



**Health Issues Centre**

A voice for everyday people

# “Don’t Call Me Frail”

**A Social Listening Report  
November 2019**

**Report to Better Health North East Melbourne**



Better Health North East Melbourne (BHNEM) is a collaboration of diverse organisations who are critical to the delivery of healthcare across the north east of Melbourne. BHNEM has a catchment that covers the local Government Areas (LGAs) of Darebin, Banyule and Nillumbik. For more information contact Alison Davies, Executive Officer, [alison.davies@emphn.org.au](mailto:alison.davies@emphn.org.au)

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## Executive Summary

This study set out to understand older adults' perception of terms associated with ageing such as 'frail' and 'geriatric' and in doing so, better understand the terminology they would prefer. Health Issues Centre implemented their Social Listening<sup>®</sup> approach on behalf of Better Health North East Melbourne, to answer this inquiry.

While most health professionals are not using the terms like 'frail' or 'geriatric' when talking to older people, there is a stigma attached to any association with the terms, such as when the term is used in a service label such as 'comprehensive geriatric assessment'. These terms may reduce a person's likelihood to access services or reduce their self-confidence.

With a widely varying perception of who is old, ranging from those over 50 years to those over 90 years, it is not surprising that finding a suitable and positive label is challenging. If labels are required people preferred the terms 'elder', 'older adult' or 'senior'. Aboriginal and Torres Strait Islander people prefer the term 'Elder' and to be addressed as 'Auntie' or Uncle'.

More importantly older adults see it as important to be defined as individuals rather than by their condition(s) or a label associated with age. They prefer positive and optimistic language that builds upon their own positive attitude and resilience which they draw upon to face the challenges of ageing positively.

This study recommends exploring how models of care can incorporate this empowering and positive approach in both terminology and approach. This includes considering renaming the 'Comprehensive Geriatric Assessment' to the 'Retaining Independence Plan' and 'Living well plan'. Another recommendation is to further explore how models of care can best meet consumers' needs and expectations to better understand preferences for being assessed, developing plans and addressing issues individually and sequentially.



## Background

Globally around 27% of older people experience frailty and many more are “pre-frail”<sup>(1)</sup>. Health Vic defines frailty as “a multidimensional geriatric syndrome characterised by a decline of physical and cognitive reserves that leads to increased vulnerability”<sup>(2)</sup>. This vulnerability can lead to an increased likelihood to experience negative health outcomes such as falls, increased recovery time from illness or surgery, hospitalisation and eventually mortality<sup>(3)</sup>. It can be important to objectively categorise older people as frail to identify their support needs, implement a holistic care plan and reduce their level of vulnerability to adverse outcomes.

Although it can be clinically useful to identify older people as frail, it is neither an enabling term for consumers nor often one they readily identify with. Older people tend to resent and reject the concept of being frail, even if they can be objectively categorised as such<sup>(4)</sup>. Being labelled as frail can have negative consequences for how older adults are treated, such as experiencing diminished power and choice in decision-making<sup>(5)</sup>. Instead of resigning themselves to incapacity, older people may compensate for experiencing some losses (e.g. of cognition or physical ability) by sustaining abilities or creating new connections<sup>(6)</sup>. They make a distinction between the body one has, as a physical object, and the body one is, as a self-identity; making a distinction between “being” frail and “feeling” frail can have important consequences for how older people respond to their situation and subsequent health and wellbeing outcomes<sup>(7)</sup>. If older people are rejecting the concept of being frail, it is important to understand what language and concepts they do identify their experiences with.

According to a study by Yale University, an older person having a negative perception of ageing can shorten their life by seven and a half years. That makes it a bigger health risk than smoking or lack of exercise<sup>(8)</sup>. A negative attitude can also slow recovery from disability<sup>(9)</sup>.

This inquiry aimed to determine the language acceptable to older people experiencing frailty. It examined terminology that people could identify with. Social Listening<sup>®</sup> was used to hear from a diverse group of older people living in the North East of Melbourne and experiencing frailty.

