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End of Life Care

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2 INTRODUCTION

Death and dying are an inevitable part of life. Improvements in public health and advances in medical treatment have led to an increase in life expectancy at the national level. Consequently, people are experiencing longer periods of ill-health before the end of life and more people are living longer with multiple health conditions. People approaching the end of their life experience a range of physical symptoms, as well as having emotional and spiritual needs. To manage these issues effectively requires integrated and multidisciplinary working between teams and across sectors regardless of whether the person is in their home, in hospital, a care home, or hospice. Families and carers of people at the end of life also experience a range of problems and will have their own specific needs which must be addressed before, during and after the person's death. [1]

The 'end of life' stage is described by NHS England as the period when people have advanced, progressive incurable conditions, and/or they may die within 12 months, and/or they suffer from life-threatening acute conditions.

End of life care should:

- Allow people at the end of life stage to live as well as possible until they die
- Take into account the wishes and preferences of the patient
- Be provided at home, in a care home, hospice or hospital depending on the needs and preferences of the individual
- Provide social, spiritual, psychological and practical support for patients, their family and carers throughout the patient's illness and into bereavement[2]

End of life care is a form of palliative care and should therefore meet the WHO (2002) definition of palliative care: "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness; through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms; physical, psychological and spiritual".[3]

Delivering care during a variable end of life time period presents many challenges, including prognostic and communication barriers across diverse life limiting diseases, each of which have heterogeneous pathways through many services. It therefore cannot be defined by one programme area.

It is acknowledged that end of life care is not an add-on service. It is a core and vital part of existing service structure. A lack of integrated end of life care provision leads to unplanned and inappropriate admissions and readmissions during the end of life period. This results in disrupted quality of care, for the patient and family, and more importantly, a failure to meet the most common wish, to die at home with family carers.

The 2008 National End of Life Care Strategy outlined three key insights for which action needed to be taken: that people didn't die in their place of choice, that we need to prepare for larger numbers of dying people and that not everybody receives high quality care. The strategy identified important areas for improvements including raising the profile of end of life care and changing attitudes to death, improving the coordination of care between agencies, identifying people approaching the end of life and involving and supporting carers throughout the dying process.

The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026 [4] was developed by a partnership of national organisations across the statutory and voluntary sectors and is an update to the 2015-2020 version which aimed to build on the 2008 National End of Life Care Strategy. The updated framework provides a basis for local decision-making and service delivery with a vision to improve end of life care through partnership and collaborative action between organisations at a local level throughout England. The framework outlines six ambitions, identified with the aim of improving the experience of the dying person and the important people in their lives. The six ambitions are outlined in figure 1 below. Each of the ambitions include a statement which describes the ambition in practice, primarily from the point of view of the dying person.

Figure 1: The six ambitions for palliative and end of life care as outlined in the National Framework for Local Action 2021-2026

Source: National Palliative and End of Life Care Partnerships (May 2021)

In 2019 a new taskforce was set up as part of a wider quality improvement program bringing together NHS and voluntary sector organisations across Leicester, Leicestershire and Rutland (LLR) to improve care for people at the end of their life. [5] The task force aimed to look at a range of areas

including end of life care planning, to ensure that patient's wishes and preferences are taken into account, and the adoption of standards to guide primary care teams caring for patients and their loved ones at the end of life stage. Evidence of the impact of this taskforce is limited.

This Joint Strategic Needs Assessment sits as part of the development of an overarching Leicester, Leicestershire and Rutland Integrated Care System (LLR ICS) End of Life and Palliative Care Strategy that complements and links all existing strategies and plans together. This five-year strategy (2023 – 2028), which is due to be launched in early 2023, will encompass end of life care for all ages and both anticipated palliative care end of life deaths as well as unexpected deaths, whilst considering the diversity of those living withing Leicester, Leicestershire and Rutland. This strategy aims to support the 'Dying Well' transformation priority of the areas which outlines a need to ensure that people have a personalised, comfortable, and supported end of life with personalised support for carers and families.

3 WHO'S AT RISK AND WHY?

End of Life care is care that helps all those with advanced, progressive and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (DH 2008).

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days), those with advanced, progressive, incurable conditions, general frailty and co-existing conditions that mean they are expected to die within 12 months, those with existing conditions if they are at risk of dying from a sudden acute crisis in their condition and those with life-threatening acute conditions caused by a sudden catastrophic event such as an accident or stroke.

(Source: General Medical Council 2010)

The Royal College of General Practitioners has issued 'Prognostic Indicator Guidance' to help GPs to identify which patients are most likely to need end of life care in the next year, so that their QOF registers provide a more realistic estimate of needs. The guidance is based on the Gold Standards Framework, a practice-based system to improve the organization and quality of palliative care services for people at home in the last year of their lives. It covers specific clinical indicators for the three main end of life patient groups: cancer, organ failure and frail elderly with dementia.

In 2021, there were 586,334 deaths registered in England and Wales; a decrease of 3.6% compared with 2020 (607,922 deaths) and an increase of 10.5% compared with 2019 (530,841 deaths).[6] In Leicester City, there were 2,973 deaths in 2021, a decrease of 2.1% compared with 2020 (3,037 deaths) and an increase of 21.3% compared with 2019 (2,451 deaths), approximately 0.8% of the Census 2021 population estimate.[7] This pattern in deaths was expected due to the Covid-19 pandemic. The Palliative Care Funding Review report[8] indicates that between 69% and 82% of deaths are likely to have palliative care needs; this means based on the number of deaths in 2021 that between 2,051 - 2,438 people who die in Leicester every year are likely to require palliative care. With an ageing

population, people are expected to live longer with increasing co-morbidities making the effectiveness and reliability of end of life care ever more important.

The leading cause of death in England and Wales in 2021 was the coronavirus (Covid-19) with 67,350 deaths (11.5% of all deaths) having this cause. Following the coronavirus, the second most common cause of death was dementia and Alzheimer's disease (10.4% of all deaths registered in 2021), followed by ischaemic heart diseases (9.7% of deaths in 2021), cerebrovascular diseases (5.0% of deaths in 2021) and malignant neoplasm of trachea, bronchus and lung (4.8% of deaths in 2021)[6]. Palliative care is required for a wide range of diseases, including most of those listed above. Most adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), advanced cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%), diabetes (4.6%) and many other conditions such as kidney failure, neurological disease, advanced dementia and rheumatoid arthritis.[9]

There are inequalities in access to palliative care; individuals who are over 85 years old, from Black, Asian and Minority Ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more deprived areas, are socially isolated, are homeless, have mental health needs, or are living in prisons receive less palliative care than others despite a comparable need. [10] More specifically with regards to deprivation, those living in the most deprived areas are more likely to die in hospital compared to those living in the least deprived areas, with those living in the most deprived areas 33% less likely to die at home compared to the least deprived.[11] There are significant differences in referral rates to palliative services for people living in different areas, even where people have the same diagnosis, and even after referral to specialist palliative care services variation in place of death by deprivation persists.

Variation in place of death by deprivation requires further exploration as it is important to understand whether such differences are a result of different preferences in place of death by deprivation status, the impact of deprivation on the likelihood of an individual being able to die in their preferred place of death or a combination of these factors. Many factors, which may influence the likelihood of an individual being able to die in their preferred place of death, could be affecting those living in deprivation when they die, for example, less appropriate housing for end of life care at home, a greater reliance on emergency care over elective care, limited or overstretched social support, lower rates of health literacy, general literacy and education resulting in less choice and planning in end of life care and the inability to bear the costs of caring for someone at home.[12]

3.1 RISK FACTORS IN LEICESTER'S POPULATION

3.1.1 3.1.1 RISK FACTORS FOR PALLIATIVE CARE NEED

3.1.1.1 Age and prevalence of conditions

As shown in table 1, the prevalence of dementia, Coronary Heart Disease (CHD), stroke, cancer, asthma and Chronic Obstructive Pulmonary Disease (COPD) is significantly lower in Leicester than in England overall.

These conditions account for much of the palliative care demand in adults, and prevalence generally increases with age. The lower prevalence of these conditions in Leicester compared to England (based on all ages of population) could be a result of Leicester's younger age profile.

Considering the prevalence within the older population we can see that the recorded prevalence of dementia in the population of Leicester aged over 65 was 4.8% in 2021, significantly higher than the value for England (4.0%).[13] As of June 2020, the over 65 prevalence of the other conditions in Leicester was 14.8% for CHD, 7.5% for stroke, 8.5% for cancer, 8.7% for asthma and 7.9% for COPD[14]. With the exception of dementia, we have been unable to compare the prevalence of these conditions in Leicester's 65+ population to the prevalence in England's 65+ population due to a lack of access to the required data.

