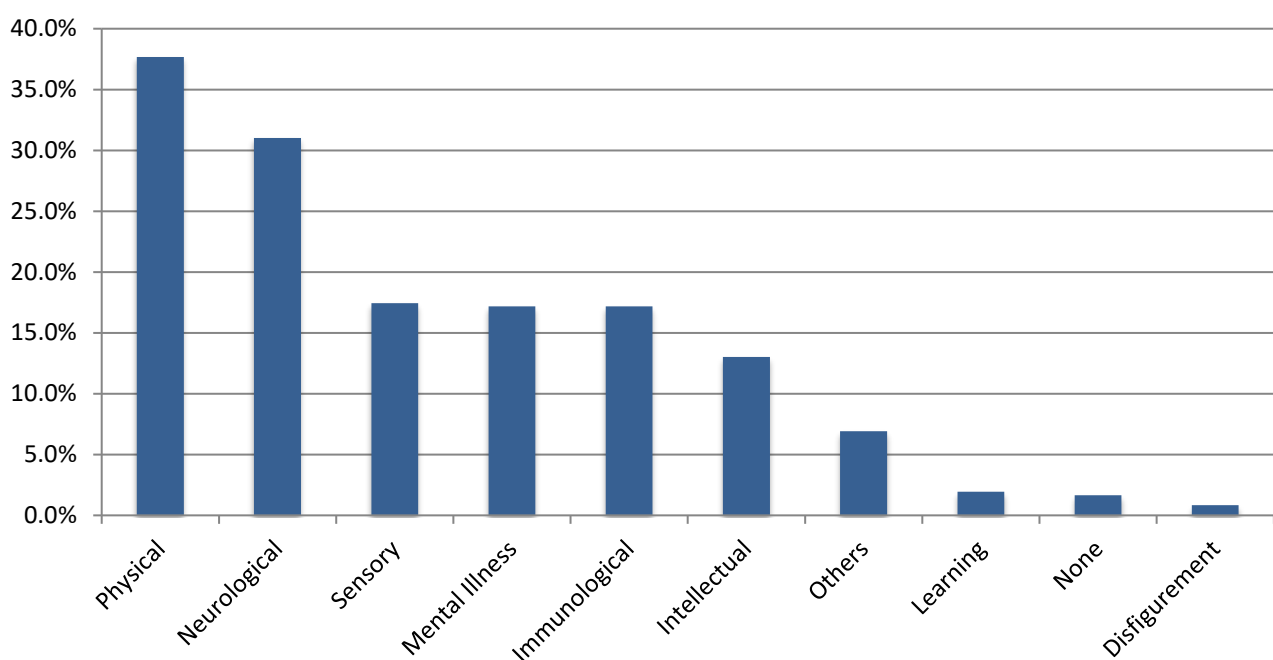
IMPAIRMENTS

Which of the following best describes your current situation or impairments?

The most selected impairments were, in order of importance: Physical, 91%; Neurological, 75%; and Sensory, Mental, and Immunological with 41% each.



Answer	%	Count
None	4%	6
Physical - affects a person's mobility or dexterity	91%	136
Intellectual - affects a person's abilities to learn	31%	47
Mental Illness - affects a person's thinking processes	41%	62
Sensory - affects a person's ability to hear or see	42%	63
Neurological – affects the person's brain and central nervous system	75%	112
Learning disability	5%	7
Physical disfigurement	2%	3
Immunological - the presence of organisms causing disease in the body	41%	62
Others, please specify	17%	25
Total	100%	150

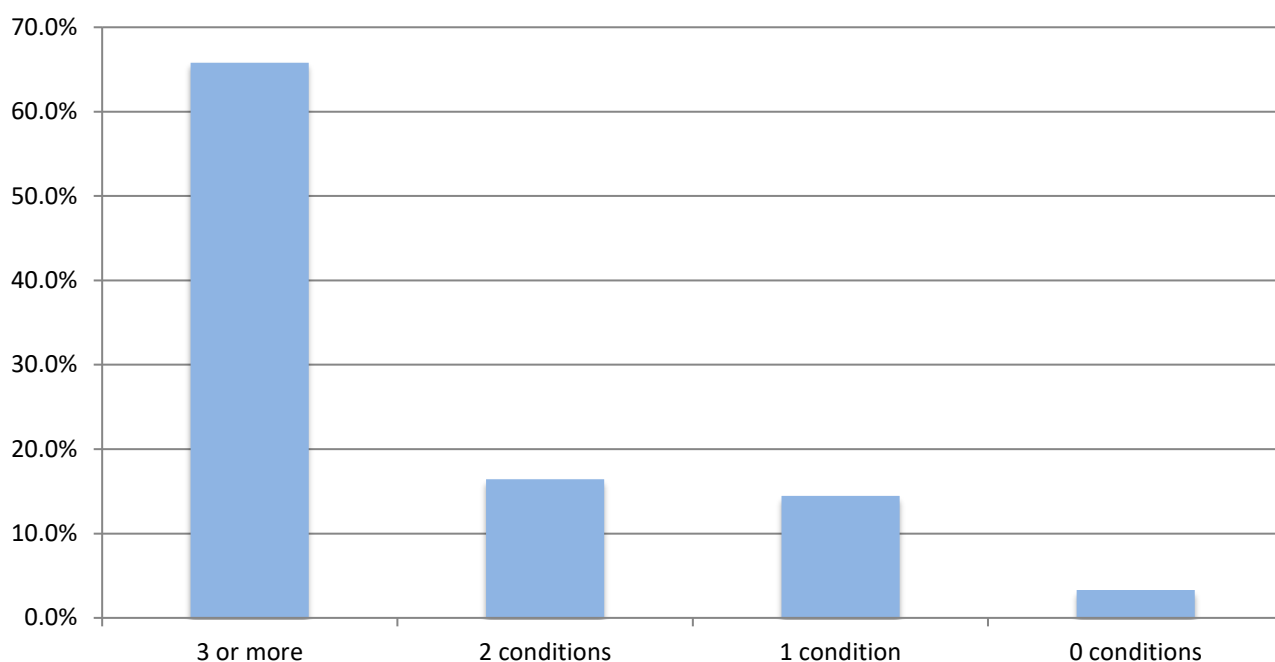


NUMBER OF CHRONIC CONDITIONS

How many chronic conditions do you have?

More than half of respondents indicated that they have three or more chronic conditions, 66%. The following group indicated they have two or more, 16%. The third-largest group indicated that they have one condition, 14%.

Answer	%	Count
0 conditions	3%	5
1 condition	14%	22
2 conditions	16%	25
3 or more	66%	100
Total	100%	152

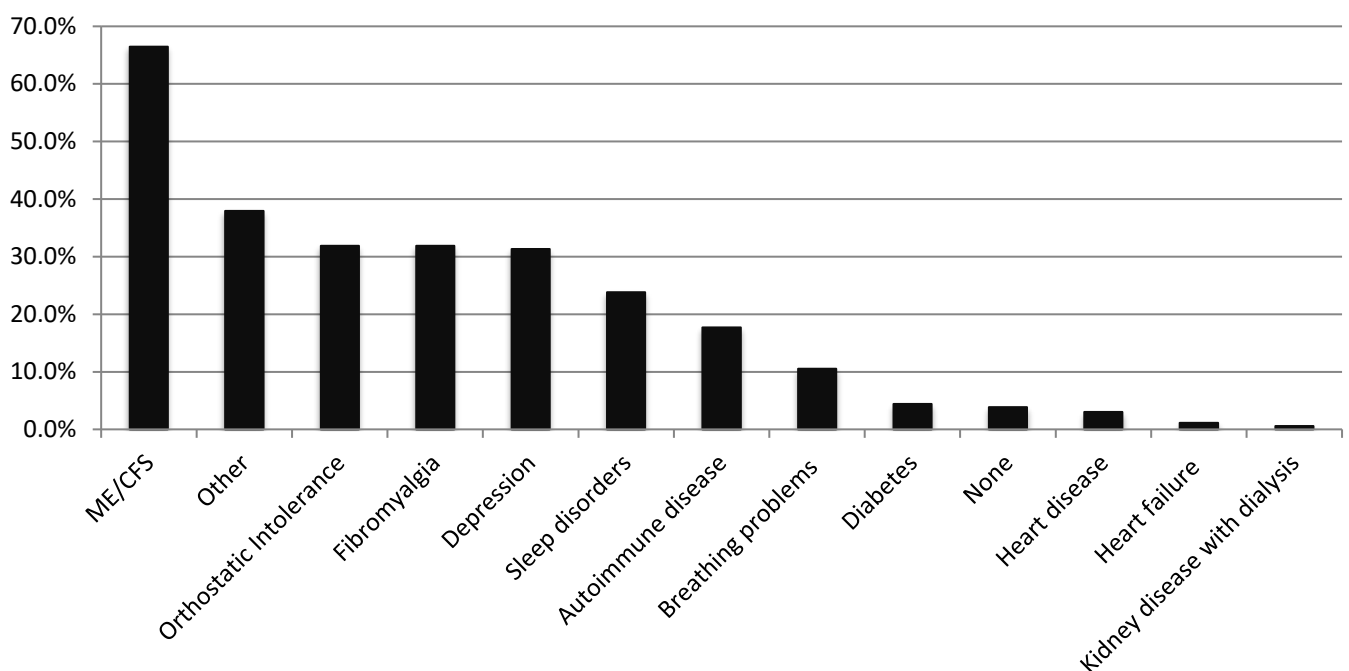


DIAGNOSED CONDITIONS

Have you been diagnosed with any of these conditions?

