

End of life care - Benchmarking in the East Midlands

June 2016



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Purpose of Report

Since its establishment in 2015 the East Midlands End of Life Care Local Leadership Group (LLG hereafter) has created “Task and Finish” groups to address specific issues associated with the improvement of end of life care across the region.

This is a report of a benchmarking exercise that was conducted for the region to highlight any unwarranted variations in access and outcomes and to identify recommendations for future action that the LLG may explore as an East Midlands collaborative to improve end of life care.

NHS IQ had already developed some guidance that covers what is measured currently (<http://www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/care-in-the-last-days-of-life.aspx>) which was taken as the starting point for this report. From the available raw data East Midlands specific data was extracted and is presented here. Individual Clinical Commissioning Group (CCG) reports have been made available to the 19 CCGs in the East Midlands.

The East Midlands Clinical Network (the Network hereafter) support team conducted a detailed review of the available data sources, the result of which is this report.

This report is a starting point, a ‘dashboard’ that should be used to provide a comparative view across the East Midlands and to prompt discussion, further investigation and improvement efforts to address unwarranted variation.

We have chosen not to give our own interpretation of the results as we are not always aware of the circumstance of care provision in a given areas. We would instead suggest that the reader should make their own interpretation of their data and its comparison to other areas.

Note

Data presented in this report is grouped into different geographical and organisational footprint categories depending on the year the relevant data were collected. Since the Health and Social Care Act in 2012, Primary Care Trusts (PCTs) were replaced by Clinical Commissioning Groups (CCGs) on 1 April 2013. There are 209 CCGs in England, 19 of which fall into the 'East Midlands' geography, and therefore fall into the remit of the Network.

The current geography of East Midlands covers five counties: Derbyshire, Leicestershire and Rutland, Lincolnshire, Nottinghamshire and Northamptonshire.

Before April 2013, however, there were three NHS Area Teams that covered the current East Midlands region:

- Derbyshire and Nottinghamshire
- Leicestershire and Lincolnshire
- Hertfordshire and the South Midlands (covers Northamptonshire)

Any data that was collected and/or published before April 2013, therefore, is either presented as NHS Area Teams or PCTs.

It is therefore difficult to conduct direct comparisons of data that was collected in different years and in different NHS landscapes.

Much of the data is old. We continue however to recommend that organisations review the apparent variation and ask questions of their own and others practice. There may be opportunities to adopt what others have found to be good practice or to discuss areas of challenge with peers. It is our aim that as new data becomes available we will continue to update this document.

Foreword by Palliative & End of Life Care Clinical Leads

Welcome to the first of our benchmarking reports for the East Midlands Clinical Network for End of Life. We have taken data that is freely available and re-produced it in a format that is relevant for the East Midlands.

This benchmarking report will allow different health communities, hospital trusts and CCGs to review how well they are performing against various national measures and provide direct comparison with their neighbouring organisations. The data clearly shows variation between counties and hospitals in terms of performance to the standards each report covers.

We hope that individual organisations will use this information to target where they may have weaknesses and disparity. Organisations are encouraged to identify other organisations who are achieving more positive results to learn from their approaches, policies and practices.

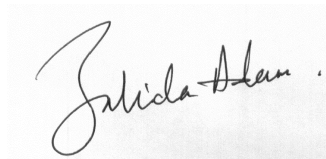
It is recommended that Commissioners consider using this information to inform their commissioning strategies for end of life care.

This document will continue to be updated as new reports are released and when the anticipated new specialist palliative care quality measures are issued in 2016 we hope to incorporate fresh data into this benchmarking report.

With the current difficulties within the NHS around funding we have produced this piece of work through the goodwill and hard work of the managerial staff at the NHS England clinical network and it is these people who should take credit for being able to produce such a comprehensive piece of work.



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Measures – identified by the End of Life Care Local Leadership Group

The following were used as a guideline for extracting measures for the benchmarking exercise in the East Midlands:

- ELCQuA measures
- VOICES survey
- National care of the dying audit for hospitals
- NICE quality statements

National audits and reports such as those listed above are a source of data that capture many of the measurements that we wish to consider in the East Midlands, which are:

- People approaching the end of life are identified in a timely way.
- There is a strategic plan for end of life care which encompasses patients with all diagnoses and care provided in any care setting and covers each step in the end of life care pathway.
- People approaching the end of life have a documented assessment of their current and anticipated physical, psychological, spiritual and cultural needs and preferences and treatment plan for symptom management.
- All organisations communicate effectively with the GP around end of life care decisions and inform general practice within 24 hours when a person dies.
- A locally agreed palliative care formulary stock of drugs (and equipment) is readily accessible to all out-of-hours medical practitioners, with robust clinical governance standards in place to protect both patients and workers.
- Proportion of deaths in usual place of residence.
- Level of access to face to face specialist palliative care services.

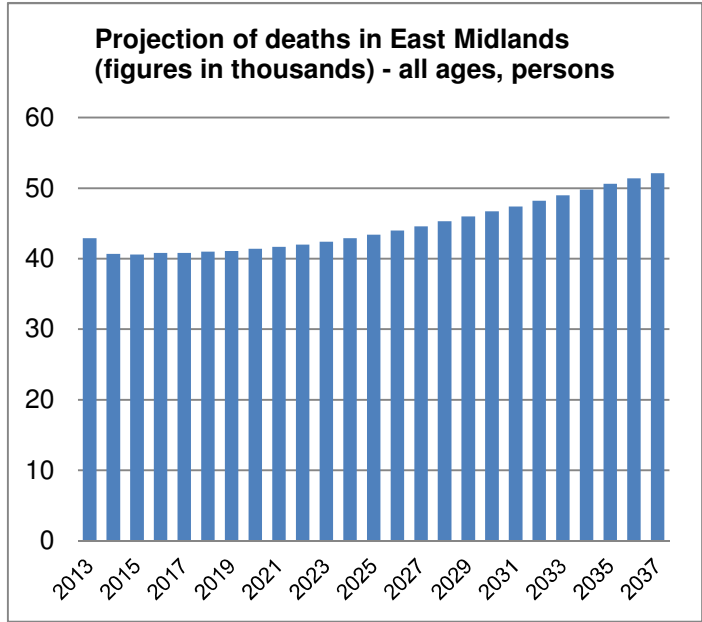
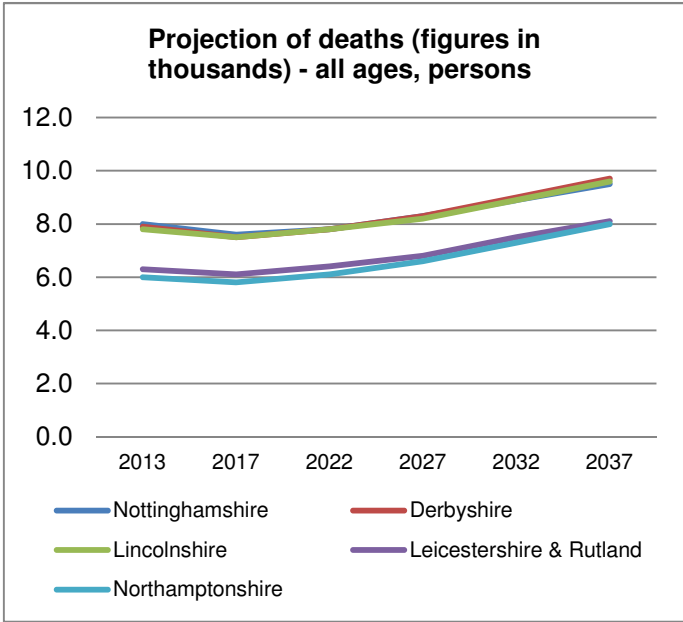
This report contains:

1. Projection of deaths
2. Quality of end of life care – National VOICES survey 2011-12 and 2012-13
3. Place of death
4. Underlying cause of death
5. Quality of end of life care – National Care of the Dying Audit for Hospitals 2013-14

1. Projection of Deaths

Source: ONS 2012-based Subnational Population Projections for England
www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2012-based-projections/rft-projected-coc.xls

Figures show that there will be a steady rise in deaths from 2015 resulting in an approximately 25% increase in deaths. This is a consistent trend across all counties.



2. Quality of End of Life Care – National VOICES Survey Outcomes – 2011-12 and 2012-13 data

Source: National Survey of Bereaved People (VOICES) by NHS Area Team (England), 2011-12

http://www.ons.gov.uk/ons/dcp171778_355031.pdf

National Survey of Bereaved People (VOICES) by NHS Area Team (England), 2012 to 2013

http://www.ons.gov.uk/ons/dcp171778_399897.pdf

It was possible to compare overall quality of care between 2011-12 and 2012-13 as both reports contained relevant data.

NHS Area Teams that fit into current East Midlands patch:

- Derbyshire and Nottinghamshire
- Leicestershire and Lincolnshire
- Hertfordshire and the South Midlands (covers Northamptonshire)

2.1 Overall quality of care – 2011-12 and 2012-13 comparisons

Question 51 of the VOICES survey asks 'Overall, taking all services into account, how would you rate the quality of care in the last three months?' The five response options, 'Outstanding', 'Excellent', 'Good', 'Fair' and 'Poor'.

'Outstanding and Excellent' and 'Fair and Poor' have been combined due to the majority of responses being given as 'Excellent'. 'Good' is not presented.

NHS Area Team	2011-2012		2012-2013	
	Outstanding /excellent	Fair/poor	Outstanding /excellent	Fair/poor
Derbyshire and Nottinghamshire	43.4	22.5	43.3	24.1
Leicestershire and Lincolnshire	40.7	25.5	41.5	23.4
Hertfordshire and the South Midlands	40.1	23.0	40.7	24.1

Between 2011-2012 and 2012-2013 the following changes are observed in the rating of overall quality of end of life care:

- There is a slight increase (1.6%) in Derbyshire and Nottinghamshire for fair/poor.
- There is a slight increase (0.8%) in Leicestershire and Lincolnshire for outstanding/excellent and a slight decrease (2.1%) for fair/poor.
- There is a slight increase (0.6% and 1.1% respectively) in Hertfordshire and the South Midlands for outstanding/excellent and for fair/poor.

2.2 National VOICES 2012-13 – NHS Area Teams

National Survey of Bereaved People (VOICES) by NHS Area Team (England), 2012 to 2013

http://www.ons.gov.uk/ons/dcp171778_399897.pdf

2012-13 report contained data that was not available in the 2011-12 report, however, and these are presented under the following headings:

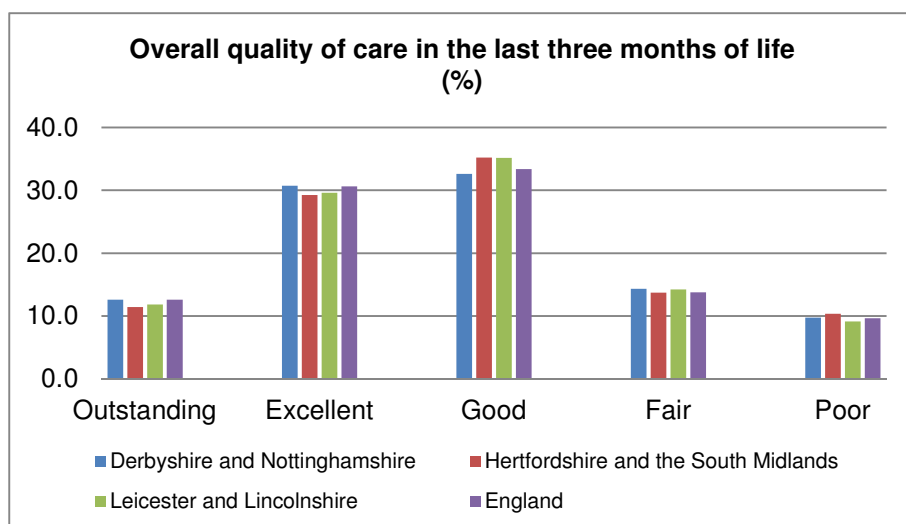
- Quality of care
- Dignity and respect
- Pain relief
- Preferred place of death
- Support for carer

2.2.1 Overall quality of care in the last three months of life

Just over three quarters of respondents rated the overall end of life care quality as good, excellent, or outstanding:

- Derbyshire & Nottinghamshire: 75.9%
- Hertfordshire & the South Midlands: 75.9%
- Leicestershire & Lincolnshire: 76.6%

NHS Area Team	Outstanding	Excellent	Good	Fair	Poor
Derbyshire and Nottinghamshire	12.6	30.8	32.6	14.3	9.7
Hertfordshire and the South Midlands	11.4	29.3	35.2	13.7	10.4
Leicester and Lincolnshire	11.8	29.6	35.2	14.2	9.1
England	12.6	30.6	33.4	13.8	9.6



2.2.2 Quality of care in different care settings and by different staff group

Settings and/or staff group that give best quality of end of life care according to the survey of bereaved:

1. Hospices (average 'excellent' rate 74.7%)
2. Care homes (average 'excellent' rate 45.6%)
3. District and community nurses (average 'excellent' rate 43.0%)

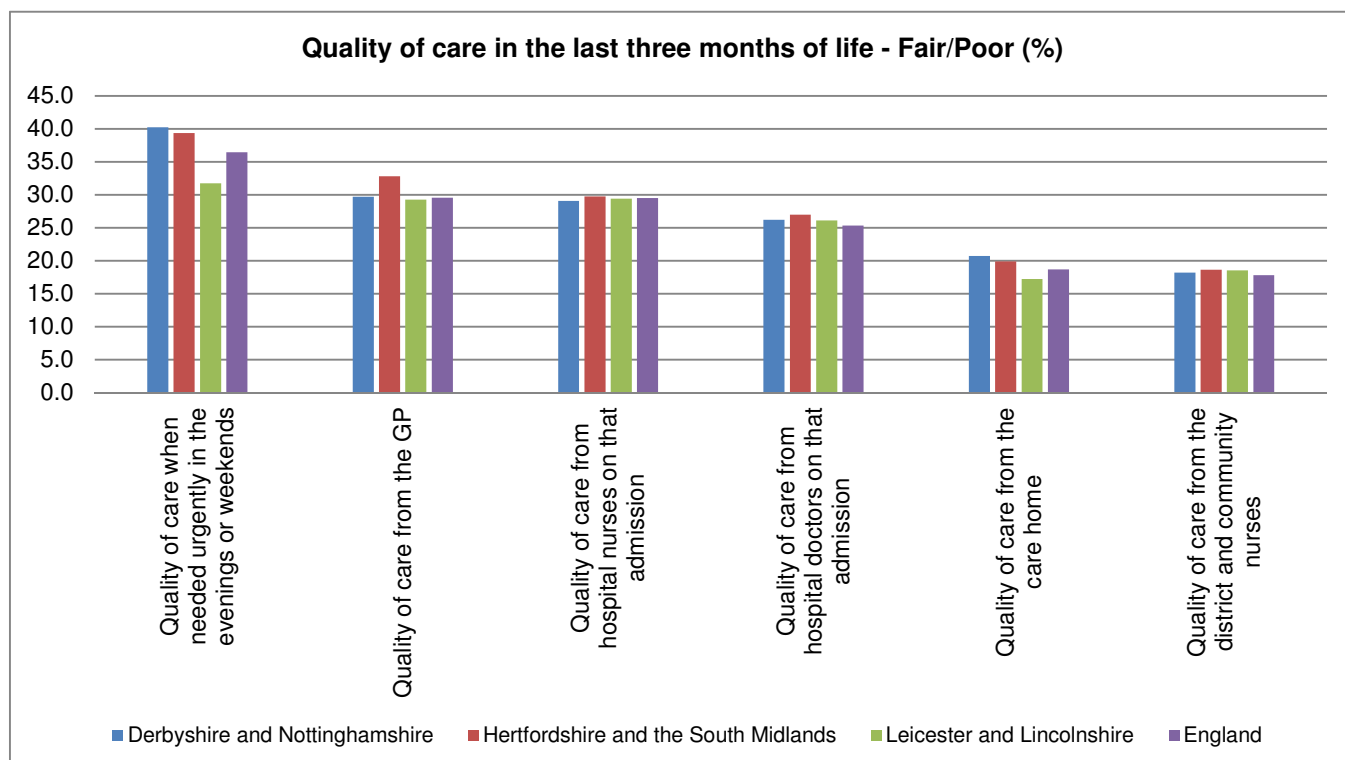
This is seen consistently throughout the East Midlands Area Teams and in England.

The table below summarises this by NHS Area Team and care setting, and the subsequent graphs show the variation of quality of care between the Area Teams.

