**Extracts from**
3. Full Guidance on using QOF to improve palliative/end of life care in primary care
4. Focus on QOF payments (April 2011)
5. Predicting deaths: estimating the proportion that are ‘unexpected’ (Feb 2011)

### Aim of using end of life registers

*Ensuring people approaching end of life are included 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*

### What do we want to know about end of life registers?

- How many people are on an EOL register in each PCT area?
- Is everyone approaching end of life included on an end of life register?
- How many additional people potentially need to be added to the register? (i.e. people who have not currently been identified who ought to be included)
- Are there clear and consistent definitions around who should be included on an end of life register across all areas?
- Are the registers regularly reviewed by multidisciplinary teams and kept up-to-date?
- What would a ‘good end of life register’ look like? For example - valid, accurate, complete and up-to-date?
- What information is included on an EOL register?

### How do end of life registers support improving quality of care at end of life?

- End of life registers support healthcare staff in working with patients to put plans in place around the patient’s care at end of life. The registers can also record preferences such as place of death for those patients approaching 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’ and the use of end of life registers is considered best practice by NICE, RCGP and the National NHS End of Life Programme.
- 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 and ensure they are included on a palliative care register, and to predict how many people may still need to be identified within their practice population as approaching end of life.
- Based on 1% of practice populations dying each year on average, (approx 20 per GP per annum), statistics suggest that around one quarter of these will die from cancer, around one third from organ failure, around one third from general frailty and the remainder classed as sudden deaths. 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.
• 3 triggers:
  o The surprise question – ‘Would you be surprised if this patient were to die in the next 6-12 months?’
  o The patient makes the choice for comfort rather than curative care
  o Specific indicators of advanced disease for the 3 main groups described above (cancer, organ failure and elderly frail/dementia) indicate that the patient is approaching end of life.

• The use of end of life registers is thought to lead to:
  o More people dying in their place of choice
  o Fewer hospital admissions

What indicators are included in the report?

• Prevalence of practice populations on an end of life register (number on a palliative care register as a proportion of the practice population) at PCT level.
• Proportion of patients on an end of life register out of the 1% of patients on average expected to die each year per GP practice (i.e. 1% of practice population) at PCT level.
• Comparison of the number of patients on an end of life register and as a proportion of the actual number of deaths per PCT area.
• % of maximum QOF points for palliative care (max 3 points per practice) that can be achieved per PCT for the following:
  o Holding a palliative care register (end of life register) of those thought to need palliative care or who have been identified as potentially in the last year of life (PC03)
  o Reviewing patients on a register at multidisciplinary team meetings on at least a 3 monthly basis (PC02)

Source data

• QOF prevalence data for palliative care registers 2008-09, 2009-10, 2010-11
• QOF achievement points 2010-11
• Primary Care Mortality Database (extract August 2011)

Caveats

• QOF data is voluntary for GPs to complete and therefore subject to variations in data quality depending on completion.
• Rankings of data may be inappropriate due to the following:
  o QOF points do not reflect practice workload issues
  o Social and demographics issues such as population age, sex, ethnicity and deprivation need to be accounted for
  o Local circumstances may differ e.g. student population, homeless population, etc
  o Co-morbidities are not taken into account

Therefore the data is not conclusive but rather should be used as a starting point for further investigation.

• 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 can not currently be accessed. Therefore the information is useful in that it provides an idea of proportions but does not track specific patients (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).

Key Findings

• Generally Y&H PCTs are in line with the England average (0.17%). Only North Lincolnshire PCT appears to be significantly below average in the Y&H region (range from the highest in our region 0.28% to the lowest 0.10%).
• For all PCTs in Yorkshire and Humber except for North Lincolnshire, 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.
• It is expected that prevalence rates for people on end of life registers should be higher given that 1% of a GP practice population is likely to die on average each year (subject to
local variation). Current Y&H results are between 10-28% of the number of people expected to die per GP practice. Whilst we are dealing with relatively small numbers of patients and not all deaths could be anticipated in advance (i.e. meet the ‘3 trigger criteria’ for inclusion on an EOL register), it is expected that prevalence rates should be higher both regionally and nationally than current data suggests.