Most respondents identified Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (includes CFS, ME or ME/CFS diagnoses) as one of their conditions, 78%. Other conditions not tabled represented the second largest group of responses, 45%. The third group identified Fibromyalgia with 38% of responses.

Answer	%	Count
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (includes CFS, ME or ME/CFS diagnoses)	78%	240
Other conditions	45%	137
Fibromyalgia	38%	115
Orthostatic Intolerance	38%	115
Depression	37%	113
Sleep disorders	28%	86
Autoimmune disease, please specify	21%	64
Breathing problems	12%	38
Diabetes	5%	16
None	5%	14
Heart disease	4%	11
Heart failure	1%	4
Kidney disease with dialysis	1%	2
Total	100%	306

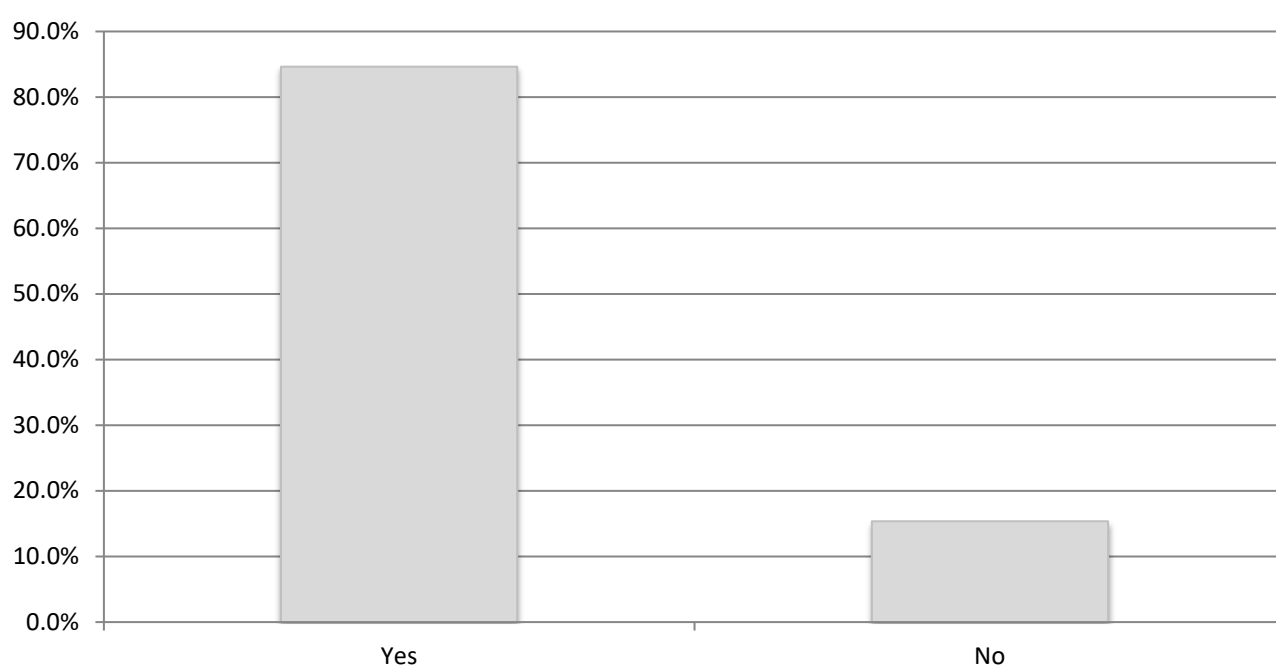


MOBILITY

Do you have difficulty getting around at home or outside your home?

Most respondents indicated having difficulty getting around at home or outside your home, 85%. Only 15% responded that they do not have such difficulty

Answer	%	Count
Yes	85%	259
No	15%	47
Total	100%	306



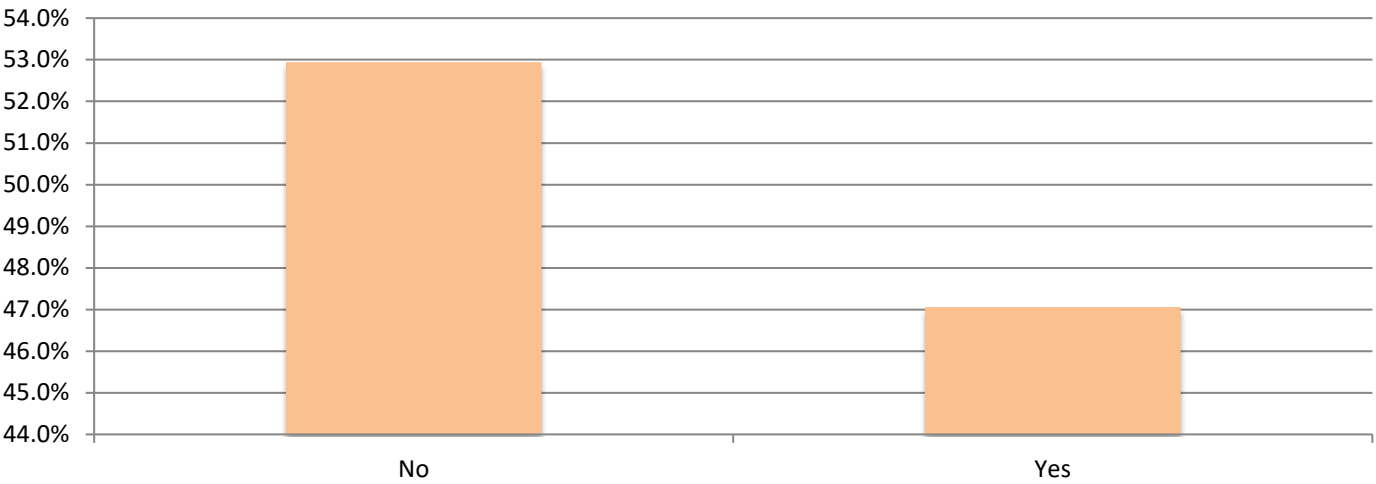
MOBILITY

Do you use a cane, wheelchair, walker, mobility scooter or some other mobility assistance device to move around at home or outside your home?

More than half of respondents, 53%, indicated that they do not use a cane, wheelchair, walker, mobility scooter or some other mobility assistance device to move around at home or outside. Nearly half of the FHBP surveyed said that they use mobility assistance to get around their home.



