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**Care and support for people with moderate frailty**

Listening to communities report

July 2024

Contents

[Acknowledgements 1](#_Toc171092990)

[Introduction 2](#_Toc171092991)

[Executive summary 2](#_Toc171092992)

[What have we been talking to people about and why? 3](#_Toc171092993)

[Who have we heard from? 4](#_Toc171092994)

[Categories of people responding to the survey: 4](#_Toc171092995)

[How did we speak to people? 5](#_Toc171092996)

[Public engagement sessions 5](#_Toc171092997)

[Survey 5](#_Toc171092998)

[What did we hear? 7](#_Toc171092999)

[Which area of Lancashire and South Cumbria do you live in? 7](#_Toc171093000)

[Do you, or someone you know and/or care for, meet the definition of someone with moderate frailty? 7](#_Toc171093001)

[If you answered yes, or the frailty is more severe, can you tell us about your biggest challenges on a day-to-day basis? 8](#_Toc171093002)

[Given your personal circumstances or those of the person you care for, how confident are you about self-care? 14](#_Toc171093003)

[Please tell us your experience of accessing support to help you or the person you care for with daily tasks in or out of the home. Please include any services or offers of support that really met your/their needs. 15](#_Toc171093004)

[Do you think we can improve upon the support (practical/emotional/physical/social) that is or isn’t provided? 18](#_Toc171093005)

[Where do you feel you or people with frailty should be cared for? 20](#_Toc171093006)

[Can you tell us what this care should look like? Should it be: 21](#_Toc171093007)

[Any other comments 22](#_Toc171093008)

[Insights we have gained from this process 23](#_Toc171093009)

[Next steps 23](#_Toc171093010)

[Appendix 1 – questionnaire demographic monitoring 24](#_Toc171093011)

# Acknowledgements

The ICB would like to thank everybody who took the time to complete the survey and participate in the engagement sessions, some of whom were willing to share personal and challenging experiences. Thanks too, for the support and involvement of several of our voluntary and community sector partners, especially AgeUK, our carer organisations, St. John’s Hospice in Lancaster, and Blackpool Coastal Housing.

# Introduction

People are living for longer with more complex conditions in older age and often require specialist care from a range of professionals in a multidisciplinary team. There are people in our community who are living with multiple health conditions, may get support for day-to-day meal preparation and cleaning from family or carers and may be struggling with meeting others and completing daily tasks due to poor mobility. People who have these issues and more can be described as having a moderate level of clinical frailty.

People with moderate frailty are attending emergency departments in significant numbers. Much of this may be avoidable, and as part of our action on frailty, NHS Lancashire and South Cumbria ICB wanted to talk to people with frailty and their carers to understand what support was in place and what more could be done to help people avoid unnecessary admissions and remain safe at home.

# Executive summary

The engagement exercise sought reach out to people with frailty and their carers to find out from their perspective what challenges they faced on a daily basis, how they access support and what could be done to make this better where they felt improvements were needed. The engagement encompassed both face-to-face opportunities and a survey, available online or in paper form. Multiple colleagues, partners and community and voluntary sector organisations were contacted. This resulted in 146 people listened to face-to-face at engagement events across Lancashire and South Cumbria and 105 survey responses completed online.

61% of survey respondents gave feedback on their biggest daily challenges and the most significant was being a carer, whether this was due to juggling work and caring for a family, or someone frail looking after someone else who was frailer, or simply the pressure of caring for someone 24/7. Other significant challenges were accessing GP, hospital appointments, support from NHS services, loneliness, isolation and depression. Over 20% of these respondents indicated that most things were a challenge – cooking, cleaning, dressing, mobility, medication, and finding help and support. This information was supported by feedback from face-to-face engagement.

86% of survey respondents gave feedback about their experiences of accessing support. The most significant of these was the struggle to know what support was available and where, and then the struggle to access it. Many felt there was a lack of information or that it was not in a form that they could easily access. This was especially felt by the visually and hearing impaired, by people with dementia, and by those who struggled with technology generally. In some areas care agencies were either not available, did not necessarily meet people’s needs and/or were expensive.

Generally, it was felt that people with frailty and their carers needed better information about what support was available and how to access it, and that many services were more accessible, adaptable, and holistic in their approach. Carers were very frustrated, and felt more effort needed to be made in listening to and involving patients and carers. This applied across NHS services and social care, where there was a call for better training, pay and status of care agencies and their staff. Other improvements identified were tailored response teams, dedicated support for people with frailty, earlier interventions for mobility issues and the reinstatement of falls prevention services where these had disappeared.

The insights captured in this report are mainly captured from white British respondents and therefore it is recommended to undertake more targeted engagement with diverse health inclusion groups to capture the voice of those who were not able to contribute based on the methods which were adopted for this engagement exercise.

# Subtitles with solid fillWhat have we been talking to people about and why?



NHS Lancashire and South Cumbria ICB is seeking to act on supporting people with frailty, especially those with moderate frailty. The ICB is aware that individuals with frailty have unmet needs and that a reduction in the non-elective admissions to hospital of this group of people is an increasing concern, both for patients and for hospital services.

Frailty is a clinical term and the clinical frailty scale (CFS), which goes from 1 to 9, measures the level of frailty of each patient, from very fit to terminally ill. People with mild or moderate frailty (CFS 5 and 6) are much less likely to have care plans and support services in place, which may contribute to their vulnerability. Improving this position requires both medical and non-medical solutions.

The ICB and its system partners wanted to better understand what people who are frail, and their carers, need from their point of view. This would help shape future service delivery and the type of care being provided.

To help understand these needs, it was important to hear the views and experiences of people who are frail and their carers. Working through voluntary and community organisations and other partners, face-to-face engagement sessions were arranged. A survey was also produced and distributed across the system.