Table 1: Prevalence of risk factors associated with a greater need for palliative care in Leicester's population[15][16]

Risk Factors	Time period	NHS Leicester City CCG	England
Dementia: QOF prevalence (all ages)	2021/22	0.5%* (significantly decreasing)	0.7%
CHD: QOF prevalence (all ages)	2021/22	2.3%* (significantly decreasing)	3.0%
Stroke: QOF prevalence (all ages)	2021/22	1.2%* (no significant change)	1.8%
Cancer: QOF prevalence (all ages)	2020/21	1.6% (significantly increasing)	3.2%
Asthma: QOF prevalence (6+ years)	2021/22	5.2%* (could not be calculated)	6.5%
Diabetes: QOF prevalence (17+ years)	2021/22	9.9%* (significantly increasing)	7.3%
COPD: QOF prevalence (all ages)	2020/21	1.4% (no significant change)	1.9%
Dementia: Recorded prevalence (aged 65 years and over)	2020	4.8% (could not be calculated)	4.0%**

Comparison to England:

Significantly lower than England
Significantly higher than England

Recent trend over previous five time periods:

Significantly increasing	↑
No significant change	→
Significantly decreasing	↓
Could not be calculated	▬

** Aggregated from all known lower geography values*

*** Value missing in source data*

Sources: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

3.1.1.2 Ethnicity

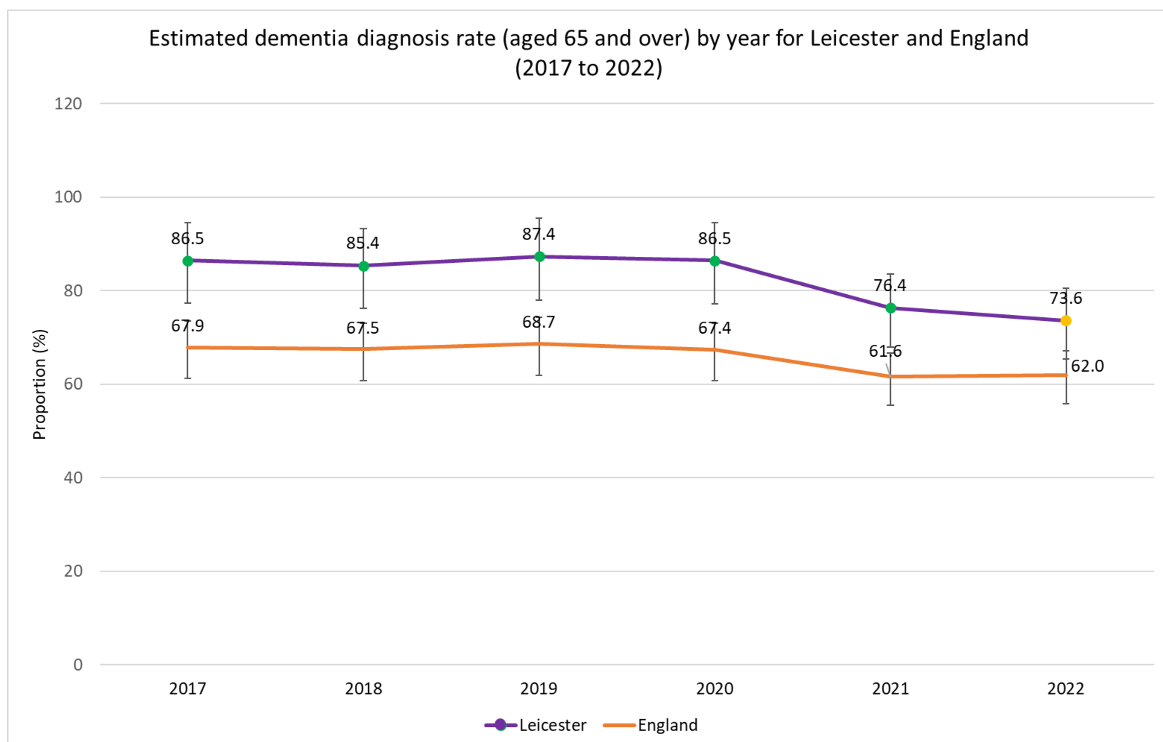
Characteristics of Leicester's population which may increase the need for palliative care in residents compared to England include the city's large South Asian and Black populations which have a higher

risk of diabetes. The prevalence of diabetes in Leicester (9.9%) is significantly higher than the England average (7.3%) and over the past five time periods the prevalence in Leicester has shown a significant increasing trend.

3.1.1.3 Importance of diagnosis rates

Despite having identified the risk factors for those most likely to need palliative care, analysing the prevalence of such characteristics within a population may not give a true picture of palliative need. This is often the result of poor diagnosis rates for such risk factors. For example, as shown in figure 2, in Leicester in 2022 the estimated dementia diagnostic rate (aged 65 and over) was 73.6%, this was not significantly different to the value for England (62.0%). The estimated dementia diagnosis rate in Leicester has decreased year on year since 2020, from 86.5% in 2020 to 73.6% in 2022. This estimate suggests that in Leicester in 2022 around 26% of those estimated to have dementia did not have a recorded diagnosis of the condition. It is important to improve the identification and diagnosis of such risk factors to advance the inclusivity and effectiveness of palliative care services, as well as to develop an improved understanding of future palliative need. A timely diagnosis enables those living with dementia, or other conditions, their carers and healthcare staff to plan accordingly and work together to improve the health and end of life care outcomes of those living with the condition.

Figure 2: Estimated dementia diagnosis rate in those aged 65 and over by year for Leicester and England, 2017 to 2022[17]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

3.1.2 Risk Factors for Insufficient End of Life Care

As outlined above, there are certain groups of people who are more likely to receive insufficient end of life care. Leicester's population has a significantly higher proportion of people belonging to most

of these groups than England overall. According to the 2021 census, the percentage of respondents reporting their ethnicity as 'not white' was 59.1% in Leicester, which is significantly higher than the 19.0% of respondents in England overall. Further to this, Leicester is ranked the 32nd most deprived of 317 local authorities in England for the Index of Multiple Deprivation 2019.[18] In 2021/22, Leicester also had a significantly higher (worse) rate of homelessness (households owed a duty under the Homelessness Reduction Act) than England with a rate of 20.6 per 1,000 population compared to 11.7 per 1,000 population for England and a significantly higher prevalence of mental health needs with 1.05% of GP practice patients in Leicester recorded on the practice disease registers as experiencing schizophrenia, bipolar affective disorder and other psychoses compared to 0.95% for England overall.[19],[20] These characteristics of Leicester's population increase the importance of inclusive and effective palliative care services. Further information about the Leicester population can be found in the Living in Leicester JSNA chapter. [21]

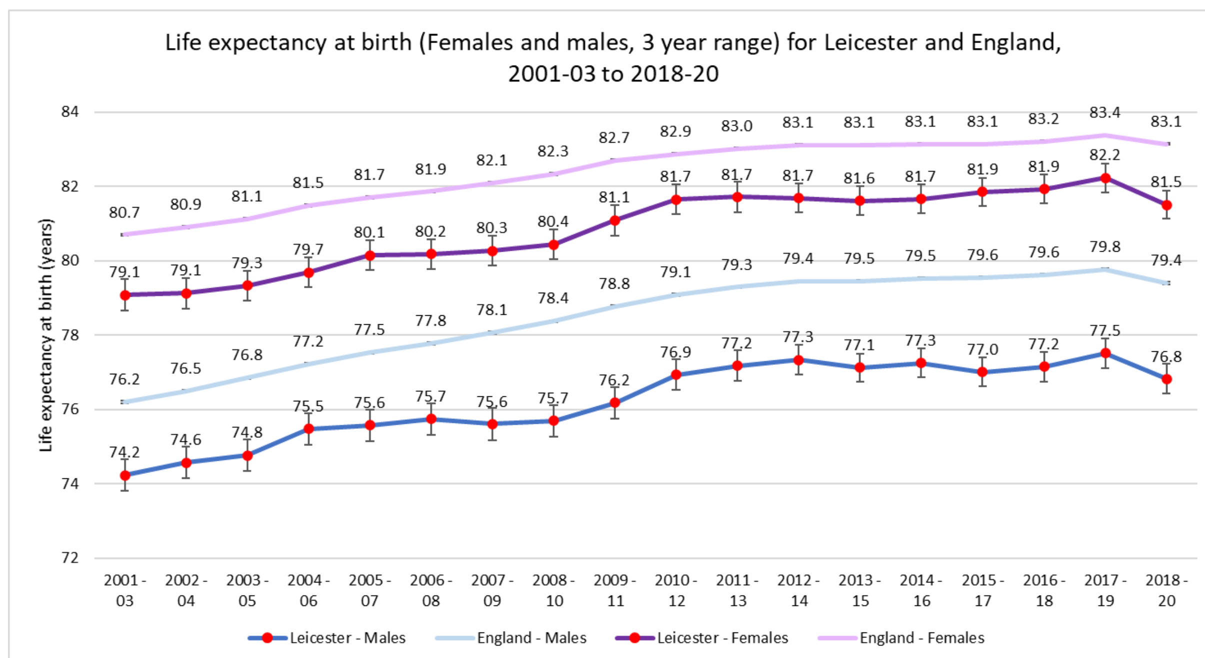
4 THE LEVEL OF NEED IN THE POPULATION

4.1 LIFE EXPECTANCY AND HEALTHY LIFE EXPECTANCY

Life expectancy at birth is the average number of years that a person living in a particular area would expect to live based on current mortality rates in that area. Healthy life expectancy at birth is the average number of years a person would expect to live in good health in a particular area based on current mortality rates in that area and prevalence of self-reported good health.