- No PCTs are currently achieving the local ambition of 50% for the calculated average number of deaths recorded on an end of life register at present, with 28% being the closest.
- 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 deaths rather than expected deaths. This suggests that on average fewer people are dying than the expected 1% for each PCT apart from East Riding. East Riding PCT has a particularly high proportion of older people in the population compared to other PCTs which could explain why this PCT had a higher number of deaths compared to the expected ratio of 1% of GP list size.
- 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%.

### Key Recommendations

- **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.**
- **GP Practice profiles include QOF points achieved across other areas which may help to provide context when comparing GP practices.**
- **Additionally consider comparing data to local population demographics to support identification of patients approaching end of life. Factors such as age, ethnicity and deprivation for example affect prevalence of disease and life expectancy. 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 (see theme on demographics and other).**
- **Practices without a register should begin to set up a register. For those practices with registers already in place, they need to work to ensure that reviews are carried out as a minimum every 3 months by multi-disciplinary teams. The reviews look at everyone on the end of life register and consider any changes and updates.**
- **The local population and prevalence data should also be triangulated with the QOF points 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.**

### Further Notes

- **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, DNACRP, etc. Going forward with the roll out of the electronic palliative care co-ordination system, these decisions can be shared across the health system to enable a more joined up approach to end of life.**
- **Consideration should also be given to supporting care homes to develop and roll out palliative care registers.**
**Excerpts from**

1. Local Preferences and Place of Death in Regions within England (Aug 2010)
3. Deprivation and Death: Variation in place and cause of death (Feb 2012)

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### Aim of enabling people to die in their preferred place of death

*Enable people to die in their chosen place of death where possible. Evidence suggests this includes reducing deaths in hospitals, and increasing deaths in people’s own place of residence and hospices*

### What do we want to know about place of death?

- 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?

### How does knowing and enabling patient preferences on place of death support improvement to quality of care at end of life?

- 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. 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.
- Generally as age increases, a preference to die at home decreases in favour of dying in a hospice. 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 one’s 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, where the hospital cannot do anything more for the patient, is neither in the best interest of the patient (as it goes against their preference for place of death), and may be more costly to the health care system.
- Preferences 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 care homes, hospitals, GP practices, hospices, ambulance and social care staff, etc can take the appropriate course of action in line with patient’s wishes.

### What indicators are included in the report?
% of people dying in the following locations: hospital, own residence, care home, hospice and elsewhere. The data is split by:

- Age bands: 0-64 years, 65 to 84 years, 85+ years
- Trend data for 2008-09, 2009-10 and 2010-11
- Comparisons data for place and age
- Y&H charts which combine and separate home and care home as care home is often seen as the person's own home.

Source data

- Data extracted on place of death from the National End of Life Care Intelligence Network profiles (NEOLCIN) for 2008-10 pooled data. Original data source ONS annual mortality extracts 2011 and United Kingdom Association of Cancer Registries (UKACR) populations dataset v.5.4
- Extract taken August 2011 from the Primary Care Mortality Database (PCMD) for the years 2008-09, 2009-10 and 2010-11

Caveats

- 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.
- PCMD data was extracted Aug 2011 and is subject to updates. Place of death categories created through links to a lookup table based on the place of death code and address. Whilst every effort has been made to make this 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.
- Data for NEOLCIN is pooled data covering 2008-10 and 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.

Key Findings

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.

**Hospital**
- Slightly more deaths in hospital seem to occur in the 65-84 years age group on average, 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).
- Bradford and Airedale PCT and areas of North Yorkshire reported the lowest % of deaths in hospital over the years (below 50%) whereas Hull PCT was high with over 60% dying in hospital.

**Own Residence**
- The % of patients dying in their own residence based on the NEOLCIN data was slightly 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 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.

**Care Home**
- The % of patients dying in a care home based on the NEOLCIN data was slightly higher in Yorkshire and Humber compared to 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.

Hospice

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.

Comparison

The place of death comparison charts for local authorities allow the proportions to be viewed by age group with hospital deaths dominating all age groups.