Summary table of quality of care:

In the last three months of the patient's life...		Derbyshire and Nottinghamshire	Hertfordshire and the South Midlands	Leicester and Lincolnshire	England
Overall quality of care	Outstanding	12.6	11.4	11.8	12.6
	Excellent	30.8	29.3	29.6	30.6
	Good	32.6	35.2	35.2	33.4
	Fair	14.3	13.7	14.2	13.8
	Poor	9.7	10.4	9.1	9.6
Quality of care when needed urgently in the evenings or weekends	Excellent	24.2	22.5	30.9	25.8
	Good	35.6	38.1	37.4	37.7
	Fair	20.7	22.9	16.9	19.8
	Poor	19.5	16.5	14.8	16.6
Quality of care from district and community nurses	Excellent	43.9	39.5	45.6	44.8
	Good	37.9	41.9	35.8	37.3
	Fair	13.2	11.7	12.9	11.5
	Poor	5.0	6.9	5.6	6.3
Quality of care from the GP	Excellent	35.2	30.3	33.4	33.6
	Good	35.2	36.9	37.3	36.8
	Fair	18.0	19.5	17.3	17.4
	Poor	11.7	13.3	11.9	12.1
Quality of care from the care home	Excellent	46.1	45.0	45.7	46.2
	Good	33.2	35.1	37.0	35.2
	Fair	12.1	12.4	10.4	12.0
	Poor	8.6	7.5	6.9	6.7
Quality of care from hospital doctors on that admission	Excellent	38.9	36.1	37.7	39.5
	Good	34.9	36.9	36.1	35.2
	Fair	15.8	16.5	14.8	15.4
	Poor	10.4	10.5	11.4	9.9
Quality of care from hospital nurses on that admission	Excellent	38.3	36.7	37.4	38.1
	Good	32.7	33.6	33.2	32.4
	Fair	16.0	17.8	16.7	17.0
	Poor	13.1	11.9	12.8	12.5
Quality of care from the staff in the hospice	Excellent	71.6	79.6	72.7	77.4
	Good	17.8	13.5	14.3	14.0

The following graphs were produced by amalgamating the figures for Excellent and Good ratings, and the figures for Fair and Poor ratings from the raw data. This was done in order to be able to present a comparative view across the NHS Area Teams, by care settings. Please note that the graphs are arranged in descending order, as per England figures.

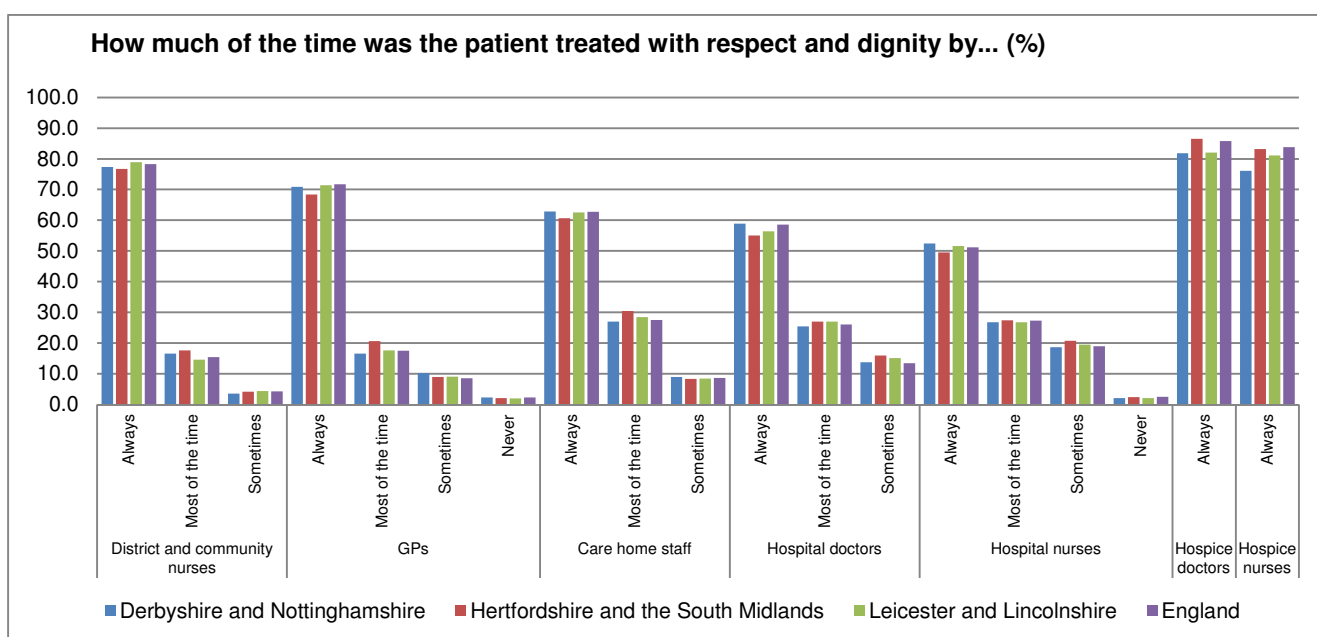


2.2.3 Dignity and respect

Settings and/or staff group who were rated highest to treat patients with dignity and respect always:

1. Hospice doctors (average 83.5%)
2. Hospice nurses (average 80.1%)
3. District and community nurses (77.7%)

		Derbyshire and Nottinghamshire	Hertfordshire and the South Midlands	Leicester and Lincolnshire	England
District and community nurses	Always	77.4	76.7	78.9	78.3
	Most of the time	16.6	17.6	14.6	15.5
	Sometimes	3.5	4.2	4.3	4.3
GPs	Always	70.9	68.3	71.4	71.7
	Most of the time	16.6	20.6	17.6	17.5
	Sometimes	10.2	9.0	9.0	8.6
	Never	2.3	2.1	2.0	2.2
Care home staff	Always	62.9	60.7	62.6	62.8
	Most of the time	27.0	30.4	28.4	27.6
	Sometimes	9.0	8.4	8.4	8.6
Hospital doctors	Always	58.9	55.0	56.4	58.6
	Most of the time	25.4	27.0	27.0	26.1
	Sometimes	13.7	15.9	15.1	13.4
Hospital nurses	Always	52.4	49.5	51.6	51.2
	Most of the time	26.7	27.4	26.8	27.3
	Sometimes	18.7	20.8	19.5	19.0
	Never	2.1	2.4	2.1	2.5
Hospice doctors	Always	81.8	86.6	82.0	85.8
Hospice nurses	Always	76.1	83.2	81.1	83.8

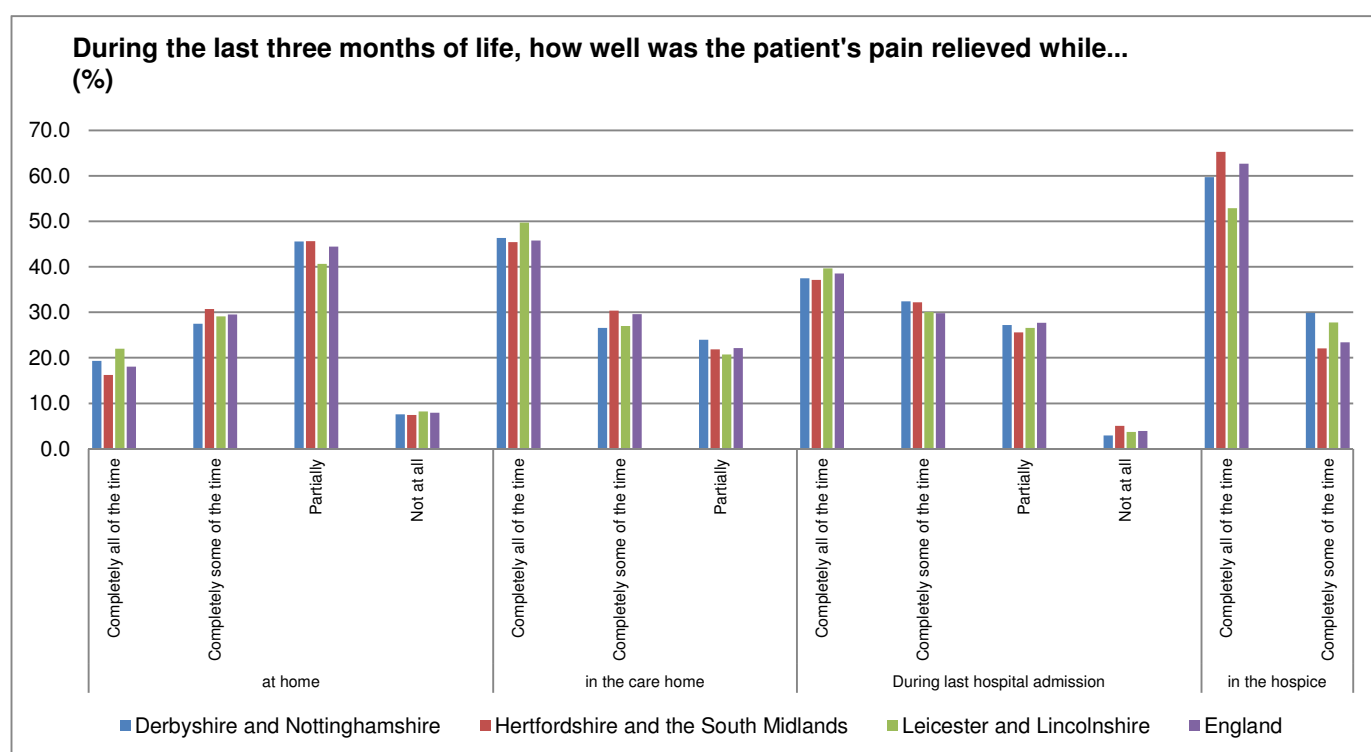


2.2.4 Pain relief

During the last three months of life, the settings that provided pain relief completely all of the time the most are:

1. Hospices (average 59.4%)
2. Care home (average 47.2%)
3. Hospital (average 38.1%)

		Derbyshire and Nottinghamshire	Hertfordshire and the South Midlands	Leicester and Lincolnshire	England
at home	Completely all of the time	19.3	16.2	22.0	18.1
	Completely some of the time	27.5	30.7	29.1	29.6
	Partially	45.6	45.6	40.7	44.4
	Not at all	7.6	7.4	8.2	7.9
in the care home	Completely all of the time	46.4	45.5	49.7	45.8
	Completely some of the time	26.6	30.4	27.0	29.6
	Partially	24.0	21.9	20.7	22.1
during last hospital admission	Completely all of the time	37.5	37.1	39.7	38.6
	Completely some of the time	32.4	32.2	30.1	29.8
	Partially	27.2	25.6	26.6	27.7
	Not at all	2.9	5.0	3.7	3.9
in the hospice	Completely all of the time	59.8	65.3	52.9	62.7
	Completely some of the time	29.9	22.1	27.8	23.4



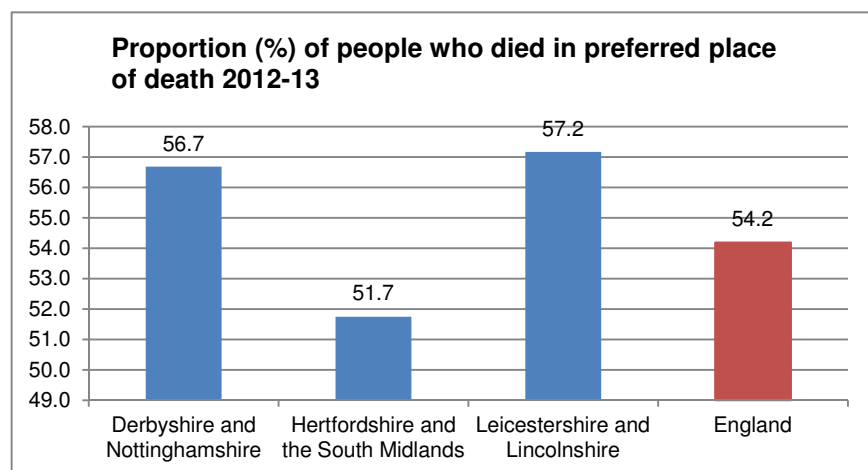
2.2.5 Preferred place of death

Summary table:

		Derbyshire and Nottinghamshire	Hertfordshire and the South Midlands	Leicestershire and Lincolnshire	England
Proportion who died in preferred place of death		56.7	51.7	57.2	54.2
Age group of people who are reported to have died in their preferred place of death	<65	15.4	17.2	13.9	16.9
	65-79	36.1	34.8	36.2	35.0
	80+	48.4	48.1	50.0	48.1
Sex of people who were reported to have died in their preferred place of death	Male	49.1	46.2	53.7	47.3
	Female	50.9	53.8	46.3	52.7
Cause of death of people who were reported to have died in their preferred place of death	Cancer	56.2	57.3	61.2	55.9
	Cardio-vascular disease	18.5	17.9	15.7	18.6
	Other cause	25.3	24.8	23.1	25.5
Place of death of people who were reported to have died in their preferred place of death ¹	Care home	9.4	12.4	12.5	11.8
	Home	79.9	68.7	79.0	74.1
	Hospice	5.3	15.0	5.3	9.9

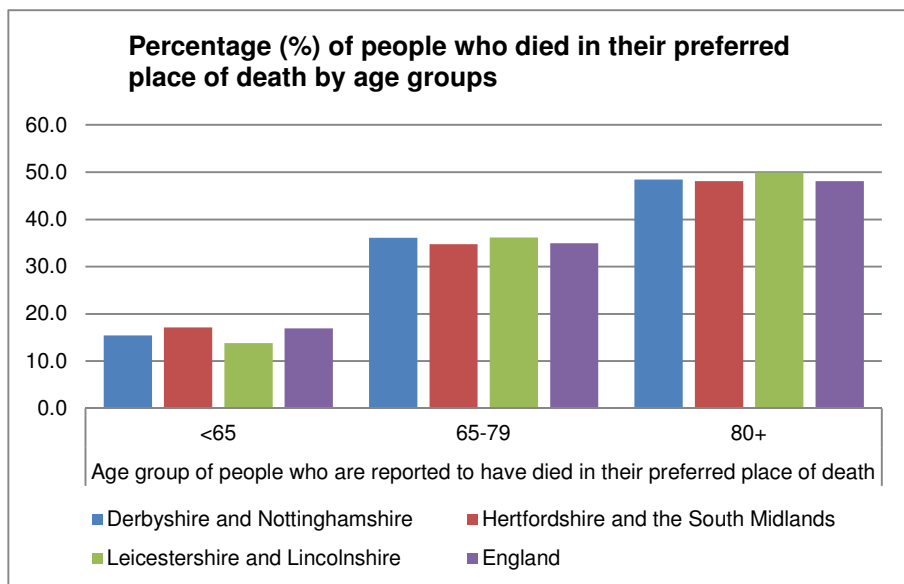
2.2.5.1 Proportion of people who died in preferred place of death

Over half the population in each area team achieved death in preferred place of death in 2012-13, with Leicestershire & Lincolnshire and Derbyshire & Nottinghamshire area teams achieving higher percentage (57.2% and 56.7% respectively) of death in preferred place of death than the England average of 54.2%. Hertfordshire and the South Midlands area team has seen a lower than England average of deaths in preferred place of death (51.7%).



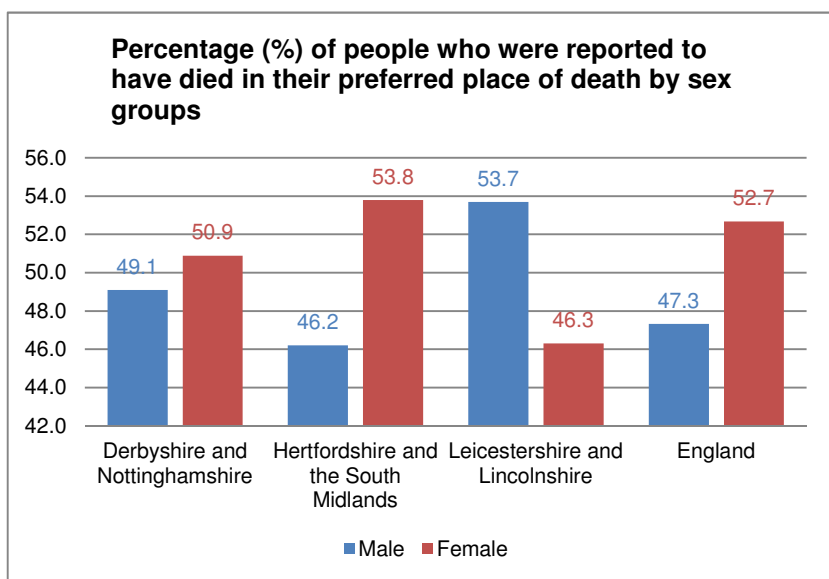
2.2.5.2 Percentage of people who are reported to have died in their preferred place of death by age group

Higher percentage of people aged 80 and over is reported to have died in their preferred place of death with an average of 48.8% across the three area teams, whereas only around a quarter of people aged less than 65 are reported to have died in their preferred place of death.