Answer	%	Count
Yes	47%	144
No	53%	162
Total	100%	306

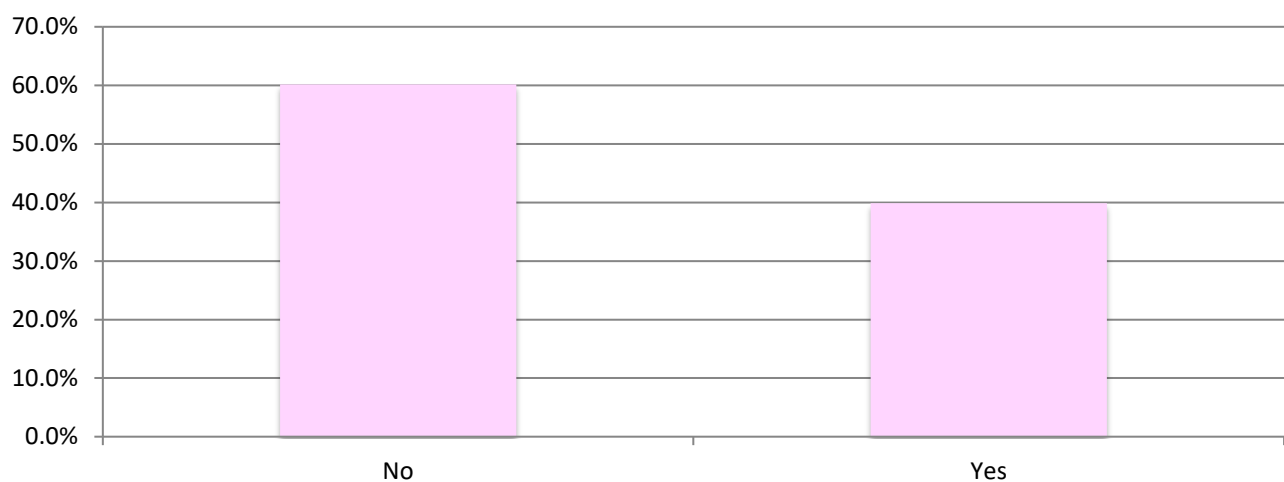
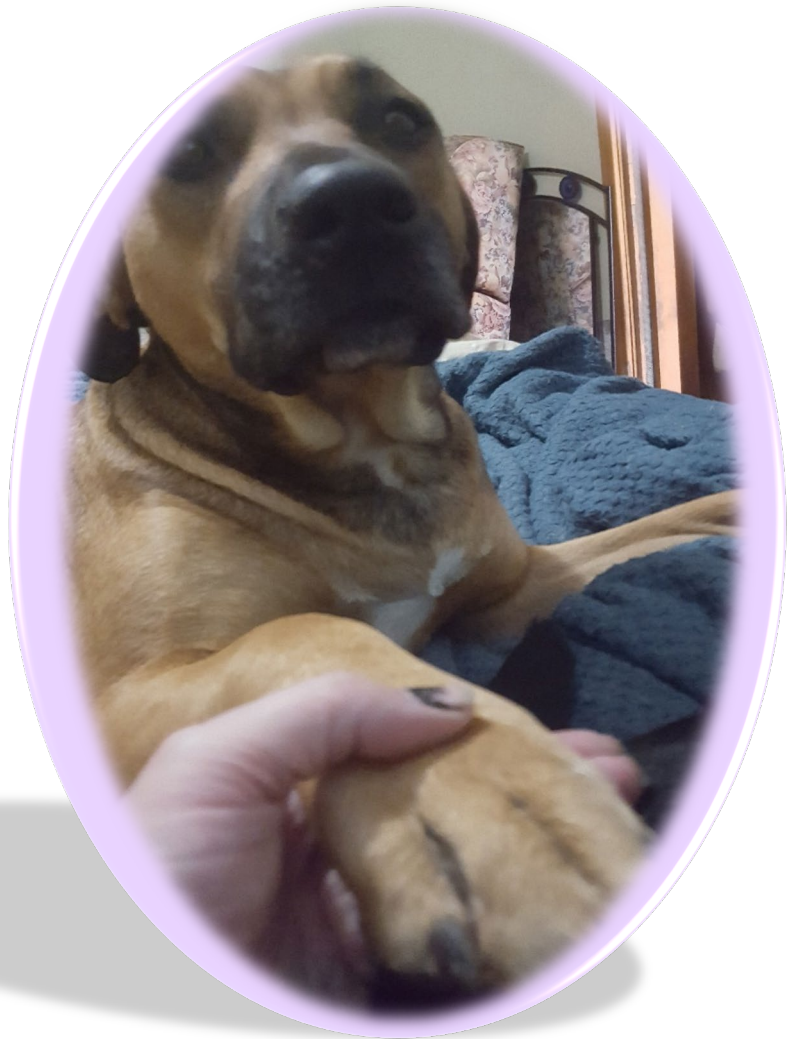


MOBILITY

Do you need the help of another person to move around, inside or outside your home?

More than half of respondents, 60%, indicated that they do not need the help of another person to move around, inside or outside their home. The other 40% need such help to move around.

Answer	%	Count
Yes	40%	122
No	60%	184
Total	100%	306

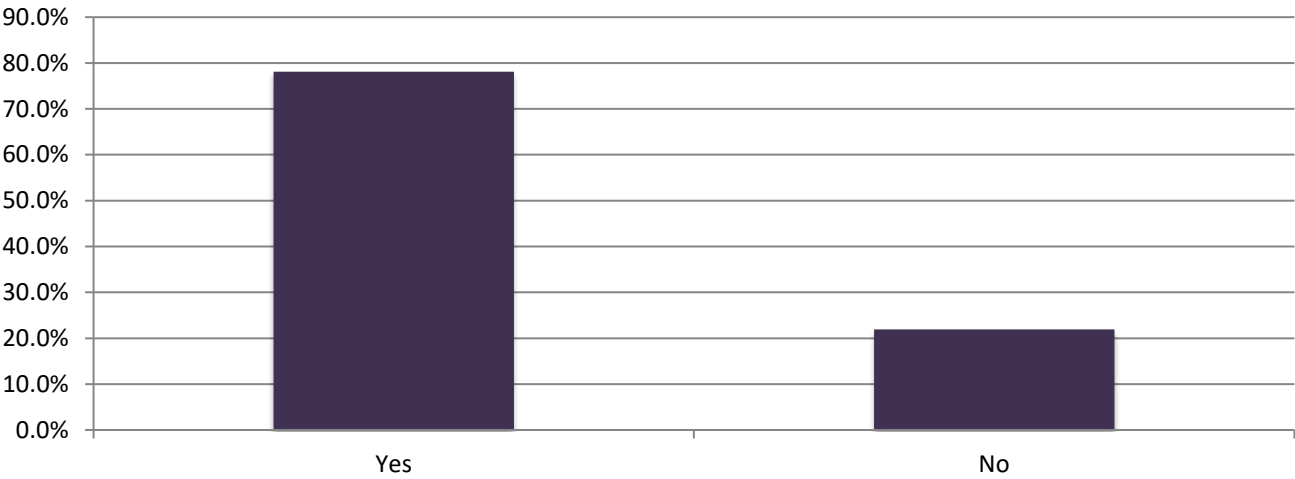


MOBILITY

Are you unable to leave the house most or all of the time?

More than three-quarters of respondents, 78%, are unable to leave the house most or all of the time. The other 22% indicated that such a situation does not apply to them.

Answer	%	Count
Yes	78%	239
No	22%	67
Total	100%	306

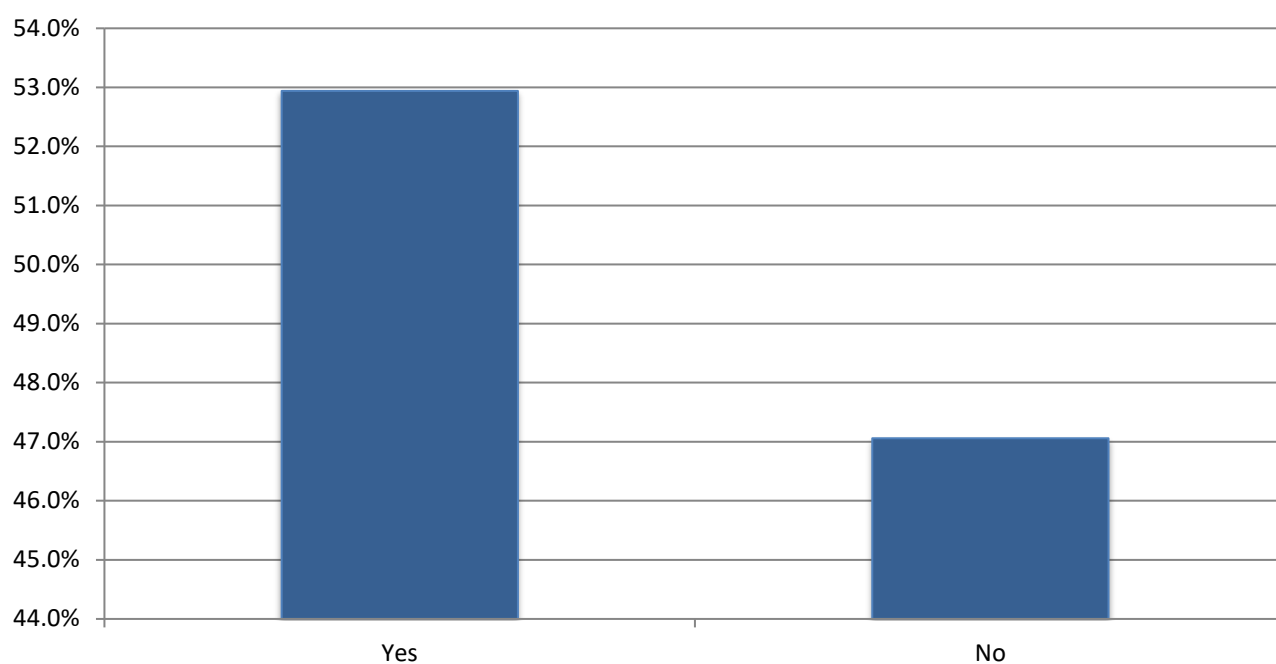


MOBILITY

Do you need to stay in bed most or all of the time?

Nearly more than half of the respondents indicated that they have to stay in bed most or all of the time, 53%. The rest of the FHBP surveyed indicated that they do not have to stay in bed most of their time.

