

## Understanding the experiences of people with a respiratory condition towards end of life

We know that caring for a family member or friend at the end of their life at home, or in a care home, can be difficult.

In Leeds, we want to make sure that people receive the care they need, where they want it, and at the right time. We want to understand if there's anything we could do differently to help prevent unexpected emergency admissions into hospital, support families and carers better, and keep people safe and well at home wherever possible.

This survey is designed to hear from staff and learn from their experiences. It is also for staff to use to record conversations with people at the end-of-life and their families and carers.

If you have any questions about this survey, please contact: [caroline.mackay2@nhs.net](mailto:caroline.mackay2@nhs.net)

### Background

We, the Leeds office of the NHS West Yorkshire Integrated Care Board (ICB), or ICB in Leeds, work with the wider Leeds Health and Care Partnership to improve the health of people in Leeds, in line with the Leeds Health and Wellbeing Strategy and the Healthy Leeds Plan.

One of the goals in the Healthy Leeds Plan is to reduce the unplanned use of health services, including emergency admissions to hospital.

The main reason for emergency short-stay hospital bed days for people approaching the end of life is 'disease of the respiratory system'. The ICB's End-of-Life population board is exploring if people's experiences of this can be improved (this includes people living with severe frailty).

For some people in this situation, hospital will absolutely be the right place for them to go. For others, it may be that if they had been supported in a different way beforehand, an unplanned hospital admission could be avoided.

We are keen to explore this possibility further, and hope to learn from the experiences of staff working in this area, people using services, and their families and carers, in the hope of improving people's experiences in the future.

Staff are invited to complete the survey to tell us about their own experiences, and can also use the survey to record conversations with people at the end of life and their family members and carers.

We understand this can be a very difficult time for people, and are grateful for any feedback people are able to share.

### Who are you filling this in as?

Please select only 1 option

- On behalf of a person living with severe frailty or approaching the end-of-life**
- On behalf of a family member / friend / carer of someone living with severe frailty or approaching the end-of-life**
- I am a member of staff**

If you answered '**On behalf of a person living with severe frailty or approaching the end-of-life**' to this question, please go to 'Do you live on your own, in a care home or with a family member / carer?'

If you answered '**On behalf of a family member / friend / carer of someone living with severe frailty or approaching the end-of-life**' to this question, please go to 'Do you live with the person you are caring for / supporting?'

If you answered '**I am a member of staff**' to this question, please go to 'What part of the system do you work in?'

## Member of staff

As a someone who works closely with this population, you are well-placed to guide us in this work, along with the people who use services, their friends, family and carers.

The focus of the [Healthy Leeds Plan](#) is the 26% of the Leeds population who live in the most deprived 10% of areas nationally. For this priority there is a particular focus on the Seacroft, Cross Gates and Middleton and Hunslet primary care network (PCN) areas. The reasons for focusing on these areas are as follows:

Seacroft PCN has the highest rate of hospital admissions for 'disease of the respiratory system', bed days per capita is highest in Cross Gates PCN, and the number of non-elective admissions in IMD1 is highest in Middleton and Hunslet PCN.

If you are able to keep these in mind when responding to the questions, it would be really helpful if you could note any differences you may have seen in the support needed by people living in these areas and the wider Leeds population.

### What part of the system do you work in?

Please select **only 1** option

- Care home
- Leeds Community Healthcare NHS Trust (LCH)
- Leeds Teaching Hospitals NHS Trust (LTHT)
- Leeds and York Partnership NHS Foundation Trust (LYPFT)
- Primary Care (GP, Dentistry, Ophthalmology, Pharmacy)
- Social care
- Third sector
- Yorkshire Ambulance Service (YAS)
- Other

Please add in the box

**Which area of Leeds do you work in?**

I work with people across Leeds

I work with people in Seacroft

I work with people in Cross Gates

I work with people in Middleton and Hunslet

Other

Please tell us where

**Do you think that some unplanned hospital admissions for disease of the respiratory system could be prevented?**

**Preventing unplanned hospital admissions**

Please select **only 1** option

I think we could prevent a lot

I think some could be prevented

I don't think many can be prevented

I don't think any can be prevented

**Please tell us more about your answer**

**We have been told that if people were better supported to manage their fear / anxiety around breathlessness some unplanned hospital admissions may be prevented. Do you agree?**

