

# Frailty, Diversity and Communication

*Improving our communication  
based on insights from the  
People's Definition of Frailty*



# People's Definition of Frailty

London Clinical Network for Frailty – Public & Patient Voice Team

**Frailty** is a word that may be used to describe your state of health or that of someone you care for.

Being described as '**frail**', having '**frailty**' or '**living with frailty**' may occur when your body loses its natural reserves. This may be due to a range of factors such as illness, disability or aspects of the ageing process.

This means frailty is:

- **Sometimes complicated:** it is not inevitable or a disease, or a list of specific conditions or symptoms
- **Individual:** it is different for everyone
- **Varied:** a range of things that may interact and impact on each other in ways they didn't use to
- **Changeable:** it can improve or get worse

Whatever the reasons, you may find:

- **You need** a bit more help to do the things you usually did
- **You take** a bit longer to 'bounce back' from something simple, like a common cold and one health problem may lead to another
- **You tire** more easily or feel less strong than you used to
- **You may feel** more apprehensive and less confident

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# Introduction

Experiences of frailty are at once universal and unique. We can have meaningful conversations about frailty across divides of age, culture, language and experience. At the same time, these divides make a difference. How people experience conversations about frailty is shaped by their backgrounds and circumstances. Unless we are reflective, communication about frailty may not work as well for those already minoritised or disadvantaged.

**Our goal is to help clinicians to have richer conversations about frailty with as diverse a range of individuals as possible.**

The purpose of this work is to engage with a broad range of people beginning to experience frailty and related health services, to support this reflection. Our goal was to test the definition of frailty and enable subsequent development of guidance to help clinicians to have richer conversations about frailty with as diverse a range of individuals as possible. To achieve this, we have sought to

understand a wide range of people's thoughts, feelings and vocabulary around frailty and to test the People's Definition of Frailty through a series of interviews and focus groups. The findings of which can be read below.

In this process, we are building on significant engagement that has happened already, driven by the London Clinical Frailty Network. In particular, we are building on their people's definition of frailty and on the background of work through which this definition was co-constructed.

In taking as our focus the way clinicians communicate with people about frailty, we are referring to any member of health and care staff directly involved in the care and treatment of individuals.

## The People's Definition of Frailty

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## **About Care City**

Care City was commissioned by the London Clinical Frailty Network and worked in partnership with UCLPartners on the research and development of this report. Care City is an innovation centre for healthy ageing and regeneration. Our mission is a happier, healthier older age for East Londoners. We pursue this mission by working as an innovation partner to East London's health and care system. We do research, innovation and development work of local benefit and national significance.

## **About London Clinical Frailty Network**

London Clinical Frailty Network is one of the London Clinical Networks (NHS London), created in January 2019, to work with partners across sectors to improve services for people living with frailty. The Network ambition is to enable people living with frailty to lead as healthy and active a life as possible for as long as possible.

## **About UCLPartners**

UCLPartners is one of 15 Academic Health Science Networks (AHSNs) across England and brings together people and organisations to transform the health and wellbeing of the population across parts of London, Hertfordshire, Bedfordshire and Essex.

# Our Approach

To test the London Clinical Frailty Network's 'People's Frailty Definition' and people's perceptions of frailty, we interviewed 93 people (77 women and 16 men), engaging them through conversations both via telephone, virtual meetings and focus groups. The age ranges were from 33-90. In each conversation, we began with a general conversation or activity about ageing and health, before moving on to introduce the notion of frailty and a more detailed look at interactions with the

health system. In this way, the conversations became semi-structured interviews and focus groups as they developed, having begun with very simple questions and activities. The first, less structured part of this process is just as important as the semi-structured part. It builds people's confidence to speak, demonstrates that we are genuinely interested in their experiences and helps to surface insights that we did not know to ask about directly.

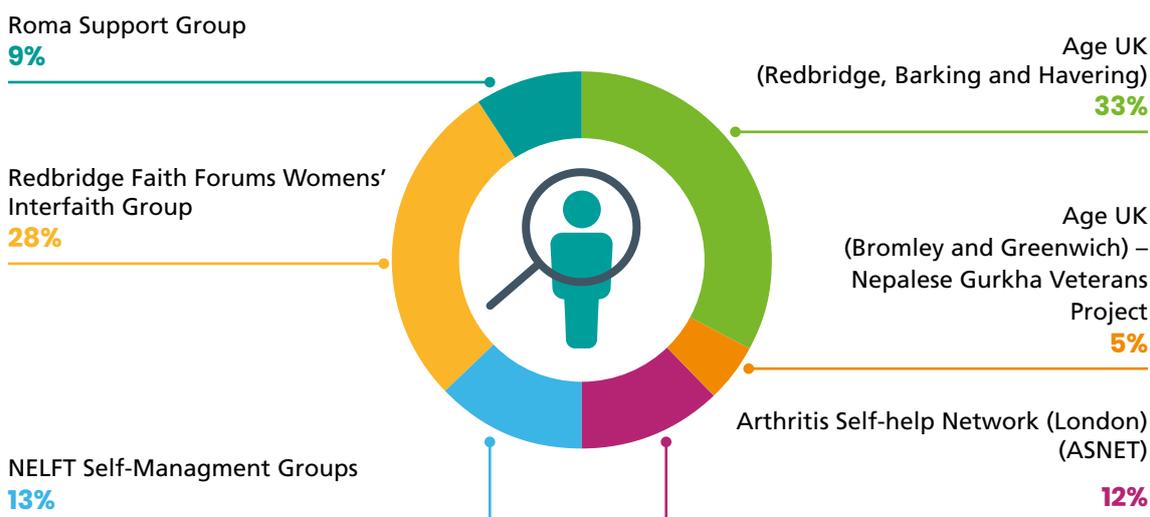
**It demonstrates that we are genuinely interested in their experiences and helps to surface insights that we did not know to ask about directly.**

