



Dying Well: an Overview of End of Life Care in North Yorkshire

**Joint Strategic Needs Assessment
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Produced by:

Public Health Team
Health and Adult Services
North Yorkshire County Council
County Hall
Racecourse Lane
Northallerton
North Yorkshire
DL7 8AD

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1. Introduction

'Dying Well' is one of the five key themes for the Joint Health & Wellbeing Strategy 2015-20. This document aims to summarise national guidance for end of life care and provide recommendations to commissioners, in the context of local data, regarding priorities for commissioning end of life care services in line with the overall Strategy.

Currently just over 1% of the population die every year. Of the 455,000 people who died in England in 2010, two thirds were aged 75 older. However, the population of the UK is steadily ageing; deaths in England and Wales are expected to rise by 17% from 2012 to 2030. North Yorkshire in particular has a large proportion of elderly residents, with a significantly larger proportion of deaths occurring in the over-85s than the national average. Services targeting those approaching the end of their lives are therefore of particular relevance to the County. The UK as a whole provides comparatively good end of life care (2015 Quality of Life Index), but some areas, such as communication and access to out of hours services, are in need of improvement. A recent estimate suggested that of the approximately 355,000 people needing palliative care services every year around 92,000 people were still not being reached.¹

There has been a shift towards increased patient choice in end of life care, particularly regarding care planning and preferred place of death. Most people in the UK are still dying in hospitals, despite the fact that preferred place of death is usually (although not always) at home. Of the 6,197 deaths in North Yorkshire in 2013, 43% occurred in hospital, with the location of non-hospital deaths being influenced by the availability of other local facilities (such as hospices) in each district. As well as being unwanted by many patients, hospital admissions at the end of life can be costly and unnecessary. These could be prevented through better service planning, communication and integration, improved staff training and wider access to out of hours care. Evidence suggests that redesigning local end of life care pathways to enable more people to die at home rather than in hospital is at worst cost-neutral, and can potentially provide a much more effective and efficient use of resources.

¹ (NICE (2011) *Guide for commissioners on end of life care for adults*)

2. What is end of life care?

It is important to differentiate between Palliative Care and End of Life Care:

What is palliative care?

Palliative care is generally for people living with a terminal illness where a cure is no longer possible. However, it can also be used by people who have a complex illness and need their symptoms controlled, and can therefore run alongside treatments intended to prolong life such as chemotherapy or radiotherapy. Although these people usually have an advanced, progressive condition, this isn't always the case.

The goal of palliative care is to help the person and everyone affected by their illness to achieve the best quality of life. Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Palliative care includes caring for people who are nearing the end of life (end of life care).

General palliative care is part of many health and social care professionals' jobs, including GPs, community nurses, social workers, care workers and spiritual care professionals. Specialist palliative care services manage more complex care problems that cannot be dealt with by generalist services. Palliative care specialists usually work in teams to provide joined-up care, and can include specialist doctors and nurses, counsellors, and specialist allied health professionals, such as physiotherapists, occupational therapists and dieticians.

What is end of life care?

End of life care is an important part of palliative care for people who are nearing the end of life. End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict.

End of life care aims to help people live as well as possible and to die with dignity. It also refers to care during this time and can include additional support, such as help with legal matters. End of life care continues for as long as it is needed.

(<https://www.mariecurie.org.uk/help/terminal-illness/diagnosed/palliative-care-end-of-life-care>)

This document focuses on End of Life Care. The General Medical Council definition of 'end of life' determines that people are 'approaching 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) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events²

² http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_guidance.asp

End of life care involves any care that is provided when a patient has reached this terminal stage; the recognition of which is largely dependent on the individual's perspective and the judgement of their health (and social care) professionals. In some cases (notably children/young adults and people with dementia) this 'end of life stage' may last longer than 12 months, and they may therefore need access to end of life care for longer.

End of life care includes the palliative management of pain and other symptoms, and also the provision of psychological, social, spiritual and practical support. The range of health and social support needed highlights the importance of an integrated service model for end of life care.

3. What are the key issues?

The overall aim of focusing on end of life care is to enable more people approaching the end of life to be cared for and to die in their place of choosing, enabling the delivery of the best possible standard of care in all end of life settings. In order to achieve this, the North Yorkshire Joint Health and Wellbeing Strategy 2015-20 highlights the following improvements to be implemented by 2020:

1. A greater range of support options for people in their last years of life.
2. More people receiving support for themselves and their families at the end of life.
3. More people dying at home or in the place that they choose.
4. Greater numbers of trained staff and carers with deeper understanding about the range of issues in end of life care.
5. Adoption of new and emerging best practice and principles around end of life care (Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 – see above).
6. End of life care being planned in an effective and sensitively appropriate way, and for staff to be adequately trained.

Discussions around dying

It is recognised that open discussion around death and dying is vitally important for the implementation of effective, patient-centred end of life care. In some cases these discussions are still not occurring, or occurring in time, due to reluctance on the part of both patient and practitioner to address what has traditionally be seen as a 'taboo' topic.

In order to overcome this barrier and to raise the profile of end of life issues there needs to be a change in the wider culture surrounding death, with particular emphasis on how, and how often, we talk about dying. This needs to firstly incorporate increased, proactive conversation between patients and practitioners regarding end of life care (including how and where a person might want to be cared for and eventually die, as well as financial and other non-health issues). However, it also needs to incorporate conversations between providers of services involving end of life and palliative care, in order to provide more coordinated, effective care.

Access for all

Whilst good local care is available it is not always consistent, and it is therefore not always accessible to all. Particular barriers to accessing high-quality end of life and palliative care include geographical location, socioeconomic status, type of disease (particularly malignant vs. non-malignant diseases), and (co)morbidities such as dementia and learning disabilities.

There must also be increasing recognition of the different types of people affected by end of life care. The aging population demonstrates that people are living longer, but

also in many cases are dying for longer as well, often with multiple comorbidities. This naturally predisposes end of life care to focus on the elderly; however, the significant number of children and young adults with life-limiting illnesses must also be considered, who will often require a different approach to end of life care (specific NICE guidance due out December 2016). Similarly, it is not only those who are dying that are affected by end of life care; families and friends must also be included in end of life planning, both as carers for the dying and as the bereaved after a death.

Timeliness of accessing services is also crucial. There should be 24/7 access to specialist advice for all those who need it, both in the hospital and in the community.

The importance of coordination

The NICE Quality standard for End of life care for adults (2011) clearly states the importance of coordinating end of life care services in order to provide high-quality care to people approaching the end of their lives (and their families):

“Many people, by the time they reach the end of their life, will have multiple conditions and complex health and social care needs. A coordinated and integrated service is needed to respond to these needs and ensure the person, and their family and carers, receives high quality, responsive and individualised care. Delivering high quality end of life care presents particular challenges because the professionals providing care work in a range of generic and specialist services and a variety of sectors, including health and social care, voluntary organisations, welfare support and private providers. Consequently end of life care services should be commissioned from and coordinated across all relevant agencies and encompass the whole care pathway.”³

Traditionally, although end of life care has been integrated into cancer care pathways it has not been so well adopted into other care pathways (for example, cardiovascular disease or diabetes). However, there needs to be an increasing emphasis in line with the 2014 WHO Global Atlas on Palliative Care on integrating end of life and palliative care into all patient pathways to make sure the best quality care is provided.

Coordinating services is also important in allowing investment in services whilst avoiding duplication. Wherever possible, end of life care services should be integrated with other existing/planned services. This includes integration of IT services to allow efficient sharing of data between organisations.

³ <http://www.nice.org.uk/guidance/qs13/resources/support-for-commissioners-and-others-using-the-quality-standard-for-end-of-life-care-for-adults-252324685>

Training

There is a wide range of practitioners that provide end of life care as part of their overall role. Whilst some of these are specialist practitioners, many are generalists such as GPs or social workers for whom end of life care is only part of their workload. It is important to provide specialist training in end of life care for both of these groups. Training should include how to identify people suitable for end of life care (using relevant clinical guidelines such as the SPICT tool or NCPC guidelines), and also management and delivery of end of life care itself, including around advanced care planning. Training should be properly documented and skills kept up to date.

Holistic care

Most of the data in this report covers the 'health' aspect of end of life care. However, this must be seen as part of the bigger picture of needs at the end of life, which includes support to both patients and carers around social, spiritual, legal and financial issues, as well as the provision of both practical and emotional support. Integrating healthcare with non-healthcare services is vital to providing good, holistic end of life care. This could be as simple as referring to the local chaplaincy service, or providing information on who to talk to about making a will. Providing support around bereavement care is also important, particularly for carers and relatives.

Often consideration of these extra needs is what makes the biggest difference to dying people and their carers/families. Assistance with these everyday problems is therefore key to making sure that people are dying well.

4. What commissioning priorities are recommended?

Commissioners should be guided by the framework set out in *Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020*, in line with the Health and Wellbeing Board Strategy 2015-20 discussed above.

Recommendations have been structured around seven key areas:

Key area	Recommendations
1. Access at all times for all people	<ul style="list-style-type: none">a. Aim to reduce inequalities in access to end of life services. This includes geographical inequalities and the existing gap between cancer and non-cancer patients, as well as ethnic and socioeconomic inequalities. This should also include groups with special requirements, such as people with dementia and learning disabilities.b. The needs of children and young people around end of life care (both as patients and as family members/carers) must also be considered. Further guidance on local paediatric palliative care priorities is available from the Yorkshire and Humber Children's Palliative Care Network.c. There should be 24/7 access to advice and key therapies (such as pain management) across the entire County.
2. Integration with other existing/planned services	<ul style="list-style-type: none">a. Integration of end of life care into existing care pathways, particularly in relation to pathways for those with multiple co-morbidities, long-term conditions, the elderly frail and those with dementia.b. Improve IT pathways across the County to enable better sharing of end of life information, particularly with emergency services (Yorkshire Ambulance Service, 999/111). The 2015 Review of Choice in End of Life Care recommended implementing shared electronic end of life care records in all areas by April 2018.c. There should also be integration with non-healthcare services. Patients and carers should be treated holistically, with support around the legal, financial, emotional, social and spiritual aspects of end of life care integrated into their overall care experience.
3. Staff training	<ul style="list-style-type: none">a. Training should cover all staff involved in end of life care, including social care staff as well as health care staff, and informal carers.

