Death matters: needs assessment for End of Life and Palliative Care in York.

City of York Council

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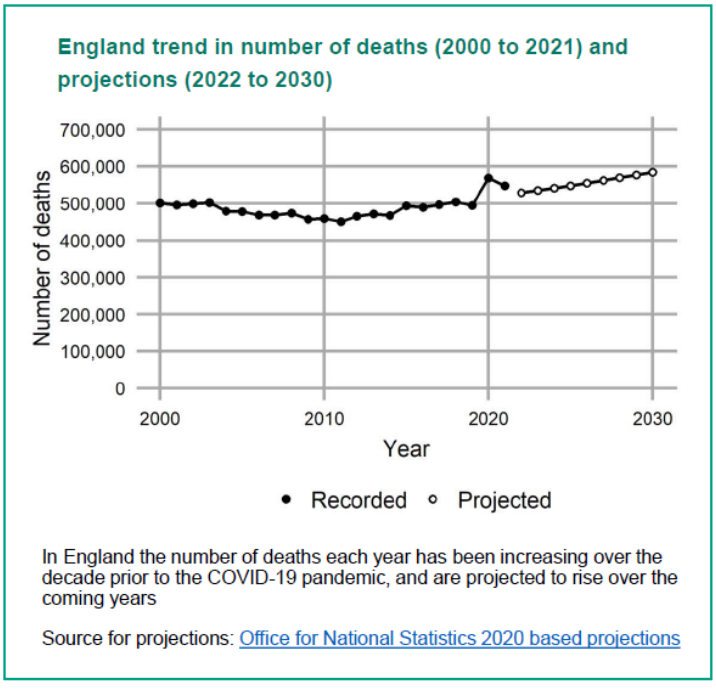
Introduction

'in this world nothing can be certain except death and taxes'

Benjamin Franklin 1789

While the certainty of taxes is debateable there is no denying that 100% of people will die. Advances in healthcare can impact on what causes most deaths and can lead to increases in the average age at which this occurs but will not make anyone live forever. Death effects everybody, and delivery of high-quality end of life care should be a healthcare priority. This is why the NHS long term plan commits to improving personalised palliative and end of life care and the 'Ambitions for Palliative and End of Life care' was published in 2015 and updated in 2021[1]. In York the Health and Wellbeing Strategy includes 'Ending life well' as one of the four stages of life in which it wants York citizens to experience the best possible health (along with start well, live well and age well)[2].

In England the number of deaths has been increasing over the decade prior to the covid 19 pandemic and is projected to continue to rise in coming years:



[1] https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

[2] https://democracy.york.gov.uk/documents/s163774/Annex%20Di%20Health%20and%20Wellbeing%20Strategy%202022-32.pdf

As a result, demands on services providing end of life care is going to increase and needs to be a priority. The 'Ambitions for Palliative and End of Life Care' document sets out six key ambitions that all dying patients should receive.

1. Each person is seen as an individual.
2. Each Person gets Fair Access to care.
3. Maximising comfort and wellbeing.
4. Care is coordinated.
5. All staff are prepared to care.
6. Each community is prepared to help.

The scope of this document is to establish any gaps in delivery of these ambitions across York, in particular exploring if there is any variance in delivering care based on deprivation, disease or distance from specialist palliative care services.

What is End of Life Care?

As described above the NHS long term plan refers to 'palliative and end of life care', but what exactly do these terms mean?

Palliative care is generally the care of patients who have an illness that is incurable. The term comes from 'pallium', the latin word for 'cloak' as its focus is to cloak, or cover up, the symptoms of an illness without curing it.[3] The origins of the specialism of 'palliative care' is largely attributed to the work of Dame Cicely Saunders a British physician who challenged the ethic that doctors focus should always be to cure but, in some patients, it is appropriate to focus on the relief of suffering and she founded the world's first modern hospice (St Christopher's hospice in South West London) in 1967. Prior to this time institutions providing care for dying people were largely religious institutions. She introduced effective pain management and insisted that dying people needed dignity, compassion, and respect, as well as rigorous scientific methodology in the testing of treatments. Saunders also introduced the idea

[3] https://www.upmc.com/-/media/upmc/services/palliative-and-supportive-institute/resources/documents/psi-history-palliative-care.pdf

of "total pain," which included the physical, emotional, social, and spiritual dimensions of distress.[4]

The world health organisation recognised palliative care as a medical specialty in 1990 and globally the majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%) but also include kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.[5]

While patients receiving palliative care have an incurable illness and the focus of palliative care is to relieve suffering rather than to bring about cure, this may be delivered alongside active treatments to slow disease progression and prolong life such as chemotherapy or radiotherapy and patients may live with incurable disease for several years.

