Leeds Health and Wellbeing Board

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Report of: Leeds Palliative Care Network

Report to: Leeds Health and Wellbeing Board

Date: 16 September 2019

Subject: Priority 12 – The best care, in the right place, at the right time: Palliative and End of Life Care for Adults in Leeds

Are specific geographical areas affected? If relevant, name(s) of area(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, access to information procedure rule number: Appendix number:	☐ Yes	☒ No

Summary of main issues

1. ***How we care for the dying is an indicator of how we care for all sick and vulnerable people" (National End of Life Care Strategy 2008/ Ambitions for Palliative and End of Life Care: A national framework for local action 2015-20)***

2. There are approximately 6850 deaths per year in Leeds. Over the last 10 years there has been a reduction in the percentage of people dying in hospital and an increase in those dying at home, in a hospice or a care home. However there are still people dying in hospital when this was not their preferred place of death, and there are some key differences for different populations, and communities.

3. This programme of work directly contributes to the Leeds Health and Wellbeing Strategy priority of 'The best care, in the right place, at the right time' through a person centred approach; this is being reflected in the next iteration on the Leeds Health and Care Plan. Leeds has an effective Palliative and End of Life Network which has driven an increase in the quality of care and also an award winning Dying Matters Partnership changing the culture around death and dying. The current Leeds End of Life Care Strategy is due to end this year and engagement has now started on a new Leeds Palliative and End of Life Framework. To support this work a revised Health Needs Assessment has been completed; additional data has been analysed using a Population Health Management approach; engagement with

people has been analysed and draft population level outcomes have been developed.

Recommendations

The Health and Wellbeing Board is asked to:

- Note the breadth of work driven by the Leeds Palliative Care Network including the work of the Dying Matters Partnership
- Recognise people receiving palliative care and those at end of life as a key priority population in city plans
- Provide feedback on the draft population level outcomes for people at end of life, and on further engagement
- Provide feedback on the draft Leeds Palliative and End of Life Framework

1 Purpose of this report

1.1 The aim of this paper is to:

- Provide an overview of the work of the Leeds Palliative Care Network, including the Dying Matters programme
- Provide an overview of the key findings from the recently updated Health Needs Assessment (HNA) and the data from taking a population health management approach to this population.
- Seek strategic steer from the Board in developing the draft outcomes for people at end of life as one of our key population groups.
- Engage the Board in the development of the 'Leeds Palliative and End of Life Framework'.

2 Background information

2.1 There are approximately 6850 deaths per year in Leeds. Common causes of death for adults are: cancer (27.1%), circulatory disease (26.7%) and respiratory disease (12.4%). Over the last 10 years there has been a reduction in the percentage of people dying in hospital and an increase in those dying at home, in a hospice or a care home. When a preferred place of death is discussed during advance care planning people are more likely to die in a place of choice. However there are still people dying in hospital when this was not their preferred place of death.

2.2 A key aspect of enabling the public to engage actively and comfortably with this aspect of life is to encourage planning and conversations about end of life care and dying. Leeds has therefore invested in a sustained five year *Dying Matters* programme, led by Public Health.

2.3 The current Leeds End of Life Care Strategy covers the five years from 2014 to 2019. This paper seeks to outline the steps being taken to agree a revised strategy for the city.

2.4 One of the recommendations from the 2014-19 End of Life Care Strategy was to consider a partnerships forum that would increase collaborative working, improve continuity of care and patient / family experience; potentially a Managed Clinical Network to improve the experience of people requiring palliative care and those at end of life.

2.5 The *Leeds Palliative Care Network* is a collaborative partnership constituted through a formal Memorandum of Understanding and governed through clear terms of reference and reporting to NHS Leeds CCG. It was formed in 2016, and has representation from across the health and care system, and is leading the way as a forerunner of an integrated provider model for this population.

2.6 The purpose of the Leeds Palliative Care Network (LPCN) is to help provider organisations work together to plan and deliver care, in the best possible way for palliative and end of life care patients, their families and carers.

2.7 Recently, the LPCN has been working alongside NHS Leeds CCG and Leeds City Council to refresh the present strategy taking account of the move towards delivering population level outcomes taking a Population Health Management approach.

