End of Life Pathway Leadership Board
Quality Report

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Preface

Context of End of Life Care

End of life care begins in the 6 to 12 months before death and ends 6 to 12 months after death. Approximately 1% of the population die each year equating to around 500,000 people, and around 20% of the health budget is spent on end of life care. The majority of people express a preference to die at home but over half currently die in an acute setting. End of life care is often poorly co-ordinated and people are inappropriately admitted into hospital. Providing high quality care at end of life is crucial for both the patient and their relatives.

The national End of Life Strategy (2008) raised the profile of end of life care around the need to give people choice over where they die, and to bring about improvements in access to high quality care for all adults approaching the end of their life. The strategy covers the key stages: 1) Discussion on end of life; 2) Assessment and care planning; 3) Co-ordination of care; 4) Delivery of high quality care in different settings; 5) Last days of life; 6) Care after death. The national QIPP work stream focuses on improving systems and practice for identifying people as they approach the end of life and planning their care. National levers include NICE guidance, a range of quality standards, markers and measures, the commissioning guide and Routes to Success for end of life services. These focus on implementing key tools such as the Liverpool Care Pathway (LCP), Preferred Priorities of Care (PPC) and Advance Care Planning (ACP) as well as improving co-ordination of care across sectors through developments such as the Electronic Palliative Care Co-ordination System (EPaCCS).

The End of Life Quality Report

The regional End of Life Pathway Leadership Board was set up to lead the development of the End of Life care across Yorkshire and Humber, in line with the national strategy. The End of Life Quality Report has been produced to support the Pathway Leadership Board in monitoring quality of end of life care across Yorkshire and Humber through:

- Understanding how the region compares with the England average
- Examining trend data and identifying patterns and themes where improvements have been made as well as areas where progress has been slow or declined
- Identifying outlier organisations through flagging local strengths as beacons of best practice as well as areas where improvements in quality for end of life care and potential cost savings could be made
- Beginning to understand how different indicators interact and impact on each other
- Encourage further exploration of data, explain the value of additional information sources and provide recommendations for action to improve quality of end of life care
- Investigate the impact that improvements in the quality of care at end of life can have on the patient and their families and carers, the healthcare systems and the local area
- Support the assessment of end of life care need in the population now and in the future

The end of life report is split into 6 main areas around key priorities for end of life care

- End of life Register - Identifying patients approaching end of life and patient preferences
- Place of death – Key national measure associated with patient’s having a ‘good’ death
- Deaths in hospital – The potential adverse effects of admitting patients at end of life to hospital
- Cause of death – Understanding how cause of death impacts on place of death and inclusion on registers
- Other – Linking the areas together in the context of rates of death, deprivation and life expectancy, projections in death and population and prevalence of conditions
- Area – Beginning to think about the geography of the localities and how this might impact on care at end of life, as well as resource and capacity constraints

In addition to this report, a supporting benchmark tool is available with a wider range of charts and indicators including summary notes and recommendations. A further set of support documents is also available to provide details on these 6 areas, why they are important and the indicators chosen. The report and accompanying tool will be updated on a bi-annual basis with new data where it is available.
Latest and Future Developments

Organisational Change

- Yorkshire and the Humber SHA combined with North East SHA and North West SHA on 1st October 2011 to form NHS North England. Currently the End of Life Quality report only covers the Yorkshire and Humber region but could potentially be expanded in the future to cover North England if required.
- As Clinical Commissioning Groups (CCGs) begin to move forward, end of life data will need to be examined at CCG level. With this in mind, where GP practice level or post code data is available (such as QOF, HES and PCMD data) this can be aggregated to CCG level and will begin to be introduced into the report.

National Developments

- Localities are beginning to develop and implement the Electronic Palliative Care Co-ordinator System (EPCCS). This involves collecting core datasets about patients. This will enable clinical teams across a variety of care settings to share core information about the patient, avoid asking patients to repeat information and enable a more co-ordinated joined up approach to end of life care. Going forward it would be useful to monitor the roll-out of this across the region and the quality and completeness of the data recorded.
- The VOICES survey (Views of Informal Carers - Evaluation of Services) is being developed and tested for the bereaved. The results could form part of the report.

Regional Developments

Progress on some of these initiatives could be included in the report:

- Standard DNACPR documentation has been developed for use across the Y&H region, including out of hours and ambulance services.
- Roll out of education and training across the region.
- Development and implementation of rapid discharge pathway across the region
- Adoption of region wide guidelines for verification of death

The National End of Life Care Intelligence Network (NEOLCIN)

- PCT profiles were published in May 2012. Currently the data from the NEOLCIN included in the quality report is for Local Authorities, however place and cause of death could potentially by analysed by PCT in future based on the data that feeds into these profiles.
- The latest reports from the NEOLCIN include: ‘What did we know that we didn’t know a year ago? New Intelligence on End of Life Care in England’. Website: www.endoflifecare-intelligence.org.uk

Local work and Queries

- This report can be developed in the future to include a section dedicated to looking at local work. This would provide an opportunity to share best practice on end of life care such as a range of different projects and initiatives undertaken around the region.
- Additionally the report can also be used to raise queries and seek examples of projects and best practice to encourage adoption of these in other areas and potentially joint projects.

If you have any suggestions for additional data items for the report, please email: Charlotte.Wood@york.ac.uk
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Data Sources

Quality Outcomes Framework (QOF) 2008-09, 2009-10 and 2010-11 data:
http://www.ic.nhs.uk/qof

Primary Care Mortality Database (PCMD) 2008-11
Data extracted August 2011

National End of Life Care Intelligence Network (NEOLCIN):
http://www.endoflifecare-intelligence.org.uk/home.aspx

Hospital Episode Statistics
Inpatient 2008-09, 2009-10 and 2010-11

The NHS Centre for Health and Social Care Indicator Portal (previously NHCOD):
https://indicators.ic.nhs.uk/webview/

Yorkshire and Humber Public Health Observatory Map of Deprivation:

2008-based sub national populations:

Disease Prevalence Models:
http://www.apho.org.uk/DISEASEPREVALENCEMODELS
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Executive Summary - key findings

- With regards to the end of life register, generally Y&H PCTs are in line with the England average (0.17%) and there has been a year on year increase in the prevalence of people on the end of life registers during 2008-09, 2009-10 and 2010-11 with the exception of one PCT within the region.

- It is expected that prevalence rates for people on end of life registers should be higher both regionally and nationally.

- There is some variation in the reported % of PCTs with a complete end of life register across the region from 90.5% to 100%. The data on the 3 monthly reviews of those patients on a register is more widely varied with no PCTs in Y&H reporting 100%.