The General Medical Council definition of 'end of life care' determines that people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people in who death is imminent (expected within hours or days) and those who have advanced incurable conditions, those with general frailty and coexisting conditions making them likely to die within 12 months, existing conditions which put them at risk of dying from a sudden acute crisis.[6]

End of life care involves any care that is provided when a patient has reached this terminal stage. It includes the palliative management of pain and other symptoms, and also the provision of psychological, social, spiritual and practical support.[7]

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[4] https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1

[5] https://www.who.int/news-room/fact-sheets/detail/palliative-care#:~:text=Palliative%20care%20is%20required%20for,%25)%20and%20diabetes%20(4.6%25

[6] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/guidance

[7] https://hub.datanorthyorkshire.org/dataset/2cb529f6-4715-4c2d-9364-a770deb03472/resource/21e21b0d-54a1-4eb0-9665-bddf2efa24ac/download/eolc-jsna-report-13-07-16.pdf

Who is involved in End of Life Care?

As people's needs are very variable as they approach the end of life many people may be involved in delivering end of life care. This can include a patient's GP who will prescribe medications to help alleviate symptoms and assess patients when their condition changes, district nurses who may administer medications, manage dressings, catheters or other nursing needs, social care providing suitable care to meet the needs of dying patients, nursing home staff, counsellors for psychological support, social prescribers, physiotherapists, occupational therapists, charitable or voluntary sector workers, faith or community leaders for spiritual support, hospital staff if admission to hospital are required and specialist palliative care services.

Specialist palliative care services is a team made of clinicians with specialist knowledge and expertise in managing patients with incurable illness with a focus on alleviating suffering. They are particularly skilled at managing patients with particularly difficult to control symptoms including for example pain, agitation, breathlessness, nausea and sickness. Across York patients may encounter specialist palliative care services in three settings:

- St Leonard's hospice
- in the community /at home
- specialist palliative care services based in York District Hospital for those patients admitted to hospital

Trends in deaths in York

Similar to national trends deaths in York have been gradually increasing for several years with a sharp rise in 2020, the first year of the Covid-19 Pandemic.

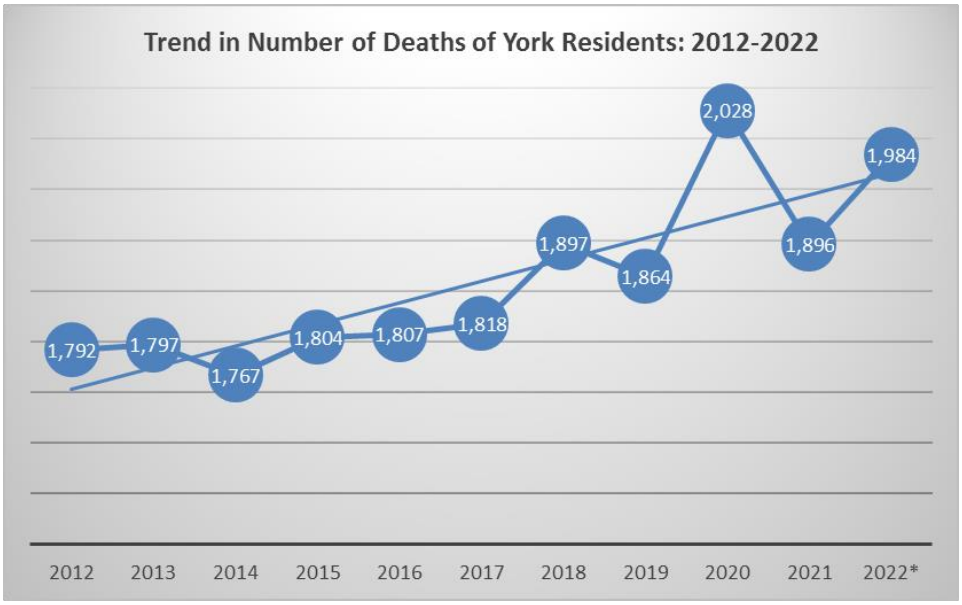

Figure 1: Trend in Number of Deaths of York Residents 2012-2022.

For the purpose of this project we have chosen to focus most closely on deaths in York in 2022, as that is the first full year since the Covid-19 pandemic in which care is less likely to have been impacted by the various lockdowns and restrictions imposed as a result of the pandemic.

