

Frailty: Language and Perceptions

A report prepared by BritainThinks on behalf of Age UK and the British Geriatrics Society

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1. Background

Wider context of this research

The term ‘frailty’ has many different meanings and applications. Age UK and the British Geriatrics Society (BGS) have identified how this varies amongst three key groups: geriatricians and other older people’s healthcare specialists, health care professionals without expertise in older people’s care and older people themselves.

Among older people’s specialists the term ‘frailty’ is used to describe a spectrum of physical and mental health states and is used to assess risk or to put together a care plan for an individual. By contrast, non-specialist healthcare professionals (HCPs), with less experience of older people’s care are thought to be more likely to use the term as shorthand for older people with complex care needs or in late old age.

Importantly, there is evidence to suggest that the term ‘frailty’ does not resonate with older people, nor is it something that they identify with. This has led some in the healthcare sector to raise concerns that, as a result, fewer older people may access the health and social care that they need. If true, this would have important implications to approaches to care for older people.

Purpose and objectives of this research

BritainThinks was commissioned by Age UK and the British Geriatrics Society (BGS) to undertake qualitative research to gain insights that can be used to help raise awareness of approaches to care that can prevent or minimise the impact of frailty on older people.

The target audiences identified as being key to this research were:

1. General public audiences, comprising:

- Older people, aged 69+, living with frailty
- Older people, aged 69+, *not* currently living with frailty
- Non professional, informal carers of older people living with frailty

2. Professional audiences, comprising:

- Managers in hospital wards
- Practice and district nurses
- Non-specialist healthcare professionals, including GPs

The research was designed to identify ways of supporting older people to:

- Identify with the *concept* of ‘frailty’ (if not the word)
- Engage with preventative strategies and frailty services (with support from healthcare professionals (HCPs) and informal carers)

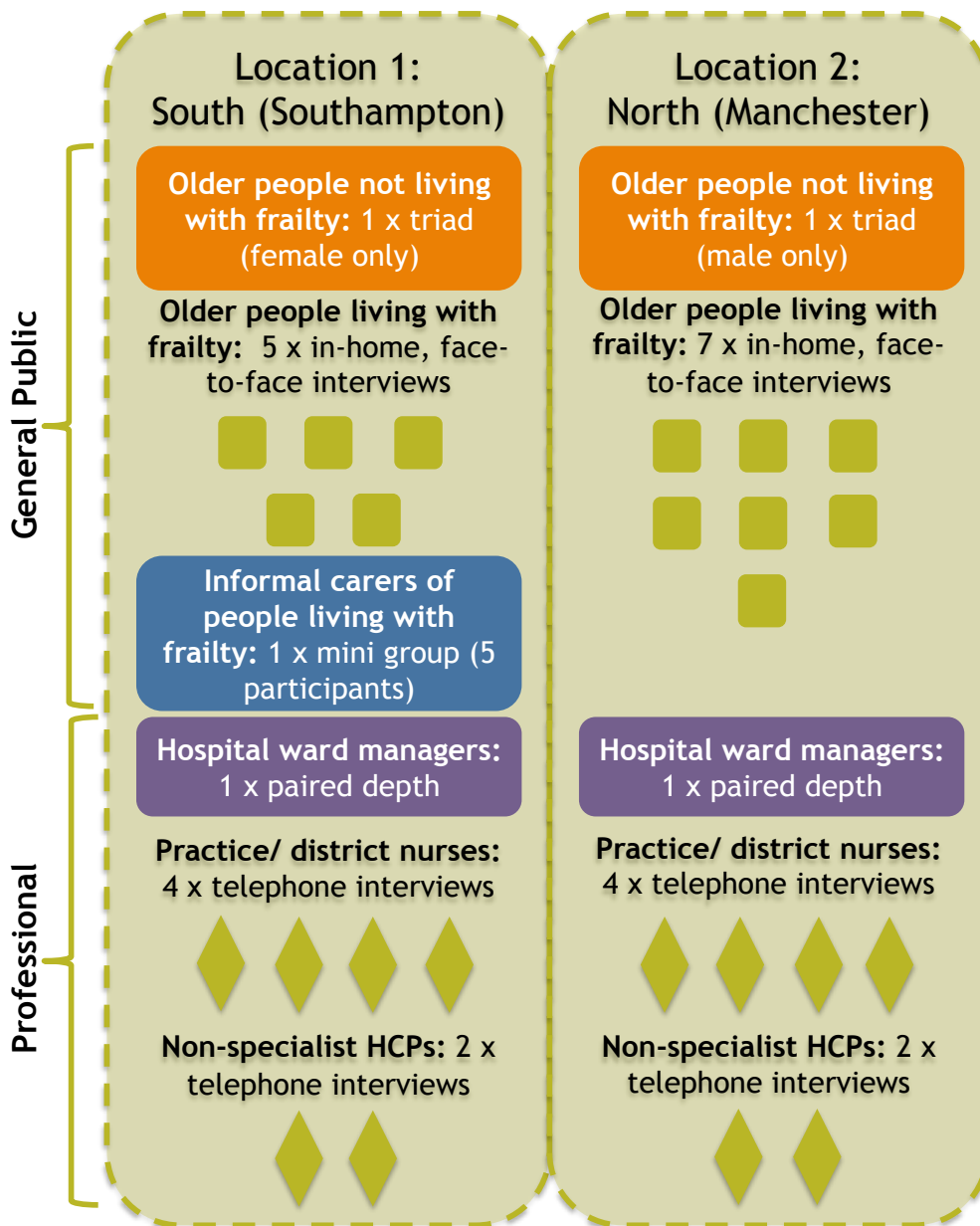
- Play a role in accessing services (such as those providing the Comprehensive Geriatric Assessment), that are designed to help them

Ultimately, the research findings are intended to feed into strategies to help reduce the impact of frailty on older people’s lives.

