Royal College of Physicians

Marie Curie

Care and support through terminal illness

End of Life Care Audit – Dying in Hospital

National report for England 2016

Commissioned by:

Acknowledgements

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Useful links

Royal College of Physicians	www.rcplondon.ac.uk
National Council for Palliative Care	www.ncpc.org.uk
Marie Curie	www.mariecurie.org.uk
Healthcare Quality Improvement Partnership	www.hqip.org.uk
Care Quality Commission	www.cqc.org.uk

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Foreword

This report presents the results of the second biennial national audit of care of the dying in hospitals in England. The first audit report, published in 2014, included data collected during 2013 from three lines of enquiry – an organisational audit of services, a case note clinical audit and a retrospective survey of bereaved carers. This second round of audit is based on data collected during 2015. The 2-year period has seen major changes in end of life care in the NHS and we are pleased that many of the audit measures show that there has been improvement in the delivery of care to dying people and those important to them.

The changes since 2013 include the momentous step, for both the NHS and the important charitable sector in end of life care, of the phasing out of the Liverpool Care Pathway. This was recommended by the 2013 Neuberger review in its report *More care, less pathway*. The Leadership Alliance had also published its report *One chance to get it right*. Further influential documents that have emerged on the English healthcare landscape in the intervening period include the Parliamentary and Health Service Ombudsman's report *Dying without dignity* and the Ambitions Framework. Finally, the National Institute for Health and Care Excellence (NICE) published its eagerly awaited guidelines on *Care of the dying adult* in December 2015. Although the latter were published *after* the data collection for the audit published here, the comprehensive audit design enables us to view the results in the light of many of their key recommendations.

As with the last audit, we present herein two elements: an organisational review of services and protocols; and a clinical case note based audit depicting the end of life care of patients who died during May 2015.

Although many questions in the current audit are identical or very similar to the 2013 exercise, enabling us to make some direct comparisons, in other aspects it has gone further and asked new and more searching questions, in both of the sections. One reason for this divergence is that we wanted the current audit to reflect the important changes since 2013 and, in particular, the recommendations of the Neuberger review and *One chance to get it right*. Thus the results are presented in such a way as to demonstrate how well trusts are performing against the 'five priorities for care' in the latter document. We have also looked carefully for evidence of 'individualised' care, as recommended by Neuberger.

I was honoured to be appointed as the clinical lead for this audit. I take great pleasure in thanking the many organisations and individuals who have helped us to shape, undertake and review the audit and this substantial report presented here. These include the colleagues and patient representatives who attended the first scoping workshop; the audit's Steering Group which comprises consumers as well as a wide range of health and social care professionals; and NHS England for its commitment and support. I must also acknowledge the dedicated team consisting of project and programme managers and a statistician at the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians, who not only undertook all phases of the work but also – with its clinical director – 'trained' me over the past year in their audit processes and methods.

The results in the following pages should give us cause for satisfaction that end of life care has – far from being set back by the phasing out of the Liverpool Care Pathway – advanced the already acknowledged British prowess in this area of healthcare. But we cannot be complacent, for it also shows areas where the NHS is under-performing against the national policy agenda. We recognise the need to continue this series of biennial audits and, to that end, we eagerly await the decision about future funding of this important work.

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Executive summary

The aim of this report is to contribute to learning that can help to improve the quality of care and services for patients who have reached the end of their lives, and who are dying in hospitals in England.

Background

Nearly half of all deaths in England occur in hospitals – 223007 out of a total of 469975 in 2014.[1] For this reason, trust boards, managers and clinicians should recognise that a core responsibility of hospitals is to deliver high-quality care for patients in their final days of life and appropriate support to their families, carers and those close to them. Government policy in recent years has reinforced this requirement.[2–5]

In 2013 the independent Neuberger review (*More care, less pathway*)[6] found that there had been failings of the Liverpool Care Pathway in achieving good deaths for a significant proportion of people who were managed using this tool. It recommended that the Liverpool Care Pathway should be phased out by 2014 and be replaced by a more individualised approach. Following this, the Leadership Alliance for the Care of Dying People report[7] (*One chance to get it right*) set out an approach to caring for dying people that healthcare organisations should adopt in the future. The new approach set out by the Alliance focuses on achieving five 'priorities of care', which make the dying person themselves the focus of care in the last few days and hours of life and exemplify the high-level outcomes that must be delivered for every dying person. The priorities for the care of the dying person are that, when it is thought that a person may die within the next few days or hours:

- this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
- sensitive communication takes place between staff and the dying person, and those identified as important to them
- the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

The Royal College of Physicians (RCP) published *National care of the dying audit for hospitals*[8] in 2014, using data collected in 2013 when the Liverpool Care Pathway was still being used. As well as building on the recommendations of the 2014 report, this 2015 RCP audit is designed to ensure that the five priorities of care for the dying person have been implemented and are monitored at a national level. National audit data will support end of life care commissioners, service providers and policymakers to audit the care and to facilitate quality improvement initiatives.

This audit comprised the following two sections.

- An organisational audit – key organisational elements that underpin the delivery of care.
- A case note review – a consecutive, anonymised case note review of all the patients who died within participating sites* within a defined time frame.

*Within the context of the audit, trusts registered their participation as either a trust *or* some or all individual hospitals within a trust. Therefore, a participating 'site' may either be a trust or an individual hospital within a trust.

Progress since the last audit

Following the Neuberger review of 2013, its key recommendation for the phasing out of the Liverpool Care Pathway in July 2014 was endorsed by all national organisations in the Leadership Alliance, which produced its ‘five priorities of care’ as an interim measure to give providers direction on how to deliver consistently good end of life care. However, there was palpable concern in some sections of the palliative care community that the gap left after the Liverpool Care Pathway’s withdrawal could result in a degradation of services to people in the last days and hours of life. This report demonstrates that, far from a deterioration, comparing the 2013 and 2015 audits, there has been a broad front of improvements in nearly all aspects of care of the dying in hospitals in those trusts who participated.

It should be said that in many areas, trusts need to perform better against national policy drivers and protocols. There are also still many items that were audited that show unreasonably wide variations between organisations. This may arise, admittedly, because of the hitherto lack of national standards: something that the publication in December 2015 of the NICE guidance *NG31: Care of adults in the last days of life*[9] will rectify.

Methods

Registration

Letters explaining the nature and purpose of the national audit were sent to chief executives and copied to clinical audit departments and palliative care leads of all acute hospital trusts in England. These were accompanied by formal registration process participation details. It was then the responsibility of each trust to register their participation and they did this by providing managerial, clinical, administration and audit representative contact details. Usernames and passwords to access a web-based data entry tool were emailed to nominated personnel within each site ahead of the audit start date. For the clinical case note review element, trusts could choose to register at either trust or hospital level. Therefore, a participating ‘site’ could either be a trust or an individual hospital within a trust.

All acute trusts in which adult patients were ‘expected’ to die were eligible to take part in the audit. Mental health trusts, ambulance trusts, children’s trusts, orthopaedic/rheumatology trusts, women’s trusts and specialist eye trusts were excluded.

Organisational element

This element sought trust-level information to gain an understanding of the size, scope and environment in which care was provided, as well as structural provisions in terms of policies and procedures for the care of dying patients and those people that are important to them. This information enabled the assessment of trust performance against key national standards and to contextualise the findings from the clinical case note review.

Clinical case note review element

This clinical element was based upon a set of case note review questions which were devised to reflect the five priorities of care for the dying patient and involved consultation with a multidisciplinary audit steering group following an initial workshop event involving another multidisciplinary group comprised of audit stakeholders. The case note review entailed a consecutive, anonymised clinical case note audit of all adult (ie aged 18 years or older) deaths occurring between 1 and 31 May 2015, where each patient had been under the care of the trust for a minimum of 4 hours.

The data entry requirement was capped at 80 patients per trust; however sites were able to continue to include further cases if they wished in order to provide themselves with a more robust local sample for benchmarking against national statistics.

Submission of data

A secure, web-based data collection tool was designed to capture data pertaining to both the organisational and clinical audit elements. Explanatory notes were devised to assist the site audit coordinators to establish a robust sample, access the web-based data entry tool and submit the organisational and clinical case note review data. Details of all audit information were sent to the named audit coordinators following registration, and data entry responsibility was decided by personnel within the participating trusts. Telephone help-line and email support services were made available during the data submission period to facilitate data collection and to answer any queries.

The data entry period for the organisational audit was between 6 July 2015 and 31 July 2015. Participating trusts were responsible for completing the online organisational audit proforma and were advised to liaise with their clinical information department in order to fill out certain elements of this organisational audit.

The clinical case note review data entry period was between 6 July 2015 and 30 September 2015. Clinical governance/information departments within participating sites were responsible for identifying and collating eligible case notes. Participating trusts were responsible for completing the case note review proforma with patient-level data derived directly from information held within the patient case notes.

Sites were also requested to provide two independent entries of the first three patient data sets for an internal inter-auditor reliability study. The ‘repeat’ entries were entered separately via a separate username and password to distinguish them from the original entries. Auditors were also advised to mark ‘repeat’ entries as such by clicking the relevant tick-box on the online proforma.

Sample

In total, 142 sites from 137 out of 142 possible trusts submitted data to the organisational audit. The number of sites being greater than the number of trusts is attributable to the fact that three trusts each submitted data for two separate sites (due to recent mergers), while two other trusts were community trusts that wished to take part in the audit. The community trusts have been excluded from the participation figures.

A total of 9302 unique patient datasets (ie a complete case note review addressing each of the clinical audit questions) were submitted for the national clinical case note review sample. These were submitted by a total of 145 sites from 139 out of a possible 142 trusts.

The sample had a median age of 82 years and 19.8% had a primary diagnosis of cancer: 51% of patients were female. The audit covered all patients who had died after a minimum of 4 hours following admission (by comparison, the 2013 audit included deaths that had occurred 24 hours following admission).

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. In addition, individual site results were downloadable separately from within the audit web tool.

Quality indicators for end of life care

In the report of the 2013 audit, we published a set of key performance indicators (KPIs), by which hospital trusts could benchmark themselves for future performance. The changing healthcare landscape and terminology have led us to re-conceive these as quality indicators (QIs) for this 2015 audit. Essentially, they retain the same function and are derived from the actual results of participating trusts during the audit.

We have chosen a range of activities, both organisational and clinical, which reflect the ‘individualised’ care plans recommended by the 2013 Neuberger *More care, less pathway* review,[6] and the ‘five priorities of care for the dying person’ which were published in the *One chance to get it right* report.[7] We particularly picked aspects of care for these QIs in which the audit showed a variance of results, with many trusts performing well but some also under-performing. The trust-level QI data presented in Appendix VI of this report show these services how their own results stand up to the national picture summarised below (Table A). We hope that they will encourage investment into changes to consolidate good achievements, or to rectify weaknesses.

Table A: National achievement against end of life care quality indicators

	CLINICAL AUDIT **Cases in clinical audit** **Clinical audit indicator**	**National result** **n=9302** **% of cases**
1	Is there documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days? **%YES**	83%
2	Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with a nominated person(s) important to the patient? **%YES**	79%
3	Is there documented evidence that the patient was given an opportunity to have concerns listened to? **%YES or NO BUT**	84%
4	Is there documented evidence that the needs of the person(s) important to the patient were asked about? **%YES or NO BUT**	56%
5	Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient's needs regarding an individual plan of care? **% YES**	66%
	ORGANISATIONAL AUDIT **Sites in organisational audit** **Organisational audit indicator**	**n=142** **% of sites**
6	Is there a lay member on the trust board with a responsibility/role for end of life care?	49%
7	Did your trust seek bereaved relatives' or friends' views during the last 2 financial years (ie from 1 April 2013 to 31 March 2015)?	80%
8A	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **medical staff**?	63%
8B	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **nursing (registered) staff**?	71%
8C	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **nursing (non-registered) staff**?	62%
8D	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **allied health professional staff**?	49%
9	Was there face-to-face access to specialist palliative care for at least 9am to 5pm, Monday to Sunday?	37%
10	Does your trust have one or more end of life care facilitators as of 1 May 2015?	59%

Key findings

Clinical patient case note review key findings

Recognition of dying

- Ninety-three per cent of patients whose death was predictable had documentation that they would probably die. In 76% of cases, a senior doctor was involved in the recognition of dying. For half the patients, recognition of dying occurred within 5 days after admission; and for half the patients this occurred less than 34 hours before death. In total, only 25% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death. In 95% of the cases where it had been recognised that the patient was likely to die, there was documented discussion with those nominated as important to the dying person.

Communication and treatment decisions

- Where there was an advance care plan, the team took the contents into account when making decisions (91%) and it was reviewed (79%); however only 4% (415/9302) of patients had documented evidence of an advance care plan made prior to admission to hospital.
- A do not attempt cardiopulmonary resuscitation (DNACPR) order was in place for 94% (8711/9302) of patients' notes at the time of death. Where sudden deaths are excluded, discussion about CPR by a senior doctor with the patient was recorded in 36% (2748/7707). Overall, for 16% (961/6072) there was no reason recorded why a discussion did not take place. Discussion about the CPR decision with the nominated person(s) important to the patient was documented in 81% of cases.
- It was recorded that 32% of patients had opportunities to have their concerns listened to and, of these, 94% were given the opportunity to have questions answered about their concerns.

Communication with people important to the patient

- In 38% of cases, there was documented evidence in the last episode of care that the patient's needs had been discussed with the people important to them.
- In total, 54% of case records showed that the needs of persons important to the person were asked about. Of these, 62% had needs identified.
- It was recorded that nominated person(s) important to 80% of patients had opportunities to discuss the patient's condition with a senior healthcare professional.
- Excluding the cases of sudden or unexpected deaths, in 84% of cases the people important to the dying patient were notified of the imminent death. Of those notified, 63% were recorded as being present at the time of death. There was documented evidence of care and support of the patient's family at the time of, and immediately after death, in 65% of cases with wide variance between different sites.

Individual plan of care

Symptom control

- Excluding sudden deaths and cases where the patient had died less than 24 hours after admission, 73% of case records showed that there had been a holistic assessment of the patient's needs with a view to making an individual plan of care.
- Of the key symptoms that could be present around the time of death, there was documented evidence that: pain was controlled in 79% of cases; agitation/delirium in 72%; breathing difficulties in 68%; noisy breathing / death rattle in 62% and nausea/vomiting in 55%. If results are restricted to those with known length of stay (LOS) ≥24 hours, there was documented evidence that anticipatory medication (prn) was prescribed for the key symptoms: for pain in 75% of cases; agitation/delirium 69%; breathing difficulties 66%; nausea/vomiting 66%; noisy breathing / death rattle 62%.
- The prescribing of specific drugs for prn and regular use, including the use of continuous subcutaneous (SC) and intravenous (IV) infusions, was extensively documented. However there were problems with the recording of some drugs on the audit data collection web tool. Thus there will be a limited analysis of these data at this time. In total, 65% of the medications that patients received had been reviewed in the last 24 hours of life.

Drinking and eating

- In the last 24 hours of life there was documented evidence that: in two-thirds of cases the patient's ability to drink had been assessed; thirty-nine per cent of patients were documented as drinking, and in 45% of cases that the patient had been supported to drink.
- In total, 18% of patients had a 'nil by mouth' (NBM) order in their last 24 hours. Ninety-three per cent of NBM orders had a documented reason. Twenty-three per cent of patients with an NBM order had been informed of it; 64% of the people important to the patient had been informed. The majority (54%) of the NBM decisions had involved a consultant (other than palliative medicine); 20% involved speech and language therapists (SALTs) and 16% a staff nurse.
- In 71% of cases, there was documented evidence that the patient had an assessment regarding the need for clinically assisted (artificial) hydration (CAH) at any time between the final admission and death. There was documented evidence that discussion regarding drinking and the need for CAH was undertaken with the patient between the *date of final admission and death* in 18%; and in 39% these discussions had taken place with nominated people, or the nominated independent mental capacity advocate (IMCA), or lasting power of attorney (LPA) for personal welfare.
- CAH was in place during the last 24 hours before death in 43% of patients.
- In 61% of cases there was documented evidence that the patient's ability to eat had been assessed in the last 24 hours of life. In 26% of cases, it was documented that the patient was eating in the last 24 hours. In 36% of cases there was evidence that the patient had been supported to eat in the last 24 hours.
- In 34% of cases, there was documented evidence that the patient had an assessment regarding the need for clinically assisted (artificial) nutrition (CAN) at any time between the time of the final admission and death. CAN was in place during the last 24 hours before death in 8% of patients.

Spiritual care

- There was documented evidence of discussion during the last episode of care regarding the patient's spiritual/cultural/religious/practical needs with 15% of patients who were capable of participating in such discussions. In a further 27% there had been discussion with a nominated person important to the patient. It was documented that in 89% of cases, the identified spiritual/cultural/religious/practical needs had been met.
- There was documented evidence of care of the patient immediately prior to, or at the time of, death in 73% of cases. Immediately after death, care of the patient was recorded in 63% of cases.

Organisational element key findings

Staffing and training

- In total, 13% of trusts (18/142) reported that they had specialist palliative care beds.
- Almost all (97%) trusts had their own specialist palliative care service; 70% also used a specialist palliative care service funded and based outside the trust.
- There was a median of 1.08 specialist palliative care (SPC) consultant whole-time equivalent (WTE) filled posts (for direct clinical care of hospital inpatients excluding those in SPC beds) per 1,000 adult beds; and a median of 5.08 clinical nurse specialist WTE filled posts per 1,000 adult beds. The availability of SPC staff around the clock varied widely, but 11% (16) of trusts offered a 24/7 face-to-face service. The availability of out-of-hours telephone service was more comprehensive, with the majority of services providing this every day of the week. Twenty-six trusts did not indicate any level of provision of face-to-face specialist palliative care involving doctors, at any time.
- Thirty-seven per cent (53/142) of sites had face-to-face access to a palliative care service Monday to Sunday, 9am to 5pm.
- Fifty-nine per cent of trusts had one or more end of life care facilitators in place.
- Ninety-six per cent of trusts had a formal in-house continuing education programme on the subject of end of life care. Formal in-house, communications skills training was available for 71% of registered nurses, 63% of medical staff, 62% of non-registered nurses and 49% of allied health professionals.

Guidance and policies

- Only 46% of trusts were involved in the Transforming End of Life Care in Acute Hospitals Programme; and only 35% of trusts are using electronic palliative care coordination systems (EPaCCSs).
- Ninety-eight per cent of trusts reported ‘locally developed programmes of work to support end of life care’, which probably represents the changes needed after the withdrawal of the Liverpool Care Pathway.
- There was a 66% uptake of a formal process for discussing and reporting on the five priorities of care.
- As of 1 May 2015, 78% of trusts had a mechanism for flagging complaints that related to end of life care. For organisations where there was an end of life care strategy group, 68% of these had complaints routinely reported to them.
- In total, 99-100% of trusts stated that they had guidance on prescribing medications for each of the five key symptoms that can be present in patients in the last days/hours of life. Most trusts had policies for ensuring patients’ comfort and dignity; and for offering family and friends access to the body after death, and a prayer room. All trusts reported that they had a policy for recording DNACPR decisions, while 80% had a policy for the deactivation of implantable cardioverter defibrillators (ICDs). Seventy-five per cent reported that they had designated quiet spaces for relatives.
- The 2014 *National care of the dying audit for hospitals* report (on 2013 data)[8] recommended that all trusts should have a named member on the board responsible for end of life care. Ninety-eight per cent have achieved this.
- The last audit also recommended that all trusts have a lay member with responsibility for end of life care on their board. Only 49% of trusts achieved this.
- Seventy-eight per cent of trusts stated that they gave leaflets to families and those important to dying patients about what to expect.

Using relative’s views and auditing care

- Sixty-five per cent of trusts had undertaken a formal audit of care for patients in the last hours or days. Seventy-six per cent fed audit results back to the trust board.
- In total, 80% of trusts sought bereaved relatives’ and friends’ views using a variety of mechanisms between 1 April 2013 and 31 March 2015. Eighty-two per cent of trusts shared the results of bereavement surveys with the clinical team; 64% with the trust board; and 31% with the public. Sixty-seven per cent of trusts reported that they implemented change to their service as a result of their assessment of bereaved relatives’ or friends’ perspectives.

Key recommendations

Clinical case note review element recommendations

- Recognition of the possibility that a patient may die should be communicated to the patient, people important to the patient and staff, and documented in the case notes as early as possible. The recognition of dying should be reviewed by a senior doctor or nurse.
- When the possibility of dying is not discussed with the patient or the nominated person important to them, the reasons for this should always be documented in the case notes.
- All professionals, especially those working with people living with chronic conditions, multiple comorbidities, and in particular people for whom future loss of mental capacity is anticipated (eg people with dementia), should initiate and encourage advance care planning.
- Assessment of holistic needs of patients, leading to an individualised care plan, should be undertaken more frequently and uniformly once it is recognised that the patient is dying. These assessments should cover:
  - all the commonly experienced symptoms seen in dying patients
  - the possible need for CAH
  - the dying patient’s ability and desire to eat
  - the possible need for CAN.
- Medication prescribed for the dying patient in the last 24 hours of life should be reviewed; and this review should record the degree of symptom control for each of the five key symptoms.

- There needs to be better documentation of justification for NBM orders and improved communication of them to patients (if they are conscious) and to those important to them. NBM orders should only be made by a senior doctor, nurse or SALT specialist.
- For patients who are unconscious or lack capacity, there should be better documentation of attempts to contact and discuss hydration and/or nutrition needs with those important to them, especially those nominated to have responsibility for decisions so that they are involved in discussions.
- The documentation should be improved regarding the:
    - discussions undertaken about the dying patient's spiritual/cultural/religious/practical needs
    - identification of the needs of the dying patient and those important to them
    - identification of patients' concerns, and those of the people important to them
    - recording who was present at the time of the patient's death
    - care of the patient undertaken immediately before and after death (especially if there were special religious/cultural requirements)

Organisational element recommendations

- Where trusts are not already using EPaCCSs or an equivalent system for record sharing, they should take steps to do so.
- All trusts should have access to specialist palliative care services 9am to 5pm, 7 days a week.
- All medical and nursing staff with responsibility for the care of dying people should attend communication skills training specifically on care in the last days/hours of life, and this should be recorded in their portfolios. Health and social care professionals should receive training or information about advance care planning (eg www.e-lfh.org.uk/programmes/end-of-life-care).
- There should be at least one lay member with specific responsibility for end of life care on every NHS trust board.
- Trusts should provide protocols to ensure provision of patient comfort, dignity and privacy – up to, including and after the death of the patient.
- All trusts should seek bereaved relatives' views, and results should be fed back to the trust's board as well as the public.
- Trusts should perform audits of end of life care and the results should be fed back to their boards.

Future opportunities and challenges

The big opportunity for the End of Life Care Audit – Dying in Hospital (and also the biggest set of challenges) in the coming years will be to align NHS practices to the new NICE guideline (NG31).[9] For example, it has highlighted many areas where access to more experienced staff and especially to specialist palliative care professionals will need to be improved. Given the current low level of 9am to 5pm, 7-day access to specialists shown in this report – never mind 24/7 access – this could have major implications for the way that NHS trusts and charitable providers must work together. New programmes of training will be needed to help staff recognise the signs and symptoms when someone may be dying – or possibly improving – and how to communicate the uncertainties around those subtle clinical changes. For clinicians, reviewing the need for maintaining hydration and discussing the advantages and disadvantages of CAH will also necessitate training and improved communication skills. Trusts in England will have to change their policies on prescribing 'as required' and in particular for 'anticipatory medications' – moving from a blanket approach to a tailored one. Overall, there will have to be explicit changes to ensure that care for dying people, and for those important to them, must become truly individualised.

We hope that the next audit in 2017/2018 will show that the upheaval in end of life care experienced in England between 2013 and 2015 will have further positive outcomes for patients, families and staff. Ideally, that audit should also encompass the full picture of end of life care in all settings.

