What matters to people living with frailty, older people at end of life, and their carers?
Commissioning for population outcomes

Engagement dates: April - May 2018

Assessment of Equality Impact and Engagement Report
FINAL V1.0
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Published Thursday 28 June 2018
Executive summary

‘Frailty is a term used to describe someone who does not bounce back quickly from an illness or accident’

Leeds’ vision for people living with frailty, older people at end of life, and their carers is that
- people will live healthier, happier and more active lives
- they will be in control of their care
- they will be supported by care which is based on their strengths and delivered within their communities.

The CCG is moving towards an ‘outcomes-based’ commissioning model, an approach that will mean we pay providers of services based on the outcomes of their service, rather than the number of procedures or interventions they carry out. We will look at measuring outcomes for different population groups and we have started our work with people living with frailty, their carers and people at end-of-life. Working with patients and providers we have identified five different outcomes, two of which are patient focussed:
- Living, aging and dying well defined by ‘what really matters’ to local people;
- Caring well, defined by ‘what really matters’ when caring.

This engagement aims to understand what matters to people living with frailty, their carers and people at end-of-life. The feedback we receive will help us develop a tool which measures the outcomes of care. Outcomes might be things like people being in less pain or seeing their family more often. The tool will help commissioners understand if interventions are helping people to care, live, age and die well.

This report outlines the findings of the engagement. The report will also help to identify any potential positive or negative impacts in relation to characteristics/groups protected by the Equality Act 2010.

We worked with voluntary sector organisations to design focus groups and interviews that would help us understand what people think about the word ‘frailty’ and ‘what matters to people’ living with frailty and their carers.

In total we spoke to 96 people living with frailty and 38 carers. We used focus groups and informal interviews to engage with them. People had mixed views on the word ‘frailty’. Carers generally found the word helpful but many people living with frailty told us that the word had negative connotations. They also identified a number of things that mattered to them, these included being socially connected, staying active and healthy, being independent, being able to do the things they enjoy, receiving good healthcare, being in control over their daily life and being able to look after themselves. The report also includes patient experience information from people at end of life and their carers, which was collected by St Gemma’s Hospice.

This report makes a series of recommendations to the CCG. The CCG will use the recommendations to identify or develop a tool that helps them to measure the outcomes of care for people living with frailty and their carers.
People’s feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

The report will be shared with those involved in the engagement and it will also be available on our website https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/.
1. Background information

a. The NHS Leeds CCG

NHS Leeds CCG is responsible for planning and buying (commissioning) the majority of health services for people in Leeds. Prior to April 2018, there were three clinical commissioning groups (CCGs) in Leeds: NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These groups have now merged to become NHS Leeds CCG.

The CCG commissions a range of services for adults and children including planned care, urgent care, NHS continuing care, mental health and learning disability services and community health services.

From 1 April 2016 the CCG began co-commissioning GP primary care services with NHS England. We do not commission other primary care services such dental care, pharmacy or optometry (opticians) which is done by NHS England through their local area team more commonly referred to as NHS England (West Yorkshire). NHS England also has the responsibility for commissioning specialised services, such as kidney care.

Leeds is an area of great contrasts, including a densely populated, inner city area with associated challenges of poverty and deprivation, as well as a more affluent city centre, suburban and rural areas with villages and market towns.

The most recent census (2011) indicates that Leeds has a population of 751,500 people living in 320,600 households, representing a 5% growth since the previous census of 2001. Leeds has a relatively young and dynamic population and is an increasingly diverse city with over 140 ethnic groups including black, Asian and other ethnic-minority populations representing almost 19% of the total population compared to 11% in 2001. There are 102 GP surgeries in Leeds.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people’s needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

b. Engagement support

We commission Voluntary Action Leeds (VAL) to support our engagement work. VAL delivers the ‘Leeds Voices’ project to undertake public and community consultations on behalf of NHS Leeds CCG. There are three distinct elements to this project:

- The **Engaging Voices** network of third sector organisations provides opportunities for seldom heard communities and vulnerable groups to get involved in consultation and engagement activities.
- The **Working Voices** project offers opportunities for businesses to enable their employees to be involved in CCG engagement activities, by allowing working people to volunteer their time to be involved in consultations within the workplace.
- Volunteer Leeds **Health Ambassadors** directly engage with the public and patients at a range of venues, public events and activities across the city.
c. Detail on health topic and engagement

Frailty is a term often used by professionals to describe the loss of body resilience, which means that in case of a physical or mental illness, an accident or other stressful event, people living with frailty will not bounce back quickly. Frailty is related to the ageing process, however, not all older people are frail, and not all individuals living with frailty are older.

It is estimated that in England there are 1.8 million people aged over 60 and 0.8 million people aged over 80 living with frailty. In Leeds it is estimated that 32,000 people are living with frailty, out of which 90% are over 60, and 62% are females. Approximately 2000 people receive end of life care.

Leeds has an ambition to be the best city in the UK for health and wellbeing. Part of that vision is that people will live healthier, happier and more active lives and that people will be in control and supported by care which is based on peoples’ strengths and delivered within their communities. Providers and commissioners in Leeds are working together to provide this vision for people living with frailty and those at the end of life, and their carers.

The CCG is moving towards an ‘outcomes-based’ commissioning approach, which means that the CCG will pay providers of services based on the outcomes of their service, rather than the number of procedures they carry out. In November 2017 a stakeholder event took place to look at developing the outcomes framework for people living with frailty and those who receive end of life care, and their carers. The event was attended by patients, carers, commissioners, third sector, local authority, primary care, community care, mental health, acute trust and the ambulance provider, who by working together identified five desirable outcomes for people living with frailty and older people at end of life in Leeds:

1. Living, aging and dying well defined by ‘what really matters’ to local people
2. Reducing disruption to people’s lives as a result of avoidable harm and numerous contact with hospital services
3. Identifying all people in this population group and assessing their needs;
4. Caring well, defined by ‘what really matters’ when caring
5. Professionals working well together across the system around the needs of people.

This engagement focused on the first and forth outcomes. It aims to understand

- What people think of the word ‘frailty’
- What outcomes really matter to people living with frailty, those at end of life, and their carers.

The feedback from the engagement will be used to identify an existing PROM (person-reported outcome measurement) tool or to develop a bespoke tool to measure the outcomes of care for people living with frailty, people at end-of-life and their carers. The tool will help providers to ensure that their services are patient-centred and improve those things that really matter to patients and their carers. The tool will also help commissioners understand if interventions are helping people to live, age and die well or care well.
2. How did we identify and engage with patients?

a. Equality analysis
An equality analysis and engagement plan (available on the website here: https://www.leedscscg.nhs.uk/get-involved/your-views/frailty-what-matters/) was developed by patients, clinicians and commissioners to ensure that the right people were consulted in the right ways. The equality analysis is a review of the actual or potential effects of services on people who identify with any of the protected characteristics outlined in the Equality Act (https://www.equalityhumanrights.com/en/equality-act/protected-characteristics). This plan helped us identify who we need to engage with and how.

Our equality analysis showed that:
- In Leeds there are approximately 32,000 people who are living with frailty, of which:
  - The majority of people are over 60 years old (90%)
  - Almost two thirds (62%, n=21,000) are female
  - There are approximately 5000 younger people with a significant level of frailty
  - Approximately 2000 people receive end of life care
  - There is an association between people living with frailty and deprivation
- Older people are more likely to be frail
- Frail people are more likely to be disabled
- BME people are more likely to become frail and less likely to use health and social care services (particularly South Asian people)
- Some long term conditions that lead to frailty are more prevalent in BME people.

b. Patient assurance
The plan was taken to the NHS Leeds Clinical Commissioning Group Patient Assurance Group (PAG) in March 2018. This group is made up of patients and assures the CCG’s governing body that adequate patient involvement has taken place during consultations and engagement. The PAG agreed that the equality analysis and engagement methods outlined in the plan were generally appropriate and asked that we consider the importance of engaging with the following groups:
- Carers
- BME groups
- People living in deprived areas.