For a full list of project objectives, please refer to the Appendix.

Methodology and sample

Overview of approach



Methodology detail

A research approach tailored to audience ensured that the specific characteristics and needs of each group were met. In addition, focussing on two fieldwork locations, Southampton and Manchester and surrounds, meant that findings were not affected by regional bias.

Research among public audiences:

- Interviews with older people living with frailty were conducted face-to-face and in-home to ensure that there were no accessibility issues for participants and that there was minimum disruption to their lives. It also helped ensure that participants felt comfortable sharing their views on a potentially sensitive and personal subject, as well as enabling the research findings to draw on observational insights as to how participants live in their homes. All in-home interviews lasted for 60 minutes.
- Older people not currently showing any outward signs of frailty, and informal carers of people living with frailty, were consulted in focus groups to enable comparison between different viewpoints and experiences.
 - Those sessions with older people lasted 75 minutes and the group with informal carers lasted 90 minutes.
 - The focus groups with older people were split by gender to try to ensure that the participants felt comfortable sharing their views and experiences.
- All interviews and groups were qualitative and semi-structured, using a discussion guide developed in collaboration with Age UK and BGS to address each of the project objectives.
 - Each discussion began with open questions before moving on to a more direct questioning approach, and the interviewer ensured that the spontaneous responses of each individual were gauged before prompting. The specific language that participants used and their non-verbal responses were also observed and used to inform later analysis. For a more detailed overview of the discussion content and stimulus materials, please see the Appendix.

Research among healthcare professionals:

- Hospital ward managers were consulted in paired depth interviews lasting 75 minutes, to reflect the time pressures facing this audience while retaining the opportunity for participants to share experiences and views.
- Interviews among practice and district nurses as well as non-specialist HCPs were conducted by telephone, again to reflect the time pressures facing this audience. Each interview lasted for 40 minutes.
- Interviews were semi-structured, although there was more direct questioning than the approach taken with public audiences, since participants were not being asked sensitive questions requiring projective techniques.

- The discussion guide explored the healthcare professionals' personal experience of the challenges associated with treating older people living with frailty, and their understanding of the concept of frailty.

Fieldwork dates

Fieldwork took place between 21st October and 5th November 2014.

Sample detail

The older people sample comprised:

- A spread of ages from 69+
- An even gender split
- A spread of socioeconomic grades
- A minimum of 3 BME participants
- A mix of older people who live alone and those living with others
- Among the audience living with frailty only, all participants showing outward signs of frailty and between 5-9 on the Rockwood Clinical Frailty Scale (see Appendix)
- Among the audience with no outward signs of frailty only, all participants between 1 and 4 on the Rockwood Clinical Frailty Scale

Those in the carers sample all provide a varying amount of support for an older person living with frailty, and the group included:

- A good mix of ages
- A good mix of gender
- 1 BME participant
- A mix of carers who live with and live separately from the older person for whom they care

The professional sample was comprised of HCPs with:

- A spread of years of experience
- Inclusion of BME participants
- An even spread of practice and district nurses (among nurses)
- A range of areas of specialism (among HCPs who do not specialise in older people's care)

Limitations to the research

The small sample sizes on this project and qualitative research method mean that the full scope of audience experience and opinion may not be represented in this report. No older people living in care homes or sheltered accommodation were consulted as part of this research, nor were any older people with a frailty score above 8, as measured on the Rockwood Frailty Scale.

Executive Summary

Responses to the language of ‘frailty’

- ‘Frailty’ as a clinical concept has a very different meaning to the way it is understood and used amongst general public audiences and non-specialist health care professionals (HCPs).
- For these audiences, frailty is related to those people who are approaching the end of their lives, malnourished and highly dependent on care. These associations mean that the word ‘frail’ is understood to refer to an *irreversible* state rather than something that could be improved or exist on a spectrum. However, these audiences took a slightly different view when considering some of the specific symptoms associated with the clinical condition of frailty (but not labeled as such), where there was a greater appreciation of being able to get better or worse over time.

The concept of frailty

- The older people we spoke to did not identify with the term ‘frail’:
 - Older people do not use the word ‘frail’ or the phrase ‘living with frailty’
 - The key barriers to identifying with the word ‘frail’ itself speak to a deep fear of losing independence, dignity and control over one’s life
 - Older people do, however, recognise the experience of *living with frailty*
 - Older people do not primarily define themselves in terms of an overall state of ‘frailty’
 - Instead, the experience of living with frailty is understood as comprising a number of specific challenges and specific solutions
 - Older people articulate their physical and mental wellbeing in terms of being able to complete everyday tasks independently
 - While older people tend to accept that it will become harder to complete these tasks as they get older, as the ability to do these things without significant support start to slip out of reach entirely, this can act as a ‘trigger point’ to accessing care/support services.
- Understanding this context, it is possible to position the concept of frailty in such a way as to encourage older people to identify with it, for example by:
 - Avoiding using the term ‘frail’ or any other all-encompassing term, but rather, use specific examples of living with frailty in order to drive self-identification
 - Using language that resonates with older people’s desire to maintain or return to a level of independent living

- Being clear that that identifying the problem is the best way to get solutions in place to help older people to achieve their goals
- Non-specialist health care professionals tend to describe an older person's wellbeing in terms of their functionality, which chimes strongly with older people's conceptions of 'frailty'.