Causes of Death of York residents: 2022

Using the Primary Care Mortality Database (PCMD), we can observe that the leading causes of death in this time period were Neoplasms (i.e. cancers, 26.7% of all deaths), followed by Circulatory Disease (25.1%), Respiratory Disease (10%); Mental, Behavioural and Neurodevelopmental disorders (8%); Diseases of the Nervous system (7.9%) and Digestive Disease (5.9%). These top six broad causes of death account for 83.7% of all deaths in 2022

Table 1: Broad cause of death for York residents: 2022

Broad Cause of Death	No.	%
Neoplasms (C00-D49)	529	26.7%
Diseases of the circulatory system (I00-I99)	498	25.1%
Diseases of the respiratory system (J00-J99)	199	10.0%
Mental, Behavioural and Neurodevelopmental disorders (F01-F99)	159	8.0%

Diseases of the nervous system (G00-G99)	157	7.9%
Diseases of the digestive system (K00-K95)	118	5.9%
Codes for special purposes (U00-U85)	78	3.9%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	73	3.7%
Not categorised using ICD10	70	3.5%
Endocrine, nutritional and metabolic diseases (E00-E89)	28	1.4%
Certain infectious and parasitic diseases (A00-B99)	26	1.3%
Diseases of the genitourinary system (N00-N99)	21	1.1%
Diseases of the musculoskeletal system and connective tissue (M00-M99)	12	0.6%
Diseases of the skin and subcutaneous tissue (L00-L99)	7	0.4%
Diseases of the blood (D50-D89)	3	0.2%
Certain conditions originating in the perinatal period (P00-P96)	2	0.1%
Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	2	0.1%
Diseases of the ear and mastoid process (H60-H95)	1	0.1%
External causes of morbidity (V00-Y99)	1	0.1%
All	1984	100.0%

Age Profile

The average age at death for all the York residents who died in 2022 was 80 years.

The average age for people dying from Circulatory Disease (81.7) and Mental, Behavioural and Neurodevelopmental disorders (88.1) was significantly higher than the York average. The average age for people dying from Neoplasms (75.6) and Diseases of the Digestive System (73.3) was significantly lower than the York average.

Table 2: Average Age at Death by Broad Cause of Death

Broad Cause of Death (Top 6 Causes)	No.	Average Age	Standard Deviation	95% CI lower	95% CI upper
Neoplasms (C00-D49)	529	75.6	12.8	74.5	76.7
Diseases of the circulatory system (I00-I99)	498	81.7	12.1	80.6	82.8
Diseases of the respiratory system (J00-J99)	199	81.4	10.8	79.9	83.0

Mental, Behavioural and Neurodevelopmental disorders (F01-F99)	159	88.1	9.3	86.7	89.6
Diseases of the nervous system (G00-G99)	157	82.1	12.3	80.1	84.0
Diseases of the digestive system (K00-K95)	118	73.3	15.7	70.4	76.2
All	**1984**	**80.0**	**13.9**	**79.4**	**80.6**

The average age for people dying in Care Homes (87.9) was significantly higher than the York average. The average age for people dying at Home (76.7) or in a Hospice (69.8) was significantly lower than the York average.

Breakdown of place of death for York residents: 2022

Based on the PCMD data, the breakdown by place of deaths for York residents is shown in the table below.

Table 3: Breakdown of place of death for York residents: 2022

Location of Death	No.	%
Hospital	904	45.6%
Care Home	453	22.8%
Home	543	27.4%
Hospice	78	3.9%
Other places	6	0.3%
Total	1,984	100.0%

Place of Death

In terms of place of death, the key measures which would enable us to understand the quality of end of life care in York would be the proportion of patients with evidence of documented advanced care plans including a preferred place, together with the proportion of patients who actually died in their preferred location. Unfortunately, we were unable to cross-reference deaths with palliative care registers in a way which would enable this. Deaths in hospital may suggest however that these patients had unmet needs leading up to their death and could be a sign of less proactive supportive care prior to death.

From published data in 2021 the percentage of York residents who died in hospital (41.6%) was statistically significantly lower than the England average (44%). The percentage who died in a care home (23.4%) was significantly higher than the England average (20.2%). There was no significant difference between the percentage of York residents who died at home, in a hospice or in 'other places' compared with the England average.