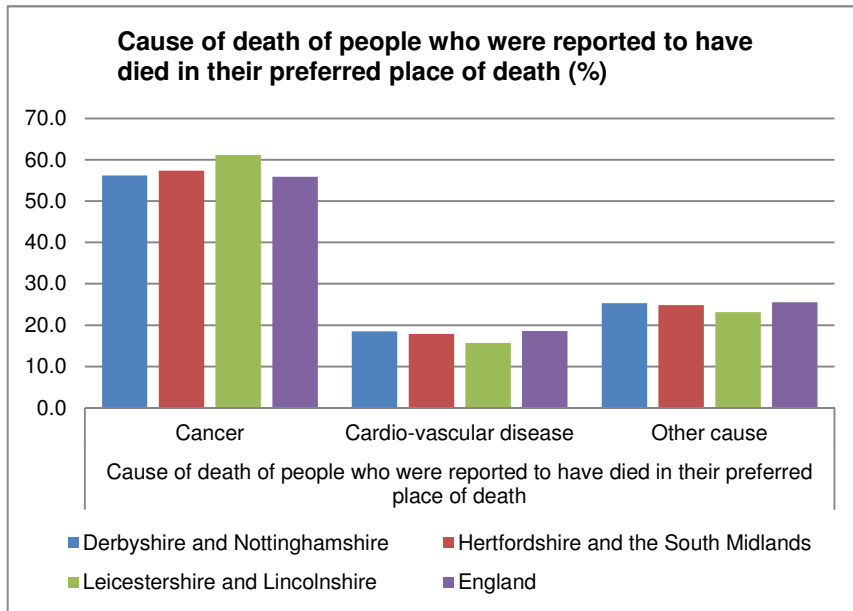
2.2.5.3 Percentage of people who were reported to have died in their preferred place of death by sex groups

On average higher percentage of women achieve death in their preferred place of death. In England, over half (52.7%) of women die in their preferred place of death, whereas under half (47.3%) of men do. Across the three area teams, a similar pattern is seen with 50.3% of women and 49.7% of men achieving death in preferred place.



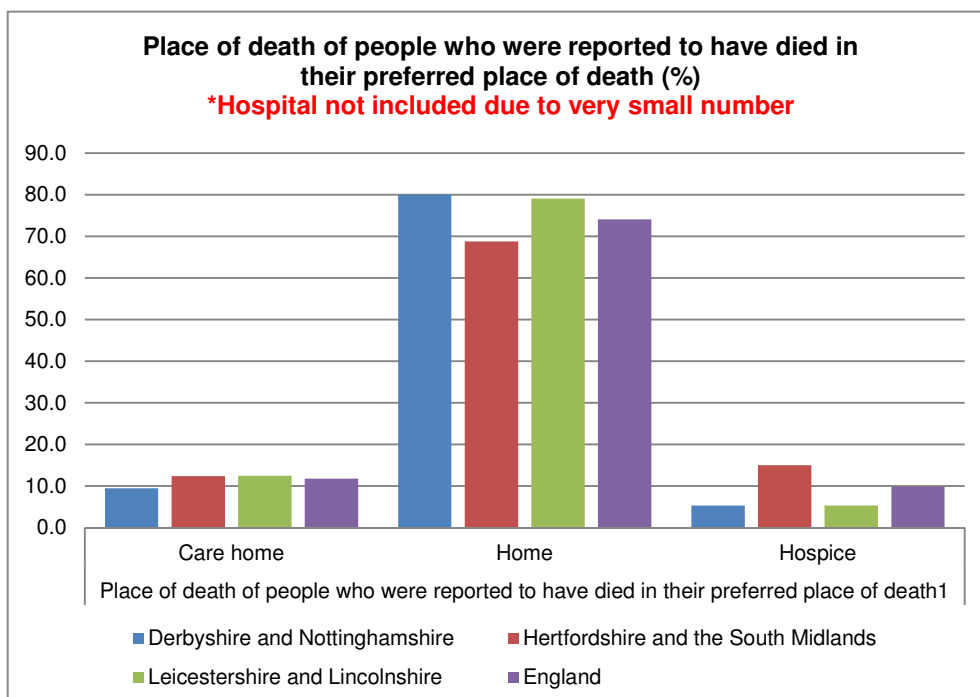
2.2.5.4 Cause of death of people who were reported to have died in their preferred place of death

Cancer is by far the predominant cause of death in people who died in their preferred place of death with over half the cohort being in this group (England 55.9% and East Midlands average 58.2%). Cardiovascular accounts for slightly over a quarter (17.4%) of the deaths of people who died in their preferred place.



2.2.5.5 Place of death of people who were reported to have died in their preferred place of death

The highest proportion of deaths of people who died in their preferred place of death was seen at home, with nearly three quarters (England 75.9% and East Midlands average 74.1%).



2.2.6 Support for carer

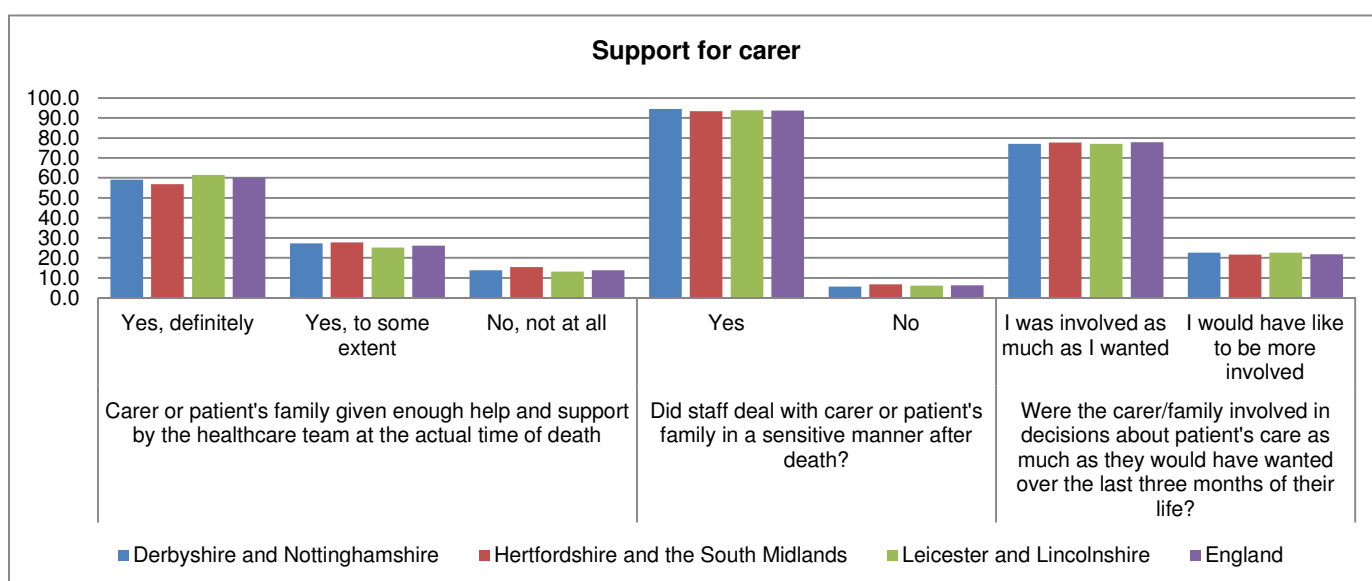
Summary table:

		Derbyshire and Nottinghamshire	Hertfordshire and the South Midlands	Leicester and Lincolnshire	England
Carer or patient's family given enough help and support by the healthcare team at the actual time of death	Yes, definitely	59.0	56.9	61.6	60.1
	Yes, to some extent	27.2	27.8	25.2	26.2
	No, not at all	13.8	15.3	13.2	13.8
Did staff deal with carer or patient's family in a sensitive manner after death?	Yes	94.4	93.3	93.9	93.7
	No	5.6	6.7	6.1	6.3
Were the carer/family involved in decisions about patient's care as much as they would have wanted over the last three months of their life?	I was involved as much as I wanted	77.1	77.7	77.0	77.9
	I would have like to be more involved	22.5	21.6	22.7	21.8

In all three area teams, over half of the respondents stated that they definitely received enough help and support by the healthcare team at the actual time of death, with around a 25% of the respondents saying that they did not receive any help or support at all.

With less than 10% of respondents saying that they were not dealt in a sensitive manner after death, there was a positive response seen in over 90% of respondents.

Around 20% of the respondents would have liked to be more involved in the decisions about patient's care in the last three months of life, with over 75% of respondents stating that they were involved as much as they wanted.



3. Place of Death

Source: National End of Life Care Intelligence Network

http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

3.1 Deaths in usual place of residence – average percentage (registered) between Q2 2013/14 to Q3 2014/15 by Counties

Note:

The periods covered are: Q2 2013/14 – Q1 2014/15, Q3 2013/14 – Q2 2014/15 and Q4 2013/14 – Q3 2014/15.

Data for counties were calculated by taking an average of the proportions as reported for each local authority within the relevant county.

The proportion of deaths in usual place of residence as registered does not change between Q2 2013/14 to Q3 2014/15 for the East Midlands as a region (45.4%). It is slightly higher than the proportion across the whole of England, which sees a slight increase over the indicated period (44.8%, 45.1%, and 45.1%).

The table below summarise the averages:

Green indicates increase from immediately previous period, amber indicates no change and red indicates decrease in the proportion of deaths in usual place of residence.

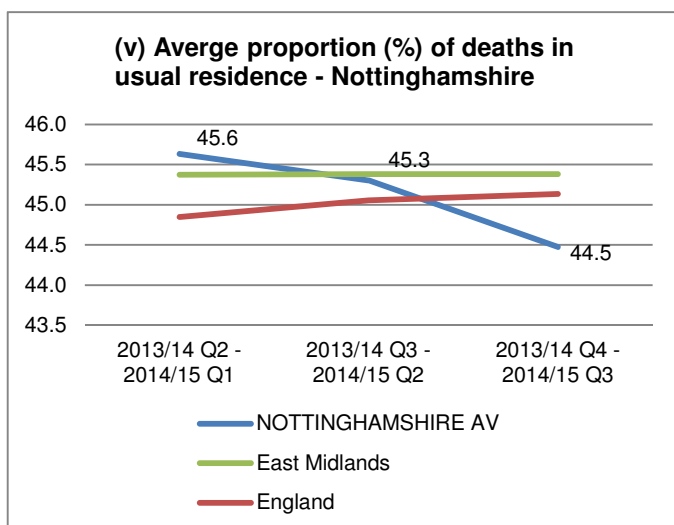
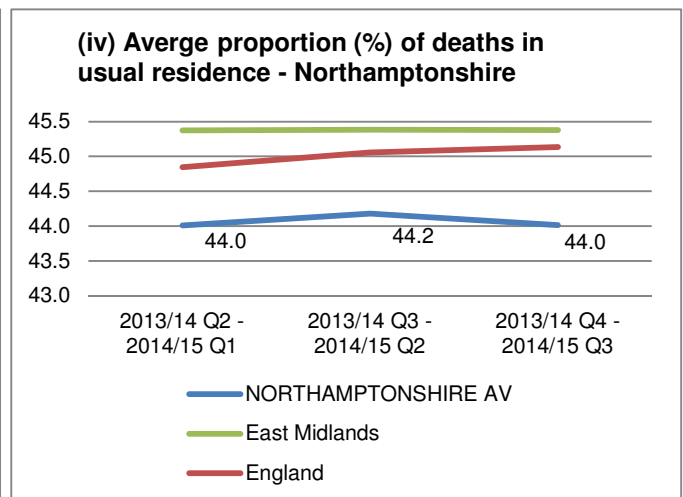
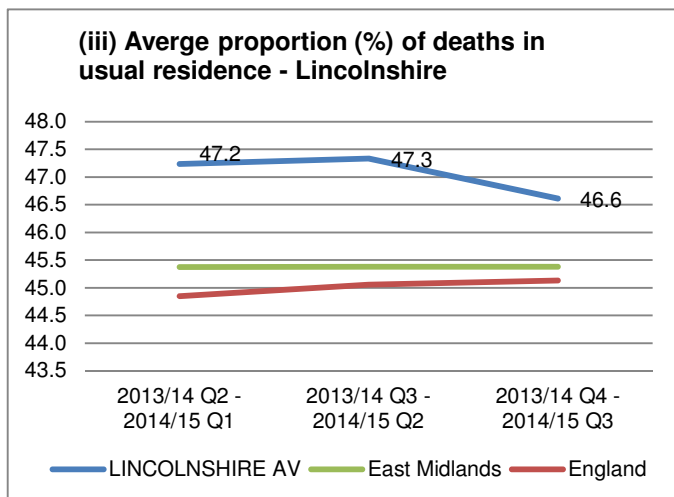
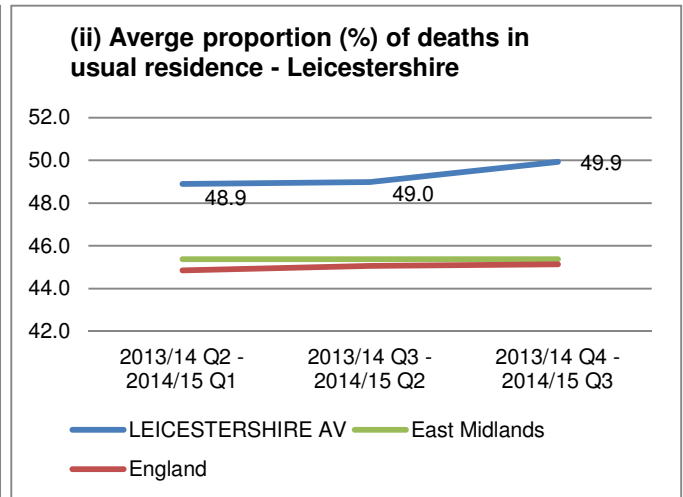
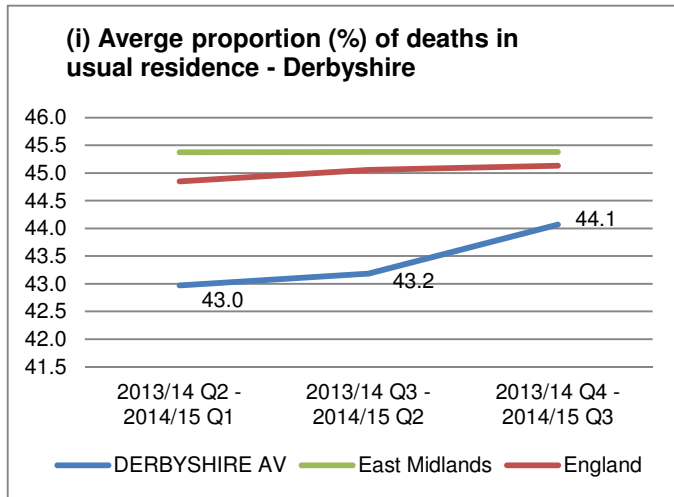
Area	2013/14 Q2 - 2014/15 Q1	2013/14 Q3 - 2014/15 Q2	2013/14 Q4 - 2014/15 Q3
Derbyshire	43.0	43.2	44.1
Northamptonshire	44.0	44.2	44.0
England	44.8	45.1	45.1
East Midlands	45.4	45.4	45.4
Nottinghamshire	45.6	45.3	44.5
Lincolnshire	47.2	47.3	46.6
Leicestershire	48.9	49.0	49.9

Derbyshire and Leicestershire have seen slight increases in the proportion of deaths in usual place of residence between the stated periods whereas Lincolnshire, Northamptonshire and Nottinghamshire have seen decreases in the proportion.

Derbyshire, Northamptonshire and Nottinghamshire have a lower average than the East Midlands while Leicestershire and Lincolnshire have higher average.