Attitudes to support

- When older people begin to find everyday tasks harder to complete, their first instinct tends to be to find their own solutions
 - Medical professionals are not seen by older people as the first port of call for receiving help with everyday challenges
- Once they move past a certain 'trigger point', however, some older people then become much more open to external support.
- For older people and informal carers, information about accessing preventative strategies and frailty services are received in the context of:
 - Beliefs that many elements of frailty are an inevitable or unavoidable part of ageing, but that losing your independence is not
 - A mixed awareness amongst these audiences of the main risks for frailty
 - A mixed awareness of the range of available preventative strategies and frailty services
 - The attitudinal barriers that older people have to engaging with strategies and services.
- In specific reference to Comprehensive Geriatric Assessment (CGA)
 - Older people in our sample were unaware of CGA, and awareness among informal carers and non-specialist health care professionals was only marginally higher
 - The name 'Comprehensive Geriatric Assessment' was disliked by older people we spoke to; however, older people do feel that it is a good idea in principle, despite reservations about the time, effort and what it would entail in practice.
- Taking this context into consideration, our hypothesis is that to encourage older people to engage with preventative strategies and frailty services, it will be important to:
 - Build on existing beliefs that 'living with frailty' is not an inevitable or irreversible part of getting older and emphasise that it is possible to maintain independence by engaging with strategies and services
 - Build on existing awareness of the risk factors for frailty, but raise awareness of lesser-known risk factors such as being overweight

- Provide a comprehensive overview of services and solutions that are available and how to access them, particularly less invasive, smaller scale services that demonstrate that getting 'support' doesn't mean going into a care home
- Raise awareness of Comprehensive Geriatric Assessment (CGA) and clarify the value that it offers
- Encourage older people to talk to their HCPs and to enquire about services to which they are entitled, and also require HCPs to engage older people on the topic, using language that resonates with older people in order to assess needs and help put services in place.

3. Responses to the language of frailty

Responses to frailty among older people and informal carers

Older people consulted in this research have a strong aversion to the term ‘frail’; it is not part of their vocabulary when they talk about themselves and their lives. Even those research participants with high scores on the Rockwood Frailty Scale did not spontaneously mention the word ‘frail’ when asked to describe their physical and mental state or that of others. Moreover, the introduction of the word tended to evoke a strong and often emotional reaction in older people, particularly older men. Several research participants expressed incredulity or offence at the term. The term was less emotionally charged for carers, but is still viewed as being extremely serious.

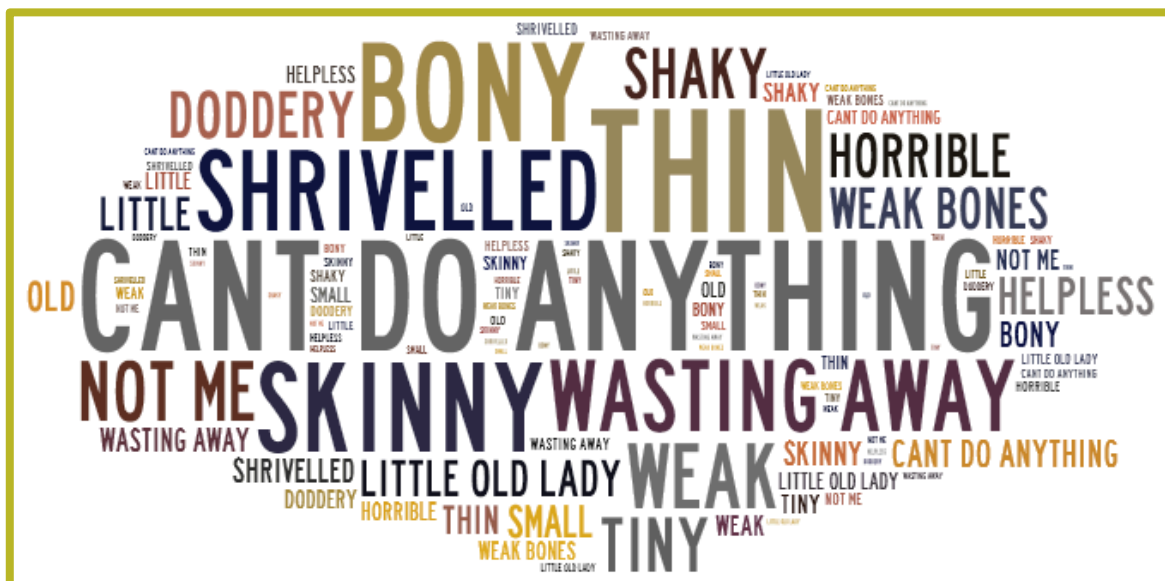
“Frail is when someone is weak, and can’t do anything much. It is that stage where you become dependent on people for most things.”

Male triad, North

“No, I’m definitely not frail. Frail means you’re dodderly and shaky. You can’t do anything at all.”

Female, 71, South, Living with frailty

This aversion seems to be driven by synonymous associations between ‘frailty’ and very severe physical (and mental) limitations. As shown in the word cloud below, research participants often described ‘frailty’ as being physically thin and unable to do anything. In addition, the term had a slight gender bias, with many participants associating the term with a ‘little old lady’.