As shown in figure 3, life expectancy at birth in Leicester has been significantly worse (lower) than England for both males and females since 2001-03. Life expectancy in Leicester in 2018-20 was 76.8 years for males and 81.5 years for females compared to 79.4 and 83.1 years for males and females in England, a difference of 2.6 years lower in males in Leicester and 1.6 years lower in females in Leicester. There was a fall in life expectancy at birth in Leicester and England for both males and females in 2018-20, with a larger decrease in Leicester. In 2018-20, the gap between life expectancy at birth in Leicester compared to England widened for both males and females. This suggests that the need for end of life care is likely to come sooner in life for residents in Leicester compared to the national average.

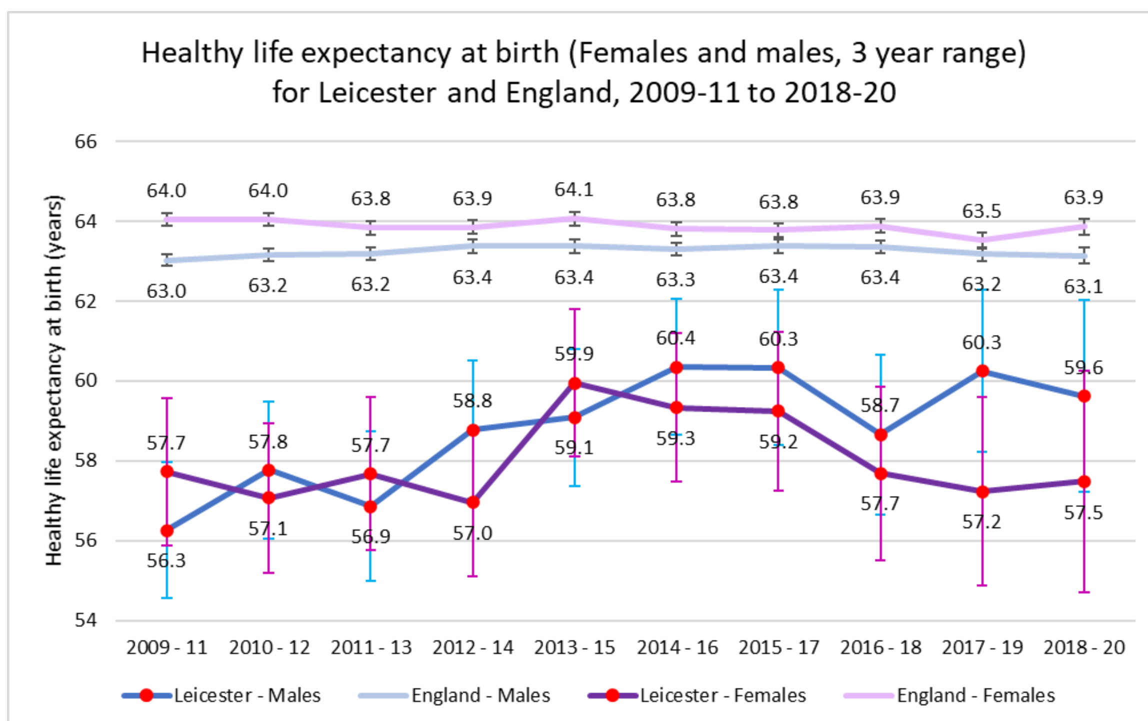
Figure 3: Life expectancy at birth (Females and males, 3 year range) for Leicester and England, 2001-03 to 2018-20 [22]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

As shown in figure 4, healthy life expectancy at birth in Leicester has been significantly worse (lower) than England for both males and females since 2009-11. In 2018-20, healthy life expectancy at birth in Leicester was 59.6 years for males and 57.5 years for females compared to 63.1 and 63.9 years for males and females in England, a difference of 3.5 years lower in males in Leicester and 6.4 years lower in females in Leicester. In 2018-20, the gap between healthy life expectancy at birth in Leicester compared to England widened for both males and females.

Figure 4: Healthy life expectancy at birth (Females and males, 3 year range) for Leicester and England, 2009-11 to 2018-20 [23]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

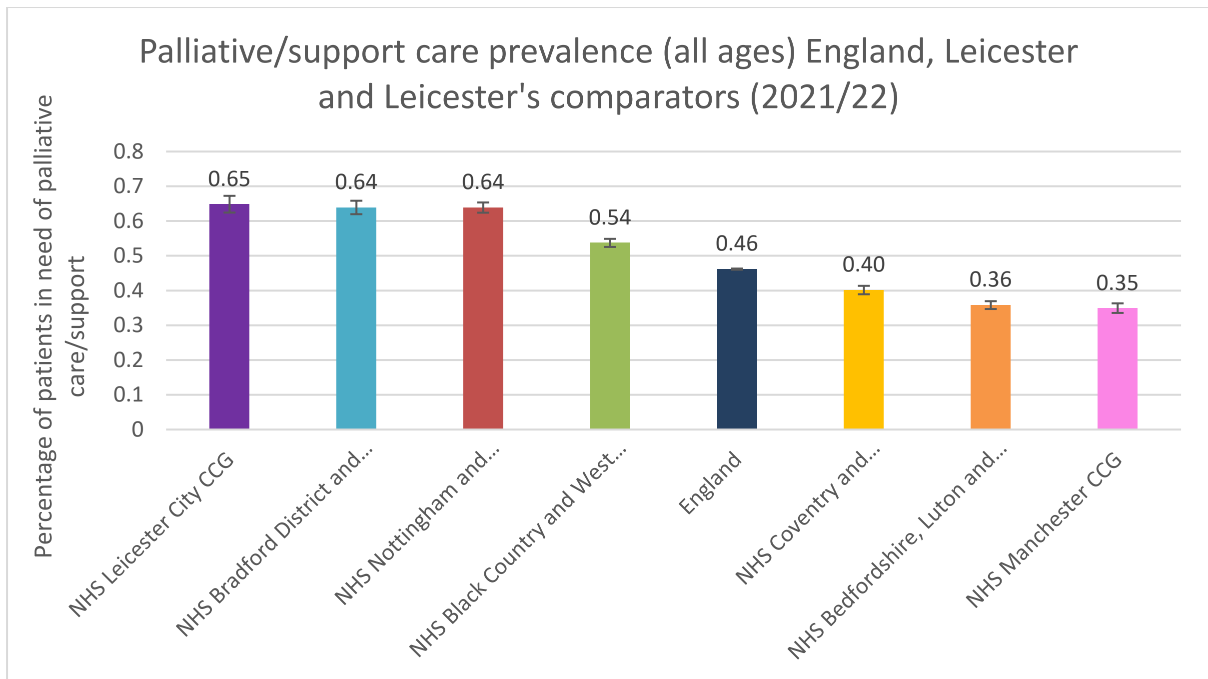
Using the 2018-20 data, the number of years not in good health (the difference between healthy life expectancy and life expectancy) in females in Leicester is 24 years, which is longer than the number of years not in good health experienced by males (17.2 years). The number of years not in good health for females and males in England for the same time period is 19.2 and 16.3 years respectively. The larger number of years not in good health for both males and females in Leicester compared to England demonstrates the importance of ensuring the availability and effectiveness of the services required within this period of life, such as palliative and end of life care, in Leicester.

4.2 PALLIATIVE/SUPPORT CARE PREVALENCE

Figure 5 shows the percentage of patients in need of palliative care/support in 2021/22 as recorded on GP practice disease registers, irrespective of age, for Leicester and it's CCG comparators. NHS Leicester City CCG has 2,768 patients on the palliative care/support register in 2021/22. Leicester City CCG has a significantly higher percentage of patients in need of palliative support/care in 2021/22 (0.65%) than England (0.46%) and four of its six CCG comparators. Leicester has the highest percentage of patients in need of palliative support/care of its comparators and England.

Of note is the significantly higher prevalence of palliative care in Leicester compared to England despite, as shown above, Leicester's significantly lower prevalence for many of the long-term conditions that are associated with a need for palliative care. As discussed above, this may be the result of the age profile of Leicester's population compared to England.