- There is variation across the region around the proportion of people dying in hospital, own residence, care homes and hospices.

- Certain areas within the region report higher levels of deaths in hospitals compared to other areas.

- Regional decline in deaths in hospital except for patients dying from respiratory disease.

- Between 45-55% of patients who die in hospital are in hospital for more than 8 days before death.

- Patients with a diagnosis of cancer are less likely to die within 3 days of admission to hospitals compared to other conditions and a higher proportion of cancer patients are cared for in the community at end of life.

- Areas with higher levels of deprivation tend to have lower life expectancy and patients are more likely to die in hospital compared to other localities.
Executive Summary - key recommendations

**Analysis**

- Explore data in more detail at CCG, GP Practice and postcode level to identify outliers and trends.
- Use sources such as end of life profiles and GP Practice profiles to provide additional context.
- Review end of life data alongside demographic data as factors such as age, ethnicity and deprivation for example that affect prevalence of disease and life expectancy.
- Triangulate data such as end of life register prevalence with cause of death to see whether patients with certain conditions are less likely to be included on a register.
- Check coding of data to ensure high data quality on end of life care.
- Examine hospital on patient deaths in more detail around number of admissions prior to death, source of and method of admission for example.

**Other**

- Practices without a register should begin to set up a register. For those practices with registers in place, ensure reviews are carried at least every 3 months by multi-disciplinary teams and increase the quality of the register in terms of accuracy, completeness, frequency of updates. Ensure consistent understanding of when a patient is placed on a register.
- Research local preferences for place of death.
- Map current end of life services and consider how these will be affected by an increased elderly population, higher numbers of deaths and greater prevalence of diseases
- Consider whether patients who die in hospital should have been admitted. Make use of to examine alternative pathways.
- Examine the discharge process within hospitals, is this efficient? Can more be done to enable patients at end of life to be discharged to die at home?
- Map current services across the locality in detail and consider what capacity is available now and what will be needed to ensure high quality end of life care in the future.
- What can be done to promote end of life services to emerging CCGs?
Section 1 – End of Life Register

End of life register - Overview

Nationally the aim is to increase the number of people approaching end of life who are recorded on an end of life register. This will help to strengthen good quality end of life care planning, reduce hospital admissions and support patients around choices such as preferred place of death. Having a good quality, up-to-date register in place that is actively used and reviewed means that appropriate plans can be put in place, in line with patient’s wishes, to provide care for patients approaching end of life. This leads to a more personalised service through better co-ordination of care and understanding of issues and preferences around DNACPR and place of death. A proactive approach to planning end of life care enables the patient to receive a higher quality of care at end of life.

End of life registers are the first level of the Gold Standard Framework Programme for community palliative care, the programme has been described as leading real improvements in care for this group of people and for establishing more organised care and better team working. The use of end of life registers is considered best practice by; NICE, the Royal College of GPs and the National NHS End of Life Programme (‘Palliative Care and the GMS Contract Quality Outcomes Framework Guidance Paper’ -2006).

Almost 1% of patients per GP Practice die each year on average. The national end of life strategy encourages GPs to identify this cohort of patients. Data on end of life registers enables the NHS to begin to investigate whether they have included all of the relevant people, and suggests possible numbers of people that may still need to be identified within their practice population as approaching end of life. Based on 1% of practice populations dying each year, statistics suggest that on average approximately one quarter of these will die from cancer, around one third from organ failure, around one third from general frailty and the remaining 10-15% are classed as ‘sudden’ deaths (‘Full Guidance on using QOF to improve palliative/end of life care in primary care’). For those of whom there is some time to prepare (i.e. where patients meet the 3 triggers for supportive/palliative care), these patients should be included on an end of life register.

Consideration should be given to the following; how many people are currently on an EOL register? Is everyone approaching end of life included on a register? How many additional people potentially need to be added to the register? Are there clear and consistent definitions of who should be included? Is the register of good quality and are they regularly reviewed? The following indicators aim to start to explore the extent to which PCTs in Yorkshire and Humber have end of life registers in place that capture the relevant population and are of good quality and reviewed regularly. Whilst the data set do not answer all of these questions, it does provide a starting point for investigation and recommendations for next steps.

End of life register - Palliative Care Prevalence

Palliative care prevalence looks at the number of people on end of life registers per GP Practice as a proportion of the total GP Practice list size. Looking at proportions rather than numbers enables comparisons between GP practices. Data has also been published at aggregate PCT and SHA level as well as by GP Practice.

The data on prevalence of palliative care and QOF points is sourced from the Quality Outcomes Framework (QOF) which originates from the Quality Management Analysis System (QMAS) database. QOF data is released annually and is voluntary for GPs to collect. The latest data covers the time period 2010-11. It was published Oct 2011 on the Information Centre’s website at: http://www.ic.nhs.uk/qof.

Figure 1 looks at the prevalence of patients on an end of life register.
The prevalence of patients on an end of life register for 2010/11 in Yorkshire and Humber (0.19%) was in line with the England average (0.17%). Only North Lincolnshire PCT in the Yorkshire and Humber region was significantly below the England average. The trend data shows that the % of patients recorded on an end of life register increased across all PCTs within the region year on year apart from North Lincolnshire.

The Gold Standards Framework suggested 10-15% deaths are classed as ‘sudden’, and around 85% of deaths are linked to cancer, organ failure and general frailty. Whilst not all deaths from cancer, organ failure and general frailty would be expected to die within 12 months, many of these should be included on the register and as part of end of life planning.

End of life register – Actual against Expected

Whilst the previous indicator suggests that Yorkshire and Humber, as a region, is in line with the national average, in the wider context the number of people on end of life registers is still significantly below what would be expected. The guidance around the Gold Standards Framework suggests that 1% of people will die on average per GP per year (an average of 20 people per GP) (‘Quality and outcomes framework for 2012/13: Guidance for PCOs and Practices’). Extrapolating the 1% per GP across the PCTs, the average number of ‘expected’ deaths per PCT area has been calculated and compared against the number of people on a register. Therefore for Yorkshire and Humber, 0.19% of the total list size was recorded on a register – this is 19% of the total expected deaths (i.e. 0.19% out of 1%).

The Gold Standards Framework suggested 10-15% deaths are classed as ‘sudden’, and around 85% of deaths are linked to cancer, organ failure and general frailty. Whilst not all deaths from cancer, organ failure and general frailty would be expected to die within 12 months, many of these should be included on the register and as part of end of life planning.