Introduction

Background

The End of Life Care Audit – Dying in Hospital is a national clinical audit funded by NHS England, commissioned by the Healthcare Quality Improvement Partnership (HQIP) and managed by the Royal College of Physicians (RCP). Additional funding was also provided by Marie Curie to assist with the dissemination and usage of the audit results for quality improvement purposes. The audit builds on the recommendations of the 2014 *National care of the dying audit for hospitals*[8] and is designed to ensure that the priorities for care of the dying person outlined in the document *One chance to get it right*[7] and summarised in the executive summary of this report are monitored at a national level. National audit data will support end of life care commissioners, service providers and policymakers to audit care and to facilitate quality improvement initiatives.

National policy context

> *I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).*

This summary statement, which was first articulated in *Every moment counts*,[10] a narrative for person-centred, coordinated care for people near the end of life produced by National Voices and the National Council for Palliative Care, has been adopted as the overarching vision in the *Ambitions for palliative and end of life care: A national framework for local action 2015-2020* (the Ambitions Framework).[11]

The Ambitions Framework was jointly developed by 27 national organisations, including NHS England and the RCP. It builds on the national *End of life care strategy* (2008)[2] and takes into account the findings and recommendations of the many reports and publications on palliative and end of life care that have been published in recent years, including *More care less pathway* (2013),[6] the independent review of the Liverpool Care Pathway, and *One chance to get it right* (2014),[7] the system-wide response to that independent review. The approach taken in the Ambitions Framework is aligned to the NHS Five Year Forward View and recognises that the emphasis in today's health and social care system is on local decision-making and delivery.

The Ambitions Framework sets out six ambitions to bring about that overarching vision:

1. each person is seen as an individual
2. each person gets fair access to care
3. comfort and wellbeing is maximised
4. care is coordinated
5. all staff are prepared to care
6. each community is prepared to help.

The Ambitions Framework identifies eight foundations that underpin all these ambitions, and building blocks that are specific to each ambition. The foundations required are: personalised care planning; shared records; 24/7 access; education and training; involving, supporting and caring for those important to the dying person; evidence and information; co-design; and leadership – all of which are pertinent to care of dying people in hospitals, as well as palliative and end of life care earlier in the illness trajectory and across all settings.

End of Life Care Audit – Dying in Hospital

In the world we now live in, improvement cannot be brought about through central direction. It requires local leadership and collective local effort, working in respectful partnership with everyone involved, to achieve improvements in all aspects of care. Robust and valid data and information are necessary to help drive quality improvement, but this can be difficult to collect and test in palliative care solely through conventional research methodologies. A national audit programme such as this is necessary to support critical evaluation and reflection on the current clinical practice regarding the care of dying people and those important to them, both within and across organisations.

This audit includes a focus on the priorities for care of the dying person, set out in *One chance to get it right*.[7] More recently, after this audit had been carried out, the NICE clinical guidelines *Care of dying adults in the last days of life* (2015)[9] has been published. This includes recommendations that reflect similar emphases to that in the priorities for care of the dying person, and for which information is sought in this audit.

It should be borne in mind that the ability of audit participants to gather and submit information is dependent on the availability of documented evidence, and so this audit can only report on what was documented and may under-represent processes of care.

Aims of the audit

The overarching aim of this audit was to improve the quality of care and services for patients who have reached the end of their life, in hospitals in England.

This aim was to be achieved via the following objectives:

1. To build on the learning from previous care of the dying audits to date, preserving and further developing the most successful design features in order to maximise its quality improvement impact while moving away from a focus on a 'pathway'.
2. To achieve and maintain close alignment with relevant national guidance – *One chance to get it right*,[7] NICE clinical guidelines and the NICE Quality Standard for end of life care – throughout the audit, as appropriate.
3. To consider how the experience of relatives and carers could be incorporated in the audit moving forwards and achieving a granularity that would enable the future comparison of providers of healthcare and address any potential for duplication.
4. To develop from the dataset markers of best practice for end of life care to enable comparison over time, with the potential to be used in other national audits.
5. To enable improvements through the provision of timely, high-quality data that will enable the future comparison of healthcare providers, and comprise an integrated mixture of named trust, multidisciplinary team (MDT) and consultant-level reporting.

Audit governance

Delivery and performance of the audit was accountable to HQIP. It was managed by the RCP and supported by a multidisciplinary and multiagency advisory steering group. Membership of this steering group reflected the breadth of clinical and service expertise needed to represent the different perspectives of end of life care within acute hospital settings. A clinical lead provided clinical guidance throughout the course of the project.

Methodology

Letters explaining the nature and purpose of the national audit were sent out to chief executives of all acute hospital trusts in England and copied to clinical audit departments and palliative care leads in each acute hospital trust. These were accompanied by details of the formal registration process for participation. It was then the responsibility of each trust to register their participation. For the clinical case note review element, trusts could choose to register at either trust or hospital level. Therefore, a participating 'site' could either be a trust or an individual hospital within a trust.

Sites registered their participation by providing managerial, clinical, administration and audit representative contact details. Usernames and passwords to access a web-based data entry tool were emailed to nominated personnel within each site ahead of the audit start date.

Organisational element

All acute trusts in which adult patients were 'expected' to die were eligible to take part in the audit. Mental health trusts, ambulance trusts, children's trusts, orthopaedic/rheumatology trusts, women's trusts and specialist eye trusts were excluded. This element sought trust-level information from participating trusts to gain an understanding of the size, scope and environment in which care was provided, as well as structural provisions in terms of policies and procedures for the care of dying patients and those people who are important to them. This information enabled the assessment of trust performance against key national standards and to contextualise the findings from the clinical case note review.

Clinical case note review element

This clinical element was based upon a set of case note review questions (see www.rcplondon.ac.uk/eolca for these) that were devised to reflect the five priorities of care for the dying patient and involved consultation with a multidisciplinary audit steering group following an initial workshop event involving another multidisciplinary group composed of audit stakeholders. The case note review entailed a consecutive, anonymised clinical case note audit of all adult (ie aged 18 years or older) deaths occurring between 1 and 31 May 2015, where each patient had been under the care of the trust for a minimum of 4 hours.

The data entry requirement was capped at 80 patients per trust; however sites were able to continue to include further cases if they wished, in order to provide themselves with a more robust local sample for benchmarking against national statistics

Tools

A secure, web-based data collection tool was designed to capture data pertaining to both the organisational and clinical audit elements.

Submission of data

Explanatory notes were devised to assist the site audit coordinators to establish a robust sample, access the web-based data entry tool and submit the organisational and clinical case note review data. Details of all audit information were sent to the named audit coordinators following registration, and data entry responsibility was decided by personnel within the participating trusts. Telephone help-line and email support services were made available during the data submission period, to facilitate data collection and to answer any queries.

The data entry period for the organisational audit was between 6 July and 31 July 2015. Participating trusts were responsible for completing the online organisational audit proforma and were advised to liaise with their clinical information department in order to fill out certain elements of this organisational audit.

The clinical case note review data entry period was between 6 July and 30 September 2015. Clinical governance/information departments within participating sites were responsible for identifying and collating eligible case notes. Participating trusts were responsible for completing the case note review proforma with patient-level data derived directly from information held within the patient case notes.

Reliability analyses

Reliability (agreement between auditors) is not the same as validity (accuracy of measure). However establishing good agreement between auditors is an important part of the process of validation, as valid data by definition will have to be reliable. Sites were requested to provide two independent entries of the first three patient datasets for an internal inter-auditor reliability study. The 'repeat' entries were entered separately via a separate username and password, to distinguish them from the original entries. Auditors were also advised to mark 'repeat' entries as such by clicking the relevant tick-box on the online proforma.

In total, 468 pairs of cases from 140 sites (6 sites with 1-2, 103 sites with 3, 21 sites with 4, and 10 sites with 5-10) were analysed. Levels of agreement were found to be generally 'good', with 77% of computed kappa values* over 0.60, 59% over 0.70 and 40% over 0.80. Of 235 kappa values computed, their median was 0.73, with an IQR of 0.62-0.88.

*Please refer to Appendix IV for an explanation of kappa values.

Confidentiality

Organisational audit and clinical case note review

No patient-identifiable data were collected as part of this audit. Audit coordinators accessed the web-based data entry tool via a unique username and password. The web-based data entry tool was accessed via a secure https website, to ensure that any data submitted were encrypted, and all submitted data were stored on a secure server.

Web server

HQIP is the data controller for the audit dataset. Access to the RCP servers is restricted. Measures have been taken to prevent unauthorised individuals accessing data stored on the RCP servers. Processes are certified to ISA 7001: the recognised standard for data security. Information held on the servers can be accessed by information technology (IT) staff. All individuals with administrative access to the website must have had a third-party security screening, as per BS 7858:2006 (the standard code of practice for the security screening of individuals).[12]

Back up of information held on the server

A back up of the server is performed on a regular basis, to ensure that a recent copy of the content can be recovered should the server fail. The back-up server is stored in a fireproof location in a building separate from the location of the computer servers.

All data made available for analysis were in electronic format. As per the current information governance policy, the project datasets will be stored for 15 years from the end of the project, and confidentially destroyed after this period of time.

Ethical approval

The audit concurs with the definition stipulated by the National Research Ethics Service (NRES) as service improvement, and as such, ethical approval was not required.[13]

Data analysis

Organisational audit

Data have been analysed using descriptive statistics and summarised in tabular format to illustrate the national picture of the provision of end of life care. This data also provides useful contextual data with which to interpret the clinical case note review findings. Sites will see their own data benchmarked against national data in associated site-level reports.

Clinical case note audit

National data have been analysed using tables of descriptive statistics:

- median and interquartile ranges (IQRs) (or occasionally 10th, 20th, 80th and 90th percentile ranges), where appropriate
- percentages relating to each of the question response options within the case note review.

Results: clinical case note audit

Presentation of results

This report gives national results for all units participating in this audit.

Where applicable, 2013 national audit data are recorded beneath tables to allow an assessment of change at the national level. However, the previous audit asked many different questions to the current audits, and only a few questions were applicable for providing historical comparisons. The inclusion criteria also varied between audits in that the previous audit required patients to have been under the care of the hospital trust for ≥24 hours, whereas it was ≥4 hours for this current audit. To make results more comparable, it has been necessary to restrict the current audit results to cases with a known length of stay (LOS) of ≥24 hours, while for some questions it was necessary to also restrict the denominator to those cases for which there was recognition of dying. Direct historical comparison can be problematic even with apparently small subtle changes in wording and this must be borne in mind when considering a temporal change in results.

Visual methods are used to convey site variation in some results. Some of the graphics are what are known as ‘funnel plots’, which are diagrams that show site results plotted against site sample size, in comparison with a line that indicates the overall national result and dotted lines that indicate limits of control. Control limits are often shaped like a ‘funnel’ and serve as boundaries. Any results falling above the upper boundary or below the lower boundary are considered to be outliers. The chance of results being outside these limits due to chance alone is very small (5% for the inner and 0.2% for the outer limits), so when site results do fall outside, these are inconsistent with the overall national result in relation to their sample size. This implies that something else is happening, non-random in nature, probably systematic organisational differences rather than randomness of scatter.

Each section of the report is preceded by a short summary of key messages and of areas needing improvement. The executive summary, earlier in this report, provides an overview of these key messages and recommendations, particularly in relation to standards relating to care in the last days of life. After the key messages and areas for improvement we present the detailed data, usually in the form of tables but sometimes figures. Text is also given to expand on the interpretation of these data, especially when extra analyses were made to bring the current audit’s selection criteria and time frames to match those of the previous audit. Finally, we present textual discussions of the findings, bringing out comparisons with the previous audit and putting the results in the context of national policy documents such as NICE guidance. Although this may seem repetitive, it provides the reader with an overview of the data for each section.

There was some data cleansing required to account for illogical data. The drug doses were particularly problematic. There was also some data cleaning required of 'other' free-text entries where these were notably large numbers.

In tables and text, please note that when categories are combined to give a combined percentage, it is the numbers that are added and not the percentages.

When presenting the results in this report, the audit questions are reproduced as they appeared on the data collection proforma.

Inclusion criteria

The included cases were: all consecutive adult patients aged 18 years or above (at the time of death) starting from 1 May 2015 and continuing to 31 May 2015, who died in hospital in England and had been under the care of the hospital trust for 4 or more hours prior to their death. Patients who died in a hospital not directly managed by the trust being audited were not to be included.

In order to cap the audit workload within reasonable bounds, sites with more than 80 eligible adult deaths were asked to audit their first 80.

Participation (clinical case note audit)

- In total, 145 sites submitted data for the clinical audit case note review element of the audit.
- Three trusts each submitted data for two separate sites (due to recent mergers) *(= 142 trusts)*.
- Three sites that submitted data were community sites/trusts that wished to take part in the audit. The community sites have been excluded from the participation figures *(= 139 trusts)*.
- Three trusts did not participate in the clinical audit, making participation 98% *(139/142)*.

There were 9770 records exported from the web-data collection tool, of which 468 were duplicate records for use in reliability analyses when paired against the original record. This left 9302 unique patients from 145 sites in the main analysis. The median number of patient records submitted by each site was 77 (IQR 51-80).

In total, 142 sites submitted data to both the organisational and clinical audits, and data from both audits enables response to the clinical audit to be estimated. From the organisational audit data, there were 9787 adult deaths meeting the clinical audit inclusion criteria in hospitals that submitted clinical data. These 142 sites actually submitted audit data on 9249 adult deaths (95%).

Note that a very small percentage of the audit deaths (1%: 97 patients) did not appear to have occurred in May 2015. These were from 52 unique sites. Two of these sites had been granted permission to collect data over a longer period, to gain a larger local sample, and these account for 31 of the 97 patients. The other instances were most likely data input errors regarding date of death. The project group decided to retain all cases in the analysis.

Where comparisons with the 2013 audit data are made throughout this report, please be aware that these refer to the previous *National care of the dying audit for hospitals,*[8] which was published in May 2014 but audited 2013 data.

Section 1: Demographics

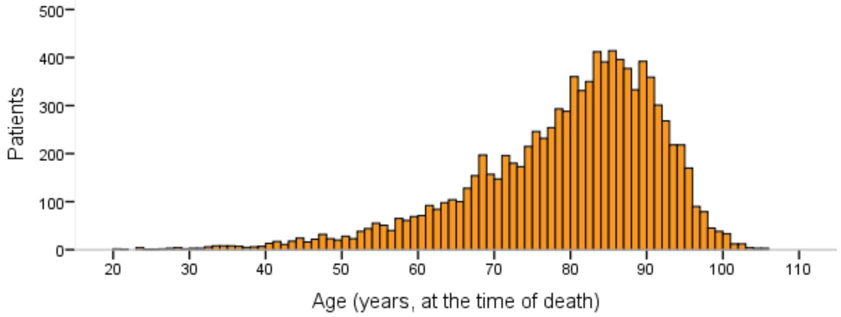
Gender

The audit sample comprised 49% (4594) males and 51% (4708) females.

Age

The mean age was 79 years, with a standard deviation (SD) of 12 years. The median age was 82 with an IQR of 72-88 years. Eight per cent (722) were aged under 60 years, 12% (1122) were aged 60-69 years, 23% (2125) were aged 70-79 years and 38% (3560) were aged 80-89 years and 19% (1773) were aged 90 years or older (Fig 1).

Fig 1: Distribution of age (years) at the time of death in the audit sample



2013 audit*: 50.6% females, median age 82 years. If the current audit is restricted to those with known LOS ≥24 hours then it is: 50.4% females and median age 82 years.*

Ethnicity

Ethnicity was documented for 87% (8101) of cases, comprising 90.6% (7337) white British, 1.4% (114) white Irish, 2.0% (160) white other, 1.1% (93) Indian, 0.5% (44) Pakistani, 0.1% (10) Bangladeshi, 1.1% (93) Asian other, 0.8% (62) black Caribbean, 0.4% (30) black African, 0.4% (30) black other, 0.2% (19) mixed and 1.3% (109) other (not specified).

Religious affiliation

Religious affiliation was documented for 70% (6482), comprising 80.5% (5219) Christian, 1.9% (120) Muslim, 0.9% (61) Hindu, 0.6% (39) Sikh, 0.5% (35) Jewish, 0.2% (12) Buddhist, 4.1% (267) any other religion (not specified) and 11.2% (729) none.

Diagnostic information

The primary diagnosis of the patients who had died is given in Table 1. Note that the diagnostic information was derived from the death certificates, with the well-known caveats about the accuracy of that source. The main diagnoses were essentially similar to those reported in the 2013 audit; even when the current audit window of subject inclusion was narrowed to those who died within 24 hours (as opposed to within 4 hours) of admission, the range and frequency of diagnoses was unchanged.

Table 1

	National audit (n=9302)	
What is the **primary diagnosis**? This is to be taken from the death certificate. 1c, then 1b and if nothing in either record then 1a		
Pneumonia	24%	2277
Cancer	20%	1843
Heart failure	10%	895
Stroke	6%	597
Chronic respiratory disease	6%	593
Neurological conditions (such as motor neurone disease)	2%	180
Other	31%	2917

***2013 audit**: pneumonia 23%, cancer 23%, heart failure 8%, stroke 8%, chronic respiratory disease 7% and other 32%. If the current audit is restricted to those with known LOS ≥24 hours, the results were: pneumonia 25%, cancer 20%, heart failure 10%, stroke 6%, chronic respiratory disease 6%, neurological condition 2% and others 30%.*

Looking at the diagnoses by age groups, cancer was more frequently seen in those under the age of 70 years, while the incidence of stroke, pneumonia and heart failure were highest in those aged 90 years and older. The breakdown of cancers by primary area is given in Table 2.

Table 2

	National audit (n=1843)	
If primary diagnosis was cancer, please specify the primary area:		
Lung	25%	461
Upper gastrointestinal	14%	266
Colorectal	11%	198
Urological system	7%	121
Breast	6%	119
Uterus/other gynaecological	6%	113
Prostate	6%	102
Brain	2%	31
Other	23%	432

***2013 audit**: lung 24%, colorectal 9%, upper gastrointestinal 9%, prostate 7% and other 51%. If the current audit is restricted to those with known LOS ≥24 hours, the results were: lung 25%, upper gastrointestinal 15%, colorectal 11%, urological system 7%, breast 6%, uterus/other gynaecological 6%, prostate 5%, brain 2% and other 23%.*

Existing comorbidity

In this audit, we asked for the presence of documented comorbidities. This was reported in 82% of the sample overall, and 69% had two or more separate comorbid conditions (Table 3). As expected, comorbidities were more commonly documented in older patients: only 13% of those aged 90 years and over had no comorbid conditions, compared with 48% of those aged under 40 years. Conversely, 32% of patients aged over 90 years had three or more comorbid conditions, compared with 9% of those aged under 40 years. The majority of comorbid diagnoses were cardiovascular, respiratory or endocrine (Table 4).

Table 3

	National audit (n=9302)	
Did the patient have any existing comorbidities documented?		
YES	82%	7605
If 'yes', how many existing comorbidities were documented?		
• ONE	31%	2386
• TWO	33%	2485
• THREE	20%	1512
• FOUR or more	16%	1222

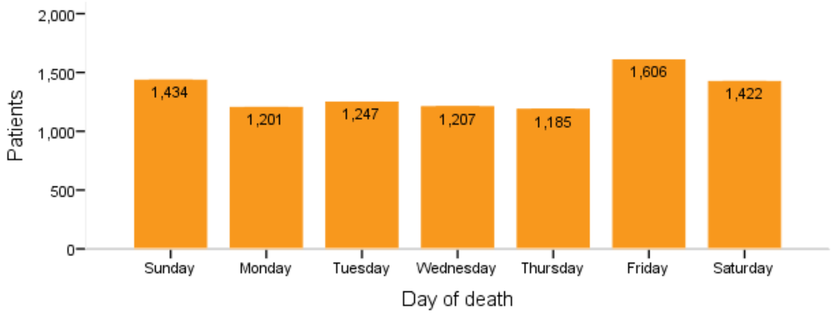
Table 4

	National audit (n=9302)	
What comorbidities? This is what is on section 2 of the death certificate.		
• Cardiovascular	47%	4414
• Respiratory	22%	2055
• Endocrine	18%	1694
• Dementia	12%	1160
• Genitourinary	11%	1033
• Malignancy	10%	923
• Central nervous system	8%	773
• Musculoskeletal	8%	712
• Other	25%	2350

Characteristics of the deaths in hospital

Deaths were reported with stable frequency from Mondays to Thursdays during the data collection period. There was a slight increase in deaths occurring on the Friday to Sunday period (Fig 2).

Fig 2: Distribution of day of death in the audit sample



Each day is defined as 00:00 to 23:59 hours.

In total, 24% (2237) of audit deaths occurred between working hours (defined as 09:00 to 17:00, Monday to Friday), 46% (4307) occurred out of hours (defined as 17:01 to 08:59 from Monday to Friday, and 17:01 Friday to 08:59 Saturday), and 30% (2758) occurred at the weekend (defined as Saturday 09:00 to Monday 08:59).

This apparent excess of deaths 'out of hours' and at 'weekends', compared with during 'working hours', is true in terms of *absolute numbers*, but it gives an artificial picture because of the unequal number of hours in the three time periods. But when expressed as the *hourly death rate* in the three periods (focusing on patients whose LOS was ≥24 hours and excluding sudden and unexpected deaths), it was 40.9 deaths per hour from 09:00 to 17:00, Monday to Friday; 39.3 deaths per hour between 17:00 and 08:59 Monday to Friday; and 41.5 deaths per hour from 09:00 Saturday to 08:59 Monday.

Where did the patients die?

This information was collected to give trusts feedback about where their audit deaths occurred. It is not analysed at a national level.

Table 5 gives the hospital departments in which the patients died: most deaths occurred in medical or critical care beds. Using the current inclusion criterion of deaths occurring 4 hours after admission, there were relatively fewer deaths in medical departments this time compared with the 2013 audit, and relatively more deaths in critical care and surgical departments. However, using the cut-off for inclusion of deaths after the first 24 hours (as per the 2013 audit), the differences were less marked.

Table 5

National audit (n=9302)		
In which hospital department did the patient's death take place?		
Medical	66.1%	6147
Critical care (includes high dependency, coronary care and intensive care)	12.6%	1173
Surgical	8.2%	765
Acute assessment unit (medical or surgical)	7.2%	669
Specialist palliative care unit as part of acute medical assessment unit	0.2%	21
Specialist palliative care unit stand-alone but in trust grounds	1.1%	104
Rehabilitation unit	0.8%	75
Accident and emergency	0.5%	47
Other	3.2%	301

***2013 audit**: medical 75%, surgical 8%, critical care 8%, acute medical assessment unit 5%, high dependency 3% and specialist palliative care unit 2%. If the current audit is restricted to those with known LOS ≥24 hours, the results were: medical 70%, critical care 12%, surgical 8%, acute assessment unit 5%, SPC unit as part of acute medical assessment unit 0.2%, SPC unit stand-alone but in trust grounds 1.2%, rehabilitation unit 0.9%, accident and emergency 0.2% and other 3.2%.*

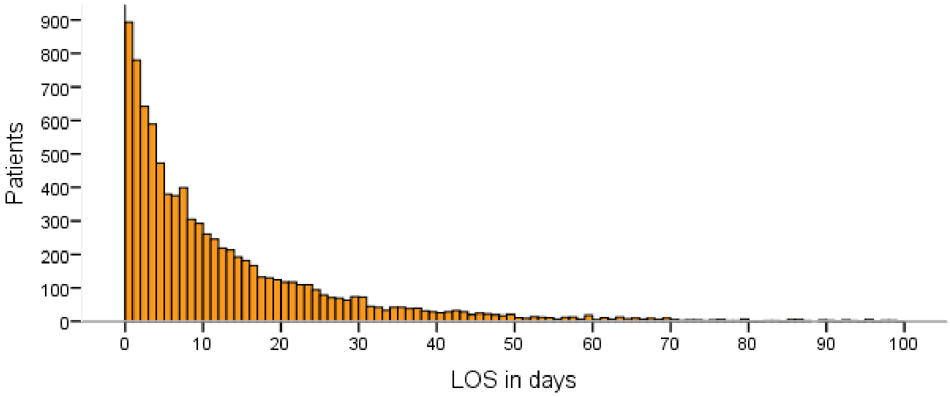
Deaths occurring in different hospital departments were also analysed by the age of the patients, and by the primary diagnosis.