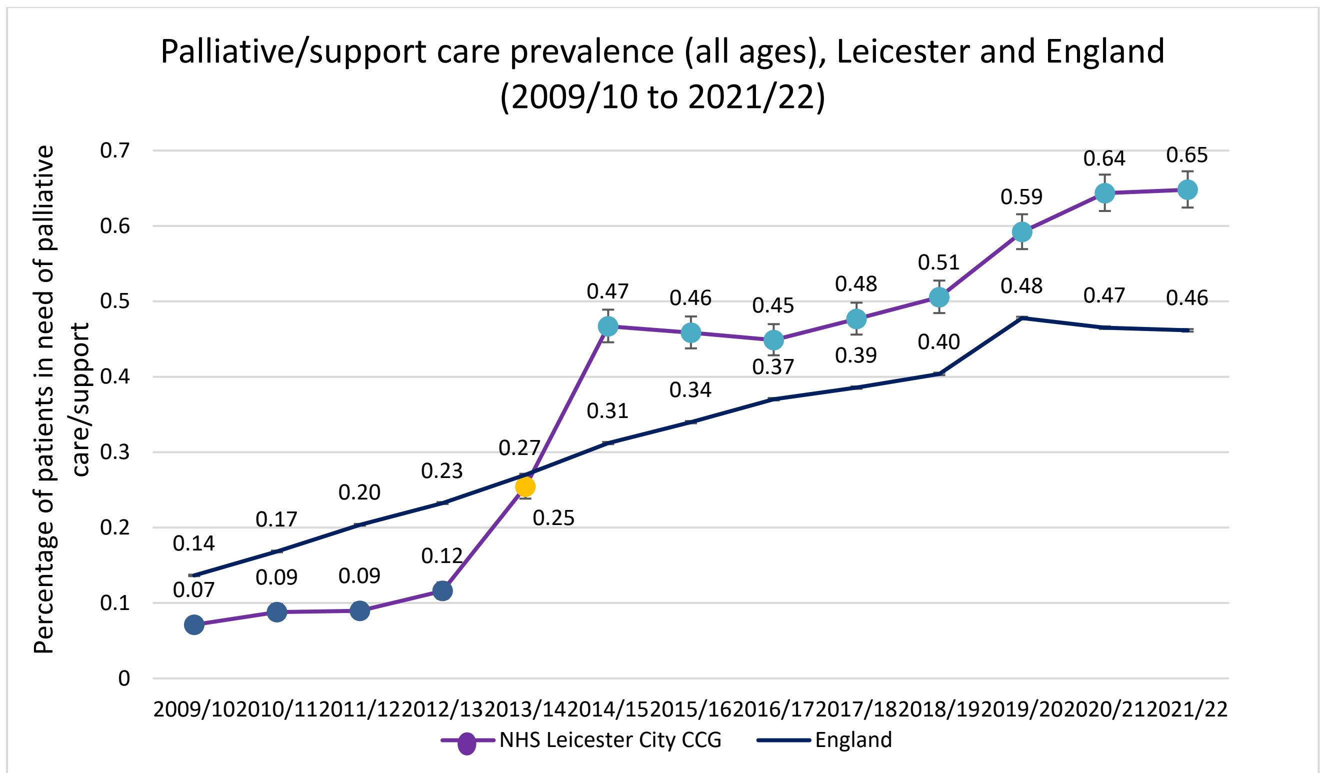
Figure 5: Palliative/support care prevalence (all ages) by area for Leicester, Leicester's CCG comparators and England, 2021/22[24]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

Figure 6 shows the percentage of patients in need of palliative care/support, as recorded on GP practice disease registers, irrespective of age for NHS Leicester City CCG and England by time period from 2009/10 to 2021/22. Between 2009/10 and 2012/13 NHS Leicester City CCG had a significantly lower percentage of people in palliative care than England. In 2013/14, the percentage of patients in need of palliative care/support in Leicester (0.25%) was not significantly different to the value for England (0.27%). NHS Leicester City CCG has had a significantly higher percentage of patients in need of palliative care/support than England since 2014/15 when the value for Leicester was 0.47% compared to 0.31% for England. Over the last five time periods the percentage of patients in need of palliative care/support in Leicester has shown a significant increasing trend from 0.48% in 2017/18 to 0.65% in 2021/22.

Figure 6: Palliative/support care prevalence (all ages) by time period for Leicester and England, 2009/10 to 2021/22



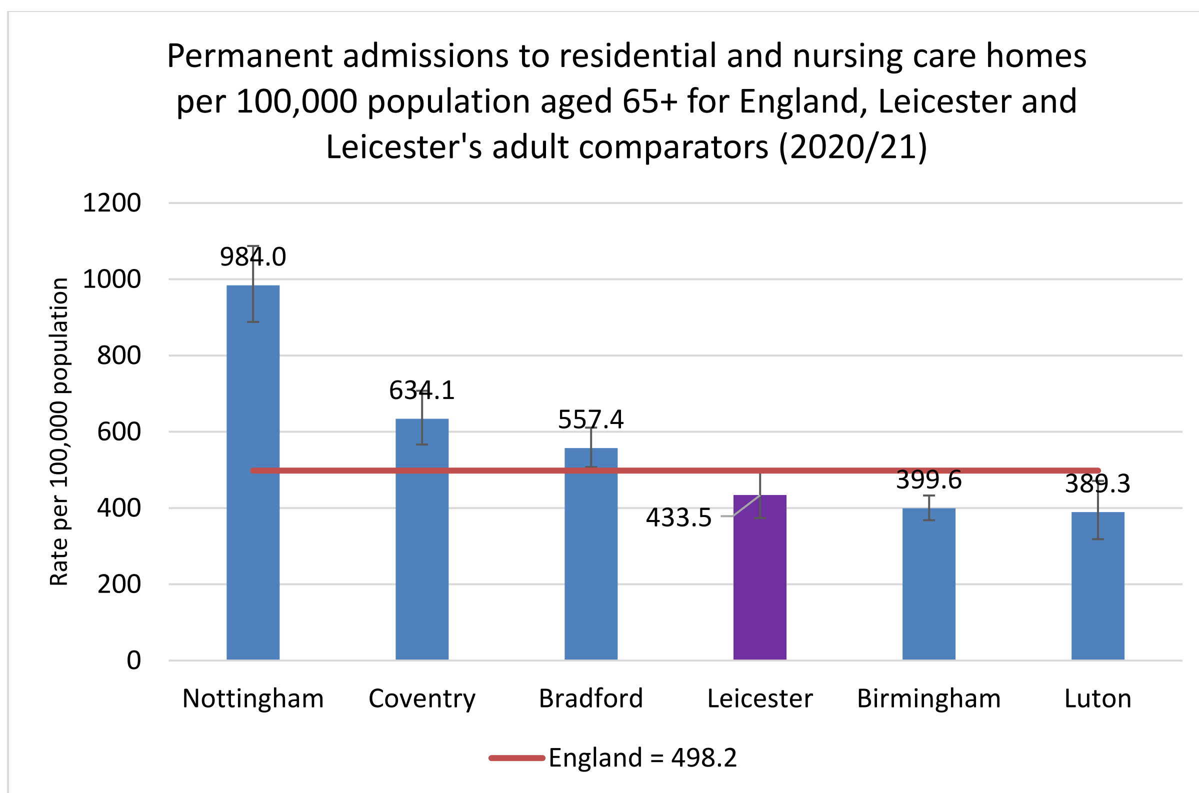
Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

4.3 PERMANENT ADMISSIONS TO RESIDENTIAL AND NURSING CARE HOMES

Note: For this indicator there is a discrepancy in the significance of the difference between the values for Leicester and England for 2016/17 and 2020/21 between those calculated here and those reported on the Office for Health Improvement & Disparities Fingertips website.

Figure 7 shows that the rate of permanent admissions to residential and nursing care homes for those aged 65+ in Leicester in 2020/21 (433.5 per 100,000 population) is not significantly different to the value for England (498.2), Birmingham (399.6) or Luton (389.3). The value for Leicester is significantly lower than that of Nottingham (984.0), Coventry (634.1) and Bradford (557.4). Leicester has the third lowest rate of permanent admissions to residential and nursing care homes for those aged 65+ in 2020/21 when compared to it's five comparators.

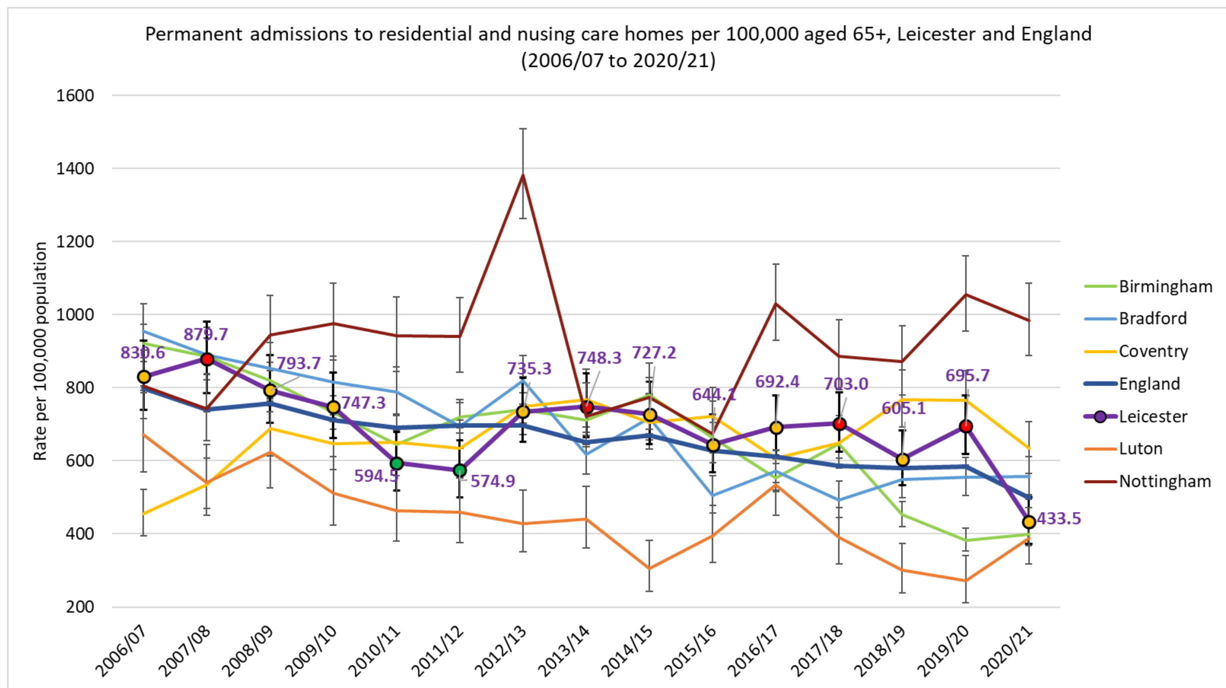
Figure 7: Permanent admissions to residential and nursing care homes per 100,000 population aged 65+ for Leicester, Leicester's comparators and England, 2020/21[25]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