Given that approximately 70-80% of deaths are potentially classed as ‘expected’ deaths, it is anticipated that the proportion of people on an end of life register who die each year should be higher than the current regional average of 19%. Including 50% of patients on an end of life register is seen as an ambition for organisations to work towards achieving. The 75% line on the chart overleaf has been included to mark the 70-80% of non-sudden (i.e. ‘expected’) deaths. The PCT closest to achieving the ambition within the region is Rotherham PCT with 28% and the furthest North Lincolnshire PCT (10%). Whilst we are dealing with relatively small numbers of patients, and not all deaths would be expected or meet the ‘3 trigger criteria’ for inclusion on an EOL register, it is anticipated that prevalence rates should be higher than current data suggests.
The proportion of patients that died between Apr’10 and Mar’11 per PCT area has been extracted from the primary care mortality database (PCMD) as at August 2011. The purpose is to compare the number of people per PCT currently on an end of life register as both a proportion of the expected number of deaths (1% of GP population), and as a proportion of actual deaths during that year. Whilst not directly comparable as the patients cannot be tracked between data sources, this does give a sense of proportions between actual and expected.

Figure 3: Proportion of people on end of life registers compared with actual deaths during 2010/11
Section 1 – End of Life Register

All PCTs, except for East Riding PCT, are showing a higher proportion of prevalence of patients on an end of life register compared to actual rather than expected deaths. This suggests on average fewer people are dying than the expected 1% in the region (apart from East Riding). East Riding has a higher proportion of older people in the population compared to other PCTs which could account for the higher number of deaths compared to the expected ratio of 1% of the GP list size.

End of life register – Quality Outcomes Framework (QOF) points achieved

The final indicators in this section focus on the QOF points achieved for the practice having a palliative care register (PC03) and reviewing this at least every 3 months (PC02). The maximum QOF points for palliative care that can be achieved for each PCT is the cumulative total for all GP Practices in the PCT area multiplied by 3 (the maximum points that can be achieved for each indicator for palliative care). The chart below looks at the % of QOF points achieved by PCT by adding together the practice points within the PCT region out of the maximum number of points available.

![Figure 4: Proportion of QOF points achieved 2010/11](image)

There is some variation in the % of PCTs with complete end of life register across the region from 90.5% to 100%. The data on 3 monthly reviews of those patients on a register is more widely varied with no PCTs in Y&H reporting 100%.

End of life register – Recommendations

The end of life register aims to capture those people approaching end of life to ensure that patients are given the appropriate level of care in line with their preferences. These indicators try to address this issues, however some caution should be used with this data as QOF data is voluntary for GPs to complete. Also rankings of data may be inappropriate due social and demographic differences, local circumstances; co-morbidities, etc. (‘Focus on QOF payments -April 2011’).
Therefore the data is not conclusive, but rather should be used as starting point for further investigation. Additionally the data from the primary care mortality database tells us which patients died in each year. However this data cannot be directly linked to those patients recorded on an end of life register as details of those patients are not available. Therefore the information provides an idea of proportions only (i.e. when comparing these 2 items we do not know whether those patients who died during in a particular year corresponded to those on the end of life register for that year).

Recommendations from the data are as follows:

- There are opportunities to explore at CCG or GP Practice level to identify outliers. Techniques such as quadrant charts or funnel plots could be useful in supporting this. Learning can be gained from areas identified as having a higher % of people on an end of life registers, for example what did they do to identify these patients? At the other end of the scale, practices with low prevalence rates may need additional support to set up a register and identify those people in their population who would benefit from being on an end of life register.

- Comparing data to local population demographics helps support identification of patients approaching end of life as factors such as age, ethnicity, and deprivation affect prevalence of disease, life expectancy and likelihood of being on an end of life register. To take age as an example, areas with older populations may feasibly have higher numbers of people on end of life registers compared with a GP practice population with a younger average age.

- Practices without a register should look at setting up a register. For those practices with registers already in place, they need to work to ensure that reviews are carried out as minimum every 3 months by multi-disciplinary teams and that the registers are updated accordingly.

- The local population and prevalence data should also be triangulated with QOF data on palliative care to understand the relationship between these indicators. For example, a PCT may be reporting 100% for having a complete register, but has a low prevalence per population suggesting that potentially not everyone has been identified who needs to be.

- As well as having a register in place and reviewing it through MDT at least every 3 months, the quality of the register is also important. For practices with registers in place the next step would be to examine the quality of end of life registers in terms of accuracy, completeness, frequency of updates and to ensure consistent understanding of when a patient is placed on a register.

- Consideration should also be given to which patients have been included on end of life registers. For example cancer patients on average make up 25% of those patients who die per GP Practice, but they account for more than 70% of those patients on an end of life register nationally. The diagnostic breakdown of patients on end of life registers needs to be assessed to help target those patient groups that have not yet been identified.

- End of life registers should be used to support advance care planning around themes such as preferred place of care and preferred place of death, DNACPR, etc. Going forward with the roll out of the electronic palliative care co-ordination systems, these decisions can be shared across the health system to enable a more joined up approach to end of life.
Place of Death – Overview

Whether a patient dies in their place of choice has become key area of focus nationally and is strongly linked to whether a patient has a ‘good death.’ National research such as Local Preferences for place of death ‘(Local Preferences and Place of Death in Regions within England’ (Aug 2010) suggest most would prefer to die at home and very few people would choose to die in hospital. Of the 500,000 people who die nationally in England each year, around 70% of people would prefer to die in their usual place of residence but only around 40% achieve this. Therefore a range of indicators have been included in the report to support work around giving people choice in where they would like to die.

The key questions that the report begins to explore are:

- What proportion of people wish to die; at home, in a care home, in a hospice or in hospital?
- Are people getting their preferred choice for place of death?
- What factors may mean people are not able to get their choice for preferred place of death? (e.g. capacity limitations such as hospice beds and lack of community based support for people dying at home)
- What additional help is required to support people who choose to die at home? e.g. ‘hospitals at home’
- Are tools such as EOL registers and Advance Care Planning in place to enable place of death to be recorded?

A study of preferences shows the majority of participants reported that they would prefer to die at home, if circumstances allowed, with hospice as the second choice which together accounted for 89% of preferences in the region ‘(Local Preferences and Place of Death in Regions within England’ (Aug 2010). Examining data on place of death helps us to investigate whether this preference is being met. Part of having a ‘good death’ is related to where the person dies and whether this is in line with their chosen place of death. The study shows that generally as age increases, a preference to die at home decreases in favour of dying in a hospice¹. Investigating preferences for place of death within the region by age group and comparing this data against actual place of death by age group is useful in supporting understanding whether people’s preferences are being met.