In response to the feedback from the PAG we have involved partners such as Carers Leeds and organisations that work with people from BME and deprived communities. These organisations are outlined this below. We also asked people to fill in equality monitoring information to allow us to understand any gaps in our work.

c. Involvement of partner organisations
We recognised that we need to work with our voluntary sector partners to engage with groups identified in the equality analysis and by the PAG. With the help of Leeds Older People’s Forum and VAL we’ve identified the following organisations to support us with this engagement:
- Age UK Leeds
- Carers Leeds
- Caring Together in Woodhouse and Little London
- Cross Gates and District Good Neighbours Scheme
- Health For All
- Horsforth Live at Home Scheme
- Leeds Community Healthcare NHS Trust
- Leeds CCG - Live Well Leeds Project
- Moor Allerton Elderly Care (MAE Care)
- Richmond Hill Elderly Action
- St Gemma’s Hospice
- St George’s Crypt
- Older People’s Actions in the Community (OPAL).
- Turning Lives Around

We held a workshop with our partners to develop a framework and plan for holding focus groups and interviews with people who are living with frailty and their carers. By coproducing facilitation guidance with our partners we were able to develop a consistent approach to our engagement. All these partners contributed to the engagement by holding focus groups or interviews with their service users.

The engagement team also promoted the engagement with the following organisations:
- 30 care homes
- MESMAC
- Community Links
- BARCA Leeds
- William Merritt Disabled Living Centre
- OWLS Neighbourhood Network
- Care and Repair
- Leeds Frailty Clinic

**d. Methods**

Following discussion with our PAG and voluntary sector partners we decided that surveys were not suitable for this engagement. We used focus groups and semi-structured interviews to understand people’s views and preferences.
3. Who replied?

In total 134 people contributed to the engagement, of which 96 were people living with frailty and 38 were carers.

In 2017 145 relatives in a range of settings took the time to engage and offer feedback using a citywide bereavement survey. The aimed to understand people’s experience of the quality of care received in the last days or hours of life across all settings in Leeds – Sue Ryder Wheatfields Hospice, St Gemma’s Hospice, Leeds Teaching Hospital Trust and Leeds Community Healthcare. We have used this feedback to help us understand what matters to people at the end of life and their carers.
4. What did people tell us?

We asked people living with frailty, their carers and people at end-of-life to tell us what they thought about the word **frailty** and **what matters to them** in terms of their health and wellbeing.

a. What did people think about the word ‘frailty’?
Most of the people who are living with frailty told us that they were uncomfortable with the word ‘frailty’. They told us that the word had negative connotations and suggests that they are weak and vulnerable. Some people told us that they found the word offensive and did not identify with being ‘frail’.

> ‘Soft – it doesn’t apply to me’.

> ‘I’m 80 and nowhere near feel as frail.’

> ‘Don’t want to be labelled – makes us angry’

> ‘Not a good word to use – negative’.

People who were caring for people living with frailty told us that the word ‘frailty’ was helpful in describing the complex reasons why people who do not bounce back quickly from illness or injury.

> ‘It makes sense to everyone particularly medics/GP.’

> ‘You can visualise a frail person. It covers a lot of different things’.

> ‘Using the word frail can be helpful in accessing services, it communicates that someone isn’t well’.

Some carers thought that while the term is useful it is important for the word not to be disempowering to people living with frailty.

> ‘Very important for people I care for not to see themselves as frail’

Both people living with frailty and their carers found it difficult to find an alternative to the word ‘frailty’.

b. What did people tell us about what matters to them?
We asked people to tell us what matters to them in terms of their health and well-being. We wanted to know what aspects of their lives were important to them and what they felt they could not live without.

Both people living with frailty and their carers told us that being **socially connected** was important to them. It was important that people maintained and developed aspects of their lives that supported them to stay in touch with friends, family and pets and access support from peers.