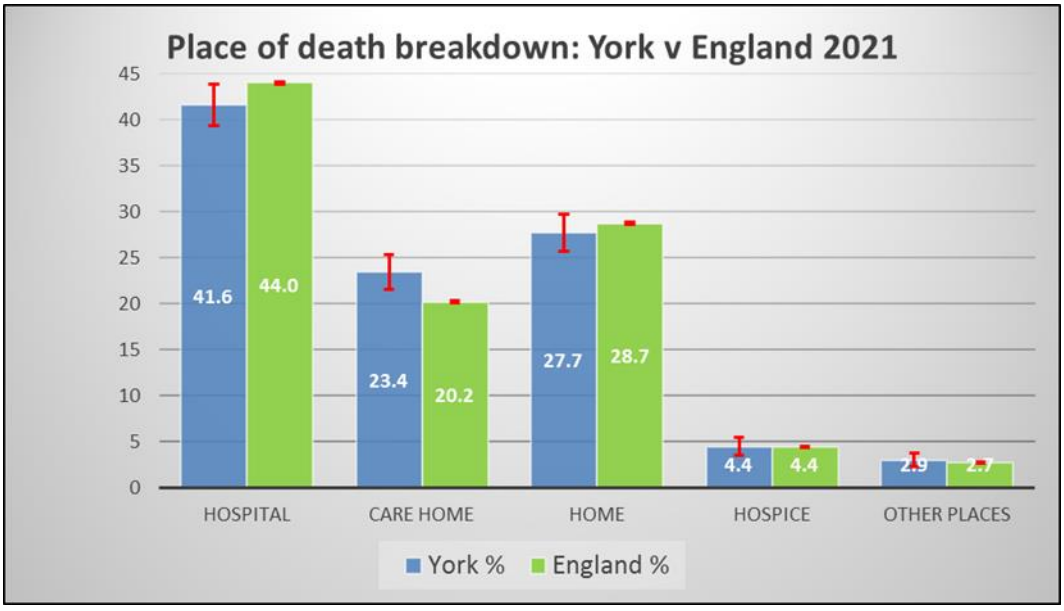

Figure 2: Place of death breakdown: York v England 2021

Nationally there is a difference between the pattern of place of death between the most and least deprived deciles. People living in the most deprived decile are statistically significantly more likely to die in hospital, at home or in 'other places'' and statistically significantly less likely to die in a care home or hospice compared with people living in the least deprived decile. Differences in age

profiles and causes of death profile of the deciles may impact on place of death.

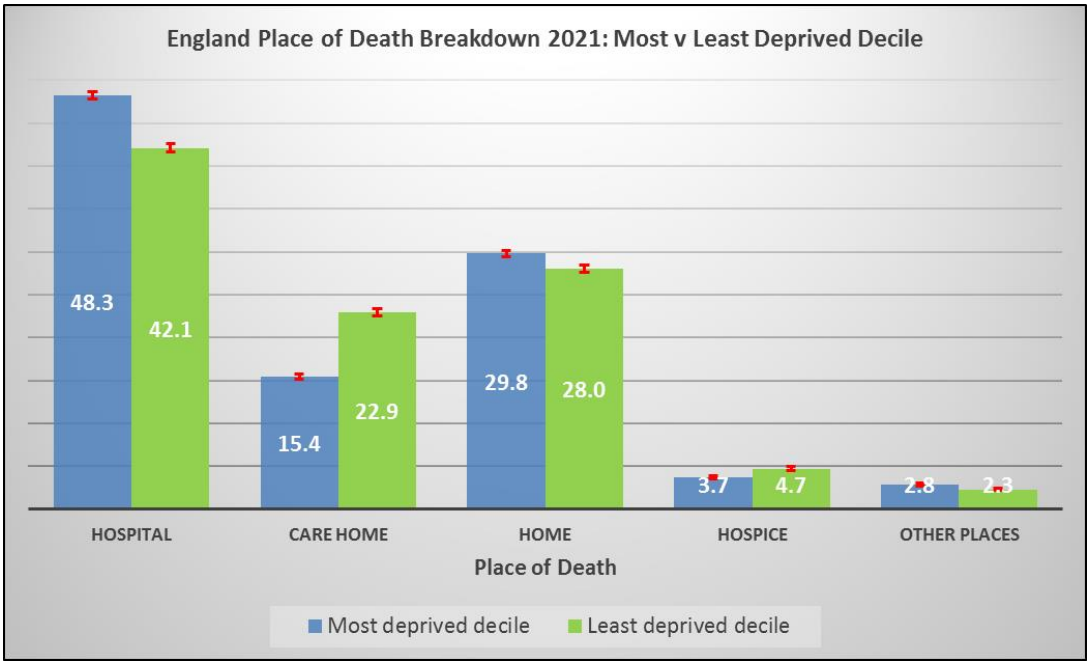

Figure 3: England Place of Death Breakdown 2021: Most v least Deprived Decile

York Place of Death Breakdown by Deprivation Quintile

The breakdown of place of death for each deprivation quintile in York is shown in the chart below. The is no statistically significant association or trend in proportion of people dying in a particular location for each deprivation quintile, however there is a deprivation gradient in those dying in hospital which holds apart from the least deprived quintile in York. The reasons for this are not clear and could be down to the play of chance in death location in 2022; given the national trends do suggest you are more likely to die in hospital if you are from a more deprived area, it is likely that if a longer time-period of data was analysed for York (i.e. with a larger 'sample size') we would see a similar pattern to what we see across the whole of England.