Ensuring that the patient dies in their preferred place is beneficial for the quality of care the patient receives and for the family in knowing that their loved ones wishes were met. As evidence points to most people preferring to die at home, this suggests that admissions to hospital for patients nearing the end of life, is neither in the best interest of the patient (as it goes against their preference for place of death), and is costly to the hospital. Preference regarding place of death is part of a suite of factors around advance care planning. Knowing the patient’s wishes around place of death and ensuring that this is effectively managed across the healthcare system means that care is better co-ordinated, and that staff in nursing homes, hospitals, GP practices, hospices, ambulance and social care staff, etc. can take the appropriate course of action in line with patients' wishes.

Place of Death

The data in the supporting benchmark tool uses pooled data 2008-10 from the national end of life care intelligence network (originally from ONS mortality data) to look at place of death by local authority by age band. This includes confidence intervals to detect the whether differences between organisations are significant (i.e. meaningful) or not. Where confidence intervals overlap these are classed as non-significant (i.e. there is no significant difference between the scores), where they do not overlap they are seen to be significantly different. Additional information has been included using data from the primary care mortality database to look at data by PCT cluster for all ages over 3 years. Please note that the two different data sources have been used to give a wider picture. They are not directly comparable as they refer to different organisational boundaries, age groups and time periods.
Section 3 – Deaths in Hospital

Figure 5: % of deaths of all ages per place of death

- Slightly more deaths in hospital seem occur in the 65-84 years age group, but across all age groups the regional and national position is above 50%.
- The % of patients dying in hospital based on the NEOLCIN data was similar in Yorkshire and Humber to the national position. Six local authorities had significantly higher proportions of deaths in hospital than the England average (i.e. the confidence intervals did not overlap with the national position on the ‘all ages’ chart). Hull and Sheffield were significantly higher across all age groups. Thirteen local authorities were significantly lower than the England average.
- Across the PCT clusters using the PCMD data all of the PCTs in South Yorkshire are above 50% for deaths in hospital but show a decreasing trend over time (apart from Doncaster).
- North Yorkshire and Bradford and Airedale PCT report the lowest % of deaths in hospital over the years (below 50%) whereas Hull PCT remains high with over 60% dying in hospital.
- The % of patients dying in their own residence based on the NEOLCIN data was lower in Yorkshire and Humber compared to the national position. Most areas in North Yorkshire had the highest proportion of deaths at home with the lowest at East Riding and York.
- The highest proportion of deaths at home is on the 0-64 age group with the lowest in the 85+ age group.
- Across the PCT clusters the PCMD the data for PCTs generally suggests an increase in the number of deaths at home over the 3 years, particularly Barnsley, Rotherham and North East Lincolnshire.

NOTE: Currently numbers of deaths for Bradford are artificially high in nursing homes and low in hospices due to coding errors in source data. This will be rectified in the next update.
Section 3 – Deaths in Hospital

- The % of patients dying in a care home based on the NEOLCIN data was slightly higher in Yorkshire and Humber compared with the national position. This is significantly higher across all age groups for Bassetlaw, Bradford and North East Lincolnshire, and significantly lower for Calderdale and Rotherham.
- Bradford stands out as having a much higher % of deaths in care homes for the younger age group (age 0-64) compared to other PCTs and the national and regional average.
- Deaths in care homes in 0-64 years age group have the lowest proportion and therefore widest confidence intervals, with 65-84 year olds a higher proportion and 85 years + the highest for all PCTs (ranging from 26-48%).
- Across the PCT clusters based on the PCMD the data, the pattern suggests a decrease in the number of deaths in care homes during 2009/10 followed by an increase during 2010/11.
- Deaths in hospices account for 5.5% of deaths in the region. The % of patients dying in a hospice based on the NEOLCIN data was slightly higher in Yorkshire and Humber compared to the national position for all age groups (except 0-64).
- The confidence intervals around the 0-64 and 85+ age groups in particular are very wide due to small numbers; therefore there is less certainty around the proportion of deaths in hospices.
- Trend patterns in the PCT cluster charts for deaths in hospices vary within clusters and between clusters.

Place of Death – Recommendations

When interpreting this data it is important to note that hospice only refers to ‘free standing hospices’, not hospice beds within other community or acute settings. Coding of hospice beds in this way may therefore skew results, for example hospice beds in an acute setting would be classed as death in hospital rather than a hospice. Additionally, PCMD data was extracted Aug 2011 and is subject to updates. Place of death categories were created through links to a lookup table based on the place of death code and address, whilst every effort has been made to be as accurate as possible, there may be some discrepancies with the NEOLCIN data. However the information has been included to enable trend data to be analysed. The NEOLCIN data includes confidence intervals around the average data point. This data is displayed by local authority. The PCMD data does not include confidence limits and is presented by PCT cluster.

Recommendations from the data are as follows:

- Exploration for preferences for place of death should also be examined locally, ideally broken down by age group and collected at postcode level where possible using a large enough sample size to make the result more meaningful (i.e. to be able to detect statistically significant differences between age groups for example). Whilst death at home is generally considered the most desirable place of death based on research, this is a proxy measure for the indicator ‘did the patient die in their preferred place of death’. Examining data for the locality by post code area is a useful technique to understand where specific issues occur such as high admissions to hospitals for people approaching end of life. Pinpointing the local area and hospital sites means that the issue can be addressed more directly through route cause analysis of the problem.

- Checking coding of palliative care in hospitals is also important to ensure that the data quality around end of life is high. Poor coding and missing data makes it harder to identify real issues that need addressing. It is therefore recommended palliative care coding is examined to ensure that trusts are confident that the data accurately reflects the situation.

- Consider what would need to change in the service for people’s preferences to be met? E.g. increasing support for people at home approaching end of life.

- Examine the capacity, resource and geographical issues involved in achieving preferred place of death. Review the services in currently in place and identify the gaps between demand for services and availability.

- Using information on the expected increases in population (particularly the elderly), the projected numbers of deaths and predicted changes to prevalence of diseases, consider likely future demands for service and the effects of this on meeting preferred place of death.
Section 3 – Deaths in Hospital

Deaths in hospital - overview

Death in hospital is considered the least likely place where most people would prefer to die and yet is the place where people are most likely to die. Death in hospital not only goes against many patients preference regarding place of death, but is also costly to the NHS. The Stockport JSNA (2006) suggests that with the exception of cancer, almost all other “expected” deaths tend to be in hospital. This section begins to look at those patients who have died in hospital and considers the effects of age, primary diagnosis and length of stay.