Length of stay (LOS)

LOS could not be accurately computed for 410 cases, due to uncertainty about the date/time of admission or of death. From the dates and times provided, 22 cases (0.2% overall from 18 sites) indicated an LOS of under 4 hours (median 2.2 hours); it was decided to include these cases in the overall analysis.

Median LOS was 7.8 days, with an IQR of 2.9-17.4 days, n=8892. Mean LOS was 13.6 days. Ten per cent of cases (870/8892) were admitted for at least 4 hours but less than 24 hours before death (Fig 3).

Fig 3: Distribution of LOS in days



The graphic was truncated at 100 days for reasons of presentation, with 0.7% of stays being more than 100 days

***2013 audit**: median LOS was 9 days, with an IQR of 4-19 days. Note that only those with LOS ≥24 hours were included. If the current audit is restricted to those with known LOS ≥24 hours then the median was also 9 days, with an IQR of 4-19 days.*

It was clear from the notes of 17% (1595/9302) of patients that they died suddenly and unexpectedly. Median LOS was 4.4 days, with an IQR of 1.4-12.1 days (n=1523) if death was sudden and unexpected, otherwise the median was 8.6 days, with an IQR of 3.3-18.4 days (n=7369).

Section 2: Priority of care – recognition of dying

‘The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.’[7]

Key findings

- In total, 93% of patients whose death was predictable had documentation that they would probably die.
- In 76% of cases, a senior doctor was involved in the recognition of dying.
- For half the patients, recognition of dying occurred within 5 days after admission, and for half the patients this occurred less than 34 hours before death.
- The recognition that the patient was thought to be dying was reviewed regularly in 91% of patients; however it should be noted that the inter-auditor reliability score for this particular question was poor.

Recommendation

- The recognition of the possibility that a patient may die should be communicated to the patient, people important to the patient, and staff, and documented in the case notes as early as possible. The recognition of dying should be reviewed by a senior doctor or nurse.

Question 1.1

In 83% (7675/9302) of patients there was documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days. If sudden/unexpected deaths are excluded then this result (%1.1=yes) is revised to 93% (7199/7707) of patients.

***2013 audit**: ‘Is there documented evidence within the last episode of care of a decision within the Multi-disciplinary Team (a minimum of a senior doctor and a trained nurse) that the patient was expected to die in the coming hours or days?’ Result: 87% with recognition documented of decision taken either by an MDT or by at least one health professional, 13% with no recognition documented. If the current audit is restricted to those with known LOS ≥24 hours then the result for audit question 1.1 was 83% (6658/7997).*

Table 6

	National audit (n=7675)	
1.2. If the answer is ‘Yes’ to question 1.1: who took part in the discussion about this recognition?		
Senior doctor (such as a consultant or GP)	76%	5811
Other doctors	71%	5437
Those important to the patient (family, close friends, carers and others important to the patient)	64%	4930
Staff nurse	32%	2494
Member of the specialist palliative care team	18%	1344
Patient	13%	978
Ward sister	11%	854
Clinical nurse specialist	8%	628
Physiotherapist	3%	226
Healthcare assistant	2%	184
Dietician	2%	153
Speech and language therapist	2%	130
Occupational therapist	1%	87
Chaplain	0.9%	72
Social worker	0.6%	47
Pharmacist	0.5%	38
Other	2%	191

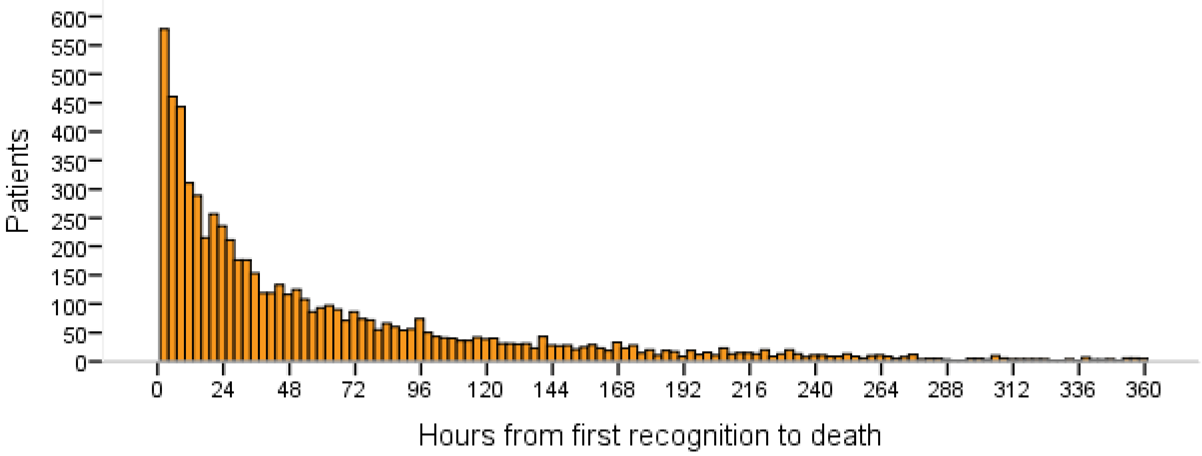
Table 7

	National audit (n=7675)
1.3. What was the date and time of the first documented evidence of the recognition that the patient would probably die in the coming hours or days?	
Median (IQR) HOURS between recognition and death	34 (11-89), n=7007*
Median (IQR) HOURS between admission and recognition	118 (25-332), n=6834**

*668 patients were excluded because of uncertainty about the date/time of recognition or of death.
**841 patients were excluded because of uncertainty about the date/time of recognition or of admission.

***2013 audit**: the median number of hours between the first documented evidence of the recognition that the patient was expected to die and the actual death was 36 hours, with an IQR of 12-89 hours. If the current audit is restricted to those with known LOS ≥24 hours then the median was 41 hours, with an IQR of 15-97 hours, n=6157.*

Fig 4: Hours from first recognition of dying to death



The graphic was truncated at 15 days (360 hours) for reasons of presentation, with first recognition of dying to death being longer than this in 2.8% of cases.

Table 8

	National audit (n=7675)	
1.4. Is there documented evidence that the recognition (1.3) that the patient who was dying was regularly reviewed?		
YES	91%*	6953
If 'yes' to 1.4, did this review include:		
• The recognition that the patient was dying	98%	6784
• That the patient was recovering	7%	499

*A kappa coefficient of agreement value of 0.42 indicates poor inter-auditor reliability for this question.

Summary

In 83% of audited deaths, there was documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days. While there is some variation between trusts, this falls within the limits of what would be regarded as random variation. When the patients for whom death was clearly sudden and unexpected were excluded, 93% of patients had documentation that they would probably die. In 76% of cases, a senior doctor was involved in recognition (Table 6) and in 64% those important to the dying person were involved in the discussion about recognition of dying. In 71% of cases, other doctors were involved and in 42% of cases, nursing staff (staff nurse and/or ward sister) took part. For half the patients, recognition occurred less than 34 hours before death (Table 7), and for a quarter of cases it was less than 11 hours before death. However some of this is explained by the inclusion of patients who died between 4 and 24 hours after admission, as when these patients are removed the median time increases to 41 hours. The recognition that the patient was thought to be dying was reviewed regularly in 91% of patients (Table 8). In 7% of patients, it was recognised that, after initial suspicion the patient was likely to be dying, there were some signs that the patient might be recovering. However, all these patients subsequently died.

In patients who died in hospital there were consistently high levels of documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days. For the majority of these decisions, senior doctors were involved in the decision-making process and there were significant levels of involvement of those important to the patient. Nurses of all levels are less often recorded as being involved. There is evidence that these decisions are almost always being reviewed regularly. However it appears that for a significant proportion of patients these decisions are being made close to death, perhaps not early enough for the person to be fully involved in decision making about their care. The fact that there were signs of recovery in a significant minority of those who subsequently died underlines how difficult these decisions are and why we need to communicate the possibilities about dying and recovery even when we cannot be certain.

One of the priorities of care for the dying person in the *One chance to get it right*[7] recommendations is that: ‘The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.’ The requirement for senior and regular review and multiprofessional involvement is also recommended. These results suggest that this recommendation is largely being followed, but in many cases there is little evidence of multiprofessional involvement.

It is encouraging to make these observations in the light of the new NICE guidance (NG31),[9] which stresses the importance of recognising the uncertainties about the possibility of dying or of recovering, and of communicating these honestly and effectively with patients and those important to them.

While there is widespread evidence of good practice, areas for improvement could include: ensuring senior review is undertaken where possible; involving nurses and other professionals more frequently in these decisions and documenting their involvement; and, where possible, ensuring that recognition of the possibility that a patient may die is documented and communicated earlier in the hospital stay.

Section 3: Priority of care – communication

‘Sensitive communication takes place between staff and the dying person, and those identified as important to them.’[7]

Key findings

- In total, only 25% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death. Overall, where there was not a documented discussion, there was no reason recorded in 17% of cases.
- In 95% of the cases where it had been recognised that the patient was likely to die, there was a documented discussion with those nominated as important to the dying person. Where there was not a documented discussion with a nominated person, there was no record of why in 49% of cases.

Recommendation

- When the possibility of dying is not discussed with the patient or the nominated person important to them, the reasons for this should always be documented in the case notes.

Table 9

	National audit (n=9302)	
2.1. Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with **the patient**?		
YES	20%*	1898
If ‘no’ to 2.1 (n=7404), were any of the following reasons documented as to why discussion did not take place?		
• The patient was semi-conscious or unconscious	44%	3226
• The patient had cognitive impairment and did not have the capacity to understand	21%	1569
• The notes indicate that the patient died suddenly and unexpectedly	13%	935
• The patient’s mental state could be ‘harmed’ by the knowledge that they were dying	0.8%	60
• There is evidence to confirm the patient’s request not to receive bad news	0.7%	55
• No reasons recorded	17%	1256
• Other	4%	303

*If sudden/unexpected deaths are excluded then this result (%2.1=yes) is revised to 23% (1788/7707). If the analysis is further restricted to where there was recognition (1.1=yes) then this result (%2.1=yes) is 25% (1772/7199). In 16% (866/5477) of those recognised as likely to die, and where there was not a documented discussion with a nominated person, there was no record of why.

***2013 audit**: ‘Is there documented evidence within the last episode of care that Health Professional recognition that the patient was expected to die in the coming hours or days had been discussed with the patient?’. The result was 19% of those with recognition. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 2.1 was 25% (1672/6658).*

Table 10

	National audit (n=9302)	
2.2. Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with **a nominated person(s) important to the patient**?		
YES	79%*	7388
If 'no' to 2.2 (n=1914), were any of the following reasons documented as to why discussion did not take place?		
• There was no nominated person important to the patient	6%	120
• Attempts were made to contact the nominated person important to the patient but they were unsuccessful	6%	116
• Independent mental capacity adviser (IMCA) unavailable	0.2%	4
• Patient had not consented / had withdrawn consent for these discussions to take place with the nominated person important to them	0.4%	8
• No reasons recorded	38%	735
• Other (classified from free text):		
o Died suddenly and unexpectedly	39%	747
o Active management, unexpected	1%	26
o Died while discharge being planned	0.2%	4
o Issues about contacting/speaking with relatives	1%	18
o Deterioration/dying not recognised	6%	118
o Other reasons	1%	18

*If sudden/unexpected deaths are excluded and the analysis restricted to where there was recognition (%1.1=yes) then this result (%2.2=yes) is revised to 95% (6811/7199). In 49% (189/388) of those recognised as likely to die and where there was not a documented discussion with a nominated person, there was no record of why.

***2013 audit**: 'Is there documented evidence within the last episode of care that Health Professional recognition that the patient was expected to die in the coming hours or days had been discussed with the nominated relative or friend or the nominated Independent Mental Capacity Advocate (IMCA)?'. The result was 93% of those with recognition. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes) the result for 2.2 was 94% (6283/6658).*

Summary

One in five patients who died had documented evidence of a discussion with a healthcare professional that they were dying (Table 9). In those for whom dying was recognised, this increased to one in every four patients. For the majority where there was not documented evidence of a discussion about dying, this was because the patients were unable to communicate or did not have the capacity to understand at the time they were recognised to be dying. However, for almost one in five (17%) there was no reason recorded for not communicating with the patient. On the other hand, when dying was recognised, a discussion was recorded in almost all cases (95%) with a nominated person important to the patient (Table 10). Where there was no discussion documented, it was most frequently recorded that this was because there was no nominated person (21%, 83) or that attempts to contact the nominated person were unsuccessful (19%, 73). However in almost half of the cases (49%, 189) where discussion was not held, there was no reason recorded.

Discussion with the patients about their imminent death appears to be infrequent, but this mostly stems from recognition of dying occurring so late that the patient is unable to have such discussions in the majority of cases. However, allowing for differences in the sample, such discussion appears to be increasing in frequency compared with the last audit. Discussion with a nominated person important to the patient is reassuringly commonplace, in line with findings in the last audit. However, in cases where communication has not occurred, documentation of the reason for non-communication is far from universal so we cannot be completely assured that every opportunity to communicate is being sought and taken.

In the *One chance to get it right*[7] recommendations, 'Sensitive communication takes place between staff and the dying person, and those identified as important to them' is the second priority of care for the dying person. The importance of communication is also stressed by NICE in its 2012 guidance CG138 *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*,[14] as well as in the new 2015 guidance NG31 on care of the dying adult.[9] This audit cannot assess the quality of the communication, but it is evident that communication is frequently occurring about the fact that the person is recognised as dying with those important to them, but less commonly with the dying person themselves.

Earlier recognition that the person is dying is necessary to allow more opportunity to discuss this with the dying person and enable their involvement in decisions about their care. Documentation needs to be improved to ensure there are always reasons recorded about why discussions are not held with the patient or their nominated representatives.

Section 4: Priority of care – the dying person and those important to them involved in decision making

'The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.'[7]

Key findings

- Where there was an advance care plan, the team took the contents into account when making decisions (91%) and it was reviewed (79%); however only 4% (415/9302) of patients had documented evidence of an advance care plan made prior to admission to hospital.
- A DNACPR order was in place for 94% (8711/9302) of patients' notes at the time of death.
- Where sudden deaths are excluded, discussion about CPR by a senior doctor with the patient was recorded in 36% (2748/7707) of cases. Overall, for 16% (961/6072) there is no reason recorded for why a discussion did not take place. Discussion about the CPR decision with the nominated person(s) important to the patient was documented in 81% of cases.
- It was recorded that 32% of patients had opportunities to have their concerns listened to and, of these, 94% were given the opportunity to have questions answered about their concerns.
- It was recorded that the nominated person(s) important to 80% of patients had opportunities to discuss the patient's condition with a senior healthcare professional.
- Deactivation of an implanted defibrillator was only recorded in 11% of those documented as having one in place. Assisted ventilation was in place for 11% of people at the time of death. Dialysis was in operation for 1.7% of people.

Recommendations

- Health and social care professionals should receive training or information about advance care planning (eg www.e-lfh.org.uk/programmes/end-of-life-care). All professionals, especially those working with people living with chronic conditions, multiple comorbidities, and in particular people for whom future loss of mental capacity is anticipated (eg people with dementia) should initiate and encourage advance care planning.
- Patients' concerns, and those of the people important to them, need to be more fully documented.
- Deactivation of implanted defibrillators should be carried out in more patients, in whom dying has been recognised.

Advance care plan

Table 11

	National audit (n=9302)	
3.1. Is there documented evidence that the patient had made an advance care plan prior to admission?		
YES	4%	415
3.2. If 'yes' (to 3.1), is there documented evidence that the team took into account the contents of the advance care plan when making decisions?		
YES	91%	376
If 'yes' to 3.2, was the advance care plan reviewed?		
YES	79%	297
If 'no' to 3.2, was the reason it was not taken into account recorded?		
YES	18%	7/39

Resuscitation and final care decisions

Table 12

	National audit (n=9302)	
3.3. Is there documented evidence that a discussion regarding cardiopulmonary resuscitation (CPR) was undertaken by a senior doctor with **the patient** that was relevant to the last episode of care?		
YES	35%*	3230
If 'no' (n=6072), were any of the following reasons documented as to why discussion did not take place?		
• The patient was semi-conscious or unconscious	38%	2312
• The patient displayed a longstanding lack of mental capacity (eg dementia) for the issue of CPR	19%	1184
• The patient displayed an acute lack of mental capacity (eg delirium) for the issue of CPR	15%	906
• The patient had asked not to be involved in this discussion	1%	71
• No reason recorded	16%	961
• Other	10%	638

*If sudden/unexpected deaths are excluded then this result (%3.3=yes) is revised to 36% (2748/7707).
In 14% (710/4959) of those recognised as likely to die and where there was not a documented discussion with the patient regarding CPR, there was no record of why.

2013 audit*: 'Is there documented evidence that a discussion regarding the CPR decision was undertaken with the patient during the last episode of care?' The result for the overall sample was 21%. If the current audit is restricted to those with known LOS ≥24 hours, the result for 3.3 was 36% (2887/7997).*

Table 13: 'Other' reasons documented as to why a discussion regarding CPR in 3.3 did not take place

3.3 OTHER reasons documented as to why discussion did not take place	Total
Death unexpected/rapid deterioration	145
Too unwell	103
Community or existing DNR or discussions had taken place	100
Active treatment/for CPR	78
Other	69
Discussion would distress	39
Language/communication barrier	34
No CPR decision made	33
Discussion with family	14
Lacked capacity	8
Discussed with junior doctor or specialist registrar (SpR) or unrecorded grade	8
Discussion refused	3
Treatment discussions only	2
Discussed with power of attorney/LPA	2
Total	638

Fig 5: Site variation in 3.3

Per cent with documented evidence that a discussion regarding CPR was undertaken by a senior doctor with *the patient* that was relevant to the last episode of care (the red line shows the national 36% when analysis excludes sudden and unexpected deaths)

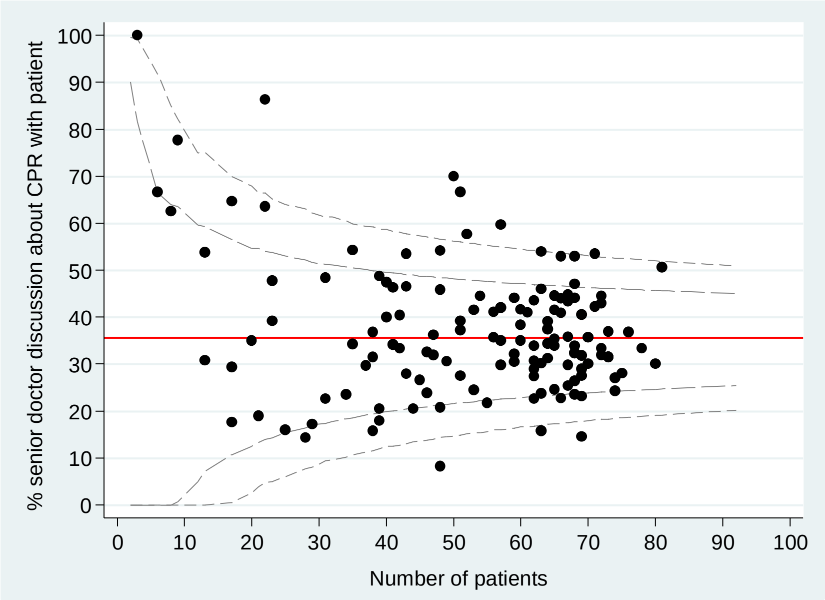


Table 14

	National audit (n=9302)	
3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior doctor was discussed with the **nominated person(s) important to the patient** during the last episode of care?		
• YES	78%*	7219
• NO	18%	1706
• NO BUT	4%	377
If 'no but' during the last episode of care it was recorded that:		
• There was no nominated person important to the patient	47%	177
• Attempts were made to contact the nominated person important to the patient but were unsuccessful	53%	200

*81% if the 'NO BUTs' are excluded from the denominator

***2013 audit**: 'Is there documented evidence that a discussion regarding the CPR decision was undertaken with the nominated relative or friend or Independent Mental Capacity Advocate during the last episode of care?' The result was 72% after the 'NO BUTs' are excluded. If the current audit is restricted to those with an LOS ≥24 hours, the result for 3.4 was 81% (6224/7681) after the 'NO BUTs' are excluded.*

There was a CPR decision in place for 94% (8711/9302) of patients at the time of their death.

***2013 audit**: 'At the time of the patient's death was there a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place?' The result was 96%. If the current audit is restricted to those with known LOS ≥24 hours, the result for 3.5 was 94% (7536/7997).*

In total, 5% (493/9302) of patients were recorded as having an implanted defibrillator in place. In the last 24 hours, deactivation was recorded in 11% (53/493) of these patients.

Assisted ventilation

A small proportion of patients (11%) were having assisted ventilation around the time of death (Table 15). Only in a minority of cases (23%) was there a documented discussion with the patient about continuing or stopping ventilation.

Table 15

	National audit (n=9302)	
3.7a. In the last 24 hours, was the patient having assisted ventilation?		
YES	11%	1009
3.7ai. If 'yes' to 3.7a (n=1009) is there documented evidence within the last episode of care of a discussion undertaken by a senior doctor regarding whether to continue or stop assisted **ventilation** with **the patient**?		
YES	23%	228/1009
If 'No' to 3.7ai (n=781), were any of the following reasons documented as to why discussion did not take place?		
• The patient was semi-conscious or unconscious	78%	612
• The patient displayed an acute lack of mental capacity (eg delirium) for this issue	4%	31
• The patient displayed a longstanding lack of mental capacity (eg dementia) for this issue	3%	20
• The patient had asked not to be involved in this discussion	0.5%	4
• No reason recorded	9%	68
• Other	6%	46
3.7aii. If 'yes' to 3.7a (n=1009), is there documented evidence that the continuation or withdrawal of **assisted ventilation** was discussed by a senior doctor with **the nominated person(s) important to the patient** during the last episode of care?		
• YES	78%	783
• NO	19%	190
• NO BUT	4%	36
If **'No but'** to 3.7aii (n=36), during the last episode of care it was recorded that:		
• There was no nominated person important to the patient	47%	17
• Attempts were made to contact the nominated relative or friend but were unsuccessful	53%	19

Assisted ventilation by patient age, primary diagnosis and place of death

Twenty-three per cent (234/1009) of all patients who were receiving assisted ventilation were under the age of 60 years.

Table 16

	3.7a. In the last 24 hours, was the patient having assisted ventilation?	
Primary diagnosis	%Yes	n/N
Chronic respiratory disease	21%	127/593
Neurological conditions	13%	23/180
Heart failure	10%	87/895
Stroke	8%	50/597
Pneumonia	8%	183/2277
Cancer	4%	82/1843
Other	16%	457/2917
Total	11%	1009/9302

Table 17

	3.7a. In the last 24 hours, was the patient having assisted ventilation?	
Place of death (hospital department)	%Yes	n/N
Critical care (includes high dependency, coronary care and intensive care)	61%	711/1173
Accident and emergency	15%	7/47
Acute assessment unit (medical or surgical)	5.2%	35/669
Rehabilitation unit	4.0%	5/75
Medical	3.6%	221/6147
Surgical	2.5%	19/765
Specialist palliative care unit as part of acute medical assessment unit	0%	0/21
Specialist palliative care unit standalone but in trust grounds	0%	0/104
Other	4.3%	13/301
Total	11%	1009/9302

If the place of death is restricted to critical care, then 62% (698/1127) of patients aged 89 or under were having assisted ventilation in the last 24 hours.

If the place of death is restricted to medical departments, then only 4% (216/6127) of patients aged 40 years or older were having assisted ventilation in the last 24 hours.