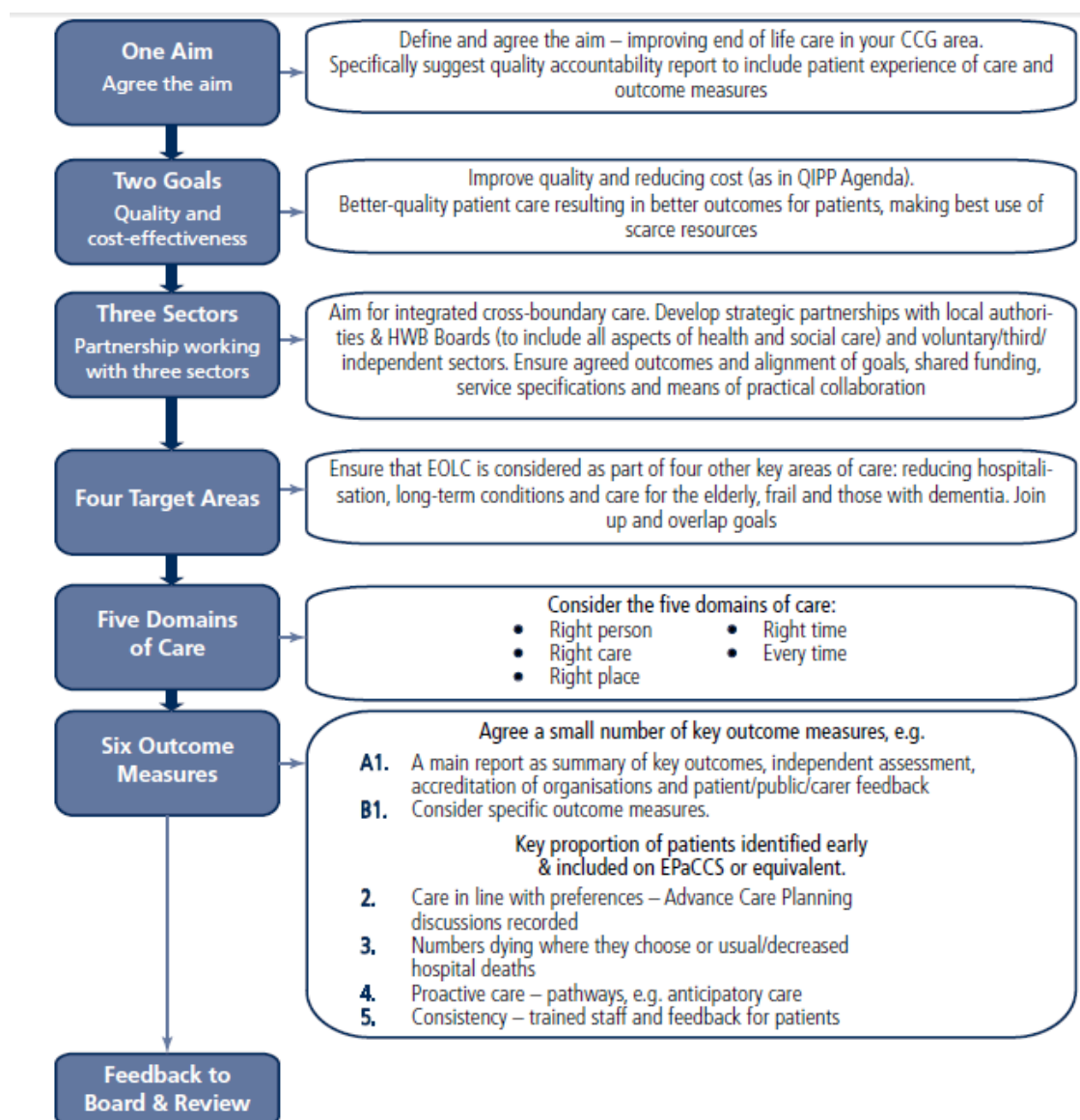
	<p>b. Training should include how to care for people and relatives and the end of life, including in the last few hours/days of life (particularly important since the withdrawal of the Liverpool Care Pathway). Training for the appropriate people should also include how to identify people suitable for end of life care (see SPICT tool, NCPC guidelines). The RCP audit also suggests training should cover advanced care planning.</p>
4. Preferred place of death	<p>a. All patients recognised as approaching the end of life should be given the opportunity to express their preferred place of death.</p> <p>b. All appropriate steps should be taken to make sure (wherever practicable) that is where they do die.</p>
5. Community engagement	<p>a. There should be appropriate involvement of voluntary sector organisations, including for issues relating to culture and faith.</p>
6. Appropriate level of care	<p>a. At the 'end of life' stage it is generally accepted that curative treatment is no longer able to provide a benefit to the patient and that the focus should shift to managing symptoms and distress. Treatments such as dialysis and chemotherapy will for the most part be best used in this palliative context. Focusing on symptom relief, particularly pain management, is key to maximising quality of life and quality of care.</p> <p>b. Aim for all patients to have an 'agreed ceiling of care' that has been discussed with the relevant medical practitioners and documented accordingly (i.e. on hospital discharge/clinic letters and patient care plans). This should incorporate formal decisions around resuscitation status (with emphasis on allowing a natural death rather than a refusal of further intervention).</p>
7. Support for carers and relatives	<p>a. End of life care needs to extend to the families and carers of those who are dying. Carers should have access to information regarding where they can get support for both the dying person and themselves as part of the drive towards person-centred care. [N.B. NYCC is currently working to produce a specific carers' resource]</p> <p>b. Bereavement support for carers and relatives following a death is also a key part of end of life care (and can</p>

	include pre-bereavement care prior to death as well, particularly regarding deaths in children and young people). There is also no specific bereavement care service for children in North Yorkshire.
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There are further national guidelines that offer advice around commissioning priorities. The Department of Health *End of Life Care Strategy: Quality markers and measures for end of life care (2009)* provides a series of quality markers with related measures of outcome intended for use by end of life care commissioners. Although written when PCTs were still the main commissioners of services, most of the markers and outcome measures continue to be relevant. This guidance can be found at:

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf

More recent commissioning guidance on End of Life Care (2012) has been produced by the Royal College of General Practitioners to help GPs, Clinical Commissioning Groups and other commissioners in supporting better care for all people nearing the end of their life. Their six key steps for commissioning End of Life Care are detailed below:



The complete RCGP guidelines can be found at <http://www.rcgp.org.uk/clinical-and-research/toolkits/~media/Files/CIRC/EOLC/RCGP-EOLC-Guidelines-Apr-2013.ashx>.

5. Who is at risk and why?

Around 1% of the population is expected to die each year; however, not all of these people are currently identified on an end of life register. Whether or not people are added to a register is largely down to the judgement of the individual clinician; this may produce variations depending on whether clinicians routinely consider conditions such as dementia and frailty indicators for end of life care, or whether their definition is more narrow (e.g. malignancies only).

The majority of deaths in North Yorkshire are caused by cardiovascular disease, cancer and respiratory disease. Malignancies cause just under a third of all deaths and yet account for a much greater proportion of people accessing end of life care; people with non-malignant diseases are therefore at greater risk of not being able to access the end of life services they require.

Although most deaths occur in the elderly population, a small but significant number of deaths occur in children and young adults. These tend to be children with life-limiting illnesses who can require palliative care for many years; identifying the point at which they require end of life care can therefore be particularly difficult.

There is also a socioeconomic influence on access to end of life care. People from the most deprived socioeconomic backgrounds are less likely to access end of life care and are more likely to die in hospital (rather than at home or in a hospice) compared to people from the least deprived socioeconomic backgrounds.

The Care Quality Commission report 'A different ending: addressing inequalities in end of life care' (May 2016) looked in detail at ten groups of people at risk of receiving poorer quality end of life care. These were:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual and transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and travellers

The report found that commissioners and services taking an equality-led approach responding to individual needs, provided a better level of care. Recommendations to achieve this included improving staff training, increasing collaboration between commissioners and providers and a focus on individual patient-centred care.

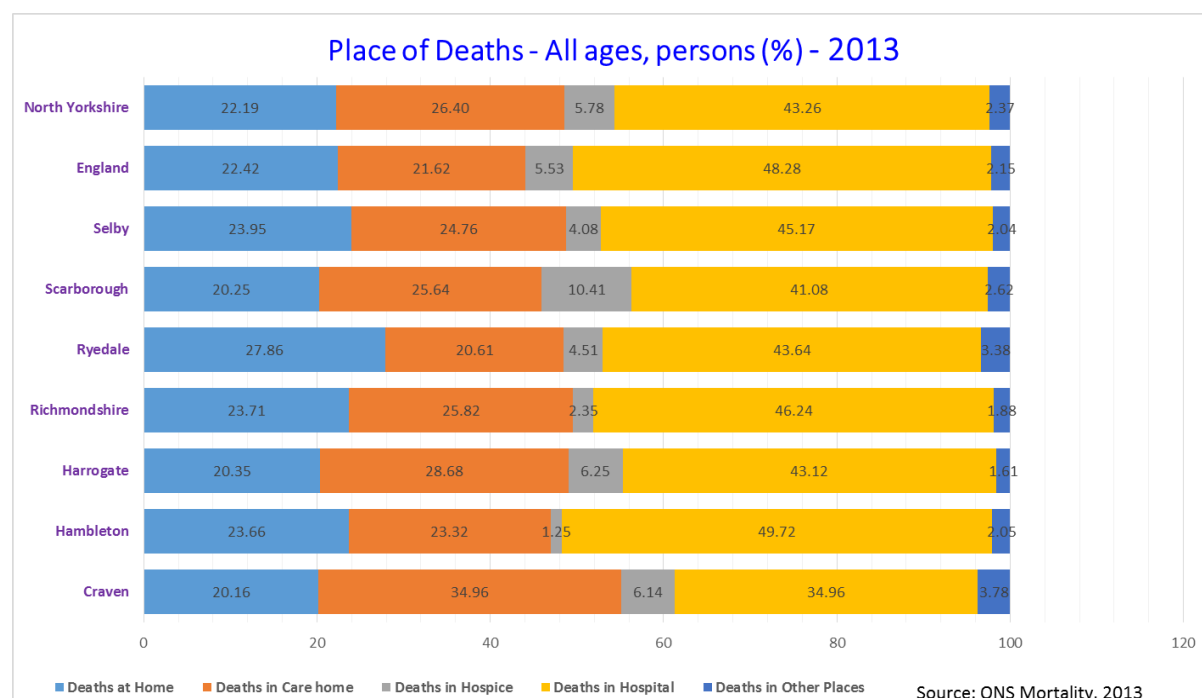
6. What is the level of need in the population?