The report focuses on some of the most common primary diagnosis found in patients who have died in hospital and considers whether some of these admissions could have been avoided. Additionally we consider; for those people admitted to hospital, how long were they in hospital from the time of admission to death? Could the patient have been discharged home in this time? What affects might age, length of stay and primary diagnosis have? How many admissions were made to hospital in the last year of life and what is the quality and cost implications of this?

Reduction in hospital admissions at end of life increases the patient’s chance of dying in their preferred place of death enabling the patient to have a better quality of life in their final days. This also enables families and carers to support their loved one at home or in a hospice environment rather than in hospital. Reduction in unnecessary admissions leads to reduction in cost and saves bed days and releases resources to be used on patients whose quality of life can be enhanced through hospital admission and also reduces pressure on ambulance services.

Deaths within 3 days of admission suggest the patient was in the final stages of their end of life pathway and therefore in many cases it can be considered that the patient should not have been admitted, particularly if they have expressed a desire to die in their own residence or in a hospice. Deaths in hospital 8 or more days after admission suggest that the hospital was not able to do anything further for the patient and therefore the patient could potentially have been discharged to die at home. Understanding more about which conditions are considered ‘expected’ causes of death versus ‘sudden death’ supports work on identifying those patients that should be on an end of life register.

To examine deaths in hospital, data was extracted from HES (Hospital Episode Statistics). The age bands, length of stay groups and ICD codes for deriving the primary diagnosis were taken from those used in the NEOLCIN report ‘Variations in Place of Death in England - Aug 2010’.

Deaths in hospital – length of stay and age

Length of stay was explored to try understand more about whether patients should be admitted to hospital in the first place, and where they have been admitted and confirmed to be dying, whether the patient should have a rapid discharge to be able to die in their place of choice. Length of stay has been examined in 3 groups:

- 0 to less than 3 days
- 4 to 7 days
- 8 or more days

The chart overleaf compares the proportion of deaths by PCT for each of these time bands.
Figure 6 shows that around 50% of patients who die in hospital were in hospital for more than one week before death and around one third died within 3 days of admission.

Charts have also been produced by PCT and Trust for age bands (18-64, 65-84 and 85+). Around 50% of patients who die in hospital were aged 65-84, around one third aged 85+ and around 15% were aged 0-64. This data can be linked to projected deaths and populations. An increasing elderly population is likely to shift this focus to a larger proportion of NHS care spent on the 85+ age group who are likely to have more frequent admission and slower recovery time on average, unless more end of life care can be carried out in the community.

Deaths in hospital – primary diagnosis

Deaths in hospital were also examined by condition in terms of the proportion of those that died with a primary diagnosis of; Cancer, Cardiovascular Disease (CVD), Respiratory Disease or other (i.e. any other primary diagnosis excluding these three). Data was extracted from HES (Hospital Episode Statistics) for 2009-10 by PCT. With regards to classifying the conditions as: “Cancer”, “Cardiovascular Disease”, “Respiratory Disease” or “other”, The following ICD codes were used:

**Cancer:** C00-C97 and D00-D48 (includes all malignant, benign and in-situ neoplasms)

**Cardiovascular disease:** I00-I52 and I60-I69 (includes rheumatic fever, rheumatic heart disease, hypertension, ischaemic heart disease, stroke)

**Respiratory disease:** J00-J99 (includes influenza, pneumonia, bronchitis, emphysema, asthma and other chronic obstructive pulmonary diseases)

**Other:** a cause of death not covered by one of the categories above.
Figure 7 compares the PCTs in Yorkshire and Humber on patient deaths in hospital within 0-3 days, 4-7 days and 8 or more days where the primary diagnosis was cancer.

**Figure 7: % of cancer deaths in hospital by length of stay**

Similar charts are available for the CVD and respiratory disease in the supporting benchmark data. Across all PCTs the lowest proportion of deaths for cancer is within 0-3 days and the highest 8 days or more. For CVD the pattern is reversed and the highest proportion of deaths that are within 0-3 days and the lowest 8 or more days. For respiratory disease the highest proportion of deaths in hospital tends to be within 4-7 days. The Stockport JSNA suggests that cancer is the only condition where it is considered acceptable to plan for end of life care and therefore there are a higher proportion of cancer patients dying in the community compared with other conditions.

Other findings from the data (see benchmark tool for more charts) reveal that across the region there has been a decline in deaths in hospital in 2010-11 for all primary diagnosis except for respiratory disease. Approximately 45-55% of patients who die in hospital are in hospital for more than 8 days before death and around one third are in for 0-3 days before death, this applies for each of the 3 defined age groups.

Approximately 50% of the patients are aged 18-64 and around 30-40% are aged 85+. Hospital deaths where the primary diagnosis was respiratory disease account for around one third of hospital deaths and CVD 20-25%. Cancer deaths are more varied across the region ranging from around 10-25% of deaths.

The largest proportion of people in hospital is the 65-84 age group, this pattern is reflected in the 3 key primary diagnosis explored. The 18-64 age group has the lowest proportion of deaths although notably this is much higher for cancer than the other primary diagnosis groups.
Data must conform to the small numbers rule to avoid the potential identification of any patient and must not be released outside of the NHS. It should also be noted that the primary diagnosis is not necessarily the same as ‘cause of death’.

**Recommendations from the data are as follows:**

- Trusts and PCTs should examine their local hospital data on patients who died following admission to hospital to dig deeper into the primary diagnosis of the patient. Does it tend to be patients with certain conditions that are admitted? Are there other services such as community services which may potentially be more appropriate for the patient?

- Are there specific patterns around post codes of admissions? Do certain areas tend to admit more patients? Can work be done with GPs and care homes around services available and appropriateness of referrals? Examining specific geographic areas or locations for sources of admissions (e.g. care homes) may highlight hot spots of high admissions.

- The current analysis looks at age bands, primary diagnosis and LOS only, further exploration could explore issues around, ethnicity, living arrangements, other diagnoses and co-morbidities, etc.

- For the patients dying within 0-3 days of admission, these patients should be reviewed to see whether admitting the patient to hospital was the optimum course of action if the patient expressed a desire to die at home. In many cases admission to hospital would be necessary, however there are likely to be a number of patients who could not benefit from this and would have had a better death had they remained at home. It would also be useful to link this data to place of death to consider what additional support would needed in the community for more patients to die at home rather than be admitted to hospital.

- For those patients who died in hospital after 8 or more days, there may be cases where the ideal course of action would have been to discharge the patient to die in their own home. Work should also be done around the discharge process. If the hospital is unable to help the patient to recover or enhance the quality of life for the patient, it may be preferable to the patient to be discharged to enable them to die at home.

