Health Needs Data Update

End of Life Care Services for Adults in Leeds

On behalf of the Director of Public Health, Leeds City Council

Date
December 2019

Contents

1 Executive Summary

This Health Needs Data Review is an update on the Health Needs Assessment (HNA) on End of Life Care Services in Leeds published in 2013. The Health Needs Assessment 2013 outlined some of the key end of life statistics to inform a number of recommendations for change. This 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.

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).
- 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.
- There has been an improvement in the number of people who have discussed their care preferences and treatment recommendations which were shared in the Electronic Palliative Care Coordination Systems (EPaCCS) record. 45% of people that died in Leeds in 2018/19 had an EPaCCS record (2627 out of 5841 people). A primary care quality improvement programme has been developed to further improve this and increase the number of people offered advance care planning.
- Three quarters (73%) of people achieved their preferred place of death between April 2018 and March 2019. This demonstrates that when preferred place of death is discussed during advance care planning, and shared effectively, people are likely to die in a place of their choice.
- 1 in 3 people who had an EPaCCS record would prefer to die in their own home (31.8%). It is also the place where a large proportion of people did die at home in 2018-19 (26.8%), however there were 5%, or 131 people during this 12 month time period, who would prefer to die at home, that 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 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). A higher proportion of males die in hospital when compared to females.
- 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.
- Some areas have a lower proportion of people dying in their preferred place of death (e.g. LS2, LS4, LS23).

- 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 qualitative review demonstrated that 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.
- 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'. Whilst some of the comments showed that investment in community service had been made, capacity was still stretched and further investment was needed:

A summary of the recommendations from this updated HNA are as follows:

Implications for the End of Life Care Strategy:

- Resources and Services - ensure that sufficient resources and services are in place to meet the needs of increasing numbers of people dying in Leeds.
- Communication - Increase the number of people offered quality conversations about advance care planning. Ensure these conversations happen regularly with people at end of life so that goals and preferences can be kept up to date and accurate and their care is tailored to their needs.
- Outcomes – 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.
- EPaCCS – Further develop tools for digital sharing of patients' treatment recommendations and care preferences to incorporate patient goals and priorities and emerging initiatives such as ReSPECT. The digital infrastructure needs to be developed to ensure electronic records are accessible across all care settings.
- Unique Referrals – collect data about unique referrals on an annual basis to enable analysis to be completed and trends explored.

Gaining a deeper understanding about people at end of life:

- 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.

2 Introduction – National and Local Strategic Context

The 2013 HNA outlined a number of national strategies for end of life care services as well as recognising that end of life care service strategies will also come under broader health agendas. The three key strategies outlined in the HNA 2013 are: the Department of Health End of Life strategy, the Palliative Care Funding Review and the NICE quality standards relating to EoLC.

Since the 2013 HNA there have been a number of new local and national strategies have been produced that support this work. The current drivers include:

- Care of dying adults in the last days of life NICE guideline (NG31)
- Care of dying adults in the last days of life Quality standard (QS144)
- End of Life Care for Adults: service delivery Quality Standard (QS13)
- Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
- The NHS Long Term Plan
- Leeds Health and Wellbeing Strategy 2016-2021
- Leeds Health and Care Plan
- West Yorkshire and Harrogate 5 Year Strategy for Health and Care

2.1 Leeds End of Life Care Commissioning Strategy for Adults 2014-19

This work was developed by the Leeds Health and Social Care Transformation Board which used the recommendations outlined in the Health Needs Assessment for End of Life Care Services 2013 to inform its aims, outcomes and commissioning intentions.

The aims of this strategy were as follows:

- To improve end of life care for people in Leeds with advanced, progressive and incurable illness
- To improve access to end of life care services, improve choice of type and place of care and reduce inequalities across the city
- To increase the proportion of patients who are cared for and die in their preferred place of care

The ***outcomes*** were:

- Pain and other symptoms should be controlled effectively
- The individual, carers and family should feel well supported and appropriately involved in their care planning
- The individual, carers and family should feel confident in the skills and knowledge of their health and social care professionals
- The individual, carers and family should know who to contact in an emergency and
- The individual should be able to die in their place of choice

The commissioning strategy included a Work Programme with leads and timescales to ensure that all 66 recommendations from the HNA would be addressed over the 5 years following its publication.

The immediate ***commissioning priorities identified for 2014/16*** were as follows:

Hospital Discharge
To provide a 7 day Specialist Discharge Service for Palliative Care patients which has the flexibility to respond to the changing needs and preferences of patients transferring from in-patient settings to the community for end of life care

Co-ordination of care
To develop a single point of access for patients 24/7 for advice and signposting

Develop seven day services
To develop a model where Specialist Palliative Care Clinical Nurse Specialists provide care 7 days a week in acute hospitals and community settings

Provide more choice of place of care in the last days of life
To develop nurse-led beds for hospice type care in the last days of life as an option for patients who do not require a specialist service and cannot be cared for at home

Ensure rapid access to care outside of hospital 24/7
To develop an enhanced district nursing service that is able to meet the requirements of the Service Delivery Framework for Palliative and End of Life Care (Leeds) with an increased number of nurses who are able to prescribe and verify expected death. Review hospice admissions system to optimise choice and efficiency for patients

Improve access to medicines
To develop an improved system for co-ordination and delivery of EoLC medication in the community including access to super holding pharmacies

Continue to provide and improve education
The current education strategy will be reviewed and refreshed in order to inform the future commissioning of education provision

Palliative Care Funding Review
Consider the implications of the Palliative Care Funding Review and develop recommendations around the way that end of life care services are commissioned

Support to Care Homes 24/7
Develop a system which provides 24/7 nursing support to Care Homes for patients in the last days of life

Improving carer support and provision of bereavement services
To develop an improved system of carer support to reduce the incidence of carer breakdown. Review bereavement services and re orientate to meet the needs of bereaved people.

Improve medical support to community staff Out of Hours
Link with 111 to develop a system whereby calls from community staff requesting GP support Out of Hours are prioritised

It was proposed that in order to provide a consistent and evidence-based approach towards implementation across all services providing palliative and end of life care, that a framework was introduced following a formal options appraisal. This proposal included an ***End of Life*** Joint ***Protocol for the Transfer of Care*** between services, and a ***Managed Clinical Network*** to provide the structure and accountability to drive real change in the system across these multiple providers. It was stated that a new performance management system would be developed to effectively monitor the outcomes of this commissioning strategy, and a health economics approach would be used to evaluate service change. This would enable commissioners to have greater control over the services provided by obtaining robust data on service performance which would inform future understanding and commissioning decisions.

2.2 Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

The Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out a vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England. The table below provides an overview of the aspects included within this tool. The full document can be found at: http://endoflifecareambitions.org.uk/

AMBITIONS FOR PALLIATIVE & END OF LIFE CARE
OVERARCHING VISION

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

	National Ambitions		
1	Each person is seen as an individual.	1.1 Honest conversation 1.2 Clear expectations 1.3 Systems for person centred care 1.4 Access to social care	1.5 Good end of life care includes bereavement 1.6 Helping people take control 1.7 Integrated care
2	Each person gets fair access to care.	2.1 Using existing data 2.2 Generating new data 2.3 Population based needs assessment	2.4 Community partnerships 2.5 Unwavering commitment 2.6 Person centred outcome measure
3	Maximising comfort and wellbeing.	3.1 Recognise distress whatever the cause 3.2 Skilled assessment & symptom management 3.3 Priorities for care of the dying person	3.4 Address all forms of distress 3.5 Specialist palliative care 3.6 Rehabilitative palliative care
4	Care is coordinated.	4.1 Shared records 4.2 A system-wide response 4.3 Clear roles and responsibilities	4.4 Everyone matters 4.5 Continuity in partnership
5	All staff are prepared to care.	5.1 Professional ethos 5.2 Knowledge based judgement 5.3 Awareness of legislation	5.4 Support and resilience 5.5 Using new technology 5.6 Executive governance
6	Each community is prepared to help.	6.1 Compassionate and resilient Communities 6.2 Practical support	6.3 Public awareness 6.4 Volunteers

Foundations – necessary for each ambition and underpin the whole

Personalised care planning	Shared records	Evidence & information	Involving, supporting and caring for those important to the dying person	Education & training	24/7 access	Co-design	Leadership

3 Local Demography

3.1 Leeds Demographic Profile

3.1.1 General Leeds Demography Data

As outlined in the HNA 2013, the 2011 census provides the most up-to-date broad demographic data for Leeds which will be updated in 2021. The 2011 census found that, for Leeds:

- 49% of the population are male and 51% are female
- 14.6% are aged 65 years and over
- 81.1% of the population is White British and 18.9% is made up of other ethnic groups.
- 4.5% of people live in households where no one has English as a main language.
- 4.2% of people self-report that they have bad health, 1.2% report they have very bad health.
- 16.6% of people identify that they have a long term illness or disability that affects their day-to-day activities
- 6.1% of people provide between 0 and 19 hours of unpaid care a week, 1.4% provide between 20 and 49 hours and 2.2% provide 50 hours or more.
- 21.3 % of households are people who live alone (68,413 people), 12% of households are made up of people who live alone are aged 65 years plus (38,312 people).

3.1.2 Data for Leeds for End of Life

The following table shows the crude death rates for Leeds from 2013 to 2018. This shows that the crude death rate is static at 0.8% per year, with slight peaks and troughs in the total number of deaths each year. The proportion of people that are dying that are aged 75+ shows slight peaks and troughs, with around two thirds of deaths being amongst this age range each year.

	2013		2014		2015		2016		2017		2018	
	Rate	Number	Rate	Number	Rate	Number	Rate	Number	Rate	Number	Rate	Number
All Ages	0.8%	6596	0.8%	6317	0.8%	6792	0.8%	6594	0.8%	6672	0.8%	6850
75+	68.5%	4515	66.6%	4204	67.5%	4582	66.1%	4360	67.0%	4470	66.2%	4537
85+	37.3%	2461	36.2%	2288	37.3%	2531	37.0%	2442	37.1%	2478	38.0%	2606

The most common causes of death in Leeds are cancer (27.1%), circulatory disease (26.7%) and respiratory disease (12.4%) (End of Life Care Profiles, Public Health England 2017). Cancer deaths for people aged 65 and over are projected to rise from 1,836 in 2011 to 2,132 in 2031 (a 16.1% increase). Non-cancer deaths expected to rise from 4,523 to 5,249 (a 16% increase) (ONS, 2011).