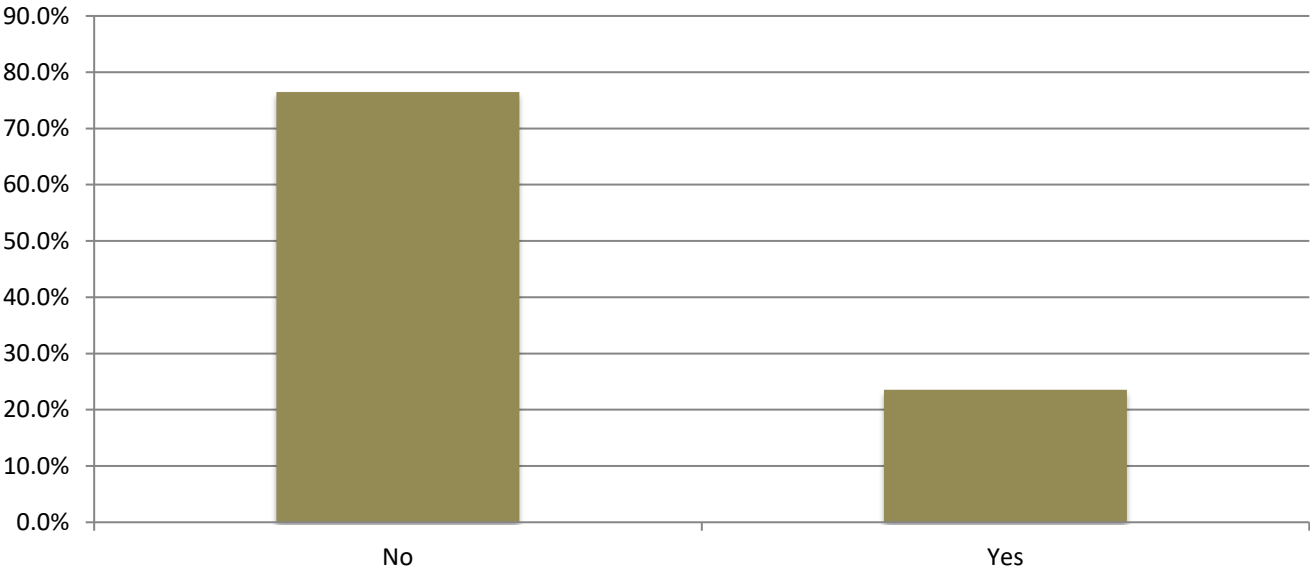
Answer	%	Count
Yes	53%	162
No	47%	144
Total	100%	306



MOBILITY

Excluding an accident or temporary illness, are you permanently unable to leave your home?
Most respondents were not permanently unable to leave their homes, 76%. However, a large number of people indicated that they were permanently unable to do so, 24%.

Answer	%	Count
Yes	24%	72
No	76%	234
Total	100%	306

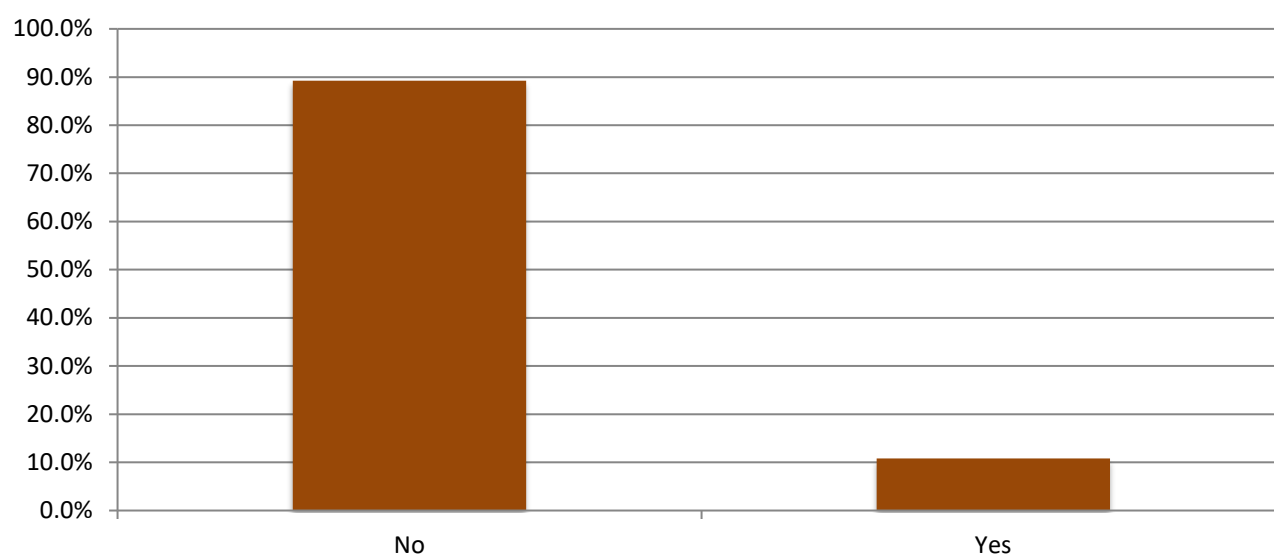


MOBILITY

Excluding an accident or temporary illness, do you permanently need to stay in your bed?

Most respondents were not permanently in bed, 89%. However, 11% of respondents indicated that they need to stay in their bed permanently.

Answer	%	Count
Yes	11%	33
No	89%	273
Total	100%	306

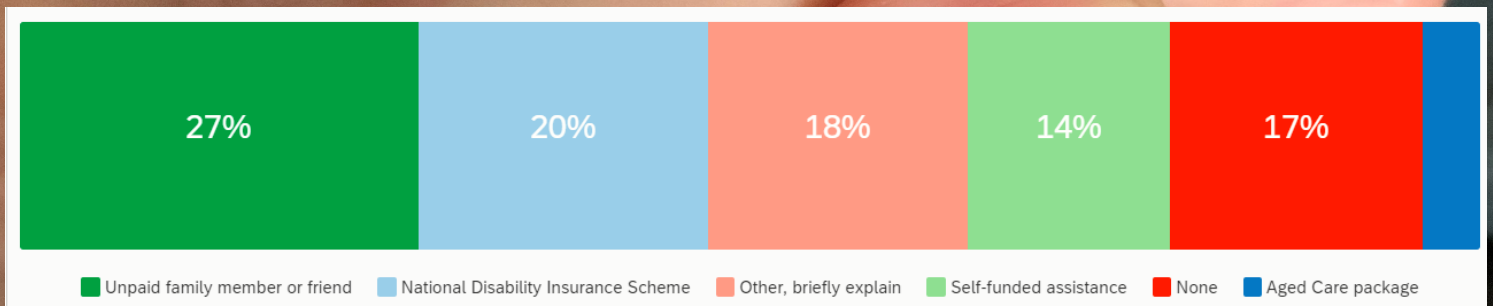


HEALTH SUPPORT

What type of health support do you receive?

Most respondents receive support from an unpaid family member or friend, 37%. The second-largest group, 20%, receive support from the National Disability Insurance Scheme, 27%. The third group refers to 'no support' or other types of support.

Answer	%	Count
National Disability Insurance Scheme	27%	40
Aged Care package	5%	8
Self-funded assistance	19%	28
Unpaid family member or friend	37%	55
Other	24%	36
None	24%	35
Total	100%	147

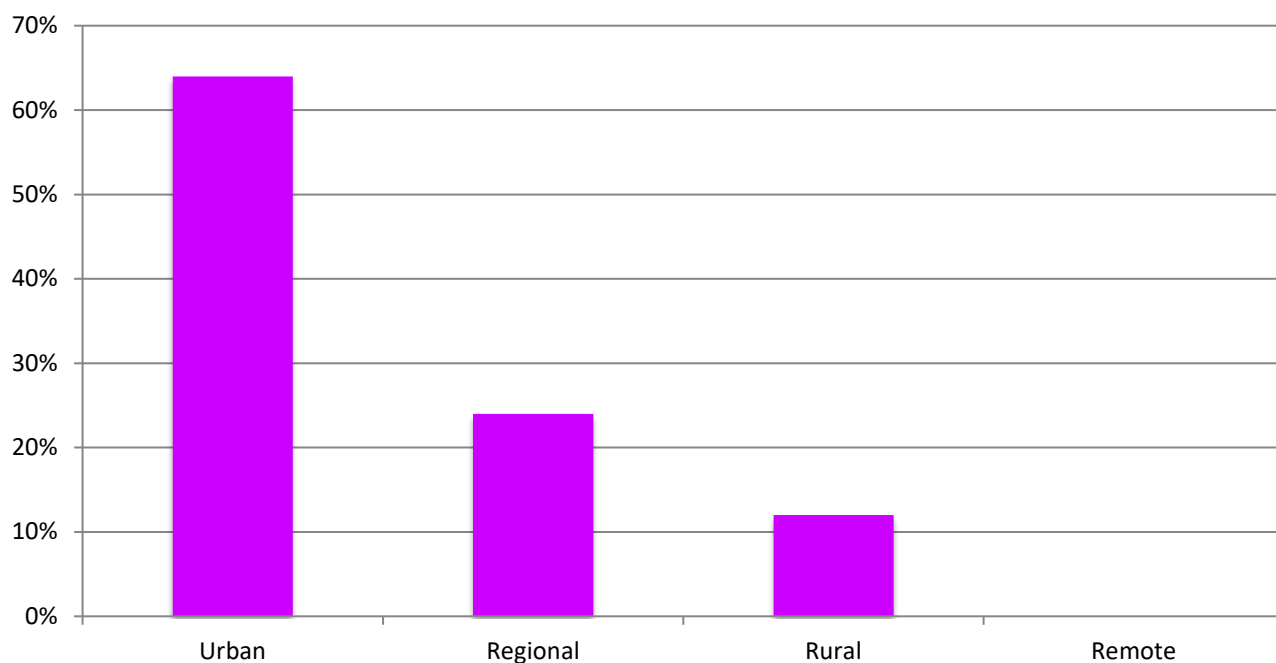


LIVING LOCATIONS

How would you describe your living location?