- Comparisons between hospital sites, specialities and down to consultant teams may also be valuable in understanding the admission criteria for people at end of life and identifying end of life pathways that lead to patients having a good death.

- Mapping services and considering bottle necks in the system is a useful way of understanding the end of life pathway and looking for ways to streamline this.

- Clear documentation through instruments such as advance care planning and the end of life register are crucial around making the decision to admit a patient. For example there may be cases where the patient is taken to hospital via the ambulance service against the patient’s wishes. However clear documentation outlining the patient’s wishes may have led to the patient being allowed to die at home rather than be admitted to hospital. Similarly clear, co-ordinated documentation could help to speed up the discharge process from hospital – enabling patients to die at home.

- Examining the hospital data by source of admission would give a wider insight into where the patients were admitted from (i.e. if a large proportion are from care homes then work could be done with care homes around this). This analysis has not been included to date due to data quality issues with coding for the source of admission field on home and care home. The method of admission (i.e. GP, A&E etc.) might also be useful to explore.

- Consider using tools such as the Cohort Model and the Yorkshire and Humber Commissioner Financial model which look at different pathways and make estimates around how many people in acute hospitals could reasonably have ended their days in alternative care settings and calculates the cost implications.
Section 4 – Cause of Death

The ‘Guide for Commissioners on End of Life Care’ (Dec 2011) notes that 75% of deaths are from cancer, diseases of the circulatory system and respiratory diseases and that cause of death affects the type of care needed in the last year of life. The cause of death also links to the likelihood that; 1) the patient was included on an end of life register, 2) the patient was admitted to hospital and 3) the patient was cared for and died in their preferred place.

What age groups are most likely to die from these conditions? Where are the people most likely to die from what conditions? How can resources be targeted to reduce deaths from certain conditions? How can understanding more about a person’s condition influence inclusion on an end of life registers. What are the different pathways for deterioration? (i.e. models of care). Are there patterns between place of death and cause of death?

Understanding more about cause of death enables adjustments in end of life services to be made in line with the needs of the local population. This allows resources to be targeted to support certain conditions where end of life care needs to be enhanced. Support could be in the form of more staff, medicine, beds, equipment etc. needed for certain conditions, education for medication management and enhanced training for staff around certain signs and symptoms.

Section two on place of death looked at an age break down of place of death and trend data by PCT cluster, section 3 looked specifically at hospitals deaths where the primary diagnosis was; Cancer CVD and Respiratory Disease. This section looks again at Cancer, CVD and Respiratory Disease and considers the proportions of deaths by age for local authorities for each of these. This section also links cause of death to place of death. See the supporting benchmark tool for more information including age break down of cause of death and place of death by cause per local authority.

The data is sourced from the NEOLCIN 2008-10 pooled data.

Causes of death – by age

The same age groups are considered as were used for section 2 place of death, namely:

- 18-64
- 65-84
- 85+

The charts overleaf look at the data for all ages by Local Authority for each of the main causes: Cancer, CVD, Respiratory Disease and also other (i.e. not Cancer, CVD or Respiratory Disease). The commentary makes reference to the range of charts in the benchmark support tool.
Section 4 – Cause of Death

Figure 8: Proportion of deaths by main cause

The highest proportions of deaths are for the 0-64 and 65-84 age groups from cancer. Regionally Yorkshire and Humber has a similar proportion of deaths to the national position overall (this is lower on 0-64 but higher on 65-84 year age group). Barnsley, Doncaster, Rotherham and East Riding are significantly higher that the England average on deaths from cancer for all ages, Bradford, Kirklees, Craven, Harrogate and Scarborough are significantly lower.

Higher proportions of deaths are for older age groups from CVD. Regionally Yorkshire and Humber has a similar proportion of deaths to the national position overall (this is higher on 0-64 and 65-84 but lower for the 85+ years age group). Bradford, Kirklees, East Riding and large parts of North Yorkshire have significantly higher proportions of deaths from CVD that the England for all age. Barnsley, Doncaster, Bassetlaw, Calderdale and Hull are significantly lower.

Higher proportions of deaths are for older age groups from respiratory disease. Regionally Yorkshire and Humber has higher proportion of deaths to the national position overall (particularly for the age groups 0-64 and 65-8). Several local authorities have significantly higher proportions of deaths from respiratory disease that the England for all ages, with only Sheffield and parts of North Yorkshire significantly lower.
Section 4 – Cause of Death

Cause and place of death

A range of charts also exists for each of the key causes linked to place of death. This tries to ascertain patterns between key causes of death and where the person is most likely to die. The charts below combine this information to give a regional and national view of the data (see benchmark support tool for more information).

Figure 9: Proportion of deaths by main cause and place of death

![Proportion of deaths by place and cause 2008-10](chart)

The regional charts suggest that fewer people die from respiratory diseases at home, patients are more likely to die in hospital from a respiratory disease than any of the other conditions. Cancer has the lowest proportion of deaths at home and the highest in hospices. Summarising the charts in the benchmark tool:

The highest proportion of deaths from cancer is in hospitals (regionally 42%) followed by own residence, then hospices with the fewest deaths in care homes. Regionally for cancer there are fewer deaths in hospitals and care homes and more in the persons own residence and hospices compared to deaths from any cause for all ages.

The highest proportion of deaths from CVD is in hospitals (regionally 58%) followed by own residence, and then care home with only a small proportion in hospices. Regionally for people dying with an underlying cause of CVD there are similar proportion for place of death as the national average.

The highest proportion of deaths from respiratory is in hospitals (regionally 65%) followed by care home, own residence with only a small proportion in hospices. Regionally for people dying with an underlying cause of respiratory disease there is a slightly lower proportion of people dying in hospital and slightly more at home and in care homes.

The highest proportion of deaths from ‘other’ is in hospitals (regionally 56%) followed by care home, own residence with only a small proportion in hospices. Regionally for people dying with an underlying cause of other there is a similar proportion of people dying in hospital compared to the national position with slightly fewer in own residence and slightly more in care homes.
The data is at Local Authority level and is pooled for 2008-10. It focuses only on the 3 main disease groups and the fourth category ‘other’ is made up of any other condition. Therefore

Recommendations from the data are as follows:

- It is recommended that organisations, particularly those with higher proportions of Cancer, CVD and or Respiratory Disease deaths, study their data to understand which age groups resources need to be targeted at to reduce deaths and to put plans in place to target support for people at end of life where required.