Dialysis

Table 18

	National audit (n=9302)	
3.7b. In the last 24 hours, was the patient having dialysis?		
YES	1.7%	162
3.7bi. If 'yes' to 3.7b (n=162), is there documented evidence within the last episode of care of a discussion undertaken by a senior doctor regarding whether to continue or stop **dialysis** with **the patient**?		
YES	14%	22/162
If 'No' to 3.7bi, (n=140), were any of the following reasons documented as to why discussion did not take place?		
• The patient was semi-conscious or unconscious	71%	100
• The patient displayed an acute lack of mental capacity (eg delirium) for this issue	5%	7
• The patient displayed a longstanding lack of mental capacity (eg dementia) for this issue	3%	4
• The patient had asked not to be involved in this discussion	-	0
• No reason recorded	9%	13
• Other	11%	16
3.7bii. If 'yes' to 3.7b (n=162), is there documented evidence that the continuation or withdrawal of **dialysis** was discussed by a senior doctor with **the nominated person(s) important to the patient** during the last episode of care?		
• YES	65%	105
• NO	33%	54
• NO BUT	2%	3
If **'No but'** to 3.7a.ii (n=3), during the last episode of care it was recorded that:		
• There was no nominated person important to the patient		1
• Attempts were made to contact the nominated relative or friend but were unsuccessful		2

Patient concerns listened to and their questions answered

Table 19

	National audit (n=9302)	
3.8a. Is there documented evidence that the patient was given an opportunity to have **concerns listened to?**		
- YES	32%	2936
- NO	16%	1475
- NO BUT	52%	4891
If 'NO BUT' (n=4891):		
- The patient displayed a longstanding lack of mental capacity (eg dementia) to raise concerns	25%	1222
- The patient displayed an acute lack of mental capacity (eg delirium) for this issue	19%	941
- The patient was semi-conscious or unconscious	56%	2728
If 'YES' to 3.8a (n=2936), is there documented evidence that the patient was given an opportunity to have **questions answered about concerns?**		
- YES	94%	2769
- NO	3%	96
- NO BUT	2%	71
If 'NO BUT' (n=71):		
- The patient displayed a longstanding lack of mental capacity (eg dementia) to raise concerns	18%	13
- The patient displayed an acute lack of mental capacity (eg delirium) for this issue	44%	31
- The patient was semi-conscious or unconscious	38%	27

Opportunities for the person(s) important to the patient to have discussions with a senior healthcare professional

Table 20

	National audit (n=9302)	
3.9. Is there documented evidence that the **nominated person(s) important to the patient** during the last episode of care was given regular opportunities to discuss the patient's condition with a senior healthcare professional?		
- YES	80%	7459
- NO	16%	1475
- NO BUT	4%	368
If 'NO BUT' (n=368):		
- There was no nominated person important to the patient	45%	167
- Attempts were made to contact the nominated relative or friend but were unsuccessful	49%	181
- Discussion was declined by nominated person(s) important to the patient	5%	20
If 'yes' to 3.9, how often were there recorded discussions with the **nominated person(s) important to the patient** and a senior healthcare professional during the last 24 hours of care?		
Median (IQR)	2 (1-3)	

Summary

There has been emphasis (*One chance to get it right*[7] and *Ambitions for palliative and end of life care*[11]) on the need for people to have the opportunity to make advance care plans so that their wishes for care at the end of life can be followed, especially when they are too ill to partake in these discussions. In this audit, only 4% (415/9302) of patients had documented evidence of an advance care plan made prior to hospital admission. However, where there *was* an advance care plan, the contents were taken into account when making decisions in 91% of cases and it was reviewed in 79% of cases. The median age of the sample was 82 years, with 82% (7605/9302) documented as having one or more existing comorbidities that could have precipitated advance care planning.

Discussing what the patient wants done if their heart stops is an essential but often difficult discussion to have. At the time of death, 94% of patients had a DNACPR decision in place. Documented evidence that a discussion regarding CPR was undertaken by a senior doctor with the patient was recorded for 35% (3230/9302) of people. When sudden and unexpected deaths are removed, this equates to 36% (2748/7707). The reasons documented for the lack of discussion are appropriate, but for 16% (961/6072) there was no reason recorded. In the 2013 audit, a discussion about CPR was carried out with 21% of the overall sample and 41% of the patients who were capable of participating in such discussions.

Following a complaint by the family of a patient who had died in an English hospital with a DNACPR order placed on her without her or the family's knowledge, in 2014 the Court of Appeal ruled that the hospital trust had violated her right to respect for private life, in failing to involve her in the process that led to making a do not attempt resuscitation (DNAR) decision (based on Article 8 of the European Convention on Human Rights). This 'Tracey ruling' has had profound implications for all the settings where people are likely to die and CPR is being ruled out. *Dying without dignity*[15] (2015) emphasised the need to improve communication by reporting that 'It is clear that healthcare professionals do not always have the open and honest conversations with family members and carers that are necessary for them to understand the severity of the situation, and the subsequent choices they will have to make'. In the current audit, the senior doctor CPR decision was documented as having been discussed with the nominated person(s) important to the patient in 81% (6224/7681) of cases with LOS ≥24 hours. This represents an increase from 72% in the 2013 audit.

Despite 80% (113/142) of sites stating that they had a deactivation of implantable defibrillator policy, only 11% (53/493) of patients who had a defibrillator had it recorded that it was deactivated in the last 24 hours of life.

Assisted ventilation was in place for 11% (1009/9302) of people. This was mainly in critical care areas, and most people were aged 69 years and under. Discussion about treatment decisions with the patient was documented in 23% (228/1009) of cases, and with people important to the patient in 78% (783/1009). The main reason recorded when no such discussion had taken place with the patient was that they were semi-conscious or unconscious (78%).

Dialysis was in place for 1.7% (162/9302) of people. Discussion about treatment decisions had taken place with the patient in 14% (22/162) of these cases, and with people important to the patient in 65% (105/162) of cases. The main reason recorded when no such discussion had taken place with the patient was that they were semi-conscious or unconscious (71%).

For 32% (2936/9302) of patients there was evidence that they were given the opportunity to have their concerns listened to, but for 16% (1475/9302) of patients there was no record of such opportunity. In 94% (2769/2936), the opportunity for patients to have questions answered about their concerns was recorded.

In 80% (7459/9302) of patients, it is documented that the nominated person(s) important to the patient had regular opportunities to discuss the patient's condition. There was a median (IQR) of 2 (1-3) of these discussions taking place in the last 24 hours of life.

Section 5: Priority of care – needs of families and others

‘The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.’[7]

Key findings

- In 38% of cases there was documented evidence in the last episode of care that the patient’s needs had been discussed with the people important to them.
- In total, 54% of case records showed that the needs of persons important to the patient were asked about. Of these, 62% had needs identified.
- Excluding the cases of sudden or unexpected deaths, in 84% of cases the people important to the dying patient were notified of the imminent death. Of those notified, 63% were recorded as being present at the time of death.
- There was documented evidence of care and support of the patient’s family at the time of and immediately after death in 65% of cases, with wide variance between different sites (Fig 6).

Recommendations

- Documentation of the needs of the dying patient and those important to them should be improved.
- Evidence of who was present at the time of death should be clearly documented.

Table 21

	National audit (n=9302)	
4.1. Is there documented evidence that the needs of the **person(s) important to the patient** were asked about?		
• YES	54%	5031
• NO	44%	4049
• NO BUT	2%	222
4.1i. If ‘Yes’ to 4.1, were any needs identified?		
YES	62%	3128/5031
If ‘Yes’ to 4.1i (n=3128), what was the outcome of identifying these needs?		
• Attempts were made to address these needs, without success	6%	182
• Needs were partially met	18%	550
• Needs were addressed successfully	73%	2274
• No record	4%	122

Table 22

	National audit (n=3128*)	
4.2. Of which of the following needs of the **person(s) important to the patient** is there documented evidence within the last episode of care that they were **assessed**?		
Psychological	71%	2223
Spiritual/religious	40%	1248
Cultural	28%	873
Practical	88%	2745

*Note that in the web tool the denominator for 4.2 was restricted to those having documented evidence that the needs of the person(s) important to the patient were asked about (ie 4.1=Yes) and if any needs were identified (ie 4.1i=Yes).

Table 23

	National audit	
4.3. (dependent on 4.2) Of which of the following needs of the **person(s) important to the patient** is there documented evidence within the last episode of care that they were **addressed**?		
Psychological	97%	2149/2223
Spiritual/religious	92%	1150/1248
Cultural	92%	800/873
Practical	95%	2615/2745

Table 24

	National audit (n=9203)	
4.4. Is there documented evidence within the last episode of care of discussion regarding the **patient's** spiritual/religious/cultural/practical needs with the **nominated person(s) important to the patient**?		
• YES	38%	3519
• NO	56%	5236
• NO BUT it is recorded that the attempts made to contact the nominated person(s) important to the patient were unsuccessful	2%	167
• NO BUT there was no nominated person(s) important to the patient	2%	169
• Missing data	2%	211

Communication at the time of dying with those important to the dying person (excluding sudden or unexpected deaths)

Table 25

	National audit (n=9302)	
4.5. Were those important to the patient notified of the patient's imminent death?		
• YES*	77%	7139
• NO	13%	1239
• NO BUT there was no person(s) important to the patient	2%	166
• NO BUT the notes indicate the patient died suddenly and unexpectedly	8	758
4.5i. If 'Yes' to 4.5 (n=7139), were those important to the patient present at the time of the patient's death?		
• YES	63%	4520
• NO	32%	2277
• NO BUT requested not to be present	5%	342
4.5ii. (n=8063**) Was anyone else recorded as being with the patient at the time of death?		
YES	36%	2910/8063

*If the earlier stated sudden or unexpected deaths are excluded then this result (4.5) is revised to 84% (6495/7707) YES; 13% (994/7707) NO; 2% (129/7707) NOT BUT there was no person(s) important to the patient; and a further 1% (89/7707) also stating NO BUT the notes indicate the patient died suddenly and unexpectedly.

**On the audit web tool this denominator applied to all those *not* answering *no* for 4.5, ie 9302-1239=8063.

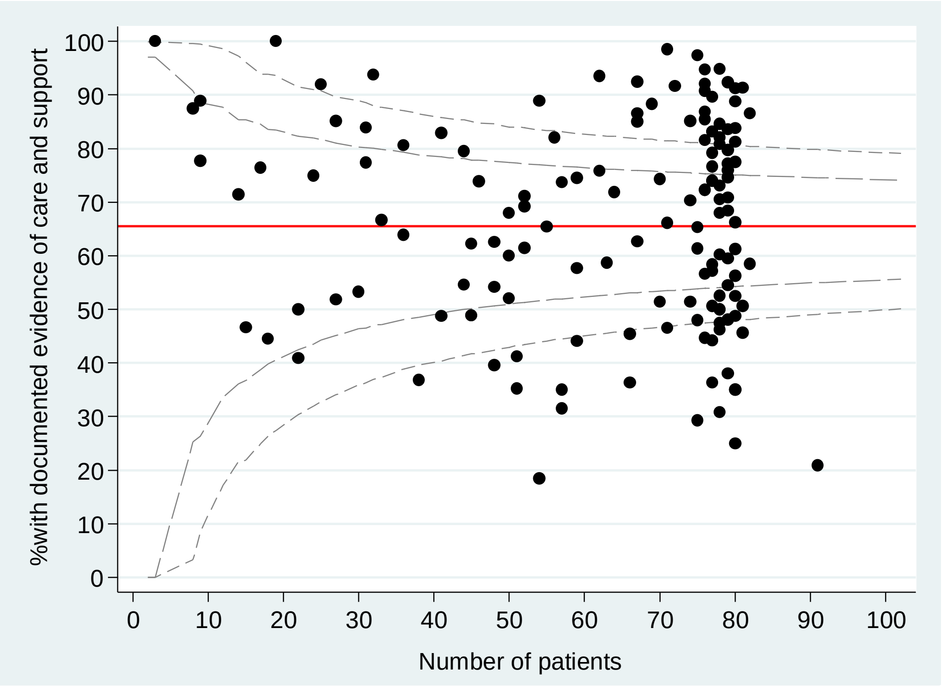
Table 26

	National audit (n=9302)	
4.6. Is there documented evidence of care and support of the patient's family and those important to them at the time of and immediately after death?		
• YES	64%*	5944
• NO	34%	3133
• NO BUT there was no family or person(s) important to the patient	2%	225
4.6i. If 'Yes' or 'No' to 4.6 (n=9077), is there documented evidence that the family and those people that are important to the deceased were given any culturally appropriate **verbal** information following the death of the patient?		
YES	56%	5103/9077
4.6ii. If 'Yes' or 'No' to 4.6 (n=9077), is there documented evidence that the family and those people that are important to the deceased were given any culturally appropriate **written** information, in the appropriate language, following the death of the patient?		
YES	44%	3993/9077

*65% (5944/9077) if the 'NO BUTs' are excluded from the denominator

Fig 6: Site variation in 4.6

Per cent with documented evidence of care and support of the patient's family and those important to them at the time of and immediately after death (the red line shows the national 65%, after excluding the 'NO BUTs' from the denominator)



Summary

Where it was recognised that the patient would probably die in the coming hours or days, this was discussed with a nominated person important to the patient in 95% of cases (6811/7199). In contrast, it was only documented in 54% of cases (5031/9302) that anyone asked about the nominated person's needs and in only a third of all cases (3128/9302) were any needs identified or explored. Yet where practical, psychological, spiritual or cultural needs *were* identified, they were able to be addressed in over 90% of cases.

Those important to the patient were notified of the patient's imminent death in 77% of all deaths included in the audit (7139/9302). Where they were notified that death was imminent, those close to the patient were recorded as being present at the time of death in 63% of cases (4520/7139). If those important to the patient were not present, someone else may have been present.

In 54% of cases, records showed that the *needs of persons important to the person* were asked about. Of these, 62% had needs identified. These identified needs were mostly practical (88% of case records) and psychological (71%) in nature; whereas 40% were spiritual/religious needs and 28% were cultural needs. There was documented evidence that >90% of cases had these needs addressed.

Support for the family and those important to the patient was higher at the time of death and after the patient has died than when the patient was alive. In 64% (5944/9302) of cases, support was given. However, culturally appropriate written information was only provided in 44% (3993/9077) of cases, despite the fact that such information is recorded as being available in 97% of trusts. There was also very wide variation between sites in the support and care given immediately after death to those important to the patient. Many sites fell outside the control limits, with some showing that support was given in more than 90% of cases while others showed support as being given in well under half of cases.

These results suggest that, while information is being provided about the physical condition of the patient, the needs of those close to the dying patient are not yet being seen as a core part of the hospital's duty of care.

Section 6: Priority of care – an individual plan of care

'An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.'[7]

Key findings

- Overall, 66% of case records showed that there had been a holistic assessment of the patient's needs, with a view to making an individual plan of care. Excluding sudden deaths and cases where the patient had died less than 24 hours after admission, this rose to 73%. There was a wide variation between trusts in this measure, with some trusts undertaking holistic needs assessments in 90-100% of cases, while there were many trusts with less than a 30% achievement (see Fig 7).
- Of the key symptoms that could be present around the time of death, there was documented evidence that pain was controlled in 79%; agitation/delirium in 72%; breathing difficulties in 68%; noisy breathing / death rattle in 62% and nausea/vomiting in 55%.
- In total, 31% of patients had been reviewed by a member of the trust specialist palliative care (SPC) team during the last admission; 23% had been reviewed by the SPC within the last 24 hours of life.
- If results are restricted to those with known LOS ≥24 hours, there was documented evidence that anticipatory medication (prn) was prescribed for the key symptoms: for pain in 75% of cases; agitation/delirium 69%; breathing difficulties 66%; nausea/vomiting 66%; and noisy breathing / death rattle 62%.
- The prescribing of specific drugs for prn and regular use, including the use of continuous subcutaneous and intravenous infusions, was extensively documented. However there were problems with the recording of some of the drugs on the audit data collection web tool. Thus there will be a limited analysis of these data at this time.
- In total, 65% of the medications that patients received had been reviewed in the last 24 hours of life. There was significant variation in this measure between trusts, with some reviewing 90-100% and some reviewing less than 40% in the last 24 hours.

Recommendations

- Assessment of holistic needs of patients, leading to an individualised care plan, should be undertaken more frequently, and these assessments should cover all the commonly experienced symptoms seen in the dying patient.
- Medication prescribed for the dying patient in the last 24 hours of life should be reviewed; and this review should record the degree of symptom control for each of the five key symptoms.

Assessment

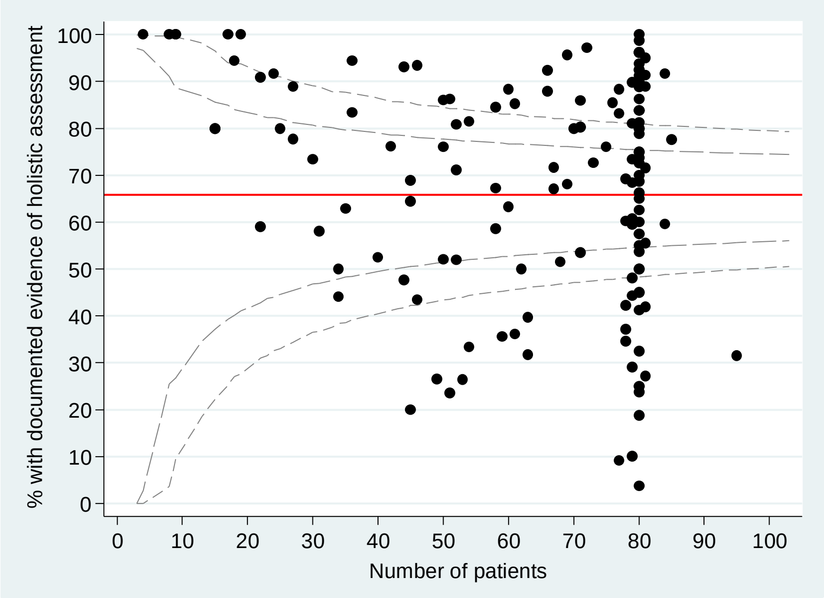
Table 27

	National audit (n=9302)	
5.1. Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient’s needs regarding an individual plan of care?		
YES	66%*	6125
5.1i. If ‘yes’ to 5.1, does this include an assessment of the following (in the last 24 hours)?		
a) Agitation/delirium	79%	4835
b) Dyspnoea / breathing difficulty	82%	5000
c) Nausea/vomiting	62%	3802
d) Pain	87%	5350
e) Noisy breathing / death rattle	67%	4077
f) Anxiety/distress	76%	4657
g) Bladder function	90%	5507
h) Bowel function	82%	5025
i) Pressure areas	92%	5659
j) Hygiene requirements	90%	5525
k) Mouth care	82%	5039

*If the sudden or unexpected deaths are excluded and the analysis is also restricted to where LOS ≥24 hours then this result (%5.1=yes) is revised to 73% (4947/6773).

Fig 7: Site variation in 5.1

Per cent with documented evidence in the last 24 hours of life of a holistic assessment of the patient’s needs regarding an individual plan of care (the red line shows the national 66%)



Symptom control

Table 28

	National audit (n=9302)	
5.2. In the last 24 hours, was there evidence documented that the symptoms the patient had were controlled?		
i) Agitation/delirium (present in 4836)		
• YES	72%	3486
• NO	28%	1350
ii) Dyspnoea / breathing difficulty (present in 4656)		
• YES	68%	3180
• NO	32%	1476
iii) Nausea/vomiting (present in 2659)		
• YES	55%	1472
• NO	45%	1187
iv) Pain (present in 4891)		
• YES	79%	3867
• NO	21%	1024
v) Noisy breathing / death rattle (present in 3704)		
• YES	62%	2307
• NO	38%	1397
vi) Other (present in 1810)		
• YES	10%	180
• NO	90%	1630

Table 29

	National audit (n=9302)	
5.3. Was the patient reviewed by a member of a specialist palliative care team:		
i) In this last admission?	31%	2844
ii) In the last 24 hours of the patient's life?	23%	2119

In the 18 trusts that stated in the organisational audit that they had an SPC unit, the percentage of patients reviewed by a member of a specialist palliative care team was i) 34% (414/1196) in this last admission and ii) 26% (313/1196) in the last 24 hours of the patient's life. Corresponding results for the trusts without an SPC unit were i) 30% (2433/8106) and ii) 22% (1806/8106).

Medication

The audit asked for much more detail about medication prescribed for the dying patient than in the previous audit. The information requested was for:

- anticipatory prescribing for the five common symptoms
- 'prn' or 'as required' medication (drugs, doses prescribed and doses given)
- drugs given by different routes
- drugs given by continuous infusions.

In some of these sections there had to be a considerable amount of data cleaning, especially with respect to drugs doses. It was also clear that it had been difficult for auditors to determine the actual doses of prn drugs given in the last 24 hours.

For these reasons, we are presenting below the key findings about drugs prescribed, expressed in terms of their main indications and routes of administration.

Table 30

	National audit (n=9302)	
5.4. Is there documented evidence (in case notes or in the prescription chart) that anticipatory medication 'prn' was prescribed for the five key symptoms that could occur in the last hours or days of life?		
a) Agitation/delirium	66%	6178
b) Dyspnoea / breathing difficulty	63%	5898
c) Nausea/vomiting	63%	5885
d) Pain	73%	6797
e) Noisy breathing / death rattle	60%	5589

***2013 audit**: 'At the time of the patient's death, is there documented evidence that medication was prescribed (prn) for the five key symptoms that may develop in the last hours or days of life?' The result was: agitation 72%, dyspnoea 63%, nausea 68%, pain 81% and noisy breathing 65%. If the current audit is restricted to those with known LOS ≥24 hours, the results were agitation/delirium 69% (5500/7997), dyspnoea / breathing difficulties 66% (5254/7997), nausea/vomiting 66% (5242/7997), pain 75% (6017/7997) and noisy breathing / death rattle 62% (4987/7997).*

Table 31

National audit (n=7272)

5.4i. **If 'yes' to any symptom in 5.4 (n=7272)**, medication and the **prescribed prn** in the **last 24 hours prior to the patient's death**:

Drug group	Relevant drugs	Drug group prescribed	
Analgesics (painkillers)	Alfentanil, diamorphine, ketamine, methadone, morphine, oxycodone, remifentanil, fentanyl	86%	6257
Antiemetics (for nausea and vomiting)	Cyclizine, haloperidol, hyoscine butylbromide, hyoscine hydrobromide, levomepromazine, metoclopromide, octreotide	79%	5773
Anxiolytics (for reducing anxiety and agitation)	Clonazepam, haloperidol, levomepromazine, midazolam	79%	5776
Noise respiratory secretions ('death rattle')	Glycopyrronium bromide, hyoscine butylbromide, hyoscine hydrobromide	71%	5185

In the last 24 hours of life, 30% (2808/9302) of patients were taking oral medications.

Table 32

National audit

If 'yes' to 5.6 (n=390), transdermal medications administered in last 24 hours:

Drug group	Relevant drugs	Drug group	
Analgesics (painkillers)	Buprenorphine, fentanyl, lidocaine	72%	281
Antiemetics (for nausea and vomiting)	Granisetron hyoscine	8%	31
Noise respiratory secretions ('death rattle')	Hyoscine	8%	31
Miscellaneous	Rotigotine	15%	57

In the last 24 hours of life there was documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place for 24% (2261/9302) of patients.