Most respondents described their living location as Urban, 63%. The following group, with 24% of responses, indicated a Regional living location. The third group, with 12% of the responses, described their location as Rural.

Answer	%	Count
Urban	63%	94
Regional	24%	36
Rural	12%	18
Remote	0%	0
Total	100%	148

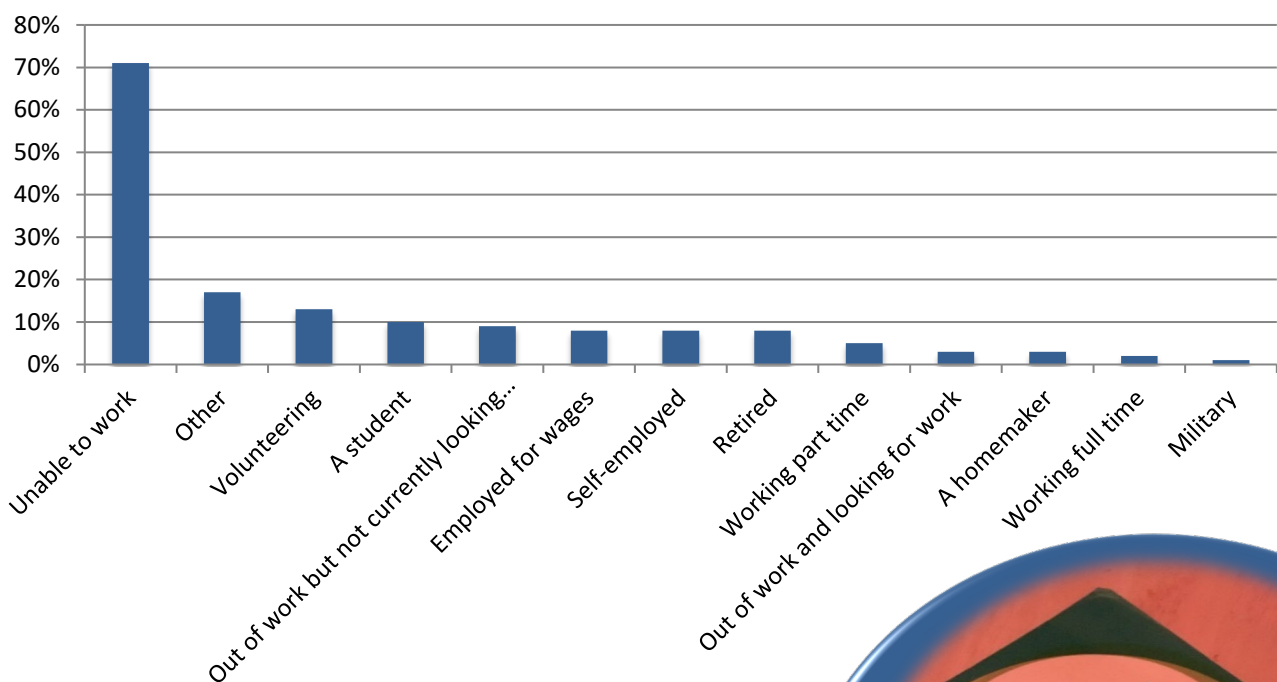


OCCUPATION AND EMPLOYMENT

Are you currently...?

Most respondents indicated that they are unable to work, 71%. The second largest group of responses received refer to other occupation or employment, 17%. The third, 13%, indicated that they are Volunteering, please specify (e.g. Volunteering for a neighbourhood group, for the library, providing activities, an environmental group, etc.)

Answer	%	Count
Employed for wages	8%	12
Self-employed	8%	12
Out of work and looking for work	3%	5
Out of work but not currently looking for work	9%	13
A homemaker	3%	5
A student	10%	15
Military	1%	1
Retired	8%	12
Unable to work	71%	107
Volunteering, please specify (e.g. Volunteering for a neighbourhood group, for the library, providing activities, an environmental group. etc.)	13%	19
Other	17%	25
Working full time	2%	3
Working part time	5%	7
Total	100%	151

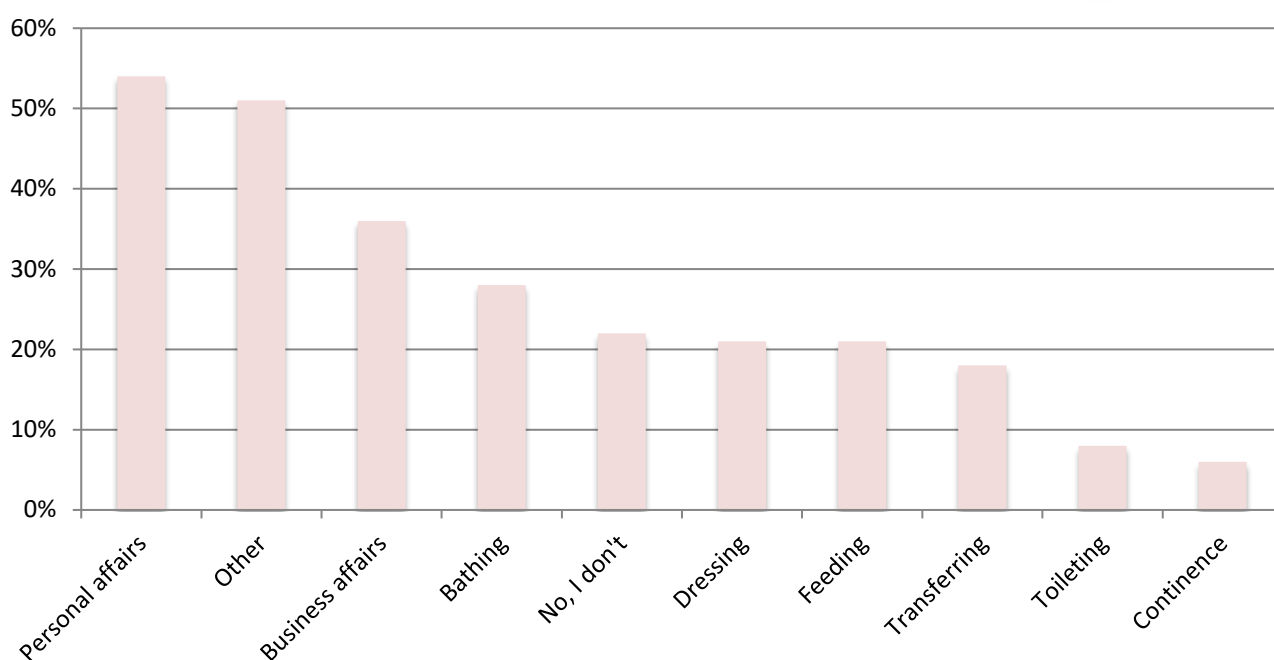
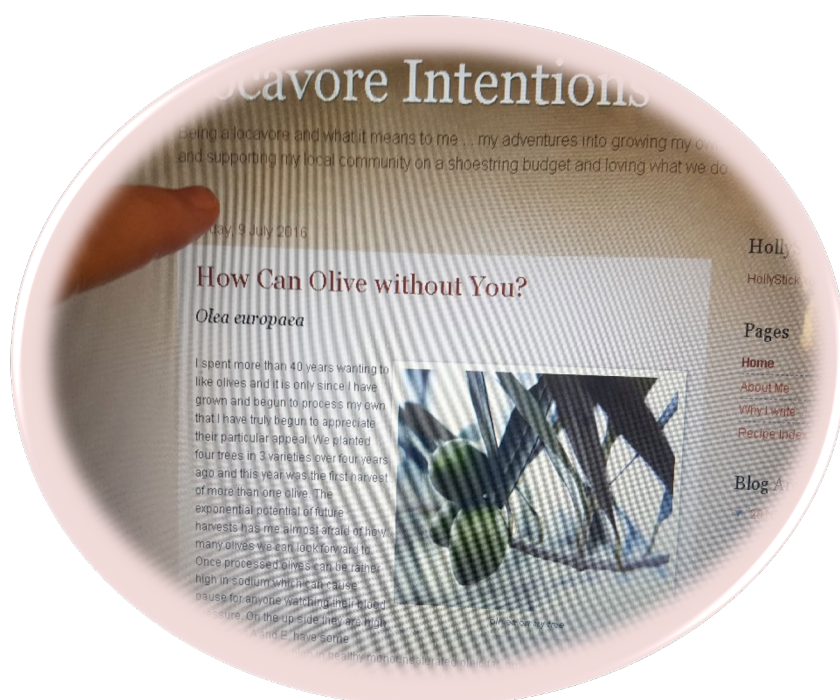


HELP FROM ANOTHER PERSON

Do you need the help of another person for these?