- Organisations should ensure high data quality for coding of the primary diagnosis field.

- This data should be linked with the end of life registers. Is their proportional coverage of patients on end of life registers with a range of conditions?

- Differences in end of life care needs depending on age and cause of death – for more detailed information/breakdown see reports on Renal Disease; Alzheimer’s Disease, Dementia and Senility, Deaths from Neurodegenerative Diseases, Liver Disease, Respiratory Disease, External Causes of Death and Estimating the Proportion of Deaths that are Unexpected. A more detailed look at the three main causes of death would provide a more targeted approach to end of life care. For example breaking down respiratory disease, the data shows that lung cancer and chronic disease have the highest proportion of deaths for 65-84 year olds, and pneumonia and respiratory infection have the highest proportion of deaths for 85+ years.

- Consider the health of the population on lifestyle choice as risk factors for the prevalence of a particular disease (e.g. obesity and heart disease, alcohol and liver disease, smoking and lung cancer, etc.). Comparing data on these risk factors could help regions to understand more about the cause of death in their local population now and future trends (see section on demographics and other for more information).

- Understand the data in more depth by considering co-morbidities associated with certain conditions (e.g. considering main as well as underlying causes).

- Research on specific areas – e.g. liver disease disproportionately affects younger age groups - 90% of people who die from this are under 70 years old. People dying from liver disease often have complex care needs and over 70% die in hospital, does your organisations data reflect the national picture?

- Understanding the type and levels of end of life care that is needed for different groups of people by diagnosis, but also within these diagnoses sub groups for age, sex, ethnicity, deprivation, etc.

- Investigate GP Practice profiles for more detailed information on disease by practice populations.
Many of the recommendations throughout this report suggest understanding more about demographics of the population, predicted changes in population and numbers of deaths and prevalence of diseases. This section explores some of this data to be used alongside the previous sections to understand more about the local areas and the impacts on the healthcare system and population. Some of the key areas include:

- Tracking numbers of deaths enables organisations to consider their data in terms of actual people. This not only links the data firmly with the patient but is also useful in other ways for example when considering issues around capacity in nursing homes and hospices.
- Monitoring rates of deaths enable the number of PCT deaths to be compared as a proportion of the population.
- Using demographic data such as age, sex and deprivation with end of life data to understand more about the likelihood of a person dying from a particular disease. Understanding this can contribute to planning end of life services in different ways to suit different localities within the region.
- Examining data on projected populations and projected deaths by age break down in line with information such as preference for place of death (primarily home but hospice for the older people) enable better planning around future end of life services.
- Understanding any changes in prevalence of diseases can be useful going forward. Future changes to prevalence of Cancer, CVD, and Respiratory Disease for example will impact on future hospital admissions and future demands for community care.

These will be looked at in to understand how this data can affect end of life services.

The part of this section considers the percentage of males and females for each of the following age groups for the region: 0-64, 65-84 and 85+ years. The largest difference is the 85+ age group where the proportion of female deaths is more than double those for males.

**Figure 10: Proportion of the population by age group**

![Proportion of the population by age group](image)

Source Data: NHS Information Centre for Health and Social Care Portal - mid 2010 estimates
Looking at the charts for rates of death per 100,000 population in the supporting benchmark tool, enables PCTs to be benchmarked on the number of deaths from all causes during 2008-10 as a proportion of their population. The split by males and females show that males have a higher death rate compared to females (see life expectancy charts). Yorkshire and Humber as a region is reporting higher death rates compared to the national average. These death rates cover all causes, so to understand the issues in more detail the death rates for specific causes would need to be examined.

**Life Expectancy and Deprivation**

It is useful to consider factors such as life expectancy and deprivation for different areas in terms of end of life. The NEOLCIN report ‘Deaths in Older Adults in England’ (Oct 2010) found that people who lived in areas in the most deprived quintile had a higher risk of dying of respiratory disease for example.

The map below of the Yorkshire and Humber region flag pockets of deprivation:

*Figure 11: Map of deprivation*

Looking at the areas in more detail down to postcode level and mapping this data across to deaths from diseases and place of place of death would reveal if there are local differences between areas of deprivation. This would enable the targeting of resources and interventions in specific areas. The GP Practice profiles include information on deprivation at practice level which would also support this work.
Projections and disease prevalence

Using available data on predicted numbers of deaths going forward and predicted increases in population is useful to support planning end of life services both now and in the future. The supporting benchmark tool includes charts by PCT cluster show a predicted stabilisation of deaths for the next few years followed by an increase from around 2028. The chart below shows the predicted increase in population over the up to 2030. Further exploration of this data by age categories would be useful in understanding these increases, particularly the extent of population increases in the older age groups.

Figure 12: Projected population and deaths

The demographic and other data section showed that Yorkshire and Humber reported higher death rates compared to the national average using standardised death rates, however the number of deaths across the region has declined slightly over the last 3 years.

Females tend to have a higher life expectancy than males and therefore tend to make up a higher proportion of the elderly population group. Deprivation levels vary across the region. Areas with higher levels of deprivation tend to have lower life expectancy overall and patients are more likely to die in hospital in these areas compared to other localities.
The projected numbers of deaths are expected to continue to rise for the East Riding and North Yorkshire and York (areas that have the highest elderly population within the region). The general pattern for the rest of the region is a slight decline and then stabilisation of deaths until around 2028 onwards, followed by an increase up to 2033 and beyond. There is an anticipated increase in population in all PCT areas from 2010 to 2030, particularly in Bradford and Leeds (more than 22% increase in population expected by 2030). Additionally the prevalence of disease in expected to increase for a range of conditions.

**Demographics and Other - Recommendations**

- Understand the profile of your population to support work on end of life care. Demographics data and information on projections help to support planning around end of life services and enable localities to begin tailoring services to meet the needs of their population and specific groups within this.

- Plan for future services based on expected increases in the number of deaths. Additionally the rise in population and ageing population means that end of life care needs will be more in demand and the move towards increased support in the community and fewer reductions to hospital will be necessary to sustain end of life services.

- Understand your local area using tools such as General Practice profiles and Local Health Profiles. Use these to compare data on age distributions, estimated prevalence of diseases, and deprivation of practice populations. Consider how these impact on end of life care in your area.

- Use PCT based end of life care profiles to compare local data with regional and national averages. Going forward it is hoped that these will become available at CCG level.

