



Leeds Palliative Care Network

Health Needs Data Update 2019

***End of Life Care Services for
Adults in Leeds***

Executive Summary

- An update on the Health Needs Assessment (HNA) on End of Life Care Services in Leeds published in 2013.
- The review provides an update of the most up-to-date information relating to End of Life Care and considers the changes that have been made, to see where improvements have been made, and where there are still challenges in Leeds.
- This review looks at: Leeds demography, especially in relation to End of Life; a comparison of data from the Health Needs Assessment 2013 to current data; a qualitative review of the data.



Key Findings 1

Common causes of death in Leeds for adults are: cancer (27.1%), circulatory disease (26.7%) and respiratory disease (12.4%).

Cancer deaths for people aged 65 and over are projected to **rise by 16.1%** (from 1,836 in 2011 to 2,132 in 2031). **Non-cancer** deaths expected to rise by **16%** (from 4,523 to 5,249).

The trend in where people died continues to change. Hospital deaths in Leeds have decreased by 10.6% since 2003 (from 56% to 45.4%), whilst the proportion of deaths at home, in hospice and in a care home have all increased.

Key Findings 2

45% of people that died in Leeds in **2018/19** had an **EPaCCS record** = An **improvement** in the number of people

Of these **73%** of people achieved their preferred place of death between April 2018 and March 2019.

1 in 3 people who had an EPaCCS record would prefer to die in their own home (31.8%).

26.8% did die at home in 2018-19;

However there were **5%, or 131 people** during this 12 month, who would prefer to die at home, that did not achieve it.

Gap between the proportion of people who said they would prefer to die in a hospital (**1.4%**) compared to those that did die in a hospital (**19.9%**) = **484** people during this 12 month

People aged **under 65 and Males** are slightly less likely to have a preferred place of death recorded or die in their preferred place of death. A higher proportion of males die in hospital when compared to females.

Key Findings 3

Lower proportions of Mixed and Black Ethnic groups have a preferred place of death recorded and die in their preferred place of death when compared to other ethnic groups.

Feedback from service users and carers showed that there were high levels of satisfaction with care provided across all settings especially in relation to management of pain and other symptoms, and privacy and dignity.

The majority of health and care professionals that responded felt that progress had been made against the recommendations of the 2013 HNA. However, a few respondents also felt that there was still room for improvement.

Greatest area for improvement: was to 'Invest further in community services to support increasing care outside of hospital'. Some investment in community service had been made but capacity is still stretched and further investment is needed

Recommendations – For the Strategy

- Ensure that **sufficient resources and services** are in place to meet the needs of increasing numbers of people dying in Leeds.
- **Increase** the number of people offered quality conversations about **Advance Care Planning**.
- Achieving **Preferred Place of Death** is only one of a number of outcomes important to people approaching the end of life. Leeds need to **develop a broader suite of patient centred outcome measures** to guide care and service development.
- Further develop tools for **digital** sharing of patient treatment and care; **EPaCCS and ReSPECT**. The digital infrastructure needs to be developed to **ensure electronic records are accessible across all care settings**.
- System providers should collect data about **unique referrals** on an annual basis to enable analysis to be completed and trends explored.

Recommendations –

To gain a deeper understanding about people at EOL

- Conduct further analysis in order to identify whether health inequalities exist between those who do and do not have an EPaCCS record.
- Develop a deeper understanding about the complex nature of people at end of life, this will enable a more accurate picture of where growth needs to be for end of life care.
- Gain further insight into why inequalities exist in relation to end of life for different equality groups (e.g. under 65's and 65-74, males and mixed and black ethnic groups).
- Explore why a higher percentage of men die in hospital than women and whether this impacts on the lower levels of males dying in their preferred place of death.
- Explore the views and experiences of patients and carers from other protected characteristics for example LGBT and people experiencing a disability.