> ‘It’s important for me not to be alone’

> ‘I enjoy going out and socialising’

> ‘It’s important for me to stay in touch with my Carers Leeds Carers Group’
Maintaining **hobbies and interests** was also highlighted by people living with frailty and their carers. People told us that it was important for them to continue doing the things that they enjoyed such as going on holiday, reading, gardening and doing arts and crafts.

> ‘As a blind person it is important for me to have access to talking books’

> ‘I would miss walking and getting out in countryside.’

It was important for both people living with frailty and their carers to receive **good quality health care**. People told us that having a good relationship with their GP and other health professionals was really important to them. Being treated with respect and dignity was another important aspect of good health care. Another important aspect of good healthcare for both people living with frailty and their carers was receiving good quality, up-to-date and accurate health information.

People living with frailty told us that feeling rushed during consultations made them feel less respected, listened to and less involved in their care.

Carers told us that it was very important to them to be recognised as care-givers by professionals and to be involved in the planning of care.

People living with frailty told us that **independence** was very important for them. They told us that being able to do everyday activities such as maintaining their personal care, going to the shops and looking after their home was very important to them.

> ‘It’s important to me to be able to do my own shopping, cleaning, cooking, etc.’

Carers also talked about the importance of independence. They told us that independence for them meant being in control of their life. People told us that this included having flexibility and freedom and being able to meet the needs of their pets and family while fulfilling their role as a carer.

> ‘I don’t want to have to rush my shopping because I left the person I care for alone’

Carers also told us that it was important that they had time to look after their own needs. Access to respite care was seen as important my many of the carers we spoke to.

> ‘It’s important for me to have time for myself’

People living with frailty told us that being **physically active and healthy** was important to them. Being mobile and being able to go for a walk, play golf and go dancing was very important to people.

> ‘I like walking, I like what I see when I walk’

Both people living with frailty and their carers told us that **access to transport** was important to them. People said that poor access to transport had a big impact on other areas of their life that mattered to them.

> ‘It’s essential to me to have good and reliable transport to get out’
c. What matters to people at end-of-life

Following discussions with the Managed Clinical Network we agreed to use existing patient feedback to help us understand the needs and preferences of people at end-of-life. From the existing engagement we were able to identify the following broad themes about what matters for people receiving end of life care:

- Staff providing care are caring, considerate and supportive.
- People’s wishes are taken in consideration.
- Good symptom Management
- Privacy & dignity - it is important to have a private space for clinical staff and patients or relatives to communicate.
- Choice in the place of death mattered – many people recognised the importance of establishing people’s wishes in good time.
- Information to people and their carers/family’s needs to be consistent

d. Equality impact: what matters to people identified through our equality analysis?

Evidencing that we have considered the impact our activities will/may have on patients and the public; and identifying changes we can make to reduce/remove any negative impacts is a statutory duty. Our equality analysis and engagement plan identified the following groups we should particularly consider and engage with as a result of this proposed change.

<table>
<thead>
<tr>
<th>Protected characteristic/group or other relevant groups</th>
<th>Positive or negative impacts/issues identified</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>The majority of people (74%) involved in the engagement were over 60 years old and the feedback reflects the view of the wider population. 26% of responses came from younger people whose answers also reflected the wider views.</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td>The majority of people involved in the engagement had disabilities and their views were consistent with the wider population. One person who had a visual impairment told us it was important to have access to talking books.</td>
</tr>
</tbody>
</table>
| **Ethnicity**                                           | 13% of the people we spoke to were from BME communities. Their feedback was consistent with the views of the wider population. Some people from this community told us that:  
  - it can be a struggle to book appointments with GP for people who do not speak English  
  - they would like for GP consultations to be longer for frail older people  
  - it is important to them to be able to speak in their own language. |
| **Gender**                                              | The majority of people (61%) involved in the engagement were female. Their views were consistent with the views of the wider population. |
| **Deprivation**                                         | Only 50% of the responders shared with us their post code. Out of which 24% were from deprived areas. Their views were consistent with the wider population. |
| **Carers**                                              | Carers’ feedback has been outlined at section 4.a and 4.b. |
5. What are the key themes from the feedback?