3.2 Key Comparator City: Sheffield

In order for the analysis to compare Leeds against areas with similar characteristics as well as the England average, Sheffield was selected as a primary comparator city for a number of reasons. Firstly, it was used as a comparator city in the Health Needs Assessment 2013 and is therefore useful in reviewing the data for the same cities in 2018. Also, Sheffield, along with Leeds, has been identified as one of England's 'core cities' so they share a similar population size. Along with this, the demographic makeup of Leeds is closely matched to that of Sheffield as demonstrated in the table below.

Domain	**Leeds**	**Sheffield**
Population	784,846	552,698
% Male	49.1	49.3
% Female	50.9	50.6
% Minority Ethnic Background	18.9	19
% Aged 65+	15.5	19.3

Source 1: Leeds Observatory, Population Data
Source 2: Sheffield Census Data 2011

It must be noted that locally available GP data suggests that there are 60,000 more people in Leeds than the census population data suggests.

4 Trends and comparisons

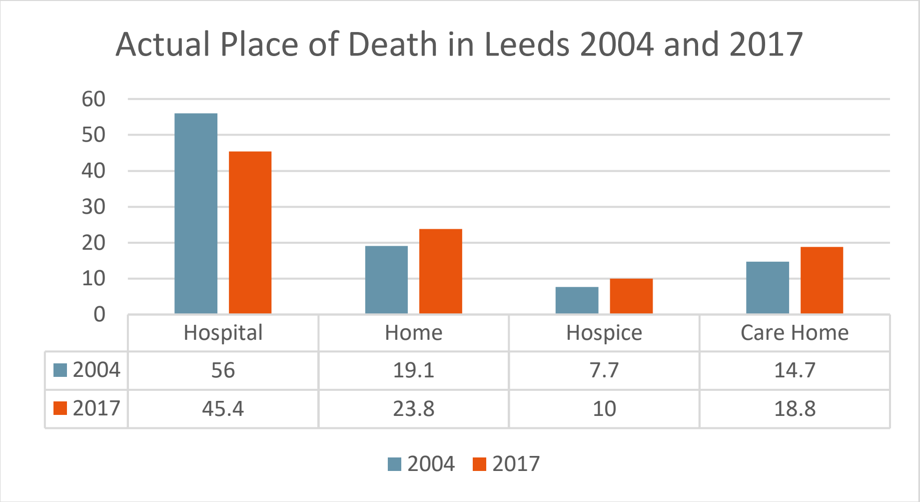
4.1 Introduction

The following section provides an update on key statistics from the 2013 Health Needs Assessment for End of Life Care Services in Leeds with the most up-to-date statistics, some of which have been taken from the End of Life Care Profiles (Public Health England) and locally available data. Where historical data is available on the End of Life Care Profiles (Public Health England) this has been used to ensure that the data sources enable accurate comparisons to be conducted. This includes: actual place of death, death in usual place of residence, preferred place of death, and cause of death. This data highlights some of the statistical trends in Leeds from 2013 to 2017 as well as comparing Leeds with the England average and in some cases with Sheffield as a comparator city.

4.2 Actual Place of Death

Actual Place of Death refers to the percentage of people who died in a given location. This data refers to the whole population.

4.2.1



	Hospital	Home	Hospice	Care Home
2004	56	19.1	7.7	14.7
2017	45.4	23.8	10	18.8

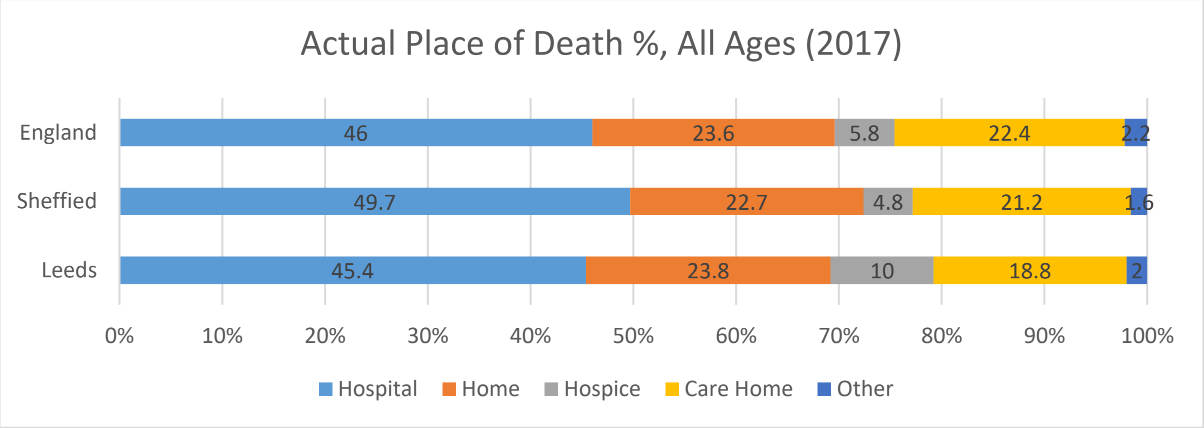
Graph 1: Trends of Actual Place of Death (%, All Ages) in Leeds 2004 and 2017. Source: End of Life Care Profiles, Public Health England

The trend in where people died has changed significantly over the last 13 years, as demonstrated in the above chart which shows that that the proportion of hospital deaths in Leeds has decreased since 2004, whilst the proportion of deaths at home, in hospice and in a care home have all increased. The smallest change in percentage of deaths from 2004 to 2017 has been in hospices, with an increase of 2.3%, whilst the largest change is with the percentage of hospital deaths, with a significant decrease of 10.6%. Therefore, this data finds that much fewer people are dying in hospital whilst there is a steady increase of people dying at home and in care homes. These trends match those that are seen nationally.

The number of deaths in each location per year is provided in the table below based on End of Life Care Profiles. This is based on 2017 data. This can be used to inform future planning of End of Life Care services and associated strategies. However it should be noted place of death data alone does not fully determine or indicate level of need or demand for end of life care. To provide a full picture additional data would need to be presented including hospital utilization data and complexity analysis.

Place of Death	Number of Deaths
Care Home	1251
Home	1584
Hospice	665
Hospital	3018

4.2.2



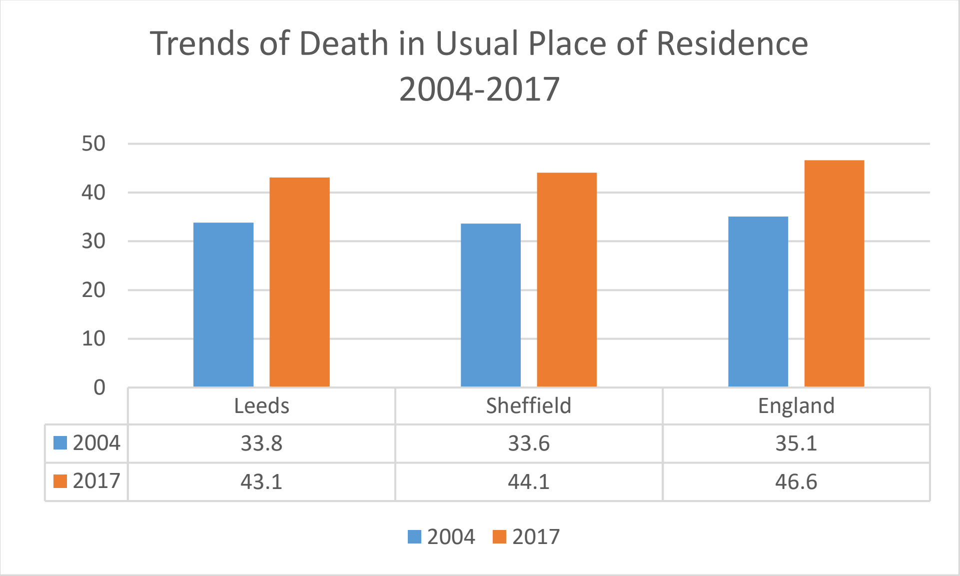
Graph 2: Actual Place of Death (%, All Ages) for Leeds, Sheffield and the England Average, in 2017. Source: End of Life Care Profiles, Public Health England

The percentage of deaths in hospital in Leeds in 2017 very closely matches that of the England average. One notable figure from this graph finds that Leeds has almost double the percentage of deaths in hospices than Sheffield. All comparators have fairly similar percentages of death at home and deaths in care homes, however it must be noted that deaths in care homes for Leeds are lower than the England average and comparator cities, which is possibly due to the commitment locally to support preferred place of death at home with Continuing Healthcare Fast Track funded care packages. Leeds historically used fast track funding to significantly enable more people to have funded care at home rather than go into a care home.

4.3 Death in Usual Place of Residence

Death in Usual Place of Residence is often the most ideal place for people to die, where people's preferred place of death has not been identified.

4.3.1



	Leeds	Sheffield	England
🟦 2004	33.8	33.6	35.1
🟧 2017	43.1	44.1	46.6

Graph 3: Trends of Death in Usual Place of Residence (DiUPR, %, All Ages) for Leeds, Sheffield and the England average for 2004 and 2017. Source: End of Life Care Profiles, Public Health England.

This table finds that the national average of the percentage of people dying in their usual place of residence has increased by 11.5%, whilst in Leeds and Sheffield the percentage has increased by 9.3% for Leeds and in Sheffield 10.5%. Since the 2013 Health Needs Assessment the increase in Death in Usual Place of Residence for Leeds was lower than the England average (0.6% vs 2.1%) due to a dip in 2016. A similar dip was also seen for Sheffield in 2015 and 2016.