3 Main issues

Leeds Palliative Care Network (LPCN)

3.1 LPCN delivers quality service improvements through a significant programme of work.[1] Some examples of projects being delivered by LPCN are as follows:

- *Secured additional resources to improve care:* For example, more equipment for nurses across all providers to improve care and a Palliative Care Ambulance Service for Leeds so journeys at end of life are caring, comfortable and safe.

- *Improved the quality of care:*
  - More streamlined systems to support transfer of care between providers
  - Ensuring Specialist Palliatives Care Consultants provide support to other long term conditions clinical teams, so difficult conversations and care planning for end of life happens earlier.
  - Improving access to medications, medicines management and guidelines.
  - Input into the Care Home quality work within the city and ensure care homes can access appropriate training.
  - Improving end of life care for people living with dementia; providing additional clinical expertise, advance care planning and best practice on pain management.

- *Improved information sharing* across all providers for continuity of care and data collection to inform further improvement work and future planning.

- *Focussed on supporting a compassionate workforce:* Delivering significant training in end of life care to organisations across the health and care system; including communications skills and embedding our approach to Better Conversations.

- *Improved public and professional access* to services, advice and support through the LPCN website (https://leedspalliativecare.org.uk); and a useful patient and carer information leaflet has been produced.[2]

[1] Copies of the Programme updates can be found via https://leedspalliativecare.org.uk/wp-content/uploads/2019/07/Programme-Overview-19-20-June.pdf
[2] Leaflet can be found via https://leedspalliativecare.org.uk/wp-content/uploads/2019/04/Palliative-and-End-of-Life-Care-Leaflet.pdf

3.2 LPCN produces annual reports, which are available on the website.[3] A valuable public feedback survey has just been completed and reported, the *Leeds Bereaved Carers Survey*, which will be used to further inform improvements and the HNA.[4]

Dying Matters

3.3 Dying Matters Partnership was established in 2015 to address a gap identified in the HNA 2013 around the need to have an open conversation about death, dying, bereavement and making plans. The partnership is a multi-agency stakeholder group which includes representatives from statutory, academic, voluntary and business sectors. The work of the Dying Matters Partnership was recognised nationally in 2017 when it was awarded:

- National Council for Palliative Care's Dying Matters Awareness Initiative of the Year Award;
- Comms 2.0 Unawards for Best Collaboration

The partnership has developed and manages a programme of work focused on enabling people in Leeds to:

- Feel more comfortable about death and dying.
- Discuss their end of life wishes with family members and/or health and social care professionals.
- Plan for their death including writing their will, registering as an organ donor and communicating their funeral wishes.

3.4 This is being achieved through three work streams:

3.4.1 *1) Stakeholder and community engagement*
Dying Matters Leeds Partnership host an event as part of the national Dying Matters awareness week each year. This gives an opportunity to place the importance of talking about dying, death and bereavement firmly on the local agenda. Events took place throughout the week with a city centre event at Leeds Kirkgate Market ('Death is Coming Ready or Not') and a range of community events supported by the Dying Matters Community Grant Fund. In addition, Leeds Bereavement Forum, in partnership with Leeds Libraries are running a series of 'death cafes' in venues across the city throughout the year. Death Cafés are an international movement dedicated to encouraging discussion about death and dying in a relaxed environment. Library staff are also offering a vast array of books available to loan relating to death, dying and bereavement.

3.4.2 *2) Building capacity*
The community grant scheme was first introduced in 2018 to encourage organisations to run their own events during Dying Matters Week and extend the reach of the programme. It was administered by Leeds Bereavement Forum and

[3] Latest LPCN Annual Report can be found via https://leedspalliativecare.org.uk/wp-content/uploads/2019/07/LPCN-Annual-Report-2018-19.pdf
[4] Leeds Bereavement Survey can be found via https://leedspalliativecare.org.uk/wp-content/uploads/2019/08/LPCN-Bereaved-Carers-Survey-2018-19-Final-report.docx.pdf

applicants could apply for up to £200. The Dying Matters Partnership has also identified a need to provide training for staff and volunteers, focusing on end of life planning and bereavement. One day training, delivered by Leeds Bereavement forum, uses the model piloted by Sue Ryder Wheatfields in 2015.