PHE's National End of Life Care Intelligence Network provides 'End of Life Care Profiles', which present data for commissioners (broken down to CCG level) regarding 170 end of life indicators.

In September 2015 PHE announced plans for a new palliative care data collection system, due to be rolled out from April 2017. Further details can be found at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/463299/Palliative_Care_Clinical_Data_Set_update_statement_25_September_Factsheet....pdf.

In 2013 there were 6,197 deaths in North Yorkshire across all age groups (1.03% of the total population).⁴ Of these, 22.2% (1,375) deaths occurred at home, 26.4% (1,636) deaths occurred in a care home, 5.8% (358) deaths occurred in a hospice, 43.3% (2,681) deaths occurred in hospital and 2.4% (147) deaths occurred in other places.

Overall, 49% of deaths occurred in the persons' usual place of residence (although this figure was lowest in the 0-64 age category at 36.5%).

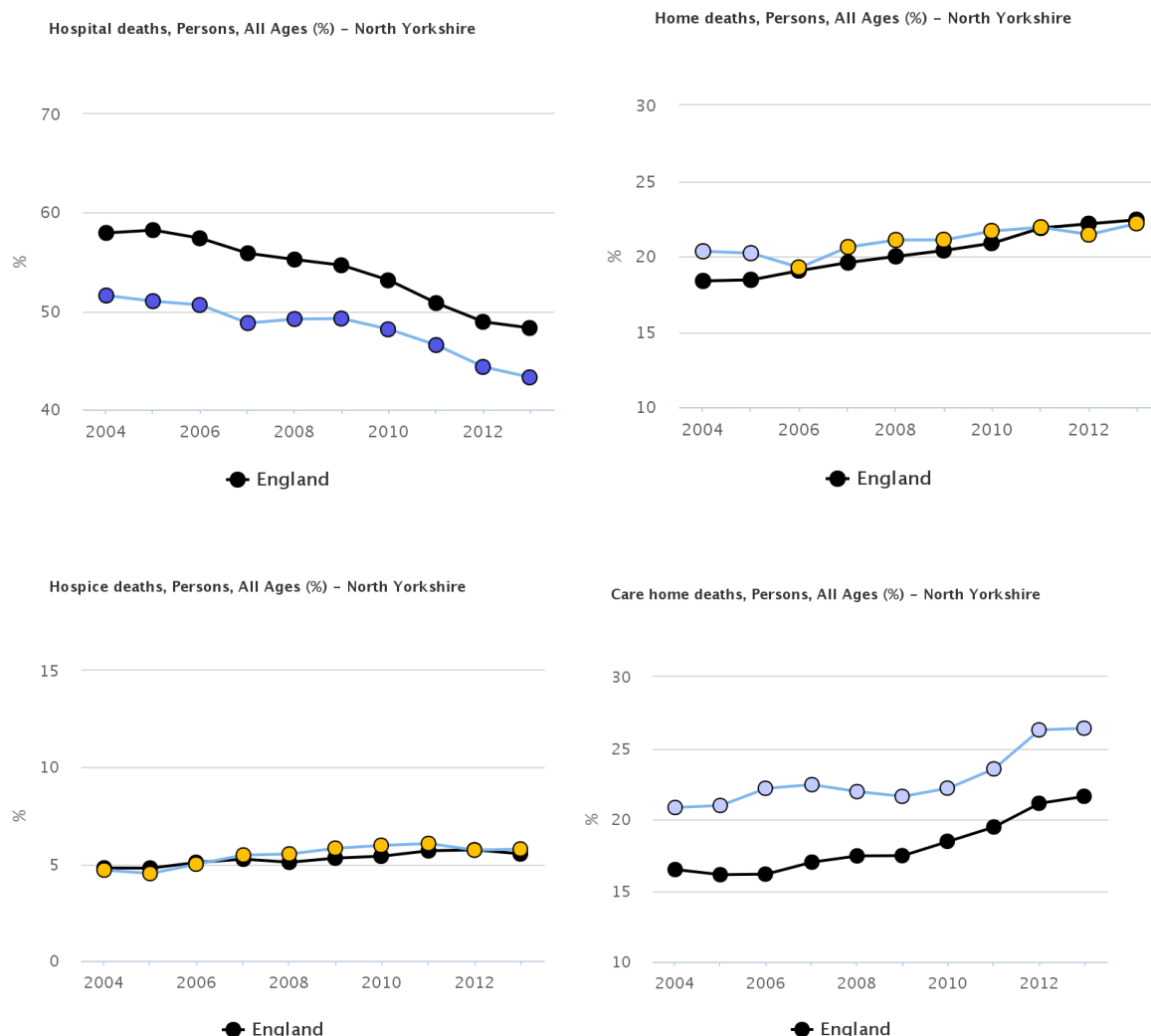


Ryedale had a significantly higher percentage of deaths occurring at home than the national average. Scarborough district has a significantly higher percentage of deaths in a hospice than the national average, whereas Hambleton and Richmondshire have a much lower rate. This may reflect inpatient hospice provision

⁴ All data taken from PHE's End of Life Care Profiles – 2013 is the most recent data available.

across these areas; St Catherine's Hospice in Scarborough covers the Scarborough district, whereas there is no inpatient hospice in Richmondshire or Hambleton (with the nearest inpatient service located in the North East at Stockton/Bishop Aukland).

As demonstrated below, the trend in locations of death for North Yorkshire have largely followed the national trends. North Yorkshire consistently has a significantly smaller proportion dying in hospital and a significantly larger proportion dying in care homes than the national average.

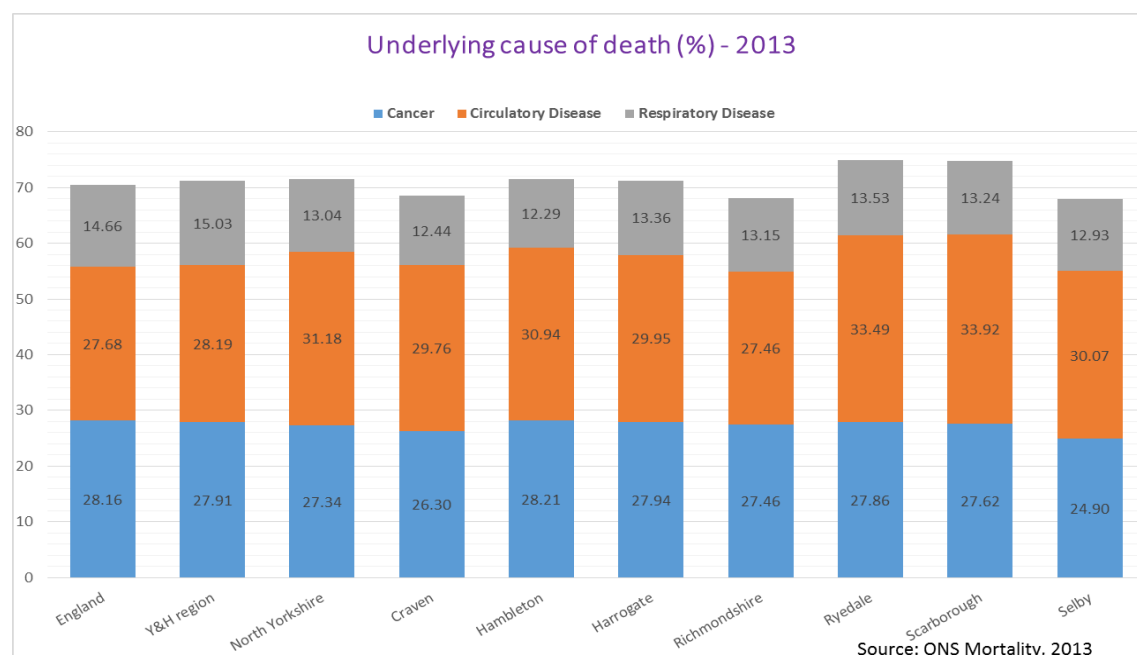


(Data from PHE End of Life Care Profiles, 2004-2013)

Cause of death

The most common underlying cause of death in North Yorkshire was circulatory disease, with cancer a close second (a reverse of the national picture). The top three causes of death (cancer, circulatory disease, respiratory disease) are all chronic conditions that can be effectively targeted through end of life care. The fact that cancer makes up only 27.91% of deaths in North Yorkshire underlines the

importance of ensuring that people dying from non-malignant diseases are appropriately targeted to receive good end of life care.