These trends are highlighted in the following line charts (presented in alphabetical order by county):

Charts highlighting trend in deaths in usual place of residence between Q2 2013/14-A1 2014/15 and Q4 2013/14-Q3 2014/15

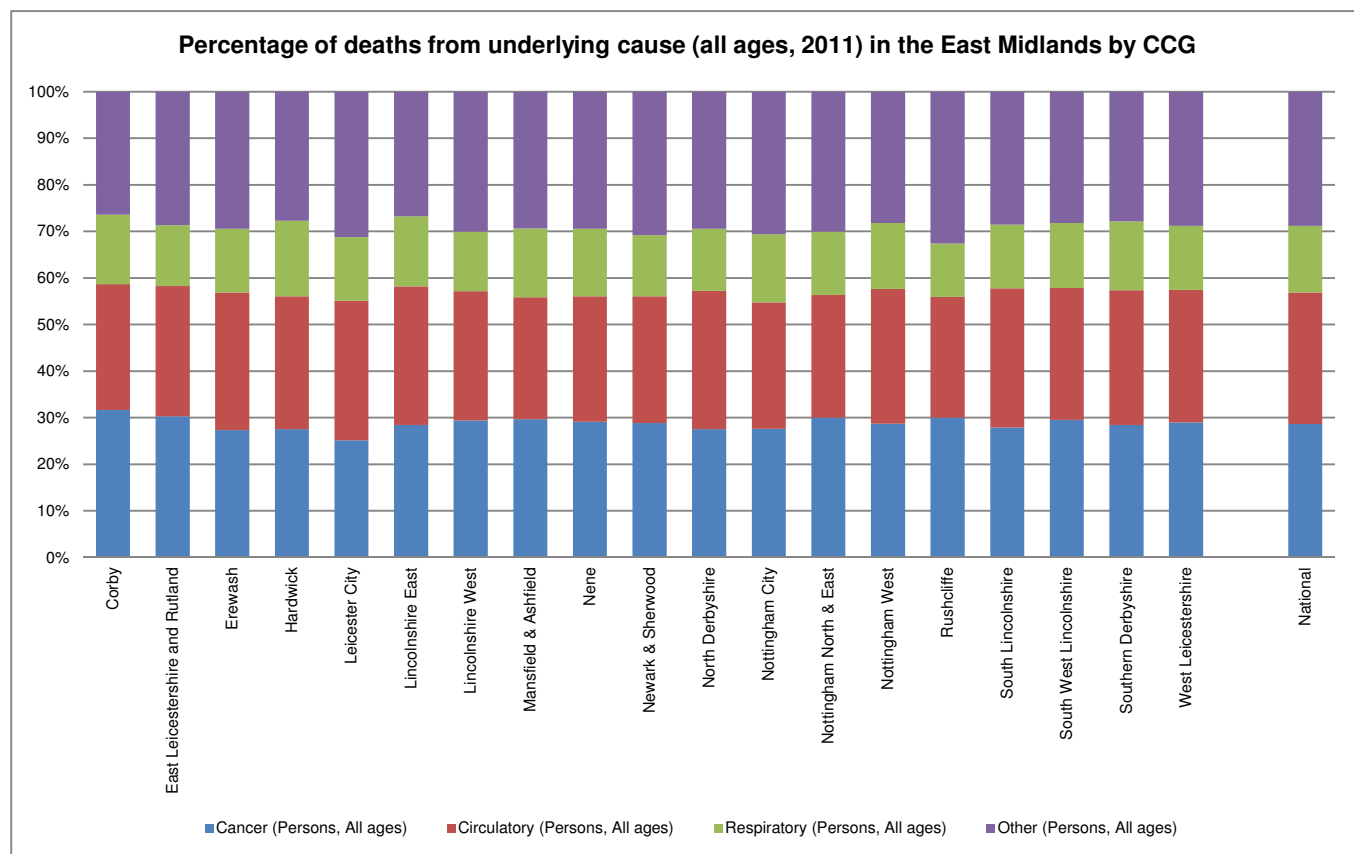


4. Underlying Cause of Death

Source: National End of Life Care Intelligence Network – End of life care profiles for clinical commissioning groups

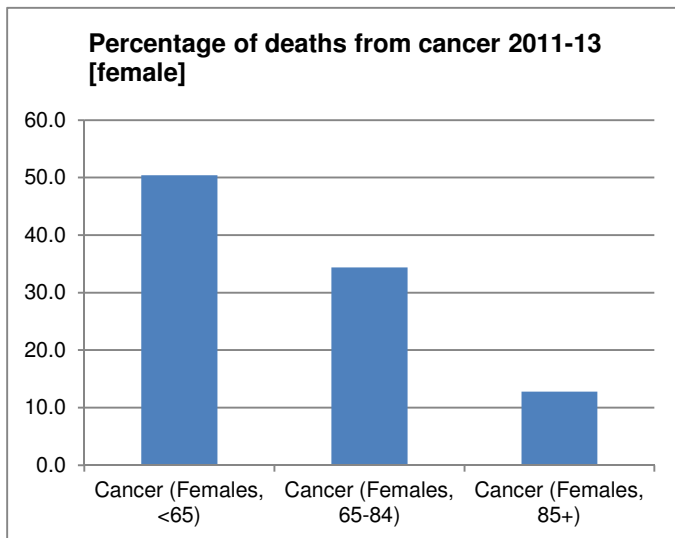
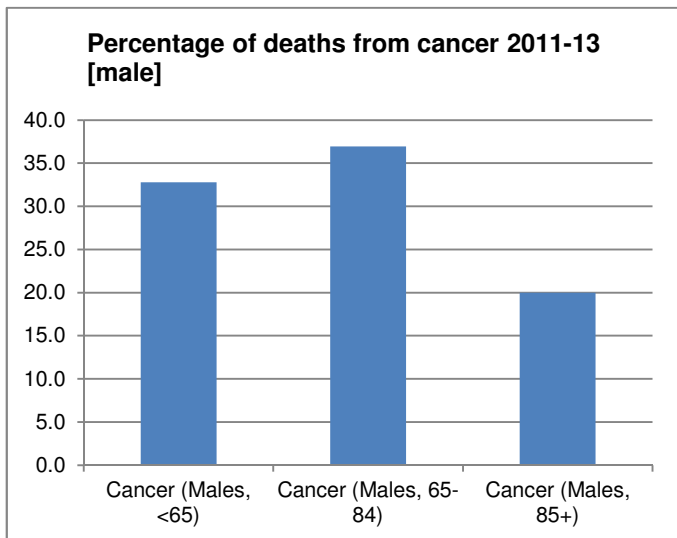
http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Cause_of_Death/atlas.html

Overall, cancer and cardiovascular diseases are the predominant causes of death, both in the East Midlands (28.7% and 28.1% respectively) and in England (28.6% and 28.3% respectively). Together they account for more than half of the deaths that occurred in 2011-13.



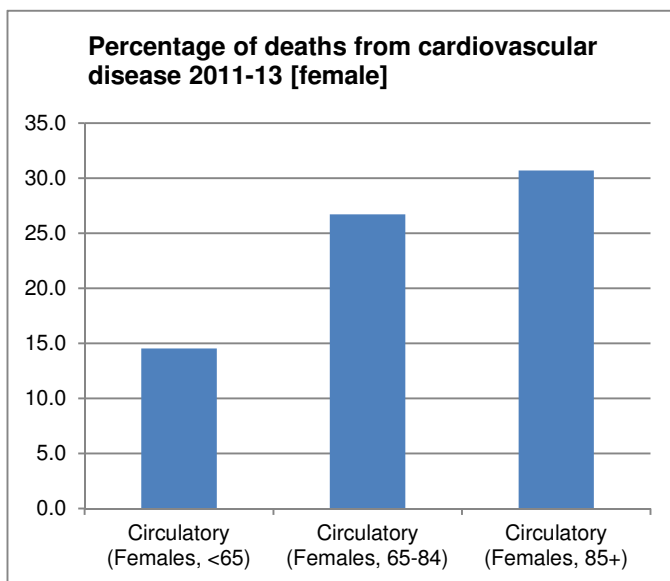
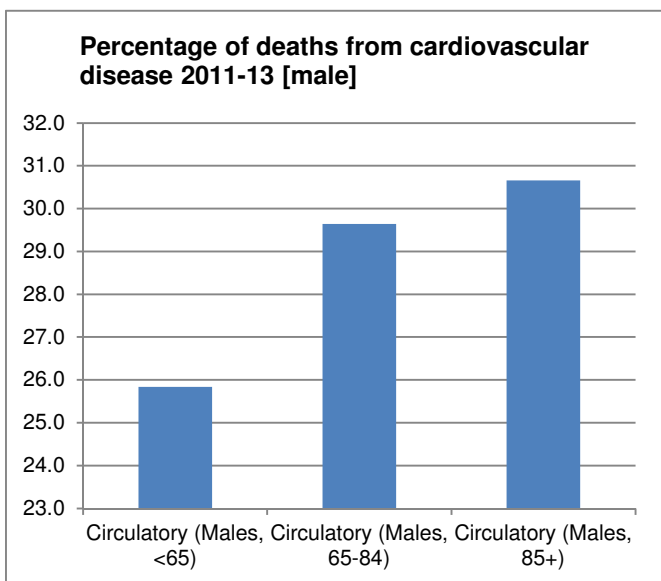
4.1 Deaths from cancer 2011-13

In the East Midlands, it seems that the proportion of people who die from cancer decreases with increasing age, with the exception of men aged between 65 and 84 whose proportion is higher than that of men aged 65 and under.



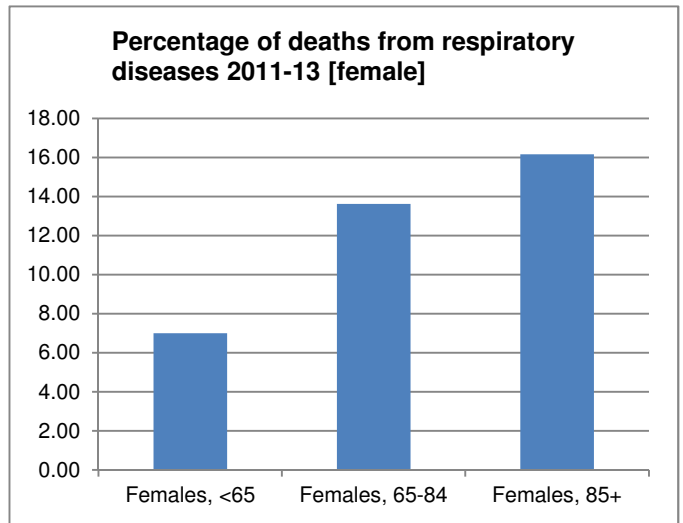
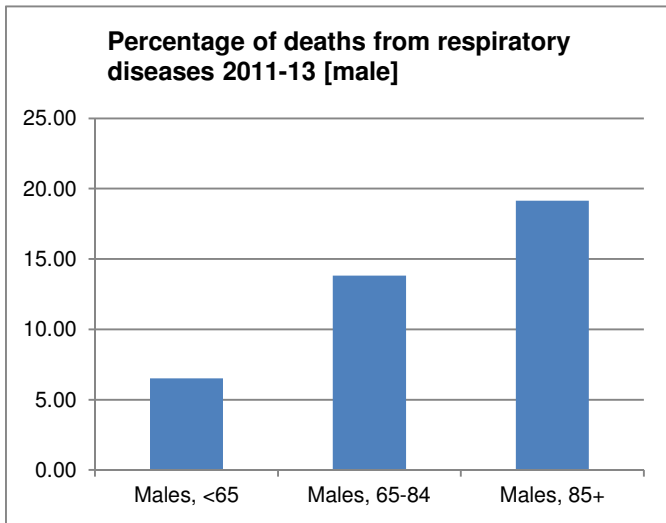
4.2 Deaths from cardiovascular diseases

In the East Midlands, the proportion of people who die from cardiovascular diseases increases with age.

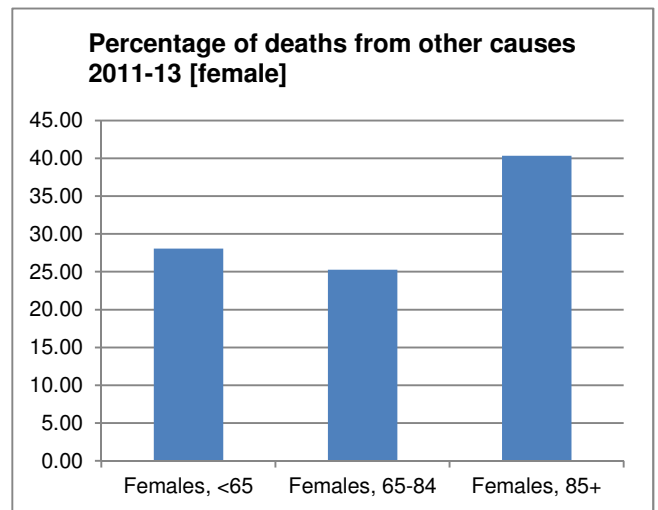
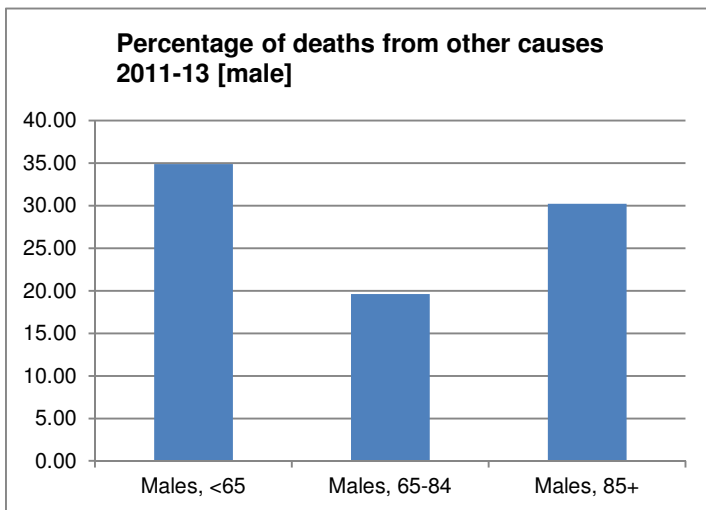


4.3 Deaths from respiratory diseases

Proportion of deaths from respiratory diseases increases with age.



4.4 Deaths from other causes



5. Quality of End of Life Care in the Hospital Trusts – The National Care of the Dying Audit for Hospitals 2013-14

Source: *National Care of the Dying Audit for Hospitals 2013-14*

<https://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

The outcomes of the National Care of the Dying Audit for Hospitals (NCDAH) 2013-14 are published at Trust level and the East Midlands Trusts data have been pulled out for the following section of the report.

All acute hospitals in the East Midlands that participated in the NCDAH in 2013-14 are:

Name of the NHS hospital trust	Name of the site participating in the audit	County
Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital NHS Foundation Trust	Derbyshire
Sherwood Forest Hospitals NHS Foundation Trust	Sherwood Forest Hospitals NHS Foundation Trust	Nottinghamshire
Kettering General Hospital NHS Foundation Trust	Kettering General Hospital NHS Foundation Trust	Northamptonshire
Northampton General Hospital NHS Trust	Northampton General Hospital NHS Trust	Northamptonshire
Derby Hospitals NHS Foundation Trust	Royal Derby Hospital	Derbyshire
United Lincolnshire Hospitals NHS Trust	Grantham and District Hospital	Lincolnshire
	Lincoln County Hospital	
	Pilgrim Hospital	
University Hospitals of Leicester NHS Trust	University Hospitals of Leicester NHS Trust	Leicestershire
Nottingham University Hospitals NHS Trust	Nottingham University Hospitals NHS Trust	Nottinghamshire

Organisational Key Performance Indicators (KPIs) and clinical KPIs have been extracted from the report.

5.1 Organisational Key Performance Indicators (KPIs)

Key: Scores that are considered to be **achieving the KPI** are highlighted in green. **Those that are not** are highlighted in red.