The study was conducted by **Health Issues Centre** (HIC), Victoria’s peak-body for consumer health. In the past four years, Health Issues Centre has developed methods for ensuring people from diverse backgrounds, the marginalised and disengaged have a say in matters that impact their own healthcare. This includes Social Listening<sup>®</sup> which involves meeting people as they go about their daily lives to better understand the collective lived experience of consumers. HIC achieves this by employing a combination of digital tools such as social media, online questionnaires, and vox-pop interviews (videos of people giving their opinions informally in public places) to engage broadly with populations. HIC conducts face-to-face and phone

consultations with consumers, their adult children, carers, and professionals working with older people to include the voices of marginalised and under-represented groups.

This project was commissioned by **Better Health North East Melbourne (BHNEM)**, which is a collaboration of diverse organisations that are critical to the delivery of healthcare across the north east of Melbourne. BHNEM has a catchment that covers the Local Government Areas (LGAs) of Darebin, Banyule and Nillumbik. BHNEM's vision is 'Connected healthcare for community wellness' and its stated role is, 'We are influential leaders who design and deliver integrated services together'. In the BHNEM catchment, just over 15% are people aged 65 and over, and the “frail aged” are one of two priority strategic areas for the service over the next 5 years.

## Methodology

The research was carried out through HIC's Social Listening<sup>®</sup> methodology which combines a number of engagement tools to access consumers who would not normally participate in formal consultation processes. This included:

### Consumer informed surveys

Face-to-face interviews were conducted to inform the development of a survey and interview questions. Interviews included a group of older Aboriginal women and a group of older men at Banyule Community Health.

### Facebook posts

The initial Facebook post (Figure 1) and online survey generated 69 comments and 14 shares. The second post (Figure 2) generated 58 comments and 23 shares.

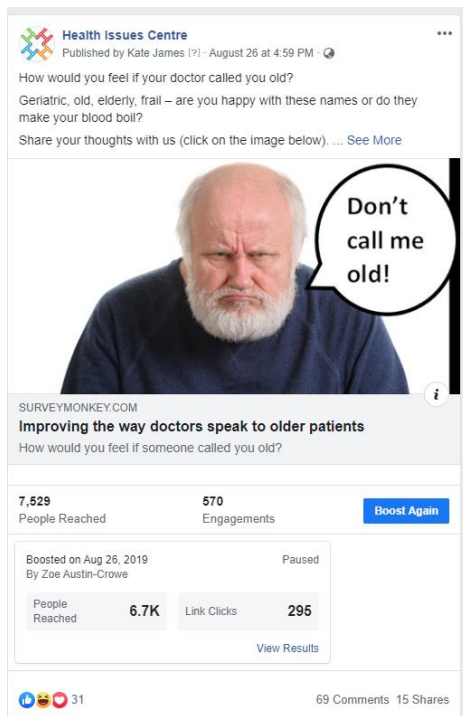


Figure 1

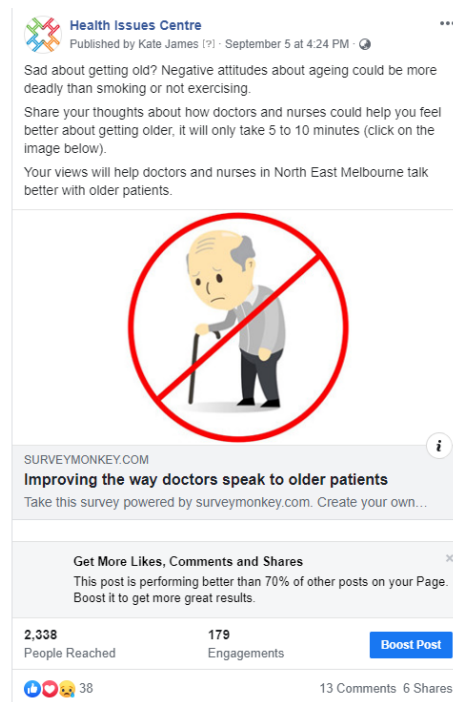


Figure 2

### Online survey

231 people completed the survey over the four weeks that it was open. Most of the respondents were in the 65 to 75 age bracket and the majority were female. To ensure the views of people aged over 75 years were differentiated the data was accordingly split so that differences in the nature of responses could be detected. Distinctions observed between gender or age groups are discussed in the results and analysis. The Facebook posts were targeted through boosts at people aged 65 years and older living in Darebin, Banyule and Nillumbik Shire. Interestingly, many of the responses received were made between 10pm and 4am.