4.4 Preferred Place of Death

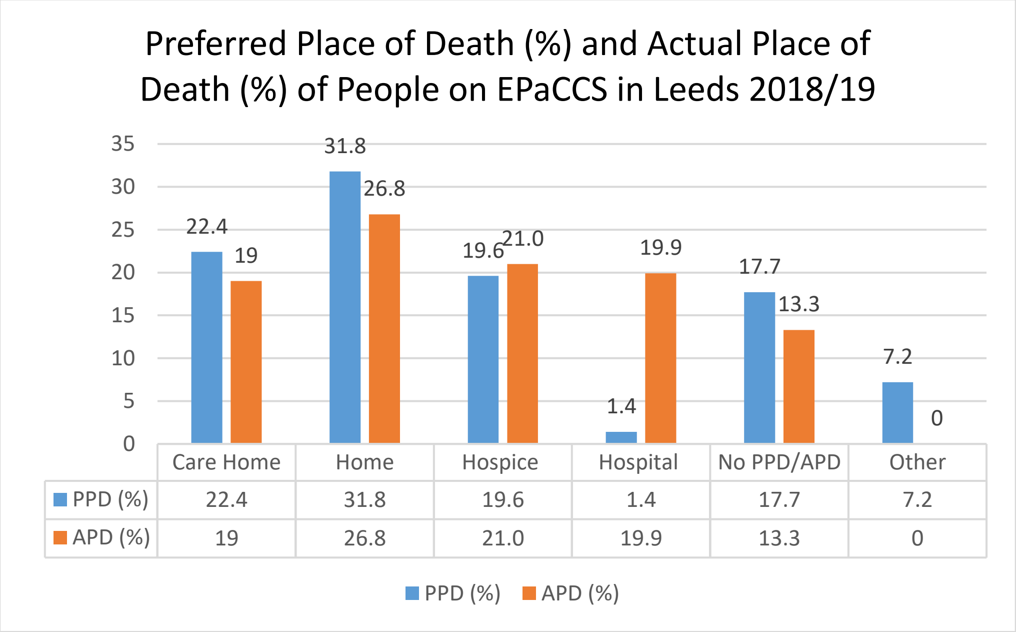
The Preferred Place of Death (PPD) refers to the place that people would prefer to die, as recorded via an EPaCCS record.

The following data only refers to people who have recorded these preferences on EPaCCS and therefore does not reflect Leeds total population. There are several limitations that need to be noted with the data presented from the EPaCCS record.

1) Leeds has an incomplete EPaCCS system reflecting only data entered by community providers. The EPaCCS report does not include preferred place death preferences recorded by hospital teams. It will therefore not capture any change of preference made as an inpatient for example those people who choose to die in Leeds Teaching Hospitals Trust (LTHT) right at the end of their lives. Preferences about place of death change over time in response to proximity to death and care needs.
2) A significant amount of data is missing in relation to actual place of death as this is manually entered into the EPaCCS record and is not present for 16-20% of records. If it is missing the records are excluded from the analysis.
3) The report only compares actual and first choice preferred place of death. First and second choice can be recorded on EPaCCS. Therefore people may be dying in second choice but we don't have figures to quantify this at present.
4) It is not known how often preferred place of death is reviewed and updated therefore we do not know how up to date the recorded preferred place of death is.

Of the 5841 deaths in Leeds in 2018/19, 2627 people had treatment recommendations and care preferences recorded in EPaCCS (45%), which is a significant improvement over time. Local incentives have been developed to further increase the number of people offered this opportunity in line with national guidance that 60% of those who die should be offered this conversation. However, 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.

4.4.1



Graph 4: Preferred Place of Death (%) and Actual Place of Death (%) of people on the EPaCCS in Leeds, 2018/19. Source: Leeds Clinical Commissioning Group (CCG) EPaCCS Data 2018-19 Report

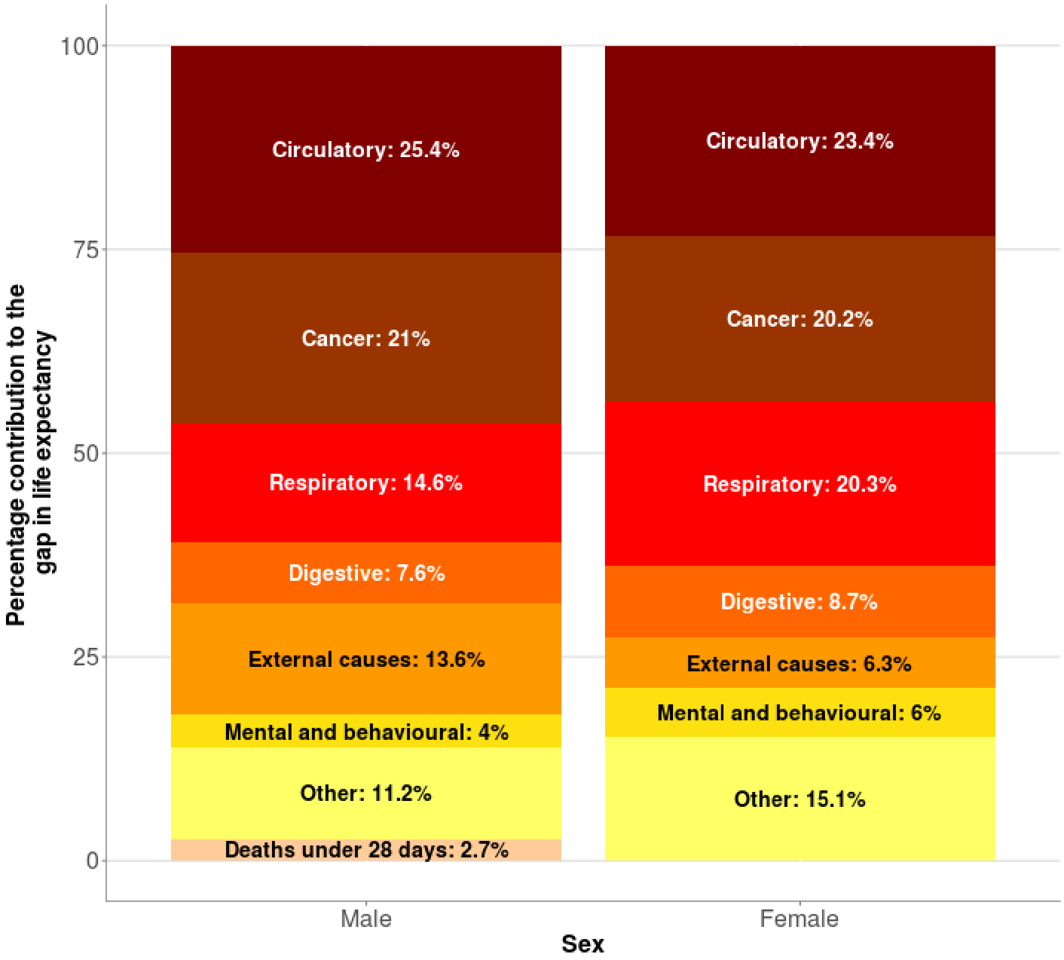
The above table highlights that almost a third of people would prefer to die in their own home (31.8%). It is also the actual place of death for a large proportion of people in 2018-19 (26.8%), however there were 5%, or 131 people during this 12 month time period, who would prefer to die at home, that did not achieve it. Furthermore, 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.

Three quarters of people achieved their preferred place of death (73%). This indicates that when preferred place of death is discussed during advance care planning people are likely to die in a place of their choice.

4.5 Underlying Cause of Death

The below chart shows the most recent scarf diagram which demonstrate the inequalities gap for key conditions affecting people living in Leeds. This shows that circulatory diseases, cancers and respiratory conditions cause the greatest inequality gap for life expectancy between those living in the most and least deprived areas of Leeds.

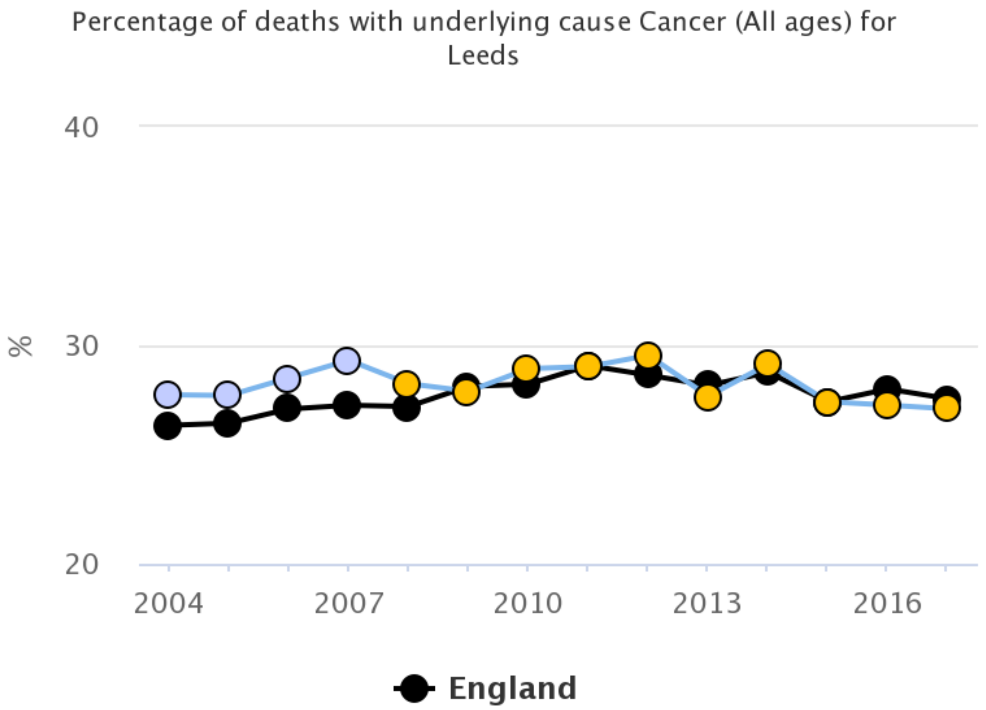
Scarf chart showing the breakdown of the life expectancy gap between the most deprived quintile and least deprived quintile of Leeds, by broad cause of death, 2015-17



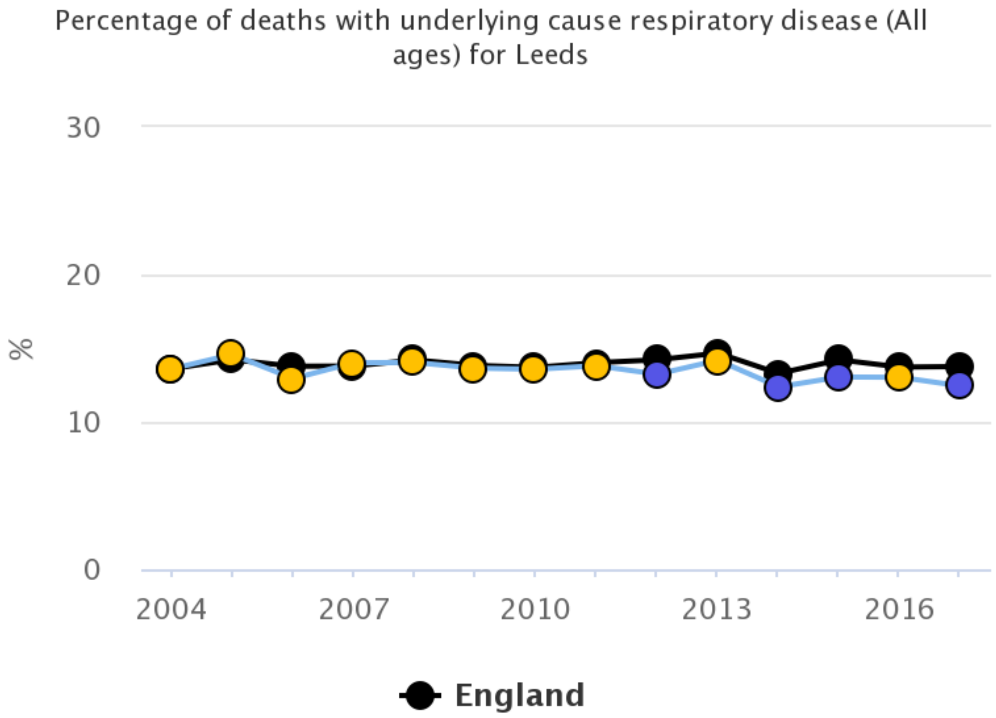
Source: Public Health England: Segment Tool

Cancer, respiratory disease and circulatory disease are the three named indicators used in the End of Life Care Profiles and the most common underlying causes of death. For this, we have only included these three indicators in comparing Leeds with the England average.