The 7 organisational KPIs are:

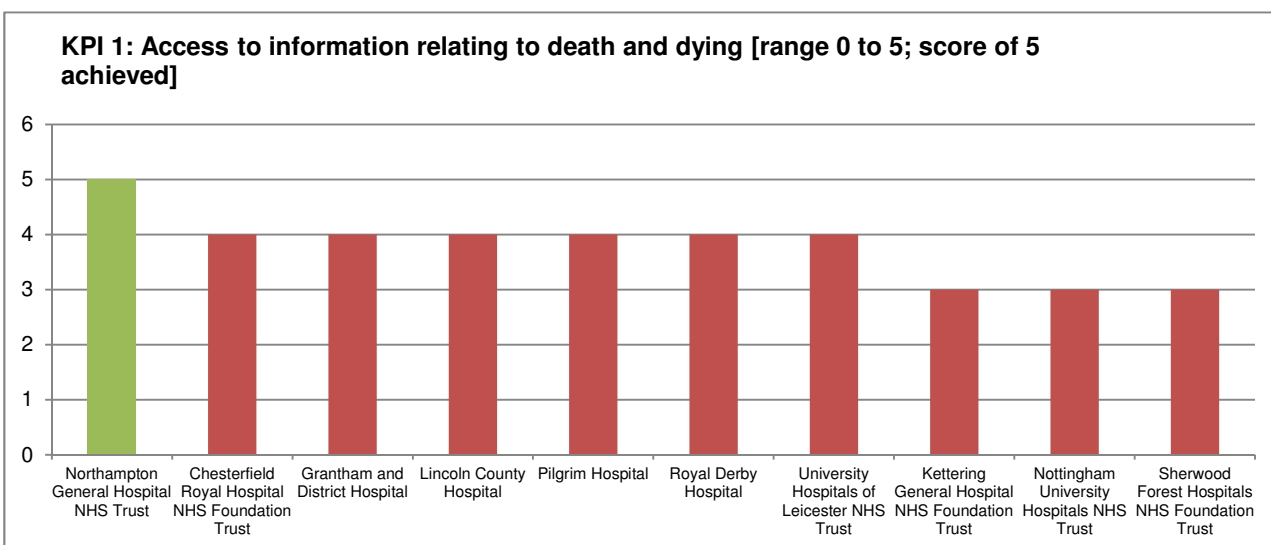
1. Access to information relating to death and dying.
2. Access to specialist support for care in the last hours or days of life.
3. Care of the dying: continuing education, training and audit.
4. Trust Board representation and planning for care of the dying.
5. Clinical protocols for the prescription of medications for the 5 key symptoms at the end of life.
6. Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient.
7. Formal feedback processes regarding bereaved relatives/friends views of care delivery.

5.1.1 Organisational KPI 1: Access to information relating to death and dying

The score ranges from 0 to 5 and those sites with a score of 5 are considered to be achieving this KPI.

Only one out of 10 sites in the East Midlands achieved this KPI in 2013-14: Northampton General Hospital NHS Trust.

Hospital	KPI 1 score (range 0 to 5)
Northampton General Hospital NHS Trust	5
Chesterfield Royal Hospital NHS Foundation Trust	4
Grantham and District Hospital	4
Lincoln County Hospital	4
Pilgrim Hospital	4
Royal Derby Hospital	4
University Hospitals of Leicester NHS Trust	4
Kettering General Hospital NHS Foundation Trust	3
Nottingham University Hospitals NHS Trust	3
Sherwood Forest Hospitals NHS Foundation Trust	3

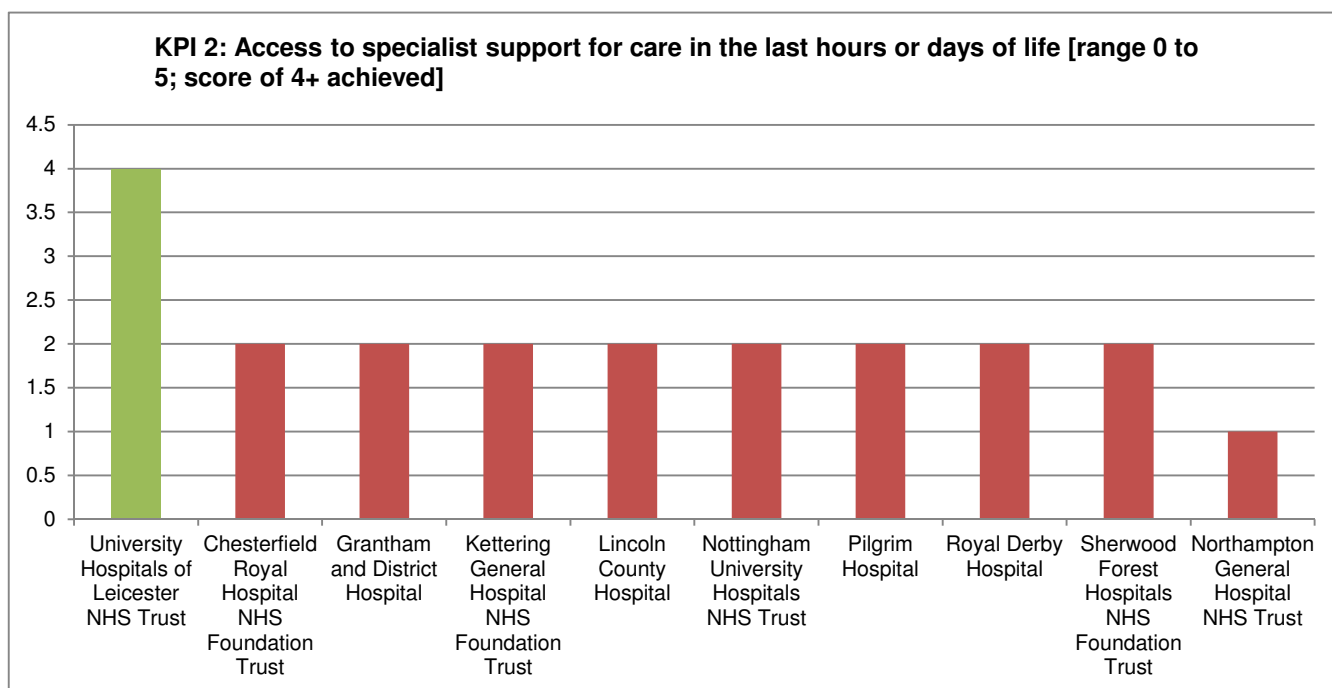


5.1.2 Organisational KPI 2: Access to specialist support for care in the last hours or days of life

The score ranges from 0 to 5 and those sites with a score of 4 and above are considered to be achieving this KPI.

Only one out of 10 sites in the East Midlands achieved this KPI in 2013-14: University Hospitals of Leicester NHS Trust.

Hospital	KPI 2 score (range 0 to 5)
University Hospitals of Leicester NHS Trust	4
Chesterfield Royal Hospital NHS Foundation Trust	2
Grantham and District Hospital	2
Kettering General Hospital NHS Foundation Trust	2
Lincoln County Hospital	2
Nottingham University Hospitals NHS Trust	2
Pilgrim Hospital	2
Royal Derby Hospital	2
Sherwood Forest Hospitals NHS Foundation Trust	2
Northampton General Hospital NHS Trust	1

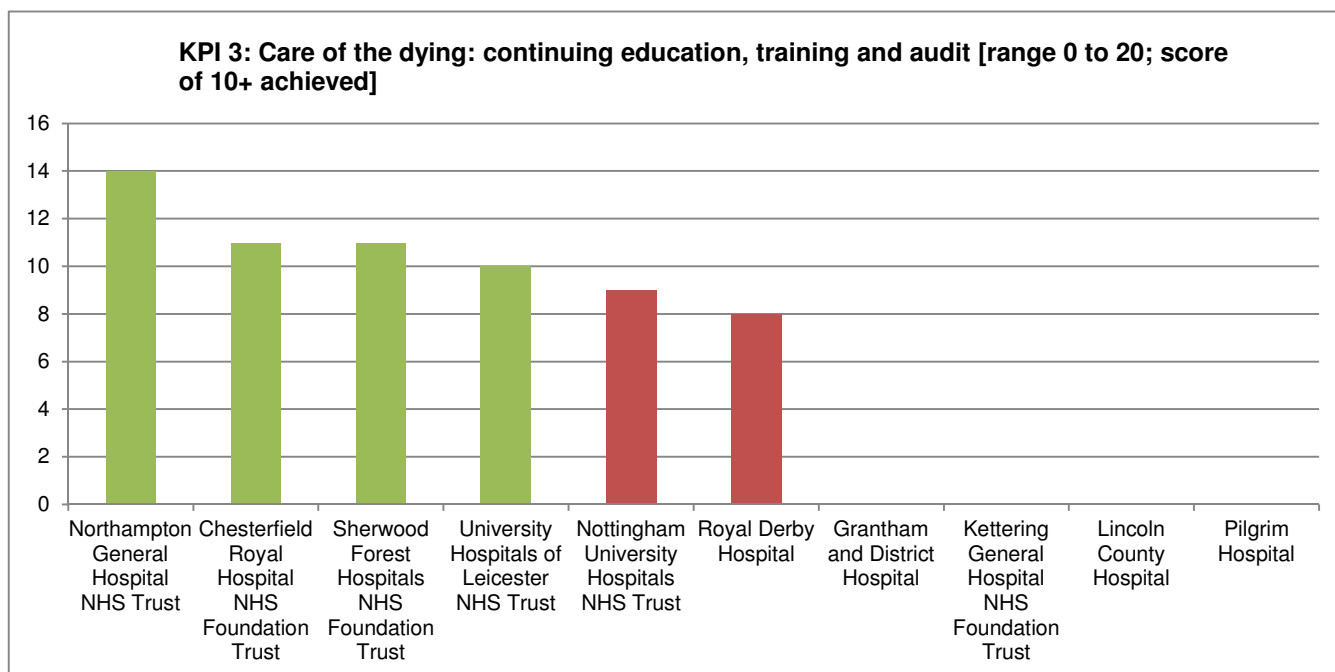


5.1.3 Organisational KPI 3: Care of the dying: continuing education, training and audit

The score ranges from 0 to 20 and those sites with a score of 10 and above are considered to be achieving this KPI.

Four out of 10 sites in the East Midlands achieved this KPI in 2013-14:

Hospital	KPI 3 score (range 0 to 20)
Northampton General Hospital NHS Trust	14
Chesterfield Royal Hospital NHS Foundation Trust	11
Sherwood Forest Hospitals NHS Foundation Trust	11
University Hospitals of Leicester NHS Trust	10
Nottingham University Hospitals NHS Trust	9
Royal Derby Hospital	8
Grantham and District Hospital	0
Kettering General Hospital NHS Foundation Trust	0
Lincoln County Hospital	0
Pilgrim Hospital	0

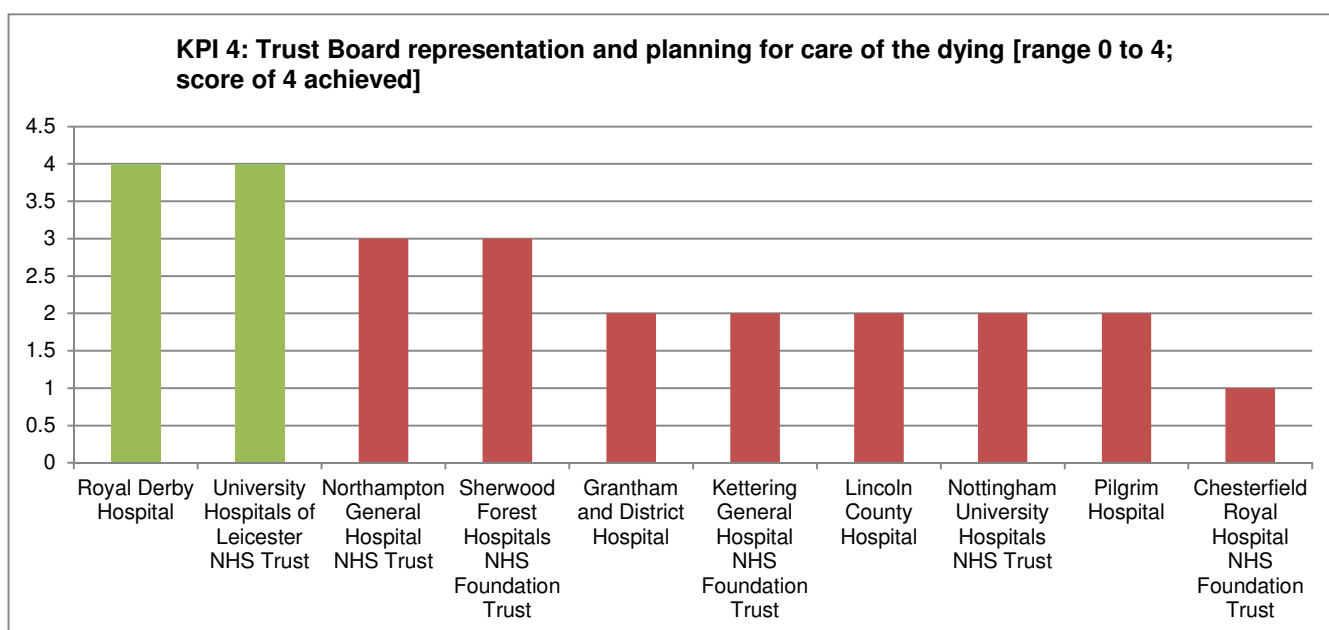


5.1.4 Organisational KPI 4: Trust Board representation and planning for care of the dying

The score ranges from 0 to 4 and those sites with a score of 4 are considered to be achieving this KPI.

Only two out of 10 sites in the East Midlands achieved this KPI in 2013-14: Royal Derby Hospital and University Hospitals of Leicester NHS Trust.

Hospital	KPI 4 score (range 0 to 4)
Royal Derby Hospital	4
University Hospitals of Leicester NHS Trust	4
Northampton General Hospital NHS Trust	3
Sherwood Forest Hospitals NHS Foundation Trust	3
Grantham and District Hospital	2
Kettering General Hospital NHS Foundation Trust	2
Lincoln County Hospital	2
Nottingham University Hospitals NHS Trust	2
Pilgrim Hospital	2
Chesterfield Royal Hospital NHS Foundation Trust	1



5.1.5 Organisational KPI 5: Clinical protocols for the prescription of medications for the 5 key symptoms at the end of life

The score ranges from 0 to 5 and those sites with a score of 5 are considered to be achieving this KPI.

All 10 sites in the East Midlands who participated in the audit met this KPI.

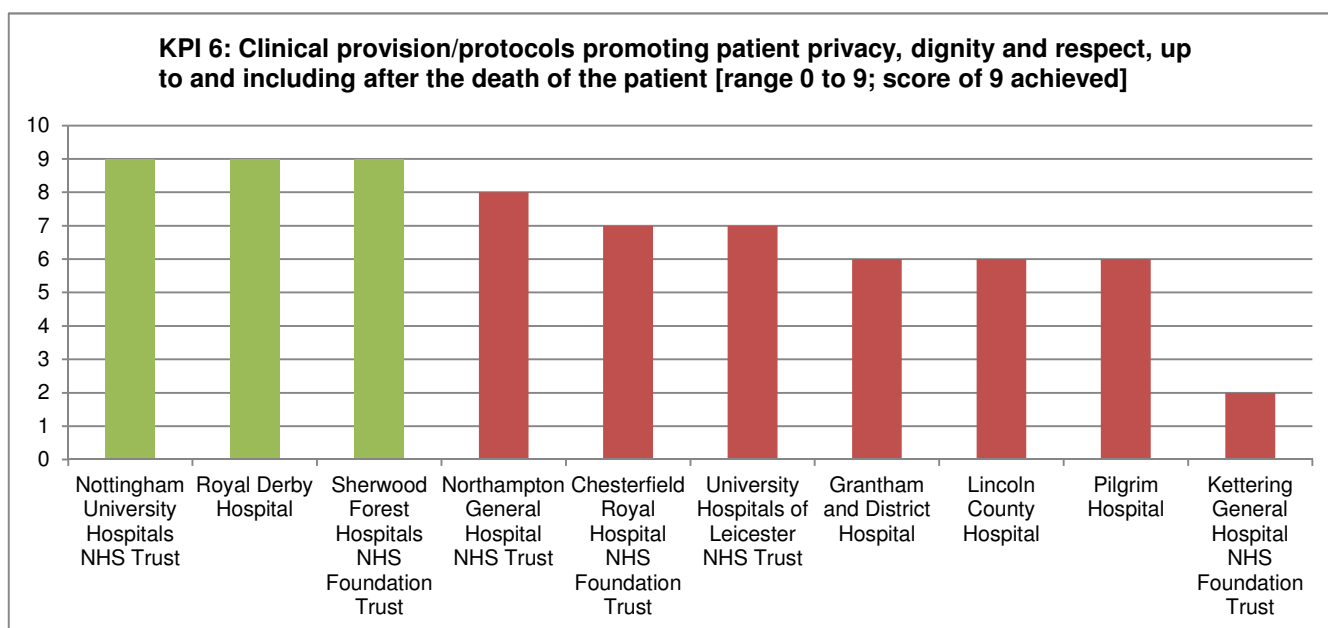
Hospital	KPI 5 score (range 0 to 5)
Chesterfield Royal Hospital NHS Foundation Trust	5
Grantham and District Hospital	5
Kettering General Hospital NHS Foundation Trust	5
Lincoln County Hospital	5
Northampton General Hospital NHS Trust	5
Nottingham University Hospitals NHS Trust	5
Pilgrim Hospital	5
Royal Derby Hospital	5
Sherwood Forest Hospitals NHS Foundation Trust	5
University Hospitals of Leicester NHS Trust	5

5.1.6 Organisational KPI 6: Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient

The score ranges from 0 to 9 and those sites with a score of 9 are considered to be achieving this KPI.