## Results and Analysis

### ‘Frail’ is a demotivating term

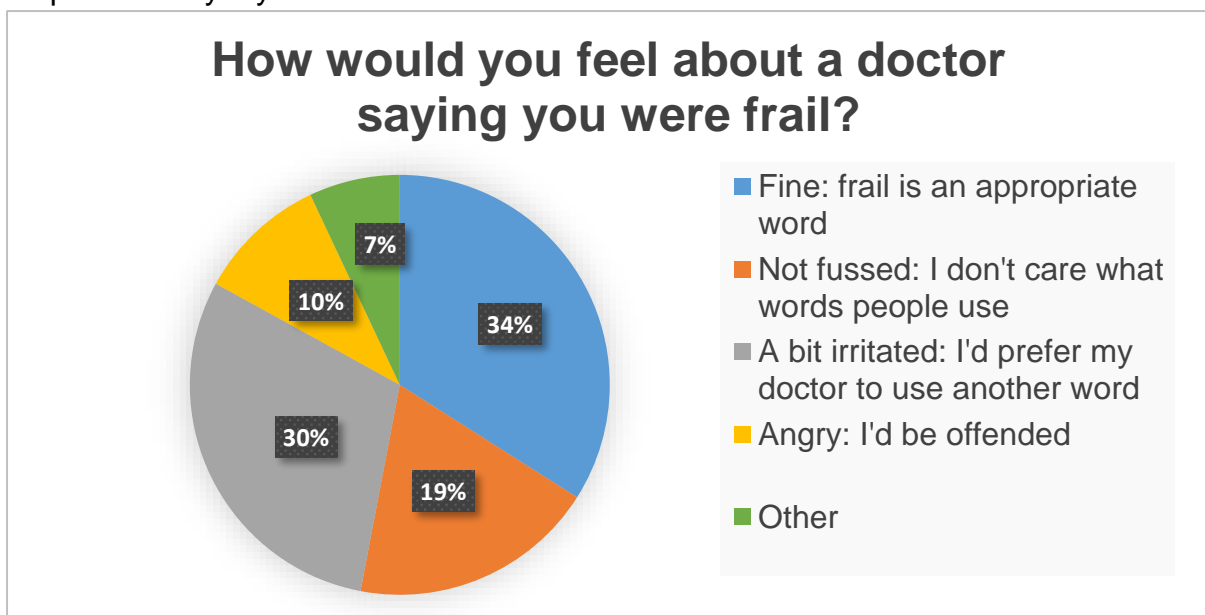
When survey respondents were asked to explain frailty most defined ‘frail’ in terms of needing assistance with everyday tasks, being very weak and having mobility problems.

When asked how they would feel about ‘frail’ being applied to them if they were having trouble doing everyday things, 53% of respondents were ‘Fine’ or ‘Not fussed’, compared with 40% being ‘A bit irritated’ or ‘Angry’ (7% provided another response). Most respondents were in the 65-75 age bracket and as such may not have experienced frailty.

While many people had not experienced the term ‘frail’ applied to them, they didn’t like the term and were more comfortable with references to symptoms (e.g. ‘unsteady’) rather than being labelled by a condition. They referred to the importance of positive contextualisation as distinct from deficit language (e.g. ‘Would you like me to help you stay independent in your own home’).

Older people generally see frailty as a very negative word and associate it with “slowly dying”. Face-to-face interviewees associated the word ‘frail’ with the end of life. They noted that it would be a very discouraging word for a doctor to use and would impact their motivation to exercise and recover.

There were seven respondents over 80 years old. While not a significantly significant sample size, more respondents were ‘A bit irritated’ or ‘Angry’ (43.5%) compared to the overall survey results. One respondent selected other and stated “I’m not frail” and 43.5% of respondents selected not being ‘Not fussed’. No one in the over 80 age bracket was ‘Fine’ with the word frail being associated with them if they needed help with everyday activities.