The comparative charts based on PCMD data for PCT clusters illustrate the proportional gap between usual place of residence (home and care home combined), acute trust, hospices and other. Deaths in hospices and other remain low across all PCTs, however the gap between hospitals and own residence varies between clusters.

Key Recommendations

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 results more meaningful (i.e. to be able to detect statistically significant differences between age groups for example). The national survey indicated that deaths at home were the first choice for most people. Conducting local surveys or auditing preferences for place of death through advance care planning and the Electronic Palliative Care Co-ordination System (EPCCS) would be useful in supporting this. 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’. Therefore gathering evidence on local preferences and aiming to meet individual patients preferred choice for place of death is the key factor.

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 root cause analysis of the problem.

Checking coding of palliative care in hospitals is also important to ensure that 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 that palliative care coding is examined to ensure that trusts are confident that the data accurately reflects the situation.

Further Notes

Investigate the feasibility of those people expressing a preference to die at home being able to do so and consider what would need to change in the service for this to happen. For example, increasing support for people at home approaching end of life. Can resources be directed to support this?

Examine the capacity, resource and geographical issues involved in achieving preferred place of death. Hospices were found to be a preference for patients aged 85+, consider what prevents a large proportion of this age group from being able to die in a hospice e.g. example lack of bed capacity? Large distance to the nearest hospice?

Review the services 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.

Despite every effort, it is not always possible for people to die in their preferred place of death. Given this, ensure that people still have the best possible death irrespective of the care setting. It is recommended that care at end of life is reviewed across the different settings to pin point where improvements could be made.
### Aim of reducing deaths in hospital for people approaching end of life

**To reduce deaths in hospital for people approaching end of life in line with patient preferences for place of death**

What do we want to know about deaths in hospital?

- What are the key causes of death of people admitted to hospital?
- Can some admissions be avoided?
- Which conditions are classed as leading to ‘expected’ deaths compared with ‘sudden deaths’?
- For those people who die in hospital, how long are they in hospital from the time of admission to death?
- What effect does age have on LOS in hospital from the time of admission to death?
- What effect does age, primary diagnosis and LOS have, if any, on each other?
- How many admissions to hospital were there in the last year of life and what were the cost implications of this?

### How does reducing deaths in hospital support improvement to quality of care at end of life?

- Reduction in hospital admissions at end of life increases the patient’s chance of dying in their preferred place of death (generally there is a low preference to die in hospital). This enables the patient to have a better quality of life in their final days.
- Enables families and carers to support their loved one at home or in a hospice environment rather than visiting hospital.
- Reduction in unnecessary admissions leads to reduction in cost and saves bed days. This releases resources to be used on patients whose quality of life can be enhanced through hospital admission.
- 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 environment.
- 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.

### What indicators are included in the report?

- Using intelligence to improve end of life care
- Variations in Place of Death in England: Inequalities or appropriate consequences of age, gender and cause of death (Aug 2010)
- QIPP indicator for End of Life Care – Nov 2011
- National End of Life Intelligence Network Models
- Exploration of deaths in hospital by PCT pooled data for (2008-11) for:
  - Age bands 0-64, 65-84 and 85+.
  - Length of stay (LOS) 0-3 days, 4 to 7 days and 8+ days
  - Primary diagnosis (Cancer, CVD, Respiratory Disease and other)

- Combinations of the above factors for Yorkshire and Humber
- Trend data for Y&H to identify any changes in patterns over the last 3 years based on age bands, LOS and primary diagnosis (2008-09, 2009-10, 2010-11)

**Source data**

- Hospital Episodes Statistics (HES) – Data extracted from the following universes: 2008-09 v.15, 2009-10 v.16, 2010-11v.14

**Caveats**

- Data must conform to the small numbers rule to avoid the potential identification of any patient.
- Data must not be released outside of the NHS
- Age bands, LOS and primary diagnosis have been defined using the same criteria as Variations in Place of Death\(^2\) and QIPP Indicator for EOL – Hospital admissions in the last year of life\(^3\)
- Primary diagnosis is not necessarily the same as ‘cause of death’
- This data looks at primary diagnosis only and does not include patients as Cancer, CVD or Respiratory Disease if it is not classed as the primary diagnosis.