Both the survey and the engagement sought to get feedback and understand views on:

• self-care,

• their experience of access to support and what improvements could be made,

• where people with frailty would prefer to be cared for and

• what this should look like.

# Group success with solid fillWho have we heard from?

105 people completed the survey and 146 people were at the engagement sessions that were held at various venues and locations across Lancashire and South Cumbria.

Although we were particularly interested in getting feedback from people who were moderately frail and/or their carers, it was neither practical nor desirable to try to limit responses to this group of people only. The survey was open to anyone to respond.

## Categories of people responding to the survey:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | | **Response Percent** | **Response Total** |
| 1 | A person who considers themselves as 'frail' | |  | | --- | |  | | 12.38% | 13 |
| 2 | A carer | |  | | --- | |  | | 31.43% | 33 |
| 3 | Someone with a long-term condition (that impacts on their daily life), but does not consider themselves to be frail | |  | | --- | |  | | 23.81% | 25 |
| 4 | A frailty specialist |  | 0.00% | 0 |
| 5 | A GP, nurse or other health professional | |  | | --- | |  | | 18.10% | 19 |
| 6 | Someone who works with people who are frail and/or their carers (local authority) |  | 0.00% | 0 |
| 7 | Someone who works with people who are frail and/or their carers (VCFSE organisation) | |  | | --- | |  | | 2.86% | 3 |
| 8 | Someone who works in local authority services or VCFSE organisations, but does not work with people who are frail and/or their carers | |  | | --- | |  | | 0.95% | 1 |
| 9 | A member of the public | |  | | --- | |  | | 18.10% | 19 |
| 10 | Other (please specify): | |  | | --- | |  | | 8.57% | 9 |
| Other (please specify): (9) | | | | |

Of the people who felt they were in the ‘other’ category, two at least had some degree of frailty, two were carers and two worked in the voluntary, community, faith and social enterprise sector (VCFSE).

The engagement sessions consisted entirely of attending existing groups and forums. Although 146 were present at these sessions and had the opportunity to get involved, approximately 45 of these chose not to participate or, when asked, felt unable or unwilling to contribute. Of those that did participate, over a third were carers. Engagement sessions were held in Blackpool, Blackburn with Darwen, Lancashire, South Cumbria and the Lancashire visual impairment forum, which is held online.

# Megaphone1 with solid fillHow did we speak to people?

To ensure feedback opportunities were as accessible as possible a range of engagement techniques were adopted. A broad range of public sector and voluntary and community sector organisations were contacted, requesting that opportunities for focus group or other types of face-ot-face engagement be circulated to existing groups and forums. In addition, the survey was circulated to ICB colleagues, partner organisations and VCFSE groups.

## Public engagement sessions

Over 200 email exchanges took place with groups and organisations across Lancashire and South Cumbria to arrange engagement sessions. Although there was a significant level of interest and eagerness to participate, this did not always result in engagement sessions being arranged. The six-week pre-election period for local elections, plus the beginning of the pre-election period for the general election, had a negative impact on some of these arrangements.

In addition to the engagement sessions with patients and members of the public, three sessions (two virtual and one face-to-face) were also held with partner groups and forums, informing them of the work on frailty and encouraging them to share the request for engagement sessions and the survey, and to get involved. There were over 50 attendees at these groups, which included PCNs, Councillors, local authority employees and VCFSE representatives.

Altogether, 11 engagement sessions were held attended by patients, carers and members of the public. These were:

* 27 February, Kiran Asian Ladies Group, Bangor Street Community Centre, Blackburn
* 18 March, Spencer Community Centre warm-hub, Blackpool Coastal Housing
* 20 March, Fleetwood Library
* 20 March, Lostock Community Centre warm-hum, Blackpool Coastal Housing
* 22 March, Kincraig Community Centre warm-hub, Blackpool Coastal Housing
* 30 April, St. John’s Hospice, Lancaster (focus group run by the hospice)
* 10 May, Lancashire Visual Impairment Forum (online)
* 10 May, AgeUK BwD Seated Exercise Class, Edgeworth
* 17 May, Furness Carers, Barrow-in-Furness
* 28 May, BwD Carers Dementia Group
* 4 June, Progress Housing Extra Care facility, Leyland

The sessions were run differently depending upon the format of the group and how people preferred to interact on the day. Some ran as focus/discussion groups, others as one-to-one discussions/interviews and some as a mixture of both.

## Survey

An online questionnaire was developed with paper copies also being made available for people to complete. The questionnaire went live on Monday 26 February and was shared with a broad range of colleagues, partners and organisations across the region, who were asked to try and promote uptake through their networks and channels. It was also shared with Health Overview and Scrutiny Committees for information and onward sharing.

# Ear with solid fillWhat did we hear?

A summary of feedback received to the questions asked during the engagement is below. To aid clarity, a distinction may be made between feedback from the survey and feedback from the engagement sessions. To effectively analyse feedback given in the online survey, responses to qualitative questions, where respondents are given a free text box to say what they wish, have been grouped into themes. This also applies to the engagement sessions.

All the graphs illustrated in this report are from the survey feedback only.

## Which area of Lancashire and South Cumbria do you live in?

## Do you, or someone you know and/or care for, meet the definition of someone with moderate frailty?

An explanation of what is meant by moderate frailty was given within the survey question (and was also used in face-to-face discussions). Moderate frailty meant someone who probably needed help with outside activities and keeping house, may struggle with stairs and with bathing and dressing. They may also struggle with managing finances, medication and making other arrangements. If the frailty was more severe than this, they were asked to tick the appropriate response.

Over 60% of survey respondents considered themselves to have moderate frailty or to be a carer of someone who was moderately frail. This is a reasonably high proportion of respondents. This was not reflected in the engagement sessions, where a lower proportion of respondents considered themselves to be frail. No-one in the survey and no-one participating in the engagement sessions objected to the term frail, although one survey respondent was unhappy that the term frail was used in his medical notes without his consent.