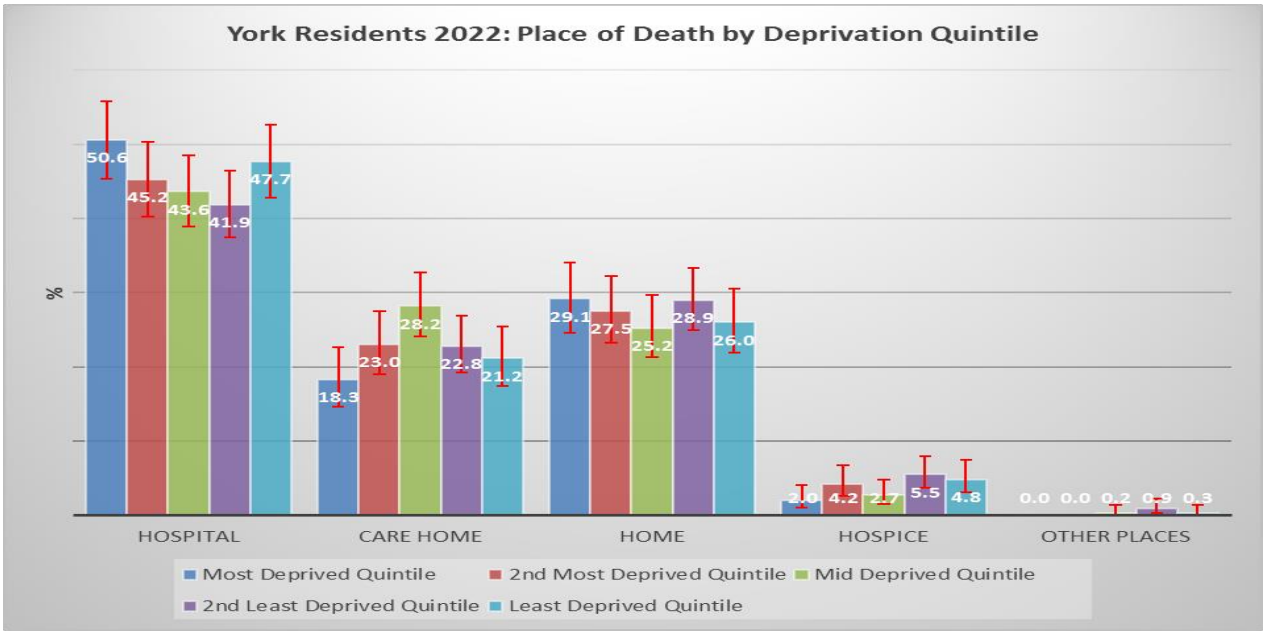

Figure 4: York Place of Death Breakdown by Deprivation Quintile: 2022

Proportion of patients on a Palliative Care register by GP practice

There is significant variation in the proportion of patients on a Palliative Care Register across GP Practices in the city. Some of this variation is explained by the differing age profiles of our registered practice populations, and QOF data is not age-standardised, meaning a practice such as Haxby Group with an older population is likely to have more patients on a register than a practice like Unity. However there is also likely to be an element of clinical practice lying behind the variation, and the data may suggest that practices with smaller palliative care registers may be missing opportunities to assess patients for end of life needs.

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↑	284,338	0.5	0.5	0.5
York GPs	–	1,781	0.7*	0.7	0.7
B82026 - Haxby Group Practice	↑	514	1.5	1.4	1.7
B82005 - Priory Medical Group	↑	541	0.9	0.9	1.0
B82083 - York Medical Group	↑	342	0.8	0.7	0.9
B82098 - Jorvik Gillygate Practice	↑	151	0.6	0.5	0.7
B82081 - Elvington Medical Practice	→	25	0.3	0.2	0.5
B82047 - Unity Health	↑	74	0.3	0.3	0.4
B82100 - Front Street Surgery	↑	23	0.3	0.2	0.4
B81036 - Pocklington Group Practice	→	43	0.2	0.2	0.3
B82080 - My Health Group	→	39	0.2	0.1	0.3
B82021 - Dalton Terrace Surgery	→	16	0.2	0.1	0.3
B82071 - The Old School Medical Practice	→	13	0.2	0.1	0.3

Source: Quality and Outcomes Framework (QOF), NHS Digital

Indicator Definitions and Supporting Information

Figure 5: Proportion of patients on a Palliative Care Register, by GP Practice, QOF 2021/22

Hospice Data

A dataset was obtained from St. Leonard's Hospice showing the services (home support as well as hospice based) which had been provided to York Residents who died in 2022.

A total of 272 York residents who died in 2022 received hospice services. 72% of those people received services on an outreach basis (e.g. Hospice at Home, Night Sitters). (These services did support more patients in 2022 than detailed here as they supported a number of patients outside the York area, these have been excluded for this analysis so they can be compared directly to York death data)

Table 4: Type of Hospice Support Received

Type of Support	No.	%
Hospice at Home	135	50%
Hospice inpatient unit	77	28%
Night Sitters Duty	48	18%
Palliative Care Support Sits	6	2%
Family Support	4	1%
IPU Outreach	1	0%
Marie Curie	1	0%
Total	**272**	**100%**

206 of the 272 people (75%) using hospice services had a Cancer diagnosis.