Yes

No

**If so, what do you think could be done to achieve this?**

**We have been told that if people, their carers and their families had more support to self-manage their condition at home, some unplanned hospital admissions could be prevented. Do you agree?**

Yes

No

**If so, what do you think could be done to achieve this?**

**We have been told that if people had a single point of contact to support care coordination at home some unplanned hospital admissions could be prevented. Do you agree?**

Yes

No

**If so, what do you think could be done to achieve this?**

**We have been told that if people (patients, carers, and staff) knew more about what was available in an area, for example, community support, unplanned hospital admissions may be prevented. Do you agree?**

Yes

No

**If so, what do you think could be done to achieve this?**

**Please could you put the four areas, as outlined above, in order based on which you think would have the greatest impact on preventing hospital admissions.**

1 - Greatest impact

4 - Lowest impact

Please enter a number **between 1 and 4** against each of the options below. **Only use each number once.**

**If we could manage people's anxiety better**

**If people, their carers and their families were better supported to self-manage**

**If people had a single point of contact to support care coordination at home**

**If we knew more consistently what services / support was available in an area**

**Data tells us that a large number of unplanned hospital admissions for diseases of the respiratory system are out of hours (before 8am and after 6:30pm, or at the weekend).**

**Why do you think that is?**

**Are there any particular groups that might need a more specific response to help prevent unplanned hospital admissions?**

- People with conditions like COPD**
- People with conditions like pneumonia**
- People living in a care home**
- People living with dementia**
- People from a diverse ethnic community**
- People with a learning disability and / or autism**
- Women**
- Men**
- People living alone**
- None of the above**

**For people who are admitted in an unplanned way, what do you think needs to happen for them to be discharged as early as possible?**



**Can you think of anything that would change that?**

**Is there anything else you'd like to tell us about any of the above?**

## On behalf of a person living with severe frailty or approaching the end-of-life

### To be read by a member of staff:

Please answer the following questions whilst thinking about your experience of being supported with your respiratory condition. This can be any service that relates to your care (community matrons, GPs, pharmacy, social care etc.)

### Do you live on your own, in a care home or with a family member / carer?

Please select **only 1** option

**On my own**

**Care home**

**With a family member / carer**

**Other:**

Please tell us where

### Where do you live?

Please select **only 1** option

**Cross Gates**

**Middleton and Hunslet**

**Seacroft**

**Other**

Please tell us where

**Please tell us about your experience of care. What would you like us to know about your experiences of care. Please tell us as much as you feel able to.**

**Do you feel there are changes that could have improved your care?**

Yes

No

**Please tell us more about your answer**

**Do you think there are changes that could help support you to stay in your own home / mean you don't have to go to hospital?**

Yes

No

**Please tell us more about your answer**

**Below are some things we have heard that might help people avoid an unexpected admission to hospital due to their respiratory condition. Do you agree with any of the below suggestions?**

**People (patients, carers / families) having better support to manage their fear / anxiety around breathlessness**

Yes

No

**People (patients, carers / families) having better support to self-manage their condition at home**

Yes

No

**Having a single point of contact to support care coordination at home**

Yes

No

**People (patients, carers, staff) having a better knowledge of what support is available in the local area**

Yes

No

**Please use this space to tell us any more about your answers, or if you think we have missed anything from the above list?**

**Is there anything else you'd like to tell us about your care?**

For the staff: please thank the person for any feedback they have shared in this survey.

After completing 'Is there anything else you'd like to tell us about your care?', please go to 'Please tick the box below if you'd like to receive a copy of the report from this work'.

## **Family / Friend / Carer of a person living with severe frailty or approaching the end-of-life**

**To be read by a member of staff:**

Please answer the following questions whilst thinking about your experience supporting someone with a respiratory condition. This can be any service that relates to their care (community matrons, GPs, pharmacy, social care etc.)