*“I would be happy that my Dr said frail on my referral to get me the services I required.” (Woman 76-80)*

*“People may be growing old, but frail is a word to describe someone on their last legs.” (Man 81-85)*

*“It is what it is - I think though this word may have had a finality context for people who perhaps were born during the 20's and 30's. It does have that connotation that you are past the use by date. It also instils the fear that the person may have to leave their home and go into care.” (Woman 66-70)*

*“It's descriptive as opposed to geriatric which feels like a classification.” (Man 61-65)*

*“I had a double knee reconstruction. I'm walking well now, but if I had of been called frail after the operation I would have believed I'd never get better. People are called frail at the end of their life.” (Male interviewee in his eighties)*

## **‘Geriatric’ is associated with the end of life**

Respondents generally did not like the word ‘geriatric’; associating it with the “end of life” and considering it to be “negative” and “old-fashioned”. This has implications for the use of terms such as **Comprehensive Geriatric Assessment**, **Geriatrician** and **Geriatric Evaluation and Management Unit**.

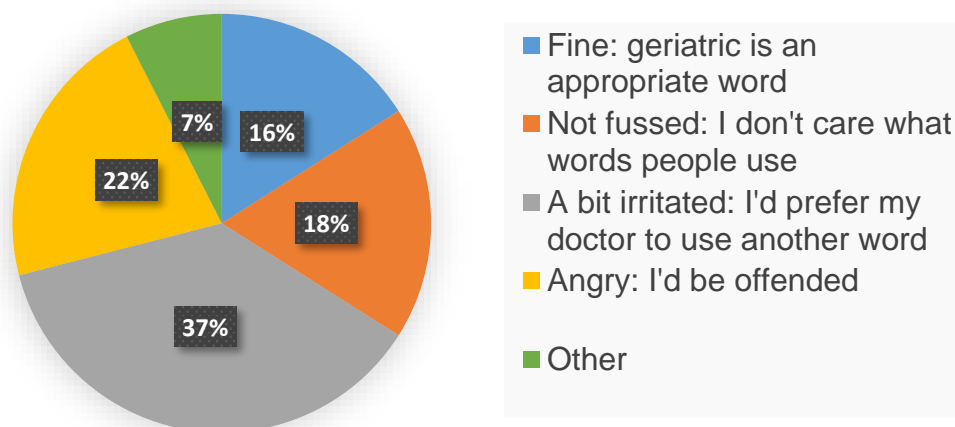
More than half of all respondents would be ‘irritated’ or ‘angry’ if the term geriatric was associated with them. While this does not indicate an extreme reaction to the terms, they are not enabling words.

Although clinicians would not directly call someone geriatric, it is implied by association, as in referring patients for a Comprehensive Geriatric Assessment.

There were no significant differences between men and women or the younger and older age group.

There was some Facebook discussion by women recalling being labelled with the term “geriatric pregnancy” for pregnancies as young as 25 years. People were obviously still feeling indignant about this decades later for the implied reduced confidence the medical profession had in their pregnancy. With 30.3 years being the average age of pregnant mothers in 2015 <sup>(10)</sup> this scenario demonstrates how understandings of age have shifted and defies the disabling label of “geriatric pregnancy” being applied to women. Consumers raised this analogy as a way of illustrating the impact the term geriatric may have on older people who may not yet perceive themselves as fitting this label.

## How would you feel if you heard the word geriatric being associated with you?



*“Geriatric to me describes someone who needs to be institutionalized because of deteriorating mental and health problems.” (Woman 86-90)*

*“Offensive because it indicates someone that is unable to look after themselves.” (Woman 71-75)*

*“It has connotations of someone who has passed their use by date.” (Woman 76-80)*

*“Old, useless, on the way out, incapable.” (Man 66-70)*

*“It has connotations of disability that isn't necessarily appropriate anymore.” (Woman 61-65)*

*“I would be angry as the person is making judgement on your body not your brain & are stripping you of your dignity.” (Man 71-75)*

*“Slightly miffed. I am coasting happily through life in complete denial about my age, until I am reminded.” (Woman 61-65)*

*“It's just a name, can't be too precious about things these days.” (Woman 61-65)*