These strong negative associations meant that the word ‘frailty’ was understood to mean an irreversible state that some older people enter into in the very final stages of their lives. It was assumed that frailty means an almost total loss of independence, and there was no sense that frailty exists on a spectrum or is a state that one can move in and out of. For example, an older person having a fall, breaking their leg and experiencing limited mobility during the recovery period, was not synonymous with participants’ definition of frailty, primarily because it was neither seen as permanent state, nor as linked to end of life. This meant that even relatively frail older people in the sample did not self-identify with the term ‘frail’ because:

- They were not (yet) experiencing the very extreme symptoms they considered to be part and parcel with frailty;
- Even if they were experiencing these symptoms, identifying with being ‘frail’ would ultimately have meant that you did not see your situation getting any better, that you are towards the end of your life, and that you have (almost) totally lost your independence.

“Do I look frail to you?! I’m not frail. That’s someone who can’t do anything, who’s wasting away. Thin and skinny.”

Male, 83, South, Living with frailty

“I don’t think there’s a cure for that.”

Male, 69, South, Living with frailty

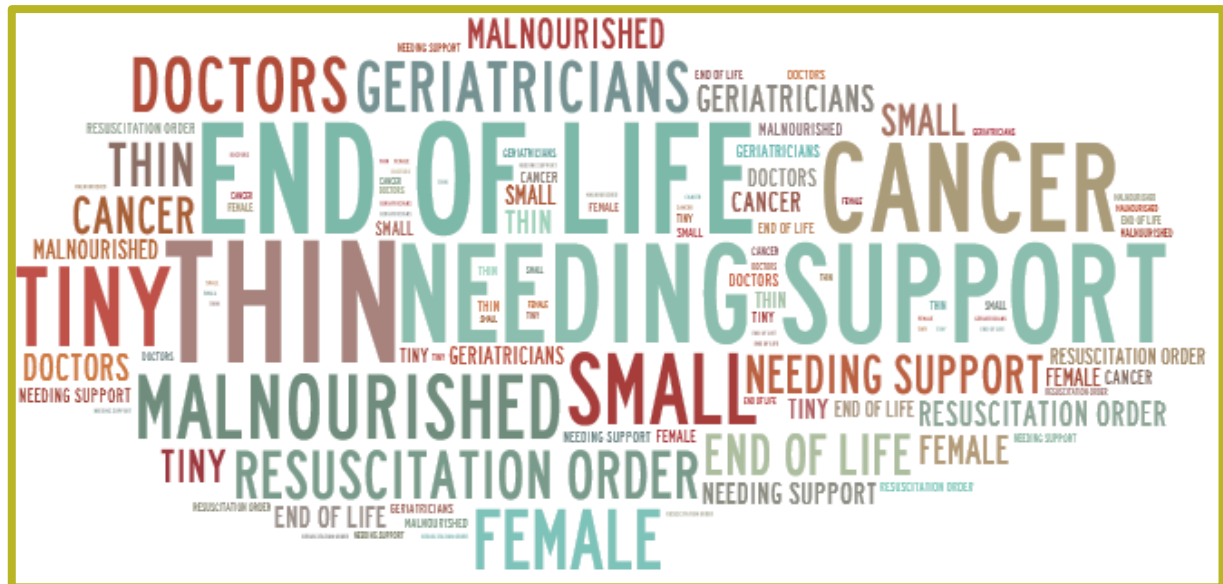
Responses to frailty among non-specialist healthcare professionals

In line with older people, non-specialist HCPs did not tend to view ‘frailty’ as a particularly useful term. The word ‘frail’ was not a front of mind term for the GPs, nurses or ward managers who participated in the research, even when asked about the language that they use to describe older patients. When prompted, the research participants tended to say that they very rarely use the term other than as shorthand in their notes or in conversations with colleagues, for a person with significant needs.

“The receptionist might call up and say ‘you’ve got a rather frail patient waiting’ and so you know you’ll need to come out and help them to the appointment.”

Practice nurse, North

Non-specialist HCPs in the sample tended, like the public, to use the word ‘frailty’ in a very narrow sense to describe state of being that is inextricably related to end-of-life care. The word cloud below illustrates the strength of these associations:



“It’s used in end of life care for patients with cancer or very old age.”

GP with more than 10 years experience, North

“A frail person is someone who is more vulnerable and less able to do day-to-day things. I would associate it with elderly patients, although I would also sometimes think of terminal cancer patients who have lost lots of weight. Someone skinny and likely to break, at an end of life state.”

GP with less than 10 years experience, South

This definition of frailty amongst non-specialist HCPs, as among the public, meant that it tended to be conceived of as a *descriptive term* for a *permanent state* rather than as a state of being that exists on a spectrum. In addition, because of their association between frailty and patients entering the end of their lives, it was typically considered to be an irreversible and one-way process. Indeed, some of the research participants reported seeing the term ‘frailty’ used as shorthand in paperwork to explain why a patient had not been resuscitated.

“I’ve only ever seen frail used by doctors in resuscitation forms as a reason for not resuscitating...I would take it to mean someone who is tiny and fragile - likely to break. It is irreversible by that stage.”

Hospital ward manager, South

In addition, non-specialist HCPs reported that they did not often use the term ‘frail’ in the context of their older patients, for a variety of reasons:

- It only refers to a small group of patients who are at the end of their lives
- They felt that older people have an aversion to the term and reported being strongly encouraged in their workplaces to avoid using any language that they would not use with a patient
- They also grouped ‘frailty’ with a host of descriptive terms such as ‘acopic’, which they felt, are increasingly falling out of favour in healthcare and being replaced by practical terms that point to specific care requirements.

4. Articulating the concept of frailty

Articulating the concept of frailty among older people

Maintaining independence

The biggest priority for the older people we spoke to tended to be maintaining their independence. This had a clear impact on the reasons why older people might seek support:

- ‘So that I feel in control’, and able to make decisions without others getting involved;
- ‘So that I keep out of the system’, out of hospital or a care home;
- ‘So that I don’t become a burden’, meaning that friends and family focus on their own lives rather than having to spend their time worrying or looking after someone.