## If you answered yes, or the frailty is more severe, can you tell us about your biggest challenges on a day-to-day basis?

**Survey and engagement session responses:**

The ICB wanted to understand the biggest challenges that people with frailty and their carers face on a daily basis and there was a broad range of responses to this question. Some of the responses were not necessarily daily issues but were nevertheless extremely prominent in the lives of respondents. 61% of survey respondents gave feedback to this question.

The main themes identified were:

1. Going to GP and hospital appointments; support from NHS services
2. Being a carer; someone frail looking after someone else who is frail, juggling work and caring
3. Most things are a challenge
4. Loneliness, isolation and depression/mental health
5. Significant other issues:
   1. Accepting frailty and its limitations
   2. Finding support in the community
   3. Rehabilitation or needs after a fall
   4. Managing their condition
   5. Preventing further deterioration
   6. Poor social care
6. Common challenges
   1. Moving round the house
   2. Moving outside the house/appointments/shopping
   3. Household chores
   4. Cleaning
   5. Cooking
   6. Medication
   7. Dressing
   8. Gardening

Some of the most significant challenges need exploring in more detail.

**Going to GP/hospital appointments; support from NHS services**

Over 20% of respondents to this question, both people with frailty and their carers, considered accessing GP or hospital appointments and/or getting the support from NHS services was one of their biggest challenges. A participant of the survey stated: “My mum also struggles with endless NHS appointments, no transport and a system for seeing her GP which doesn't accommodate her needs and frailties.”

Other respondents mentioned not only the challenge of accessing services, but the ramifications of this as they see it from their perspective. One stated: “Challenging to get through to GP … when you are elderly, frail, deaf and poorly trying to speak to a GP should be easier. Mum lives alone. It’s a struggle to get GP to visit Mum in person ….they miss other medical problems doing over the phone consultations and these difficulties lead to Mum not getting antibiotics or steroids in good time which then means she ends up needing IV antibiotics and so this leads to frequent hospital admissions.”

It is perhaps, important to take account of these points when considering our solutions to care and support in the community.

These concerns are heightened still further for people with visual impairments, hearing impairments and other disabilities. Responses stated:

* “The NHS is getting less and less accessible for blind people. As things become more complex (people are asked to use machines/screens), which doesn’t help blind people; access is made more difficult for them.”
* “Deafness awareness is patchy and NHS among the worst offenders; how do you expect a profoundly deaf person to cope with a system in which calls are repeatedly made to a mobile phone when NHS has been asked to use TEXT ONLY; or unhelpful garbled messages left on Voicemail declining to identify even the department involved and committing only to 'trying again later’”.

Some carers indicated that where they manage to give regular support to the person with frailty to attend appointments, whether moderately or severely frail, this becomes an expectation from the NHS and there is little flexibility or support when this can’t happen. For example: “we get resistance from NHS services when asking for home visits on some occasions because we do take her to so many appointments that it is expected that we will be available all of the time which is just not possible. Access to services at home is limited anyway and is getting worse. The needs of complex patients need to be recognised and not treated as a burden by NHS services.”

Respondents mentioned the struggle to travel to hospital appointments due to a lack of good transport; this is keenly felt in rural areas. However, it would be wrong to assume that people in urban areas will always find transport easier, due to cost-of-living challenges and the lack of public transport.

* “More and more people are living where facilities are gone; buses disappearing, and they struggle to get to places.”
* “We know of someone visiting their husband in a care home; there are no buses. It is costing her £40 a day on taxi fares, every day, to see her husband.”

When in hospital, people with moderate or severe frailty remain in need of physical and emotional support, not just from staff, but from their family/carers. However, some carers indicated that getting support and information from the hospital can be challenging; they are not listened to, their input or queries dismissed, ignored or unwanted. From a carer/family perspective, a simple request for information, for example, is not untoward, but can be both challenging and upsetting.

“So hard to find anyone on the ward in person or on the phone who can tell next of kin what medical problems the patient has, results of any tests, why tests being done, what the hospital care plan is….. you call in and ask but the person looking after them is never available….you get a half story from someone - any nurse should be able to give next of kin accurate updates i.e., what medical issues there are, what tests/treatments have been done and the outcomes, what will happen next.”

This leads to the most strident area of response in this engagement, the voice of, and challenges to, carers.

**Being a carer; juggling work and caring**

A third of those who responded to this question identified that their biggest challenge was being a carer. This could be because of the relentless, sometimes 24/7 nature of caring for someone. It could be because the person who is the carer is also frail, may have multiple health conditions themselves and/or is elderly (80 plus). It could be because the carer is trying to work, and/or look after their own family, as well as care for the person who is frail. Examples of all these challenges can be found in the responses received:

* “Juggling their support needs physically and emotionally in organising support or input that they need even for the smallest of tasks. Juggling my own long term health conditions, family life with small young children and getting a work life balance.”
* “As someone who is frail and also a carer day to day can be very difficult for the 2 of us. My husband who I care for has breathing problems (COPD) which can make the simplest of tasks very difficult. I myself am still recovering from hip surgery after a fall last year in which I broke my hip so am limited as to what I can do safely.”
* “Everything (is a challenge). I make meals and do the cleaning and never leave my mum for more than 2 hours during the day.”
* “24/7 caring for my husband who is registered partially sighted and has Alzheimer’s.”