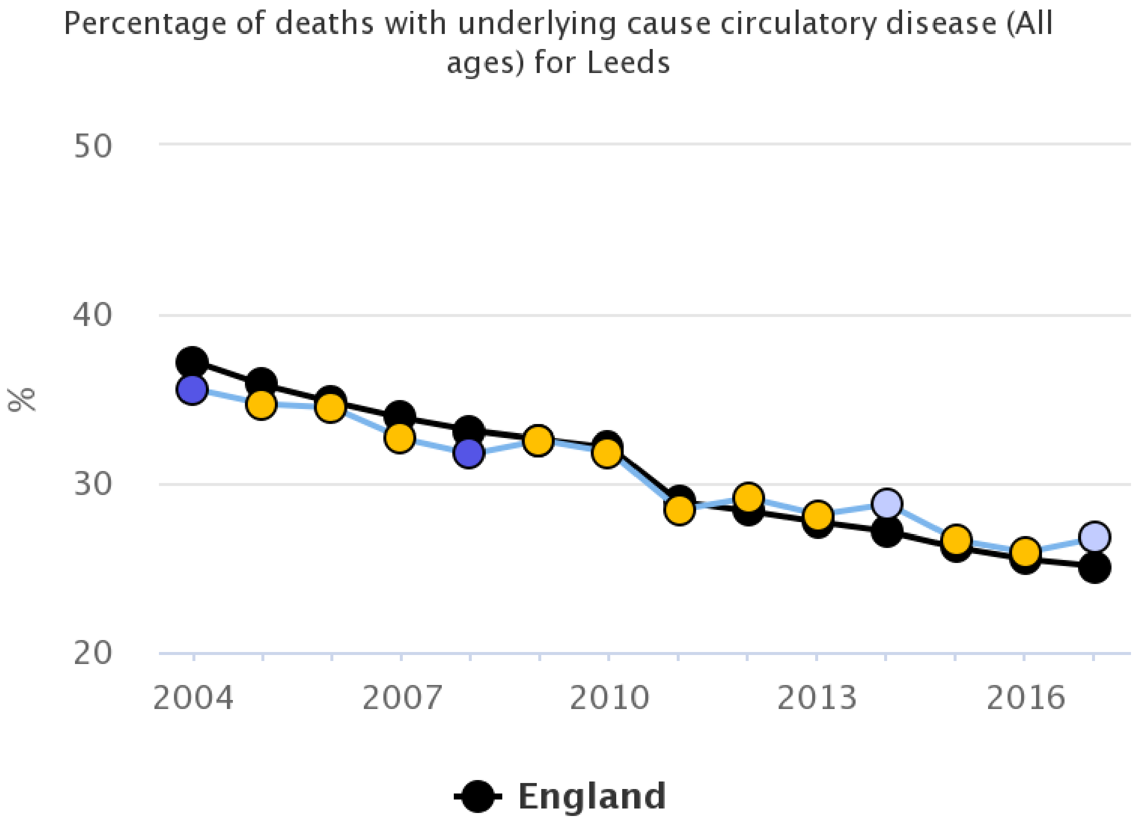
The chart below displays a similarity between the percentages of cancer deaths in Leeds with cancer deaths in England. Leeds has a slightly lower percentage of deaths to cancer compared to Sheffield (27.1% and 28.1% respectively for 2017).



The chart below graph shows that up until 2011 Leeds had similar proportions of respiratory disease deaths to England average, following which the levels for Leeds have started to lower in comparison. Sheffield has been consistently lower since 2008, with the percentage of deaths to respiratory disease being higher in Leeds than Sheffield (12.4% and 11.5% respectively for 2017).



The chart below shows that deaths to circulatory diseases have been gradually declining over the years for Leeds and the England average. Whilst Leeds has shown similar results to the England average for most years, in 2014 and 2017 there was an increase in circulatory deaths in Leeds when this was steadily declining for the England average. The most recent data shows that Leeds and Sheffield have similar percentages of deaths to circulatory disease (26.7% and 26.6% respectively for 2017), however both are higher than the England average (25.1%).



5. Inequalities

This section of the Health Needs Assessment aims to identify whether there appears to be any inequalities in end of life care and outcomes between people in different population groups. This has a focus on whether there are any groups that are less likely to have a preferred place of death recorded and whether they are less likely to die in their preferred place of death. Information for this section has been taken from a data set that represents all patient deaths in Leeds who have an EPaCCS record in the financial year 2018/19. Please note that it is unknown whether health inequalities exist between those who do and do not have an EPaCCS record, which possibly requires further exploration. In addition, the report does not include any data for people with Learning Disabilities as the dataset does not include the required data to analyse any inequalities that may affect this group. This should be a recommendation for future analysis, and connection with other relevant data sets for this population group.

5.1 Age

Under 65's the least likely to have a preferred place of death (PPoD) recorded or die in their preferred place of death. This suggests that those that are in the older age ranges are slightly more likely to be asked about their preferences.

	Under 65	**65 -74**	**75 -84**	**85+**
PPoD Not Recorded	86	136	174	243
PPoD Recorded	227	387	562	751
Grand Total	313	523	736	994
% that have PPoD recorded	72.5	74.0	76.4	75.6

	Under 65	**65 -74**	**75 -84**	**85+**
PPoD Achieved	179	305	416	488
PPoD Not Achieved?	72	111	137	189
Grand Total	251	416	553	677
% that achieved PPoD	71.3	73.3	75.2	72.1

5.2 Gender

Males are slightly less likely to have a preferred place of death recorded. They are also less likely to die in their preferred place of death (70.1% vs 75.7%). Furthermore, a higher proportion of males die in hospital when compared to females (25.6% vs 20.6%).

	Female	**Male**
PPoD Not Recorded	348	304
PPoD Recorded	1095	880
Grand Total	1443	1184
% that have PPoD recorded	75.9	74.3

	Female	**Male**
PPoD Achieved	797	624
PPoD Not Achieved?	256	266
Grand Total	1053	890
% that achieved PPoD	75.7	70.1

Actual Place of Death	**Female**	**Male**	**Grand Total**	**Females %**	**Male %**
Care Home	339	160	499	27.5	15.3
Home	370	334	704	30.0	32.0
Hospice	269	283	552	21.8	27.1
Hospital	254	268	522	20.6	25.6
Grand Total	1232	1045	2277	100%	100%

5.3 Ethnicity

Due to low numbers of deaths in some of the detailed ethnic groups, for the purpose of this report the data has been analysed by broad ethnic groups. Where notable inequalities were identified in the more detailed data these will be mentioned.

Looking at the more detailed ethnic groupings, people from an ‘Asian – Pakistani’ and ‘Asian – Indian’ background were more likely to die at home than other ethnic groups (76.9% and 50% respectively). As a comparison the proportion of deaths at home for people from a ‘White British’ background was 35.7%. This is contrasted by relatively lower levels of deaths in care homes and hospices for these groups.

Mixed and Black ethnic groups (e.g. Mixed - Any other mixed background; Mixed - White and Asian; Mixed - White and Black African; Mixed - White and Black Caribbean) were less likely to have a preferred place of death recorded (54.5% and 63.6% respectively). Looking at the more detailed data for Black ethnic groups this appears to be due to the numbers of people from Black African backgrounds that did not have a preferred place of death recorded. Furthermore, looking at the more detailed ethnic groupings for the Asian community shows that those from an ‘Asian – Indian’ background are less likely to have a preferred place of death recorded (65.2%).

	PPoD Not Recorded	**PPoD Recorded**	**Grand Total**	**% PPoD Recorded**
Asian	14	43	57	75.4
Black	12	21	33	63.6
Mixed	5	6	11	54.5
Other ethnic groups	60	157	217	72.4
White - Any other White background	16	44	60	73.3
White British	539	1682	2221	75.7
White Irish	6	22	28	78.6

Mixed and Black ethnic groups were also less likely to die in their preferred place of death (57.1% and 63.6% respectively). Furthermore, looking at the more detailed ethnic groupings for the Asian community shows that those from an 'Asian – Indian' background are also less likely to die in their preferred place of death (58.8%).

	PPoD Achieved	PPoD Not Achieved	Grand Total	% that Achieved PPoD
Asian	34	13	47	72.3
Black	14	8	22	63.6
Mixed	4	3	7	57.1
Other ethnic groups	108	43	151	71.5
White - Any other White background	31	9	40	77.5
White British	1211	442	1653	73.3
White Irish	19	4	23	82.6

5.4 Deprivation

The dataset included the first part of the Leeds postcode and the percentage of people that died in their preferred place of death for each of these. To enable analysis to be completed to look at whether there were any differences between the experiences of those living in the most and least deprived areas in the city deprivation scores for the postcode districts were calculated.