**Key Findings**

- 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.
- 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 diseased the highest proportion of deaths in hospital tends to be within 4-7 days.
- The largest proportion of people dying 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.

**Key Recommendations**

- 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 at end of life that are more likely to be admitted to hospital? Are there other services such as community services which may potentially be more appropriate for the patient?
- Are there specific patterns around postcodes 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. To explore this in more detail the PCMD can be used to identify numbers of patients by postcode areas that have died in hospital. Additionally, the GP Practice profiles include data on emergency admission rates by GP Practice for Cancer, CHD and Respiratory Disease as well as others. The rates are compared against the PCT and England average.
The current analysis looks at age bands, primary diagnosis and LOS only; further exploration could explore issues around, ethnicity, living arrangements, other diagnosis 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.

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. It is recommended that the discharge pathway is examined to understand any reasons why discharges for end of life patients may be delayed.

Analysis of the number of admissions to hospital in the last year of life would also be useful.

Further Notes

- 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.
- Work could be done around looking at whether the patient should have been admitted in the first place – for example if they are on an end of life register and have specified a preference to die at home, it was perhaps not in the best interest of the patient to have been admitted to hospital.
- Additionally 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 through a rapid discharge programme.
- 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.
- Yorkshire and Humber commissioner financial model looks at how many people in acute hospitals could reasonably have ended their days in alternative care settings and calculates the cost implications. This model might be worth exploring for specific areas.
Aim of understanding cause of death

To understand the causes of death in the region and the impact that cause has on age of death and place of death

What do we want to know about deaths in hospital?

- What age groups are most likely to die from what conditions?
- Where are 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 cause of death and place of death?

How does information on cause of death support improvement to quality of care at end of life?

- Enables adjustments to end of life services to be made in line with the need of the population.
- Targets support to certain conditions where end of life care needs to be enhanced.
- Support could be in the form of more resource needed for certain conditions, education for medication management, enhanced training for staff around identification of certain signs and symptom and support pathway management of patients at end of life.

What indicators are included in the report?

- All deaths from cancer – all ages, 0-64 years, 65-84 years and 85+ years
- All deaths from cancer – in a hospital, in own residence, in a care home, in a hospice
- All deaths from CVD – all ages, 0-64 years, 65-84 years and 85+ years
- All deaths from CVD – in a hospital, in own residence, in a care home, in a hospice
- All deaths from Respiratory Disease – all ages, 0-64 years, 65-84 years and 85+ years
- All deaths from Respiratory Disease – in a hospital, in own residence, in a care home, in a hospice
- All deaths from other (not cancer, CVD or respiratory disease above) – all ages, 0-64 years, 65-84 years and 85+ years
- All deaths from other (not cancer, CVD or respiratory disease above) – in a hospital, in own residence, in a care home, in a hospice

Source data

- National end of life care intelligence network profiles 2008-10
Caveats

- Pooled data by local authority
- Limited to 3 main disease groups and other.

Key Findings

Cancer

- Higher proportions of deaths are for the 0-64 and 65-84 age groups from cancer. 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 than the England average on deaths from cancer for all ages, Bradford, Kirklees, Craven, Harrogate and Scarborough are significantly lower.
- 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.

CVD

- Higher proportions of deaths are for older age groups from CVD. 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 than the England average for all age. Barnsley, Doncaster, Bassetlaw, Calderdale and Hull are significantly lower.
- 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.

Respiratory Disease

- Higher proportions of deaths are for older age groups from respiratory disease. Yorkshire and Humber has higher proportion of deaths compared 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.
- The highest proportion of deaths from respiratory disease 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.

Other (not Cancer, CVD or Respiratory Disease)

- Higher proportions of deaths are for the 0-64 and 85+ age groups from other. Regionally Yorkshire and Humber has lower proportion of deaths compared to the national position for all ages (this is mostly the effect of the 65-84 age group). Sheffield is the only local authority with significantly higher proportion of deaths from other compared to the England average, whilst Barnsley, Rotherham, parts of North Yorkshire and all of the Humber area are significantly lower.
- 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.