Three out of 10 sites in the East Midlands who participated in the audit met this KPI:

Hospital	KPI 6 score (range 0 to 9)
Nottingham University Hospitals NHS Trust	9
Royal Derby Hospital	9
Sherwood Forest Hospitals NHS Foundation Trust	9
Northampton General Hospital NHS Trust	8
Chesterfield Royal Hospital NHS Foundation Trust	7
University Hospitals of Leicester NHS Trust	7
Grantham and District Hospital	6
Lincoln County Hospital	6
Pilgrim Hospital	6
Kettering General Hospital NHS Foundation Trust	2

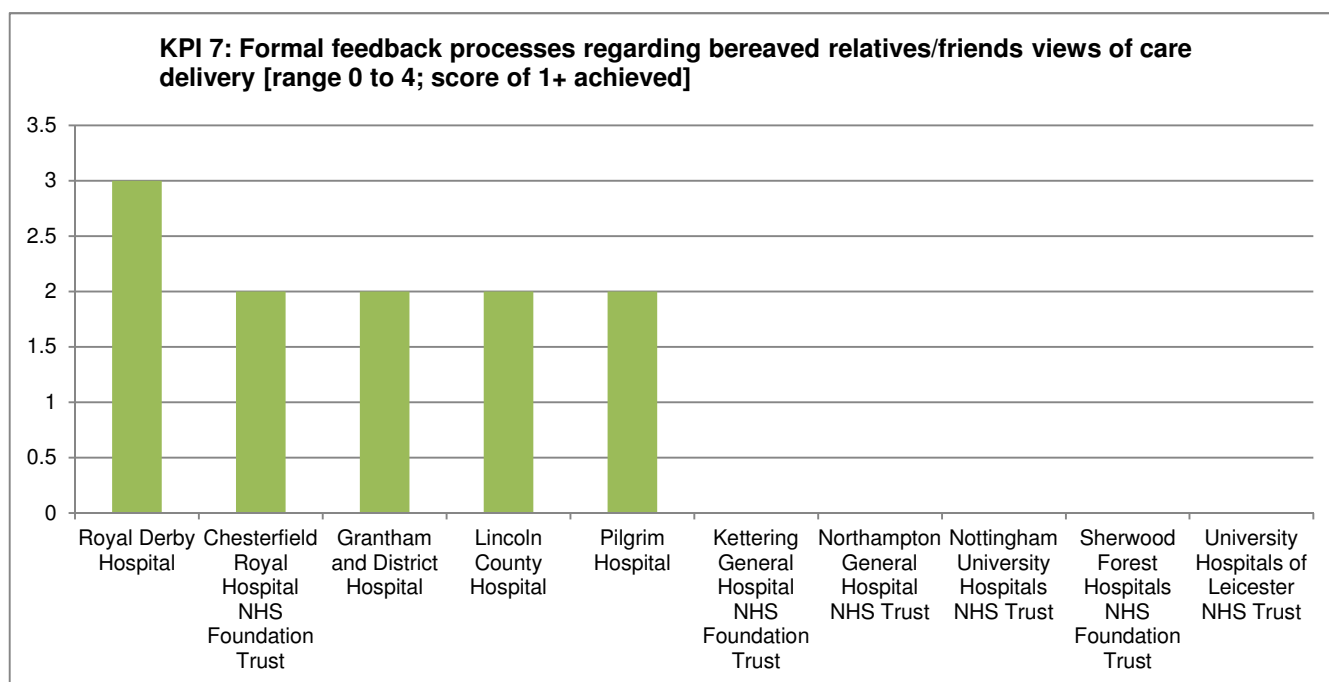


5.1.7 Organisational KPI 7: Formal feedback processes regarding bereaved relatives/friends views of care delivery

The score ranges from 0 to 4 and those sites with a score of 1 and above are considered to be achieving this KPI.

Half the sites (n=5) in the East Midlands who participated in the audit met this KPI:

Hospital	KPI 7 score (range 0 to 4)
Royal Derby Hospital	3
Chesterfield Royal Hospital NHS Foundation Trust	2
Grantham and District Hospital	2
Lincoln County Hospital	2
Pilgrim Hospital	2
Kettering General Hospital NHS Foundation Trust	0
Northampton General Hospital NHS Trust	0
Nottingham University Hospitals NHS Trust	0
Sherwood Forest Hospitals NHS Foundation Trust	0
University Hospitals of Leicester NHS Trust	0



5.2 Clinical Key Performance Indicators (KPIs)

There are 10 clinical KPIs that measure, directly or indirectly, the quality of end of life care:

1. Multi-disciplinary recognition that the patient is dying.
2. Health professional's discussion with both the patient and their relatives/friends regarding their recognition that the patient is dying.
3. Communication regarding the patient's plan of care for the dying phase.
4. Assessment of the spiritual needs of the patient and their nominated relatives or friends.
5. Medication prescribed prn for the 5 key symptoms that may develop during the dying phase.
6. A review of interventions during the dying phase.
7. A review of the patient's nutritional requirements.
8. A review of the patient's hydration requirements.
9. A review of the number of assessments undertaken in the patient's last 24 hours of life.
10. A review of the care after death.

Key: Upper quintiles are highlighted in green and lower quintiles are highlighted in red in the tables.

5.2.1 Summary

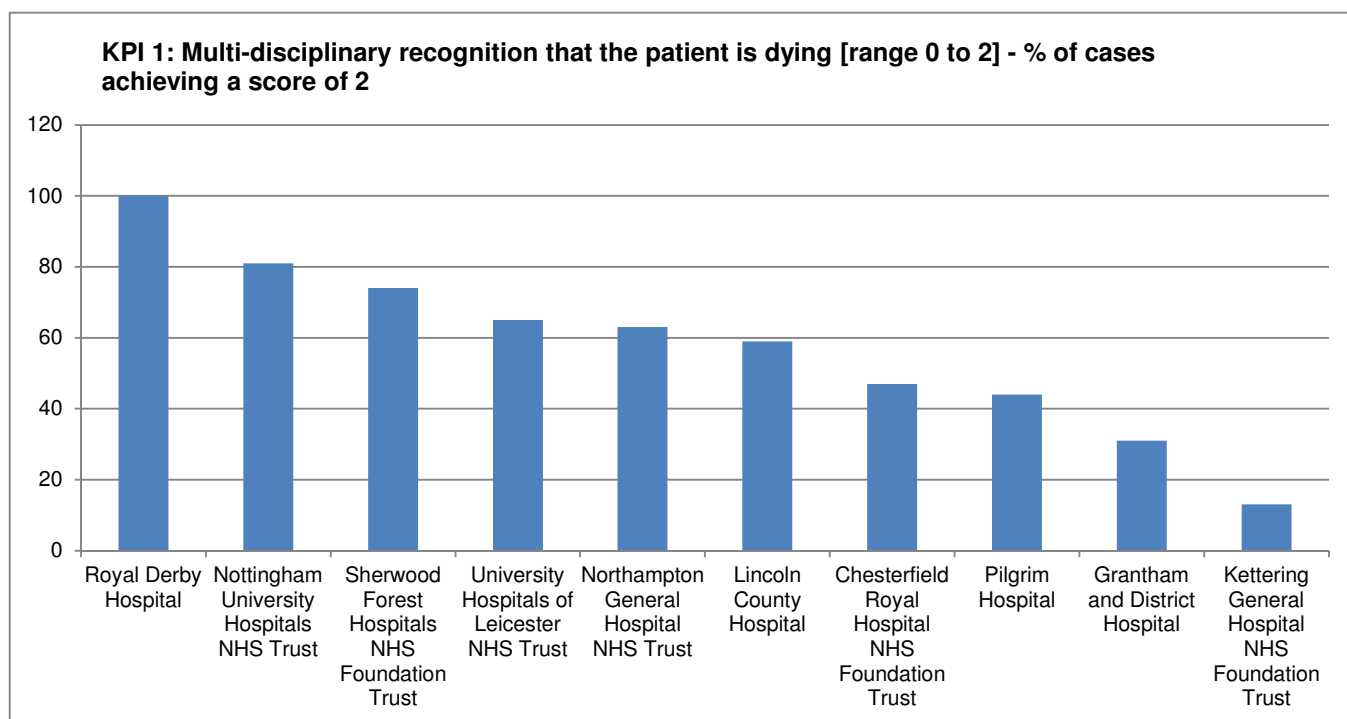
- Royal Derby Hospital showed the highest percentage of cases achieving required scores for 8 clinical KPIs (1 to 8).
- Kettering General Hospital is in the lower quintile for 8 out of 10 KPIs (1-4, 6-9).

5.2.2. Clinical KPI 1: Multi-disciplinary recognition that the patient is dying

This is not an indication of ‘timely’ recognition – it does not give an indication of how long before the patient dies they are recognised as dying.

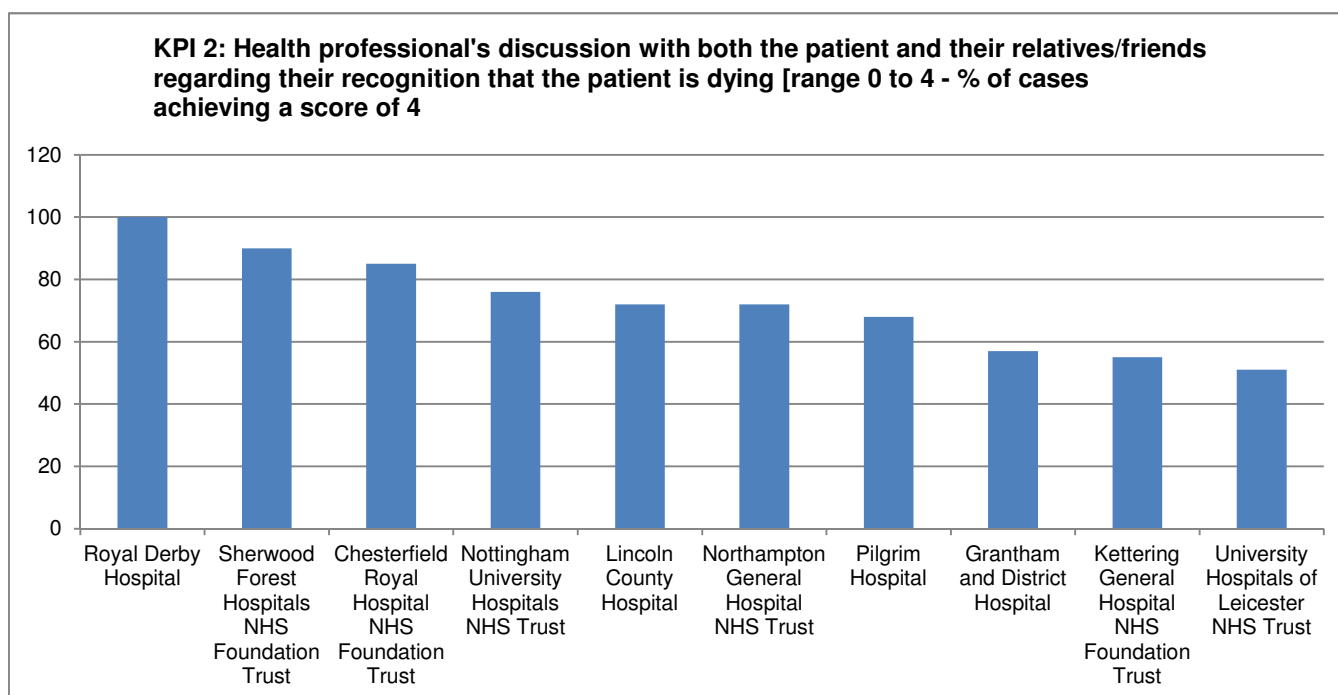
In the East Midlands the number of cases achieving a score of 2 for multi-disciplinary recognition that the patient is dying ranges from 13% at Kettering General Hospitals NHS FT to 100% at Royal Derby Hospital.

Hospital	KPI 1 (score range 0 to 2): % of cases achieving a score of 2
Royal Derby Hospital	100
Nottingham University Hospitals NHS Trust	81
Sherwood Forest Hospitals NHS Foundation Trust	74
University Hospitals of Leicester NHS Trust	65
Northampton General Hospital NHS Trust	63
Lincoln County Hospital	59
Chesterfield Royal Hospital NHS Foundation Trust	47
Pilgrim Hospital	44
Grantham and District Hospital	31
Kettering General Hospital NHS Foundation Trust	13



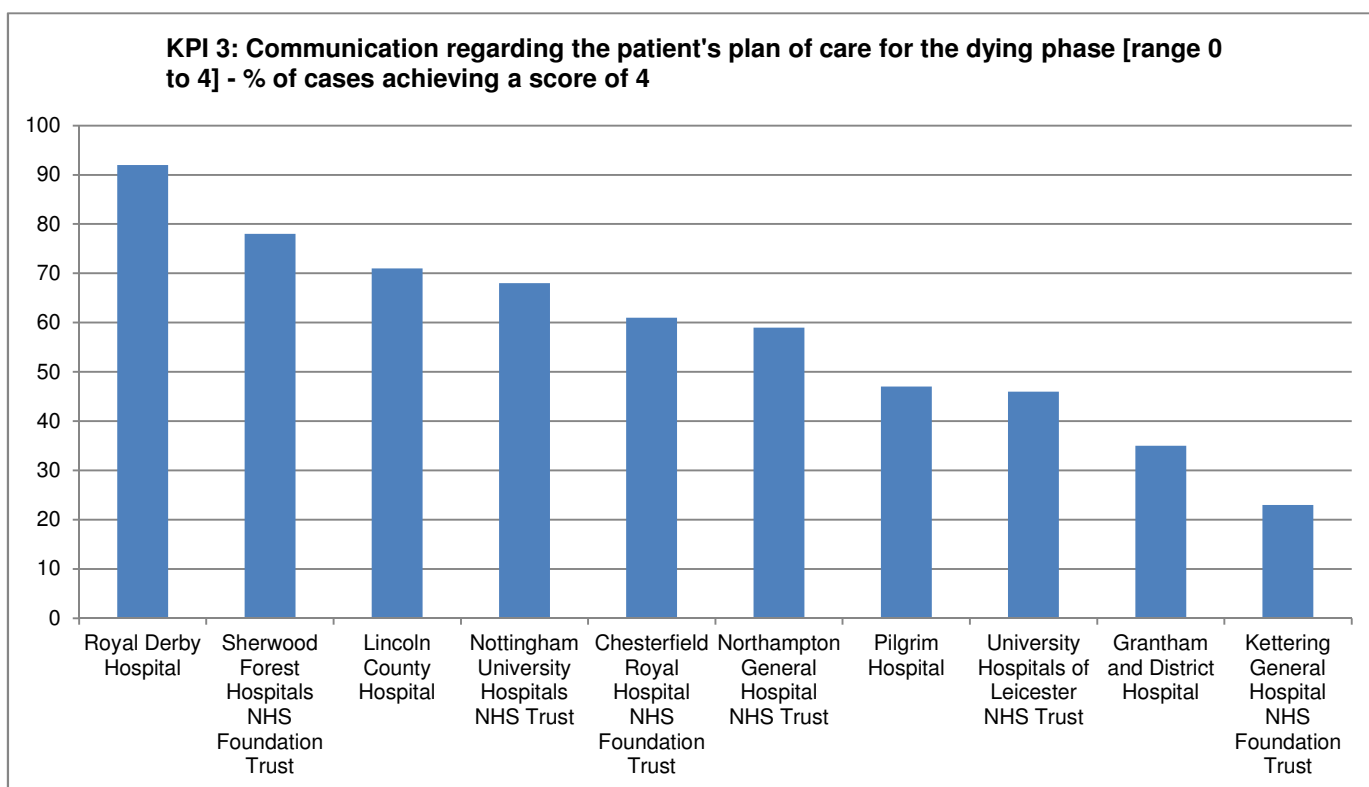
5.2.3 Clinical KPI 2: Health professional's discussion with both the patient and their relatives/friends regarding their recognition that the patient is dying