A number of themes can be identified through the engagement process:

- Most people living with frailty did not identify themselves as being frail and many found the word derogatory.
- Carers of people living with frailty found the term ‘frail’ useful.
- Both people living with frailty and their carers said that being **socially connected** is important.
- Both carers and people living with frailty told us that being **able to do things they enjoy** and give them a sense of purpose, matters to them.
- **Receiving good quality health care** is important for people across all groups. This included being listened to and being treated with dignity.
- People living with frailty told us that **independence** and being able to do everyday activities is important to them.
- It’s important for carers to be able to **look after themselves** and get respite when they need.
- **Access to transport** to get to appointments is important both to carers and people living with frailty.
- For BME groups being able to **book appointments** and **access services in their own language** is important.
- For people at end of life is important to have **privacy** to discuss plans with health care professionals.
- **Having a choice** is important across all groups we have spoken to.
- **Working with the third sector** is a valuable way to engage with people who are frail and their carers.
6. Recommendations

Following the engagement, the commissioners are asked to consider ways to:

1. Be mindful of using the word ‘frailty’ with people who are frail.
2. Develop a ‘what matters’ tool for people living with frailty that measures people’s:
   a. Feelings of being socially connected
   b. Ability to do the things they enjoy
   c. Experience of using healthcare services, in particular whether they feel they have been listened to and treated with dignity
   d. Independence
   e. Access to transport
3. Develop a ‘what matters’ tool for people who care for people with frailty that measures people’s:
   a. Feelings of being socially connected
   b. Ability to do the things they enjoy
   c. Experience of using healthcare services, in particular whether they feel they have been listened to and treated with dignity
   d. Ability to look after their own needs
   e. Access to respite
   f. Access to transport
4. Develop a ‘what matters’ tool for people at end-of-life that measures:
   a. People’s experience of care
   b. How people’s wishes are taken in consideration
   c. Privacy
   d. Choice in where people die
   e. People’s views on the availability and relevance of information provided
5. Be mindful of the specific needs of seldom heard groups, in particular
   a. Providing accessible information and appointments
6. Be mindful of the value of the third sector in engaging with frail people, people at the end of life and their carers
7. What will we do with the information?

The report will be shared with all the people involved in the project. The report will also be included in our next e-newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services. We will also share the report with organisations involved in the engagement. The report will also be available on our website here: https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/.

The commissioner will use the report to develop a tool which measures what matters to people living with frailty, people at end-of-life and their carers.

The website will be updated to outline how the project team have used people’s feedback to develop a tool. We will also outline how we have used people’s feedback in the CCG Annual review of Engagement 2018-19.

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.
Appendix A – Detail about the people involved

We want our engagement activities to involve people from the different communities that live in Leeds. When we ask people to get involved we also ask people to give us some information about themselves so that we have a better understanding of which groups are represented. Using this information we will work hard at future events to invite people from under-represented communities. Patients are able to opt out of giving personal information and this means that we do not have information able all the people who contributed to this engagement. Of the total number of people we have engaged (134), 123 completed the equality and monitoring form either partially or fully.

**Responses**

- People living with frailty: 72%
- Carers: 28%

**Gender**

- Female: 62%
- Male: 23%
- No information: 15%
### Transgender

- Yes: 0%
- No: 33%
- Prefer not to say: 1%
- No information: 66%

### Age

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Disability

- Long standing condition: 34
- Learning difficulties/disability: 4
- Mental Health: 12
- Physical or Mobility: 35
- Hearing: 14
- Visual: 8
- Other: 3

Carer

- No information: 44%
- Yes: 35%
- Prefer not to say: 1%
- No: 20%
Alternative formats

An electronic version of this report is available on our website at https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/ or please contact us direct if you would like to receive a printed version.

If you need this information in another language or format please contact us by telephone: 0113 84 35470 or by email: andra.szabo@nhs.net

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