“I don’t want to worry [my children] because they have their own families and problems. You don’t want to admit that you need help.”

Female, 71, South, Living with frailty

In line with their desire for independence, older people tended to articulate their wellbeing in terms of their ability to independently carry out everyday tasks. The most consistently mentioned activities by which one’s degree of independence was assessed were:

- *Domestic activities*: including things like cleaning, dusting and vacuuming; washing and ironing; and shopping for groceries and preparing meals. These activities were mentioned particularly by women as critical to maintaining the status quo;
- *Social activities*: going out with friends and family to restaurants, cafes, pubs, cinemas, organised events, bingo and shops
- *Outdoor activities*: gardening and walking.

“My friend and I go out to the shops for a look around and a cup of tea and a piece of cake. It’s the highlight of my week.”

Female, 83, North, Living with frailty

The ‘scale of independence’

The older people that took part in the research conceived of their ability to live independently as being on a scale, measured in terms of everyday tasks and their ability to complete them without assistance. Using participants’

own definitions and experience of independent living, we pulled together a *scale of independence*; moving up this scale indicates a reduced ability to complete tasks independently, as outlined below:

Stage 1	<p>Being able to do the everyday tasks that are critical to maintaining the status quo without any support from others</p> <ul style="list-style-type: none"> • For older women, this is particularly about keeping up the routine at home • For older men, this is often tied up with outdoor and social activities
Stage 2	<p>Being able to do everyday tasks to maintain the status quo with some minor adaptations or ‘light touch’ support</p> <ul style="list-style-type: none"> • This is often done through coping mechanisms that older people develop themselves • In some circumstances, this type of support comes through informal help from others, particularly relatives
Stage 3	<p>Being almost or totally unable to do the everyday tasks important to maintaining the status quo without (significant) support</p> <ul style="list-style-type: none"> • Coping mechanisms and adaptations are no longer sufficient to ‘get by’
Stage 4	<p>Becoming almost or totally unable to manage personal hygiene without (significant) support</p> <ul style="list-style-type: none"> • This is viewed by older people as a distinct ‘step up’ in terms of invasiveness of support
Stage 5	<p>Losing independence entirely and becoming totally reliant on support</p> <ul style="list-style-type: none"> • This is seen as synonymous with entering into a care home or hospital for many older people

Older people tended to accept that they would start to find everyday tasks more difficult as they got older, and to be quite proud of the coping mechanisms that they had devised for themselves. For many, moving from the first stage on the ‘independence spectrum’ into the second is viewed as a relatively natural and inevitable consequence of physical and mental ageing.

“I have got a shopping trolley for heavy things. It’s about accepting that you need aids of some sort from now on.”

Female triad, South

By contrast, moving from the second stage of the ‘independence scale’ and into the third emerged as a trigger point for older people, seemingly often motivated by resistance to, or fear of, moving further up the spectrum.

"I switched to a smaller Hoover but now even that is too much for me to push around on most days. It's made me realise that I do need to let my daughters do things for me."

Female, 71, South, Living with frailty

Risk factors to independence

Despite being acutely aware of their own position on the 'independence scale', and any change in their capabilities, awareness of the risk factors associated with the clinical definitions of frailty tended to be low, even among frail older people.

There were *some* risk factors that the research participants generally recognised, including:

- **Chronic illnesses:** such as COPD, severe arthritis and osteoporosis, which are generally understood as gradually and inevitably pushing older people up the spectrum over time
- **Recuperating from acute illness or operations:** such as falls or hip replacements, which are viewed as pushing older people up the spectrum temporarily
- **Poor diet:** this tends to be understood in terms of simply not eating enough rather than nutrient deficiencies, for example, only a minority associated Vitamin D with bone strength

"I had my hip done a few years ago and I got a taste of a week of living like an invalid."

Female, 76, North, Living with frailty

However, other risk factors were generally unrecognised, including:

- **Being overweight:** many older people seem to associate being overweight with having a good appetite as well as being sturdier and stronger. However, notably the few older people in the sample who were overweight did recognise obesity as a risk factor, and identified how it makes people weaker, puts pressure on joints and makes moving around more difficult
- **Other unhealthy lifestyle choices in younger age:** while older people certainly assume that smoking and drinking alcohol are 'bad' for your health, they struggle to make any explicit link between these behaviours and the clinical concept of frailty.

"I know that having all this fat makes it much harder for me to move around. I'm always out of breath."

Male, 83, South, Living with frailty

Language

There was great consistency in the language older people used to describe the experience of different stages of the independence scale:

Stage of the independence scale	Language used to describe this stage
<i>Stage 2: Being able to do everyday tasks to maintain the status quo with some minor adaptations or 'light touch' support</i>	"Getting slower" "Feeling tired" "Lacking in strength"
<i>Stage 3: Being almost or totally unable to do the everyday tasks important to maintaining the status quo without (significant) support</i>	"Struggling" "Feeling frustrated" "Feeling low" "Finding things tough"
<i>Stage 4: Becoming almost or totally unable to manage personal hygiene without (significant) support</i>	"Losing control" "Not coping" "Feeling vulnerable" "Feeling weak"
<i>Stage 5: Losing independence entirely and becoming totally reliant on support</i>	"Giving up"

There was also consistency in the language that older people used to spontaneously talk about the 'trigger point' on the spectrum (that is the transition from stage two up to stage three), which typically centred on words and phrases that referred to their mood and state of mind. This frame was interesting, reflecting as it did a commonly expressed belief in the interviews, that the process of ageing is dependent on one's attitude and outlook on life as much as on one's physical state. Among the older people we spoke to feeling 'frustrated', 'low' and that they were 'struggling' emerged as words that resonated particularly strongly.