Hospital	KPI 2 (score range 0 to 4): % of cases achieving a score of 4
Royal Derby Hospital	100
Sherwood Forest Hospitals NHS Foundation Trust	90
Chesterfield Royal Hospital NHS Foundation Trust	85
Nottingham University Hospitals NHS Trust	76
Lincoln County Hospital	72
Northampton General Hospital NHS Trust	72
Pilgrim Hospital	68
Grantham and District Hospital	57
Kettering General Hospital NHS Foundation Trust	55
University Hospitals of Leicester NHS Trust	51



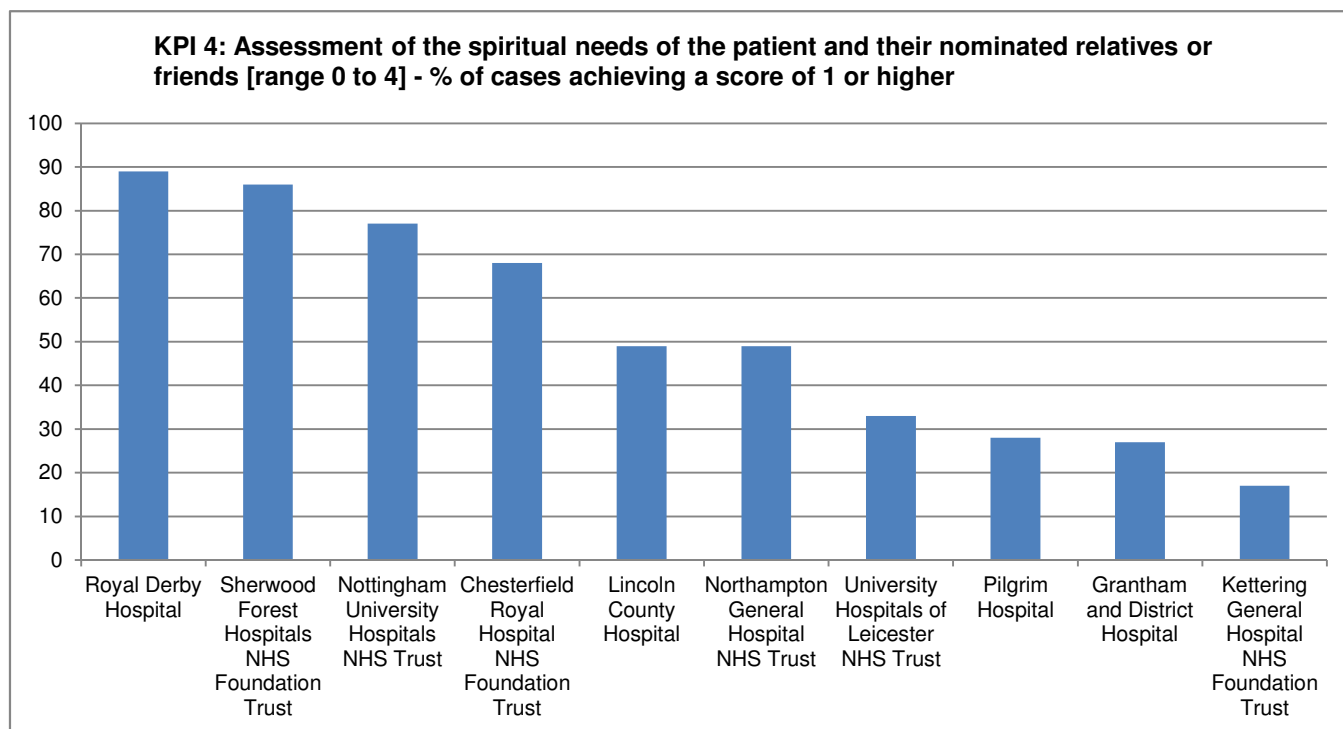
5.2.4 Clinical KPI 3: Communication regarding the patient's plan of care for the dying phase

Hospital	KPI 3 (score range 0 to 4): % of cases achieving a score of 4
Royal Derby Hospital	92
Sherwood Forest Hospitals NHS Foundation Trust	78
Lincoln County Hospital	71
Nottingham University Hospitals NHS Trust	68
Chesterfield Royal Hospital NHS Foundation Trust	61
Northampton General Hospital NHS Trust	59
Pilgrim Hospital	47
University Hospitals of Leicester NHS Trust	46
Grantham and District Hospital	35
Kettering General Hospital NHS Foundation Trust	23



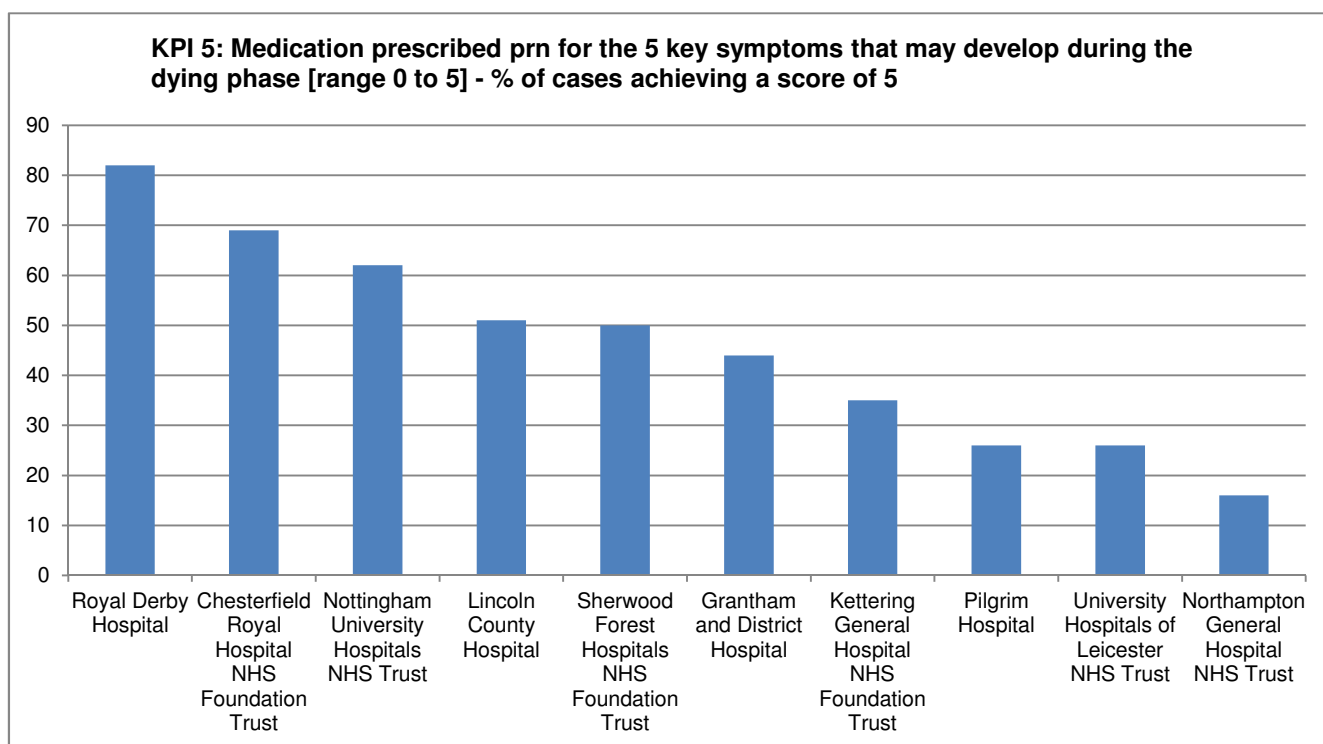
5.2.5 Clinical KPI 4: Assessment of the spiritual needs of the patient and their nominated relatives or friends

Hospital	KPI 4 (score range 0 to 4): % of cases achieving a score of 1 or higher
Royal Derby Hospital	89
Sherwood Forest Hospitals NHS Foundation Trust	86
Nottingham University Hospitals NHS Trust	77
Chesterfield Royal Hospital NHS Foundation Trust	68
Lincoln County Hospital	49
Northampton General Hospital NHS Trust	49
University Hospitals of Leicester NHS Trust	33
Pilgrim Hospital	28
Grantham and District Hospital	27
Kettering General Hospital NHS Foundation Trust	17



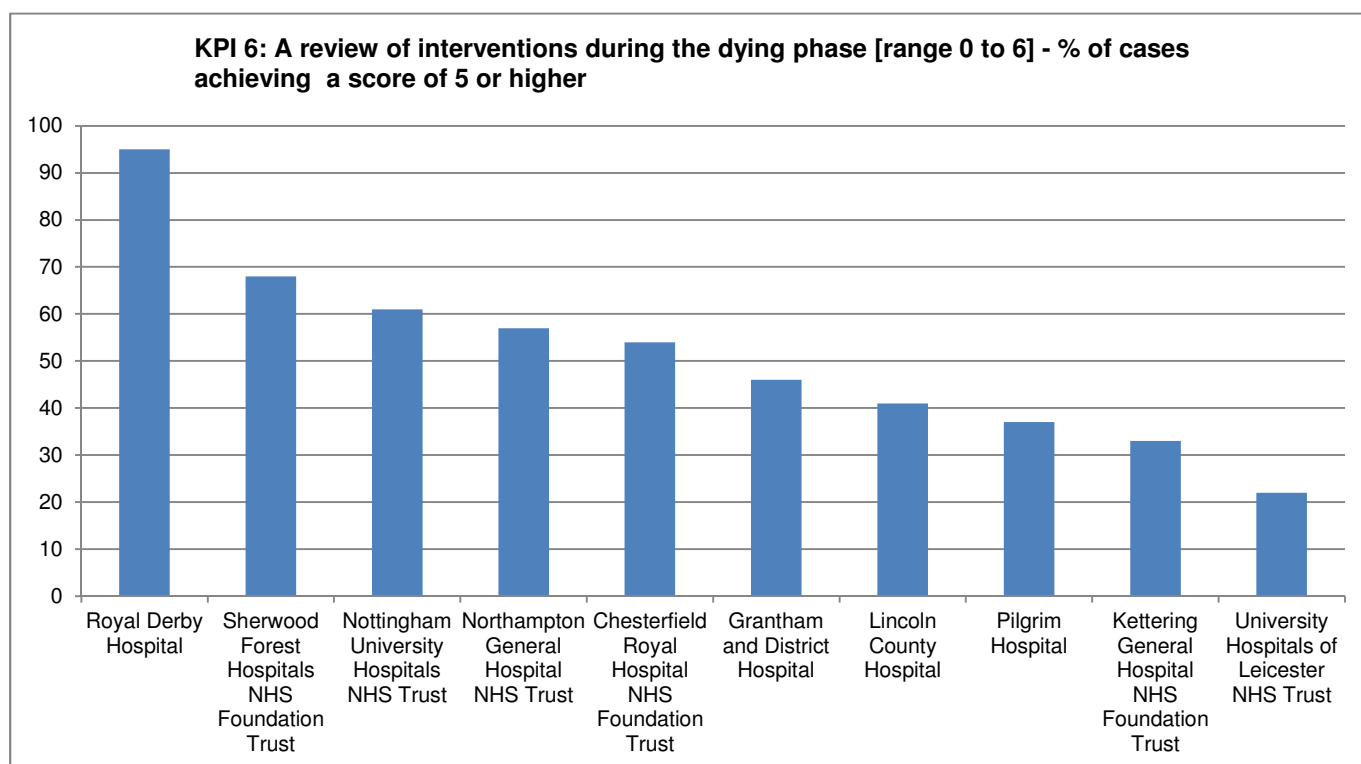
5.2.6 Clinical KPI 5: Medication prescribed prn for the 5 key symptoms that may develop during the dying phase

Hospital	KPI 5 (score range 0 to 5): % of cases achieving a score of 5
Royal Derby Hospital	82
Chesterfield Royal Hospital NHS Foundation Trust	69
Nottingham University Hospitals NHS Trust	62
Lincoln County Hospital	51
Sherwood Forest Hospitals NHS Foundation Trust	50
Grantham and District Hospital	44
Kettering General Hospital NHS Foundation Trust	35
Pilgrim Hospital	26
University Hospitals of Leicester NHS Trust	26
Northampton General Hospital NHS Trust	16



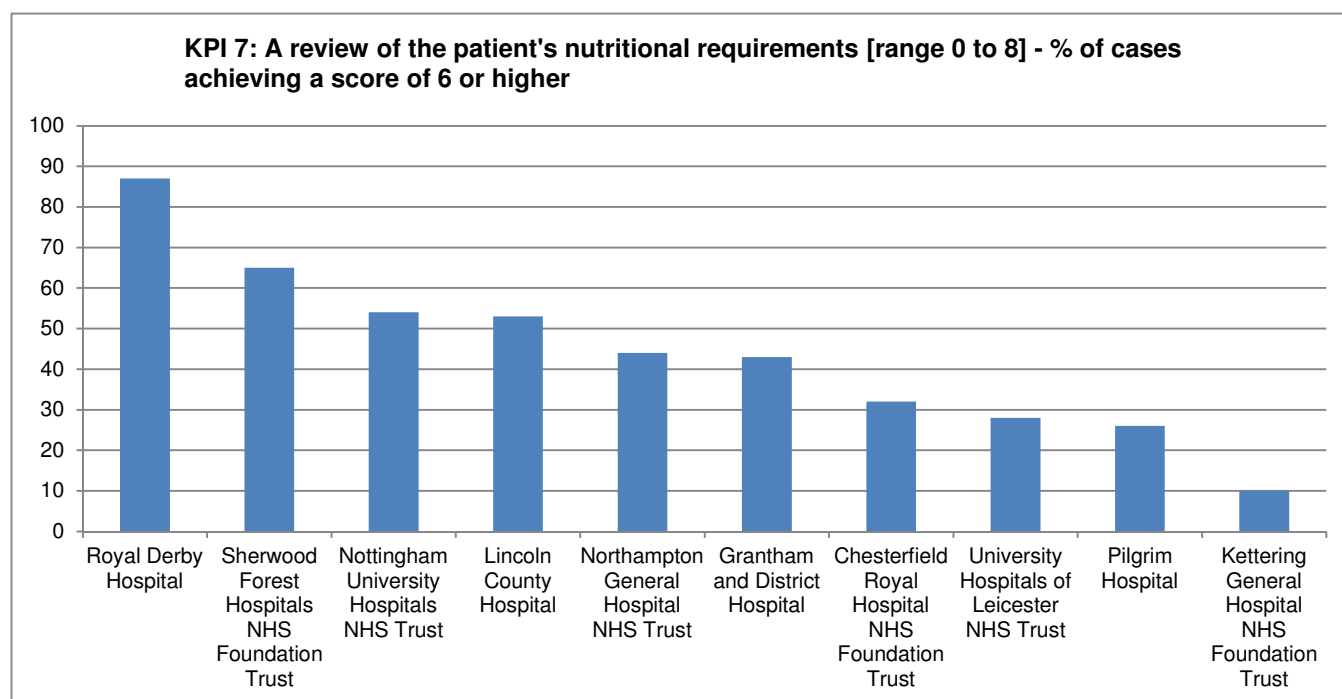
5.2.7 Clinical KPI 6: A review of the interventions during the dying phase

Hospital	KPI 6 (range 0 to 6): % of cases achieving a score of 5 or higher
Royal Derby Hospital	95
Sherwood Forest Hospitals NHS Foundation Trust	68
Nottingham University Hospitals NHS Trust	61
Northampton General Hospital NHS Trust	57
Chesterfield Royal Hospital NHS Foundation Trust	54
Grantham and District Hospital	46
Lincoln County Hospital	41
Pilgrim Hospital	37
Kettering General Hospital NHS Foundation Trust	33
University Hospitals of Leicester NHS Trust	22