3.4.3 *3) Communications and Marketing*
A communications plan is in place to ensure clear, consistent messages are given during Dying Matters weeks. A social media plan helps to publicise events and a website has been developed to share real life stories and promote the activities within the programme.

Updated Health Needs Assessment

3.5 A Health Needs Assessment (HNA) on End of Life Care Services in Leeds was published in 2013. This formed the foundations for the Leeds Clinical Commissioning Groups to commission services which met identified needs and contributed to people in Leeds experiencing good end of life care (EoLC).The NHS Leeds CCG EoLC commissioning strategy was published in 2014.

3.6 To further understand the current service delivery and demographic impacts an updated Health Needs Assessment Review has now been produced. This identifies opportunities for improvement and will help inform future priorities for Leeds.

3.7 A summary of the key findings from this update are as follows:

- 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).
- Hospital deaths in Leeds have decreased by 10.6% since 2017 (from 56% to 45.4%), whilst the proportion of deaths at home, in hospice and in a care - home have all increased.
- 45% of people that died in Leeds in 2018/19 were on an Electronic Palliative Care Coordination System (EPaCCS; 2627 out of 5841 people). Local incentives have been developed to further improve this towards the national target of 60%. This suggests that at present over half of people that died in Leeds did not have discussions about their preferences towards the end of life.
- 73% of those that died between April 2018 and March 2019 who were on an EPaCCS register achieved their preferred place of death. This demonstrates that when preferred place of death is discussed during advance care planning people are likely to die in a place of their choice.
- Almost a third of people on an EPaCCS register would prefer to die in their own home (31.8%). In 2018-19 26.8% of people did die at home, however there were 5%, of people (131) during this 12 month time period, who would have preferred to die at home, but did not achieve it.
- There is a big 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%). This equates to around 484 people during this 12 month time period that died in a hospital when this was not their preferred place of death.

- People aged under 65 and 65-74 are slightly less likely to have a preferred place of death recorded or die in their preferred place of death.
- Males are slightly less likely to have a preferred place of death recorded. Males are also less likely to die in their preferred place of death when compared to females (70% and 76% respectively). They are also more likely to die in hospital.
- Lower proportions of Mixed (e.g. Mixed - Any other mixed background; Mixed - White and Asian; Mixed - White and Black African; Mixed - White and Black Caribbean) 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.
- There is still more work to be done in line with the vision of the Leeds Health and Wellbeing Strategy to improve the health of people of the poorest the fastest and our approach to Inclusive Growth with some areas having a lower proportion of people dying in their preferred place of death (e.g. LS2, LS4, LS23). Further analysis is being undertaken in relation to linkages to areas that experience higher levels of deprivation.

3.8 The qualitative review demonstrated that the majority of health and care professionals that responded felt that progress had been made against the recommendations of the HNA 2013. However, a few respondents felt that there was still room for improvement. Responses suggested that the area for greatest improvement: was around the recommendation to 'Invest further in community services to support increasing care outside of hospital' in line with our Leeds Left Shift approach and 'working with' approach. Whilst some of the comments showed that investment in community services had been made, capacity was still stretched and further investment was needed. This needs to be considered particularly in the context of the capacity and workforce we need to meet future demographic challenges outlined in the Joint Strategic Assessment and as we continue to work to increase the number of people dying at home, in a hospice or a care home.

Future Strategic Plans and delivering Population outcomes

3.9 On 21 November 2018 LPCN hosted a Strategic Planning Event attended by 63 people, which identified early priorities for improvement and further action.[5]

3.10 Over recent months LPCN has worked with partners, commissioners and public health colleagues to start to develop population level outcomes for people in need of palliative care and at the end of life, and to understand *Population Health Management* methodology. Some initial information about variation within each Local Care Partnership has been shared and there is a plan to add hospice data to the Leeds data set to improve future information. Public Health have also revised and updated the HNA 2013 (as detailed above).