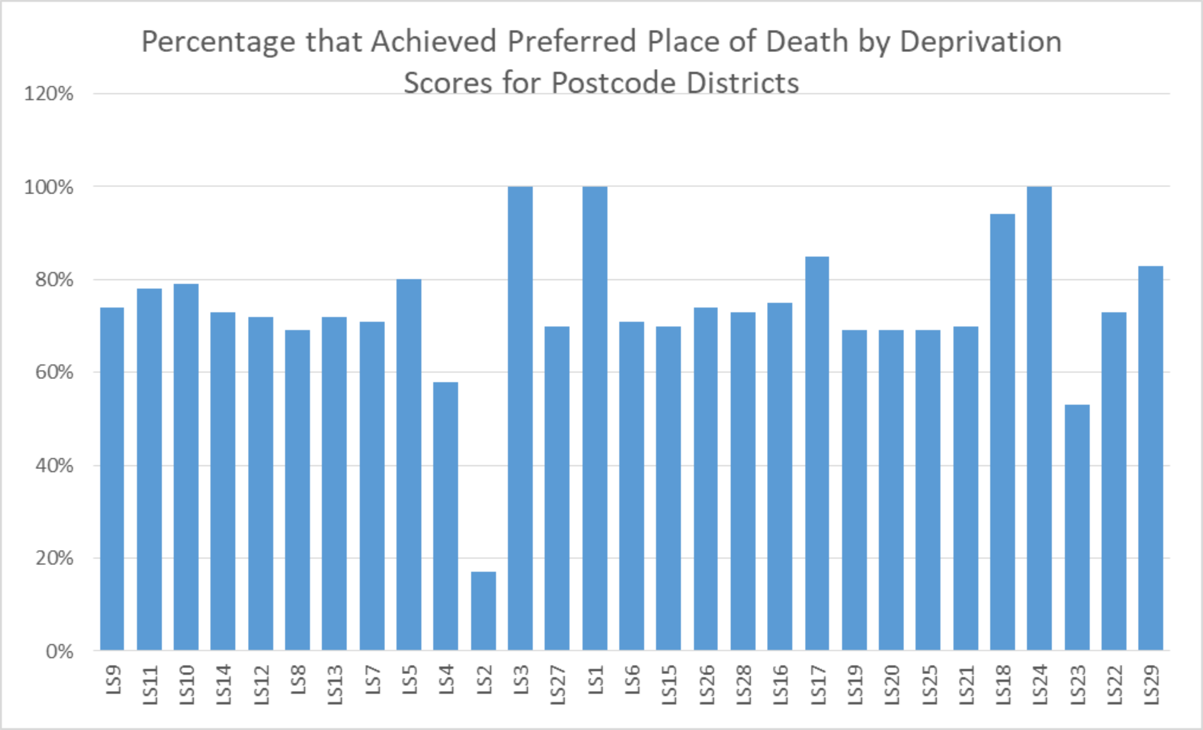
The table and graph below outlines the postcode districts ranked by IMD2015 and GP registered population (July 2019), rank 1 being the most deprived and rank 45 being the least deprived.

From data there is no correlation between deprivation and the percentage of those people who achieved their preferred place of death. However it is worth noting that:

- Three areas recorded below 60% for the achievement of their preferred place of death. Two of these postcode districts were in the more deprived areas of the city.
- Those areas achieving 100% preferred place of death are more likely to be in the least deprived areas in the city. However the numbers recorded in each postcode district are small and therefore the data is not robust enough to draw a correlation.

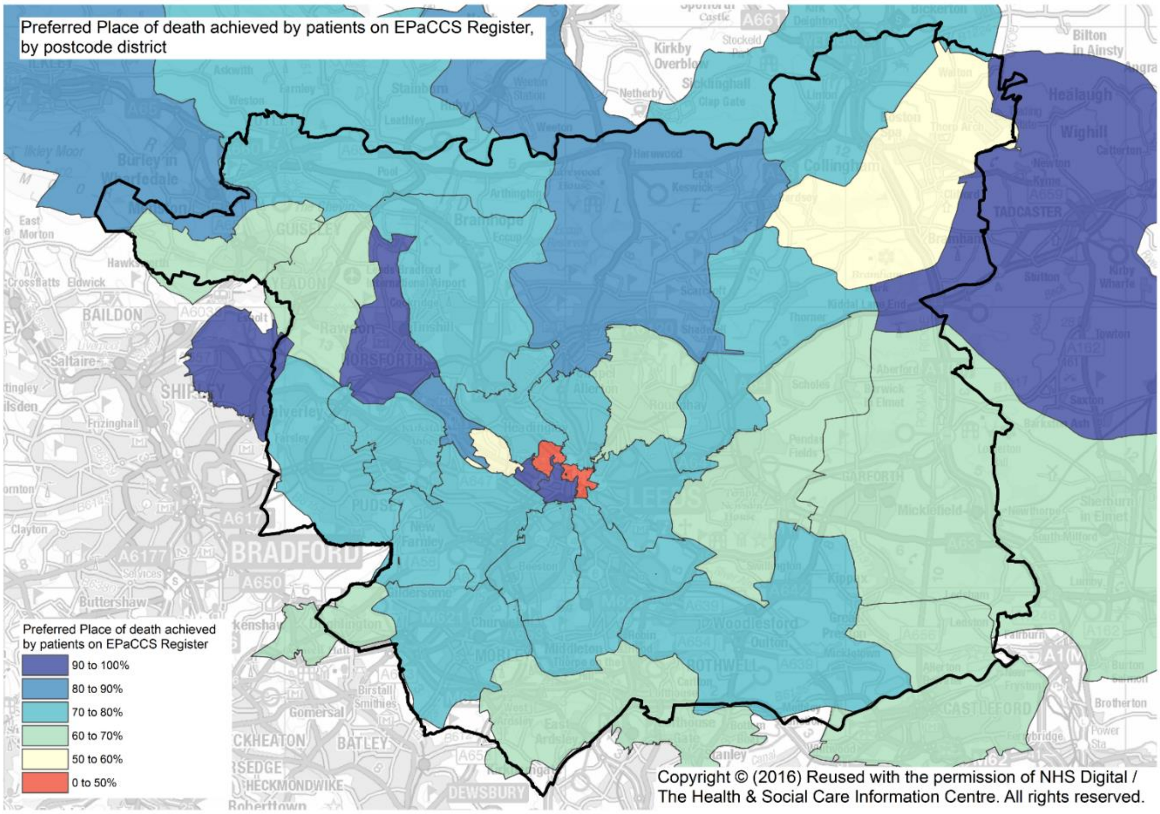
Postcode districts ranked by IMD2015 and July19 pops	Rank	PPoD Achieved	PPoD Not Achieved	Grand Total	% that Achieved PPoD
LS9	1	62	22	84	74%
LS11	3	80	22	102	78%
LS10	5	115	30	145	79%
LS14	6	74	27	101	73%
LS12	7	57	22	79	72%
LS8	8	87	39	126	69%
LS13	9	49	19	68	72%
LS7	10	32	13	45	71%
LS5	11	16	4	20	80%
LS4	14	7	5	12	58%
LS2	18	1	5	6	17%
LS3	21	1	0	1	100%
LS27	23	59	25	84	70%
LS1	24	1	0	1	100%
LS6	25	37	15	52	71%
LS15	26	80	35	115	70%
LS26	27	57	20	77	74%
LS28	30	67	25	92	73%
LS16	31	47	16	63	75%
LS17	35	88	16	104	85%
LS19	36	29	13	42	69%
LS20	38	20	9	29	69%
LS25	39	78	35	113	69%
LS21	40	35	15	50	70%
LS18	41	32	2	34	94%
LS24	42	7	0	7	100%
LS23	43	17	15	32	53%
LS22	44	35	13	48	73%
LS29	45	5	1	6	83%

Table outlining the preferred place of death data by postcode districts ranked by IMD2015 and GP registered population (July 2019), rank 1 being the most deprived and rank 45 being the least deprived



Graph 5: Preferred Place of Death (%)of people on the EPaCCS in Leeds, 2018/19 by postcode district ranked by IMD2015 and GP registered population (July 2019)

In line with the above, the map below shows that some areas have a lower proportion of people dying in their preferred place of death (e.g. LS2, LS4, LS23).



6. Perspectives of Service Users and Carers

6.1 What matters to people at end of life?

Eighteen organisations in Leeds engaged with 132 services users to identify ‘What matters to me?’ in relation to end of life care. The following summarises the key statements/priorities from this engagement.

Group	**Priorities**
End of Life	• Staff providing care are caring, considerate and supportive. • People’s wishes are taken into consideration • Information to people and their carers/family’s needs to be consistent • Privacy • Choosing where to die

Source: NHS Leeds. 2018. ‘What matters to people living with frailty, older people at end of life and their carers?: Engagement Report’

6.2 Bereaved Carers Survey

The Bereaved Carers Survey aims to understand people’s experience of the quality of care their relative/friend received in the last days or hours of life across different health care settings in Leeds including hospital, hospices, care homes and their own homes. Respondents provided feedback on the place/environment where their relative or friend had died and how satisfied they were with the care around symptom management, religious/cultural support, privacy, dignity and personal care. The returned questionnaires (204) were analysed by Healthwatch Leeds and St. Gemma’s Academic Unit for Palliative Care

Overall 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. Areas where improvements could be made have been highlighted and shared within each organisation and action plans have been developed. To increase representation of peoples experience in the community next year we are working with colleagues in the CCG and in General Practice so that all bereaved family carers are offered the opportunity to feedback during the survey timeframe.

Click here to view the report.

7. Perspectives of Healthcare Staff

The Health Needs Assessment 2013 provided an in depth analysis of the perspectives of a range of stakeholders, including: service users, carers, the bereaved, and heath and care staff. This Health Needs Assessment Review aimed to identify if the perspectives around End of Life Services in Leeds in 2013 required any updating to give a better understanding of current perspectives.

7.1 Methodology

A survey was designed to identify if health and care staff perceived whether the recommendations outlined in the 2013 HNA had been achieved. The aim of this being to identify whether they felt improvements had been made or whether there was further scope for development, which would inform future service planning and strategies. The survey included both closed and open questions.

Nineteen respondents completed the survey, which included a range of healthcare staff including front line staff as well as commissioners and consultants. The survey was sent out via the Leeds Palliative Care Network membership and the Dying Matters Partnership with the aim of reaching a diverse group of people and perspectives on the End of Life Care services across Leeds.

It should be noted that where respondents stated ‘don’t know’ to the open ended questions, the comments that they made results have been removed, as not to skew the results with invalid responses.

7.2 Results

Overall the results highlight the positive progress that has been made against the 2013 recommendations. For all but one of the recommendation, 60% of participants and above indicated that progress had been made against them. The one area where a higher proportion of participants (37.5%) felt that progress had not been made was for the recommendation ‘*Invest further in community services to support increasing care outside of hospital’*. The comments indicated that this was because capacity was still stretched and further investment was needed.