Articulating the concept of frailty among HCPs and informal carers

Non-specialist HCPs and carers were attuned to the fact that having an independent lifestyle is the biggest motivator for older people in terms of taking action to safeguard their health and wellbeing. Moreover, non-specialist HCPs and informal carers tended to feel strongly that it was their role to support older people in this goal as far as possible.

"Professionally, older people are 80+ but it doesn't always feel like that. It's really dependent on their condition and their state of mind. They just want to go back home and be as independent as they can be. And if they can't then they normally sort of start to give up."

Hospital ward manager, South

In line with older people themselves, these audiences also preferred to articulate an older person's wellbeing in terms of their 'functionality', measured by the extent to which everyday tasks can be completed independently. This was typically driven by:

- **A recognition of the kind of language older people are likely to respond to best:** that is, language orientated towards older people's main goal of maintaining their independence; language that is practical and sensible in its tone, and language that is neutral rather than emotive
- **A belief that this is the most useful way of thinking about older patients' needs:** that is, using terms that are concrete and directly related to the older patients' specific support needs, rather than descriptive or general terms

"The language we use for older patients is mostly in terms of function. It's not especially personal or emotional a lot of the time - it's to the point. We'd say 'to retain their independence, someone at this functionality needs this type of support'."
Hospital ward manager, South

5. Attitudes to support to prevent and manage frailty

Attitudes to support among older people

Most of the older people in the sample reported that they would *not* automatically look for external sources of support on experiencing the clinical symptoms of frailty. Even those who did say that they might look for some support did not consider the GP to be the most appropriate port of call in the first instance. There is a host of factors, which may inhibit an older person from accessing care, but for the purposes of this study we focused on what we felt were two important reasons behind a reticence to seek out support:

1. **Limited understanding of what ‘support’ might look like:** among some older people, impressions of available support tended to veer towards the extreme (i.e. in-home carers and care homes, which both represent a real loss of independence), with limited awareness of any less invasive forms of support;

“I wouldn’t tell this gentleman [in the case study] to go to his GP, no... He can still get about so he doesn’t need a carer or to go to a home. He’s better off managing on his own for as long as he can.”
Male, 79, North, living with frailty

2. **A belief that clinical conditions take a precedence over general physical and mental ‘wellbeing’:** several older people in the sample dismissed terms such as ‘wellbeing’ and ‘quality of life’ as ‘self-indulgent’ or ‘airy fairy’. The belief that doctors - who tend to be highly respected and who older patients feel that they rarely know well - should not be ‘bothered’ with non-clinical conditions was common.

“Why on Earth would I tell my GP it’s taking me longer to do the ironing and I can’t get out into the garden any more?! He’s a serious doctor who I go to when I’ve got an ailment, he doesn’t need to be bothered with that rubbish.”

Female, 73, South (5 on Rockwood Frailty Scale)

As a result, older people tended to say that their first instinct when they notice a reduction in their capabilities would be to look for their own solutions *rather* than external sources of support. ‘Sorting things out for myself’ and ‘making my own decisions’ was seen as critical for maintaining

independence and avoiding ‘spiralling’ into long-term care. Older people also reported the importance of ‘keeping up appearances’ and avoiding admitting that there is a problem to the outside world.

These self-identified coping mechanisms tended to centre around:

- **Small aids and gadgets older people find themselves or are recommended by friends and family:** shopping trolleys, grabbers, walking sticks, non-slip bath mats, reminder post-it notes;
- **Taking breaks and rests:** for example, doing the ironing over several hours with breaks in between;
- **Paying for informal, non-invasive help (for those who can afford it):** gardeners, cleaners, ‘odd jobs men’.

When faced with certain tasks slipping out of reach, and these coping mechanisms no longer being sufficient to ‘get by’, *some* older people said that they would start to become more open to external support. This was much more true of those in the sample who had received some form of external support in the past, either through being picked up by ‘the system’ because of an acute condition such as a heart attack or fall, or because family living nearby might have arranged for some additional support.

These experiences had left these older people with a more nuanced understanding of support, namely that they recognise that support is not solely extreme or invasive, but that it can offer practical solutions to help them maintain their independence. As a result, this group were much more informed about other types of practical support that might be available, such as hand rails in the home and walking frames.

Case study: Maureen

Three years ago, Maureen fell down the stairs at home, causing her to break two ribs. When she returned home from hospital, she was visited by an occupational therapist, who recommended fitting an additional hand rail to assist her walking up and down the stairs, as well as hand rails in the bathroom.

This was all support that Maureen didn’t previously know was available, and that she appreciated, allowing her to come home to recover from her fall rather than stay in hospital. This experience has made her open to asking for more help in the future as and when she needs it.

By contrast, older people who had less nuanced understandings of external forms of support were more likely say that they would continue to try and manage for themselves. This group were less likely to have had direct exposure to in-home support in the past, though were not necessarily any less likely to have received medical treatment.

Indeed, several research participants with ongoing health conditions such as heart conditions reported feeling that they received ‘more than enough

attention’ from HCPs as it is and that any decline in their independence was probably an inevitable and natural consequence of their condition. They also tended to take the view that if there was any way of making ‘life easier’ or ‘coping better’ without much intervention, then a doctor or nurse would surely have mentioned it already as part of a check-up or other appointment.