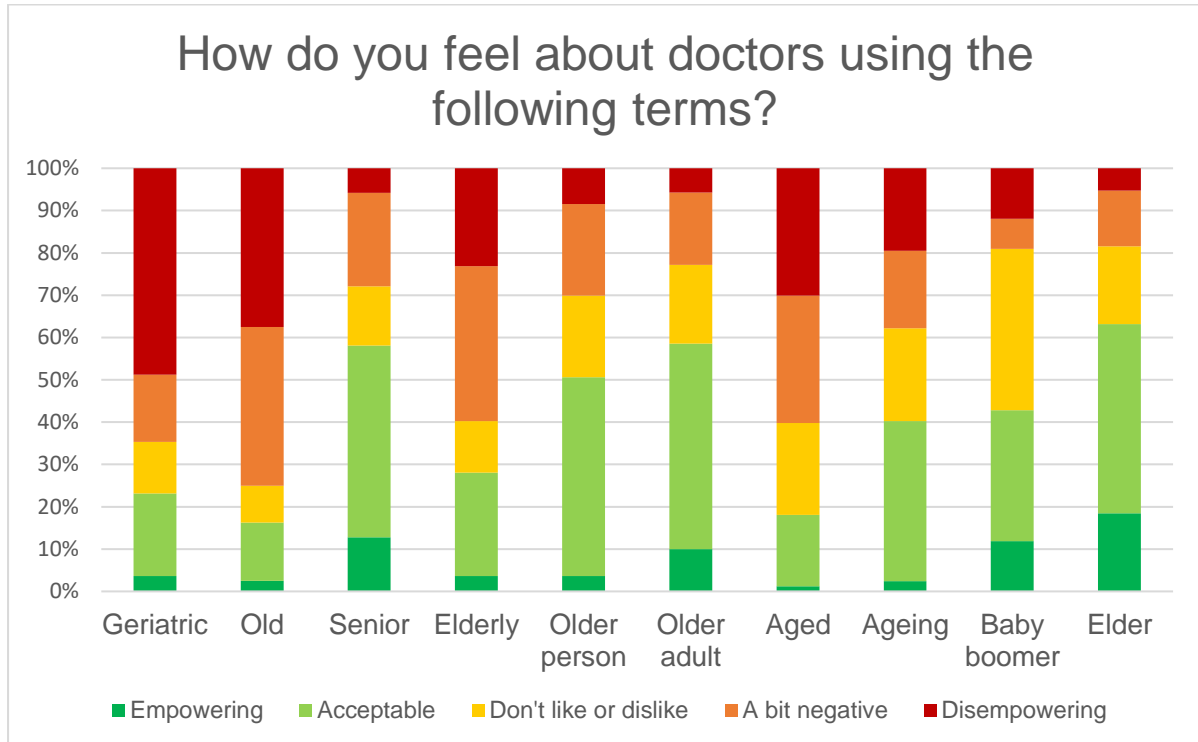
### Variations among cohorts

The majority of survey respondents were aged 65-75 years, and therefore might not be experiencing symptoms that would lead them to access services that include the word “geriatric” in their label. However, we found an insignificant difference in responses for participants in the 76-80 age bracket and no difference for people who were over 80 years and who would more likely have encountered the term.

Neither were there significant difference between men and women nor with consumers who identified as Aboriginal and Torres Strait Islander (Aboriginal) people.

## ‘Elder’ is the label of choice

Older people generally don’t want to be labeled. Many older people believe it leads to them not being treated as individuals and healthcare professionals making assumptions about their having cognitive problems, and/or a lack of ability to change or get better.



When specifically asked about their feelings towards different terms used to describe older people ‘Elder’ was the most popular label among survey respondents, followed by ‘older adult’ and ‘senior’. The term ‘Baby Boomer’ had a low disapproval rate making it another term to consider using. The term ‘senior’ was most popular when conducting face-to-face interviews. Aboriginal people have a clear preference for the term ‘Elder’.

In the survey neither gender liked the terms; ‘geriatric’, ‘old’, and ‘aged’. There was no consensus about the terms ‘ageing’ with some people liking the term, some disliking and some expressing a neutral response.

*“Nobody likes to be typecast into a certain group with the associated assumptions. Ageing is acceptable to me as it is a process. Senior infers a lifetime of valid contribution to society rather than a problem that needs to be fixed.” (Woman, 55-60 years)*

*“An elder is more respectful. All the other terms are labels that are often used in a negative way by the whole population. Ageist speak is always disrespectful. My age and illness is what I am.” (Woman, 76-80)*

*“Most of us feel fine and being referred to in some of the above terms is very depressing.” (Woman, 66-70)*

*“...why have a label at all?” (Woman 61-65)*

## **Differentiating phases of ageing**

Older people were generally surprised and annoyed that ‘geriatric’ was associated with them by the health system once they turned 65.