The full results are presented in appendix 1.

8. Recommendations

Implications for the End of Life Care Strategy:

- Resources and Services - ensure that sufficient resources and services are in place to meet the needs of increasing numbers of people dying in Leeds.
- Communication - regular conversations are needed with people at end of life so that care is tailored to their needs and goals and preferences can be kept up to date and accurate.
- Outcomes – 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.
- Complexity of need – a deeper understanding about the complex nature of people at end of life is required, this will enable a more accurate picture of where growth needs to be for end of life care.
- EPaCCS – Further develop tools for digital sharing of patients' treatment recommendations and care preferences to incorporate patient goals and priorities and emerging initiatives such as ReSPECT. The digital infrastructure needs to be developed to ensure electronic records are accessible across all care settings.
- Advance care plans – Increase the number of people offered quality conversations about advance care planning.

Gaining a deeper understanding about people at end of life:

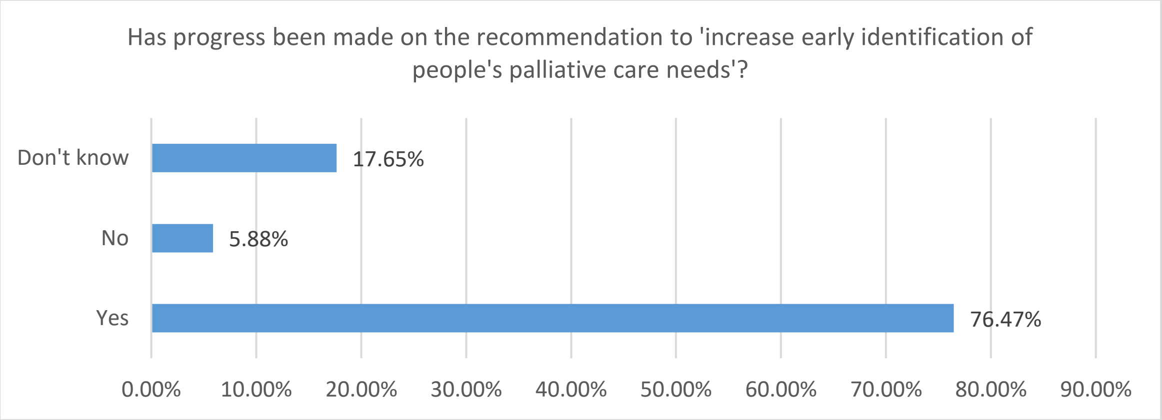
- Conduct further analysis in order to identify whether health inequalities exist between those who do and do not have an EPaCCS record.
- Gain further insight into why inequalities exist in relation to end of life for different equality groups (e.g. under 65's and 65-74, males and mixed and black ethnic 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.

Appendix 1 - Results from the health and care staff survey

The results from the health and care staff survey are presented below. The survey was structured around the recommendations from the 2013 Health Needs Assessment. Participants were asked to give their perspective in terms of progress made against each of the recommendations. A thematic analysis of comments provided by respondents to each recommendation is also given. All quotes highlighted below have been anonymised, this is in line with the privacy statement used for the survey.

Recommendation 1a: Increase early identification of people's palliative care needs

These figures show that there is overwhelming agreement that progress has been made on increasing early identification for palliative care. From further analysis into additional comments made to this question, it seems that although many people agree that progress has been made, there are many who believe that this progress has only been partial.



The following comments find a generally positive response to the progress that has been made regarding early intervention and specifically in non-cancer conditions. However, individual participants referred to improvements that could be made in relation to early identification for dementia patients and referrals from hospital settings (it was unclear which particular settings this relates to). A couple of participants stated that whilst progress had been made there was generally room for greater improvement.

The following statements highlight where specific progress has been made and where there is still room for improvement.

Partially agree that progress has been made:

"Yes, but still a priority area as it is still frequently too late to allow fulfilment of people's preferred place of death"

"I think we've made some modest progress on identifying the last year of life in non-cancer conditions. For people with dementia, we would like to support more conversations whilst a person still has capacity to develop and express what they might want near the end. I don't think we've made much progress at that"

"I feel that there has been some progress but remain concerned that late referrals are still generated in hospital settings"

“There has been some improvement but there is room for more. It is good that we have more evidence now”

Disagree that progress has been made:

“Working within learning disabilities, I have not witnessed an improvement in early identification”

Recommendation 1b: Sharing of comparative GP practice-level end of life care information with individual GP practices

The majority of respondents agreed to some extent that progress had been made on sharing of end of life care information within GPs. Those that did not agree specifically mentioned ongoing logistical issues that prevents data sharing. One comment notes the problems with the GP practice software EMIS, whilst another comment states the importance of not only having an EPaCCS but also to discuss and share the data from it.

“*This has been delayed due to data quality issues with producing reports. This appears to have been resolved and we are awaiting reports to share with GP practices”*

“Sharing becomes difficult when a [GP] practice is on EMIS rather than SystemOne”

“EPaCCS data is shared but I am not sure if GPs share across the practice and discuss the information in any way”

Recommendation 1c: Continue to work to ensure End of Life Care is included in care pathways for all diagnosis which could end in death

Most respondents commented that they agreed to some extent that progress had been made on continuing to work to ensure End of Life Care is included in care pathways for all diagnoses which could end in death. The below comments look at this in specific detail.

“We have referenced this in the dementia care pathway…giving people the opportunity to discuss what they might want at the end of life”

“Within LCH there is greater awareness within Neighbourhood Teams and long-term condition services of recognising palliative care needs for patients regardless of condition”

“*Palliative care input into specialty MDTs has increased. This has helped to improve the care offered for patients at the end of life and to increase skills amongst clinicians working in a range of specialties”*

Recommendation 1d: Prioritising increasing rolling out of Advance Care Planning for people diagnosed with dementia which would ideally be happening before the person enters the last 12 months of life.

Most respondents commented that they agreed to some extent that progress had been made on the above recommendation, however half of those that commented felt that there were still improvements to be made.

Fully agree:

"There has been a general increase in staff awareness of Advance Care Plans and recording of patients' wishes"

Partially agree:

"There has been some progress in this area, but more needs to be done in order to ensure that people with Dementia are able to have a meaningful say in the care that they receive at the end of life"

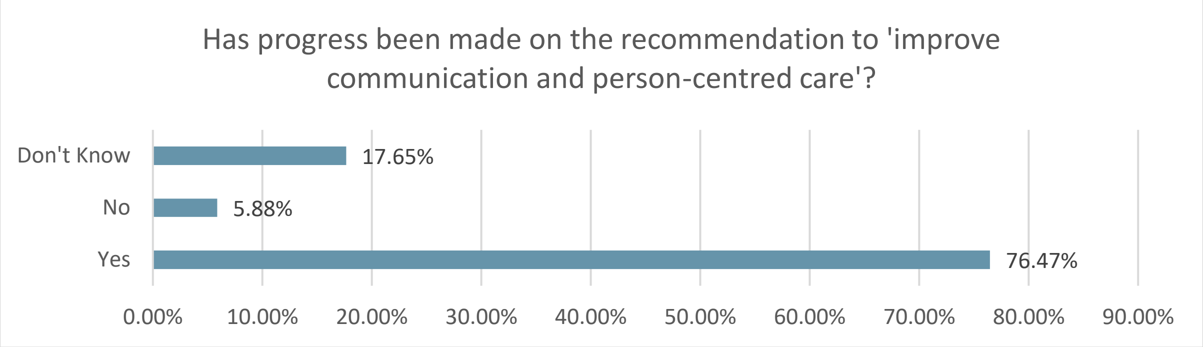
"Improving - a long way to go still"

Disagree:

"There appears to be a great deal of frustration and lack of knowledge of the palliative care register with GP practices, which limits the identification and planning stages required before the last 12 months of life"

Recommendation 2a: Improve Communication and Person-Centred Care

There was an overwhelming sense that progress had been made in relation to improving communication and person-centred care. Further comments made to those questions are provided below.



Fully Agree:

"Improvement in electronic systems and the sharing of essential information to support care across organisations and in clinical settings"

"The Neighbourhood Team model supports this approach to care"

"I do feel that patients are involved in their care and decisions"

"I have worked in this field for many years and agree that progress has and continues to be made in relation to patient centred care"

Partially Agree:

"I can't envision a time when communication is perfect every time, but we certainly seem to be more acutely aware of person-centred care and communication does seem to be improving"

"There is always more improvement to make, but the launch of the ReSPECT process will have significant impact on the conversations and communication between patients and health professionals"

"Clinicians seem to be very stretched for time and some are task-oriented which impacts on this"

Recommendation 2b: GPs/Advance Nurse Practitioners have adequate time to have sensitive conversations about End of Life with people reaching the last 12 months of life

The comments provided to this question suggested that further progress could be made to ensure that GPs/Advance Nurse Practitioners have adequate time to have sensitive conversations about End of Life. It is broadly noted that this is still an area with room for improvement and that the ability to have these conversations is not consistent throughout Leeds.

Fully agree:

"Having a Palliative care lead allows for staff to have longer with patients discussing sensitive information"

Partially agree:

"Time is stretched, particularly in primary care, and although there is the opportunity for these conversations to take place, additional time would always be welcomed"

"This service is varied across the city"

Disagree:

"This is still a challenge for all community practitioners"

"Hospice Community Nurse Specialists are in a better position in terms of time, but they may not see patients early enough and don't see all patients with a need to have the opportunity for such conversations"

"I doubt that GPs have increased capacity"

Recommendation 2c: Ensuring workforces are trained to have sensitive End of Life conversations with patients, carers and families.

The majority of respondents commented that they agreed that progress had been made to ensure workforces are trained to have sensitive End of Life conversations with patients, carers and families. The comments highlighted the improvements that have been made to training and the expansion of training to more staff working in palliative care. However, gaps in training were also highlighted by a few respondents, suggesting that further training was required in the wider workforce and amongst those who could have conversations with patients, carers and family members at an earlier stage.