Most respondents need the help of another person for personal affairs (e.g. Centrelink claims, insurance claims, housing), 54%. The second biggest response type was Other with 51%. The third biggest response was business affairs (e.g. rates and utilities) with 36% of the responses.

Answer	%	Count
Bathing	28%	42
Contenance	6%	9
Dressing	21%	31
Feeding	21%	31
Toileting	8%	12
Transferring	18%	26
Business affairs (e.g. rates and utilities)	36%	53
Personal affairs (e.g. Centrelink claims, insurance claims, housing)	54%	80
Other	51%	76
No, I don't	22%	33
Total	100%	148

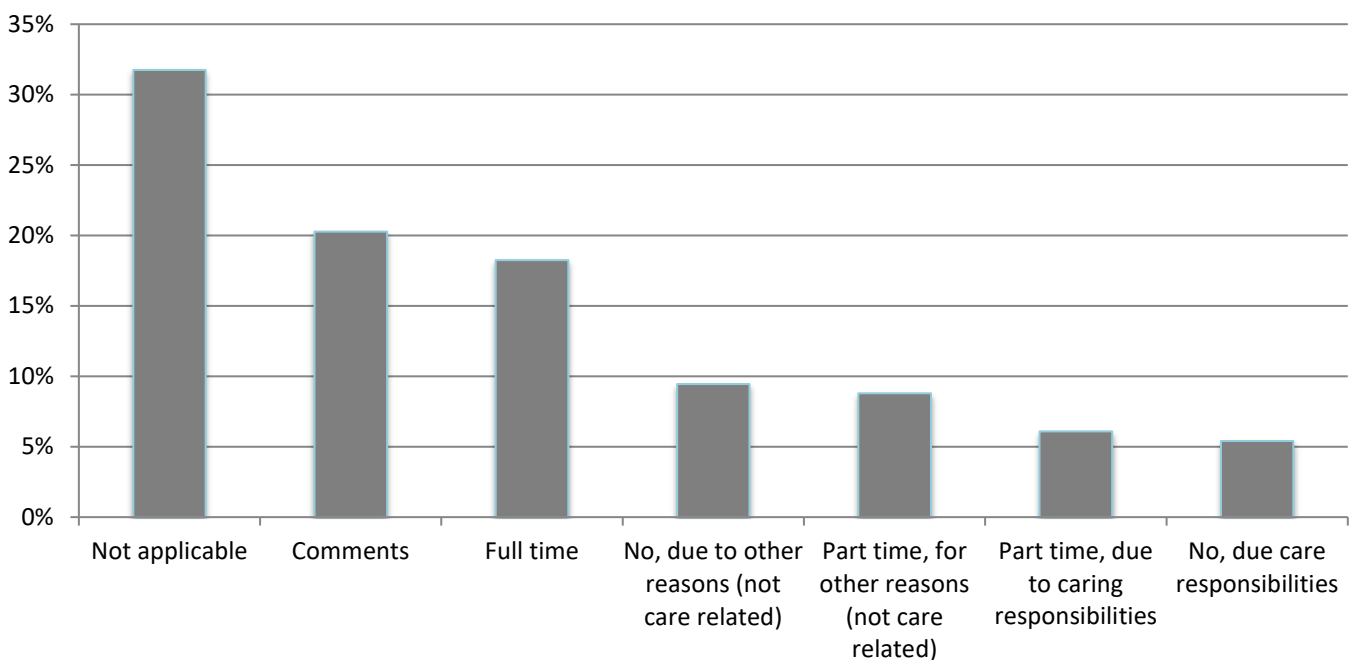


CARERS EMPLOYMENT

Is your carer (spouse/partner/family member/children/friend) employed?

In most cases, 32%, this question did not apply to respondents. The second-largest response type was selected as comments, 20%. The third group indicate that their carer is employed full time, 18%

Answer	%	Count
Not applicable to my case	32%	47
Full time	18%	27
Part-time, due to caring responsibilities	6%	9
Part-time, for other reasons (not care related)	9%	13
No, due care responsibilities	5%	8
No, due to other reasons (not care related)	9%	14
Comments	20%	30
Total	100%	148

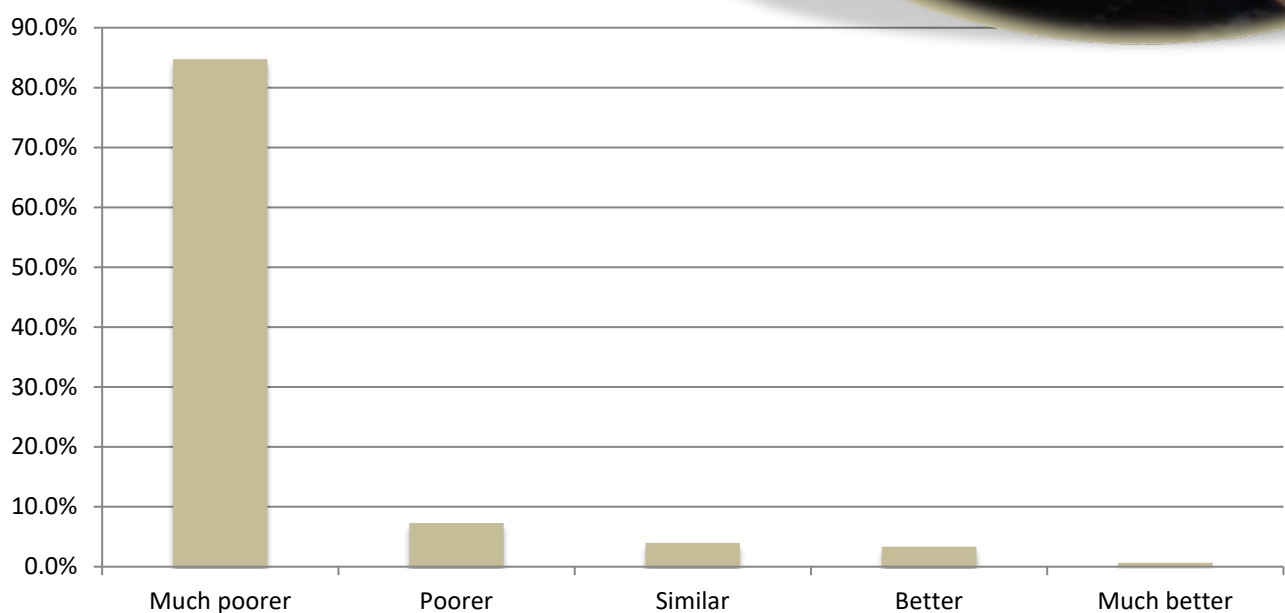


PERCEIVED HEALTH STATUS

Compared to people your age, what do you think of your health?

In most cases, 85%, respondents think their health is much poorer when compared to people their age. The second largest response type was poorer, 7%. The third group indicate that their health was similar to people their age, 4%.

Answer	%	Count
Much better	1%	1
Better	3%	5
Similar	4%	6
Poorer	7%	11
Much poorer	85%	128
Total	100%	151