Table 5: Diagnosis

Diagnosis	No.
(Y1002) Cancer - Digestive Organs	58
(Y1009) Cancer - Other Specified Sites	48
(Y1010) Cancer - Respiratory & Intrathoracic	34
(Y1016) Other Non Cancer Diagnosis	30
(Y1013) Heart / Circulatory Disease	21
(Y1003) Cancer - Eye, Brain & Other CNS	12
(Y1001) Cancer - Breast	11
(Y1007) Cancer - Lymphoid / Haematopoietic	11
(Y1008) Cancer - Male Genital Organs	9
(Y1011) Cancer - Urinary Tract	9
(Y1005) Cancer - Ill Defined, Unspecified	7

(Y10b2) Chronic Respiratory Disease	7
Degenerative Nervous System Diseases (Y1012)	5
(Y1004) Cancer - Female Genital Organs	4
(Y1006) Cancer - Lip, Oral Cavity, & Pharynx	3
(Y1012) Degenerative Nervous System Diseases	3
Total	**272**

Are those accessing specialist palliative care representative of deaths across York?

The chart below shows the breakdown by deprivation decile of all York residents who died in 2022 and those received Hospice based services against all those who died in 2022.

Higher proportions of those who received hospice services resided in the less deprived areas of York compared with the average for York.

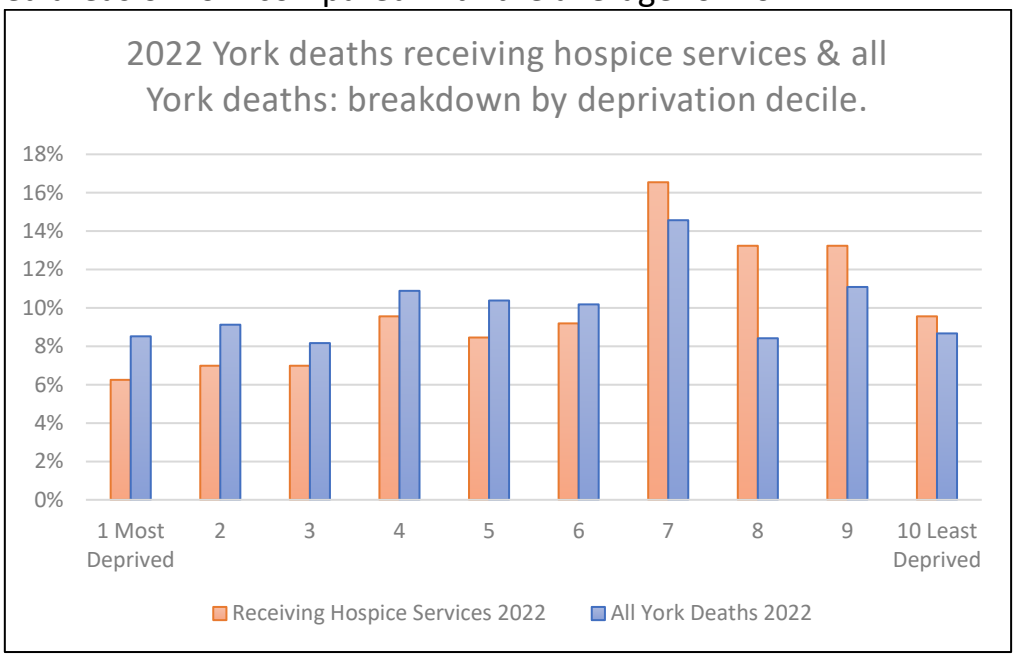

Figure 6: 2022 York deaths receiving hospice services & all York deaths: breakdown by deprivation decile.

Age Breakdown

The age profile of all those receiving hospice care is shown against all deaths in York in 2022 in the chart below. Amongst people using hospice services there were higher proportions in the 0-45, 45-64, 65 -74 and 75-84 age groups but a lower proportion in the 85+ age band compared with the profile for all York deaths.