Fully agree:

"Work on preparing the workforce has made a huge difference from my perspective. I rarely speak to a patient or family where communication has not been open, honest and supportive"

"Progress has been made within Leeds Community Healthcare as more staff are trained and supported in practice"

Partially agree:

"Training is in place but there is a lack of role models in practice"

"I think the workforce who deliver care at the very end of life (24-48 hours) are pretty well trained – I think the priority should be training those dealing with life limiting illnesses on starting discussions much earlier"

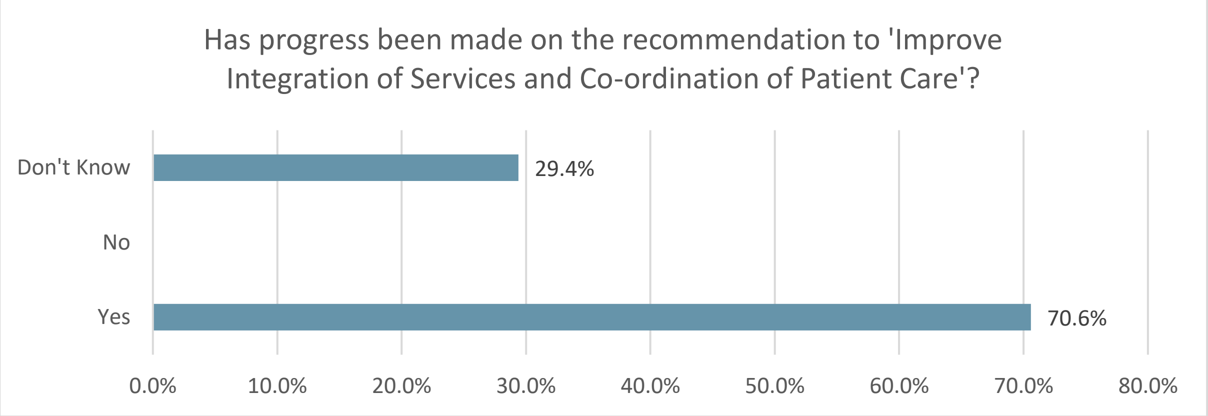
"Further work needs to be carried out to ensure that all health professionals are able to have difficult, sensitive End of Life conversations with patients. Training is taking place but a wider roll out to more groups would be welcomed"

Disagree:

"I feel much more needs to be done in this area, with staff in all organisations and at all levels"

Recommendation 3a: Improve Integration of Services and Co-ordination of Patient Care

The below figures show that there was general agreement that progress has been made to improve integration of services and co-ordination of patient care.



Further analysis into additional comments made to this question, suggests that Neighbourhood teams and EPaCCS have positively contributed to integration and coordination of care. However, a couple of respondents suggested that whilst some progress had been made, improvements could still be made in relation to the number of professionals involved in End of Life Care and breakdown in communication due to LTHT being unable to view EPaCCS.

Fully agree

"Great work on Transfer of care, Palliative Care Network also ensures as consistent approach as is possible".

"Neighbourhood teams integrated with social care, therapists and rehabilitation staff. Improvements to working relationships with primary care and specialist palliative care services"

"Neighbourhood Team model introduced supports this approach to care"

"Links between providers have improved significantly, in particular between the hospices and the LTHT wards"

"EPaCCS seems a positive step"

"Yes, integration has been progressing over recent years, it is also important to be mindful of each services skills and knowledge and the contribution each brings to the patients care"

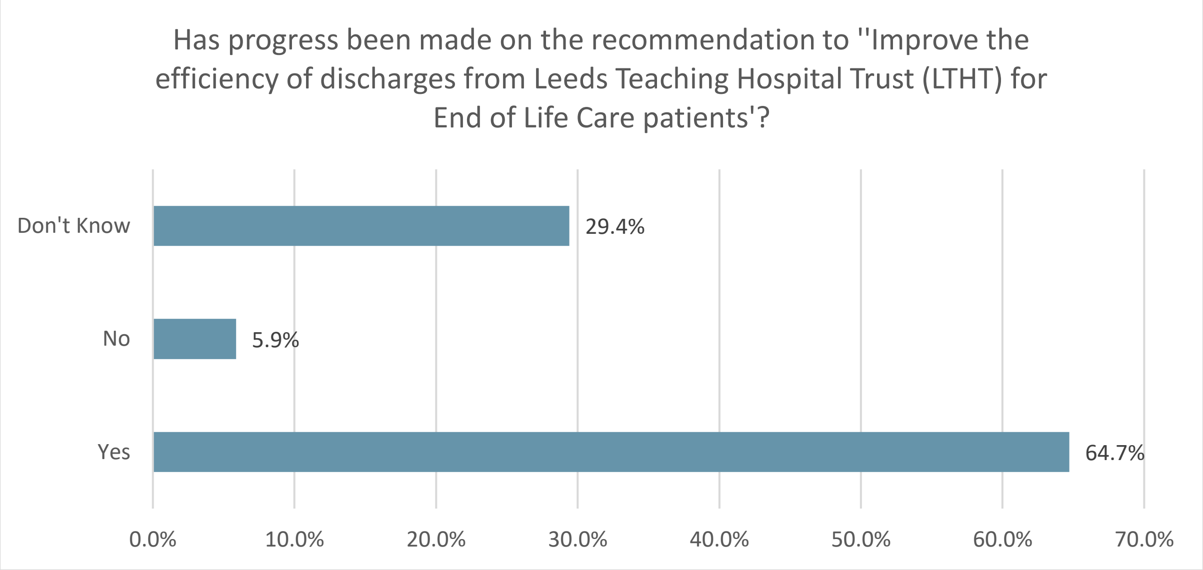
Partially agree

"SystmOne and PPM/LCR has helped with this & EPaCCS. A review of Gold Standards meetings would be helpful to explore what works well and areas of improvement. IPU referrals meetings via LTHT and St Gemma's beneficial. Patients and families still report confusion over services and concerns re the number of people involved"

"EPACCS are good - but big gap that it is invisible to the hospital and importantly that it is really hard for hospital staff to find out how to get this started - as a consequence communication too often breaks down after fast track discharge"

Recommendation 4a - Improve the efficiency of discharges from LTHT for End of Life Care patients

The below figures show that there was general agreement that progress has been made to improve the efficiency of discharges from Leeds Teaching Hospital Trust (LTHT) for end of life care patients.



Further analysis into additional comments made to this question, suggests that rapid discharges and greater staff awareness in LTHT and Neighbourhood Teams have resulted in an improvement in the efficiency of discharges. A number of respondents suggested that whilst some progress had been made, improvements could still be made in relation to making the discharge smooth, consistent and timely.

Fully agree

“Rapid discharge plan from wards and RDP from A/E both excellent pieces of work. Lots of training and support for Ward based staff, a heightened awareness of the idea that patients / families may want to go home for EoLC.”

“Rapid discharges in the last days of life - A&E pathway. Also more awareness in Neighbourhood Team of the need to support this - patients at very EoL are a priority for discharge within capacity and demand tools. Still some challenges with 7 day in reach ie. at weekends (LCH discharge Facilitator role is not a 7 day service)”

Partially agree

“Progress has been made, but there is a need to ensure that the process is as smooth as possible. This work will be helped by efforts to identify patients at the end of life earlier”

“Yes has definitely improved with the model of dedicated ward discharge coordinators/facilitators supporting discharges for end of life care. However, there is inconsistency within this model and not all discharge facilitators /coordinators engage with supporting fast track discharges as their focus is on ASC/CIC beds /CHC. Still feel a dedicated palliative care discharge team with specialist skills /knowledge of this type of discharge would improve the process for this group of patients”

“To some extent - but all too often it still takes far too long and death in hospital before discharge can be sorted happens too often”

“Yes I agree , though this is inhibited by services demand and capacity to facilitate discharges, this requires on going monitoring and a city wide action plan”

“Agree to a degree but more room for improvement. A&E work positive. Sometimes patients still discharged without relevant services being informed. Not always care packages or community nurses available to provide services”

Disagree

"I suspect that this has been overshadowed by the 'DToC' system where the focus is more on allocating responsibility for delay. The limitations of capacity for social care will tend to work against achieving this aim"

"There remains a greater number nationally of people with learning disabilities dying within hospitals rather than home or potential preferred place of care. This may be due to the continued failure to identify potential end of life and planning stages involved to provide this element of care"

Recommendation 4b - Develop a model of specialist End of Life Care discharge facilitators in LTHT.

A number of respondents were unaware if the recommendation to develop a model of specialist End of Life Care discharge facilitators in LTHT had been delivered. Of those that provided a comment relating to the discharge facilitators, A few respondents provided clear comments that this had been actioned. A couple of respondents seemed a little uncertain about the progress that had been made in relation to this recommendation, which may simply be due to the nature of the respondents' roles or due to a lack of information.

Fully agree

"Yes - these roles were integrated within discharge team, with training/support of Palliative Care Discharge Facilitator"

"Fantastic progress, the model we have in place seems to work with general discharge facilitators who have the skills to work with Palliative patients, supported by Palliative care discharge facilitator"

"Increased multi-agency working with health case managers, LCH EoL discharge facilitators who support neighbourhood teams with attendance at care planning meetings and work closely with LTHT discharge facilitators"

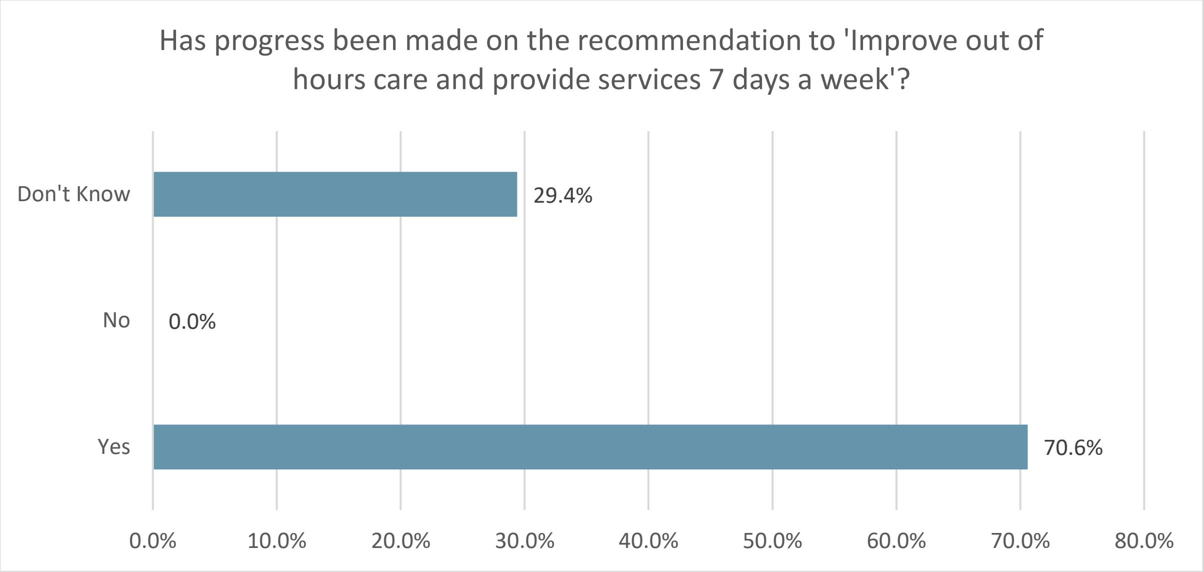
Uncertain

"I think we have started this work , but this requires further consideration and funding if we are to offer a service than can support all End of Life patients leaving LTHT"

"Not sure - no experience of anyone specialist facilitating discharge unless we've involved palliative care for some other reason and they then help with discharge. Perhaps these people work elsewhere"

Recommendation 5 - Improve out of hours care and provide services 7 days a week

The below figures show that there was general agreement that progress has been improve out of hours care and provide services 7 days a week.