***2013 audit**: 'At the time of the patient's death, is there documented evidence that a CSCI of medication was being administered?' The result was 28%. If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.7 was 26% (2101/7997).*

Fig 8: Site variation in 5.7

Per cent with documented evidence in the last 24 hours of life that a CSCI of medication was in place (the red line shows the national 24%)

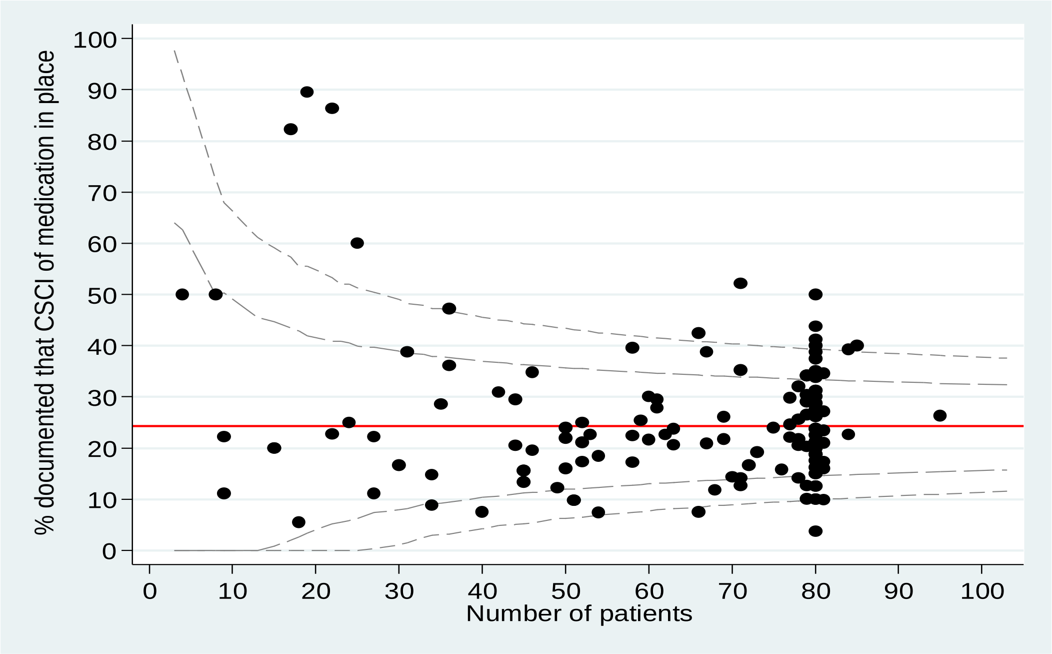


Table 33

	National audit		
5.7i. **If 'yes' to 5.7** (n=2261), medication prescribed in the CSCI in the last 24 hours prior to the patient's death:			
Drug group	Relevant drugs	Drug group	
Analgesics (painkillers)	Alfentanil, diamorphine, ketamine, methadone, morphine, oxycodone, remifentanil, fentanyl	86%	1955
Antiemetics (for nausea and vomiting)	Cyclizine, haloperidol, hyoscine butylbromide, hyoscine hydrobromide, levomepromazine, metoclopromide, octreotide	54%	1222
Anxiolytics (for reducing anxiety and agitation)	Clonazepam, haloperidol, levomepromazine, midazolam	78%	1774
Noise respiratory secretions ('death rattle')	Glycopyrronium bromide, hyoscine butylbromide, hyoscine hydrobromide	41%	924

In the last 24 hours of life there was documented evidence that a continuous intravenous infusion of medication (including patient controlled analgesia – PCA) was in place in 5.2% (482/9302) of patients.

Table 34

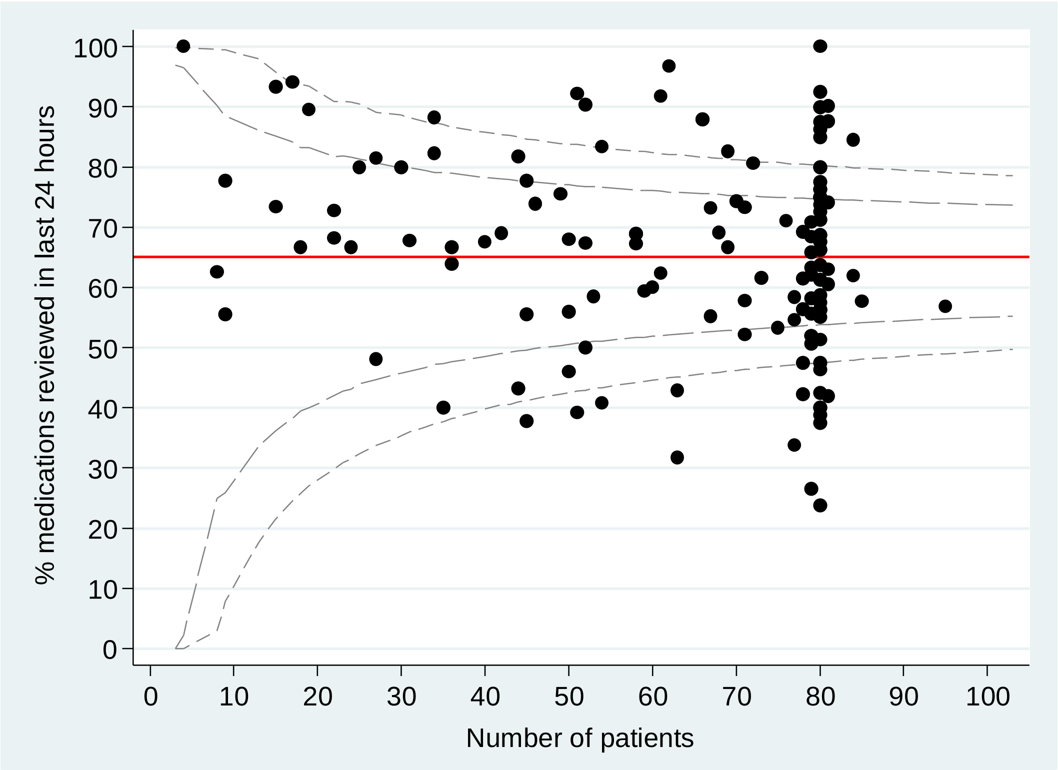
		National audit	
If 'yes' to 5.8 (n=482), **medication prescribed** and in the **IV/PCA** in the last 24 hours prior to the patient's death:			
Drug group	Relevant drugs	Drug group	
Analgesics (painkillers)	Alfentanil, diamorphine, ketamine, methadone, morphine, oxycodone, propofol, remifentanil, fentanyl	75%	361
Antiemetics (for nausea and vomiting)	Cyclizine, granisetron, haloperidol, hyoscine butylbromide, hyoscine hydrobromide, levomepromazine, metoclopromide, ondansetron	4%	19
Anxiolytics (for reducing anxiety and agitation)	Clonazepam, haloperidol, levomepromazine, midazolam, propofol	55%	266
Noise respiratory secretions ('death rattle')	Glycopyrronium bromide, hyoscine butylbromide, hyoscine hydrobromide	2%	12

There was documented evidence that 2% (188/9302) of patients had been prescribed rectal medication in the last 24 hours of life.

For 65% (6052/9302) of patients there was documented evidence (from case notes or prescription charts including electronic systems) that any of the medications the patient received were reviewed in the last 24 hours of life.

Fig 9: Site variation in 5.10

Per cent with documented evidence (from case notes or prescription charts including electronic systems) that any of the medications the patient received were reviewed in the last 24 hours of life (the red line shows the national 65%)



Drinking and assisted hydration

Key findings

- In two-thirds of cases there was documented evidence that the patient's ability to drink had been assessed in the last 24 hours of life. This figure is unchanged if sudden and unexpected deaths were excluded. In total, 39% of patients were documented as drinking in the last 24 hours. In 45% of cases there was evidence that the patient had been supported to drink in the last 24 hours.
- Eighteen per cent of patients had a 'nil by mouth' (NBM) order in their last 24 hours. There was some noticeable variation between trusts in the frequency of NBM orders. In total, 93% of NBM orders had a documented reason. Twenty-three per cent of patients with an NBM order had been informed of it; 64% of the people important to the patient had been informed. The majority (54%) of the NBM decisions involved a consultant (other than palliative medicine); 20% of the orders involved speech and language therapists (SALTs) and 16% involved a staff nurse.
- In 71% of cases, there was documented evidence that the patient had an assessment regarding the need for clinically assisted (artificial) hydration (CAH) at any time between the time of the final admission and death. There is considerable variation between trusts in the assessment for CAH (Fig 11): some trusts assessed between 90-100% patients and some assessed less than 50%.
- There was documented evidence that discussion regarding drinking and need for CAH was undertaken with the patient between the *date of final admission and death* in 18%; and in 39% of cases these discussions had taken place with the nominated people, or the nominated independent mental capacity advocate (IMCA), or LPA for personal welfare.
- CAH was in place during the last 24 hours before death in 43% of patients. There was variation between trusts in this measure, with some recording CAH being in place in up to 70% of cases, and others recording 0-20%.

Recommendations

- NBM orders should only be made by a senior doctor, nurse or SALT specialist.
- There needs to be better documentation of justification for NBM orders and improved communication of them to patients (if conscious) and to those important to the patient.
- Assessment of the possible need for CAH needs to be undertaken and documented more uniformly once it is recognised that the patient is dying.
- For patients who lack capacity, there should be better documentation of attempts to contact and discuss hydration needs with those important to the patient, including those nominated to have responsibility for decisions.

Table 35

	National audit (n=9302)	
5.11. Was there a documented assessment of the patient's ability to drink in the last 24 hours of life?		
YES	67%*	6195
5.12. Is there evidence that the patient was supported to drink in the last 24 hours of life?		
YES	45%	4229
5.13. Was the patient drinking in the last 24 hours of life?		
YES	39%	3584

*If sudden or unexpected deaths are excluded then the percentage for 5.11 is revised to 67% (5154/7707).

Table 36

	National audit (n=9302)	
5.14. Was there a 'nil by mouth' order in place in the last 24 hours of life?		
YES	18%	1635
5.14i. If 'yes' to 5.14, who made the decision for nil by mouth?		
• Consultant – specialty other than palliative medicine	54%	880
• Speech and language therapist	20%	321
• Staff nurse	16%	269
• Specialist registrar	9%	140
• Non-consultant career-grade doctor	7%	120
• Dietician	5%	83
• Consultant – palliative medicine	4%	72
• Junior (trainee) doctor	4%	69
• Ward sister	3%	41
• Clinical nurse specialist (CNS) – palliative care nurse	1%	21
• CNS – other specialty	1%	21
• Patient	0.7%	11
• Healthcare assistant	0.4%	6
• Palliative medicine doctor – other	0.3%	5
• Pharmacist	0.2%	3
• Other	4.3%	71

Fig 10: Site variation in 5.14

Was there an NBM order in place in the last 24 hours of life? (The red line shows the national 18%)

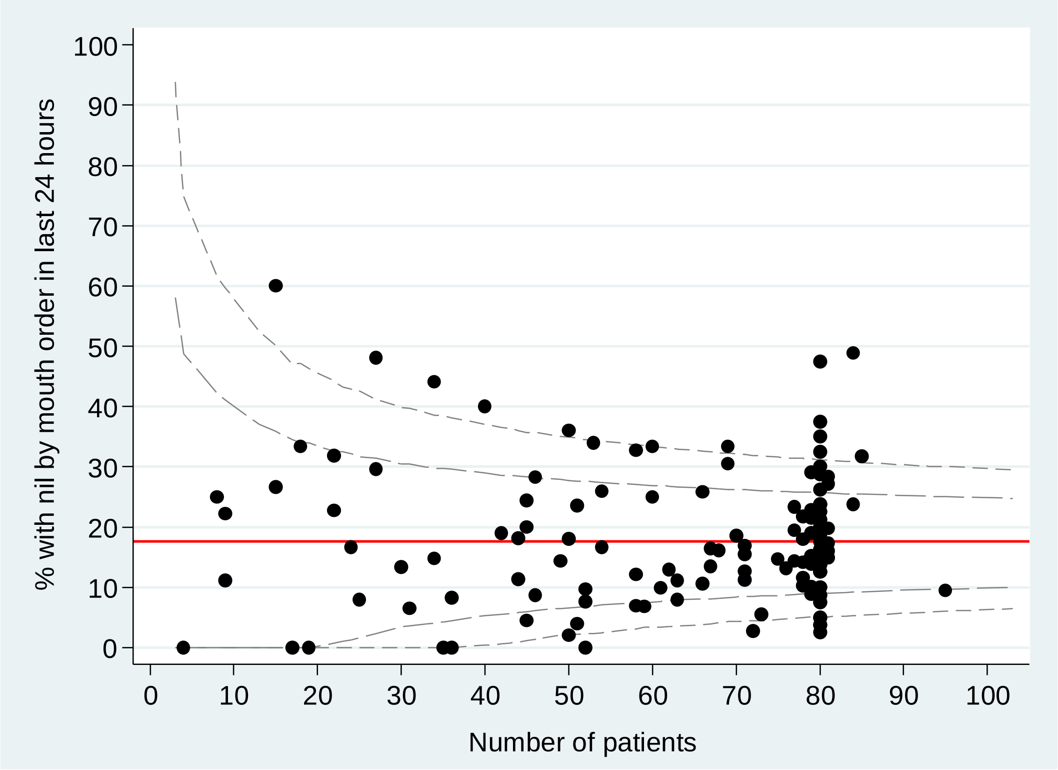


Table 37

	National audit (n=1635)	
5.14ii. Was there a documented reason for the NBM decision?		
YES	93%	1517/1635
If 'yes' to 5.14ii (n=1517), what was the reason for the NBM decision:		
Patient too drowsy/ill	41%	629
Patient unable to swallow	39%	585
Patient did not want to	0.3%	4
Other	20%	299
If 'yes' to 5.14 (n=1635), was the patient informed about the NBM decision?		
YES	23%	381/1635
If 'yes' to 5.14 (n=1635), were people important to the patient informed about the NBM decision?		
YES	64%	1050/1635

There was documented evidence for 71% (6565/9302) of patients that an assessment regarding their need for CAH was made at any time between the time of the final admission and death. There was considerable variation between sites on this aspect of care – some sites reported assessment of CAH needs in 90-100% of cases, while others recorded it in 10-40% (Fig 11).

***2013 audit**: 'Is there documented evidence that an assessment regarding the patient's need for CAH was made following recognition that the patient was expected to die in the coming hours or days?' The result was 59% of patients where there was recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for audit question 5.15 was 74% (4895/6658).*

Fig 11: Site variation in 5.15

Per cent with documented evidence that an assessment regarding the patient's need for CAH was made at any time between the time of the final admission and death (the red line shows the national 71%)

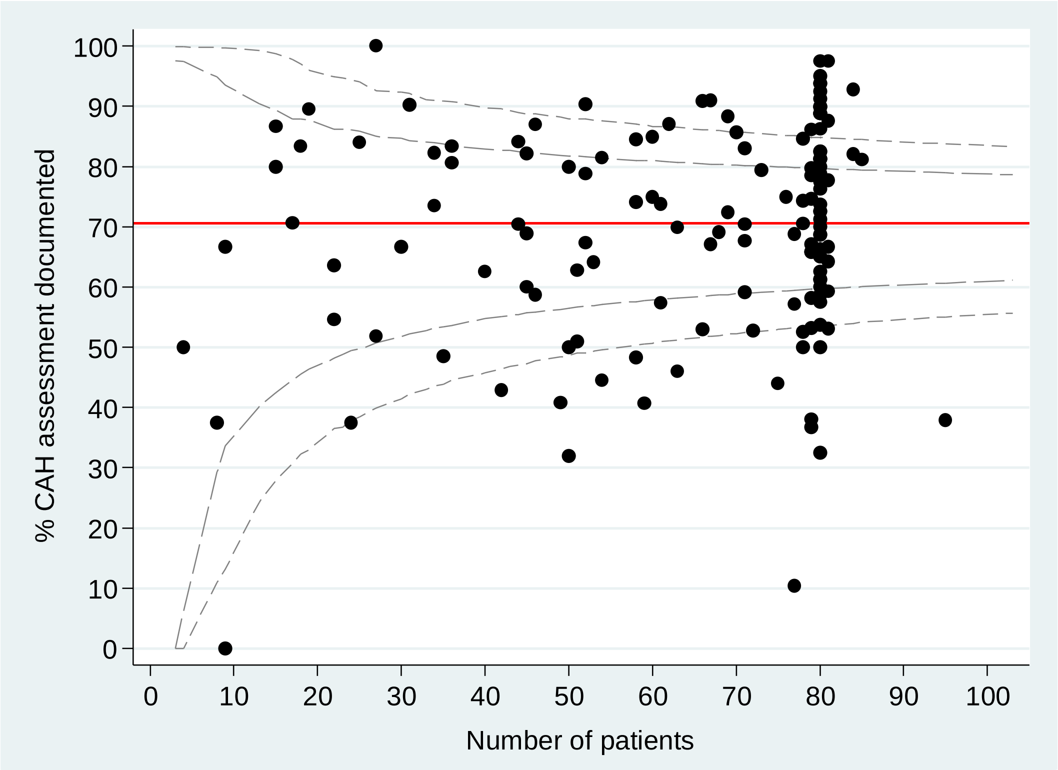


Table 38

	National audit (n=9302)	
5.16. Is there documented evidence that a discussion regarding drinking and need for assisted forms of hydration was undertaken **with the patient** in the time between the final date of admission and of death?		
YES	18%	1671
If 'no' to 5.16 (n=7631), were any of the following reasons documented as to why discussion regarding drinking and need for assisted forms of hydration did not take place?		
• The patient displayed a longstanding lack of mental capacity (eg dementia) for the issue of drinking and hydration	14%	1085
• The patient displayed an acute lack of mental capacity (eg delirium) for the issue of drinking and hydration	10%	744
• The patient was semi-conscious or unconscious	36%	2759
• The patient had asked not to be involved in this discussion	0.2%	16
• The patient was taking oral fluids up until death	16%	1257
• No reason recorded	21%	1614
• Other	2%	156

***2013 audit**: 'Is there documented evidence that a discussion regarding hydration options/care was undertaken with the patient, following recognition that the patient was expected to die in the coming hours or days?' The result was 7% of those where there was recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.16 was 19% (1256/6658).*

Table 39

	National audit (n=9302)	
5.17. Is there documented evidence that a discussion regarding hydration needs was undertaken with the nominated relative or friend or the nominated independent mental capacity advocate (IMCA), or LPA personal welfare at any time between the time of the final admission and death?		
YES	39%	3595
If 'no' to 5.17 (n=5707), were any of the following reasons documented as to why discussion did not take place?		
• Attempts to contact them were unsuccessful	2%	127
• IMCA unavailable	0.1%	5
• LPA for personal welfare unavailable	<0.1%	1
• Nothing recorded	85%	4847
• Other	13%	727

***2013 audit**: 'Is there documented evidence that a discussion regarding hydration options/care was undertaken with the nominated relative or friend or the nominated IMCA, following recognition that the patient was expected to die in the coming hours or days?' The result was 36% of those with recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.17 was 45% (2975/6658).*

Table 40

	National audit (n=9302)	
5.18 In the last 24 hours before the patient's death, was clinically assisted (artificial) Hydration (CAH) in place?		
YES	43%	4020
If **'yes'**, what was the route?		
• SC	6%	251
• Nasogastric (NG)	5%	204
• Percutaneous endoscopic gastrostomy (PEG)	2%	67
• IV	87%	3498

***2013 audit**: 'At the time of the patient's death was clinically assisted (artificial) Hydration (CAH) in place?' The result was 29%. If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.18 was 41% (3282/7997).*

Eating and assisted nutrition

Key findings

- In 61% of cases there was documented evidence that the patient's ability to eat had been assessed in the last 24 hours of life. In 26% of cases it was documented that the patient was eating in the last 24 hours. In 36% there was evidence that the patient had been supported to eat in the last 24 hours.
- In 34% of cases, there was documented evidence that the patient had an assessment regarding the need for clinically assisted (artificial) nutrition (CAN) at any time between the time of the final admission and death.
- CAN was in place during the last 24 hours before death in 8% of patients.

Recommendations

- There should be more frequent assessment of the dying patient's ability and desire to eat.
- For patients who are unconscious or lacking capacity, there needs to be more documentation that the nominated person was involved in decisions about feeding and the possible need for CAN.

Table 41

	National audit (n=9302)	
5.19. Was there a documented assessment of the patient's ability to eat in the last 24 hours of life?		
YES	61%	5632
5.20. Is there evidence that the patient was supported to eat in the last 24 hours of life?		
YES	36%	3335
5.21. Was the patient eating in the last 24 hours of life?		
YES	26%	2431
5.22. Is there documented evidence that an **assessment** regarding the patient's need for CAN was made at any time between the time of the final admission and death?		
YES	34%	3197

***2013 audit**: 'Is there documented evidence that an assessment regarding the patient's ability to take oral nutrition was made following recognition that the patient was expected to die in the coming hours or days?' The result was 59% for those with recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.19 was 62% (4126/6658).*

***2013 audit**: 'Is there documented evidence that an assessment regarding the patient's need for CAN was made following recognition that the patient was expected to die in the coming hours or days?' The result was 45% for those* *with recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.22 was 39% (2565/6658).*

Table 42

	National audit (n=9302)	
5.23. Is there documented evidence that a discussion regarding eating and need for assisted forms of nutrition was undertaken **with the patient** in the time between the final date of admission and of death?		
YES	14%	1322
If 'no' to 5.23 (n=7980), were any of the following reasons documented as to why discussion regarding eating and need for assisted forms of nutrition did not take place?		
• The patient displayed a longstanding lack of mental capacity (eg dementia) for the issue of eating and nutrition	13%	1074
• The patient displayed an acute lack of mental capacity (eg delirium) for the issue of eating and nutrition	9%	727
• The patient was semi-conscious or unconscious	34%	2721
• The patient had asked not to be involved in this discussion	0.2%	18
• The patient was eating up until their death	16%	1279
• No reason recorded	24%	1892
• Other	3%	269

***2013 audit**: 'Is there documented evidence that a discussion regarding nutrition options/care was undertaken with the patient, following recognition that the patient was expected to die in the coming hours or days?' The result was 7% of those where there was recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.23 was 15% (1027/6658).*

Table 43

	National audit (n=9302)	
5.24. Is there documented evidence that a discussion regarding nutrition needs was undertaken with the nominated relative or friend or the nominated IMCA, or LPA personal welfare at any time between the time of the final admission and death?		
YES	28%	2641
If 'no' to 5.24 (n=6661), were any of the following reasons documented as to why discussion did not take place? (multiple responses were possible)		
• Attempts to contact them were unsuccessful	2%	125
• IMCA unavailable	0.2%	10
• LPA for personal welfare unavailable	0.1%	5
• Nothing recorded	78%	5226
• Other	13%	886
• Missing data (none of the above)	6%	416

***2013 audit**: 'Is there documented evidence that a discussion regarding nutrition options/care was undertaken with the nominated relative or friend or the nominated IMCA, following recognition that the patient was expected to die in the coming hours or days?' The result was 29% where there was recognition of dying. If the current audit is restricted to those with known LOS ≥24 hours and recognition of dying (1.1=yes), the result for 5.24 was 33% (2202/6658).*

Table 44

	National audit (n=9302)	
5.25. At the time of the patient's death was CAN in place?		
YES	8%	758
If **'yes'**, what was the route?		
• NG	67%	511
• PEG	13%	96
• IV	20%	151

***2013 audit**: 'At the time of the patient's death was CAN in place?' The result was 7% for the overall sample. If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.25 was 8% (667/7997).*

Spiritual, cultural, religious and practical needs

Key findings

- There was documented evidence of discussion during the last episode of care regarding the patient's spiritual/cultural/religious/practical needs with 15% of patients who were capable of participating in such discussions. In a further 27%, there had been discussion with a nominated person important to the patient.
- There was considerable variation between trusts with respect to the recording of these discussions with *either the patient or the nominated person important to the patient*: the national average was 42% but many trusts recorded these discussions for 60-100% of cases, while many also recorded them for less than 20% of cases (see Fig 12)
- It was documented that in 89% of cases, the identified spiritual/cultural/religious/practical needs had been met.

Recommendation

- The documentation of discussions about the dying patient's spiritual/cultural/religious/ practical needs is low and should be increased.