The challenge was also significant for those caring for someone with dementia. Responses via the survey and the face-to-face engagement sessions, one which was with a dementia carer’s group, highlighted the added dimension dementia can bring to a carer’s daily tasks; the heightened behaviours, aggression and unpredictability people with dementia can show. Almost all dementia carers spoke about the lack of understanding within health and social care of people with dementia. They also spoke about the fact that a dementia diagnosis was often missed off the patient records, which caused deep frustration:

* “I rang for patient transport for my husband, who has dementia, but I was told I wasn’t allowed it because it wasn’t for me. I had to cancel the appointment. Every time I go for an appointment, they never realise he has dementia. They say it should be on his notes, but they never put it down.”
* “My husband (with dementia) was in hospital. I was not allowed in the appointment, because they didn’t think he had dementia, because he sounded so coherent. They wouldn’t believe me. They don’t understand dementia. My husband can sound so normal, but he can be telling them a load of nonsense.”

The additional challenge for carers, above and beyond their caring role, was navigating the system and getting help and support for the person they cared for, and, for themselves. Several carers, both in the survey and via face-to-face engagement, indicated that they did not know how to access information and where to go for this:

* “What is available? Where do I find it? How? Where is the information? Shouldn't it be accessible in a walk-in one-stop high-street position?”
* “As a carer the biggest challenge is finding the right organisation/department or person on the phone and not spending hours going from one person to another and often not being able to rectify the problem.”
* “Getting the right person at the right time is key. At the moment it is so complicated and time consuming. The eligibility criteria is far too much. If you contact social care you can be two hours going through questions/forms. This all has an impact on the carers themselves. They often end up in hospital themselves.”

**Loneliness and isolation:**

Over 10% of survey respondents to this question also identified that the loneliness and isolation they, or the person they cared for, felt because of their frailty, was a daily challenge. This was echoed by people met in the engagement sessions. One OAP and wheelchair user considered their main challenge to be “cooking meals, cleaning the house and overcoming loneliness.” Others referred to loneliness and their mental health.

There is perhaps, a general perception that the elderly frail within Asian families, due to the culture of extended family living, would not be included in those feeling lonely and isolated. However, the engagement session with an elderly Asian women’s group challenged this assumption, as they told us the following:

* Most women in the group are on their own most days and struggle to get out; some rarely go out at all (this group may be their only venture outside)
* Many are isolated and depressed
* The traditional Asian culture of living with the extended family and being able to support elderly parents/grandparents is being abandoned by the younger generation – they either prefer to have their own homes, leaving the elderly relative on their own, or, if the elderly relative does live with them, leave them on their own all day and/or expect too much from them
* Collectively, they prefer to stay in their own homes and not go into care homes
* Encouraged to tell their problems to their GP but this is not the normal approach for many
* Some may be bullied or abused by family members
* The group needs information about the services available as they don’t have access to it (language, isolation, not going out, family restrictions)
* Voluntary support provided via this group: seated exercise classes; can manage to give a few a lift/transport using own car; trying to arrange a café – can only do so much on their own.

**Other challenges:**

Almost a quarter (23.4%) of survey respondents to this question indicated that everything was a challenge. This is a significant proportion of respondents. Many listed the various tasks they found challenging. Some of these tasks have been referred to in this report as ‘common challenges’, mentioned occasionally by other respondents. These include cleaning, cooking, dressing, and mobility, both inside and outside the home.

A reasonable proportion of survey respondents identified other challenges, such as managing their health condition, finding support in the community and poor social care support. It is unclear whether the later meant social services, which came in for some praise, or paid carer organisations, which was an area of concern for some (and is explored further in the section of accessing support).

Several frail respondents indicated dealing with fatigue and their ‘low mood’ was a challenge. They could be frustrated because they were too tired to do what they needed to do and that things took longer. They may find they are “sitting there, can’t be bothered to do anything, even to take a cup into the kitchen sometimes.” In addition, for many of the elderly generation, asking for help is not something they find comes easy, and even though help may be available, it is something “people are reluctant to accept,” or that they don’t want “people to think you can’t manage,” even thought they can’t manage.

Finding support has been identified as a challenge, and both survey respondents and people at engagement sessions felt that, as part of this, the push towards digital solutions was an additional challenge, even if respondents were able to use computers or smart phones. “Got asked to send a picture of what was wrong but couldn’t do this.” Furthermore, “the forms are too complicated for our age group,” or that “they all ask the same questions. Also, you don’t hear anything for ages and so you give up.” Although some have the support of their ‘adult’ children or young people, this still presents a difficulty, and more so for those without this family support.

It is worth noting that almost a fifth of the survey respondents worked in the health service (GPs, nurses or other health professionals), but largely they too contributed to the challenges identified above from a carer perspective. Only a few gave a more professional based response, but it is valuable to finish this section on ‘biggest challenges’ from this perspective, as they add to rather contradict the points made by others.

It is fair to point out that some respondents felt let down by rehabilitation services. However, the professional perspective given by one respondent gave some context to this:

* "Unrealistic expectations - reliance on rehabilitation services to carry out restorative rehab when this is not realistic in the context of severe frailty.

Lack of recognition and appropriate initiation of personalised care and support planning/ advanced care planning for severely frail people"

Another professional effectively summarised this whole section with their contribution:

* “I regularly visit and assess/support patients who I would consider as being moderately frail. There are many struggles that I see with patients and their families including having difficulties with their activities of daily living, so mobility, meal prep, washing/bathing/dressing, medication administration/management etc. People with frailty and their families often suffer with fatigue/low mood/anxiety/frustration/loneliness. Patients often struggle to manage their long-term conditions, and this results in more GP visits/hospital admissions.”

## Given your personal circumstances or those of the person you care for, how confident are you about self-care?

An explanation of what is meant by self-care was given within the survey question (and as previously, was also used in face-to-face discussions). This was that self-care is about keeping fit and healthy, understanding when you can look after yourself, when a pharmacist can help, and when to get advice from your GP or another health professional. If you or the person you care for have a long-term condition, self-care is about understanding that condition and how to live with it. This will include making sure you follow your management plan or care plan if you have one.