Place of death by cause

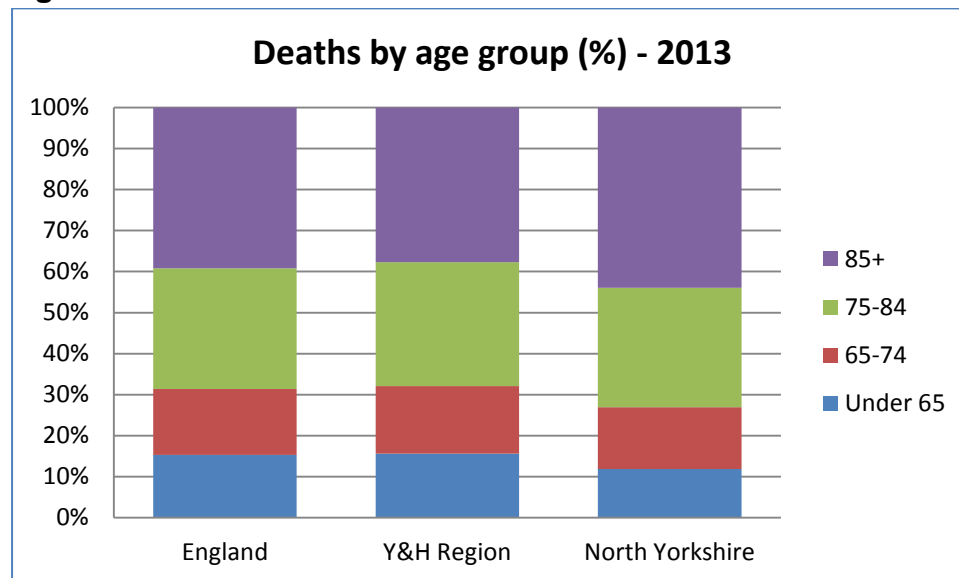
The End of Life Care Profiles also look at place of death by cause on a CCG level. Mostly there is little variation from the overall place of death for each CCG.⁵ However, it is worth noting that:

1. Vale of York has significantly higher numbers of hospice deaths for cancer than for all other diseases (which follows the known trend for patients accessing hospices).
2. Scarborough & Ryedale have significantly lower deaths in hospital and significantly higher deaths in care homes and hospices for all diseases, not just cancer (which may reflect recent work by the hospice to improve equality of access between patients with different diseases).
3. Hambleton, Richmondshire and Whitby have significantly lower numbers of deaths in hospices (and significantly higher numbers in hospital and at home) for cancer (which reflects the lack of inpatient hospice facilities in the CCG area).

PHE has also recently released data on place of death in dementia patients. North Yorkshire has a high prevalence of dementia, of whom 75.9% die in their usual place of residence, with a lower than average number (23.7%) dying in hospital.

⁵ Full details regarding place of death by cause for each CCG can be found at: http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_and_Cause_of_Death/atlas.html

Age at death



(Data from PHE End of Life Care Profiles 2013)

As expected for an area with an ageing population, North Yorkshire has a larger proportion of deaths in the over 85s, with a smaller proportion in the under 65s (65-74 and 75-84 deaths both similar to national and regional averages). Further breakdown of data is needed in the 0-65 age category to better determine the levels of neonatal, infant and child mortality.

Place of death by age data from the End of Life Care Profiles has been included as Appendix E. There are no particular anomalies in these data, although people aged 0-64 do have more deaths in hospital and 'Other' locations than older age groups.

7. What is the projected level of need?

Population projections from the Office of National Statistics suggest that the population of North Yorkshire will increase by 12,000 from around 604,000 in 2013 to around 616,000 by 2020.⁶ However, the number of people in the North Yorkshire population aged over 65 is due to increase by 17,000, from around 138,000 to around 155,000.

If the death rate in North Yorkshire remains the same as for 2013 (1.03%) the number of expected deaths (and therefore the potential number of people who may need end of life care) in 2020 is likely to be around 6,220. However, given the increased proportion of the population over the age of 65 it is likely that the death rate (and correspondingly the number of people requiring end of life care) will be higher.

⁶<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/localauthoritiesinenglandtable2>

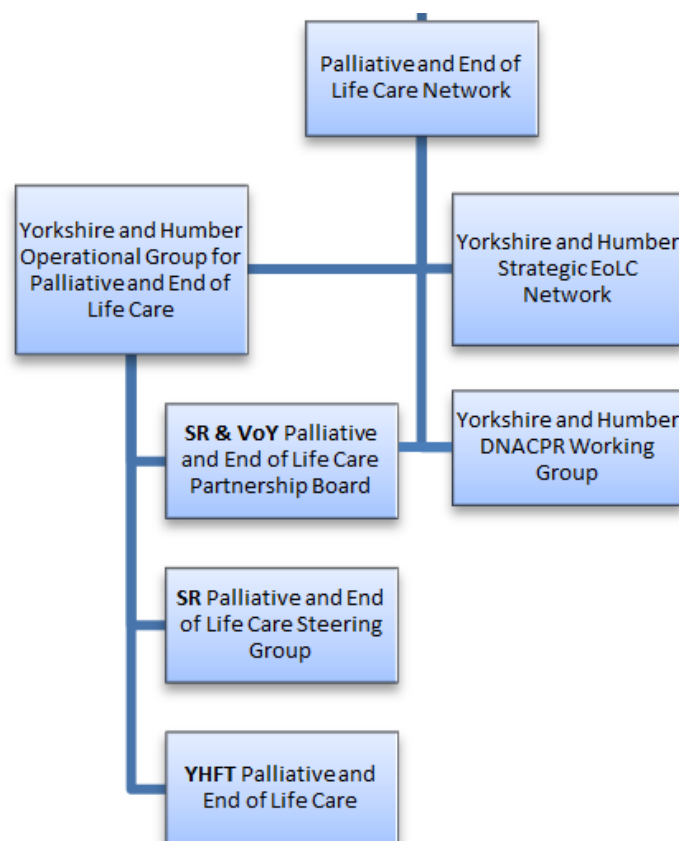
8. What services are currently provided?

Commissioners may wish to utilise existing networks, which already contain links to the main end of life care providers, to help achieve more integrated services across the County. Some networks are more active than others, but most contain a range of specialists from different organisations including CCGs, hospital trusts and local hospices.

Local partnerships

There are Cancer Locality Boards and End of Life Care Locality Groups in each CCG area. Membership includes representatives from general practice, commissioning groups, cancer network, acute hospital trusts, patient groups, public health, hospices (N.B. not all groups currently contain all of these members).

Below is an example of how local boards fit into the regional and national End of Life Structure, based on Scarborough & Ryedale area:



The Yorkshire Cancer Network also has a Sub Regional Palliative & End of Life Care Group covering North and West Yorkshire. Further details (including membership and current action logs) can be found at:

<http://www.ycn.nhs.uk/html/groups/endoflife/index.htm>

Children and Young People

There is a separate strategic network for younger people: the Yorkshire and Humber Children and Young People's Palliative Care Network. The network meets quarterly and is open to any interested local practitioners. It has an executive group and four working subgroups: research, education and workforce, clinical and transition. It is linked to a range of regional and sub-regional networks through its members, and also has formal links with the Yorkshire and Humber End of Life Care Group. The network also runs a region-wide education programme for nursing and medical staff in paediatric palliative care.

The Network recently commissioned a review of paediatric palliative service provision across Yorkshire and the Humber, an overview presentation of which can be found at: <http://www.swscn.org.uk/wp/wp-content/uploads/2014/03/Anton-Mayer-Provision-of-Specialist-Paediatric-Care.pdf>. The report recommends the joint commissioning by current service providers and CCGs of a 'hub and spoke' model of care, as outlined in their report above. The Network has just secured funding for a Network Coordinator to help drive the delivery of these recommendations.

There is also a separate Yorkshire and Humber CYP Cancer Network Group, with members including representatives of the Yorkshire Cancer Network, Martin House Children's Hospice, each of the region's Foundation Trusts and a service user representative.

Hospices

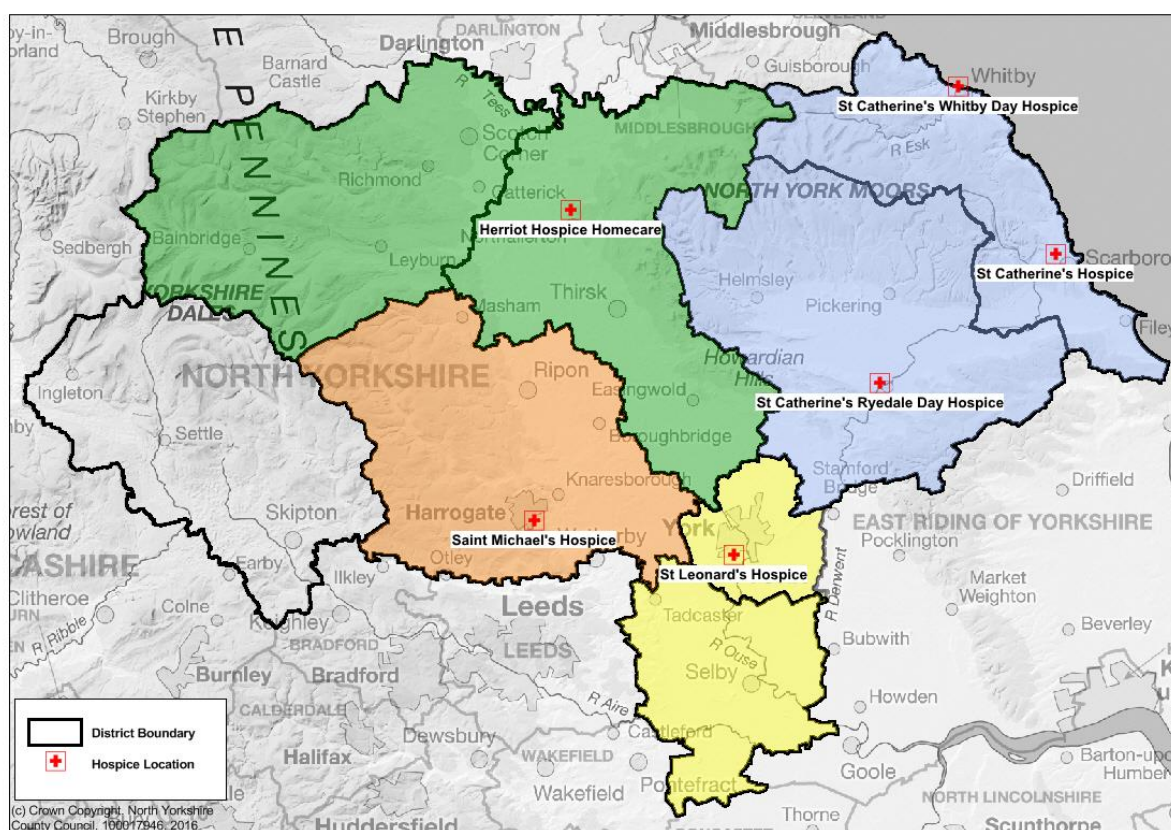
The main source of voluntary sector end of life care is provided by hospices, which have become increasingly important in line with the renewed focus on community care and patient choice. Whilst largely beneficial, the hospice movement (particularly its situation outside the NHS) has provided some challenges, including the allocation of funding and agreed leadership/ownership of end of life services. Hospices themselves are also going through a transformation in terms of the services they provide, and are seeking ways in which to diversify to ensure they offer the best range of services for their patients.