The term was seen as particularly ill-suited to people aged 65 to 79 years. The concept of differentiating two age demographics was floated by some interviewees; with one age group as 65 to 79 years referred to as ‘senior’ or ‘older person’, and then 80 years plus when the term ‘elderly’ was considered appropriate.

When asked at what age someone is old, the responses varied dramatically with a range of response from over the age of 50 to over the age of 90. It is worth reflecting how we differentiate phases of youth (toddler, baby, pre-teen, teen etc) yet we lump the phases of ageing into a single identity.

*“Personally, I think the age range is wrong. I think of geriatric as 80+. Yet am aware of the physical and cognitive impairments that starts as we reach 60+. Life expectancy has changed dramatically. Maybe we need a pre-80 descriptor.”  
(Woman, 64)*

## **‘Elder’ is the label of choice for Aboriginal people**

In contrast to European culture where there is no universally accepted term for older people, Aboriginal culture designates the term ‘Elder’ for anyone over 50 years (‘Senior’ was considered a ‘white person’ term and ‘old’ was seen as disrespectful).

The respectful way to address someone more senior than you is ‘Auntie’ or ‘Uncle’. It is seen as disrespectful to call an Aboriginal person who might be older than you by their first name and ‘Mr’ and ‘Mrs’ are seen as ‘white people’ terms.

## **Label may negatively impact health and wellbeing**

A clear message from this study is that older people want to feel that healthcare professionals respect them. While the following concerns may be addressed in ‘best practice’ clinics, participant feedback suggest they are not universal standards.

### **Healthcare practitioners dismissing health conditions as old age:**

Many people in the study felt that their health conditions were dismissed as just being part of old age and therefore appropriate help wasn’t given. This was a particular concern to Aboriginal women (and women in general) who seemed to have a large number of ‘carer’ responsibilities for their grandchildren, children, friends, spouses and their parents well into their older years.

*“To be called old appears to mean, if you’re old there is no help for you...”*

*“They could stop using the term ‘at your age’ as if that makes whatever is wrong with you just something you have to put up with because of your age.”*

*“I don't think of myself as 'geriatric'. My mind still sees myself as a younger person, and to be described as 'geriatric' type-casts me as decrepit and 'past it'. Just do regular tests and take my difficulties as they arise and don't just write it off as a 'normal' part of the aging process.” (Man 61-65)*

*“The doctor just said I had age related problems. It feels like an excuse not to investigate further.” (Woman 66-70)*

### **Healthcare practitioners not validating patient accounts of their own health:**

Older people did not want to be categorised as old because they didn't want to be automatically branded as people with memory loss or other cognitive conditions.

Some older people reported that healthcare practitioners have assumed that they have memory problems when their description of their health and treatment doesn't match with their medical records.

In general, older people would just like to be listened to more and asked more questions. They would also prefer that healthcare practitioners talk to them rather than their relatives.

Conversely, the men's group did not mind healthcare practitioners talking to their relatives rather than them despite the fact that they emphasised the importance of feeling respected. However, they felt that their relatives (always women) listened better so it made sense that the doctors talked to them.

*“Each is an individual, some are quite with it, others not so much, should not be lumped in one basket.” (Woman, 71-75 years, carer of an older person)*

*“The terms are stripping you of your dignity and respect and each person should be judged on their own merits and capacity rather than being categorised by words on a form.” (Man, 71-75 years)*

*“I prefer a Doctor, nurse and other professionals to speak directly to me and not to the person accompanying even if it a family member, so many take for granted you are not able to understand directions.”*

*“See me as a person not a set of symptoms and listen to what matters to me about living my life and provide their skills to support that.”*

### **Respect begets trust:**



While patients may struggle to judge how good a healthcare professional is based on their medical skills, they do know when their communication and interpersonal skills are strong and are therefore more likely to judge them based on the latter.

*“Being called by your name and not being referred to by dear, darl, sweetie, such disempowering terms (OK if have rapport with the person already).”*

Relationships with healthcare professionals were far more important than the specific ‘terms’ or language being used to describe them. A good relationship was based on mutual respect which built trust in the health professional.