Figure 8 shows the rate (per 100,000 population) of permanent admissions to residential and nursing care homes for those aged 65+ in Leicester and England between 2006/07 and 2020/21. Over the previous five time periods the rate for Leicester has shown a significant decreasing and improving trend, this is in line with the goal of reducing the number of care home placements in favour of community support. Since 2011/12, the performance in Leicester has fluctuated and has been significantly worse than England or there has been no significant difference to England. In 2020/21, the most recent time period, the rate of permanent admissions to residential and nursing care homes for those aged 65+ in Leicester (433.5 per 100,000 population) was not significantly different to the rate for England (498.2). In line with expectations given the presence of the Covid-19 pandemic, there was a large decrease in the rate of permanent admissions to residential and nursing care homes aged 65+ in Leicester in 2020/21 (433.5 per 100,000 population) compared to the previous year (695.7 per 100,000 population), a smaller decrease was witnessed in England (2019/20: 584.0 per 100,000 population, 2020/21: 498.2 per 100,000 population), Coventry (2019/20: 766.5 per 100,000 population, 2020/21: 634.1 per 100,000 population) and Nottingham (2019/20: 1054.7 per 100,000 population, 2020/21: 984.0 per 100,000 population). New care home admissions/placements were scaled back in Leicester during this period and more people were cared for at home, this resulted in a strain on family carers.

Figure 8: Permanent admissions to residential and nursing care homes in those aged 65+ (rate per 100,000 population) in Leicester and England, 2006/07 to 2020/21

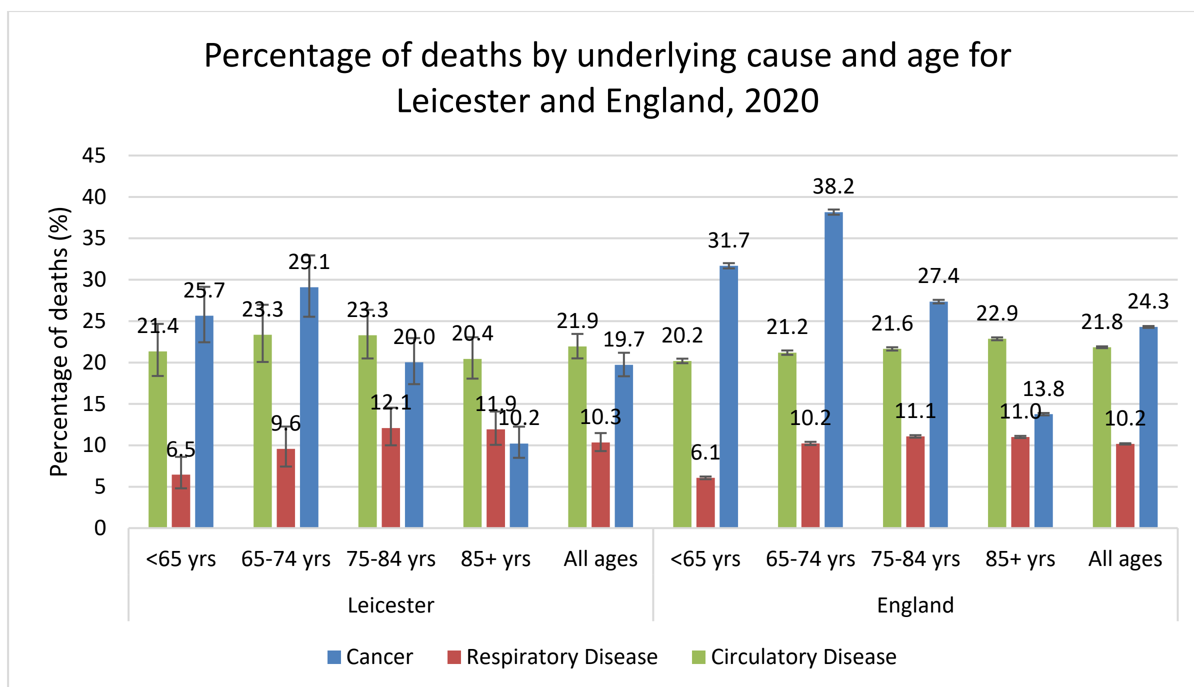


Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

4.4 DEATHS BY UNDERLYING CAUSE

Figure 9 shows the percentage of deaths by underlying cause and age for Leicester and England in 2020. Three of the leading causes of death in England are CVD (24% of all deaths), Cancer (22% of all deaths) and respiratory disease (10% of all deaths). In 2020, Leicester had a significantly lower percentage of deaths by Cancer than England across all age groups. There was a significantly lower percentage of deaths by respiratory disease than by cancer or circulatory disease in Leicester and in England, with the exception of the 85+ group in Leicester where the percentage of deaths by respiratory disease (11.9%) was not significantly different to that of cancer (10.2%). In 2020 in Leicester, there was a significant decrease in the percentage of deaths by cancer with each increasing age group from 65-74 to 85+.

Figure 9: Percentage of deaths by underlying cause and age for Leicester and England, 2020[26]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

4.5 PLACE OF DEATH

Monitoring who dies and where is important in delivering high quality palliative and end of life care. The Ambitions for Palliative and End of Life Care Framework highlights that personal choice in place of care and death is fundamental to the lived experience of the dying and their families.[27] Research by Dying Matters (2017) found that around 70% of people want to die at home. For several years, the National Institute for Health and Care Excellence Quality Standard (QS13) for End of Life Care has used 'place of death' as a quality indicator for palliative and end of life care.[28]

Table 2 shows the percentage of deaths by age and place of death for Leicester and England in 2021. Compared to England, there was a significantly higher percentage of deaths in hospitals for Leicester residents of all ages (46.2% in Leicester and 44.0% in England) and for those aged below 65 years (52.4% and 45.6% respectively), at home for those of all ages (30.8% and 28.7% respectively) and in other settings for those aged 85+ (2.3% and 1.3% respectively). Leicester had a significantly lower percentage of deaths in hospice settings than England for all five age groups as well as a significantly lower percentage of deaths in care home settings for residents of all ages and in hospital for those aged 85+. Over the previous five years, the percentage of deaths in a home setting in those of all ages and 85+ in Leicester has shown a significant increasing trend. In comparison, the percentage of deaths in a care home in those of all ages, in hospital settings for those aged 85+ and in hospice settings for those aged below 65, 75-84 and all ages in Leicester has shown a significant decreasing trend over the last five years. The high percentages of deaths in the home across all age categories highlights the importance of improving community nursing services and social care to ensure that people have all the help that they need to have the best possible end of life experience at home and that the families and carers of the patient can be supported appropriately throughout this difficult time.[29]

Table 2: Percentage of deaths by age and setting for Leicester and England, persons, 2021[30]

Age	Value	Home	Care Home	Hospital	Hospice	Other	Total
<65 yrs	Leicester Count	254	18	365	17	43	**697**
	Leicester %	36.4 →	2.6 →	52.4 →	2.4 ↓	6.2 →	100
	England %	37.1	2.4	45.6	6.8	8.1	100
65-74 yrs	Leicester Count	192	36	276	23	11	**538**
	Leicester %	35.7 →	6.7 →	51.3 →	4.3 →	2.0 →	100
	England %	34.5	7.7	48.6	6.7	2.4	99.9
75-84 yrs	Leicester Count	236	124	402	9	20	**791**
	Leicester %	29.8 →	15.7 →	50.8 →	1.1 ↓	2.5 →	99.9
	England %	28.9	17.3	47.5	4.6	1.6	99.9
85+ yrs	Leicester Count	227	346	320	9	21	**923**
	Leicester %	24.6 ↑	37.5 →	34.7 ↓	1.0 →	2.3 →	100.1
	England %	22.7	35	38.8	2.1	1.3	99.9
All Ages	Leicester Count	909	524	1363	58	95	**2949**
	Leicester %	30.8 ↑	17.8 ↓	46.2 →	2.0 ↓	3.2 →	100
	England %	28.7	20.2	44.0	4.4	2.7	100

Comparison to England:

Significantly lower than England

Significantly higher than England

Recent trend over previous five time periods:

↑ significantly increasing

→ No significant change

↓ Significantly decreasing

Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

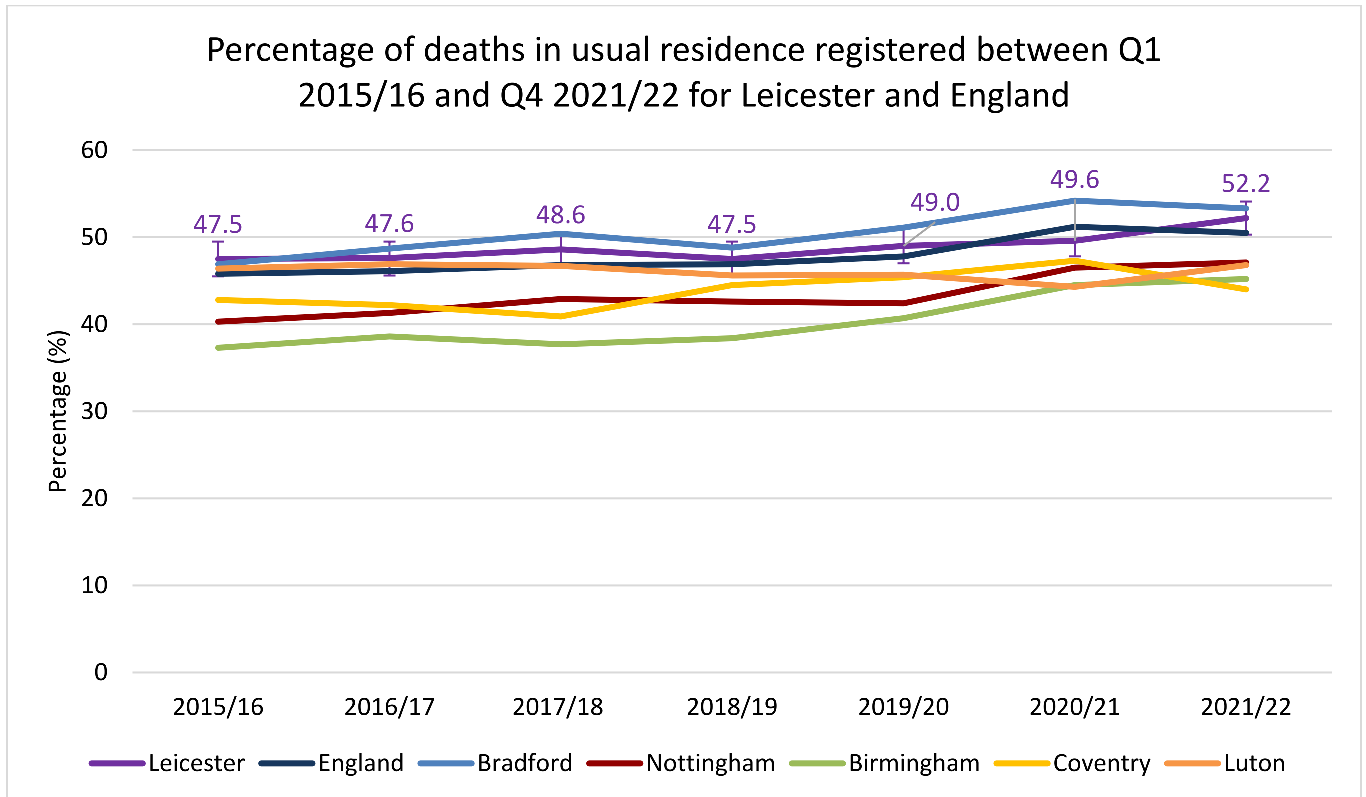
4.6 DEATHS IN USUAL PLACE OF RESIDENCE

Most people would prefer dying at home if there is sufficient support for their condition. Deaths in usual place of residence can be used as a proxy indicator of preferred place of death.

Between the financial years 2015/16 and 2021/22, the percentage of deaths in usual residence in Leicester was higher than the percentage in England, with the exception of 2020/21 where the percentage in England (51.2%) was higher than that of Leicester (49.6%). The percentage of deaths in usual residence in Leicester has not been significantly different to the value for England across the financial years 2015/16 to 2021/22. Over the last four years, since 2018/19, the percentage of deaths in usual residence in Leicester has shown an increasing trend from 47.5% to 52.2%. A similar trend has been witnessed across many of Leicester's comparators, the percentages in England, Coventry and Bradford have decreased between the two most recent periods. In the 2021/22 financial year Leicester had the second highest percentage of deaths in usual residence (52.2%) compared to it's five comparators, with only Bradford (53.3%) having a higher proportion of deaths in usual residence. The percentage of deaths in usual residence in Leicester in 2021/22 (52.2%) was significantly higher than the percentage in Coventry (44.0%), Birmingham (45.2%), Luton (46.8%) and Nottingham (47.1%). The Covid-19 pandemic will have affected the most recent three years of data.

Note: Figures are for deaths registered in financial years (Q1: April-June, Q2: July-September, Q3: October-December, Q4: January-March). Data for Q4 2021/22 is provisional.

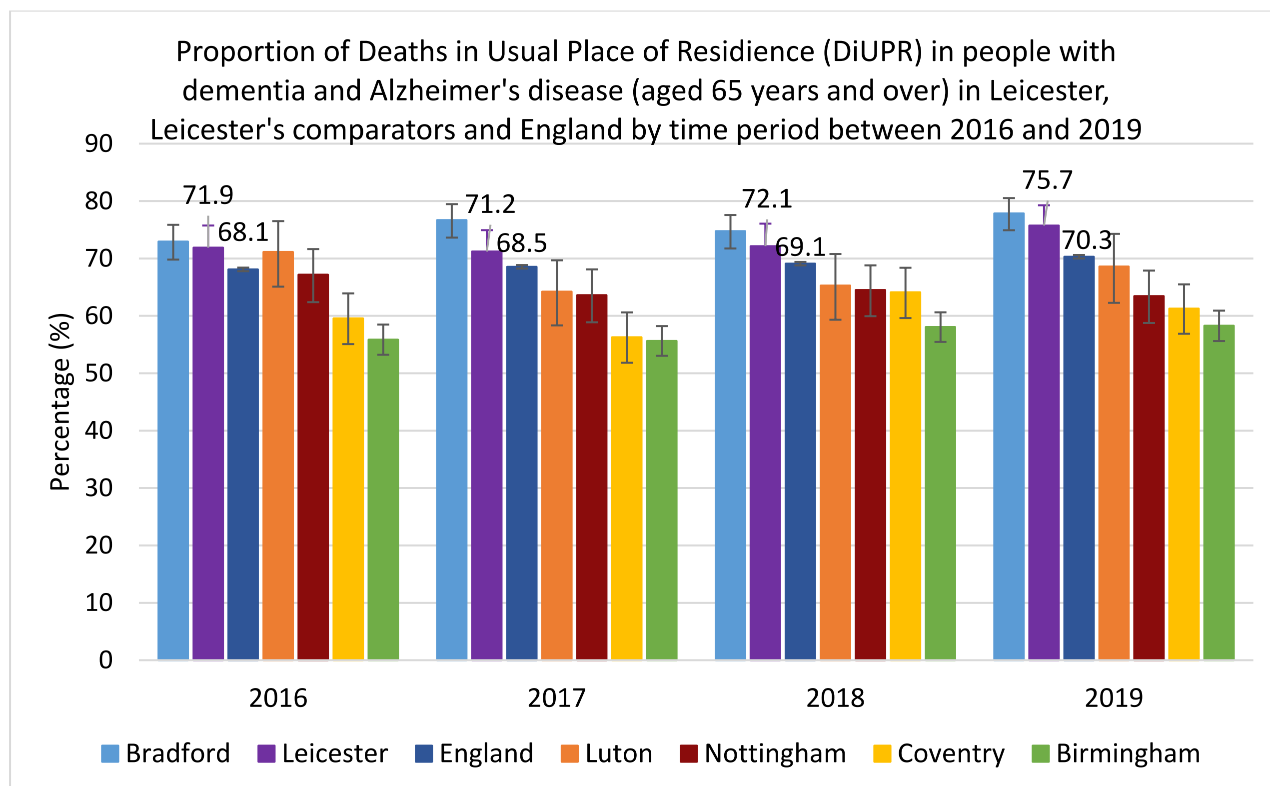
Figure 10: Percentage of deaths in usual residence registered by financial year in Leicester, Leicester's comparators and England between 2015/16 and 2021/22[31][32]



Source: Office for National Statistics

Between 2016 and 2018, the proportion of deaths in usual place of residence for people aged 65 years and over with dementia and Alzheimer's disease in Leicester was not significantly different to the proportion in England overall. Leicester had the second highest proportion of deaths in usual place of residence in people aged 65 years and over with dementia and Alzheimer's disease compared to it's five comparators since recording of this indicator began in 2016, with only Bradford having a higher proportion across the four time periods. The proportion in Leicester increased year on year from 71.2% in 2017 to 75.7% in 2019, a similar pattern was witnessed in England, Luton and Birmingham. In 2019 in Leicester, the proportion of all dementia and Alzheimer deaths in those aged 65 years and over which took place in their usual place of residence (75.7%) was significantly higher (better) than in England (70.3%), Nottingham (63.4%), Coventry (61.3%) and Birmingham (58.3%).

Figure 21: Proportion of deaths in usual place of residence in people aged 65 years and over with dementia and Alzheimer's disease in Leicester, Leicester's comparators and England by time period between 2016 and 2019[33]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

Previous data has shown that the percentage of deaths in usual place of residence varies with age and underlying cause of death. However, recent data for these indicators is not available.