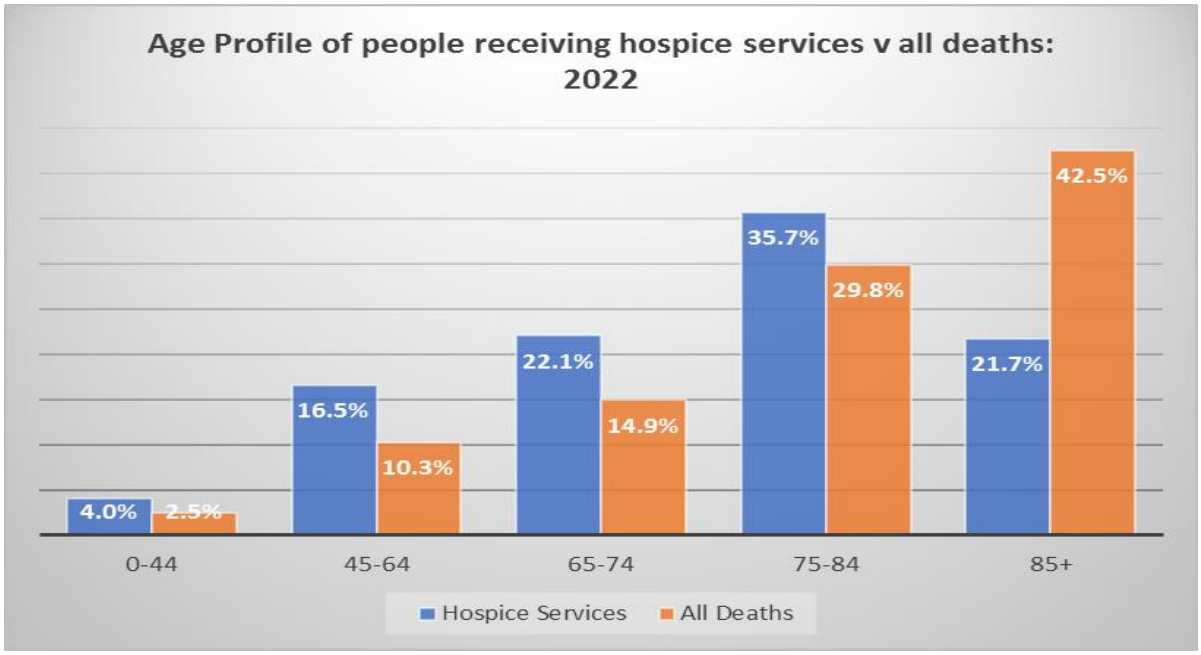

Figure 7: Age profile of people receiving hospice services v all deaths: 2022.

Analysis by Distance from the Hospice.

The proportion of people using hospice services who lived less than 2.4 miles from the hospice was lower and the proportion living more than 3.5 miles from the hospice was higher compared with the profile for all York deaths.

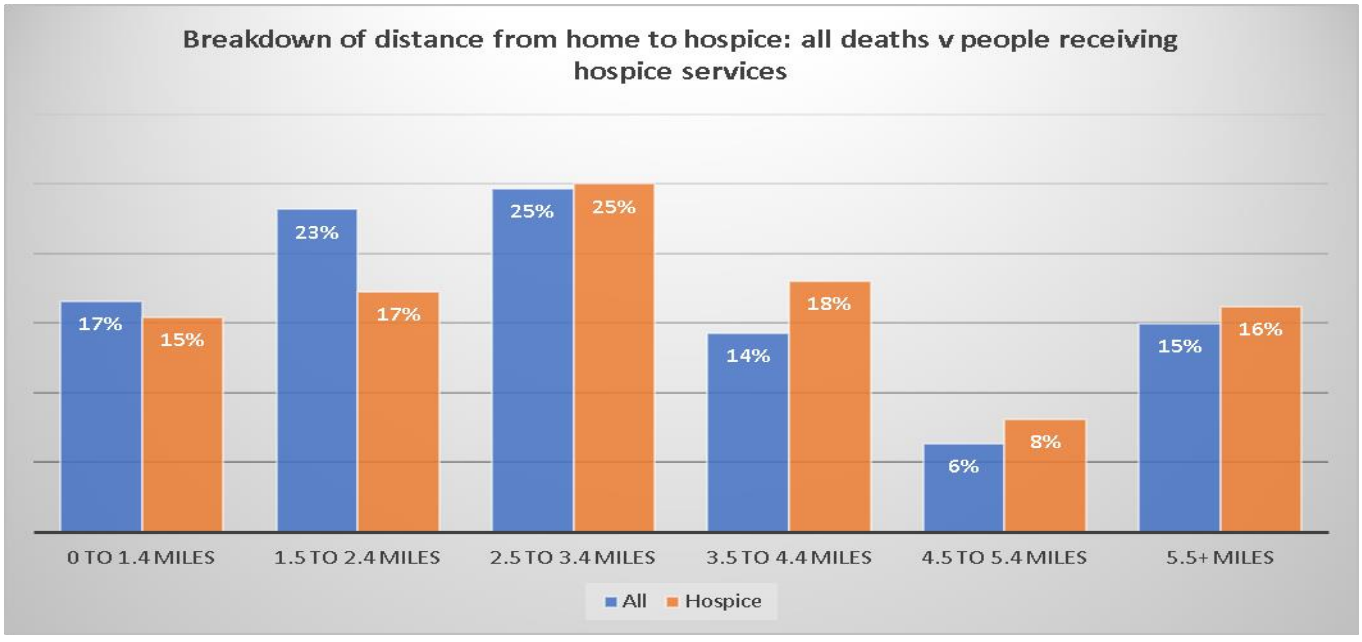

Figure 8: Breakdown of distance from home to hospice: all deaths v people receiving hospic services.

