Frailty Workshops – facilitator guidance V1.1

Background notes

Frailty is a term 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. More about Frailty can be found here: https://www.england.nhs.uk/ourwork/ltc-op-eolc/older-people/frailty/

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. More information about this can be found in Health and Wellbeing strategy here: https://www.leeds.gov.uk/docs/Health%20and%20Wellbeing%202016-2021.pdf

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. 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, which are:

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 focuses on the first and forth outcome from the above and aims to define **'what outcomes really matter**' to people living with frailty, those at end of life, and their carers. The engagement activities will help produce a list of themed areas that define 'what matters', such as remaining independent, being in control, being active and socially connected. The feedback 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. The tool will help commissioners understand if interventions are helping people to live, age and die well or care well.

1. **What is the aim of the engagement?**
   *'To understand **what matters** to people who are 'frail' and/or at end-of-life and their carers and those nearing end of life so that we can develop a measurement tool to evaluate the impact of interventions'*

2. **What the engagement is <u>not</u>?**
   - An opportunity to find solutions to people's individual problems (although you might want to pick up issues identified outside of the session.
   - An opportunity to suggest what might matter to people (put words in people's mouths).

3. **What methods should we use?**
   - An interactive workshop should be held with groups where possible
   - The guidance could also be used to facilitate individual ad-hoc discussions/conversations

4. **How long should the engagement sessions last?**
   As long as it takes! It might depend on the capacity of the people you are working with, how long you/they have or how successful the session is.

5. **How should we introduce the engagement?**
   Explain to the group/individual that:
   - The main organisations in the NHS are *providers* (who provide healthcare – GP surgeries, hospitals etc) and *commissioners* who plan and pay for health services (Clinical Commissioning Groups (CCG))
   - The CCGs in Leeds are **changing the way they plan and pay for health services**
   - They are moving away from paying for 'activity' (the number of hip operations carried out) and **focusing more on 'outcomes'** (what difference did the activity actually make to the individual and their carer)
   - Instead of paying the hospital every time they carry out an intervention (activity) the commissioners will be paying them based on a set of outcomes including what difference the intervention has had on the patents' ability to live the life they want.
   - The commissioners think that this approach will help patients and their carers live healthier, happier and more active lives while improving patient care.
   - Everyone will have a different idea about what a 'good outcome' looks like. For some people it will be less pain, for others it might be that they feel more able to see family and friends.
   - The commissioners want to understand what matters to people so that they can develop a tool to measure how successful the outcomes are from a patient and carer perspective.

6. **How can we facilitate the discussion?**
   The discussion should centre around the following topics:

   What do people think of the word 'frailty'?
   a. Does this create positive or negative images?
   b. Should we be using the word 'frailty' to make it more acceptable (like we do with 'cancer')?
   c. What other word might we use that describe this group of people?

   What matters to people who are frail and their carers or those nearing end of life?
   d. What words describe what matters to you (as a carer or as a patient)?

e. What activities do you enjoy doing? What would you miss if you couldn't do it anymore? (hobbies, chores, socialising etc)
f. What activities are essential to you? What would you struggle to manage without? (transport, support, healthcare, socialising etc)
g. What would you like to be different when you/the person you care for have had an intervention such as a hip operation?
h. Thinking about your conversations with healthcare professionals, what do you value about your interactions with professionals? Did you feel involved? Did you know what to expect? Did you know that the benefits/limitations and risks were?
i. What information, support or interventions did you receive that were helpful? What else would have helped you?
j. What would you like to be different for the person who you care for, or who cares for you?

Feel free to use case studies or participatory tools to help you engage if you think it will improve the session. Speak to the engagement team if you want support with this chris.bridle@nhs.net andra.szabo@nhs.net 0113 8435473.

7. **How do people want to share what matters with professionals?**
Once we have developed a tool, how would people like to fill this in?
   - Online
   - With the healthcare professional
   - Other

8. **How will we know if we have missed engaging with keys groups?**
Where possible please capture the equality details from people you have engagement with using the attached form. This will help us ensure we have engaged with people with different protected characteristics.

9. **How should we record the session?**
Understanding what people discussed in the session is essential if we are to theme the feedback and make sense of it. Please take notes during the session/interactions, focussing on:
   - Personal information (name/contact/GP practice – if people are happy to give their information so that we can feedback following the engagement)
   - How people understand the word 'frailty'
   - What matters to patient and carers
   - Equality monitoring

10. **What happens next?**
We will write up and theme what people have said into a short report. We will also outline what we already know about the experience of people living with frailty/at end-of- life and their carers. We can share the report with anyone who gives us their contact details. The report will also be put onto our website.

We will use people's feedback to decide what tool we will use to measure 'what matters to people with frailty (and those who care for them)'. There are a number of existing tools we could use to do this or we could develop a bespoke tool. We will hold a workshop with voluntary sector organisations who work directly with people with frailty and their carers to help us agree the tool.

11. **What if I have questions about the engagement?**
If you have questions contact: chris.bridle@nhs.net or andra.szabo@nhs.net, 01138435473.

Recording your session/interaction

Name of your organisation:

Facilitators:

Date:

Number of patients:

Number of carers:

Number of people at end-of-life:

Contact details of participants (if people want us to share the engagement report with them directly) – fill in equality monitoring form for each participant (see overleaf)

What did people think about the word 'frailty'?

What did people tell you about what matters to them?

Anything else?

Equality Monitoring Form

Name:	Address:	Email/phone:

My postcode is:	My GP surgery is:

What gender are you?

☐ Female	☐ Male	☐ Prefer not to say

Transgender - is your gender identity different to the sex you were assumed to be at birth?

☐ Yes	☐ No	☐ Prefer not to say

Pregnancy and Maternity

☐ I am pregnant	☐ I have given birth within the last 26 weeks
☐ Not applicable	☐ Prefer not to say

What is your age?

☐ Under 16	☐ 16 - 25	☐ 26 - 35
☐ 36 - 45	☐ 46 – 55	☐ 56 - 65
☐ 66 – 75	☐ 76 - 85	☐ 86 +
☐ Prefer not to say		

What is your sexual orientation?

☐ Bisexual (both sexes)	☐ Heterosexual/straight (opposite sex)	☐ Lesbian/gay woman (same sex)
☐ Gay man (same sex)	☐ Prefer not to say	

Do you consider yourself to belong to any religion?

☐ Buddhism	☐ Christianity	☐ Hinduism
☐ Islam	☐ Judaism	☐ Sikhism
☐ No religion	☐ Prefer not to say	
Other (please state)		

What is your ethnic background?

Asian, or Asian British	Black, or Black British	Mixed/ multiple Ethnic groups	White	Other
☐ Chinese	☐ African	☐ Asian & White	☐ British	☐ Arab
☐ Indian	☐ Caribbean	☐ Black African & White	☐ Gypsy/Traveller	☐ Other
☐ Pakistani	☐ Other	☐ Black Caribbean & White	☐ Irish	
☐ Other		☐ Other	☐ Other	
If any other ethnic background, please state here:			☐ Prefer not to say	

Do you consider yourself to have a disability? Please tick all that apply

Under the Equality Act 2010 a disability is defined as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'.

☐ Long-standing illness or health condition e.g. cancer, diabetes, HIV, etc		
☐ Learning disability/difficulty	☐ Mental Health condition	☐ Physical or mobility Visual
☐ Hearing	☐ Visual	☐ Other (please state)
☐ Prefer not to say		

Do you look after, or give any help or support to a family member, friend or neighbour because of long term physical disability, mental ill-health or problems related to old age?

☐ Yes	☐ No	☐ Prefer not to say