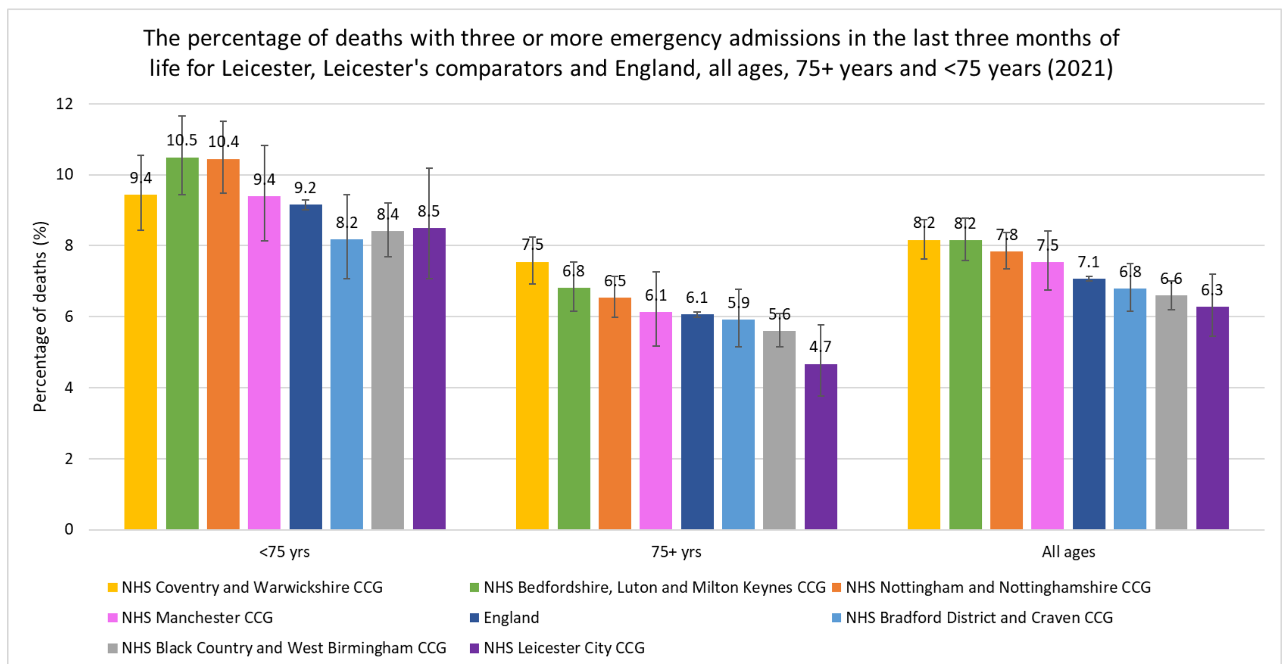
4.7 DEATHS WITH THREE OR MORE EMERGENCY ADMISSIONS IN THE LAST THREE MONTHS OF LIFE

This indicator is intended as a measure of the quality of end of life care services. When this measure is high it could indicate: poor identification of people at risk of death, poor planning and availability of services and/or poor communication, co-ordination and information sharing. In 2020, this indicator will have been affected by many factors, in particular the impact of COVID-19 on admissions to hospital and changes in the way end of life care was delivered in the community should be considered when interpreting this data.[34]

Figure 12 shows the percentage of deaths with three or more emergency admissions in the last three months of life by age group for Leicester, Leicester's comparators and England in 2021. In 2021, Leicester had the smallest percentage of deaths with three or more emergency admissions in the last three months across all ages and 75+ years population and the third lowest percentage in those aged <75 years. In 2021, Leicester had a significantly lower percentage of deaths with three or more emergency admissions in the last three months across all ages (6.3%) than Nottingham and Nottinghamshire CCG (7.8%), Bedfordshire, Luton and Milton Keynes CCG (8.2%) and Coventry and Warwickshire CCG (8.2%). The percentage of deaths with three or more emergency admissions in

the last three months in those aged 75+ in 2021 was significantly lower in Leicester (4.7%) than in England (6.1%), Nottingham and Nottinghamshire CCG (6.5%), Bedfordshire, Luton and Milton Keynes CCG (6.8%) and Coventry and Warwickshire CCG (7.5%). In 2021 in Leicester the percentage of deaths with three or more emergency admissions in the last three months of life was significantly lower in those aged 75+ years than in those aged <75 years.

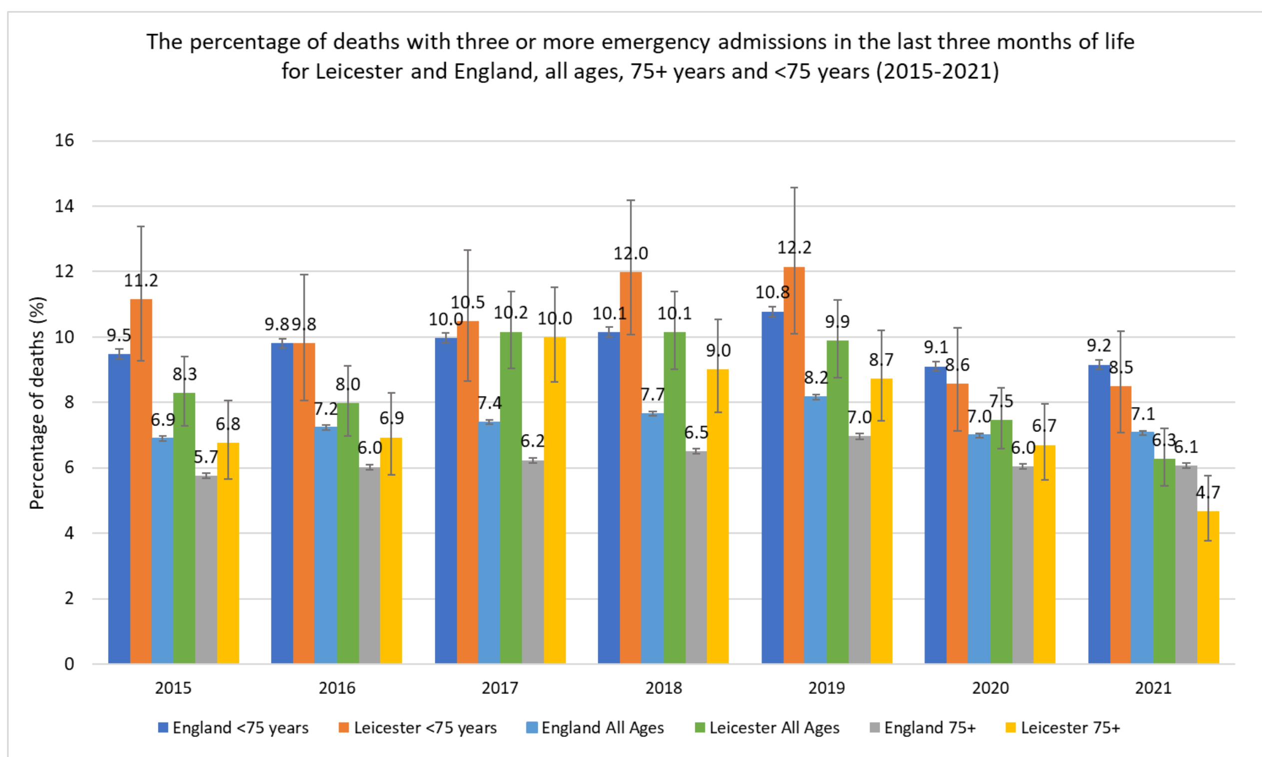
Figure 12: Percentage of deaths with three or more emergency admissions in the last three months of life in Leicester, Leicester's comparators and England by age group (2021)[35]



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

Figure 13 shows the percentage of deaths with three or more emergency admissions in the last three months of life for all ages, over 75 and below 75 year populations for NHS Leicester City CCG and England by year between 2015 and 2021. The percentage of deaths with three or more emergency admissions in the last three months of life in both the all ages and 75+ population in Leicester has shown a significant decreasing and improving trend over the last 5 time periods, from 10.2% to 6.3% and 10.0% to 4.7% respectively. The percentage of deaths with three or more emergency admissions in the last three months of life in those aged below 75 years in Leicester has shown no significant change over the last 5 time periods and has not been significantly different to the value for England since recording of the indicator began in 2015.

Figure 13: Percentage of deaths with three or more emergency admissions in the last three months of life for Leicester and England by age group and time period (2015 – 2021)



Source: Office for Health Improvement and Disparities: https://fingertips.phe.org.uk

5 CURRENT SERVICES IN RELATION TO NEED

Adult end of life care in Leicester City is provided by a community health service provider, an acute hospital (across 3 sites), 62 GP practices, one out of hours provider, one walk in centre, one urgent care centre, one mental health trust, Leicester City Council adult social care services, East Midlands Ambulance Service, externally commissioned home care services and the voluntary and independent sectors including one adult hospice. Admiral Nurses are employed across LLR and tend to support people living with dementia who have complex or palliative needs.

The main palliative care services in the community, to support patients in their home in the last days of life are:

- **Specialist Palliative Care**: LOROS provide a multi-disciplinary holistic assessment and care for adults with complex palliative needs, regardless of diagnosis that cannot be adequately managed in other settings or by general palliative care professionals, and their families. LOROS provides a ‘face to face’ service 5 days per week from 8.30am to 5.00pm, with supporting 24/7 advice line. They also offer a “befriending / sitting” service.
- **Hospice At Home service**: The service delivered by Marie Curie is available seven days a week from 7.00am to 10.00pm. The out of hours unscheduled night care will be provided by the Leicestershire Partnership Trust night nursing service to ensure appropriate care, support, assessment and symptom management is provided over a 24-hour period to prevent unavoidable hospital admissions.
- **Community Nurses**: the LPT Macmillan Nurses and the LOROS specialist nursing teams work 5 days a week, from 8.30 to 5.00pm.