We worked with a range of groups to set up virtual focus groups and individual interviews based on those we could access during the pandemic restrictions. Where virtual conversations were not possible interviews were held by telephone.

We held 12 focus groups; 10 groups participated in online meetings and 2 by telephone conference calls. We were also able to interview 5 people individually by the telephone and 10 individuals through virtual meetings. These interviews included people with learning disabilities and their families, travellers and people who are homeless.

We adapted our methods of communication with groups and individuals according to their preference of medium and ensuring accessibility for people with impairments, disabilities and language barriers.

## Focus groups breakdown



## Gender breakdown



## Medium of conversations



# Frailty and Communication

“Frailty may occur when your body loses its natural reserves. This may be due to a range of factors such as illness, disability or aspects of the ageing process. This means frailty is sometimes complicated, is individual, and is varied and changeable.”

# Frailty and Communication

Frailty is personal and complex. While clinicians need to be alert to the ways in which class, race, gender, language, religion, sexuality and other differences can create systematic disadvantages for some people, there are few hard and fast rules about these relationships. However, our conversations suggest that there are a range of different fears, challenges and barriers that people may face in seeking to communicate about frailty, and that these are more likely and more significant for minoritised and disadvantaged people.

Work around frailty and communication is not new. The people's definition of frailty, co-constructed through the work of the London Clinical Frailty network, is as follows:

**“ Frailty is a word that maybe used to describe your state of health or that of someone you care for. Frailty may occur when your body loses its natural reserves. This may be due to a range of factors such as illness, disability or aspects of the ageing process. This means frailty is sometimes complicated, is individual, and is varied and changeable. ”**

**The question is, what other tools help to describe frailty and help individuals to describe their own experiences of frailty?**

This definition does not work perfectly for everybody, but no definition ever could. It works well as one 'tool in the toolbox' for communicating about frailty. The question is, what other tools help to describe frailty and help individuals to describe their own experiences of frailty?

This document seeks to offer some answers to this question for clinicians. In the process, it also highlights a set of fears and barriers that people can face in conversations about frailty and recommendations for overcoming them.

## Fears

- Fear of labelling
- Fears about losing independence
- Fears of medicalisation
- Fears about not being able to access health and social care

## Barriers

- Barriers created by cultural differences around ageing
- Barriers of understanding and sense-making
- Barriers of language
- Barriers around capacity to take and chase-up actions
- Barriers to information about what is available and what to do next
- Unable to navigate the systems

These fears and barriers are more likely to occur for minoritised and disadvantaged people, but there are no hard-and-fast rules about which will be significant for an individual and how they will be experienced. Clinicians should be aware of the evidence base and curious about each unique individual. The most important thing is to build the communication skills and vocabulary that help them to personalise conversations about frailty for each individual.

In this document, we look at four elements of communication around frailty:

1. **Introducing and describing frailty**
2. **Supporting a rich conversation about frailty**
3. **Feeding back the results of a frailty assessment**
4. **Concluding and following up a conversation about frailty**

Across these four elements, we have broad advice for how clinicians might frame approaches to communication to account for the diversity of people they will encounter:

1. Introducing and describing frailty – **understand and reassure**
2. Supporting a rich conversation about frailty – **communicate carefully and invite ‘teach back’**
3. Feeding back the results of a frailty assessment – **Contain emotion and share decision-making**
4. Concluding and following up a conversation about frailty – **translate into meaningful, supported action**

Beyond these broad frames, we suggest a set of design principles for rich conversations about frailty:

- Understand and validate the broad range of reactions to the idea of frailty
- Recognise that the idea of frailty can be most challenging for younger people and/or people with milder frailty, and consider the lens of ‘health and well-being’ or ‘vulnerability’ as an alternative if necessary
- Use the language of experience – how it feels – to help people grasp frailty
- Build on people’s own vocabulary for frailty – understand what frailty means to them
- Hold the strong emotions and beliefs that conversations about frailty can stir
- Focus on areas of strength and confidence around people’s health and independence
- Co-construct goals and decisions about the future
- Pro-actively help people to access the support they need with and *beyond* the health system

## 1. Introducing and describing frailty

Some people need significant encouragement about the purpose of a focus on frailty. However, while people can be initially uncertain, a significant majority are open to supportive conversations about frailty.

In introducing a conversation about frailty, a clinician may initially need to focus on providing reassurance and understanding. Clinicians may need to be particularly alert to fears of labelling, fears of medicalisation, and to the complex effects of different perceptions of and cultures of ageing.