Hospital use in the 3 months prior to death

One goal of anticipatory care planning would be to avoid unplanned hospital use at the end of life, with community and hospice-based support being made available to avoid what is often a distressing and unhelpful admission into an acute setting. HES data analysed below shows that for the former Vale of York CCG area, for most recent years we have had an above-average percentage of our end-of-life patients with three or more admissions in the last three months of life:

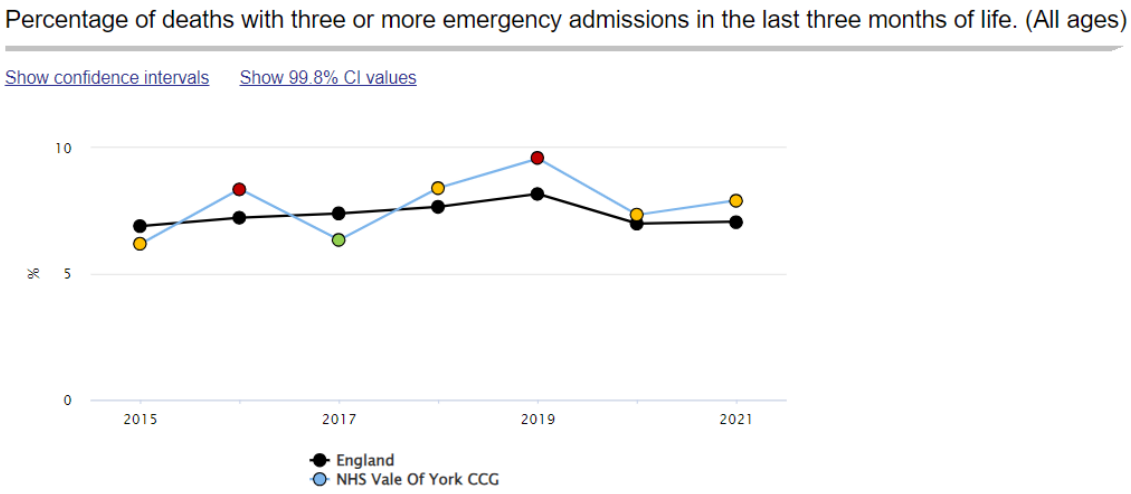

Figure 9: End-of-life patients with three or more admissions in the last three months of life

Conclusions of the Health Needs Assessment

- Similar to national trends, deaths are rising in York. Compared to national trends there are comparatively fewer people die in hospital in York and more people die in care homes.

- Nationally people living in the most deprived deciles are more likely to die in hospital but there was no statistically significant correlation between place of death and deprivation in York.

- When compared with all deaths across York there was a higher proportion of patients accessing specialist palliative care services from the least deprived deciles.

- The conditions being managed by specialist palliative care services in York is not representative of deaths across York. In particular cancer is over representative, accounting for 75% of patients accessing specialist palliative care services in the hospice and community but only 26.7% of deaths. While cancer patients may be more likely to develop symptoms which are difficult to manage and require specialist palliative care service this difference is so marked it could be suggested there are non cancer patients who would benefit from specialist palliative care services and not getting access to this.

- Those over 85 years of age are significantly less likely to access specialist palliative care services in the hospice or community in York. It is not clear from this data whether this is representative of barriers for this age group accessing services or is more representative of the conditions more likely to cause the deaths of this age group being underrepresented as described above. There is also a greater proportion of deaths in nursing homes when compared with national data and it is possible deaths in this more supported environment may genuinely need less specialist input. This data may however suggest that care homes in York may be a potential place to target specialist care services in the community.

- There is variation in the proportion of registered patients at York GP practices who are on a palliative care register, and practices with smaller

palliative care registers may be missing opportunities to assess patients for end of life needs

- A higher proportion of patients in York tend to have emergency admissions in the last three months of life
- Living closer to the hospice does not appear to make you more likely to access specialist palliative care services, if anything you are more likely to access these services if you live further away.

Recommendations

The data included in the report suggests a number of recommendations for further partnership working, quality improvement and integration of care in the city around the needs of those at the end of life:

1. More comprehensive linkage and sharing of data should be done in York to cross reference patients accessing specialist services and the extent to which they had recorded advanced care plans, DNACPR decisions, and preferred place of death
2. Work should be done to improve care and avoid emergency admissions in the months leading up to death, including proactive work with patients on a palliative care register to plan for and understand their wishes during a period of health deterioration, as well as sharing of advanced care plans with ambulance services
3. Closer inspection needs to be given to the reasons that the most deprived people in York's population are not accessing specialist palliative care services and consideration of whether this cohort can be targeted to improve uptake.
4. Improved awareness amongst referring health care professionals and care givers is needed that specialist palliative care services are available and may be beneficial for non-cancer patients and those over 85 years of age.
5. Consideration of the commissioning of a palliative care service that targets care homes may improve access to specialist services for those over 85 and those with non-cancer conditions.