This group tended to understand support as being synonymous with a total loss of independence and free choice. Consequently, they say that it is something that they aim to avoid for as long as possible, even if they do find themselves moving up the ‘spectrum’ of frailty.

Case study: Akhtar

Akhtar is finding it increasingly difficult to do things for himself, and the furthest he can walk outdoors is now the corner shop at the end of his road. This often makes him feel down and even ‘useless’, but he would never say this to anyone, not even his wife.

Akhtar is managing an ongoing heart condition and feels he spends more than enough time being poked and prodded by medics. His main goal is to stay out of hospital or a care home, and he’d rather keep his head down than get sucked in to ‘the system’. Besides, if there was anything his GP could do, surely he’d have mentioned it by now?

Non-specialist HCP perceptions

Non-specialist HCPs tended to be highly attuned to the barriers to older people seeking support to cope with the symptoms of frailty. Most of the non-specialist HCPs in the sample recognised low levels of understanding of the nuance of support available as a major barrier to older patients seeking support for themselves, and consistently cited older patients’ fear of hospitals and care homes. On top of this, GPs in particular referenced older patients’ unwillingness to raise ‘trivial’, non-clinical issues with them, either out of respect, or because of low levels of concern about holistic health and wellbeing among older people.

“Older patients often like to be formal and respectful. To the point that they’ll carry on doing something, even if it might not be right for them, just because a doctor has told them to do it.”

GP, South, Less than 10 years experience

Building strong relationships with older patients over time was felt to be absolutely critical to overcoming low levels of awareness of available support and unwillingness to raise non-clinical issues with HCPs. GPs in the sample in

particular tended to say that this would provide an opportunity for much more general and personal conversations about their patients' lives, ability to cope, and potential sources of support. Without this rapport, they suspected that similar conversations would be treated with suspicion by most older patients.

Several GPs expressed frustration about the difficulty of establishing and maintaining these relationships in practice given short appointment times and busy schedules.

"It's so much easier with a patient I've had for some time because I can see changes in them over time, and I don't have to ask. I'm fortunate because most of the people here have lived here their whole lives and always will. But in more urban areas with bigger populations it's much more difficult."

GP, North, More than 10 years experience

Attitudes of informal carers

Informal carers were also highly conscious of barriers to accessing support among their older relatives, and several reported 'taking matters into their own hands' to overcome them. These research participants tended to have a strong sense of, and interest in, older people's holistic health and wellbeing, even if they did not necessarily use that language.

Notably, this included older informal carers, such as spouses of older people, who tended to take the view that an older person's ability to complete day-to-day tasks independently *is* of interest and importance to medical professionals (even if they might not make this link when thinking about their own health and wellbeing).

"I used to put off going to the doctors but my wife made me go in the end. I was afraid of learning the truth but she put me right."

Male, 69, South, living with frailty

Several of the informal carers in the sample could recount instances in which they had made themselves responsible for older people accessing frailty services. This included making appointments, accompanying the older person to the appointment, and speaking on their behalf by listing their health and wellbeing challenges in detail.

“We’ll get into the appointment and the GP will ask him how he is and he’ll say ‘I’m fine’. But he’s not fine! So that’s where I’ll take over and go through everything.”

Female carer

Attitudes to Comprehensive Geriatric Assessment

Awareness of Comprehensive Geriatric Assessment (CGA) was extremely low among all audiences:

- Public audiences, including older people themselves and informal carers, tended to be totally unaware of the role of CGA;
- Perhaps surprisingly, awareness of CGA was also relatively low among non-specialist HCPs. For instance, although several of the HCPs who took part in the research could describe a similar kind of approach available in their practice (e.g. a joined-up service looking at an older person’s overarching support needs) none were familiar with the ‘CGA’ label.

“The idea is that support should be more integrated, I know, and consultants from the nearest hospital are doing a lot more to try to get out into the community so it’s more joined up. But I haven’t heard it called that at all, no.”

GP, North, More than 10 years experience

The CGA’s title emerged as a major barrier to public engagement and ultimately their understanding of the approach. Among research participants, the strongest and most consistent criticisms included:

- The length and complexity of the three words and the title overall as a result
- The inclusion of the word ‘geriatric’, which was universally rejected by older people and carers, often with some offence, as it is associated with very old people who are nearing the ends of their lives
- The acronym CGA, which communicated very little sense of what the service might offer and was easily forgotten, for instance, by the end of each interview not one older respondent could recall the name of the service, or the acronym

Alternative suggestions tended to be simpler, and much more colloquial. Older people and informal carers who participated in the research advised that an alternative name should:

- Be less clinical and medical sounding
- Be short, simple and memorable

- Indicate that the service is aimed at the over-65s without the inclusion of ‘geriatric’, for instance, simply by providing a minimum age, or referring to ‘older people’ explicitly
- Be positive, and position the service as something that an older person is shaping and driving, rather than being a passive participant

“How about an over-65s MOT? That sounds approachable and everyone knows what an MOT is.”

Informal carer

Despite objections to its name, public audiences could identify several positive aspects of the CGA service in principle. This was particularly true of carers, who tended to welcome the service being comprehensive, holistic and joined-up in its approach.

Some older people also viewed the involvement of specialists as a positive feature of the CGA service. However, there was notable confusion among the older people who participated in the research, as to whether the ‘specialists’ would be medical consultants such as cardiologists, or specialists in support for older people including geriatricians, occupational therapists and district nurses. Of the two interpretations, the former tended to be received more favourably, and seen as an opportunity to see real experts who could identify potential health problems before they develop.