Crucially, some defensiveness or resistance to the notion of frailty is normal, because of the range of different views of health, of themselves and of the future that people hold. Certainly, many people do not like the word itself. This uncertainty from people is very often an early form of engagement with the idea of frailty, as they work to make it their own and to make it useful.

### Diverse responses to 'frailty'

People do not come to conversations about frailty with either a medical perspective on frailty or as a blank slate, waiting for frailty to be explained. People have their own notions of frailty. Very often, people think of frailty in the ways clinicians understand severe frailty. They may use the word 'frail', for example, to express concern about someone who is ill, whose health is deteriorating or has become less mobile.

**“ My father was ever so frail in the last weeks of his life. ”**

**“ When I had pneumonia, then I was frail. ”**

People also often think about frailty specifically in relation to mobility.

**“ That describes me – mobility wise I feel like I am finished. I'm 64 and I can't... walk very far, am so slow. If people looked at me they wouldn't think I was frail, but I am. ”**

The people we spoke to about frailty agreed that there are different cultures of ageing, with particular differences by ageing and ethnicity. For example, there was a sense that people with connections to East Asia or the Indian sub-continent were more positive about ageing and a stronger association between ageing and wisdom and status. However people were also strongly of the view that varying cultures are complex and multi-faceted and that multi-cultural Britain creates a blend of values which need to be considered.

The people we spoke to also said that for any one individual, greater commitment to caring for them is as likely to be experienced as pressure or guilt as it is the security of being cared for. As a result – although clinicians may be part of their own localities and individual populations and know them deeply – it is important not to make assumptions about perceptions of frailty.

The majority of the people we spoke to did not like the word frailty – to varying degrees – in the way that the health system is using it. A few people saw it as disrespectful or offensive. People were unlikely to describe themselves as frail – even where they were experiencing mild frailty – and they were a bit more likely to describe themselves as 'vulnerable'.

In fact, people made cases for the use of various words – vulnerable, elderly, lacking resilience or robustness – but nothing about the conversations we had suggests that those words would have had more universal appeal in place of frailty. As we describe in the next section, this response to the word frailty is important to be aware of but not to be over-anxious about – it is not an insurmountable barrier to good communication.

“ *I don't agree with that word, its rude, belittling. Instead, find out what I want, find out how people want to be addressed, just ask me and relate to me as me.* ”

## Fear and the idea of frailty

The idea of frailty can prompt fearful reactions in a range of ways. However, our conversations suggested that there are two related fears that it is particularly important for clinicians to be mindful of.

These are fears of:

- Labelling and medicalisation
- Losing independence

Many people we spoke with felt they had suffered as a result of being **labelled** in the past, in one way or another. For some people we spoke to, their sense of the effect that labelling has had on their lives was very strong, and it is important not to under-estimate this feeling. Negative experiences of labelling and associated fears are likely to correlate very roughly with disadvantage, so this is particularly important.

For clinicians invested in the study of frailty, engaging with fears about labelling may be difficult to engage with. One of the foundational ideas of the study of frailty is that unless we can name and describe frailty and people with frailty, we cannot learn about them and help them. However people are worried about some of the negative effects of labelling that are not essential to this process of learning.

“ *Once you've been categorised as 'frail', that's then another label you have to battle.* ”

There seem to be at least two elements to the fear of labelling. The first is about labels' social effects on people's social status, dignity and privacy. The second is about the institutional effects of labels – the way bureaucracies can label people, and then judge people by these labels rather than their own unique circumstances.

People are also fearful of the way the label of frailty might take them down a path towards greater **medicalisation** of their health and well-being.

“ *Fears? Going into hospital and not getting back to how you were.* ”

Clinicians may be very conscious of pressure on time and resources and a need to allay demand for healthcare. However, in our interviews and focus groups, there were examples of people worrying that clinicians may be biased towards more, rather than less, intervention and medicalisation, and it is important to be aware of this anxiety.

While these fears are very real, they are also largely open to reassurance if they are properly acknowledged:

- People want to be understood as an individual and not to be judged. They want to be explicitly reassured that the issue of ‘labelling’ is understood, and that conversations about frailty are about understanding them and helping them.
- People have themselves suggested practical examples of the purpose of the notion of frailty:
  - The ability for hospitals to spot people quickly who might need more tailored care.
  - The ability to give people an ‘express’ service when they are brought to hospital (because of the greater negative effects of being hospitalised, etc).
- Relatedly, to the extent that it is possible, people want to be reassured by clear statements about privacy and information-sharing.
- People are very responsive to the idea that conversations about frailty are about prevention and protecting their health and independence. For example, people are frustrated about the idea (repeated to us numerous times) that ‘you get falls prevention when you fall!’.

People also hold fears about their ability to **access** the healthcare they need. This fear is not prompted by conversations about frailty, but it colours their responses. Many people we spoke with were concerned about poor access to health services generally and by a lack of deeper, longer conversations about the complexity of managing their health overall.

People are very conscious of the impact of COVID-19 on their health and mobility, and anxious about the ways in which this has further complicated their access to healthcare (despite huge efforts from the health system).