North Yorkshire has three main inpatient hospices for adults: St Michael's (Harrogate & District), St Leonard's (York, Vale of York) and St Catherine's (Scarborough, Ryedale and Whitby). Inpatient hospice services for Craven, Hambleton and Richmondshire are all located outside of the County.

Paediatric hospice facilities are also provided out of area at Martin House Children's Hospice (Boston Spa). The most recent data (April 2015) shows that 40 of their 326 patients were from North Yorkshire.⁷

⁷ <http://www.martinhouse.org.uk/documents/annual-review-2015/index.html#8-9>

Map of hospice coverage by hospices located within North Yorkshire



For more details on hospice provision see Appendix C.

Voluntary sector

Voluntary sector organisations are a useful resource that can help inform and provide end of life services, and should be included when discussing integrated care as well as for raising awareness.

Within the voluntary, community and social enterprise sector there are several organisations across the County involved with helping and supporting people with end of life care issues. This includes hospices and hospice at home, plus various support groups for hospice services in and out of the County. Further information on voluntary sector provision in North Yorkshire can be found through the North Yorkshire Forum for Voluntary Organisations directory of voluntary and community organisations, available at www.vcsdirectory.org.uk. Currently there are 216 organisations listed when searching for 'end of life care'.

There are a substantial number of community and charitable organisations involved in end of life care. The National Council for Palliative Care (NCPCC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. As well as providing guidance and information, the NCPCC runs training and conferences for professionals, and also encourages public

discussion of death through the 'Dying Matters' campaign (which includes an annual Awareness Week – this year from 9th-15th May 2016).

Many organisations that are not specifically targeted at end of life care, such as Age UK and Mencap, also include end of life care as part of a more holistic approach to the individual. Similarly, local community interventions such as hospices are also essential for the provision of good community-based end of life care.

There has also been a recent surge in interest in end of life and palliative care among the general population. Some of this has been coordinated via charities and other formal organisations; for example, hospices are able to recruit large numbers of volunteers to help both with funding and service provision, which significantly reduces their running costs. However, there has also been increasing interest from the public at a grassroots level, largely spurred on by local communities or wider online communities (via social media). There are end of life forums in various online communities (such as Facebook), offering online social support and information. Twitter hosts a variety of 'end of life' hashtags (e.g. #eol, #endoflifecare, #criticalconvo, #deathliteracy), several of which are linked to regular tweet chats on end of life issues (e.g. #EOLchat (weekly tweet chat), #DWDchat (dying with dignity – every third week)). In 2015 there was even a festival dedicated to talking about end of life issues (Pushing Up Daisies Festival, Todmorden).

Specialist palliative care services

The following local hospital trusts provide specialist palliative care services:

- Airedale NHS Foundation Trust
- Harrogate & District NHS Foundation Trust
- York Teaching Hospitals NHS Foundation Trust
- South Tees Hospital NHS Foundation Trust

All provide inpatient and some community services. Most services are limited to daytime hours Monday-Friday.

For further details of individual services, please see Appendix B.

Nursing services

A list of care homes in North Yorkshire that provide end of life/palliative care can be found in Appendix D.

There is no specific domiciliary care service commissioned for end of life patients in North Yorkshire. However, there is a 'fast track discharge' pathway enabling hospital patients identified as being within the last few days of life currently to be transferred to appropriate community care, which may include domiciliary services.

Examples of End of Life Care initiatives in North Yorkshire

Palliative Care and End of Life Toolkit

An online Palliative Care and End of Life Toolkit has been produced by Dr Mike Brookes (GP at Reeth Medical Centre and RCGP/Marie Curie Palliative and End of Life Clinical Support Fellow), which can be accessed at www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx. This collates much of the online information and resources around palliative and end of life care into a central location, designed to be used not only by clinicians and commissioners but also by patients, families and carers.

Scarborough & Ryedale integrated end of life services

Scarborough and Ryedale CCG have commissioned two new end of life care services. The first is an integrated Hospice at Home service that combines several existing services, namely St. Catherine's Hospice at Home Service, the Marie Curie Multi Visit Evening Service and the Marie Curie Planned Visit Service. The Hospice at Home service aims to facilitate discharges from hospice or hospital, respond to crises and enable patients to die at home where this is their preferred location. In addition, the CCG has also commissioned a Care Home Link Nurse Service to provide end of life care to patients in care homes.

Death Cafés

Several locations in North Yorkshire (Settle, Thirsk) have joined the global 'Death Café movement, putting on regular, open-invite events for people to discuss end of life issues. Death Cafés began in 2011, and have quickly become a social franchise centred on people (often strangers) gathering in community locations to 'eat cake, drink tea and discuss death'.⁸ Death Cafes involve group-directed discussion of death with no agenda, objectives or themes. They act as discussions group rather than grief support or counselling sessions. Thirsk Death Café meets twice a month, whereas Settle Death Café meets more informally. St Leonard's Hospice (York) also holds occasional Death Cafés, which have included bringing in solicitors to offer advice on legal concerns around dying (writing wills etc.) as well as having hospice staff on hand to provide expert opinions and support.

The Gold Line

The Gold Line is part of Airedale NHS Foundation Trust's 'Bringing Healthcare Home' project, which seeks to simplify end of life care and enable more people to die at home. Besides the Gold Line, the project also involves trying to develop an electronic healthcare system to co-ordinate end of life care, and training staff to start conversations with people around death and dying.

⁸ <http://deathcafe.com/what/>

The Gold Line itself is a 24/7 phone service staffed by senior nurses at Airedale Hospital, available to people in Airedale, Wharfedale, Craven and Bradford who are on the Gold Standards Framework. The nurses provide direct advice and support, and can also arrange admissions and home visits as required through their links to other services. As well as a telephone line, some patients are also provided with iPads to enable face-to-face communication via a video link. The service is available to care homes as well as individuals. The Gold Line nurses can access patients' records, and so can provide coordinated practical support as well as emotional support.

The Gold Line currently works with nearly 1200 people at the end of life, and answer more than 500 phone calls a month. The service has made a positive impact on the number of people at the end of life attending A&E, being admitted to hospital and requiring extra home visits from GPs/community nurses. In 2014/15, only 13% of people registered with the Gold Line died in hospital (compared to the national figure of 58%). A financial evaluation of the service is currently underway.

For more information on the Gold Line (including a short film following a patient's story and a carer's experience of using the service) please see: <http://www.health.org.uk/content/overview-gold-line> or <http://www.airedale-trust.nhs.uk/services/the-gold-line/>.

The Sunflower Centre, York

The Sunflower Centre is the new day centre for St Leonard's Hospice. It provides a range of wellbeing services to dying people and their families from York and Vale of York. It aims to provide holistic care, with support provided for emotional and spiritual issues as well as physical symptoms. Some of the services are available via referral only, but they have weekly drop-ins and fortnightly drop in bereavement sessions available to anyone affected by terminal illness (both patients and carers).

As well as art therapy and diversional therapies (such as painting, creative writing or mindfulness) patients and carers also have access to free complementary therapies such as aromatherapy, Reiki and reflexology. Sessions are also available on managing symptoms such as anxiety, breathlessness and living with the risk of falls. The overall aim of the Sunflower Centre is 'to enable patients to achieve the things that are important to them and to keep control of their lives and illness as much as possible'.

For more information, please see: <http://www.stleonardshospice.org.uk/Patients/Hospice-Care/Sunflower-Centre>.

9. What needs might be unmet?

Local areas of unmet need largely reflect national areas of unmet need. These areas are particularly targeted in the recommendations for commissioning. Some of the key areas include:

Access to preferred place of dying

Not all patients are being asked about their preferred place of death, or having this documented; most deaths still occur in hospitals despite preferred place of death most commonly being at home. An increased use of advanced care planning would take this into account, and also potentially prevent unnecessary hospital admissions.

Integration of end of life care into all care pathways

Whilst end of life care is commonly integrated into cancer pathways, this is not always the case for other illness pathways such as dementia, diabetes, cardiovascular disease (e.g. heart failure pathways) etc.

Co-ordinated IT system

An EPaCCS system as recommended in national guidance would enable better sharing of information between services. This would promote efficiency by decreasing duplication, and ensure that patient care plans are better adhered to.

Access to inpatient hospice facilities

Not all parts of the County have access to inpatient hospice facilities within the County itself (Craven, Hambleton, and Richmondshire). Similarly there is no children's hospice within North Yorkshire. The nearest hospice is therefore a considerable distance for some residents (although Hambleton and Richmondshire do have access to Hospice at Home).

Training

The RCP end of life care audit suggests that not all people involved in palliative care are receiving sufficient training. More training regarding identification of palliative patients and advanced care planning are two areas that have been particularly highlighted as requiring further attention.

Out of hours access

Not all hospital inpatients have 24/7 access to a specialist palliative care team. Similarly not all people in the community have 24/7 access to advice and key therapies such as analgesia.

Holistic care

Integration of legal, financial, spiritual, emotional and social care alongside health care when planning end of life care services.