Almost half of all survey respondents were confident or very confident about self-care. Almost a third more were fairly confident. However, a fifth of respondents were not confident or not at all confident, and this was reflected in some of the comments received both in the survey and in face-to-face engagement sessions around challenges and accessing support. It is also important to note that several respondents had lost their confidence, usually following a fall or similar trauma.

* “I used to be fairly confident and self-care was fine. Now due to inactivity following a fall, I'm reliant on carers, neighbours and family. They are brilliant but it isn't the same. Accessing help wasn't at all easy. Social services could not help. The care agency have been fine, but they can only do short times.”

Some respondents and people in focus group sessions felt that self-care, where getting advice from GPs and other health professionals/services, was not helped by long waiting times for appointments. “Been waiting 4 weeks to see GP after being told by district nurse needed to see GP,” or the ever-increasing reliance on digital solutions which remains a challenge for many frail people, especially those with memory problems and dementia, or with some disabilities.

## Please tell us your experience of accessing support to help you or the person you care for with daily tasks in or out of the home. Please include any services or offers of support that really met your/their needs.

**Survey and engagement session responses:**

86% of survey respondents gave feedback on their experience of accessing support to help with daily tasks. As previously, there was a significant range of points made by respondents and these can broadly be summarised into the following themes:

1. No/limited access to services and support; few options available; it’s a constant struggle to access support and navigate the system
2. Even when aware of services remains a struggle/battle to access them
3. Challenge for carers to balance care and work or family commitments
4. Struggle to find care agencies/or support from care agencies doesn’t meet needs and is expensive
5. Struggle following discharge from hospitals/discharge is too quick in some cases; lack of support/follow-up (community rehab issue)
6. When services are provided they may end too quickly
7. Increasing use of technology, phones and apps causes confusion and makes it difficult for some
8. Better communication between NHS and social care
9. Lack of information available
10. Services a range of respondents found difficult to access included:
    1. Social care/services
    2. Occupational therapy/rehabilitation
    3. Mental health
    4. GPs
    5. Diabetic foot screening
    6. Frailty team (Blackpool)
    7. Carer provider services
11. Services a range of respondents felt were providing a good service:
    1. District nurses
    2. Occupational therapy/physiotherapy
    3. Pharmacies
    4. AgeUK and Regenerage (Age Concern)
    5. Social prescribing
    6. Doctors and nurses
    7. Carer support service
    8. Citizen’s Advice
    9. Frailty team (Blackpool)

Both survey respondents and people attending engagement sessions spoke about accessing services being a challenge. They reiterated the problem of not knowing what support and services are available. Many don’t know where to go for this information and feel it would be beneficial if there was one place they could rely on where this information was available. Where it is available, or where they have been directed to it, it may not be in a form they can readily access or understand.

* “Not getting any (support). I have been disabled for 30 years now after having double bypass, now heart failure. Husband of 45 years has looked after me. Now he is very ill, can barely move, shakes something bad, insulin dependent, so we struggle.”
* “I resorted to begging; frustration to get help for my late husband.”

Some respondents and engagement session attendees felt more information and support could be given when attending for diagnosis, or that opportunities for signposting at that time were not used. “When you register a death, you have to ‘tell us once’. Why can’t they do this for illnesses, e.g. Parkinson’s? They know it’s not going to get any better so why not provide help then, at diagnosis. We were told ‘not ill enough yet, come back when can’t walk/hip gone etc.’”

Although many spoke of the challenge to access NHS services in response to the previous question, and continued to do so here, there was a greater emphasis in the responses to this question around accessing social care and assisted living support.

* “There is often a lack of provision available for patients to access to help them with their daily tasks. If patients are self-funding, they are often left to try and navigate finding a carer for themselves which is often difficult as they don't always have family to support with this and are very often not online.”
* “Private Neuro Physiotherapist has provided training and support to whole family. No offers of help from anywhere else. Adult social care supplied a minimal amount of equipment after about a year and a lot of chasing. Occupational Therapist visited after two years.”
* “I didn’t know what equipment was available. I now have plenty, but I had falls until I knew what equipment was available.”

Several respondents highlighted a few issues relating to paid carers. Some indicated it was difficult to find carers where they live; this was especially true of more rural areas. Where carers were available, they were often felt to be expensive. Others, though given a budget to pay for carers, found it difficult to appoint carers, who either did not respond or turned up for an interview then did not appear again. Some respondents also felt the support from carers was inadequate or structured in a way that patients would not get the maximum benefit. Underlying this was an understanding that many carers are poorly paid, under-trained, and often not placed on a professional footing.

* “We cancelled the package of care provided by the council (morning visits and bedtime). This was due to the time slots and variability of time attending and change in staff. We now use a private company run by two people, arrive same time each morning etc and staff consistent. person is much happier.”
* “The service is there but not particularly convenient e.g., carers who help getting up and going to bed reduce the day to about 7 hours.”
* “We were awarded a card to help pay for help with my husband’s care, I contacted a care company last August and we had a visit from them explaining our needs and they went away saying they would be in touch in a few days’ time - we are still waiting some 6 months on ..... feel totally let down by the system.”
* “We couldn’t get any carers to come to Kirkby; we had to put her (mother?) in a home. Getting carers in various areas around here is vey difficult. Carers are not mental health trained. Carers are leaving their jobs and going to BAE to get better employment. We need more incentives for carers – they are only paid the living wage.”

Although by no means universal, frustration was expressed about delays in discharge for medication and for other reasons, which can be extremely tiring and upsetting for frail and/or elderly patients and to their families/carers. After discharge, some spoke of not receiving the support they were expecting or that it finished too soon. A community rehabilitation nurse summed this up succinctly. “Often frail patients are unable to access the community without help - we help them to improve their mobility but then there is no-one to continue the support when we discharge - then there is an expectation for rehab services to continue providing long term support."

As in the previous section on daily challenges, some survey respondents and engagement session attendees continued to raise their concerns about their difficulty in using computers, smart phones and other digital means.