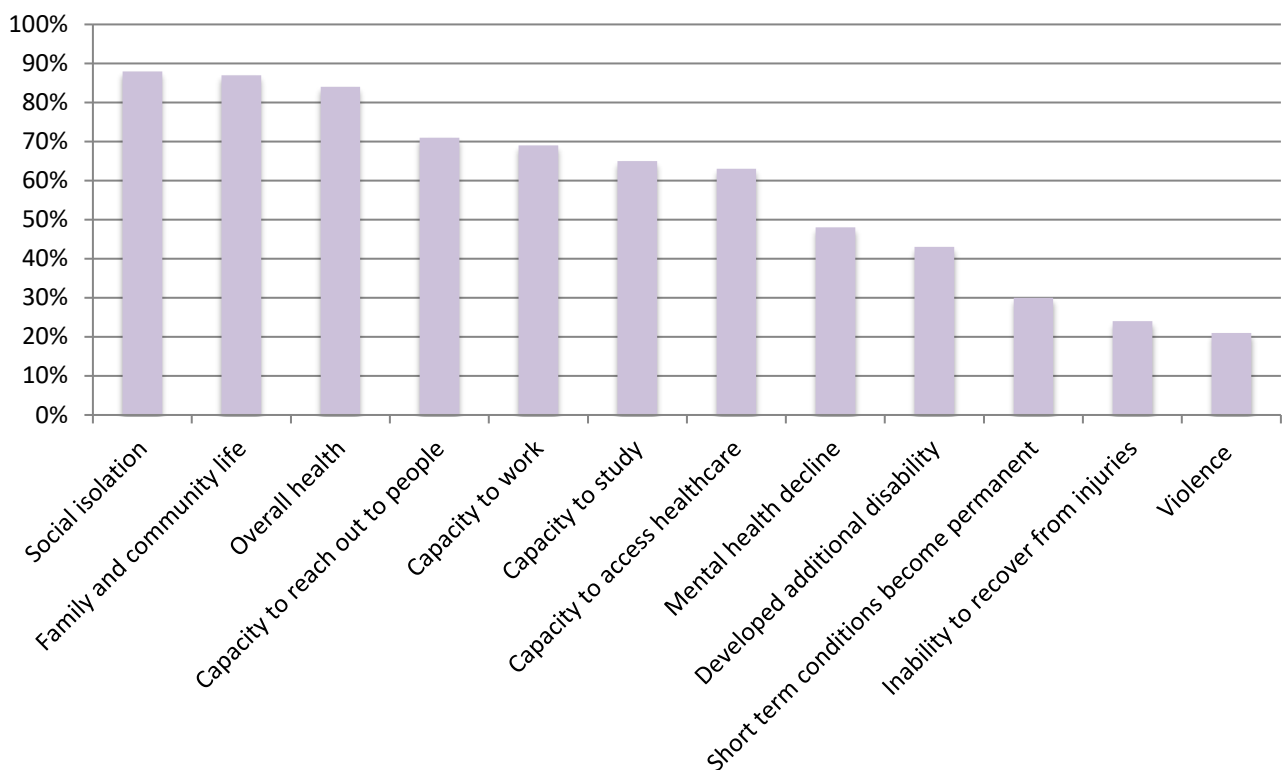
HEALTH DETERIORATION

In the last year, have you experienced...

Most FHBP reported social isolation, 88%. A reduction of their capacity to participate in family and community life, 87%. A reduction in their overall health of 84%.



Answer	%	Count
Social isolation	88%	125
Reduction of your capacity to participate in family and community life	87%	124
Reduction in overall health	84%	119
Reduction of your capacity to reach out to people	71%	101
Reduction of your capacity to work	69%	98
Reduction of your capacity to study	65%	92
Reduction of your capacity to access healthcare	63%	89
Mental health decline	48%	68
Development of a new additional disability	43%	61
That short term conditions become permanent	30%	42
Inability to recover from injuries	24%	34
Violence (inclusive of physical, verbal, etc., by family or services). Specify if you feel comfortable:	21%	30
Total	100%	142

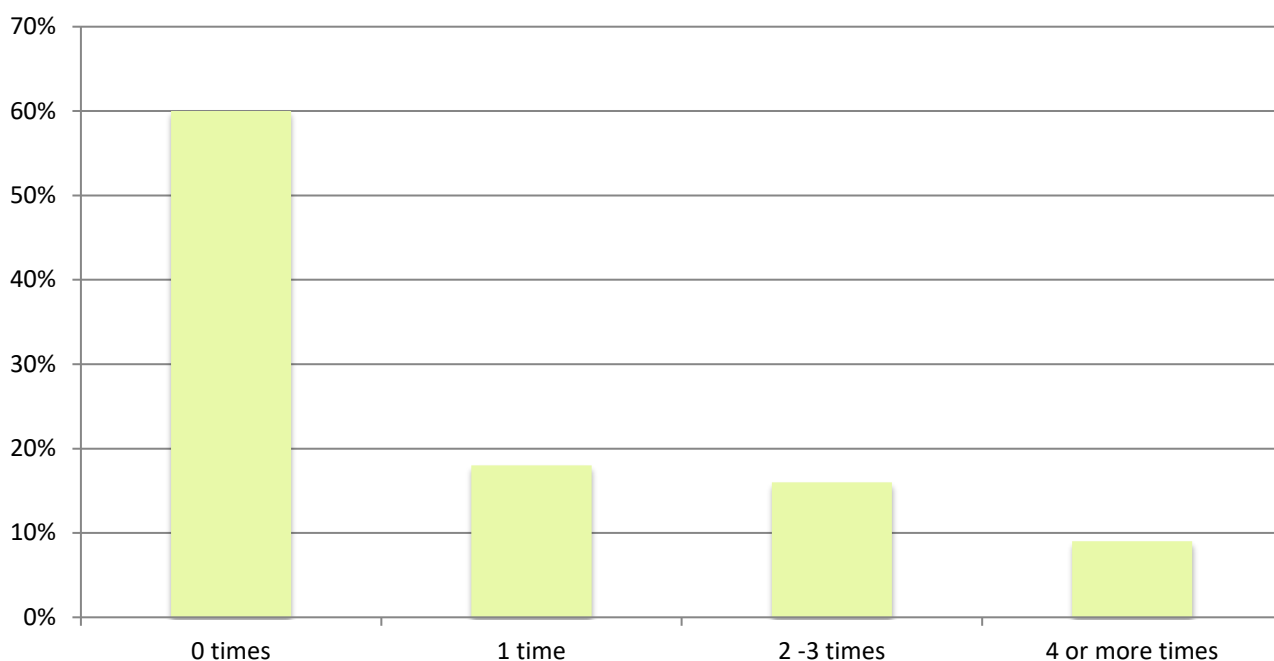


HOSPITAL ADMISSIONS

Please indicate the number of hospital admissions and unplanned re-admissions, including all presentations through the emergency department, within the previous 12 months.

From 2019 until 2020 more than half of the respondents, 60%, reported zero hospital admissions. However, 18%, reported one time and 16% reported from two to three times.

Answer	%	Count
0 times	60%	89
1 time	18%	26
2 -3 times	16%	23
4 or more times	9%	13
Total	100%	148

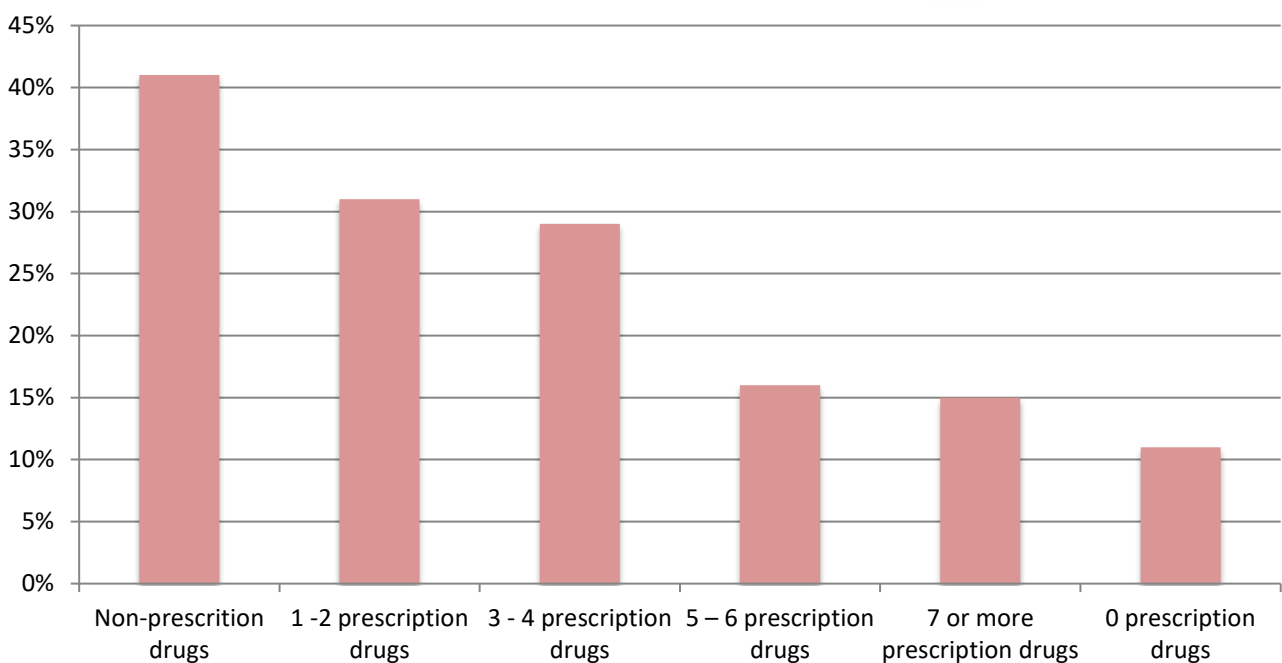


PRESCRIPTION DRUGS

How many different prescription drugs do you need to take each day?

Less than half of the respondents to this question indicated that they take non-prescription drugs but cannot access them due to cost, or inability to get a practitioner to provide, or inability to access, 41%. The second biggest group, with 31% of the responses, says that they take from one to two prescription drugs each day. The third group, with 29% of the responses, refer to taking from three to four prescription drugs.