10. What evidence is there for effective intervention?

In 2014 the World Health Assembly passed the first ever world resolution on palliative care, which focused on strengthening palliative care as a component of integrated treatment throughout the life course.⁹ A UK national strategy for End of Life Care was initially produced in 2008,¹⁰ which highlighted the importance of integrated and coordinated services and promoted a whole system approach to commissioning end of life care. It has since been updated with a more community focus in line with the changes in NHS services that have occurred since 2008, to form *Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020*. This new framework has been set up by the National Palliative and End of Life Care Partnership (made up of statutory bodies including NHS England, Public Health England (PHE), charities and patient and professional groups), and is intended as a framework for local leaders to plan and implement better local services for palliative and end of life care. The framework sets out six key ambitions:



The framework identifies eight key foundations that need to be in place in order to realise these ambitions:

⁹ http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_31-en.pdf

¹⁰ <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

1. Personalised care planning

- Everyone approaching the end of life should be offered the chance to create a personalised care plan.

2. Shared records

- Electronic systems should record end of life preferences, and should be shared across health and social care providers. Care plans should also be available to the dying person themselves.

3. Evidence and information

- Service providers should participate in national initiatives to collect comprehensive, robust and anonymous data.

4. Involving, supporting and caring for those important to the dying person

- This must include good bereavement and pre-bereavement care, plus a recognition of their role as part of the person's caring team.

5. Education and training

- Every professional should be competent and up to date, with frameworks in place to make sure the correct training is provided in order to deliver this.

6. 24/7 access

- Every person at the end of life should have 24/7 access to services.

7. Co-design

- End of life care systems should be co-designed with people who have personal and professional experience of end of life care.

8. Leadership

- CCGs and local authorities (especially the Health and Wellbeing Board) championing a collaborative, population-based, proactive approach to commissioning.

Other national guidelines of note include *NICE (2011) Guide for commissioners for end of life care for adults*,¹¹ which again focuses on commissioning person-centred end of life care. However, as this was written before the 2013 NHS restructuring although the general principles remain relevant, many of the specifics relating to PCTs etc. are now outdated. A more detailed chronological report of the changes in national legislation around end of life and palliative care can be found in the BMA literature review of end of life care and physician-assisted dying at <http://www.bma.org.uk/endoflifecare>.

A more extensive list of relevant national and international literature can be found in Appendix A.

¹¹ <https://www.nice.org.uk/guidance/cmg42>

11. What additional needs assessment is required?

There are several areas for which data is not currently available in a single accessible location, but is held by multiple different partners. This is often where data exists only at a service or GP practice level, or even at individual patient case level (for example in advanced care plans). In order for commissioners to better provide and monitor services it would be beneficial to have a collated source for some of these sets of data. An electronic records system (EPaCCS – see below) would go some way to addressing many of these; national guidance advises local areas to implement an EPaCCS system as soon as possible.

Information on staff training

Staff training has consistently been identified as an area requiring further exploration. Specialist palliative care services will have records of their own staff training; however, it is less clear what training has been offered to those in positions that fall under more general palliative and end of life care (social workers, care home staff primary care staff etc.)

Potential sources of data:

- Hospice data – staff run training sessions (e.g. Scarborough and Ryedale CCG commission St Catherine's Hospice to run training in care homes).
- Specialist palliative care services (regarding specialist training).
- Staff training data from individual organisations regarding their own workforce
 - Including care homes, Yorkshire Ambulance Service, voluntary organisations, social care, primary care, domiciliary care.

How many people who need end of life care are identified on a suitable register?

Currently end of life status is recorded in primary care via the practice palliative and supportive care register (QOF requirement). However, the accuracy of this relies on coding by individual practices; some will focus mainly on patients with end stage malignancies, whereas others will cover a wider range of conditions including dementia and frailty. Given that roughly 1% of the population dies each year, it is expected that about the same number would be on the register at any given time – if there are significantly fewer people on the register it is likely not all people suitable for end of life care are being identified by this method. Some practices may choose to use the Gold Standards Framework to support the palliative register (for more information see <http://www.goldstandardsframework.org.uk/>).

The 2008 National End of Life Care strategy recommended electronic palliative care coordination systems (EPaCCS) as the ideal way to document information about individuals approaching the end of life, in a manner that could be shared between relevant health and social care professionals (and potentially the patients themselves). This is primarily aimed at being a care planning tool, although would

also act as a register for those needing palliative care. Currently only 35% of hospital trusts use EPaCCS (RCP audit data), although there are multiple national recommendations for it to be rolled out to all areas.

Potential sources of data:

- Palliative and supportive care register (GP practices)
 - Collected by all practices, but caveats regarding accuracy as above.
- EPaCCS (electronic palliative care) system
 - Unfortunately, no EPaCCS system currently exists for North Yorkshire.
 - Harrogate has been selected as part of the vanguard for implementing New Care Models; part of the Palliative Care work involved includes the introduction of an EPaCCS system (alongside improved palliative care training for generalists and improved links to specialist palliative care).
- Other end of life care tools, such as the Gold Standards Framework, AMBER bundle, DNACPR or the rapid discharge pathway.

Information on patient experience

In order to design the most appropriate services it is vital to understand the needs of service users; in this case both the dying person and their carers/family. The emotional experience of care is often the most significant part from a service user perspective,¹² an area that is not well conveyed by quantitative data. Individual services should already gather information around patient satisfaction as part of an audit/quality improvement process, and the VOICES survey provides national level data; however, there is no data for North Yorkshire at a local authority level.

Potential sources of information:

- Patient feedback forms for individual services (hospital, hospice etc.)
- VOICES survey (National survey of bereaved people)¹³

Information on preferred place of death

Most people's preferred place of death is at home; however, it would be incorrect to assume this is true for everyone. Whilst overall we should be trying to shift location of death from hospitals to the community, there should be focus on trying to identify preferred place of death for all people approaching end of life, and aim to comply with these wishes wherever possible.

Preference regarding place of death should be recorded in all care plans, including those for individual disease pathways and care homes. It is also a proposed

¹² <http://spcare.bmj.com/content/4/3/291.full>

¹³ Latest release available at:

<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/2015-07-09>

component of the electronic palliative care system (EPaCCS), although this has not yet been implemented across North Yorkshire.

Desirable information on preferred place of death would include:

- How many people identified as requiring end of life care have expressed a preferred place of death?
- What proportion of those who express their preference actually die there?

Potential sources of data:

- Patient care plans
 - Nursing Home care plans
 - Cancer care plans
 - Advanced Care Plans
 - Enhanced Service care plans (Harrogate – for top 4% population at highest risk of unplanned hospital admission)
- GP practice data
- Marie Curie and Macmillan care pathways for long-term conditions

Assessment of non-health needs

Most of the data provided has been around the health needs of people at the end of life. However, it is recognised that end of life care is much more holistic, and needs to include provision of social care, spiritual care, legal assistance, general wellbeing advice and emotional support both for the dying and for their families. It is unclear how many people at the end of life know where and how to access services that support these extra needs, and how many people (and from what backgrounds) are actually using them.

Potential sources of information:

- VOICES survey
- Hospital chaplaincy services
- Patient care plans

Access to services among different socioeconomic groups

As already discussed above, some societal groups are less likely to access services than others. Existing data gives access to facilities and place of death by geographical, age and disease status; however, it does not show if there are differences in usage between people from different socioeconomic backgrounds, ethnic minorities etc. There is also limited data to show what the cause of any discrepancies might be, whether it is through lack of knowledge of a service/understanding of what it does, differences in willingness to persevere

towards obtaining services, or simply not wanting the services available (including for cultural reasons).

Potential sources of information:

- Patient level data from services (hospitals, hospices etc.)
 - Data on socioeconomic status, ethnicity etc.
- Discussions with individual patients

Detailed funding arrangements

The funding structure for end of life care is complex, in part because end of life care is provided by different health and social care providers as part of their general workload as well as specialist palliative care teams. Some funding streams are therefore by necessity non-specific and so difficult to quantify. The rise of the hospice movement has meant that much end of life care funding is now raised and spent by the voluntary sector. However, although this is supplemented by public funding it is not always clear how funding and expenditure are divided between the two sectors. As an example, the 2016 Royal College of Physicians End of Life Care audit found that although 97% of trusts had their own palliative care service, 70% were also using a specialist palliative care service funded and based outside the trust.

Potential sources of information:

- NHS Hospital Trusts (for specialist palliative care services)
- Clinical Commissioning Groups
- End of life care QOF (primary care)
- Hospices (e.g. Martin House annual review)¹⁴
- Other voluntary sector organisations (e.g. Macmillan)

Cost-effectiveness

Providing good community care for people at the end of life is likely to be cost effective, particularly with regards to avoiding hospital admissions. The Nuffield Trust research report 'Exploring the cost of care at the end of life' (2014) estimated the hospital and non-hospital costs for people in the last 90 days of life, and used these estimates to assess the potential impact of a community nursing service (Marie Curie) on the overall cost per patient at the end of life. They found that with appropriate community services care costs were likely to be lower by around £500 (for the types of care considered), even allowing for the commissioning costs of home-based end of life nursing support.¹⁵

¹⁴ <http://www.martinhouse.org.uk/documents/annual-review-2015/index.html>

¹⁵ For further information and cost breakdowns, see the full Nuffield report at http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf

Potential sources of information:

- PHE has commissioned a review of the health economics of end of life care services. The final commissioning tool and report should be available by the end of June 2016. (Contact: Panos Zerdevas, PHE Senior Economist, York)

12. What are the next steps?

1. North Yorkshire Health and Wellbeing Board are currently appointing a 'theme sponsor', who will make sure that the key targets of the 'Dying Well' theme from the Joint Health and Wellbeing Strategy 2015-2020 are addressed by 2020.
2. Commissioners should consider reviewing current and prospective end of life care services to make sure the commissioning recommendations discussed above are appropriately included.
3. Commissioners to consider using (and expanding) existing networks of end of life care professionals to help achieve the recommendations above.
4. Commissioners and NYCC Public Health Team to review the forthcoming health economics report on the costs of end of life care, which is being produced by Public Health England in collaboration with the University of York (due for completion end of June 2016).

13. Acknowledgements

This report has been written by Dr Victoria Turner, Public Health Specialty Registrar at North Yorkshire County Council (victoria.turner@northyorks.gov.uk).