* “Everything is online these days, but not everyone can use this. There are no telephone numbers. You can’t ring anyone.”
* Some have video appointments – but it is difficult with login, registration, being in an online waiting room. Why can’t they use something easier like WhatsApp?”

Not only can there be a struggle to use these, but the resulting frustration can also be amplified by the fact some find it doesn’t help in accessing the right treatment or that their ailments are not correctly or fully identified. It has already been noted that the use of some digital solutions does not always help those with visual or hearing impairments or other disabilities, even when some other digital solutions may directly benefit them.

As part of this question, people were asked to identify any services or offers of support that really met their needs. Most of the services mentioned as providing services that met people’s needs also failed to meet the needs of others or were difficult to access. It is, therefore, about getting it right every time for everyone – so easy to say, less easy to implement. AgeUK, Regenerage (previously Age Concern) and carer support organisations were praised by all respondents who mentioned them.

The quote below from one survey respondent summarises most of the feedback received about accessing support – the good, the bad and the frustrating.

“"I have found that it is a constant battle to get services involved. They are very reluctant to accept referrals and very quick to discharge patients after minimal intervention. This included the Frailty service.

There is absolutely a dearth of information and support for anyone with a rectal prolapse. In fact, we had to learn how to reduce it from the internet as no clinician would guide us. The matron services are completely overwhelmed with huge caseloads, so discharging patients at 96 leads to family anxiety and caused us to lose our point of contact for anxieties.

Early supported discharge didn't turn up after my Dad was discharged from BVH in November and when I queried this was told that 6 weeks on was too late to access rehab. We find that despite the implementation of the Integrated Care hubs, EPC system and EMIS, that the services are fragmented, and communication is poor. We have to repeat the history over and over again.

Many times, we have had to go back to the GP for referrals when a previous one was or should have been still open.

Social services really have been no help. They ask questions then say they can’t help.

Good service from the Occupational Therapy and Physiotherapy staff from Fylde EPC as well as good response times from the District Nurses."

## Do you think we can improve upon the support (practical/emotional/physical/social) that is or isn’t provided?

Over 60% of survey respondents felt we could improve on the support that is or is not provided to people with frailty and/or their carers, with a further 30% feeling it was possible to do so. 71% of all survey respondents then went on to tell us how this could be done. The main themes arising from this feedback are summarised below:

1. Promote/advertise/make more evident what services are available – including information/signposting/catalogue of services/and improved/better designed website information and accessibility to this
2. Easier access to/availability of/adaptable services, including GP, hospital, social care
3. More information, support and resources for carers
4. Better monitoring/regulation of paid carer organisations/providers
5. Listening to and involving patients/carers; ‘do with’ rather than ‘do to’ approach
6. Provide or improve structured care plans
7. Improve communication/transparency
8. More joined up approach from statutory and other providers including:
   1. Better tailored response teams
   2. Early intervention for mobility issues
   3. Dedicated caseworker
   4. Designated health professional to regularly check/monitor frail people at home
   5. Bring back ‘Steady on Falls’ team in community
   6. Development of a support system for the frail
   7. More funding and support for frail people in the system
   8. Focus on prevention
   9. Investment in activities for the elderly and in transport
9. Other points made:
   1. Physio/OT in hospital can be better organised – follow the patient within hospital
   2. Under 65’s who are frail can fall through gaps
   3. Blanket approach to rules can harm/undermine patients with specific conditions (coeliac patient re gluten free prescriptions)

Much of the summary information above needs little further explanation. The pleas for better, clearer, more accessible information and signposting were clear throughout the engagement. As noted above, suggestions for improvement ranged from having “a catalogue of services brochure to make sure all the services which are on offer are advertised in one place,” to “information to be given to each household via post or email,” and updating “the information that GPs provide to people in the community." One respondent identified a caveat however, which was that it was not “helpful to refer people to charitable organisations or parts of the NHS who are not aware they're being quoted as a source of help/relied upon to remedy NHS deficiencies.”

Some of the suggested improvements demanded a more system wide, structured approach to care.

* “Develop a support system that is structured, easy to access and understands the large range of circumstances it will have to deal with.”
* "Freely available information re services and support available with systems that allow self-referral back into a service within a set time frame. Practical support for carers who are struggling / hitting a crisis.”
* “More rehab staff able to offer rehab at home that is not time limited but based on outcome and achievement of goals.”

In addition, there was a call for more dedicated clinical support for frail people. “Have a designated health professional (maybe someone from the GP practice) who looks after an individual elderly frail person i.e., they check up on them in person regularly to make sure they have required care in place, that they have District nurses booked to come in to change dressings regularly etc., check that they don’t have any new medical symptoms which could lead to a hospital admission; check that the patient is managing / has their medications.”

Mobility is a key issue for many frail people and Occupational Therapy and Physiotherapy was mentioned by numerous respondents, both positively and negatively. From this arose a suggestion for how this may be organised within hospitals. “My mother was in hospital 5 weeks, 3 of which in major trauma. Most of the time was spent in bed or chair. No work was done to get her up and walking because every time she changed ward (4 times) she got a new team. She was then discharged. If the OT/physio was allocated to the patient not the ward, then they could have done something to help her mobility. Instead, none of the OT/physio had time to work with her before she was moved.”

Several survey respondents and engagement session attendees also felt that falls prevention services were not what they used to be, or had disappeared altogether, and felt this was detrimental to support for frail people and hospital admissions.

## Where do you feel you or people with frailty should be cared for?

Most survey respondents (72.5%) felt that care for people with frailty should be provided at home wherever possible. This was endorsed by most people seen during the engagement sessions.