*“Stop bloody using the word "we" when making an enquiry re health status i.e. "How are we today?" It's still rife!”*

### **Positive attitude**

The resilience and positive attitude of older people was evident in their commentary and the language we use should reinforce rather than diminish that resilience. This attitude was crucial in people managing to cope with multiple chronic conditions, while maintaining a positive outlook.

*“It's not so much the word the doc's use but the way they are delivered; the condescension, looking down, babying, etc. That is the real problem.” (Woman 61-65)*

### **Who do you turn to?**

Most survey respondents were open to receiving help, but there was a marked difference in who they were happy to see. When asked what they were open to doing if they were struggling to do everyday things around the house, 90% of survey respondents welcomed an occupational therapist, 73% were open to doing a ‘Frailty assessment’ and 67% were interested in seeing a geriatrician.

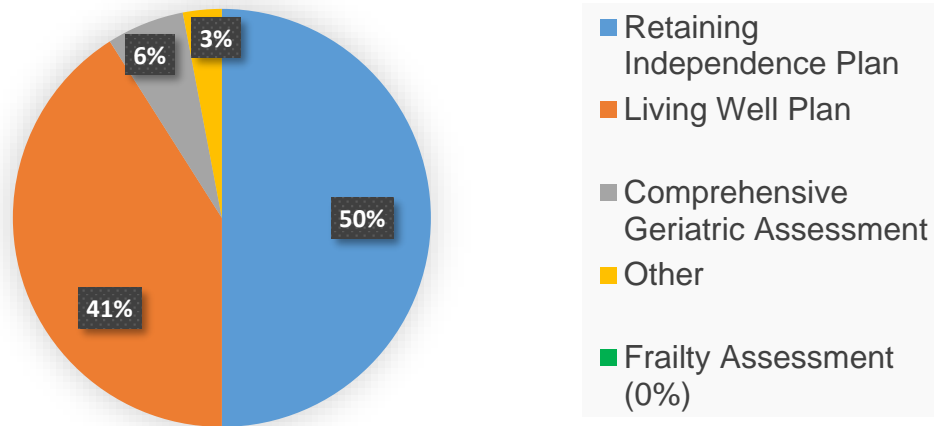
**33% of older people said they wouldn't see a Geriatrician if they were struggling to do everyday things around the house.**

*“It's offensive to be categorised into a certain group because of age and I would be reluctant to see a doctor under those circumstances. You see a specialist for that organ or health issue not because of age.” (Man 71-75)*

### **What's in a name?**

Given older people's general negative views about the terms ‘geriatric’ and ‘frail’, we decided to test how seniors feel about names like *Comprehensive Geriatric Assessment* and *Frailty Assessment*.

## Which assessment would you be more likely to want to do?



*“Assessment means somebody else interfering in your life I would prefer to ask for help if and when I need it.” (Man 81-85)*

These results indicate that branding impacts the likelihood of older adults seeking or accepting health assessments, and that names that are focused on positive outcomes are more likely to drive take-up rates.

While ‘plans’ were generally preferred to ‘assessments’, ‘plans’ weren’t palatable to everyone. Some respondents didn’t like the idea of a health professional sitting down with them and making a plan. They felt that, no matter what was said about it being a joint process, the healthcare practitioner would be in the driving seat rather than them. They also didn’t like the idea of their life being mapped out for them.



## Conclusion and recommendations

This study found that while most health professionals are not using the terms like 'frail' or 'geriatric' when talking to older people, there is a stigma attached to any association with the terms, such as when the term is used in a service label such as 'Comprehensive Geriatric Assessment'. These terms may reduce a person's likelihood to access services or reduce their self-confidence.

If a label is required, 'elder' or 'older adult' are the preferred terms. Aboriginal and Torres Strait Islander people prefer the term 'Elder' and to be addressed as 'Auntie' or 'Uncle'.

Older people would like to be defined as individuals rather than by their condition(s).

Wherever possible it is preferable to substitute value-laden terms like 'geriatric' and 'frail' with terms that imply well-being and that have positive and optimistic connotations, for example 'Retaining Independence Plan' and 'Living well plan'.

Building upon an older person's positive attitude appears to be important in helping them maintain their independence, determination and sense of well-being.

Further exploration should be undertaken to understand how a model of care and the language associated with it can best meet consumers' needs. For example, concepts such as undertaking assessments, developing plans and addressing issues individually and sequentially.

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