“ *My doctor will say, ‘I’m sorry – we can only talk about one thing or two things’.* ”

“ *If you go to hospital A&E with a fracture, they look at the fracture, they won’t look at other conditions the person has.* ”

### **People with mild frailty**

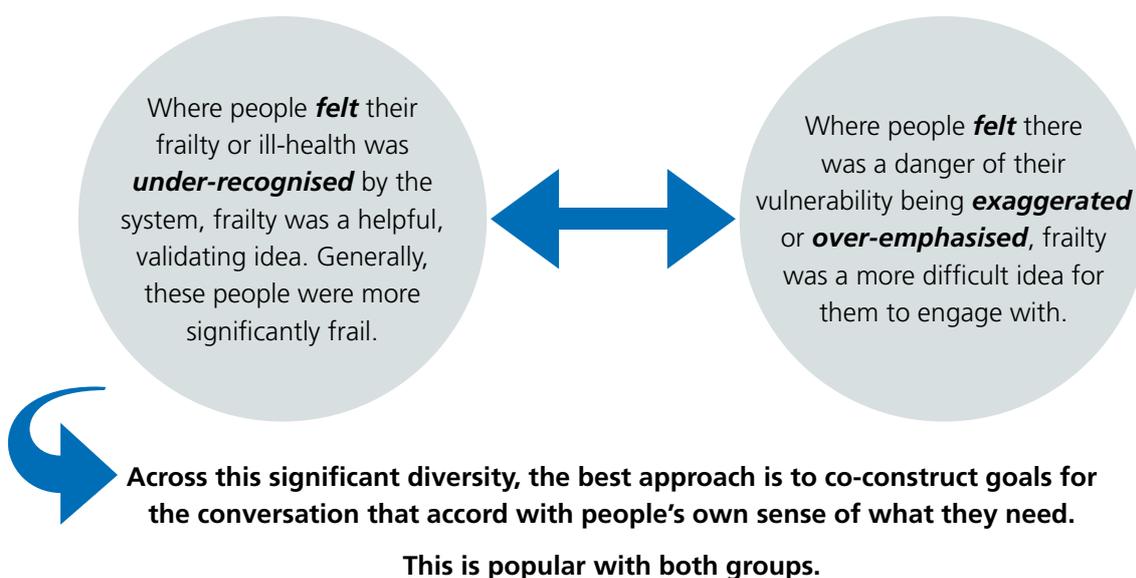
While there were few patterns in responses, there did seem to be a pattern in people’s responses to frailty by their health status.

While it is perhaps counter-intuitive, people who were more mildly frail or approaching frailty were more resistant to conversations about frailty. For them, the dangers of their vulnerability being exaggerated were more visible, and the benefits of a conversation about frailty were less clear. It was for these people that the conversation about frailty most clashed with their pre-existing notion of what frailty meant. There are perhaps some parallels here with experiences around end-of-life discussions – people are often better able to engage with these difficult issues as they become closer and more real for them.

In contrast, people who were more significantly frail were more open to discussions of frailty. As well as naturally being more at ease with discussions of their own frailty, it was easier to see the practical benefits of the conversation.

Although we did not test the phrase 'pre-frail' with people, based on our findings we would not anticipate it to generate a very positive response. It is for the healthiest people that the lens of frailty may have the predictably negative effects on a conversation. While this is not primarily an equality consideration, for people who approach frailty younger, this may be a particular challenge.

For some younger and/or people with mild frailty, they were keen to talk about simply their 'health and well-being' rather than frailty – and some were happier to describe themselves as vulnerable than frail. There may be a trade-off here for clinicians to manage between protecting the feelings of this younger/healthier group and the clarity of the conversation. But it is important for clinicians to be conscious of this pattern and advocate improved self care to reduce the risks of increasing frailty.



### Recommendations: Introducing and describing frailty

For a productive conversation about frailty, some people will need reassurance and to hear positive messages about its purpose and potential benefits.

Conversations about frailty should be:

- **Positive** – about building on what you are doing to stay well, and not about making assumptions based on age
- **Private** – not about labelling or interfering in your life
- **Practical** – The word frailty is not important – it's about what is helpful for you. You do not *feel* frail, and we want to help keep it that way.

The purpose of a conversation about frailty is to ensure that your care is:

- **Preventative** – helping you stay on top of your health
- **Tailored to you** – giving you the healthcare you need
- **Focused on the whole person** – paying attention to your wishes and what helps you to stay healthy

## 2. Supporting a rich conversation about frailty

Once a clinician has introduced the concept of frailty, they can engage an individual around the issue. Some people will particularly benefit from help to make sense of frailty in the context of their own lives and language/narrative. A clinician's job in this context may be to communicate carefully, listening to people's own vocabulary around frailty, personalising as much as possible and helping people to connect the idea of frailty to their own lives.

As we saw, many people dislike the word frailty. Where people have concerns or questions, the best approach is to seek to understand and reassure. Building on this reassurance, a clinician can seek a conversation about frailty. One route in to this conversation is the People's Definition of Frailty.