[5] https://leedspalliativecare.org.uk/wp-content/uploads/2019/05/The-Future-of-Palliative-and-End-of-Life-Care-in-Leeds-.pdf

3.11 A *Strategy Advisory Group* has also been established so that senior representative from all partner organisations can guide, inform and influence future strategic developments.

3.12 The 'end of life segment' is currently those people identified within GP End of Life Care registers. Quality improvement work is ongoing this year to increase early recognition and registration of people approaching the end of life, and work with the public on this will be part of the 2020 Dying Matters Campaign.

3.13 A key step to improving Population Health is to describe the outcomes we aspire to achieve for that population. The Strategy Advisory Group has created a draft *Outcomes Framework* based on:

- What people in Leeds have told us matters most about end of life care during recent engagement:
  - Staff providing care are caring, considerate and supportive.
  - People's wishes are taking into consideration
  - Information to people and their carers/family's needs to be consistent
  - Privacy
  - Choosing where to die

- National evidence and good practice.

Wider consultation on the Outcomes Framework is being planned with people and providers, jointly with NHS Leeds CCG and Leeds City Council. These outcomes are in draft and the Strategic Advisory Group would welcome Board members' steer both on the outcomes and the engagement process (Appendix 1).

3.14 To support the delivery of the outcomes and from work to date the LPCN are developing a Framework (Appendix 2) which will inform the provider response to the outcomes. The Framework takes account of:

- Priorities for improving end of life care identified at the Future of Palliative Care in Leeds Strategy event (November 2018)
- Ambitions for Palliative and End of Life Care – a National Framework for action (2015-2020)
- NHS Long Term Plan 2019
- Leeds End of Life HNA Review 2019
- Bereaved Carers Survey 2018-19
- What matters most at end of life to people in Leeds
- Strategy Advisory Group and Outcomes working group analysis
- Feedback from Leeds Clinical Senate and Leeds Academic Health Partnership

4 Health and Wellbeing Board governance

4.1 Consultation, engagement and hearing citizen voice

4.1.1 Population Health Management engagement process with people occurred during April and May 2018 which resulted in identifying 'What matters to people at end of life in Leeds'.[6]

Engagement with 18 organisations to collect feedback from those living with frailty, those at the end of their lives and their carers was conducted as part of the development of the Clinical Strategy for Frailty and End of Life. 132 service users identified the priorities for people living with frailty, carers and those at end of life. The latter included the following for end of life:

- Staff providing care are caring, considerate and supportive.
- People's wishes are taking into consideration
- Information to people and their carers/family's needs to be consistent
- Privacy
- Choosing where to die

4.1.2 Bereaved Carers Survey undertaken October 2018 – January 2019 received 204 responses from relatives whose family member had died in various places across the care system.[7]

4.1.3 Stakeholder engagement was conducted as part of the Health Needs Assessment (HNA) for End of Life Care for Adults in Leeds (2013) and a review of these findings is underway. The HNA identified a need to open a debate about death, dying, bereavement and making plans.

4.1.4 Stakeholder and community engagement is a key work stream in the Leeds Dying Matters programme, which ensures that citizens are engaged an involved with the annual programme of activity. A programme of engagement events take place during Dying Matters week each year.

4.2 Equality and diversity / cohesion and integration

4.2.1 Inequalities in health are a key issue for older people with ill health and social impacts affecting the poorest in the city disproportionately.

4.2.2 The Health Needs data review recognises the inequalities in end of life care and outcomes between people in different population groups and recommends gaining further insight into why inequalities exist in relation to end of life for different equality groups. Specific equality issues raised are:

- People aged under 65 and 65-74 are slightly less likely to have a preferred place of death recorded or die in their preferred place of death
- Males are slightly less likely to have a preferred place of death recorded. Males are also less likely to die in their preferred place of death when

[6] https://www.leedsccg.nhs.uk/get-involved/your-views/frailty-what-matters/
[7] https://leedspalliativecare.org.uk/wp-content/uploads/2019/08/LPCN-Bereaved-Carers-Survey-2018-19-Final-report.docx.pdf

compared to females (70% and 76% respectively). They are also more likely to die in hospital.