There were, however, several limitations that they felt would make them unlikely to ask for the service in practice, including that:

- Older people can struggle to understand the links between a seemingly disparate collection of services
- There is some concern and confusion about how someone would access the service; some older people were concerned about how long the assessment would take, which specialists they would see, and what effort would be required on their part.
 - These concerns were especially true of older people who were already managing serious health conditions and who said that they wanted to avoid further ‘hassle’ and medical intervention in their lives
- The end goal and ultimate benefit of the assessment could be unclear to older people, especially those who lack nuanced understandings of what support can look like beyond carers and care homes.

“Having different specialists looking at different parts of your life sounds like a lot of effort and tiring.”

Female, 72, South, Living with frailty

Implications

Our hypothesis is that to encourage older people to engage with preventative strategies and frailty services, it will be important to:

- Build on existing beliefs that ‘living with frailty’ is not an inevitable or irreversible part of getting older and emphasise that it is possible to maintain independence by engaging with strategies and services
- Build on existing awareness of the risk factors for frailty, but raise awareness of lesser-known risk factors such as being overweight
- Provide a comprehensive overview of services and solutions that are available and how to access them, particularly less invasive, smaller scale services that demonstrate that getting ‘support’ doesn’t mean going into a care home
- Raise awareness of Comprehensive Geriatric Assessment (CGA) and clarify the value that it offers
- Encourage older people to talk to their HCPs and to enquire about services to which they are entitled, and also require HCPs to engage older people on the topic, using language that resonates with older people in order to assess needs and help put services in place.

6. Appendix

Research Objectives

What does the term ‘frailty’ mean to these audiences and how far do they identify with it?

- How do they define the term?
- What are associations with frailty?
- *For HCPs specifically:*
 - In what circumstances do they use the term? How widely/narrowly do they use the term?
 - How useful a term do they find it?
 - What might they use instead?
- *For older people specifically:*
 - What elements of frailty do they identify with vs. not identify with?
 - What are barriers and drivers to identifying with frailty?
 - How can the concept of frailty be best described and presented in order that older people feel comfortable to identify with it (for example using alternative terminology)?

What are older people’s awareness and experience of preventative strategies and specialist health care services?

- Are older people sufficiently engaged with the risks and preventative strategies for frailty?
 - What are the key barriers and drivers to acting on health, wellbeing and social factors that contribute to living with frailty?
 - Specifically, what are the barriers and drivers to demanding care that may help to, for example, mitigate the risks of surgery or to get the best out of a hospital admission (e.g. requesting a comprehensive geriatric assessment)?
- What specialist healthcare services are older people aware of?
 - How have they become aware of these services?
 - Have they accessed these services personally?
- To what extent is the term frailty a barrier to older people accessing specialist healthcare services?
 - How might any negative impact from using the term be mitigated, for example by using alternative terminology?

What are HCPs’ perceptions around older people’s care and the role of older people specialists?

- Is there any indication that this audience consider that there is “there’s nothing we can do” for older people living with frailty?
- What is the understanding around the outcomes that frail older people want to achieve from care?

What is the optimum way to communicate to older people on this issue?

- Which messages are most effective at engaging older people and motivating them to take appropriate action?
- What materials would convey the messages best, in what format and through which channel(s)?

Rockwood Frailty Index (as used to identify participants)

<i>Statement</i>	<i>Rockwood Score</i>
I am active and have good energy levels	Score of 1
I exercise fairly regularly	
I do not have any medical conditions or symptoms that affect my day-to-day life.	Score of 2
I do some exercise, more so when the weather is good	
I have some medical problems but for the most part my symptoms do not have a big impact on my day-to-day life.	Score of 3
I am not regularly active (aside from walking)	
I am able to get by on my own but I tend to take quite a long time to carry out day-to-day tasks	Score of 4
I get tired during the day	
I can carry out most day-to-day tasks by myself but need some help/support with things like heavy housework, transport and/or managing my finances.	Score of 5
If I am going out of the house I really need someone to come along with me to help.	Score of 6
I find it difficult to use stairs.	
I need help to bathe/shower.	
I am now dependent on someone to come in and help me with my personal care - I am no longer able to manage this myself	Score of 7
I am now completely dependent on a carer and/or am terminally ill	Score of 8/9

Overview of discussion content

Research among public audiences:

- At the beginning of each interview or group discussion, pen portraits were used to prompt discussion around some of the key symptoms associated with the clinical condition of frailty, and to explore how they related to participants' own lifestyles (please see below).
- There was also a section exploring the daily routines of those living with frailty and any changes that they have noticed over time, in

order to understand how they have experienced getting older and the type of language they use to describe this process.

- The final section used a more direct form of questioning to understand participants' awareness and experience of preventative strategies and specialist healthcare services.
- Interviews ended with a closing section in which participants were given the opportunity to ask any questions.

Pen portraits used in interviews and groups with public audiences

Joy is 76 and loves spending time with her daughter and grandchildren. She doesn't walk very quickly and struggles to keep up if they go out together. She also feels quite unsteady on her feet and has nearly tripped up a couple of times when she's been out with her daughter.

After spending a day with them she feels exhausted and still feels tired days afterwards. She sometimes feels quite low and finds herself crying for no particular reason. Joy doesn't want to admit to her daughter that she struggles.

Derek is 79 and loves gardening. He used to be able to spend most of the day in his garden but he doesn't have the energy he used to and it is getting overgrown. He also struggles to carry his groceries home.

Derek has a much smaller appetite nowadays and it can sometimes seem like an effort to make a proper meal for himself. He has gradually lost weight over the past 5 years or so.

He can be quite forgetful - not remembering where he's put his reading glasses or struggling to remember someone's name.