“*Frailty may occur when your body loses its natural reserves. This may be due to a range of factors such as illness, disability or aspects of the ageing process. This means frailty is sometimes complicated, is individual, and is varied and changeable.*”

For some people, this definition will be helpful, and for some, less so. As a result, it is important to treat this definition as **one tool in the toolbox**. Indeed, it may be more productive for clinicians to think of the People's Definition of Frailty as the **first and best description of frailty, rather than as the definition of frailty**. If it does not land well with people, there are also other descriptions they can offer.

The risk in relation to the definition seems to be that the clinician falls into one of two conversational traps, and this risk may be greatest where the cultural backgrounds of clinician and individual are furthest apart:

- First, it is easy to drift ever so slightly into a **debate** about what frailty means. While there were no striking patterns to responses to the word 'frailty', there was very little evidence of flexibility in these perceptions. People's feelings about terms such as frailty are not easy to predict and may not follow an obvious logic. However, that does not mean that clinicians can easily redefine these terms for people.
- Second, it is common to define a technical term and then apply it, immediately using the word in its technical sense in conversation. In most conversation, this does not happen, and many people have little or no experience of rapidly internalising and applying a definition like this. It is easy for a clinician to drift into conversation which is **technical** in this sense, which can create confusion.

As we tested out other descriptions of frailty with people from a diverse range of backgrounds, there were no clear winners. There were some passionate suggestions, but they were no more universally popular ones. However, there did seem to be a clear trend – the language of experience proved more accessible to people than the language of ideas.

Trickier	Easier
...a combination of different illnesses...	...small things can have a big impact...
...the interaction of different illnesses or body systems...	...it can take you longer to bounce back...
...something that is complex...	...vulnerability, lack of robustness, lack of resilience...
...frailty is a syndrome, health state or condition...	...one illness can lead to another...

Perhaps this is simply about keeping the language around frailty as straight-forward as possible. However, it also speaks to the emotional element of a conversation about frailty. It would be easy for clinicians seeking to open a conversation about frailty to feel defensive, or that people’s objections to the word or the idea are shooting the messenger. Effective communication about frailty is also about seeing that this too is a conversational trap – to help people think through frailty, a clinician needs to stay focused on the individual and what is useful and productive for them.

### Helping people to describe frailty for themselves

In seeking to understand frailty, people seemed to be trying to make it their own – to make sense of it in the context of their own lives. Understanding frailty seemed to be tied very closely to the act of saying what frailty was for me, in the context of my life. It seemed that conversations that allowed people to do this were conversations that fostered understanding and engagement. The best way to show people what frailty means is to show them what it means for *them*.

**The best way to show people what frailty means is to show them what it means for *them*.**

Crucially, this approach to fostering understanding and engagement is resilient to diversity – it works for people with a broad range of different stories and contexts. As a result, much of what we heard from people about how to communicate around frailty effectively was reminiscent of the work about ‘shared decision-making’ in health.

However, diversity does mean that clinicians must be careful to frame frailty in the right way for the right people. For example, for many people we spoke to, the notion that frailty made it ‘tougher to bounce back’ after an illness or setback was very helpful and engaging. However, for some, living with illness or disability, the idea of ‘bouncing back’ felt a very long way off.

### English as a barrier

For some of the people we spoke to, English was not their first language, and this raises questions about language and access to interpreters as a barrier to rich conversations about frailty.

It is vital to have accessible translated materials and to ensure access to interpreters where needed. With the shift to remote consultations, interpretation is changing quickly, and there are significant opportunities to use new technology to grow access to interpretation where it is required.

However, the language barrier is also a broader issue than interpretation. The best services focus on communication as a core part of their business. Professionals value information about how individuals best communicate alongside clinical information. Where and through what channel should conversations about frailty happen? Do family members or carers have a role to play in communication? The best services capture this information at the earliest opportunity, to support clinicians to communicate effectively with a broad range of individuals.

More generally, the principle is that more accessible communication is also better for people with English as an additional language – as well as for people with low health literacy or learning disabilities. Keeping descriptions simple, focusing on the descriptions that prove useful and engaging, understanding and building on people's own vocabulary for frailty, focusing on areas of strength, co-constructing goals – these principles work well for those less confident with English as well as everyone else.

## Recommendations: Supporting a rich conversation about frailty

The People's Definition of Frailty is useful, but in seeking to communicate with a diverse range of individuals, it is best to see this as *one description* of frailty, rather than *the definition*. It is one tool in the toolbox.

*Understanding frailty for you:*

- *With gradual increases in frailty, small things can have a bigger impact on your health and it can take longer to bounce back. Because of that, keeping well is important.*
- *We want to understand this for you – what 'small things' should we be looking out for and how can the health and social care system best help you bounce back?*

When talking about frailty, it may be helpful to draw on the new

### Shared decision-making NICE guideline (NG 197):

- 'Chunk and check' (breaking down the information that you want to discuss, and that you need the person to understand, into smaller, more manageable forms rather than providing it all at once and checking their understanding of it) the content you want to share about frailty
- Ask people to 'teach back' what they are hearing, framing it in their own words, and build on this formulation in the conversation where possible
- Offer them the opportunity to share anything else that they want to talk about

*Thinking about what would make this conversation helpful for you:*

- *What does independence mean in your life and how can we help to protect/ keep it?*
- *How might we help you stay active and on top of your health?*
- *What worries do you have about maintaining your health and independence that you would like to talk about?*
- *Ask them if there is anything else they would like to discuss*

At the end of the meeting summarise the conversation and together make a plan for the next steps.