Table 45

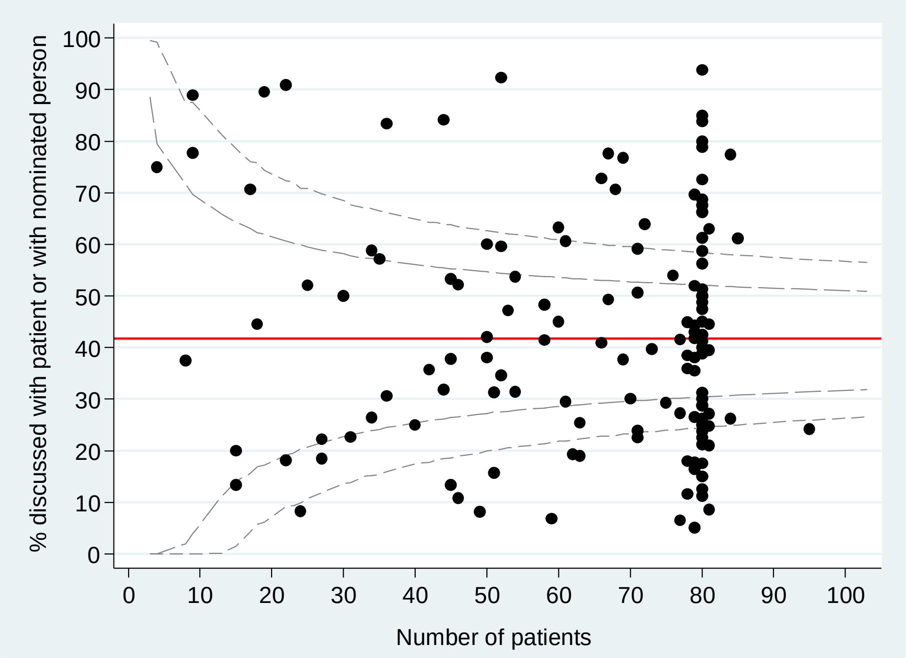
	National audit (n=9302)	
5.26. Is there documented evidence within the last episode of care of discussion regarding the patient's spiritual/cultural /religious/practical needs with patients who were capable of participating in such discussions?		
• Yes, to the patient	15%	1366
• Yes, to the nominated person important to the patient as a proxy for the patient	27%	2520
• No to the patient or the nominated person important to the patient as a proxy for the patient	56%	5237
• There was no nominated person important to the patient	1%	94
• Attempts were made to contact the nominated person important to the patient but were unsuccessful	1%	85

If sudden or unexpected deaths are excluded and the analysis is also restricted to where there was recognition (1.1=yes), then this result (5.26) is revised to: 15% (1079/7199) Yes – to the patient; 32% (2276/7199) Yes – to the nominated person important to the patient as a proxy for the patient; 52% (3729/7199) No to the patient or the nominated person important to the patient as a proxy for the patient; 1% (59/7199) There was no nominated person important to the patient; 1% (56/7199) Attempts were made to contact the nominated person important to the patient but were unsuccessful.

***2013 audit**: ‘Is there documented evidence within the last episode of care that a discussion took place **with the patient** regarding their spiritual needs (wishes, feelings, faith, beliefs, and values)?’ The result was 11% of the overall sample. If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.26 – ‘Yes, to the patient’ was 16% (1242/7997).*

Fig 12: Site variation in 5.26

Per cent with documented evidence within the last episode of care of discussion regarding the patient’s spiritual/ cultural/religious/practical needs with either patient or with the nominated person important to the patients (the red line shows the national 42%, 3886/9302)



Of the patients who had participated in such discussions (either directly or via a proxy), the spiritual/cultural/ religious/practical needs identified during the course of the discussion were ultimately met for 89% (3450/3886).

Individual plan of care

Key findings

- There was documented evidence in 56% of cases that the team were aware of an individual plan of care for the dying person. In 96% there was evidence that the plan had been followed. In 86% it was documented that the plan had been reviewed.
- There was considerable variation between trusts in recording that the team were aware of an individual plan of care for the dying person: compared with the national average of 56%, there were many trusts that achieved this in 80-100% of cases and many others where it was documented in less than 40% of cases (see Fig 13).
- During the last 24 hours of life, it was documented that the patient's condition was reviewed a median of seven times.
- There was variation in the frequency of assessment in the last 24 hours of life by the setting of the patients. The highest number of assessments was in critical care (median 9, IQR 5-15) and the lowest was in specialist care units (median 5, IQR 3-11).

Recommendation

- The documented frequency of the team's awareness of an individual care plan for the dying patient was low and needs to be increased.

Table 46

		National audit (n=9302)	
5.27. Is there documented evidence that the team were aware of an individual plan of care for the person who is dying?			
	YES	56%	5186
If **'yes'**, was this followed?			
	YES	96%	4991/5186
If **'yes'**, was this reviewed?			
	YES	86%	4476/5186

Fig 13: Site variation in 5.27

Per cent with documented evidence that the team were aware of an individual plan of care for the person who is dying (the red line shows the national 56%)

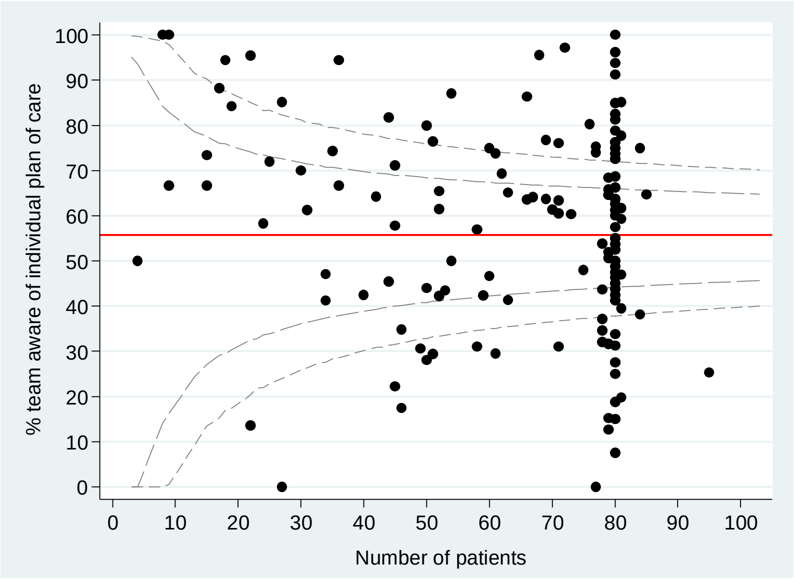


Table 47

	National audit (n=9302)
5.28. During the last 24 hours of the patient's life, how many times was it documented that the patient's condition was reviewed by a doctor or nurse?	
Median (IQR) times reviewed	7 (4-11)
20-80th centile range	4-12
10-90th centile range	3-16

If sudden or unexpected deaths are excluded and the analysis is also restricted to cases where there was LOS ≥24 hours and there was recognition (1.1=yes), then this result (5.28) is revised to median (IQR) 7 (5-11), 20-80th centile range 4-12, 10-90th centile range 3-16, n=6327.

***2013 audit**: 'During the last 24 hours of the patient's life, how many clinical assessments by a doctor or nurse regarding the patient's condition were documented?' The overall result was in categories: <5 assessments 18%, 5-10 assessments 57%, 11-15 assessments 15%, 16-20 assessments 5.2%, 21-25 assessments 2.6%, 26-30 assessments 1.3% and >30 assessments 1.2%.*

If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.28 was: <5 assessments 25%, 5-10 assessments 48%, 11-15 assessments 16%, 16-20 assessments 6.1%, 21-25 assessments 2.4%, 26-30 assessments 1.4% and >30 assessments 1.0%.

Care immediately prior to and after death

Key findings

- There was documented evidence of care of the patient immediately prior to, or at the time of death, in 73% of cases.
- Immediately after death, care of the patient was recorded in 63% of cases. There was considerable variation between trusts in the documentation of care of the patient immediately after death: compared with the national average of 63%, many trusts documented this occurring in 80-100% of cases, while others recorded it in less than 40% of cases (Fig 14).

Recommendation

- The documentation that there was care of the patient immediately before and after death (especially if there were special religious/cultural requirements) needs to be increased.

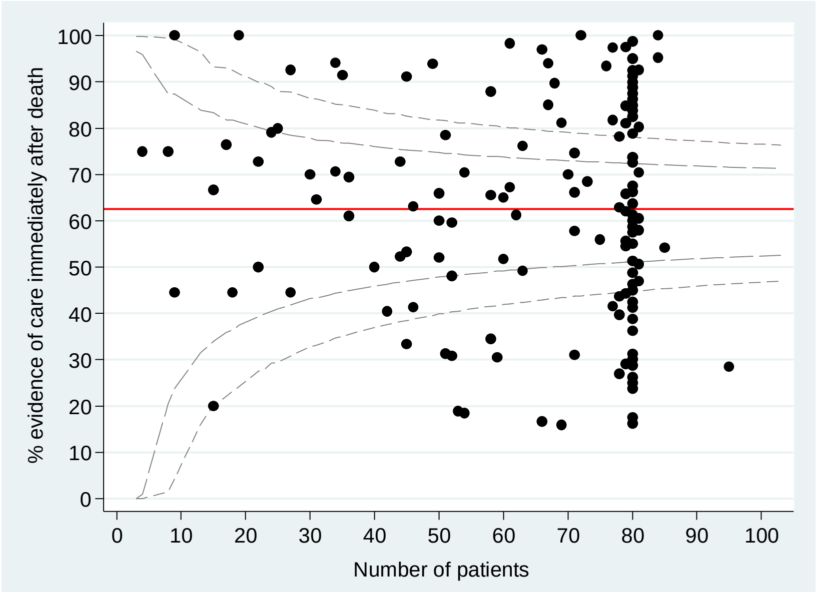
Table 48

	National audit (n=9302)	
5.29. Is there documented evidence of care of the patient immediately prior to or at the time of death?		
YES	73%	6774
5.30. Is there documented evidence of care of the patient immediately after death?		
YES	63%	5815

***2013 audit**: 'Is there documented evidence that the care of the body of the deceased was undertaken?' The result was 46% of the overall sample. If the current audit is restricted to those with known LOS ≥24 hours, the result for 5.30 was 62% (4972/7997).*

Fig 14: Site variation in 5.30

Per cent with documented evidence of care of the patient immediately after death (the red line shows the national 63%)



Summary

An individual plan of care

Overall, 66% of case records showed that there had been a holistic assessment of the patient's needs, with a view to producing an individual plan of care. If sudden deaths and cases where the patient had died less than 24 hours after admission were excluded, this rose to 73% of cases. There was a wide variation between trusts in this measure, with some sites undertaking holistic needs assessments in 90-100% of cases, while others reached less than a 30% achievement (Fig 7).

The most commonly assessed needs were pressure areas (92%); hygiene requirements and bladder function (90%); pain (87%); and mouth care, bowel care and breathing difficulties (82%). The needs that were assessed in <80% of cases were agitation/delirium; nausea/vomiting; noisy breathing / death rattle; and anxiety/distress.

In total, 31% of patients had been reviewed by a member of the trust specialist palliative care (SPC) team during the last admission; 23% had been reviewed by the SPC within the last 24 hours of life. Comparing sites with the SPC beds and those without specialist beds, there was a small difference in the SPC frequency of reviews, with 4% of extra reviews in the sites with the SPC beds.

Of the key symptoms that could be present around the time of death, there was documented evidence that pain was controlled in 79% of cases; agitation/delirium in 72%; breathing difficulties in 68%; noisy breathing / death rattle in 62% and nausea/vomiting in 55%.

Medication

Compared with the 2013 audit, there were many more questions asked about the details of prescribing in the last days of life, in particular about the use of 'prn' or as required and anticipatory prescriptions, the use of patches and of continuous subcutaneous and intravenous infusions. The audit also searched for details of doses of drugs prescribed and actually given in the last 24 hours of life. However there were problems with the recording of some of the drugs on the audit data collection web tool.

If results are restricted to those with known LOS ≥24 hours, there was documented evidence that anticipatory medication (prn) was prescribed for the key symptoms: for pain in 75% of cases; agitation/delirium 69%; breathing difficulties 66%; nausea/vomiting 66%; and noisy breathing / death rattle 62%.

Overall and for those reporting symptoms, analgesics (painkillers) were prescribed for prn use in 86% of cases; antiemetics (for nausea and vomiting) in 79%; sedatives in 79%; and drugs for noisy breathing / death rattle in 71%.

In the last 24 hours of life, 30% of patients were taking oral medications; 4% were having medication delivered via a patch; 24% were having medications via a subcutaneous infusion; 5% via an intravenous infusion; and 2% received rectal medication.

With subcutaneous infusions, the frequency of prescribing was: painkillers in 86% of cases; sedatives 78%; antiemetics 54%; and death rattle 41%. With intravenous infusions, the frequencies were: painkillers 75%; sedatives 55%; antiemetics 4%; and death rattle 2%.

In total, 65% of the medications that patients received had been reviewed in the last 24 hours of life. There was significant variation, with some trusts reviewing 90-100% and some reviewing less than 40%.

Nil by mouth (NBM)

Nil by mouth (NBM) decisions were in place for 18% of patients and there was great variation between sites (Fig 10), with some sites classifying nearly 50% of dying patients as NBM. In total, 23% of patients, and 64% of those important to the patient, had been informed of the NBM decision. Also, 93% of NBM orders had a documented reason, which included: 'patient too drowsy/ill' in 41%; 'patient unable to swallow' in 39%; and 'other' in 20%.

The majority (54%) of the NBM decisions had involved a consultant (other than palliative medicine); 20% involved speech and language therapists (SALTs); 16% involved a staff nurse; and 9% of NBM orders involved a trainee doctor (specialist registrar). Consultants in palliative medicine had been involved in an NBM order in 4% of cases. It is unclear whether these NBM orders were multidisciplinary team decisions or unilateral decisions.

Drinking and assisted hydration

The perceived lack of hydration of dying patients was one of the commonest complaints reported by the public to the Neuberger review of the Liverpool Care Pathway. The new NICE guideline NG31 on 'Clinical care of adults in the last days of life' is very clear on the importance of maintaining hydration, either by patients being allowed and supported to drink, or by clinically assisted forms of hydration.[9]

In the last 24 hours of life, 45% of patients were being supported to drink. This was not information that was collected previously, and it shows that, while interest in eating and drinking may decline as death approaches, many patients are still taking some food and drink. It is of note that 39% of patients were documented as drinking in the last 24 hours.

Overall, the need for clinically assisted hydration (CAH) was assessed in 71% of patients and this was given in the last 24 hours before death in 43% of patients. Where LOS was ≥24 hours and death was recognised, the need for CAH was assessed in 74% of cases (4895/6658). CAH was given in 41% of cases (3282/7997) where LOS was ≥24 hours. Both of these figures represent increases from the previous 2013 audit figure (59% assessed and 29% given CAH). There is considerable variation between trusts in the assessment for CAH (Fig 11): some trusts assessed between 90-100% of cases and some assessed less than 50%.

The 2013 audit asked whether, for patients with LOS ≥24 hours and who were recognised to be dying, there was documented evidence that discussion regarding drinking and the need for CAH was undertaken with the patient, giving a result of 7%; using the same parameters in the current audit, the result is 19%. Reasons why there had not been discussion with the patient regarding drinking and the need for CAH included: patient was semi-conscious or unconscious (36%); longstanding lack of capacity for this decision (14%); acute lack of capacity (10%); patient taking oral fluids up until death (16%); and no reasons recorded (21%).

In 39% of cases, there was documented evidence that discussion regarding hydration needs was undertaken with the nominated relative/friend or the nominated IMCA, or LPA for personal welfare at some time between the date of final admission and death. In the 2013 audit, this question was asked for patients with LOS ≥24 hours who were recognised to be dying, giving a figure of 36%; using the same parameters in the current audit the result is 45%. Reasons for not holding these discussions included unsuccessful attempts to contact them in 2% of cases; but in 85% of cases there was no reason recorded.

The routes used for CAH were: IV in 87%, SC in 6%, NG tube in 5% and PEG tube in 2%.

Eating and assisted nutrition

In the last 24 hours of life, 36% of patients were being supported to eat and 26% of patients were documented as eating in the last 24 hours.

Restricting the analysis to patients with LOS ≥24 hours and those recognised to be dying, 62% of cases had documented evidence that the patient's ability to eat had been assessed in the last 24 hours of life. This figure is essentially unchanged from the 2013 audit, which asked about 'the patient's ability to take oral nutrition'.

For 34% of patients, there was documented evidence that an assessment regarding the need for clinically assisted (artificial) nutrition (CAN) at any time between the time of the final admission and death had taken place. The comparative figure for the 2013 audit (for patients with LOS ≥24 hours and recognised to be dying) was 45%. Using the same parameters (LOS ≥24 hours and recognition of death), in the current audit the figure is 39%.

In 28% of cases, there was documented evidence that discussion regarding nutrition needs was undertaken with the nominated relative/friend or the nominated independent mental capacity advocate (IMCA), or LPA for personal welfare at some time between the date of final admission and death. In the 2013 audit, this question was asked for patients with LOS ≥24 hours and recognised to be dying, giving a figure of 29%; using the same parameters in the current audit the result is 33%. Reasons for not holding these discussions included unsuccessful attempts to contact them in 2%; but in 78% of cases there was no reason recorded.

Clinically assisted nutrition (CAN) was in place during the last 24 hours before death in 8% of patients. In the 2013 audit, this question was asked for patients with LOS ≥24 hours, giving a figure of 7%; using the same parameters in the current audit the result is again 8%. The routes used for CAN were: NG tube (67%); IV (20%); and PEG tube (13%).

Spiritual, cultural, religious and practical needs

There was documented evidence of discussion during the last episode of care regarding the patient's spiritual/cultural/religious/practical needs with 15% of patients who were capable of participating in such discussions. In a further 27%, there had been discussion with a nominated person important to the patient. In 56% of cases there had been no such discussions with the patient or with their nominated proxy.

In the 2013 audit, this question was asked for patients with LOS ≥24 hours and recognised to be dying, giving a result of 11%; using the same parameters in the current audit the result is 16%.

There was considerable variation between trusts with respect to the recording of these discussions with either the patient or the nominated person important to the patient: the national average was 42%, but many trusts recorded these for 60-100% of cases, while many also recorded them for less than 20% of cases (Fig 12). It was documented that in 89% of cases, the identified spiritual/cultural/religious/practical needs had been met.

Individual plan of care

Both the Neuberger review and the new NICE guideline NG31[9] have stressed the need for making individual care plans for dying patients. The NICE guidance also emphasises the need for the plan of care to be shared with the patient, those important to them and among the multiprofessional team. NICE NG31 recommends that the patient's needs are reviewed regularly, and that the individual care plan is updated accordingly.

There was documented evidence in 56% of cases that the team were aware of an individual plan of care for the dying person. There was considerable variation between sites in recording that the team were aware of an individual plan of care for the dying person; compared with the national average of 56%, there were many trusts that achieved this in 80-100% of cases and many others where it was documented in less than 40% of cases (Fig 13). In 96% of cases there was evidence that the plan had been followed, and the plan was reviewed in 86%.

During the last 24 hours of life, it was documented that the patient's condition was reviewed a median of seven times. This figure is unchanged if sudden or unexpected deaths are excluded, and where LOS was ≥24 hours and dying was recognised.

In the 2013 audit, a different question was asked for patients with LOS ≥24 hours, ie the number of reviews were in categories of: <5 assessments; 5-10; 11-15; 16-20; 21-25; 26-30; >30 assessments. Comparing the 2013 audit with the current audit, there was very little difference in the reporting of these categories, with the category of <5 assessments rising from 18% in 2013 to 25% in 2015; and a fall in 5-10 assessments from 57% to 48%.

There was variation in the frequency of assessment in the last 24 hours of life by the setting of the patients. The highest number of assessments was in critical care (median 9, IQR 5-15) and the lowest was in specialist care units (median 5, IQR 3-11).

Care immediately prior to and after death

There was documented evidence of care of the patient immediately prior to, or at the time of, death in 73% of cases. The care of the patient immediately after death was recorded in 63% of cases. There was considerable variation between sites in the documentation of care of the patient immediately after death: compared with the national average of 63%, many sites documented that this occurred in 80-100% of cases, and many others recorded it in less than 40% (Fig 14).

Results: Organisational audit

Participation figures – organisational audit

- In total, 142 sites submitted data for the organisational audit.
- Three trusts each submitted data for two separate sites (due to recent mergers) *(= 139 trusts)*.
- Two sites that submitted data were community sites/trusts that wished to take part in the audit. The community sites have been excluded from the participation figures *(= 137 trusts).*
- Five trusts did not participate in the organisational audit, making the participation rate 96% *(137/142)*.

Temporal comparison with the previous organisational audit (2013)

The 2013 audit summarised responses from 131 trusts. Some of the questions asked in the 2013 audit are the same as the questions asked in this current audit, and some have only minor variation in wording, which should allow comparison. Where possible and as relevant, comparable results from the previous audit are inserted as a footnote below each table.

Section 1: Personnel responsible for submitting trust data for this audit

Table 49

	National audit (n=142)	
1a. What is the discipline of the auditor completing the organisational audit data collection form?		
Clinical governance/audit staff	6%	9
Medical staff	44%	63
Nursing staff	23%	33
End of life care facilitator/team	20%	29
Data manager	-	-
Other*	6%	8

*Other comprised: audit staff and lead palliative care consultant, clinical operational manager (specialist palliative), hospice practice development lead, MDT facilitator, medical and nursing staff, nursing and clinical governance staff, palliative care education lead, trust end of life care clinical lead.

2013 audit: *clinical governance/audit staff (14%), medical staff (24%), nursing staff (24%), end of life care / Liverpool Care Pathway facilitator (25%), data manager (-) and other (12%).*

In total, 81% (115/142) of auditors completing the organisational audit data form were a member of the hospital specialist palliative care service (78% in the 2013 audit).

Section 2: Background information regarding the trusts/hospitals participating in the audit

Key findings

- In total, 13% of trusts (18/142) reported that they had specialist palliative care beds.
- Only 46% of trusts were involved in the Transforming End of Life Care in Acute Hospitals Programme; and only 35% of trusts are using EPaCCSs.
- Ninety-eight per cent of trusts reported 'locally developed programmes of work to support end of life care', which probably represents the changes needed after the withdrawal of the Liverpool Care Pathway.
- The 2014 *National care of the dying audit for hospitals* report[8] (on 2013 data) recommended that all trusts should have a named member on the board who is responsible for end of life care: 98% have achieved this.
- The 2014 audit report also recommended that all trusts have a lay member with responsibility for end of life care on their board. Only 49% of trusts have achieved this.
- In total, 59% of trusts had one or more end of life care facilitators in place.

Recommendations

- There should be at least one lay member with specific responsibility for end of life care on every NHS trust board.
- Where trusts are not already using EPaCCSs or an equivalent system for record sharing, they should take steps to do so.