Answer	%	Count
0 prescription drugs	11%	16
1 -2 prescription drugs	31%	47
3 - 4 prescription drugs	29%	44
5 – 6 prescription drugs	16%	25
7 or more prescription drugs	15%	23
Is there something (e.g. vitamins or non-prescription drugs) that you need to take but you cannot access due to cost, or inability to get a practitioner to provide, or inability to access, please explain:	41%	62
Total	100%	152

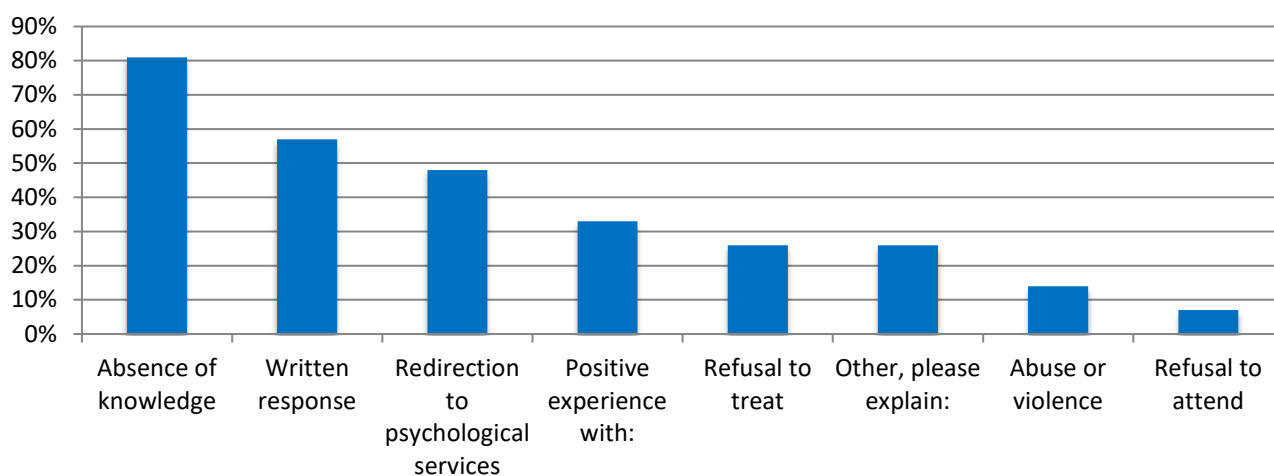


EXPERIENCES WITH AMBULANCE AND HOSPITAL SERVICES

Please share any relevant experience in relation to the ambulance and hospital services

In this question, 81% of respondents reported absence of knowledge. The second biggest group, 57% of respondents, explained their experience in a written response. The third largest group, 48% of responses, were redirected to psychological services.

Answer	%	Count
Explained experience	57%	71
Refusal to treat	26%	33
Abuse or violence	14%	18
Absence of knowledge	81%	101
Redirection to psychological services	48%	60
Refusal to attend	7%	9
Other	26%	32
Positive experience	33%	41
Total	100%	125

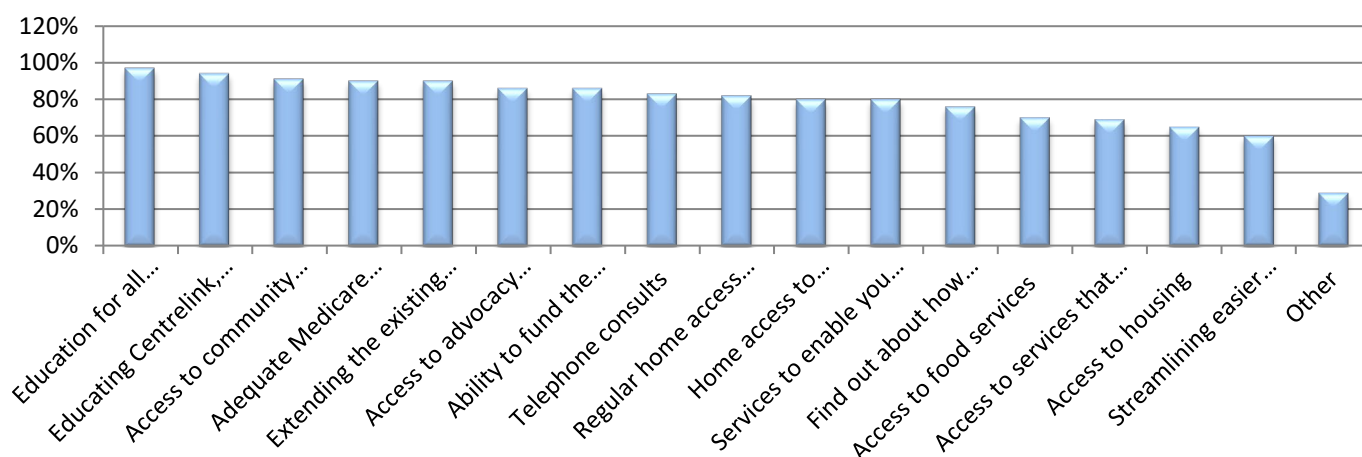


IMPORTANT NEEDS

Please, check the boxes that you consider important to help you or other Australians who are facing similar problems to yours

The top three types of help that surveyed FHBP indicated were: Education for all health professionals and service providers about people with their needs, 97%; Educating Centrelink, NDIS, and government services about paperwork difficulties, 94%; Access to community care services, for example, NDIS, Aged Care packages, 91%.

Answer	%	Count
Education for all health professionals and service providers about people with your needs	97%	142
Educating Centrelink, NDIS, and government services about paperwork difficulties, e.g. providing more time or accepting GP reports rather than specialist paperwork only	94%	138
Access to community care services, for example, NDIS, Aged Care packages	91%	134
Adequate Medicare rebates for home visits	90%	133
Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound	90%	132
Access to advocacy services (including legal) in order to assist with the day to day issues (e.g. NDIS access, DSP access, discrimination, access to insurance policies, domestic violence, etc.)	86%	127
Ability to fund the testing and medical reports required to access benefits	86%	126
Telephone consults	83%	122
Regular home access to a general practitioner	82%	120
Home access to psychology (or psychological) services	80%	118
Services to enable you to keep living in the community	80%	118
Find out about how many Australians are living with similar problems to yours to generate faster solutions	76%	112
Access to food services (e.g. Meals on Wheels)	70%	103
Access to services that are equivalent to the help provided by home palliative care services, for example, regular home visits by a nurse or GP	69%	102
Access to housing or accommodation arrangements	65%	95
Streamlining easier access to patient transport	60%	88
Other, please explain:	29%	42
Total	100%	147



INFERENCES AND COMMENTS

This survey's findings concord with Ricky Buchanan's report: <https://notdoneliving.net/justinvisible/> in uncovering a series of complex, incapacitating and debilitating illnesses, or injuries, which result in mobility issues. Numerous members of these populations are indeed unified by these shared circumstances: being trapped and unable to leave home. ^{1,2,3}

The surveyed FHBP demonstrated with their responses that they are under-served and under-researched Australians (mostly young adults, females) afflicted by chronic conditions and rare diseases (e.g. Myalgic encephalomyelitis/chronic fatigue syndrome) which are not always recognised as disabilities but are likely to increase (e.g. Autonomic dysfunction - 'Long COVID') ¹⁶.

Many Frail, Homebound, and Bedridden People receive no support to access clinical services and may not have a regular primary care provider, such as a GP, because the Australian health system has been designed around patients' physical attendance (as COVID-19, consumers, and these responses have demonstrated).^{1,2,3,6,7,8,9}

Having a health care system designed around physical attendance has had a profound impact on this group for decades, as they have reported.¹ They have described reduced overall health - morbidity and mortality-, inability to recover from minor injuries or illnesses, isolation, loneliness, depression and several other health and societal issues. ^{1,2,3,6,7,8} This information and survey results reveal a serious health care inclusion problem with medical and psychosocial implications that affect people in many negative ways, translating into increased costs to taxpayers for medical, disability and mental health expenses ^{1,2,3,6,7,8,9}

Currently, telehealth is only available for patients who have physically attended a consultation within the last 12 months.^{2,3,7,8,9} Nationally and internationally, telehealth projects are rarely developed to a point of sustainability and deployment. ^{10,11} Deficient scientific approaches to stakeholders' participation in research obstruct the generation of transferable evidence-based and fit-for-purpose health solutions for FHBP. ^{2,3,6,7,8,10,11,12}

The Australian health care system must move beyond patients' physical attendance, but such movement has to be co-developed¹⁴, perhaps considering technological health care solutions intended to empower consumers, integrate care, and create more effective health and wellbeing services for Frail, Homebound and Bedridden Australians.^{2,3,9,12,13,14} This statement has become our vision after considering COVID 19 learnings and the preliminary analysis provided.



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Organisations:

ME/CFS SA. Consumer co-researchers.

ME/CFS AU. Consumer co-researchers.

Leon Studio

Non-for-profit industry partners:

- The Help Me Feed Foundation.
- Flinders University: Heart health 'Nurse Cora' Team.

Flinders University |The Caring Futures Institute (CFI) themes:

- better lives, better communities, better care, and better systems

and its cross-cutting themes:

- methodological innovations, knowledge translation, technology, health and social care economics.

NHMRC Centre of Research Excellence in Frailty and Healthy Ageing.

Health Analytics Research Collaborative | Health Translation SA (HARC)

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