### 3. Feeding back the results of a frailty assessment

In talking to people from a broad range of backgrounds beginning to experience frailty about their own health and independence, and about their future we were struck both by the huge range of attitudes and perceptions we heard from people, and by some common patterns.

A strong minority of the people we spoke to had a sense of youthful invulnerability. Many described themselves – in various ways – as children of the Sixties, who had always lived with finger-wagging about their lifestyles. The danger seemed to be that conversations about frailty might seem like more of the same ‘finger-wagging’ – best ignored rather than heeded. Again and again, people said that what mattered was staying ‘young at heart’ – active in mind and spirit as much as body.

“ *What matters is that you’re young at heart.* ”

“ *We were the first teenagers, really.* ”

“ *We don’t seem old we seem young.* ”

For other people, conversations about frailty prompted much more anxiety, and for some they were even ‘shocking’. Frailty brings risks to people. The fewer **resources** people have, the less they can do to mitigate these risks, and they have more to fear. For some people, having fewer options and resources means they have less reason to be pro-active about their health.

More generally, there is **fear** in talking about frailty. People regularly talked about the shock of the idea they were frail. This was about facing mortality, but also practical concerns about driving licences, the effects on people they care for and of disruption to their lives.

“ *Some people have to make really hard choices when they realise they are frail – it’s dangerous – it’s very difficult to accept.* ”

“ *If I was told I was frail, I would be shocked, but I would rather know.* ”

“ *It is a reality-check that you are entering the later stages of your life.* ”

However, people with fewer resources or more to fear from frailty did not necessarily present with greater anxiety about frailty. It would be easy to think that there are two types of people; those who are fearful about frailty and its effects and those who are very confident. We do not think that is correct. Many of the people who talked about feeling ‘young at heart’ seemed to be working hard to maintain morale and confidence around their health. People often had similar fears and similar desires to tackle them with positivity and optimism – people varied a lot in their ability to sustain that positive mindset.

For those with a stronger outward sense of invulnerability, it would be tempting to think that they need a stronger ‘reality check’ to help them to see the value of healthy behaviours. Our sense was that – whether people share bluster or anxiety – conversations about frailty are inherently challenging, particularly for those with fewer resources or less family support. This suggests a need for clinicians to work with this confidence rather than against it.

## Frailty and motivation

The route to engaging and motivating healthy behaviour is not through fear and anxiety about ageing. For most people – whether it is visible or hidden – this fear is already there, and can easily become too much for them.

As a result, clinicians need to work with people to find positive motivators that work for them. The first and primary motivator for the people we spoke to was **independence**. For many people, beyond frailty, there is a deep concern about independence. Help to retain independence is highly-prized, because it impacts not just individuals but whole families and friendship groups.

A second clear motivator was mobility. People talked about the range of barriers to their own mobility, including:

- Fears about incontinence
- Fear of falling
- Lack of access to mobility scooters
- Fear of losing disability benefit

## Frailty and data

People were very keen to hear data *about them*, rather than medical information about ageing. From online experiences to simple interactions like an electricity bill, they were used to services knowing a lot about them. This seemed to connect back to the concern about labelling. To honour the promise that they are not being labelled, some people needed clinicians to demonstrate that they were working from medical information about them as an individual, rather than basing decisions on general evidence about ageing.

“ *My age is general – I want you to look at the specifics about me.* ”

## Recommendations: Feeding back the results of a frailty assessment

Introducing the results of a frailty assessment:

- Contextualise the assessment around people’s sense of what frailty means for them and their aims for the conversation
- Be clear around data and that people are not being judged or labelled
- Recognise that people may be feeling fear or anxiety about frailty, and daunted by the task of accessing the help they need
- Work with rather than against people’s sense of youthfulness or optimism, linking this to action
- Dedicate sufficient time to talking through actions and next steps, making as clear and specific actions as possible about what the individual and clinician will do next
- Anchor people’s actions around something encouraging or habit-forming; peer support, feedback, routine, etc
- Ask about the support people need to be able to take action

## 4. Concluding and following up a conversation about frailty

Some people will need pro-active help to access the support they are entitled to from the health system and other public services. In this context, the role of the clinician in concluding and following up a conversation about frailty is to help translate the conversation into meaningful, supported action.

To take action following a conversation about frailty, follow-up within the health system may be most straight-forward. Many of the things people most need are:

- Outside of the health system
- Complex in terms of eligibility
- Under-resourced

Perhaps the most important example of this is about access to social care. Many people we spoke with talked about the cost and complexity of accessing appropriate care and support, and clearly this is a very significant factor in people's experiences of frailty. This is an extremely important issue for many people but particularly for more disadvantaged people.

It will vary from place to place how significant a frailty assessment might be in shaping access to social care, but in some places they do play an important role. Understanding this relationship locally – and helping people to understand it – could be vitally important.