Stakeholders consulted include:

- North Yorkshire County Council Public Health Team
- Harrogate & Rural District Clinical Commissioning Group
- Scarborough & Ryedale Clinical Commissioning Group
- Partnership Commissioning Unit
- Public Health England: Health Economics team
- Dr Mike Brookes, GP at Reeth Medical Centre and Royal College of General Practitioners/Marie Curie Palliative and End of Life Clinical Support Fellow
- Age UK North Yorkshire

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14. Appendix A: National and international guidance

NICE

End of life guidance overview page:

<https://www.nice.org.uk/guidance/service-delivery--organisation-and-staffing/end-of-life-care>

Guide for commissioners on end of life care for adults

NICE commissioning guidelines [CMG42], December 2011

<https://www.nice.org.uk/guidance/cmg42>

End of life care for adults

NICE quality standard [QS13], November 2011

<https://www.nice.org.uk/guidance/qs13>

Care of dying adults in the last days of life

NICE guidelines [NG31], December 2015

<https://www.nice.org.uk/guidance/ng31>

Improving supportive and palliative care for adults with cancer

NICE guidelines [CSG4], March 2004

<https://www.nice.org.uk/guidance/csg4>

Palliative care for adults: strong opioids for pain relief

NICE guidelines [CG140], May 2012

<https://www.nice.org.uk/guidance/cg140>

Guidance on **End of life care for infants, children and young people** is due for publication in December 2016

An update is planned for Supportive and palliative care in adults, with an anticipated publication date of January 2018. The draft scope of this guidance can be found at <https://www.nice.org.uk/guidance/indevelopment/GID-CGWAVE0799/consultation/html-content>.

Department of Health

NHS outcomes framework 2015-16

<https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016>

Relevant indicator: Improving the experience of care for people at the end of their lives

4.6 Bereaved carers' views on the quality of care in the last 3 months of life

One chance to get it right

LCP review: response to recommendations, June 2014

<https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Improvements to care in last days and hours of life: one year on from the 'One chance to get it right' report

<https://www.gov.uk/government/publications/improvements-to-care-in-the-last-days-and-hours-of-life>

Choice in end of life care

An independently-led review, published February 2015

<https://www.gov.uk/government/publications/choice-in-end-of-life-care>

Choice in end of life care: government response

5th July 2016, response to independent report (above)

<https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response>

2010-2015 government policy: end of life care

Policy paper for 2010-15 Lib Dem/Conservative government

<https://www.gov.uk/government/publications/2010-to-2015-government-policy-end-of-life-care>

Review of the Liverpool Care Pathway for dying patients

July 2013

<https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Spiritual care at the end of life: a systematic review of the literature

January 2011

<https://www.gov.uk/government/publications/spiritual-care-at-the-end-of-life-a-systematic-review-of-the-literature>

End of life care strategy: quality markers and measures for end of life care

June 2009 (2005-10 Labour government)

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf

End of life care strategy: promoting high quality care for adults at the end of their life

July 2008 (2005-10 Labour government)

<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

Public Health England

National end of life care intelligence network - Palliative Care co-ordination: core guidance (Implementation guidance)

National information standard, March 2012 (updated September 2015)

http://www.endoflifecare-intelligence.org.uk/resources/publications/implementation_guidance
Generic NEoLCIN website: <http://www.endoflifecare-intelligence.org.uk/home>

Improving palliative care data collection

Proposal for national collection of individual level data

September 2014 (updated September 2015)

<https://www.gov.uk/government/publications/improving-palliative-care-data-collection-joint-statement-from-phe-and-nhs-england>

Faith at end of life: a resource for professionals, providers and commissioners working in communities

January 2016

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/496231/Faith_at_end_of_life_-_a_resource.pdf

End of Life Care Profiles

Data collection for end of life issues

<http://fingertips.phe.org.uk/profile/end-of-life?wb48617274=22840C6D>

World Health Organisation

Global Atlas of Palliative Care at the End of Life

WHO and WPCA (World Palliative Care Alliance), January 2014

<http://www.who.int/cancer/publications/palliative-care-atlas/en/>

Resolution of the World Health Assembly WHA67.19

First ever world resolution on palliative care, April 2014

http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_31-en.pdf

European Palliative Care Research Collaborative (EPCRC) and the European Association of Palliative Care (EAPC)

Produced sets of guidelines on:

- Use of opioid analgesics in the treatment of cancer pain (May 2012)
 - http://www.epcrc.org/publication_listfiles.php?id=mKSDu3SdcE9sqhHgXk6
- The management of depression in palliative care
 - http://www.epcrc.org/publication_listfiles.php?id=B37xKfhn62SbYIFIsBsd
- Clinical practice guidelines on cancer cachexia in advanced cancer patients
 - http://www.epcrc.org/publication_listfiles.php?id=mWdBCMI5eXVlcNFk7Gng

Other resources

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

<http://endoflifecareambitions.org.uk/>

The 2015 Quality of Death Index: Ranking palliative care across the world

A report by The Economist Intelligence Unit

<http://www.economistinsights.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>

Palliative care and End of Life toolkit

<http://www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx>

Care Quality Commission: 'A different ending: End of life care review'

Addressing inequalities in end of life care

<http://www.cqc.org.uk/content/different-ending-end-life-care-review>

Nuffield Trust: Exploring the cost of care at the end of life (2014)

Comparing current costs with Marie Curie care model

http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf

British Medical Association: End of life care and physician assisted dying

Literature review and qualitative analysis of discussions with the medical profession and the general public on end of life care and dying

<http://www.bma.org.uk/endoflifecare>

Housing LIN (Learning and Improving Network): 'End of Life Care: Helping people to be cared for and die at home'

Practice briefing looking at how to provide good end of life care in the home

http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Practice_briefings/HLIN_PracticeBriefing_PHE_EndOfLife.pdf

International Observatory on End of Life care

<http://www.lancaster.ac.uk/fhm/research/ioelc/>

The National Council for Palliative Care

<http://www.ncpc.org.uk/>

Gold Standards Framework

<http://www.goldstandardsframework.org.uk/>

RCGP commissioning guide for End of Life Care

<http://www.rcgp.org.uk/clinical-and-research/toolkits/~media/Files/CIRC/EOLC/RCGP-EOLC-Guidelines-Apr-2013.ashx>

Supportive & Palliative Care Indicators Tool (SPICT)

Tool to identify people at risk of deteriorating and dying, with one or more advanced conditions, for palliative care needs assessment and care planning

<http://www.spict.org.uk/>

King's College London Institute of Palliative Care

<http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/index.aspx>

On the Brink: The Future of End of Life Care

Report by the End of Life Care Coalition

<http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf>

2015 VOICES Survey (National Survey of Bereaved People)

<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

Priorities for care of the dying person leaflet

<http://www.nhs.uk/media/2483136/pfcdp-leaflet2.pdf>

Living and dying with dignity: The best practice guide to end-of-life care for people with a learning disability

https://www.mencap.org.uk/sites/default/files/documents/2009-04/best_practice_guide.pdf

End of Life care in heart failure: a framework for implementation

<http://www.nhs.uk/media/2574509/end-of-life-care-in-heart-failure-framework-for-implementation.pdf>

Details of 'end of life' twitter hashtags

<http://www.symplur.com/topic/end-of-life/>

Appendix B: List of NHS Palliative Care services in North Yorkshire

Airedale NHS Foundation Trust

Under the Bradford, Airedale, Wharfedale and Craven Palliative Care Managed Clinical Network (information from their website).

Catherine Batt (MCN Secretary)

Telephone: 01274 323507

Email: catherine.batt@bdct.nhs.uk

<http://www.palliativecare.bradford.nhs.uk/Pages/Home.aspx>

Airedale Hospital Palliative Care Team visit patients in Airedale Hospital.

Telephone: 01535 292184

<http://www.airedale-trust.nhs.uk/services/palliative-care/>

Airedale and Craven Community Palliative Care Team are based at Manorlands Hospice, Sue Ryder, in Oxenhope; the Craven team member also has a base at Skipton Hospital. Members of this team can visit you in patient's own homes, and work closely with your GP and district nurses.

Telephone: 01535 642308.

<http://www.sueryder.org/Care-centres/Hospices/Manorlands>

Airedale Hospice at Home Team is based at Airedale Hospital. This team works alongside existing community services to provide nursing care and welfare benefits advice to Airedale residents towards the end of life.

Nursing team: 01535 294656

Benefits advice: 01535 338716

Marie Curie Nursing Service works in Bradford, Airedale and Craven districts to complement existing services. The nurses are able to provide periods of nursing care in the home, day or night. This service can be arranged via the district nurse.

Airedale Hospital also runs The Gold Line, a telemedicine service for patients on the Gold Standards Framework (further details available in Section 8, above).

Harrogate & District NHS Foundation Trust

Harrogate NHS Trust Specialist Palliative Care Team support patients in Harrogate District Hospital as inpatients and outpatients. It also provides community support to Harrogate, Ripon and the surrounding district, both in patients' own homes and in nursing or residential homes.

Service hours:

- Monday to Friday 8.30am - 5.00pm

York Teaching Hospitals NHS Foundation Trust

York Specialist Palliative Care Team works both in the community and at the following sites:

- [The York Hospital](#)
- [The New Selby War Memorial Hospital](#)
- [St Monica's Hospital Easingwold](#)
- [Archways Intermediate Care Unit](#)
- [White Cross Rehabilitation Hospital](#)
- [St Helens Rehabilitation Hospital](#)

Inpatient hospital services run at York Hospital, and outpatient services run in Selby and York. Team members are generally either community-based or hospital-based.

Service hours:

- Community - Monday to Friday 8.30am to 4.30pm
- Hospital - Monday to Friday 8.00am to 4.00pm

Scarborough Hospital Specialist Palliative Care Team works with patients in Scarborough and Bridlington Hospitals. Patients are seen either on the ward or in outpatient clinics.

South Tees Hospital NHS Foundation Trust

Hambleton and Richmondshire community specialist palliative care team provides psychological support and expert advice to patients, and indirectly acts as a resource for other professionals.

Service hours:

- 8.30am to 4.30pm Monday to Friday (excluding bank holidays).