Table 50

	National audit (n=142)	
2a. How many hospitals within your trust were eligible for inclusion in the case note review element?		
One	50%	71
Two	30%	43
Three	11%	16
Four	5%	7
Five	1%	2
More than five*	2%	3
Median (IQR)	1 (1-2)	

*6, 7 and 12

2013 audit: *stated as median 1, IQR 1-2*

Table 51

	National audit (n=142)		
2b. What types of bed, as well as numbers of each, did your trust have on 1 May 2015?			
	Median	IQR	Total
• Medical	150	98-209	24095
• Surgical	172	107-244	25775
• Acute medical admissions unit	44	30-60	6762
• Rehabilitation	19	0-38	3564
• Oncology	9	0-30	2810
• Cardiology unit	26	12-42	4580
• Respiratory unit	28	3-51	4615
• Renal unit	0	0-22	1697
• Care of older people unit	68	14-118	10726
• Specialist palliative care unit	0	0-0	278
• Paediatric	40	23-61	6943
• Teenage and young adult unit	0	0-0	223
• Intensive care	16	11-28	3693
• Maternity	49	28-73	7882
• Other	23	0-50	6311
Total number of adult beds in the trust*	684	449-916	102788

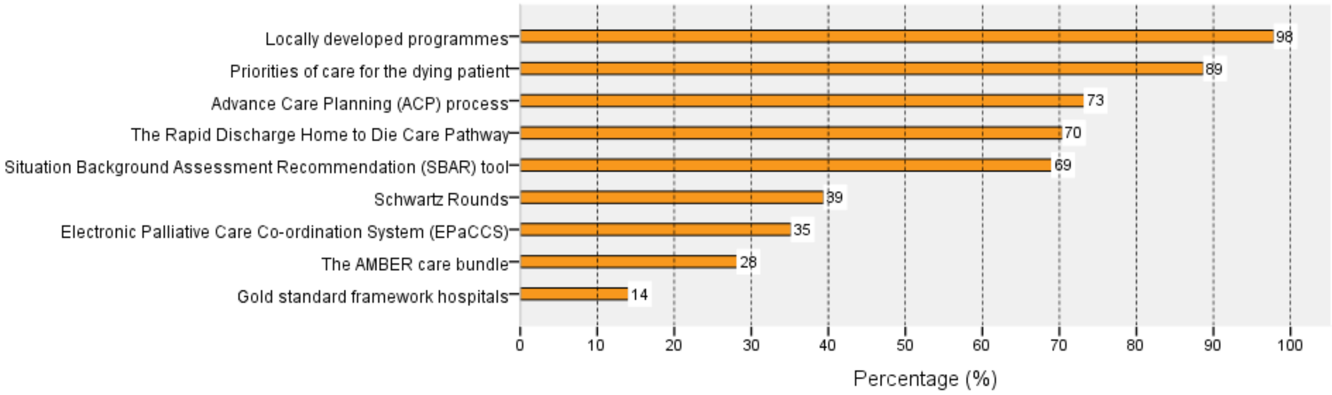
*This field is calculated from figures entered in audit question 2b, excluding paediatrics and the teenage and young adult unit.

The 278 specialist palliative care unit beds were from 13% (18/142) of trusts.

A small number of trusts reported difficulty in separating out beds; in particular, overall the ‘medical’ bed number may overestimate the actual numbers, with specific types of medical bed being underestimated.

In total, 46% (66/142) of trusts were involved in the Transforming End of Life Care in Acute Hospitals Programme. If the specialist hospital trusts are excluded then this gave 48% (65/136) of trusts that were involved in the programme.

Fig 15: Which of the following are used within your trust?



2013 audit: *ACP 55%, EPaCCS 21%, AMBER 19% and rapid discharge home to die care pathway 59%*

Table 52

	National audit (n=142)	
2e. Does your hospital trust have a named member of the trust board for end of life care?		
YES	98%	139
2f. Is there a lay member on the trust board with a responsibility/role for end of life care?		
YES	49%	70

2013 audit: *53% with a named member of trust board for care of dying, as at 1 May 2013*

Table 53

	National audit (n=142)	
2g. Does your trust have one or more end of life care facilitators as of 1 May 2015?		
YES	59%	84
2gi. What is the profession of the end of life care facilitator?		
Medical		9
Nursing		83
Other*		5

*Others comprised: AMBER facilitator is a CNS, end of life facilitator, occupational therapist, technical support developing electronic resources and not stated.

2013 audit: *55% with one or more end of life / care of the dying facilitators working within the trust as at 1 May 2013*

The number of contracted end of life care facilitator posts and the number currently employed in these posts as of 1 May 2015 were:

- Contracted medical n=9, WTE median 2.0; nursing n=83, WTE median 1.0, IQR 0.8-2.0; and other n=5, WTE median 0.4
- Filled medical n=9, WTE median 2.0; nursing n=83, WTE median 1.0, IQR 0.8-1.7; and other n=5, WTE median 0.0

2013 audit: *contracted medical n=2, both WTE 1.0; nursing n=66, WTE median 1.0, IQR 0.6-1.0; and other n=2, WTE 0.4 and 0.5*
2013 audit: *established medical n=2, WTE 0.3 and 0.7; nursing n=67, WTE median 1.0, IQR 0.7-1.0; and other n=2, WTE 0.4 and 0.5*

Section 3: Audit and evaluation

Key findings

- In total, 65% of trusts had undertaken a formal audit of care for patients in the last hours or days: 76% fed audit results back to the trust board.
- Sixty-six per cent of trusts had a formal process for discussing and reporting on the five priorities of care.
- As of 1 May 2015, 78% of trusts had a mechanism for flagging complaints that related to end of life care.
- For organisations where there was an End of Life Care Strategy Group, 68% of these had complaints routinely reported to them.

Recommendation

- Trusts should perform audits of end of life care and feed the results back to their boards.

Table 54

	National audit (n=142)	
3a. Was a formal audit of care delivery for patients in the last hours or days undertaken in the previous financial year (ie between 1 April 2014 and 31 March 2015)?		
YES	65%	92
3b. Were these results fed back to clinical teams?		
YES	97%	89/92
3c. Were these results fed back to the trust board?		
YES	76%	70/92

2013 audit: *in 56% of trusts a formal audit of care delivery for patients in the last hours or days was undertaken between 1 April 2012 and 31 March 2013. In total, 88% of audit results were fed back to clinical teams, and 68% were fed back to the trust board.*

Table 55

	National audit (n=142)	
3d. Was an action plan produced in the financial year (ie between 1 April 2014 and 31 March 2015) to promote improvement in end of life care in your hospital trust?		
YES	91%	129
3e. Was this action plan fed back to clinical teams?		
YES	88%	114/129
3f. Was this action plan fed back to the trust board?		
YES	83%	107/129

2013 audit: *In 72% of trusts an action plan was produced between 1 April 2012 and 31 March 2013 to promote improvement in care of the dying within the trust. In total, 89% of action plans were fed back to clinical teams, and 70% were fed back to the trust board.*

In 83% (118/142) of trusts, end of life care was reported on at least annually at trust board level (ie between 1 April 2014 and 31 March 2015). In 71% (84/118) of these, there was carer and public representation within these discussions/reporting processes.

***2013 audit:** In 58% of trusts, care of the dying was reported on at least annually at trust board level (ie between 1 April 2012 and 31 March 2013). In 72% of these, there was patient and public representation within these discussions/reporting processes.*

Table 56

	National audit (n=142)	
3g. Within your trust quality governance structure, was there a formal process for discussing and reporting on the five priorities of care between 1 April 2014 and 31 March 2015?		
YES	66%	94

***2013 audit:** In 69% of trusts a formal process existed between 1 April 2012 and 31 March 2013 within the trust or quality governance structure for discussing and reporting on care of the dying.*

Table 57

	National audit (n=142)	
3j. As of 1 May 2015, did your trust have a mechanism for flagging complaints that related to end of life care?		
YES	78%	111
3ji. What number of complaints, relating to end of life care, did your trust receive between 1 April 2014 and 31 March 2015? (Known for 87/111)		
Median (IQR), range, total complaints	6 (3-11), 0-102, 1037	
Median (IQR), range of complaints received per 1000 adult deaths in the same financial year	5 (3-9), 0-61	
3jii. Are complaints related to end of life care routinely reported to the End of Life Care Strategy Group?		
No End of Life Care Strategy Group	14%	16/111
Of those with an End of Life Care Strategy Group:		
YES	68%	65/95
No	29%	28/95
Not known	2%	2/95

A mechanism for flagging complaints relating to end of life care was present in 67% (12/18) of the trusts with SPC unit beds and in 80% (99/124) of trusts without SPC unit beds.

For the 87 trusts that stated the number of complaints received, the median (IQR) number for the nine trusts with SPC beds was 6 (2-12), range 0-14; and for 78 trusts without SPC beds it was 6 (4-11), range 0-102.

Section 4a: Trust demographics as at 1 May 2015

Key findings

- In total, 78% of trusts stated that they gave leaflets to families and those important to dying patients about what to expect. Leaflets were used after the patient died in 97% of cases.

Recommendation

- Information about coping with dying and what to do after death should be available in a variety of formats.

Table 58

	National audit (n=142)	
	Median (IQR)	Total
4a. Number of adult beds in the trust	*684 (449-916)*	102788, n=142
4b. Number of adult single patient occupancy rooms in the trust per 100 adult beds*	*22 (15-28)*	23467, n=139
4c. Number of all adult deaths occurring in the previous financial year (ie 1 April 2014 to 31 March 2015) per 100 adult beds	*206 (172-228)*	202407, n=142
4d. Number of *all* adult deaths occurring in the national data collection period (ie 1 May 2015 to 31 May 2015) per 100 adult beds	*16 (14-19)*	16520, n=142
4e. Number of all adult deaths meeting the audit inclusion/exclusion criteria, occurring in the national data collection period (ie 1 May 2015 to 31 May 2015) in those hospitals that submitted data to the case note review, per 100 adult beds	*14 (12-17)*	14498, n=142

*Note that trusts had particular difficulty in obtaining accurate numbers of adult single occupancy rooms (4b)

Section 4b: Supportive information for those important to patients

Table 59

	National audit (n=142)	
4f. Does your trust give the following written information to families and those people that are important to the patient while the patient is dying and when the patient has died?		
• A leaflet outlining the changes that may occur in patients in the hours before death (eg the *Coping with dying* or *What to expect when someone important to you is dying* leaflets or equivalent)	78%	111
• A leaflet explaining local procedures to be undertaken after the death of a patient (for relatives or friends)	97%	138
• Department for Work and Pensions (DWP) leaflet 1027, *What to do after a death in England and Wales* or equivalent?	90%	128

2013 audit: *90% of trusts gave a leaflet outlining the changes that may occur in patients in the hours before death. Note that the specific reference to the two example documents was not given in the 2013 audit nor was the reference 'for families and those people that are important to them'. Seventy-six per cent gave* A leaflet explaining local procedures to be undertaken after the death of a patient *and 91% gave the Department for Work and Pensions (DWP) leaflet 1027* What to do after a death in England and Wales *or equivalent.*

Section 5: Availability of trust-wide continuing education and training

Key findings

- In total, 96% of trusts had a formal in-house continuing education programme on the subject of end of life care.
- Formal in-house, communication skills training was available for 71% of registered nurses, 63% of medical staff, 62% of non-registered nurses and 49% of allied health professionals.

Recommendation

- All medical and nursing staff with responsibility for the care of dying people should attend communication skills training specifically on care in the last days/hours of life, and this should be recorded in their portfolios.

Education and training on care of the dying

Question 5a: Between 1 April 2014 and 31 March 2015 there was a formal in-house continuing education training programme on the subject of end of life care in place at 96% (136/142) of trusts.

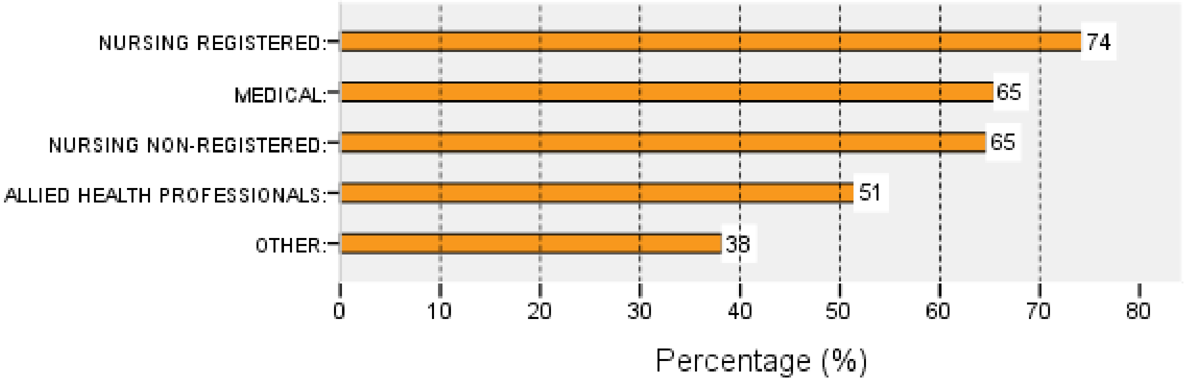
2013 audit: *82% had a formal in-house continuing education training programme on the subject of care of the dying during the financial year 1 April 2012 to 31 March 2013.*

Table 60

	National audit (n=136)		
5b. In the period between 1 April 2014 and 31 March 2015, what continuing education and training was available for the following staff groups?			
Medical	1 April 2014 to 31 March 2015		_1 April 2012 to 31 March 2013*_
• E-learning	47%	64	*54%*
• Update session (every 6-12 months)	68%	93	*63%*
• Session in trust mandatory training	22%	30	*19%*
• Session in trust induction programme	58%	79	*51%*
Nursing – registered**			
• E-learning	51%	70	*54%*
• Update session (every 6-12 months)	70%	95	*69%*
• Session in trust mandatory training	29%	39	*28%*
• Session in trust induction programme	63%	86	*52%*
Nursing – non-registered			
• E-learning	46%	63	*53%*
• Update session (every 6-12 months)	64%	87	*60%*
• Session in trust mandatory training	24%	32	*23%*
• Session in trust induction programme	52%	71	*45%*
Allied health professionals			
• E-learning	44%	60	*52%*
• Update session (every 6-12 months)	53%	72	*50%*
• Session in trust mandatory training	19%	26	*20%*
• Session in trust induction programme	34%	46	*29%*
Other			
• E-learning	33%	45	*Not asked*
• Update session (every 6-12 months)	39%	53	*Not asked*
• Session in trust mandatory training	15%	20	*Not asked*
• Session in trust induction programme	26%	35	*Not asked*

*As per the 2013 audit. **The 2013 audit used the term 'qualified' rather than 'registered'.

Fig 16: Between 1 April 2014 and 31 March 2015, did this formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for the following staff? (Audit question 5c.)



***2013 audit:** medical 61%, nursing qualified 69%, nursing non-qualified 56% and allied health professionals 48%.*

Note that the above percentages are based on a question 5a=Yes denominator, unlike the quality indicator results in the executive summary which take all sites as the denominator.

Overall, formal in-house, communication skills training was available for 71% of registered nurses, 63% of medical staff, 62% of non-registered nurses and 49% of allied health professionals.

Section 6: Trust-wide access to specialist palliative care support

Key findings

- Almost all (97%) trusts had their own specialist palliative care service; 70% also used a specialist palliative care service that is funded and based outside the trust.
- There was a median of 1.08 SPC consultant WTE filled posts (for direct clinical care of hospital inpatients) per 1000 adult beds; and a median of 5.08 clinical nurse specialist WTE filled posts per 1000 adult beds.
- The availability of SPC staff around the clock varied widely, but 11% (16) of trusts offered a face-to-face 24/7 service. Thirty-seven per cent (53/142) of sites had face-to-face access to a palliative care service Monday to Sunday, 9am to 5pm.
- The availability of an out-of-hours telephone service was more comprehensive, with the majority of services providing this every day of the week.
- In total, 26 trusts did not indicate any level of provision of face-to-face specialist palliative care involving doctors, at any time.

Recommendation

- All trusts should have access to specialist palliative care services 9am to 5pm, 7 days a week.

Table 61

	National audit (n=142)	
6ai. Is there a specialist palliative care service provided by the trust?		
YES	97%	138
6aii. Does your trust have access to a specialist palliative care service funded and based outside of the trust?		
YES	70%	100

For the assessment and treatment of hospital inpatients (excluding those in SPC beds), the median (IQR) consultant WTE filled posts per 1000 adult beds (Q4a) was 1.08 (0.70-1.96).

Similarly excluding hospital inpatients n SPC beds, the median (IQR) clinical nurse specialist WTE filled posts per 1000 adult beds (Q4a) was 5.08 (3.85-6.92).

For all 142 trusts, there was a mean of 0.31 SPC consultant WTE filled posts (for direct clinical care of hospital inpatients in SPC beds) per 1000 adult beds; and a mean of 0.71 clinical nurse specialist WTE filled posts per 1000 adult beds. When the sample was broken down according to the trusts that had their own SPC beds (18/142) and those that did not have SPC beds (124/142), the following picture emerged. Regarding SPC consultants, there was a mean of 1.26 WTE consultant posts in trusts with SPC beds, and a mean of 0.17 WTE consultant posts in those without SPC beds. Regarding SPC nurses, there was a mean of 1.31 WTE nurse posts in trusts with SPC beds, and a mean of 0.62 WTE nurse posts in those without SPC beds.

Table 62

	National audit (n=142)	
6c. Please indicate the level of **face-to-face** specialist palliative care service in your trust (applicable as at 1 May 2015).		
	Doctor	Nurse
24 hours per day, 7 days per week	13	9
9-5, 7 days a week	3	38
9-5, Mon to Sat only, exceptionally 7 days if required	-	1
9-5, Mon to Sat only	-	8
9-5, Mon to Fri only, exceptionally 7 days if required	36	8
9-5, Mon to Fri only, exceptionally Sat if required	4	-
9-5, Mon to Fri only	56	77
Exceptionally 7 days if required	4	-
Exceptionally Sat if required	-	1
None of these	26	-

To aid interpretation and to simplify matters in further analyses, the level of face-to-face options were reclassified as: none; Monday to Friday, 9am to 5pm only; more than Monday to Friday, 9am to 5pm but not 24/7; and 24/7. The last two 'exceptionally' options (n=5) were omitted from this classification, as their meaning was unclear.

Thirty-seven per cent (53/142) of sites had face-to-face access to a palliative care service Monday to Sunday, 9am to 5pm.

Table 63

	National audit (n=142)		
6c. Level of out-of-hours **(telephone)** specialist palliative care service in the trust (applicable as at 1 May 2015)			
	Yes	Exceptionally	No
Out-of-hours telephone service **(Monday to Friday)**			
• Doctor	127	NA	15
• Nurse	84	NA	58
Out-of-hours telephone service **(Saturday)**			
• Doctor	124	6	12
• Nurse	89	3	50
Out-of-hours telephone service **(Sunday)**			
• Doctor	124	6	12
• Nurse	86	4	52

***2013 audit:** The question about out-of-hours telephone service was asked differently, in that there was no split by doctor/nurse nor by day of the week. In all, 91% had an out-of-hours telephone service available as at 1 May 2013.*

The availability of SPC staff around the clock varied widely, but only a minority of trusts offered an out-of-hours or a 24/7 service. Specifically, combining doctor and/or nurse availability (ie considering when one or other was available) then 11% (16/142) of trusts offered a 24/7 service, 49% (70/142) offered a better than Monday to Friday, 9am to 5pm service but not a 24/7 service, while 39% (56/142) offered only a Monday to Friday, 9am to 5pm service.

Trusts that had an SPC bedded unit were more likely to have a higher level of out-of-hours doctor service for dying patients.

The 18 trusts that had an SPC bedded unit were more likely to have a higher level of out-of-hours doctor service for dying patients: 22% (3) offered a 24/7 service; 56% (10) offered a more than Monday to Friday, 9am to 5pm but not a 24/7 service; 22% (3) had a Monday to Friday, 9am to 5pm only service; and none had no face-to-face doctor service.

Section 7: Trust-wide clinical provisions and protocols

Key findings

- In total, 99-100% of trusts stated that they had guidance on prescribing medications for each of the five key symptoms that can be present in patients in the last days/hours of life.
- Most trusts had policies for ensuring patient comfort and dignity, and for offering family and friends access to the body after death and a prayer room (Fig 17).
- All trusts reported that they had a policy for recording DNACPR decisions, while 80% had a policy for the deactivation of implantable cardioverter defibrillators (ICDs). Seventy-five per cent reported that they had designated quiet spaces for relatives.
- There was a wide variation between trusts on support services for people important to the dying patient (Fig 18) and for staff and volunteers (Fig 19).

Recommendation

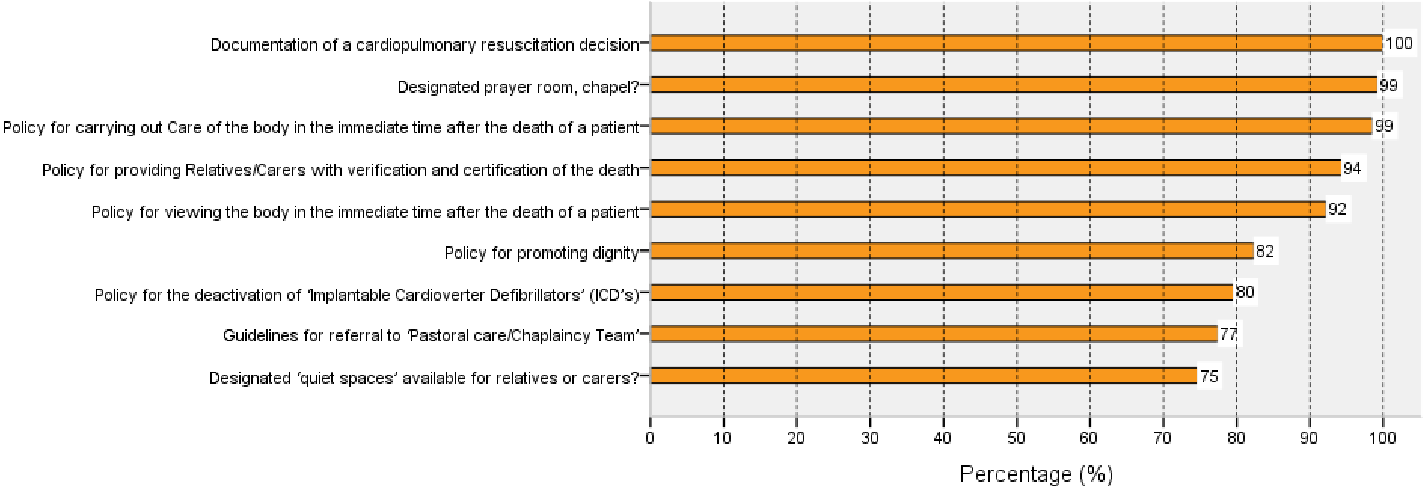
- Trusts should provide protocols to ensure provision of patient comfort, dignity and privacy up to, including and after the death of the patient.