- Lower proportions of Mixed (e.g. Mixed - Any other mixed background; Mixed
- White and Asian; Mixed - White and Black African; Mixed - White and Black Caribbean) 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

4.2.3 Dying Matters and related activities are delivered in a range of different settings and localities in order to engage with different population groups.

4.3 Resources and value for money

4.3.1 LPCN is funded £105K per annum by NHS Leeds CCG. There is an Executive Group that direct and support the LPCN which delivers significant improvement benefit beyond the value of the resourced clinical and management time, due to the commitment and engagement of staff from all the partner organisations.

4.3.2 The Dying Matters programme is funded by the NHS Leeds CCG. A budget of £36,250 was allocated to the Dying Matters programme in 2015. In 2017 a further sum of £4500 per year for a period of five years was agreed. Additional resources have been provided by private sector partners who have given time and resources free of charge. Officers leading the project are part of Public Health, within the Adults and Health Directorate of LCC. The partnership is led by the Head of Public Health for Older People. The Ageing Well Officer has day to day responsibility for developing the programme and provides the main resource; with other officers covering key areas as part of their roles.

4.4 Legal Implications, access to information and call In

4.4.1 There are no access to information and call-in implications arising from this report.

4.5 Risk management

4.5.1 LPCN hold a Risk Register and a System Issues log. The main challenge to this work is the limitations of the workforce capacity both in delivering care and undertaking improvement work. Looking at new workforce models and working collaboratively will provide some alleviation.

5 Conclusions

5.1 Leeds has an effective Palliative Care and End of Life Network which has driven the increase in the quality of care and an award winning Dying Matters Programme with citizens. However the recent revised HNA demonstrates there is still further improvement that needs to be made to achieve the outcomes that matter most to people.

5.2 The current Leeds End of Life Care Strategy is due to end this year and consultation is now started on a new Leeds Palliative and End of Life Framework. To support this work a revised Health Needs Assessment has been completed; additional data has been analysed using a Population Health Management approach and some draft population level outcomes have been developed

6 Recommendations

The Health and Wellbeing Board is asked to:

- Note the breadth of work driven by the Leeds Palliative Care network including the work of the Dying Matters Partnership
- Recognise people receiving palliative care and those at end of life as a key priority population in city plans
- Provide feedback on the draft population level outcomes for people at end of life, and on further engagement
- Provide feedback on the draft Leeds Palliative and End of Life Framework

7 Background documents

7.1 None.

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How does this help reduce health inequalities in Leeds?
It is nationally recognised that there continues to be unacceptable geographic variation and inequality in the end of life care people receive. The recent revised HNA is aiming in part to understand this for Leeds, and the work to agree population level outcomes for people at end of life for Leeds, with a specific focus on those who are the poorest, will aim to redress these issues by focusing on what is important to people and their carers.

How does this help create a high quality health and care system?
This programme of work directly contributes to the Health and Wellbeing Strategy priority of 'The best care, in the right place, at the right time'. The work of the LPCN has shown to increase the quality of care for people in Leeds, and the development of the outcomes framework will aim to drive this further.

How does this help to have a financially sustainable health and care system?
The work of the LPCN is already an excellent example of an emerging integrated provider model. Moving forward the development of the outcome framework , supporting providers to further work in an integrated system to support people to achieve what is important to them and their carers is critical to the sustainability of a future health and care system.

Future challenges or opportunities

- Culture change to ensure everyone is prepared to have conversations about dying and death
- Increasing the use of EPaCCs/Advance Care Planning
- Training of health and care workers
- Increasing funding for palliative and end of life within the community
- Developing a Single Point of Access supporting end of life care for people in Leeds

Priorities of the Leeds Health and Wellbeing Strategy 2016-21	
A Child Friendly City and the best start in life	
An Age Friendly City where people age well	X
Strong, engaged and well-connected communities	X
Housing and the environment enable all people of Leeds to be healthy	
A strong economy with quality, local jobs	
Get more people, more physically active, more often	
Maximise the benefits of information and technology	X
A stronger focus on prevention	
Support self-care, with more people managing their own conditions	X
Promote mental and physical health equally	X
A valued, well trained and supported workforce	X
The best care, in the right place, at the right time	X