**...they did not know what wider support was available to them to help them to sustain their health and independence...**

Other kinds of follow-up may also be important for people. For people who are struggling with social challenges such as isolation, there may be third sector partners locally to whom they can be referred. Equally, adaptive equipment at home may help to sustain people's independence.

Crucially, many of the people we spoke to said to us both that they did not know what wider support was available to them to help them to sustain their health and independence and that they would not know who to ask. The more conversations around frailty are backed by strong systems for helping people to navigate what's available and clarity about how to use them, the better.

One source of confusion for people seems to be around support for mobility. There was significant interest in strength and balance classes, falls prevention and falls risk assessments for the home, but real confusion about what people were entitled to. Building on this interest and pro-actively helping people to resolve these questions can make a significant difference.

## Frailty and primary care access

In general, inequalities of access to healthcare are much smaller than inequalities in health outcomes. People do have fears about healthcare and challenges in accessing it, but they should not be over-stated.

However, this is not true for four groups, who face significant barriers to accessing primary care:

- People who are homeless
- Travelling communities
- People with learning disabilities
- Asylum seekers

## Frailty and homelessness

Frailty is tough for this group to engage with because their lack of access to housing and appropriate care undermines the credibility of conversations about frailty. For example, many people with frailty are in high-support need hostels, which are not CQC-registered, and so they go without the support they need.<sup>1</sup>

However, in the homeless sector, frailty assessments are starting to play a role as a systematic way to identify needs. Access to appropriate help and support should then follow, but this is a complex area, as recognised in The Health and Care Vision for London. The causes and consequences of homelessness are often linked, and there is also limited availability to supported housing.

“ ***A frailty assessment was pivotal in securing sheltered housing for one of our homeless clients. He rejected it 3 times because he thought it was just another scary, dangerous hostel.*** ”

## Frailty and travelling communities

For the eight people from the travelling community who we spoke with, frailty was also a difficult idea to engage with. Frailty was not a concept used in their culture, and their focus was more on the challenges of accessing the healthcare they needed.

Because of their difficulties in accessing primary care, they made greater use of urgent care services at their local hospital. While that is not how the health system is designed to be used, it was also notable how positive they were about the help they received in hospital. They contrasted the prompt, respectful service with their experiences outside of the UK. However, seeking hospital help when significantly ill meant that they had much less engagement around chronic, ongoing issues, so that some of the ideas around frailty were more unfamiliar to their experiences of health and healthcare.

People we spoke with had starkly varying experiences of accessing interpretation services, so that they had different levels of understanding of their own health and healthcare. This fitted a much broader pattern of their struggles to reliably understand and access complex systems of public services, within and beyond healthcare.

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<sup>1</sup> Rogans-Watson, R., Shulman, C., Lewer, D., Armstrong, M. and Hudson, B. (2020), "Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel", *Housing, Care and Support*, Vol. 23 No. 3/4, pp. 77-91. <https://doi.org/10.1108/HCS-05-2020-0007>

They had sought medical help to advocate for housing and social care appropriate to their diminishing health, but the NHS had been unable to help them. As Nuffield Trust and the Health Foundation observed when looking at these issues, ‘the inequality gap is greatest for measures that are heavily affected by issues beyond the NHS’s control such as poor housing and social care.....ambulatory care sensitive issues’.<sup>2</sup> As a result, the people we spoke to rely heavily on dedicated third sector support organisations, and these would be vital partners for NHS services looking to support travelling people with frailty.

## Frailty and people with a learning disability

Many people with a learning disability will face challenges engaging with the notion of frailty, and communicating with clinicians around the issue of frailty. The words ‘frailty’, ‘frail’ and ‘clinical frailty assessment’ are not seen as accessible words for people with a learning disability. However, much of the guidance in this document – keeping communication simple, focusing on individuals’ own hopes and experiences – will help people with a learning disability just as it will others.

However, following COVID-19, there is a particular challenge for people with a learning disability in engaging around frailty, which is important to highlight. In the first NICE COVID-19 Rapid Guideline: Managing COVID-19 NG 191 (March 2020), treatment priority was in part based on the Clinical Frailty Scale. The Clinical Frailty Scale is an assessment of a person’s level of frailty expressed as ability to live independently. Based on this scale, many people with learning disabilities will have a high score. There is a concern that for some people with learning disabilities, level of interventions and treatments during the early phase of the COVID-19 pandemic were determined by this score, rather than individual health and circumstances.

**These guidelines were revised in April 2020** and the guidance is now that the clinical frailty assessment should never be used to assess people with long term disabilities, (e.g. cerebral palsy) with a learning disability or autism. However, for some people with learning disabilities, there seems to be a lasting impact on their perceptions of the frailty discourse. Some associate ‘frailty’ with a danger that they will not be treated or looked after, or will be de-prioritised relative to other individuals. This will be important to track carefully, and perhaps merits further research into possible responses and mitigations.