**Do you live with the person you are caring for / supporting?**

**Yes**

**No**

**Where does the person you are supporting / caring for live?**

Please select **only 1** option

**Cross Gates**

**Middleton and Hunslet**

**Seacroft**

**Other**

Please tell us where

**Please tell us about your experience of care while supporting someone. What would you like us to know about your experiences supporting someone. Please tell us as much you feel able to.**

**Do you feel there are changes that could improve the care of the person you are supporting?**

Yes

No

**Please tell us more about your answer**

**Do you think there are changes that could help the person you are supporting stay in their own home / mean they don't have to go to hospital?**

Yes

No

**Please tell us more about your answer**

**Below are some things we have heard that might help people avoid an unexpected admission to hospital due to their respiratory condition. Do you agree with any of the below suggestions?**

**People (patients, carers / families) having better support to manage their fear / anxiety around breathlessness**

Yes

No

**People (patients, carers / families) having better support self-manage their condition at home**

Yes

No

**Having a single point of contact to support care coordination at home**

Yes

No

**People (patients, carers, staff) having a better knowledge of what support is available in the local area**

Yes

No

**Please use this space to tell us any more about your answers, or if you think we have missed anything from the above list?**



**Is there anything in particular that would help you as a family member / friend / carer?**

**Is there anything else you'd like to tell us?**

**For staff: please thank the person for the feedback they have shared in this survey.**

After completing 'Is there anything else you'd like to tell us?', please go to 'Please tick the box below if you'd like to receive a copy of the report from this work'.

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## A bit about you, finding out more and getting involved

You're nearly finished. Thanks for taking the time to answer those questions. We've got one more page left with two sections, and you'll be done.

One of the sections focuses on something we call 'equality monitoring'. We deliver a wide range of services, and we need to know who is benefiting from our services and who might be missing out. We would really appreciate you answering the questions by ticking the boxes that you feel best describes you. Some questions may feel personal, but any information we collect in this survey will be kept confidential and secure (you can view our privacy statement online: <https://www.westyorkshire.icb.nhs.uk/privacy-notice>)

The other section gives you the opportunity to join our Involving You Network. This is a health and care involvement network in Leeds. If you provide us with your contact details, you will be added to our network and you'll receive a monthly newsletter as well as opportunities to get involved and have your say on your areas of interest in health and care in Leeds (you can unsubscribe at any time). If you want to find out more about the Involving You Network before joining, please contact Adam Stewart on [adam.stewart1@nhs.net](mailto:adam.stewart1@nhs.net) or 0113 221 7723. You can also visit: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/>

To finish the survey, you need to head to the next page and click 'submit' at the bottom of the page, even if you don't answer any of the questions.

**Please tick the box below if you'd like to receive a copy of the report from this work**

**I would like to receive a copy of the involvement report**

**Please provide your name and the details of the method in which you'd like to receive the report (for example email address or postal address)**

## Your details

**First name**

**Last name**

**Email address**

**Organisation name**

## Equality Monitoring Form

It is important to us that all communities across Leeds have their say in shaping local services.

Equality monitoring collects data about people, it is important for us to collect and make sense of this information to make sure we provide the right services and the impact of services on different communities. This information helps us understand which communities' views are being heard and which are not.

Your information will be protected and stored securely in line with data protection rules and no personal information will be shared. If you would like to know how we use this information, please visit our privacy notice: <https://www.westyorkshire.icb.nhs.uk/privacy-notice>

Please answer the questions below. Some of the questions may feel personal and you do not have to answer them but telling us more about yourself will help us improve our services in Leeds.

### What is the first part of your postcode?

**Example LS23, LS7:**

Prefer not to say.

### What is your gender? (Please tick one option)

Male

Non-Binary

Female

Prefer not to say.

I describe my gender in another way.

**(Please tell us):**

### What is your age?

Under 16

56 - 65

16 - 25

66 - 75

26 - 35

76 – 85

36 - 45

86 or over

46 - 55

Prefer not to say.

### What is your religion?

(Please tick one option)

No religion

Christian (including Church of England, Catholic, Protestant and all other denominations)

Buddhist

Hindu

- Jewish  Sikh  
 Muslim  Prefer not to say.  
 Other religion **(please tell us):**

### What is your ethnic group?

(Please tick one option)

- Prefer not to say.