- For key end of life areas such as end of life registers, place of death, cause of death and deaths in hospital, consider the indicators around these in the context of demographic and prevalence data. This provides context to the indicators and may help to explain differences between results. This data must be considered as part of the overall picture to gain a true understanding of end of life care before action is taken.
This section of the report is currently under development. It is however worth discussing the type of information that will be incorporated into the report. Some of the key questions we will be considering are:

- How big is the area? What is the nature of the area? e.g. rural, urban, coastal, etc.
- How far do people living at different postcodes need to travel to hospital? Hospices? What are the local transport links like?
- How many beds are available in hospitals to support end of life care? How many beds are there in hospices and care homes in each area?
- What is the staff to patient ratio for different end of life services?
- What end of life services/pathways exist for each area?
- What are the financial resources available to spend on end of life care?

Examining local areas in terms of geography, drive times, capacity and resources is useful for understanding end of life services. To improve quality of care at end of life, it is important to understand the structure of the area, e.g. consider the following: to what extent is the capacity in place for people to die in their place of choice? How might this change in the future? If Trust X receives most end of life patients from the same region and has a good understanding of hospice facilities and end of life registers, how would this compare to Trust Y which is on the border of the locality and receives emergency admissions for patients at end of life from a range of areas and it is difficult to co-ordinate?

Understanding distances, drive times and local transport is useful in understanding why people may prefer to die in certain places, and why there preferences may be difficult to meet? (e.g. patient wishes to be discharged from hospital to die at home but the distance by ambulance from hospital to home outs the patient at greater risk. Mapping the local hospices, hospitals and care homes is useful to understand the number of beds available in different settings. Are there areas of under/over utilisation? Accounting for patient choice, should services in hospitals be transferred into the community?

In terms of resources, consider whether staffing levels sufficient to provide a high quality end of life service in line with patient wishes. Do staff have the correct level of training and education to make decisions with the patient around the best course of action for patients approaching end of life? What is the current spending for your area on end of life by service? Can changes be made to improve end of life services and make cost savings to reinvest in end of life care?

Although currently under development, some recommendations can be considered. For example:

- Map current services across the locality in detail. What capacity is available now? What will need to be available to achieve high quality end of life care across the locality? How will the transition period in the NHS affect end of life services?
- What can be done to promote end of life services to emerging CCGs?
- What information exists for your area in QIPP plans? Contracts? Quality Accounts?
- How might levers such as the outcomes framework and CQUINs be used to enhance quality of care at end of life?
- To what extent has training at end of life being rolled out across the locality?
- Examining the locality by post code level, have areas been identified where there is limited community support at end of life or lack of hospices available? What could potentially be done to support these areas?
- Skills for health functional analysis – this tool could be used to support service managers to identify workforce structures and required competences to ensure individuals receives quality care in their last year of life3
Summary

This report aims to bring together data on end of life from a range of sources and has made a number of observations from the data by benchmarking organisations and looking at the data across key themes. Various suggestions have been made both for further exploration of data and also other recommendations for actions which organisations may wish to consider adopting.

Appendix A includes a diagrammatical representation of the key themes discussed in the report to try understand the interrelationship between them in terms of how the demographics of an area for example can influence different aspects of end of life care.

With regards to the recommendations made throughout the report both around exploring data further and considering how the quality of end of life care can be improved, Appendix B lists a range of suggestions that could support further work on this.

With regards to further exploration of data, a number of reports and information sources such as end of life profiles and GP Practice profiles have been suggested as useful material. The supporting benchmark tool includes a list of data sources used including web links for information and appendix C lists a range of reports and materials used in the creation of the report.

The information in this report and supporting benchmark tool should be used a starting point for investigation and to identify areas to learn from.
Appendix A - Interrelationships

EOL Themes
- End of Life Register
- Place of death
- Admissions to hospital

Demographics
- Deprivation
- Age and sex
- Ethnicity
- Population

Area, Capacity and Resources
- Geography (landscape, drive times)
- Capacity (beds, services)
- Resources (staff, finance, equipment)

Condition/Pathway
- Type of disease/condition
- Pathway
- Prevalence

The diagram shows the interrelationship between factors influencing the quality of end of life care provided. Local differences in demographics, prevalence of diseases, geography and available capacity and resources all impact on this. Benchmarking areas is useful for identifying points of investigation but differences between areas should be understood in the context of these factors.

Each of these overarching factors is made up of different elements that influence the likelihood of being on an end of life register, achieving preferred place of death and being admitted to hospital at the end of life.

Areas with high levels of deprivation are linked to lower quality of end of life care as they people are less likely to be on an end of life register and more likely to die in hospital. The age structure of the population affects the capacity required and resources needed to ensure high quality end of life care.

Prevalence of specific diseases is influenced by age, sex, ethnicity and deprivation. Areas with high numbers of smokers are more likely to have higher levels of respiratory diseases. Understanding risk factors in the population and prevalence of disease is necessary to target resources effectively for end of life planning.

The geography of the area influences the level and quality of end of life care. Large urban towns for example will require a different end of life care set up compared with rural areas with hard to reach places.

The Factors relate to the end of life key themes such as place of death, but are also influenced by and impact on each other.
Appendix B – Supporting Concepts

Statistical and Technical

- **Funnel Charts** – used to identify outliers
- **Quadrant Charts** – compare organisations on a measure by current score and movement since last measure
- **Forecasting** – predicting future trends/patterns in data
- **Statistical testing** – testing significance of differences and relationships using t-tests, correlations, regression analysis
- **Confidence intervals** – comparing differences between groups
- **Capacity and flow analysis** – looking at pathways and throughput
- **Weighting and standardisation of data** – enable comparison of data by adjusting for age and sex differences
- **Statistical process control charts** – measure changes to processes and the impact of interventions

Improvement and Other

- **Pathways** – looking at the efficiency of the patient journey and reducing waste
- **Process Mapping** – identifying opportunities for improvement in the process
- **Identifying gaps in service** – what is missing? How can this be addressed?
- **Identifying bottle necks in services** – what is the weak point in the service?
- **Demand management** – planning and forecasting to ensure patients receive the best possible end of life care
- **Discharge planning** – ensuring patients are discharged from hospital in a timely manner
- **Root cause analysis** – identifying the underlying cause of a problem and how it can be addressed

Other

- **Communication** – for example promoting the work of hospices within the region
- **Education and Training on end of life care** – E-learning modules
- **Service Planning** – designing a service for the locality
- **Using the models** – training on the 3 NEOLCIN models
- **End of life tools** – training on using LCP, advance care planning
Appendix C – Bibliography

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**National End of Life Care Intelligence Network**


**National End of Life Care for Adults**


**National Institute for Health and Clinical Excellence**

[http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp)

**National Council for Palliative Care**


**The Gold Standards Framework**