LOROS CNS	LPT CNS
The nurses specialise in palliative and EOL care, irrespective of diagnosis and will provide specialist nursing care in patients' own homes which includes: • Specialist nursing assessment, advice and care planning • Case managing patients with complex palliative care needs • Single contact or episodic interventions • Involvement in Gold Standard Framework practice meetings • Psychological assessment at Level 2 • Extended nurse prescribing • Care co-ordination and case management • Symptom control and management • Specialist advice to patients and carers and other professionals • Advanced care planning • Pre-emptive prescribing	The nurses specialise in palliative and EOL care, irrespective of diagnosis and will provide specialist nursing advice for complex symptoms both physical and psychological in the patients' own homes which includes: • Specialist nursing assessment, advice and care planning • Case managing patients with complex palliative • care needs • Single contact or episodic interventions • Involvement in Gold Standard Framework • practice meetings • Psychological assessment at Level 2[1] Extended nurse prescribing • Care co-ordination and case management • Symptom control and management • Specialist advice to patients and carers and other professionals • Advanced care planning • Pre-emptive prescribing • Ensuring patients are signposted to the appropriate key worker if their symptoms are resolved

For children there are additional support services such as Rainbow Hospice and Diana End of Life services. Children's end of life care services are covered in the Children's JSNA.

In Leicester, Leicestershire and Rutland, the Integrated Community Specialist Palliative Care service, a team of nurses and Healthcare Assistants from Leicestershire Partnership NHS Trust and LOROS, look after patients with life-limiting illnesses who have complex palliative care needs, especially pain and symptom management, as well as patients who are in the last days of life.[36] This often includes when appropriate intervention has failed to control symptoms, when symptoms are escalating, when patients or families and carers require psychological and spiritual care or if there are any other problems that other healthcare professionals are unable to manage. There are a range of different support levels available, including telephone advice, one off assessments, ongoing management and personal care. The Integrated Community Specialist Palliative Care service also offer advice and support to other members of the community health service about the best way to manage the needs of their patients.

6 PROJECTED SERVICES USE AND OUTCOMES

[1] As outlined in NICE Improving Outcomes Guidance for Palliative Care

Based on an estimated increase of 28.7% in the number of deaths in the UK, the table below predicts around 3,150 deaths in Leicester in 2043, an increase of 702 deaths from 2019 [37] The estimated palliative need is calculated as 69%-82% of all deaths, equivalent to 2,176-2,585 patients based on the estimated number of deaths in Leicester in 2043. The QOF palliative care register in 2021/22 listed 93% of the total number of deaths in 2021. Carrying forward this percentage of 93% to the estimated number of deaths in Leicester in 2043, an estimated 2,932, an additional 164, patients will require palliative care by 2043. Depending on the method used to calculate the estimated need by 2043, Leicester may experience an increase in demand for end of life care services. There is more recent data available which could be used in calculating the number of death projections. However, the more recent data covers periods of the Covid-19 pandemic, which was an unusual time for deaths, and as such a fairer comparison is judged to be against pre-pandemic data such as that of 2019.

Table 3: Estimated number of deaths in Leicester City – projected from 2019 - 2043

	Actual year end mid-2019	Estimated year end mid-2043
Number of deaths UK	604,707	778,000
Number of deaths Leicester	2,451	3,153
Estimated palliative need (69-82% of deaths) Leicester	1,691-2,010	2,176-2,585

Sources: ONS Deaths Registered in England and Wales 2019, ONS National Population Projections: 2018-based interim

7 UNMET NEEDS AND SERVICE GAPS

Services need to work together to fully support the person at the end of their life, along with their carer's and family. There is limited coordination between the key stakeholders in end of life care which results in the wishes of patients not being granted and the opportunity to identify patients with palliative care needs often being missed, resulting in less effective, reactive care.

There is a lack of confidence to talk about the end of life and preferred plans and limited understanding of the importance and benefits of planning and outlining wishes.

There are clear inequalities in access to and quality of end of life care received for particular groups. A stronger understanding of unmet need in these affected groups, such as those who are from BAME backgrounds, identify as LGBT, are from more deprived areas or those who are homeless, is required.

There is inadequate support available for carers throughout the dying process. Carers are often responsible for coordinating health and social care services for someone approaching the end of life, and find it difficult to access the services available often because of lack of awareness.

There is also a lack of awareness of the existing bereavement support available.

There is limited up to date evidence available regarding the effectiveness of end of life care, both at a national and local level. The level of understanding of satisfaction with, and views on, the effectiveness of end of life care of those receiving the service as well as their carers, family and staff working in end of life and palliative care roles is poor.

8 RECOMMENDATIONS FOR CONSIDERATION BY COMMISSIONERS

Follow the basis for local decision-making and service delivery, as set out by The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026, to improve end of life care through collaborative action between organisations in the Leicester area and beyond.

Commissioners should review and follow the advice set out in the upcoming (early 2023) Leicester, Leicestershire and Rutland Integrated Care System (LLR ICS) End of Life and Palliative Care Strategy.

The data for Leicester suggests that the city has a higher proportion of deaths at home or in the individuals usual place of residence. This would indicate that a higher proportion of end of life care is provided at home by carers and likely by family. This should be considered by commissioners when reviewing and following any end of life strategy.

The identification and documentation of people who may be in their last year of life is helpful to service planners for commissioning future services for people in the last year of life. Timely identification is required to ensure people's needs are met at the end of life (for example, being cared for in the place they want to). The national primary care snapshot audit in End-of-Life Care 2010/11 looked at over 7,000 clinical records. NICE concludes "Most significantly though it found that those people included on the palliative care register were more likely to receive well-co-ordinated care (for example handover to out-of-hours, anticipatory prescribing) and more likely to have been offered an advance care planning discussion and to die in their preferred place of choice." (NICE Guideline NG 142 End of Life for Adults: Service Delivery. Evidence Review pp 9-10).[38] Identifying those who are likely to be approaching their last year of life is likely to be undertaken in a variety of clinical settings using a mixture of traditional clinical experience and expertise – augmented in some cases by the use of more structured prognostic tools such as the Supportive and Palliative Care Indicators Tool (SPICT).

In Leicester, Leicestershire and Rutland (LLR), the current risk stratification system, the Johns Hopkins Adjusted Clinical Groups (ACG®) System, includes a Mortality Risk Score (MRS) which clinicians can use to supplement their assessments to identify suitable patients for whom to consider initiating an end-of-life discussion. Scores greater than 85 indicate cases where an initial review of the clinical records is worthwhile to help select those in whom a discussion on future care arrangements might be helpful. Further analysis should be carried out in LLR to confirm the statistical performance of the MRS at scores above 85, and additional engagement with primary care on use of the marker should be considered. In February 2023, there were 2,960 Leicester patients with a mortality risk score of 85 or more. Of these, the majority are older adults (65+ years).

More specifically, the key recommendations for consideration are to ensure:

- The opportunity for patients to discuss their personal needs and preferences, which should be taken into account whenever possible;
- Coordinated care and support, including the use of electronic solutions to storing care plans so that these can be accessed across sectors to allow for better collaborative care;
- Rapid access to specialist advice and assessment;
- High quality care and support during the last days of life;

- The closing of the inequality gap through better understanding of need and access barriers for our more disadvantaged and vulnerable communities;
- Services that treat people with dignity and respect; and
- Appropriate advice and support for carers at every stage of the dying process.

There are a number of additional areas that can be further addressed.

Raising awareness

- To tackle the taboo within society about discussing death and dying – promotion of conversations about death and dying
- Appropriate involvement of voluntary sector organisations, particularly for issues relating to culture and faith

Patient identification

- Proactive pre-end of life identification: linking the palliative care register with other long-term conditions registers, to identify patients at risk of being at end of life, so that discussions and advance care planning can be anticipated, rather than reactionary. This is particularly relevant for patients with dementia, but the system also needs to recognise the frail elderly, who do not easily fit into a long-term conditions definition.
- For proactive pre-end of life identification through linking the palliative care register with other long-term condition registers to be as effective as possible, a decrease in diagnosis rates for many conditions over the Covid-19 pandemic should also be recognised. For example, in Leicester the estimated dementia diagnosis rate (aged 65 and over) has fallen over the pandemic period (from 87.4% in 2019 to 73.6% in 2022)[39] because of various factors such as lack of presentation to primary care and the suspension of memory assessment services. Efforts should be made to improve this trend going forwards to allow for more effective proactive pre-end of life identification through the linking of the registers.

Education

- Formal education: supports the upskilling of generalist staff through dedicated training from specialist staff
- Mentoring and coaching model: creates a “buddy” system for generalist staff to learn directly from specialist staff, for example, to obtain confidence and competence for the delivery of Information Plans where discussions regarding death and dying are not as familiar to generalist staff groups
- Patient and carer empowerment: so that patients can understand what services are available to meet their needs and carers have the confidence to care for their loved one in their preferred place of care

Information

- Improve the sharing of data to enable co-ordinated care. It will facilitate a more streamlined service, from identifying patients with end of life needs, to communicating a patient’s preferences around resuscitation or place of death
- Improving information and support to front line staff and hard to reach groups, to ensure that patients and their carers know what services are available to support them and that they do have a choice in where they can be cared for, and where they can choose to die.

9 KEY CONTACTS:

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