20% of survey respondents said ‘Other’ and specified their reasons for doing so. Most of these gave similar responses that related to three main points:

* Where the person is safest/wants to be cared for
* It depends on the level of need and/or the support available
* Care needs to be individualised on a case-by-case basis

Some engagement session attendees expressed their concern that in paying for their care “it is frightening to think we’re going to lose our home.” Another indicated this was what happened to him. ““I was in care for 14 months. They took everything off me, my house, my savings. I couldn’t afford to stay at home and care for my wife.”

An AgeUK representatives told us that most people want to be at home. “Even people in care homes want to be back in their own home. Most people are in there because they need a hoist or because they need a specific bit of support.” It serves as a reminder that a proportion of care home residents at least, are not there by choice but have no alternative.

## Can you tell us what this care should look like? Should it be:

A little under a half of survey respondents felt that care should be a mixture of daily care and on call. 24 respondents (23.5%) said other and specified their reasons. In the main, these were:

* All the above
* Care should be provided on a case-by-case basis/depending on individual need/be a flexible pathway
* Needs to be regularly assessed
* Remainder repeated one of the options they were asked to choose from

One health care professional who responded felt that care for people with frailty “should be well assessed for individual requirements with an assessment process which includes: the individual, relevant clinicians, OT and carers but include cohesive community care, access to socially inclusive activities and underpinned with adequate clinical and occupational oversight and be reassessed frequently for efficacy and need.”

A carer added their perspective. “People with frailty need to be checked on daily to help spot deterioration quickly so that it can be dealt with before it becomes a crisis. We do have carer support for my mum twice a day, but family fill in for the rest of the time including overnight. Frail people need a lot of support and overnight is often overlooked as part of care packages but that is when most accidents happen and when they are at their most vulnerable.”

For people being cared for at home, which the feedback indicates is where most people want to be cared for, the point concerning care packages an overnight support is a significant one and deserves consideration.

## Any other comments

32 survey respondents (30.5%) made additional comments. These covered a significant range of issues/points. These were:

* Need to invest in social care (care workers), make it a proper profession, provide training/NVQ
* The system is complicated and lacks cohesion, with too many people involved in delivery; it’s also unfair
* The cared for and carer need to be at the heart of the service; holistic approach needed
* Advocate the ‘Circles of Support’ approach
* Need to mobilise elderly within hospital – mitigating falls by keeping elderly people in bed a dreadful policy that contributes to disability
* Struggle to cope with modern approach; going online or speaking via phone, which has been made a tortuous method of communication
* People will try to hide frailty/vulnerability to avoid going into hospital
* More funding needed
* Just want support and can’t get it without going private
* Labelled frail without consent

Several respondents felt that, although “everyone was doing their best,” it was important to “invest in social care (community care provision) and make this a proper profession. Some of the lowest paid people are looking after the most vulnerable without much support or education." It was also felt that by some that paid carers “all work hard, but never seem to have time to treat him as a person.”

Others felt strongly that "a conversation about mobilisation within the hospital must be had. The mitigation of falls by keeping elderly people in bed, is a dreadful policy and leads to unnecessary disability. To resort to a hoist for all transfers as a first option is cruel.” There is no doubt, circumstances when there is no alternative means of transfer, but it is worth noting that care staff have also indicated that the use of hoists can “hurt, frighten and upset” those being transferred.

One respondent finished their feedback with the plea that we should “only provide the care when it is needed and talk to and listen to unpaid carers who, in a lot of circumstances, are in the best position of knowledge regarding the cared-for.”

# Exclamation mark with solid fillInsights we have gained from this process

In reaching out to groups, forums and individuals about frailty, through health colleagues and others, it became clear that many health and care staff are treating, supporting or dealing with people with all levels of frailty, but some may well be doing so in pockets of isolation. This is not to say that the care is not effective, but raised the possibility that there could be areas of duplication or good practice that may benefit from being shared. This indicated that, to some degree at least, an even greater systematic consideration of frailty and how people with frailty are supported may be possible.

Several of the voluntary and community groups contacted during the engagement exercise felt that some of the people whose voice most needed to be heard would only have the opportunity if visited in their own home. They also felt that surveys, sometimes considered too general a form of engagement, would be the best way of getting their feedback. Utilising this methodology, using goodwill alone, may reap some benefits, but a more targeted and resourced approach would be even better.

It can be all too easy to assume that in this digital age, everyone just inputs into a search engine and finds out all they need to know. For many who are frail and for those who care for them, this is either not possible or not beneficial. This is not something that can or should be overlooked.

There is anecdotal evidence that the term frailty itself is disliked by members of the public, and by others, but none of the respondents or engagement session attendees expressed any concern for this in their feedback. As a term it seems to be generally well understood – any alternatives may risk be less so.

The support of people with frailty places a great burden on the NHS. This process has revealed that the burden is greater on the unpaid carers who shoulder the day-to-day care and support for people with frailty, and in some case, may be doing so despite the NHS and its partners rather than because of them.

The insights captured in this report are mainly captured from white British respondents and therefore it is recommended to undertake more targeted engagement with diverse health inclusion groups to capture the voice of those who were not able to contribute based on the methods which were adopted for this engagement exercise.

# Next steps

This report will be shared with the ICB’s Acton on Frailty group, which will consider how the feedback provided may feed into the further development of the frailty strategy and/or its implementation. It will also be shared with the ICB Public Involvement and Engagement Advisory Committee.

# Appendix 1 – questionnaire demographic monitoring

The graphs below identity the demographics of people responding to the survey. The ICB uses this information to monitor responses against protected characteristics and measure the equity of the feedback provided. Completing the demographic questions is optional and respondents can prefer not to answer any or all these questions. Most respondents normal complete these questions and this is the case here.