The Lambert Memorial Community Hospital in Thirsk lists palliative care as one of the services it offers. However, the hospital is currently closed to inpatients due to staffing shortages (to be reassessed in January 2016).

The Friary Community Hospital in Richmond also lists palliative care as one of the services it offers. It is not clear whether this service is run by the GPs who provide the hospital medical care or if there is specialist service provision (ditto for Thirsk Hospital).

The James Cook Hospital has a Specialist Palliative Care team that supports inpatients and outpatients at the James Cook. One of the specialty doctors in the team also runs a small number of sessions at The Friarage Hospital in Northallerton.

Service hours:

- Monday to Friday from 8.30am to 4.30pm excluding public holidays

Appendix C: Local hospice care

Hospices in North Yorkshire

Hospice	Contact	Area covered	Inpatient	Outpatient	Day care	H@Home
Herriot Hospice Homecare	18 Omega Business Village, Thurston Road, Northallerton, North Yorkshire 01609 777413	Hambleton and Richmondshire	No	No	No	Yes
Saint Michael's Hospice	Crimple House, Hornbeam Park Avenue, Harrogate, North Yorkshire 01423 879687	Harrogate & District	Yes	Yes	Yes	Yes
St Catherine's Hospice	Throxenby Lane, Scarborough, North Yorkshire 01723 351421	Scarborough, Whitby, Ryedale and parts of East Yorkshire	Yes	Yes	Yes	Yes
St Catherine's Ryedale Day Hospice	Malton Community Hospital, Middlecave Road, Malton, North Yorkshire 01947 821049		No	No	Yes	No
St Catherine's Whitby Day Hospice	5 Mulgrave Crescent, Whitby, North Yorkshire 01947 821049		No	No	Yes	No
St Leonard's Hospice	185 Tadcaster Road, York, Yorkshire 01904 708553	York, Vale of York	Yes	Yes	Yes	Yes

The hospices listed above are for over-18s only.

The nearest children's hospice is [Martin House](#) in Boston Spa (West Yorkshire). It provides services for North, East and West Yorkshire. Children must be between 0-19 years on first referral.

Martin House Children's Hospice, Grove Road, Boston Spa, Wetherby, LS23 6TX

01937 845045

The nearest hospice for Craven residents is [Sue Ryder - Manorlands Hospice](#) in Oxenhope (West Yorkshire). It provides services for Craven, Airedale, Wharfedale and parts of Bradford.

Hebden Road, Oxenhope, Keighley, West Yorkshire
01535 642308

The nearest hospice for Bentham is [St John's Hospice](#) in Lancaster. It provides services for North Lancashire, South Cumbria and Craven.

Slyne Road, Lancaster, Lancashire
01524 382538

[Butterwick Hospice Care](#) in the North East (Stockton/Bishop Auckland) also covers North Yorkshire. This includes hospice care for both over 18s and under 18s.

[St Theresa's Hospice](#) in Darlington also covers North Yorkshire, providing hospice at home, day therapy, inpatient care and family support & bereavement services.

8 Skinnergate, Darlington DL3 7NJ
01325 240040

Appendix D: Nursing Homes providing Palliative/EoL Care

(Information gathered from www.carehome.co.uk) – N.B. it is not clear how it is determined which care homes are defined as ‘providing palliative/end of life care’.

City of York

- [Fulford Nursing Home](#)
- [Connaught Court](#)
- [Barchester The Meadowbeck Care Home](#)
- [Barchester Mulberry Court Care Home](#)
- [The Lodge](#)
- [Woodlands Neurological Rehabilitation Centre](#)
- [Lime Tree House](#)
- [Birchlands Nursing Home](#)
- [Derwent House Care Home](#)
- [Somerset Nursing Home](#)
- [Moorlands Care Home](#)
- [Broadway Lodge](#)
- [Apple Tree Care](#)

Craven

- [Barchester The Dales Care Home](#), Draughton
- [Barchester Threshfield Court Care Home](#) , Threshfield
- [Anley Hall](#), Settle
- [The Craven Nursing Home](#) , Skipton
- [Ingleborough Nursing Home](#), Ingleton

Hambleton

- [Greenwell House](#), Bedale
- [Barchester Mount Vale Care Home](#) , Northallerton
- [Leeming Garth Care Home](#), Northallerton
- [Bedale Grange Care Home](#), Bedale
- [Oak Trees Care Home](#) , Alne
- [Sowerby House](#), Thirsk
- [Southwoods](#), Northallerton

Harrogate

- [Oaklands Residential Home](#) , Kirk Hammerton
- [Grosvenor House Care Home](#) , Harrogate
- [Barchester Thistle Hill Care Centre](#), Knaresborough
- [Bilton Hall Nursing Home](#) , Harrogate
- [The Crest Care Home](#) , Harrogate

- Southlands Care Home , Harrogate
- Hampden House , Harrogate
- Belmont House , Starbeck
- Vida Hall , Harrogate
- Clova House Care Home , Ripon
- Long Meadow Nursing Home, Ripon
- The Coach House Nursing Home , Ripon
- 14 Manor Road , Knaresborough

Richmondshire

- Rosedale Nursing Home , Catterick Garrison
- Morris Grange Care Home , Richmond

Ryedale

- The Abbey Residential Home, Malton
- Alba Rose, Pickering

Scarborough

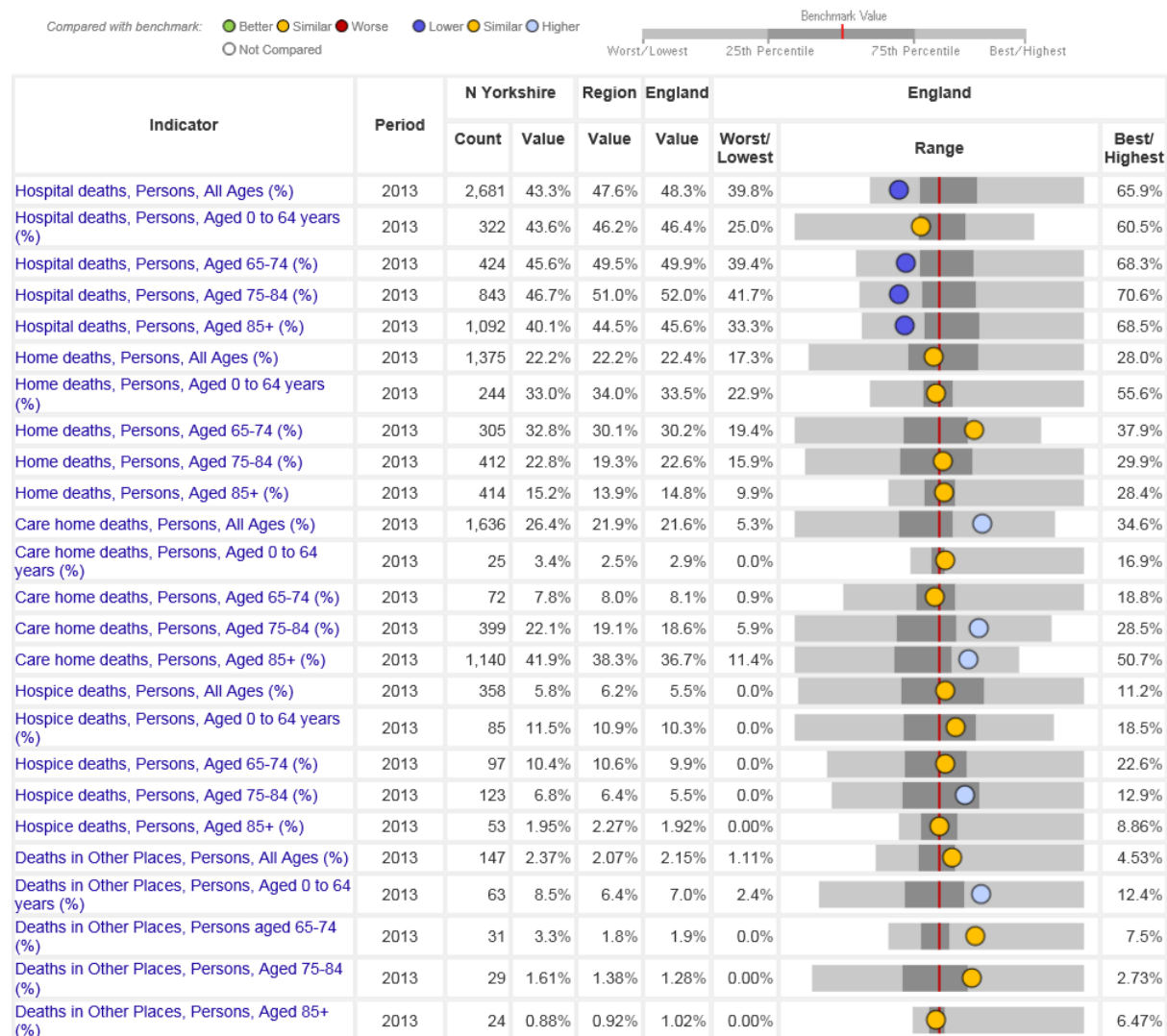
- Esk Hall Care Home, Whitby
- Dunollie Care Home, Scarborough
- Whitby Court Care Home, Whitby
- Green Park Nursing Home, Scarborough
- Pinfold Lodge , Filey
- Peregrine House, Whitby
- Tree Tops, Scarborough
- Rambla Nursing Home, Scarborough
- The Lodge, Scarborough
- St Bernadette's Nursing Home , Scarborough
- St Helens Nursing Home, Scarborough
- Moorview House, Whitby
- Briar Dene Retirement Home , Scarborough
- Derwent Cottage, Scarborough
- Woodlands Nursing Home , Filey

Selby

- Barchester Highfield Care Home, Tadcaster
- Lake & Orchard Care Centre , Kelfield
- The Grange, Selby
- Mansion House, Selby
- Hilltop Manor, Sherburn in Elmet
- Tudor House Nursing Home , Selby
- Denison House Care Home, Selby

Appendix E: Further local data

1. Location of death by Age data



(PHE End of Life Care Profiles, 2013)