Further analysis into additional comments made to this question showed that whilst a couple of respondents felt that the recommendation had been fulfilled, a number of respondents suggested that whilst some progress had been made improvements could still be made.

Fully agree

"LTHT team now 7 day service, works well from my perspective"

"7-7 8-5 SPC face-face in all settings has made a significant difference - as evidenced by reduced complaints, and more appropriate use of consultant on-call service, with less calls related to general staff distress"

Partially agree

"Better availability of advice. Not always a good thing that Fast Track care planning meetings are organised out of hours as it's not possible to provide medical input when this might be needed e.g. when family members struggling with inevitability of death even when they have been told"

"Some services are available at all times, and the hospices will accept referrals out of hours. However, there is work to do to ensure that all patients receive the highest quality care at all times and that hospital admission is used as a last resort out of hours"

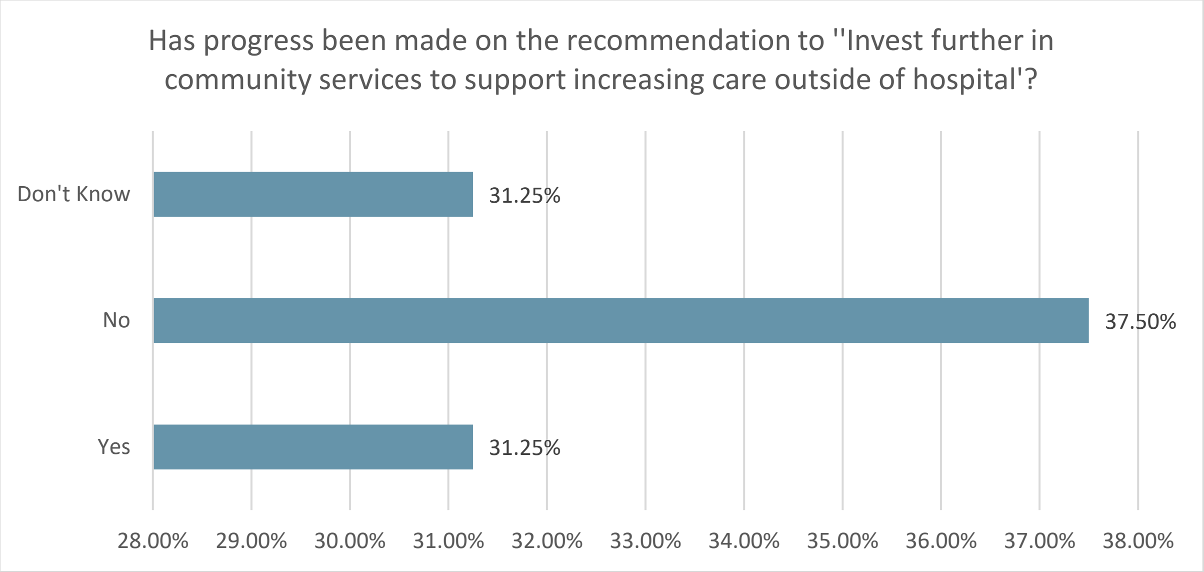
"Progress made during the day to ensure medication is available to support symptom management - although this is an ongoing challenge"

"Yes, but there is still a way to go if we are to truly offer a 7 day a week service. This will require further funding and staffing"

"Yes in some ways but worse in others. Issues with OOH forms going to YAS/NHS111 unresolved. Good that GPs read S1 more than before which helps decision making. OOHs GP service can be stretched at times though and quality of GPs variable. LCH nursing service can be stretched at times resulting in delays in care. 7 day service in hospice community teams and LTHT palliative care team good but again can be stretched at times"

Recommendation 6a - Invest further in community services to support increasing care outside of hospital

The below figures show that a higher proportion of respondents disagreed that progress has been made to invest further in community services to support increasing care outside of hospital. It must be noted that when looking at the number of respondents who stated 'yes' or 'no', the numbers were fairly similar.



Whilst some of the comments showed that investment in community service had been made, capacity was still stretched and further investment was needed.

"Community services and care agency support remains very stretched"

"Further investment is required , for example we only have 2 Community Palliative Discharge Facilitators , they cannot possibly offer a 7 day a week service"

"Community services are very stretched in all services and reading the NHS Plan and plans for further early discharge, hospital avoidance etc this is of great concern"

"I can see the investment but also the increased demand"

Recommendation 6b - Increase community nurse capacity

A couple of respondents commented that they were unaware if the recommendation to increase community nurse capacity had been delivered. Of those that provided a comment relating to community nurse capacity, a few respondents felt that further capacity and investment was needed and a couple of comments suggested that capacity did not meet the demand.

"There has been some increase in capacity, but further increases would be welcomed"

"Some challenges around recruitment, however there shift of resources not widely evident"

"Further investment required as the resources needs to match the ever increasing needs"

"Increasing service demand"

"See no evidence of this"

Recommendation 6c - To support continuity of care in community settings

A couple of respondents commented that they were unaware if the recommendation to support continuity of care in community settings had been delivered. A couple of respondents associated progress around this recommendation with the named clinician in the neighbourhood teams and connections between the hospital and community team. However, a couple of people made comments highlighting that they had not seen progress in this area.

"Named clinician in place within Neighbourhood teams"

"Links between hospital and neighbourhood teams are strong and well-developed"

"Progress made within Neighbourhood Teams to identify key staff and increase continuity, however this remains a challenge"

“I can't see that progress has been made in this key area”

“Not seen this working in my areas of practice - there's still a huge barrier between hospital and community”

Recommendation 6d - The provision of a named key worker that co-ordinates care

Very few respondents provided comments on whether progress had been made on the recommendation to provide a named key worker that co-ordinates care. Of those that did comment, a couple highlighted that progress had been made. One comment was made highlighting that it would be useful for dietetics services involved in a person’s care could be informed if an identified key worker is in place.

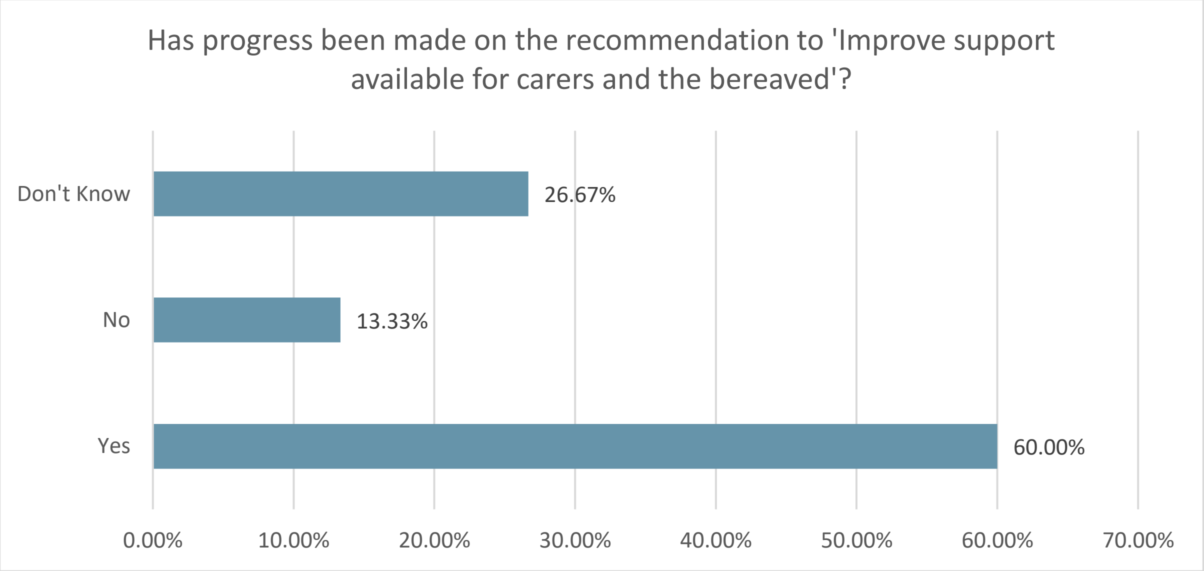
“HCM Co-ordinates (non-clinical) care for FT patients, I believe this works very well”

“Patients have an allocated case manager, however this remains a challenge across services”

“Not aware that a key worker is identified for the patients referred to our service but such an identified link would help so that dietitians could liaise and coordinate an approach regarding the patient's nutritional goals”

Recommendation 7 - Improve support available for carers and the bereaved

The below figures show that there was general agreement that progress has been made to improve support available for carers and the bereaved, however a quarter of respondents were unaware if the recommendation had been delivered.



Further analysis into additional comments made to this question showed that whilst a couple of respondents felt that the recommendation had been fulfilled, a number of respondents suggested that whilst some progress had been made improvements could still be made.

Fully agree

"LTHT have a Bereavement CNS"

"From my perspective, the employment of the bereavement specialist nurse has the potential to massively improve the support we at the Trust offer"

"Specific services with Carers Leeds and Leeds Bereavement Forum / Mind - though I'm not sure if they have recurrent funding yet"

Partially agree

"Yes, but could further improve - more awareness of support available and importance of bereavement support. This may not be equitable across all patient groups and partly dependent on services involved"

"Still more could be done but LCH staff very good at continuing to support bereaved"

"Carers and the bereaved are at the heart of the services offered by the hospices. Progress has been made to increase the availability of these services, but there is more to do, and any inequities between relatives of patients who have died in the hospice and those who have died in other settings need to be addressed"

Disagree

"I feel that more needs to be done, and support should be offered earlier"