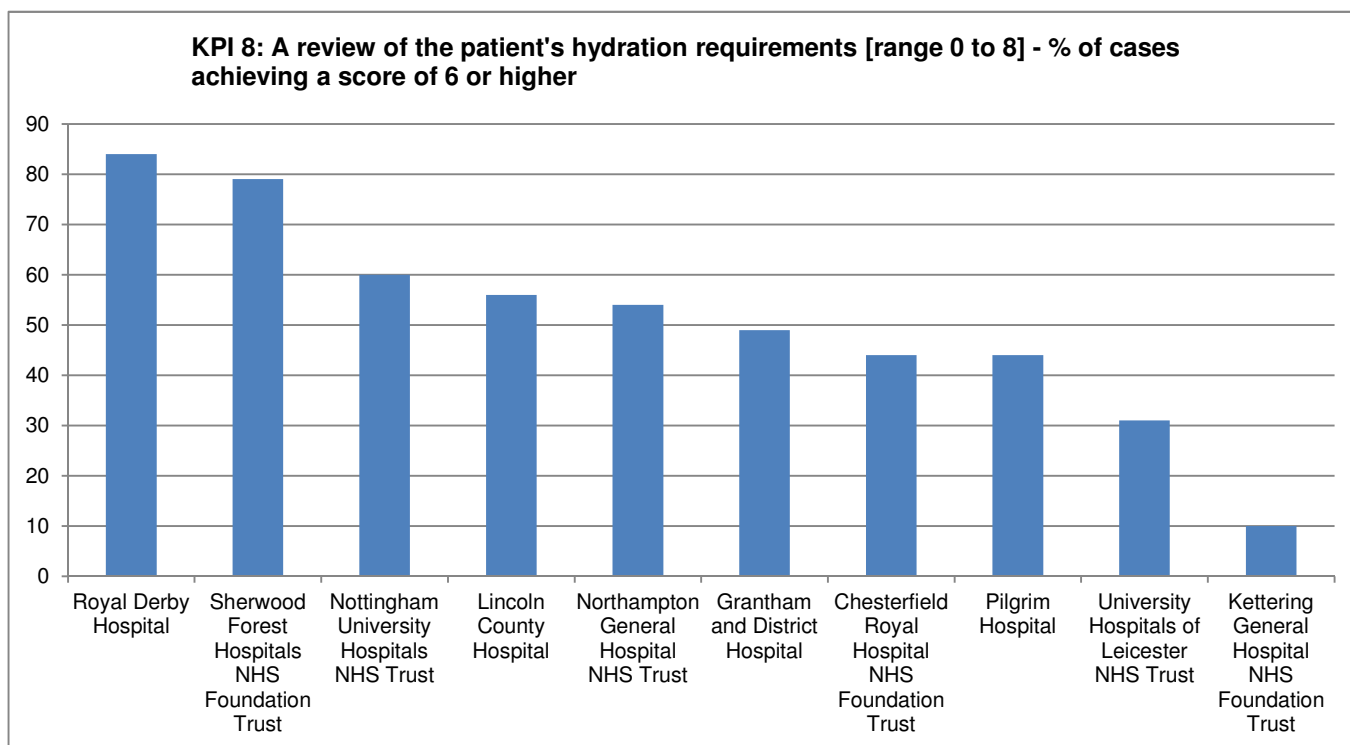
5.2.8 Clinical KPI 7: A review of the patient's nutritional requirements

Hospital	KPI 7 (score range 0 to 8): % of cases achieving a score of 6 or higher
Royal Derby Hospital	87
Sherwood Forest Hospitals NHS Foundation Trust	65
Nottingham University Hospitals NHS Trust	54
Lincoln County Hospital	53
Northampton General Hospital NHS Trust	44
Grantham and District Hospital	43
Chesterfield Royal Hospital NHS Foundation Trust	32
University Hospitals of Leicester NHS Trust	28
Pilgrim Hospital	26
Kettering General Hospital NHS Foundation Trust	10



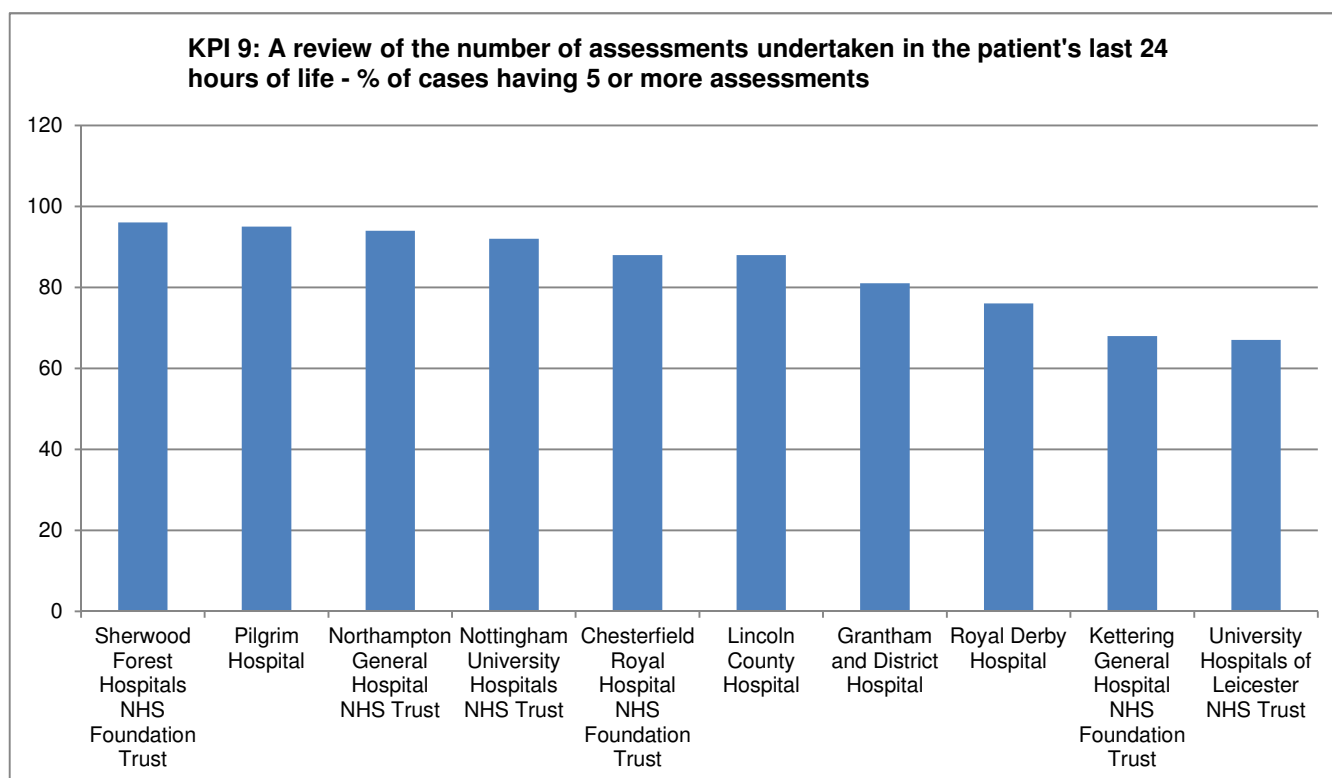
5.2.9 Clinical KPI 8: A review of the patient's hydration requirements

Hospital	KPI 8 (score range 0 to 8): % of cases achieving a score of 6 or higher
Royal Derby Hospital	84
Sherwood Forest Hospitals NHS Foundation Trust	79
Nottingham University Hospitals NHS Trust	60
Lincoln County Hospital	56
Northampton General Hospital NHS Trust	54
Grantham and District Hospital	49
Chesterfield Royal Hospital NHS Foundation Trust	44
Pilgrim Hospital	44
University Hospitals of Leicester NHS Trust	31
Kettering General Hospital NHS Foundation Trust	10



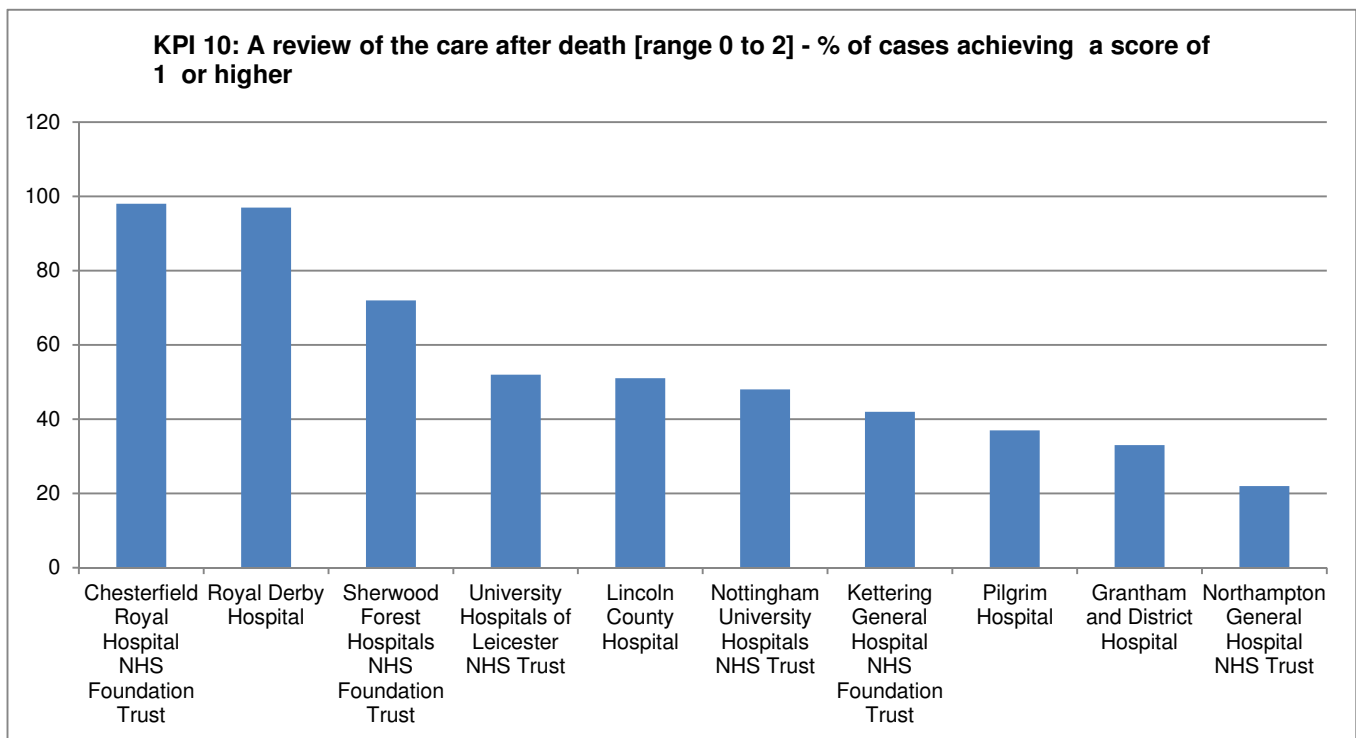
5.2.10 Clinical KPI 9: A review of the number of assessments undertaken in the patient's last 24 hours of life

Hospital	KPI 9: % of cases having 5 or more assessments
Sherwood Forest Hospitals NHS Foundation Trust	96
Pilgrim Hospital	95
Northampton General Hospital NHS Trust	94
Nottingham University Hospitals NHS Trust	92
Chesterfield Royal Hospital NHS Foundation Trust	88
Lincoln County Hospital	88
Grantham and District Hospital	81
Royal Derby Hospital	76
Kettering General Hospital NHS Foundation Trust	68
University Hospitals of Leicester NHS Trust	67



5.2.11 Clinical KPI 10: A review of the care after death

Hospital	KPI 10 (score range 0 to 2): % of cases achieving a score of 1 or higher
Chesterfield Royal Hospital NHS Foundation Trust	98
Royal Derby Hospital	97
Sherwood Forest Hospitals NHS Foundation Trust	72
University Hospitals of Leicester NHS Trust	52
Lincoln County Hospital	51
Nottingham University Hospitals NHS Trust	48
Kettering General Hospital NHS Foundation Trust	42
Pilgrim Hospital	37
Grantham and District Hospital	33
Northampton General Hospital NHS Trust	22



6. APPENDICES

Appendix 1 – Membership of the benchmarking task and finish group

Name	Job Title	Organisation
Emma Roberts	Head of Service - Specialist Palliative Care	County Health Partnerships Nottinghamshire
Joan Mercer	Head of Service Transformation and Improvement	Health Partnerships Nottinghamshire
Pauline Love	GP	North Derbyshire CCG
Anne-Marie Carey	Consultant Specialist Palliative Medicine	Ashgate Hospice, Chesterfield
Heidi Scott-Smith	Deputy Chief Nurse	NHS Erewash CCG
Karen Ashcroft	Development Manager	LOROS Leicestershire & Rutland Hospice

Appendix 2 – Method of data extraction and presentation

The following national audits and guidelines were used to extract measures that would inform the benchmarking of the quality of palliative and end of life care in the East Midlands:

- National care of the dying audit for hospitals
- NICE quality standards
- VOICES survey of the bereaved
- 5 priorities for care of the dying

The initial document that pulled together the measures from the above documents were shared with the LLG members at a meeting and an open discussion narrowed down the measures significantly. A task and finish group was then set up for the purpose of carrying out a benchmarking exercise in the East Midlands by collecting and analysing relevant and necessary data. As there was already a wealth of data available for end of life care as highlighted by NHS Improving Quality (NHSIQ), it was agreed that such existing resources should be used to produce an initial report around the quality of end of life care.

The available data hosted on the NHSIQ website and other related links were matched against the agreed measures, then only data from the East Midlands region or organisations within it was extracted. In order that any variations in quality of end of life care across the region are

highlighted, the data is presented in a comparative manner, whether it be between geographical areas or between organisations.

Appendix 3 – Introduction to data from the NCDAH 2013-14

Extract from the National Care of the Dying Audit for Hospitals report May 2014:

The 2013/14 audit represented a departure from previous audits which had been based on the goals of care within the Liverpool Care Pathway for the Dying Patient (LCP). Whilst the standards of care in this audit continued to be based on relevant national policy (*see list below) it involved a case note review of a sample of all patients dying in hospital, regardless of whether they were supported by a framework of care in the last hours or days of life. The audit questions were also informed by the 44 recommendations of the Independent Review of the Liverpool Care Pathway undertaken by Neuberger and colleagues in 2013 (**see below).

This audit comprised the following three sections.

- An organisational audit – key organisational elements that underpin the delivery of care.
- A case note review – a consecutive, anonymised case note review of the all patients who died (excluding sudden unexpected deaths) within participating sites within a defined timeframe.
- An optional local survey of the views of bereaved relatives or friends – using a validated self-completion questionnaire (CODE) (***)see below) to assess care delivery in the last days of life.

* National policies and guidelines:

1. Department of Health. *End of life care strategy: promoting high quality care for all adults at the end of life*. London: DH 2008.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [Accessed 7 March 2014]
2. Department of Health. *End of life care strategy: quality markers and measures for end of life care*. London: DH, 2009.
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf [Accessed 7 April 2014]
3. National Institute for Health and Clinical Excellence (NICE). *NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers*. London: NICE, 2011. www.nice.org.uk/nicemedia/live/13845/60322/60322.pdf [Accessed 7 April 2014]
4. Department of Health. *The Mandate: a mandate from the government to the NHS commissioning Board: April 2013 to March 2015*. London: DH, 2012.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf [Accessed 7 March 2014]

5. General Medical Council. *Treatment and care towards the end of life: good practice in decision making – guidance for doctors*. London: GMC, 2010. www.gmc-uk.org/static/documents/content/End_of_life.pdf [Accessed 7 March 2014]
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Method

A retrospective audit design gathered data on aspects of the organisation of care within each Trust including relevant structures, processes and policies. Clinical data were recorded from consecutive case-notes of at least 50 patients per site who had died during May 2013. The local survey of bereaved relatives' views was optional, as some sites had existing local processes for this purpose. Those that wished to participate sent out anonymised questionnaires to relevant families or friends which could either be completed online or in hard copy.

All data were analysed descriptively and key performance indicators for the organisational and clinical elements were developed, reflecting accepted national standards.

Sample

Nationally, 131 trusts (90% of those eligible) comprising 150 individual hospital sites submitted data to the organisational audit. A total of 6,580 patient data sets (representing 149 sites) were submitted for the national clinical sample. The sample had a median age of 82 years and 23% had a diagnosis of cancer. 51% of patients were female. For 48% of the sample, care was supported by a framework for care in the last hours or days of life. Thirty six trusts (27% of those participating) undertook the local survey of bereaved relatives; 858 of the 2,313 questionnaires which were distributed (37%) were returned and were suitable for analysis.

From the East Midlands, 8 trusts comprising 10 individual hospital sites submitted data to the NCDAAH in 2013-14. The number of cases for individual clinical KPIs is displayed in the relevant sections.

Each participating site received an individual report of their performance against the national sample for the organisational and case note review elements of the audit. The results of the national sample for the local survey of bereaved relatives' views were also included. In addition, individual site results were downloadable separately from within the audit web tool.

Appendix 4 – Contact details

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