#### Asian or Asian British

- Bangladeshi  Chinese  
 British Indian  Pakistani

- Any other Asian background **(Please tell us):**

#### Black, Black British, Caribbean, or African:

- African  Caribbean

- Any other Black background: **(Please tell us):**

#### Mixed or multiple ethnic groups

- White and Asian  White and Black Caribbean  
 White and Black African

- Other Mixed background **(please tell us):**

#### White

- English, Welsh, Scottish, Northern  
Irish, or British  Gypsy or Irish Traveller  
 Irish  Roma

- Other White background **(please tell us):**

#### Other ethnic groups

- Arab  Kashmiri  
 Ghurkha  Kurdish

- Any other ethnic background **(please tell us)**

### Do you have a disability?

- Yes  No  Prefer not to say.

## Do you have any long-term conditions, impairments, or illness?

(Please tick all that apply or go to next question if not relevant)

- |   |   |
|---|---|
| <input type="checkbox"/> Prefer not to say.   | <input type="checkbox"/> <b>Learning, understanding, concentrating or memory:</b> (such as Down's Syndrome, stroke, or head injury) |
| <input type="checkbox"/> <b>Physical or mobility impairment:</b> (such as using a wheelchair, difficulty walking or using your hands) | <input type="checkbox"/> <b>Learning disability</b>   |
| <input type="checkbox"/> <b>Hearing impairment:</b> (such as being D / deaf or hard of hearing)                                       | <input type="checkbox"/> <b>Neurodivergent condition:</b> (such as autism, ADHD, dyslexia)  |
| <input type="checkbox"/> <b>Sight impairment:</b> (such as being blind or partially sighted)  | <input type="checkbox"/> <b>Long term condition:</b> (such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)            |
| <input type="checkbox"/> <b>Mental health condition:</b> (such as having depression, schizophrenia, bipolar disorder)                 |   |
| <input type="checkbox"/> Other: (please write in):  |   |

## Are you a carer? (Do you provide unpaid care or support for someone who is older, disabled or has a long-term condition)

- |                              |  |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> No  |  |

## What is your sexual orientation?

- |   |  |
|---|--|
| <input type="checkbox"/> Asexual  | <input type="checkbox"/> Heterosexual / Straight |
| <input type="checkbox"/> Bisexual                                       | <input type="checkbox"/> Lesbian                 |
| <input type="checkbox"/> Gay  | <input type="checkbox"/> Pansexual               |
|   | <input type="checkbox"/> Prefer not to say.      |
| <input type="checkbox"/> I prefer to use another term (please tell us): |  |

## Does your gender identity match the one you were given at birth?

(This refers to people who identify as 'Transgender', which is a term used to describe people whose gender identity is not the same as the sex registered at birth.)

- |                              |   |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Prefer not to say. |
| <input type="checkbox"/> No  |   |

## The cost of living can affect our mental and physical health. How would you describe your current financial situation?

(Please tick one option)

- |   |   |
|---|---|
| <input type="checkbox"/> <b>Very comfortable</b> (I have more than enough money for food and bills and a lot left over) | <input type="checkbox"/> <b>Just getting by</b> (I have just enough money for food and bills and a nothing left over) |
| <input type="checkbox"/> <b>Quite comfortable</b> (I have enough money for food and bills, and some left over)          |   |

- Really struggling** (I don't have enough money for food and bills and sometimes run out of money)
- I don't know.
- Prefer not to say

(We ask this question to help us understand the impact of income on experiences of services or health)

### Are you pregnant or have you given birth in the last six months?

- Yes
- No
- Prefer not to say.

### Do you care for a child / children under the age of 19? If so, what ages are they?

(Please tick any that apply)

- No
- 0 to 4
- 5 to 9
- 10 to 14
- 15 to 19
- Prefer not to say.

### What is your relationship status?

(Please choose one option)

- Divorced
- Live with partner
- Married or Civil Partnership
- Other: (please write in):
- Single
- Widowed
- Prefer not to say.

### What is your employment status (please tick any that apply)?

- Student – Further education (Sixth Form, College)
- Student – Higher Education (University)
- Employed - Full time.
- Employed - Part time.
- In receipt of state benefits (e.g., Personal Independence Payment, Universal Credit)
- Not in employment
- Apprenticeship or training
- Retired
- Prefer not to say.

Other: (please write in):

**Thank you for taking the time to complete this form.**