Key Recommendations

- It is recommended that organisations, particularly those with higher proportions of cancer, CVD and or respiratory 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. Consider if there is sufficient proportional coverage of patients on end of life registers in relation to the 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
A 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, research 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 organisation's 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.
- Again the GP practice profiles are a useful source of data on key conditions.

Further Notes

- Contemplate using the whole systems partnership cohort model and Yorkshire and Humber Financial model to simulate likely end of life care needs for a typical population of 100,000 over time focusing on implications of early recognition and reduced hospital admissions and considers patterns for a key range of diseases.
- Potential future planned reports available from NEOLCIN on a range of conditions (e.g., Cancer, CHD, etc) could be useful in supporting understanding of conditions.
Using additional data on rates of death, deprivation, life expectancy, projections in populations and numbers of death and prevalence of conditions

To understand local demographics, current and future rates and trends in death, population and prevalence of diseases that impact on end of life care

What other information can help support improving quality of care at end of life?

- What proportion of the population is male and female? And what is the age breakdown of PCT populations?
- What is the death rate by PCT? How many deaths are there per PCT? And what is the proportional gender split?
- What is the life expectancy for males and females?
- What are the levels of deprivation across the region?
- Has the number/proportion of deaths changed over time?
- What are the future predictions for populations and numbers of deaths in the next 5, 10, 20 years?
- How is the expected prevalence of key diseases expected to change going forward? How might this impact on planning for end of life now?

How can this information be used to support improvement to quality of care at end of life?

- Tracking numbers of deaths enables organisations to consider their data in terms of actual people. This not only links the data firmly with patients but is also useful in other ways for example when considering issues around capacity in nursing homes and hospices (links to section 2 ‘Place of Death’ and section 6 ‘Area’)
- Rates of deaths enable the number of PCT deaths to be compared as a proportion of the population.
- Demographic data such as age/sex and deprivation affect the likelihood of the age and condition a person dies from. 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 breakdown in line with information such as preference for place of death, (primarily home but hospice for the older people), enables 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.

What indicators are included?

- Proportions of males and females and age breakdown (0-64, 65-84 and 85+)
- Death rates from all causes per 100,000 population
- Trend data for deaths by PCT
- Proportions of deaths split by age and sex

Extracts from
2. Deaths in Older people in England 2010
- Standardised Hospital Mortality Rates (SHMR)
- Life expectancy for males and females at birth and at age 65 and deprivation scores per PCT
- Projected deaths up to 2033 and projected population to 2030.
- Prevalence of some conditions and predicted prevalence in the future.

### Source data

- Primary Care Mortality Database (extract August 2011)
- The NHS Information Centre for Health and Social Care Indicator Portal (previously NCHOD)
- The NHS Information Centre for Health and Social Care mortality data
- YHPO website (originally sourced from [www.communities.gov.uk](http://www.communities.gov.uk))
- 2008-based sub national populations – sub national statistics unit ONS
- Disease Prevalence Models – The Network of Public Health

### Caveats

- Prevalence current Dec 2011, future predictions for 2020 is based on older data.
- Range of data sources used covering different time periods
- Primary care mortality database is an extract as at August 2011 and is subject to updates

### Key Findings

- Yorkshire and Humber reported higher death rates compared to the national average using standardised death rates.
- 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.
- Deprivation levels vary across the region. 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.
- 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.
- 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).
- The prevalence of disease in expected to increase for a range of conditions.

### Key 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.

### Further Notes

- Understand your local area using tools such as General Practice profiles and Local Health Profiles.
- Use the NEOlCIN PCT End of Life profiles to compare local data with regional and national averages, ideally these will be by CCG going forward.
- 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.
Examine localities in relation to end of life care in more detail through understanding the influences that the geography of an area and the available capacity and resources influence end of life care.

What other information can help support improving quality of care at end of life?

- 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?

How examining geography, drive times, capacity and resources contribute to improving quality of care at end of life?

- 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?
- Are 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?

What indicators are included?
- To be determined

**Source data**
- To be determined

**Caveats**
- To be determined

**Key Findings**
- To be determined

**Key Recommendations**
- 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?

**Further Notes**
- Skills for health functional analysis – this tool could be used to supports service managers to identify workforce structures and required competences to ensure individuals receives quality care in their last year of life.