**Age**

| **Which age range are you in?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | 17 or younger |  | 0.00% | 0 |
| 2 | 18-20 |  | 0.00% | 0 |
| 3 | 21-29 | |  | | --- | |  | | 1.96% | 2 |
| 4 | 30-39 | |  | | --- | |  | | 3.92% | 4 |
| 5 | 40-49 | |  | | --- | |  | | 11.76% | 12 |
| 6 | 50-59 | |  | | --- | |  | | 16.67% | 17 |
| 7 | 60-69 | |  | | --- | |  | | 19.61% | 20 |
| 8 | 70-79 | |  | | --- | |  | | 22.55% | 23 |
| 9 | 80 and over | |  | | --- | |  | | 22.55% | 23 |
| 10 | Prefer not to say | |  | | --- | |  | | 0.98% | 1 |
|  | | | answered | 102 |
| skipped | 3 |

Generally, there was a reasonably broad range of respondents across the age groups. Over 60% of respondents were aged 60 or above but very few respondents were aged below 40. Given the nature of the topic and the targeted engagement, this is not unexpected, but nevertheless compounds issues raised regarding some people under 65 also being considered frail.

**Gender**

| **Which of these best describes you?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | Male | |  | | --- | |  | | 20.39% | 21 |
| 2 | Female | |  | | --- | |  | | 76.70% | 79 |
| 3 | Non-binary | |  | | --- | |  | | 0.97% | 1 |
| 4 | Prefer not to say | |  | | --- | |  | | 1.94% | 2 |
|  | | | answered | 103 |

| **Is this the same gender you were given at birth?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | Yes | |  | | --- | |  | | 97.03% | 98 |
| 2 | No |  | 0.00% | 0 |
| 3 | Prefer not to say | |  | | --- | |  | | 2.97% | 3 |
|  | | | answered | 101 |
| skipped | 4 |

**Disability**

| **Please choose the category that best describes your level of disability.** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | No disability | |  | | --- | |  | | 43.14% | 44 |
| 2 | Wheelchair user | |  | | --- | |  | | 0.98% | 1 |
| 3 | Hearing impairment | |  | | --- | |  | | 7.84% | 8 |
| 4 | Visual impairment | |  | | --- | |  | | 0.98% | 1 |
| 5 | Physical impairment | |  | | --- | |  | | 18.63% | 19 |
| 6 | Multiple impairments | |  | | --- | |  | | 17.65% | 18 |
| 7 | Learning disability | |  | | --- | |  | | 0.98% | 1 |
| 8 | Mental health | |  | | --- | |  | | 5.88% | 6 |
| 9 | Prefer not to say | |  | | --- | |  | | 3.92% | 4 |
|  | | | answered | 102 |
| skipped | 3 |

Given the topic under consideration and the older age of a significant proportion of respondents, it is not surprising to see a higher level of disability amongst respondents than is normally the case. Over 60% of respondents felt they had a level of disability, with almost a fifth of these having a physical impairment and another fifth having multiple impairments.

**Sexual orientation**

| **What is your sexual orientation?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | Heterosexual/straight (attracted to the opposite sex) | |  | | --- | |  | | 91.09% | 92 |
| 2 | Gay/lesbian (attracted to the same sex) | |  | | --- | |  | | 0.99% | 1 |
| 3 | Bisexual (attracted to both sexes) |  | 0.00% | 0 |
| 4 | Prefer not to say | |  | | --- | |  | | 7.92% | 8 |
|  | | | answered | 101 |
| skipped | 4 |

**Religion/belief**

| **What is your religion/belief?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| 1 | Christian | |  | | --- | |  | | 66.02% | 68 |
| 2 | Jewish |  | 0.00% | 0 |
| 3 | Hindu |  | 0.00% | 0 |
| 4 | Muslim |  | 0.00% | 0 |
| 5 | Sikh |  | 0.00% | 0 |
| 6 | Buddhist | |  | | --- | |  | | 0.97% | 1 |
| 7 | No religion/belief | |  | | --- | |  | | 25.24% | 26 |
| 8 | Prefer not to say | |  | | --- | |  | | 4.85% | 5 |
| 9 | Other (please specify): | |  | | --- | |  | | 2.91% | 3 |
|  | | | answered | 103 |
| skipped | 2 |

Most survey respondents were either Christian or who had no religion or belief. There was a poor level of response from other faiths/religions, although this was redressed somewhat by the face-to-face engagement sessions.

**Ethnicity**

| **What is your ethnicity?** | | | | |
| --- | --- | --- | --- | --- |
| **Answer Choices** | | | **Response Percent** | **Response Total** |
| **White** | | | | |
| 1 | British | |  | | --- | |  | | 97.09% | 100 |
| 2 | Irish | |  | | --- | |  | | 0.97% | 1 |
| 3 | East European |  | 0.00% | 0 |
| 4 | Other | |  | | --- | |  | | 0.97% | 1 |
| **Asian or Asian British** | | | | |
| 5 | Indian |  | 0.00% | 0 |
| 6 | Pakistani |  | 0.00% | 0 |
| 7 | Bangladeshi |  | 0.00% | 0 |
| 8 | Any other Asian background |  | 0.00% | 0 |
| **Mixed** | | | | |
| 9 | White and Black Caribbean | |  | | --- | |  | | 0.97% | 1 |
| 10 | White and black African |  | 0.00% | 0 |
| 11 | White and Asian |  | 0.00% | 0 |
| 12 | Any other mixed background |  | 0.00% | 0 |
| **Black or Black British** | | | | |
| 13 | Caribbean |  | 0.00% | 0 |
| 14 | African |  | 0.00% | 0 |
| 15 | Any other black background |  | 0.00% | 0 |
| **Other Ethnic Group** | | | | |
| 16 | Chinese |  | 0.00% | 0 |
| 17 | Any other Ethnic Group |  | 0.00% | 0 |
| 18 | I do not wish to disclose my ethnic origin |  | 0.00% | 0 |
|  | | | answered | 103 |
| skipped | 2 |

Almost all respondents were White British, but, as with religion/belief, this was redressed by some of the face-to-face engagement sessions.