## A note on frailty and asylum seekers

We did not succeed in speaking to asylum seekers as part of this study, despite making efforts to do so. We know that – as for travelling communities – access to primary care is a very significant challenge. For example, recent research found that the ‘uptake of GP registration by recent entrants to the UK has been low; less than a third (32.5%) of new entrants to England who are eligible for tuberculosis screening at ports register with a GP’.<sup>3</sup>

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<sup>2</sup> The Health Foundation and Nuffield Trust, ‘Quality and Inequality’ ([https://www.nuffieldtrust.org.uk/public/files/2020-01/quality\\_inequality/v2/](https://www.nuffieldtrust.org.uk/public/files/2020-01/quality_inequality/v2/))

<sup>3</sup> Stagg HR, Jones J, Bickler G, et al. Poor uptake of primary healthcare registration among recent entrants to the UK: a retrospective cohort study. *BMJ Open* 2012;2:e001453. doi:10.1136/bmjopen-2012-001453

# Conclusion

Because people are diverse and frailty is complex, the best approach is to develop a way of communicating with people about frailty that is curious about individuals and open to diversity.

The majority of people we spoke to did not like the word frailty. We think the best way to manage this dislike is better communication rather than better words.

**The best ways to make conversations about frailty accessible are also the ways to make these conversations accessible to the most people.**

Communication around frailty will not be perfect and will not perfectly compensate for wider injustice and inequality. However, the *best* ways to make conversations about frailty accessible are also the ways to make these conversations accessible to the *most* people. There are few inherent iniquities in using frailty to frame conversations with people about their health and well-being. This is an optimistic

finding that suggests significant potential for a broad set of design principles for rich conversations about frailty:

- Understand and validate the broad range of reactions to the idea of frailty
- Recognise that the idea of frailty can be most challenging for younger people and/or people with milder frailty, and consider the lens of 'health and well-being' or 'vulnerability' as an alternative if necessary
- Use the language of experience – how it feels – to help people grasp frailty
- Build on people's own vocabulary for frailty and understand what frailty means to them
- Hold the strong emotions and beliefs that conversations about frailty can stir
- Focus on areas of strength and confidence around people's health and independence
- Work together to develop goals and decisions about the future
- Pro-actively help people to access the support they need with and beyond the health and social care system

However, there are some specific challenges that our conversations with people identified:

There is a challenge for younger and/or people with milder frailty in engaging with frailty. Additionally, because disadvantage is associated with more rapid ageing, to an extent this is a more significant barrier for people who are disadvantaged. Where people find it harder to make frailty their own by describing what it means for them, conversations about frailty are more difficult. Where people are less accustomed to think about frailty and declining health, a more aspirational lens than frailty – such as 'health and well-being' or 'vulnerability' – may be more useful. However, this must be balanced against the risk that this makes conversations less focused and precise.

There are also some challenges around the actions that follow from conversations about frailty, which may at times undermine the credibility of the conversations. Many people are concerned about the cost of accessing care and support and by the complexity of accessing wider assistance with sociability and mobility. Clear systems and narratives to help with this are vitally important.

There are also some very significant barriers for specific groups of people to engaging with conversations around frailty. People who are homeless, travelling communities and asylum seekers face structural barriers to accessing the healthcare, care and support that they need, which undermines clinicians' ability to match meaningful action to the goals they establish together. We suggest that that these areas of challenge would all merit ongoing work. There is also a specific problem about some new, negative connotations of frailty, based on people's experiences of COVID-19 – particularly people with learning disabilities – that need to be understood and countered.

There is a broader set of questions for the health and care system about equality, frailty and the place of frailty assessments. Engagement in conversations around frailty is a necessary first step towards comprehensive assessment of a person's needs. However, there is a tension between the needs of an individual and the needs of a population sharing a limited pool of resources. Frailty assessments may uncover issues beyond healthcare – for example social care and housing, which are not within the control of the clinician having the conversation around frailty. For the credibility

**Connecting meaningfully with people's hopes and fear about frailty has near-universal motivational power.**

and sustainability of wider work around frailty, the question of the relationship between frailty assessments and expectations for access to wider systems of public services is important to address.

Finally, one of the surprises of our conversations with the ninety-three people that we met with was the amount of time we spent talking about the power of positive thinking. People's feelings about frailty varied hugely, but a significant majority agreed that they wanted to be positive, optimistic and pro-active about their health. The differences were as much as anything about people's ability to sustain this positive mindset. While talking about the body's diminishing natural resources is inherently anti-aspirational, connecting meaningfully with people's hopes and fear about frailty has near-universal motivational power. Across spectrums of class, race and creed, people want to hold on to the independence and mobility they have and to avoid falls and stays in hospital. If the NHS, Social Care and Third Sector can communicate about frailty in ways that connect with those very human desires, they can engage very large numbers of people, almost irrespective of background and belief. The key is that this communication will look different for different people, and needs to be built around their own experiences and circumstances.

***Care City, London Clinical Frailty Network and UCLPartners***

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# Further Resources

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# Authors

- Care City, John Craig and Julie Atkins
- London Clinical Network for Frailty, NHS England & NHS Improvement, Bettina Wan, Shaun Crowe, Catherina Nolan and Deepak Singh
- London Clinical Network for Frailty, Public and Patient Voice Team, Helen Bristow, John King and Marite Austrins
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