Table 64

	National audit (n=142)	
7a. Guidance for the prescription of medications for patients in the last hours or days of life:		
• Agitation/delirium	100%	142
• Dyspnoea / breathing difficulty	100%	142
• Nausea/vomiting	100%	142
• Pain	99%	141
• Noisy breathing / death rattle	99%	141

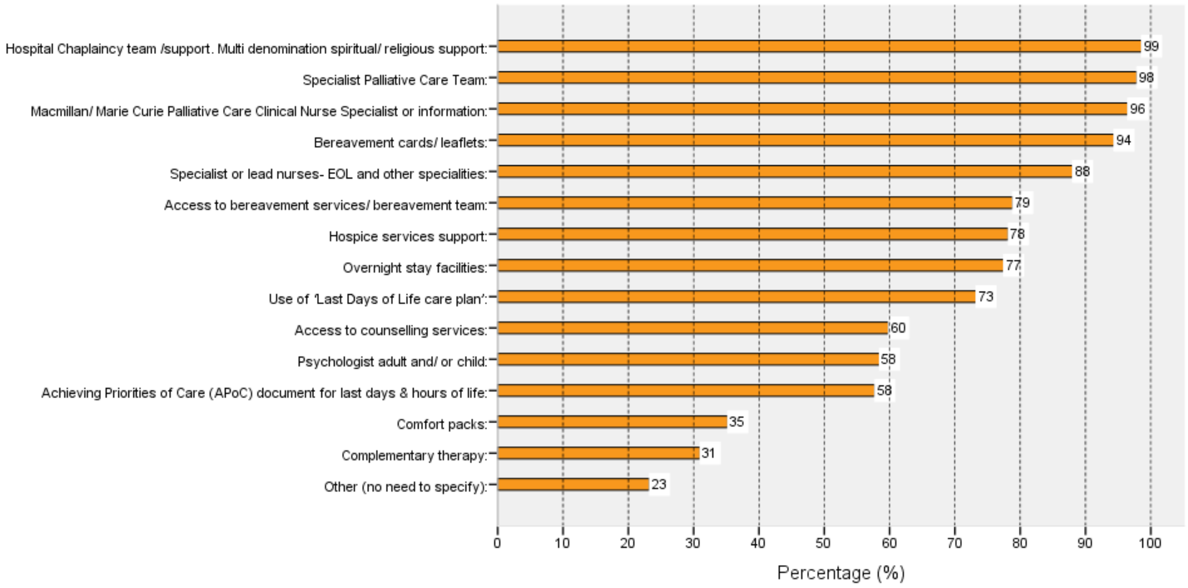
2013 audit: *Protocols for the prescription of medications for patients' symptoms at the end of life: pain 99%, agitation 99%, noisy breathing 99%, nausea and vomiting 99%, and dyspnoea 98%.*

Fig 17: Prevalence of trust-wide clinical provisions and protocols promoting patient comfort, dignity and privacy – up to, including and after the death of the patient (questions 7b-7j)



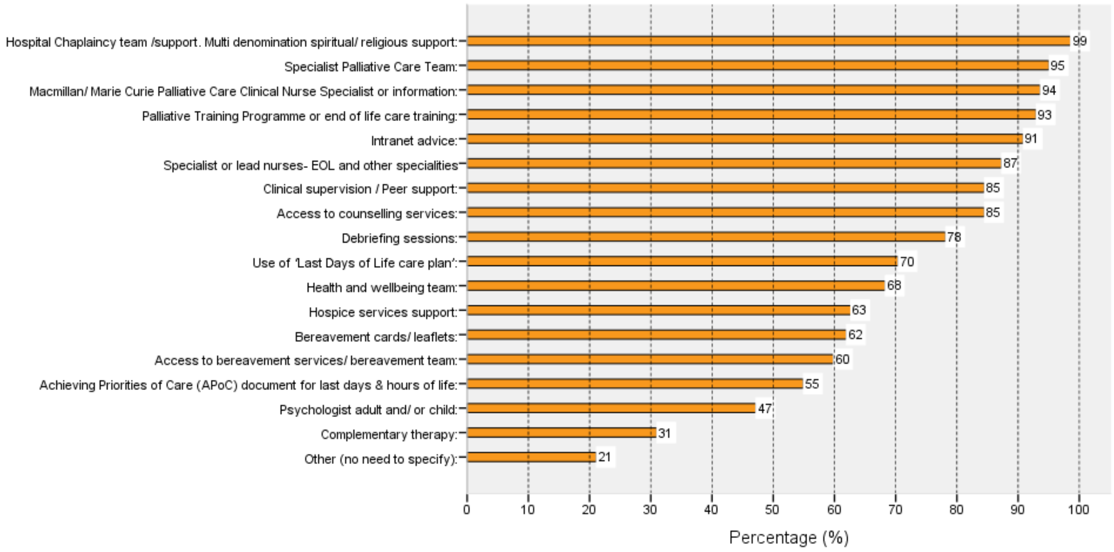
2013 audit: *clinical provision/protocols up to and including after the death of the patient: pastoral care/chaplaincy 70%, for decision and documentation of a DNACPR order 100%, for the deactivation of ICDs 75%, for carrying out care of the body in the immediate time after the death of a patient 96%, for providing relatives/friends regarding the verification and certification of the patient's death 85%, for viewing the body in the immediate time after the death of a patient 82%, designated formal quiet spaces available for relatives/friends 64% and designated religious/spiritual rooms 100%.*

Fig 18: Please state what support processes are available in the trust for people important to the dying patient (question 7k)



Note also that a question was asked about access to 'PALS volunteers / Patient Support Services / Patient Experience Team' and while this was intended to refer to access for people important to the dying patient, this question was inadvertently worded on the web tool as referring to staff and volunteers. Consequently, this was omitted from the analysis.

Fig 19: Please state what support processes are available in the trust to staff and volunteers (question 7k)



Section 8: Bereaved relatives' or friends' perspectives

Key findings

- Eighty per cent of trusts sought bereaved relatives' and friends' views using a variety of mechanisms between 1 April 2013 and 31 March 2015 (Table 65).
- Eighty-two per cent of trusts shared the results of bereavement surveys with the clinical team; 64% with the trust board; and 31% with the public.
- Sixty-seven per cent of trusts reported that they implemented a change to their service as a result of their assessment of bereaved relatives' or friends' perspectives.

Recommendation

- All trusts should seek bereaved relatives' views, and results should be fed back to the trust's board as well as the public.

Table 65

	National audit (n=142)	
8a. Did your trust seek bereaved relatives' or friends' views during the last 2 financial years (ie from 1 April 2013 to 31 March 2015)?		
YES	80%	114
8ai. If 'yes', did you use a questionnaire?		
YES	94%	107/114
8aii. If yes, what is the name of the questionnaire you used? (tick one option only)		
• CODE questionnaire / modified CODE	27%	29/107
• FAMCARE	19%	20/107
• In-house or locally developed questionnaire/survey	45%	48/107
• Questionnaire within *Guidance following bereavement*	8%	9/107
• VOICES bereavement questionnaire/survey	23%	25/107
• Other	12%	13/107
8b. Were the results shared with:		
• The clinical teams (medical/nursing)	82%	93/114
• The trust board	64%	73/114
• The public	31%	35/114

Note that 29% (31/107) of trusts used more than one questionnaire (26 used two questionnaires, 4 used three questionnaires, 1 used four questionnaires), while 31% (33/107) of trusts used only an in-house or locally developed questionnaire/survey.

2013 audit: *34% of trusts sought bereaved relatives'/friends' views during the 2 financial years 1 April 2011 to 31 March 2013. Of these, 82% used a specific questionnaire and 82% shared results with clinical teams.*

Of the trusts that had sought bereaved relatives' or friends' views during the last 2 financial years, 67% (76/114) had implemented change to their service as a result.

Summary of organisational audit results

Background information

In total, 98% (139/142) of trusts reported ‘locally developed programmes of work to support end of life care’. This probably represents the need for local initiatives after the use of the Liverpool Care Pathway ceased in 2014. Forty-six per cent (66/142) of trusts were involved in the Transforming End of Life Care in Acute Hospitals Programme. EPaCCs was used by 35% (50/142) of trusts, which has increased from the 21% reported for 2013. The ambition of the National Information Board is for national roll-out of EPaCCs by 100% of providers by 2020.

The 2013 audit recommended that all trusts should have a named member on the board who is responsible for end of life care, and 98% (139/142) of trusts have achieved this. It also recommended that trusts should have a lay member with responsibility for end of life care on their board. Only 49% (70/142) of trusts achieved this.

As of 1 May 2015, 59% (84/142) of trusts had one or more end of life care facilitators in place, compared with 55% on 1 May 2013.

Audit, evaluation and complaints procedures

A formal audit of care for patients in the last hours or days had been undertaken by 65% (92/142) of trusts between 1 April and 31 March 2015. In the 2013 audit, it was reported as 56% for the period 1 April 2012 to March 2013. In total, 76% (70/92) of trusts had fed back the audit results to their trust board, compared with 68% in the 2013 audit.

The uptake of a formal process for discussing and reporting on the five priorities of care was 66% (94/142).

In 83% (118/142) of trusts, end of life care was reported on at least annually at trust board level (ie between 1 April 2014 and 31 March 2015). In 71% (84/118) of these, there was carer and public representation within these discussions/reporting processes. In the 2013 audit, 58% of trusts reported on care of the dying at least annually at trust board level (ie between 1 April 2012 and 31 March 2013); and in 72% of these, there was patient and public representation.

As of 1 May 2015, 78% (111/142) of trusts had a mechanism for flagging complaints that related to end of life care. For organisations where there was an End of Life Care Strategy Group, only 68% (65/95) of these had complaints routinely reported to them. Having SPC beds did not appear to influence the trusts having a mechanism for reporting complaints about end of life care.

Trust bed composition and mortality rates as at 1 May 2015

The 142 participating trusts reported having a total of 102788 beds; the median (IQR) number of beds (excluding paediatrics and teenage and young adult unit beds) per trust was 684 (449-916). Participating trusts had a median of 22 single beds per 100 adult care beds.

Out of the 142 sites, 18 (13%) had their own specialist palliative care (SPC) bedded units. These contained a total of 278 SPC beds, representing 0.27% (278/102,788) of all the hospital beds.

Trusts reported a median of 206 deaths per 100 adult care beds in the whole financial year of 2014-2015, and a median of 16 deaths per 100 adult care beds during the national data collection period. Of these, a median of 14 deaths per 100 adult care beds met the audit inclusion/exclusion criteria.

Giving out supportive information

In total, 78% (111/142) of trusts stated that they gave leaflets to families and those important to dying patients about what to expect *before* death; this compared with 90% in the 2013 audit. Use of leaflets explaining local procedures after a patient had died was 97% (138/142).

Note that the Department for Work and Pensions (DWP) leaflet 1027 *What to do after a death in England and Wales* was withdrawn from use on 3 September 2015. Information can now be found on www.gov.uk ('What to do after someone dies') and it is likely that trusts will increasingly direct families to this resource, but printed leaflets will still be needed for specific populations.

Availability of trust-wide continuing education and training

In total, 96% (136/142) of trusts had a formal in-house continuing education programme on the subject of end of life care. There were variations between trusts in the provision of education programmes by different mechanisms and for different staff groups. Across the staff groups, there was a slight reduction (3-8%) in e-learning since the 2013 audit and an increase (5-11%) in education via induction programme. Twenty-two per cent (30/136) of trusts provided mandatory training sessions on end of life care to doctors, 29% (39/136) to registered nurses and 24% (32/136) to non-registered nurses. There were no significant differences in the provision of such training for these staff groups from the 2013 audit.

With respect to communication skills training specifically on care in the last days and hours of life, there was a small trend towards increased training since 2013, with 74% (101/136) of trusts offering this to registered nurses; 65% (89/136) to medical staff; 65% (88/136) to non-registered nurses and 51% (70/136) to allied health professionals from 1 April 2014 to 31 March 2015.

Trust-wide access to specialist palliative care support

Almost all (97%, 138/142) trusts had their own specialist palliative care service; 70% (100/142) also used a specialist palliative care service that is funded and based outside the trust.

For all 142 trusts, there was a mean of 0.31 SPC consultant WTE filled posts (for direct clinical care of hospital inpatients in SPC beds) per 1000 adult beds; and a mean of 0.71 clinical nurse specialist WTE filled posts per 1000 adult beds. When the sample was broken down according to the trusts that had their own SPC beds (18/142) and those that did not have SPC beds (124/142), the following picture emerged. Regarding SPC consultants, there was a mean of 1.26 WTE consultant posts in trusts with SPC beds, and a mean of 0.17 WTE consultant posts in those without SPC beds. Regarding SPC nurses, there was a mean of 1.31 WTE nurse posts in trusts with SPC beds, and a mean of 0.62 WTE nurse posts in those without SPC beds. The availability of SPC staff around the clock varied widely, but only a minority of trusts offered an out-of-hours or a 24/7 service. Specifically, combining doctor and/or nurse availability (ie considering when one or other was available) then 11% (16/142) of trusts offered a face-to-face 24/7 service, 49% (70/142) offered a better than Monday to Friday, 9am to 5pm service but not a 24/7 service, while 39% (56/142) offered only a Monday to Friday, 9am to 5pm service. Thirty-seven per cent (53/142) of sites had face-to-face access to a palliative care service Monday to Sunday, 9am to 5pm.

The 18 trusts that had an SPC bedded unit were more likely to have a higher level of out-of-hours doctor service for dying patients. Doctors more frequently offered an 'out of hours' telephone service than nurses.

In total, 18% (26/142) of trusts did not indicate any level of provision of face-to-face specialist palliative care by doctors at any time.

These findings should be considered in the context of the new NICE guideline for 'Clinical care of adults in the last days of life' (NG31, December 2015),[9] where recommendations are made about access to specialist level of help and advice for healthcare professionals working with dying people. In the section on 'Shared decision-making', the guidance states:

> *1.3.3 Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life. The named healthcare professional should give information about how they can be contacted and contact details for relevant out-of-hours services to the dying person and those important to them.*
>
> *1.3.9 Ensure that shared decision-making can be supported by experienced staff at all times. Seek further specialist advice if additional support is needed.*

Under the section 'Pharmacological interventions', the NICE guideline states:

> *1.5.9 Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.*

Although other 'experienced' hospital staff including senior consultants and ward sisters could fulfil some of these recommendations, there will clearly be an expectation in the future that around-the-clock access to specialist palliative care will have to be addressed by the majority of hospital trusts.

Trust-wide clinical provisions and protocols

In total, 99-100% of trusts stated that they had guidance on prescribing medications for each of the five key symptoms that can be present in patients in the last days/hours of life.

Most trusts had policies for ensuring patient comfort and dignity, for offering family and friends access to the body after death, and a prayer room. The areas that were not covered by >90% of trusts were: 77% (110/142) stated that they had a policy for referral to pastoral care / chaplaincy team; and 82% (117/142) stated that they had a policy for promoting dignity.

All trusts reported that they had a policy for recording DNACPR decisions, while 80% (113/142) had a policy for the deactivation of implantable cardioverter defibrillators (ICDs). Seventy-five per cent of trusts (106/142) reported that they had designated quiet spaces for relatives.

There was a wide variation between trusts on support services for people important to the dying patient, and for staff and volunteers. Areas in which support services for people important to the dying patient were reported by <70% of trusts were: access to counselling services; psychologist; achieving priorities of care document; comfort packs; and complementary therapies. Support services reported by <70% of trusts for staff and volunteers were: health and wellbeing team; hospice services support; bereavement cards/leaflets; access to bereavement services; achieving priorities of care document; psychologist; and complementary therapies.

Bereaved relatives' or friends' perspectives

In total, 80% (114/142) of trusts had a mechanism for seeking bereaved relatives' and friends' views between 1 April 2013 and 31 March 2015. In the 2013 audit, this figure had been 34%.

Ninety-four per cent (107/114) of trusts had used a questionnaire for this purpose: a variety of tools were used, with 45% (48/107) using their own in-house questionnaire.

Nationally available questionnaires were used by the majority of trusts (57%, 61/107). The tools used were: CODE (27%, 29/107); VOICES (23%, 25/107); and FAMCARE (19%, 20/107). In the previous audit, 82% of trusts had used a specific questionnaire.

In total, 82% (93/114) of trusts shared the results of bereavement surveys with the clinical team; 64% (73/114) with the trust board; and 31% (35/114) with the public. Sixty-seven per cent (76/114) of trusts reported that they had made a change to their service as a result of their assessment of bereaved relatives' or friends' perspectives.

Appendix I: References

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Appendix II: Glossary

Advance care planning: The process of discussing the type of care and treatment that a patient would or would not wish to receive in the event that they lose capacity, in order to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs; and it ideally also involves and meets the needs of those close to the patient.

Advance decision: A statement of a patient's wish to refuse a particular type of medical treatment or care if they become unable to make or communicate decisions for themselves. They are called advance decisions in England and Wales. If an advance refusal is valid and applicable to the person's current circumstances, it must be respected. It will be legally binding on those providing care in England and Wales provided that, if it relates to life-prolonging treatment, it satisfies the additional legal criteria.

Assisted ventilation: A machine that does the work of breathing for a patient, or assists a patient to breathe, when he or she is unable to do so independently.

Bereavement: The overall response to a loss, which includes the process of 'recovery' or healing from the loss.

Capacity: The ability to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate their wishes. Capacity always refers to a specific decision, as a person may have capacity for one decision but not for another.

Cardiopulmonary resuscitation (CPR): A procedure used when a patient's heart stops beating: it can involve compressions of the chest or electrical stimulation.

Clinically assisted hydration (CAH): This includes intravenous or subcutaneous infusion of fluids (use of a 'drip'). The fluids may be also given via a pre-existing tube in the nose (nasogastric) or directly in the stomach (percutaneous endoscopic gastrostomy – PEG). The term 'clinically assisted hydration' does not refer to help given to patients to drink, for example sips of water.

Clinically assisted nutrition (CAN): This includes nasogastric feeding and percutaneous endoscopic gastrostomy (PEG). In some cases if there is a pre-existing central venous line (for example in a critical care unit), feeding may be given intravenously. The term 'clinically assisted nutrition' does not refer to help given to patients to eat, for example spoon feeding.

Clinician: A health professional, such as a doctor or nurse, involved in clinical practice.

Cohen's kappa co-efficient: When two individuals attempt to code the same information, Cohen's kappa (often simply called kappa) can be used as a measure of agreement between the two individuals. Kappa adjusts for the amount of agreement that could be expected due to chance alone. Kappa lies between -1 and +1. A value of 1 implies perfect agreement and values less than 1 imply less than perfect agreement (perfect agreement is rare). Altman[16] suggests one possible interpretation of kappa.

- Poor agreement = less than 0.20
- Fair agreement = 0.20 to 0.39
- Moderate agreement = 0.40 to 0.59
- Good agreement = 0.60 to 0.79
- Very good agreement = 0.80 to 1.00

Dialysis: This includes haemodialysis and peritoneal dialysis, which are processes to remove waste products, maintain the balance of chemicals and fluid in the body, and supporting the kidneys when they are not working well.

DNACPR: Is an abbreviation of ‘do not attempt cardiopulmonary resuscitation’, which is a decision not to attempt CPR if a patient’s heart or breathing stops. The decision not to attempt cardiopulmonary resuscitation should be discussed with the patient (unless this would cause extreme distress) and with the family. The decision is signed and recorded in the patient’s notes and reviewed as required.

End of life: Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes those patients who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events. The term ‘approaching the end of life’ can also apply to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment and care may lead to their death. The term ‘last days of life’ is reserved for those who are very close to death, within hours or days.

Hydration: The process of providing water or fluid by mouth, tube, subcutaneously or intravenously.

Independent mental capacity adviser (IMCA): Neuberger recommendation 32 suggests that: ‘for each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity’.

Inter-auditor reliability: The second coding of a number of audit data collection forms by an independent auditor, to assess the level of agreement in coding. Reliability (agreement between auditors) is not the same as validity (accuracy of measure). However establishing good agreement between auditors is an important part of the process of validation, as valid data by definition will have to be reliable. (See Cohen’s kappa coefficient.)

Interquartile range (IQR): Where appropriate, the IQR is presented within the tables. It often gives a more useful indication of the range of scores for an outcome than a simple median or mean. Twenty-five per cent of cases score below the first stated value, 50% of cases have a score that lies between the two values, and 25% have a score that lies between the higher value and 100%. Comparing one’s own score against this IQR allows a judgement of how well a trust/hospital has performed in comparison with the others.

Legal proxy: A person with legal authority to make certain decisions on behalf of another adult. Legal proxies who can make healthcare decisions include: a person holding a lasting power of attorney (England and Wales) or a court appointed deputy (England and Wales).

Mean: The conventional way of expressing an average, made by adding up all the scores and dividing by the number of scores. If a sample is not uniformly distributed, eg if there are many outliers on one or other side of the median (see below) then the mean gives a distorted picture.

Median: An alternative way of expressing the average, found by arranging all the recorded values in order and then selecting the one in the middle. Exactly half of the sample will have values below that number and exactly half will be above it.

Nasogastric (NG): This refers to a tube that goes in through the nose and into the stomach, which is used for the administration of medication or for fluids or feeding when oral intake is not suitable.

Palliative care: Care towards the end of life that aims to provide relief from pain and other distressing symptoms, to integrate the psychological and spiritual aspects of the person’s care and to offer a support system that allows people to live as actively as possible until their death. The objective is to support patients to live as well as possible until they die and to die with dignity.

Percutaneous endoscopic gastrostomy (PEG): This is an endoscopic procedure in which a tube (PEG tube) is passed into a patient’s stomach through the abdominal wall, usually to provide feeding when oral intake is not adequate. This makes use of the natural digestive process of the gastrointestinal tract.

Symptom: An upsetting or distressing feeling a patient has that indicates a disorder or disease.

Specialist palliative care services: These are those services with palliative care as their core speciality and that are provided by an interdisciplinary team, under the direction of a consultant physician in palliative medicine.

Those important to the patient: Anyone nominated by the patient, close relatives, partners, close friends, paid or unpaid carers outside the healthcare team and independent advocates. In some circumstances, it may include attorneys for property and financial affairs, and other legal proxies.

Appendix III: Steering Group membership

Name	Title
Professor Sam Ahmedzai	Clinical Lead for the End of Life Care Audit – Dying in Hospital Emeritus Professor, the University of Sheffield
Dr Kevin Stewart	Clinical Director, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians (RCP)
Tony Bonser	Trustee for the National Council for Palliative Care (NCPC) Chair of the NCPC People in Partnership User Group Local (North Western) Champion for the Dying Matters Consortium Fundraiser and Spokesperson for Macmillan Cancer Support
Dr David Brooks	Immediate Past President of the Association of Palliative Medicine
Professor David Jones	Director, The Anscombe Bioethics Centre
Tom Gentry	Policy Adviser, Age UK
Derek Lowe	Medical Statistician, CEEU, RCP
Siôn Morris	Project Manager, CEEU, RCP
Janet Husk	Patient Safety and Quality Improvement Programme Manager, CEEU, RCP
Rhona Buckingham	Operations Director, CEEU, RCP
Linda Cuthbertson	Head of PR and Public Affairs, CEEU, RCP
Professor Bill Noble	Medical Director, Marie Curie Cancer Care
Dr Bee Wee	National Clinical Director for End of Life Care, NHS England
Dr Liz Sampson	Senior Clinical Lecturer, Marie Curie Palliative Care Research Unit, University College London
Ann Heaton	Patient and Carer Network, RCP
Suzie Daniels	Patient and Carer Network, RCP
Giselle Martin-Dominguez	End of Life Nutrition and Hydration group member, Royal College of Nursing Assistant Director – Quality, North London Hospice
Jocelyn Hinds	Data and Intelligence Manager, National Council for Palliative Care
Katie Lindsey	Programme Manager for the National End of Life Care Intelligence Network, NHS England
Dr Jackie Morris	Dignity Champion, British Geriatrics Society

Appendix IV: Data reliability summary statistics

For categorical data, the kappa statistic was used to measure agreement. Kappa values of 0.41 to 0.60 are said to indicate moderate agreement, values of 0.61-0.80 indicate good agreement while values of over 0.80 are very good. In practice any value of kappa much below 0.50 will indicate inadequate agreement. Often, agreement is an amalgamation of separate components. One component is the agreement between auditors as to whether or not they find the required information, and another is agreement in data when both auditors have found relevant information. Where possible, this distinction is made. The kappa statistic does not measure the nature of any disagreement between auditors and for this we need to inspect the raw data tables. Any future attempt to improve on the reliability of any audit item (ie when planning a repeat audit) will bear most fruit if it focuses on the more frequent discrepancies in judgement. For numerical data, the percentage with exact auditor agreement is reported, as is the quantification of the extent of disagreement between auditors.

The nesting of some questions that are conditional on the response to previous questions sometimes resulted in rather small denominators within the national audit proper, and consequently very small denominators in this re-audit sample. For such questions and also for rare findings (low prevalence) the confidence interval around the estimate of kappa is often wide or not computable. For rare findings, a low kappa value may appear paradoxical, as it does not reflect the high rate of overall agreement; for example in the vast majority of cases both auditors may agree on 'No' as a response with 'Yes' being a rare finding – a low kappa statistic in this instance would indicate inability of auditors to agree on the rare finding of 'Yes', or put in another way an inability to agree on distinguishing between 'Yes' and 'No'.

In summary, levels of agreement were found to be generally 'good' with 77% of computed kappa values over 0.60, 59% over 0.70 and 40% over 0.80. Of 235 kappa values computed, their median was 0.73, with an IQR of 0.62-0.88. Kappa value distribution by section of clinical audit proforma was as tabulated and depicted in Table B and Figure A below.

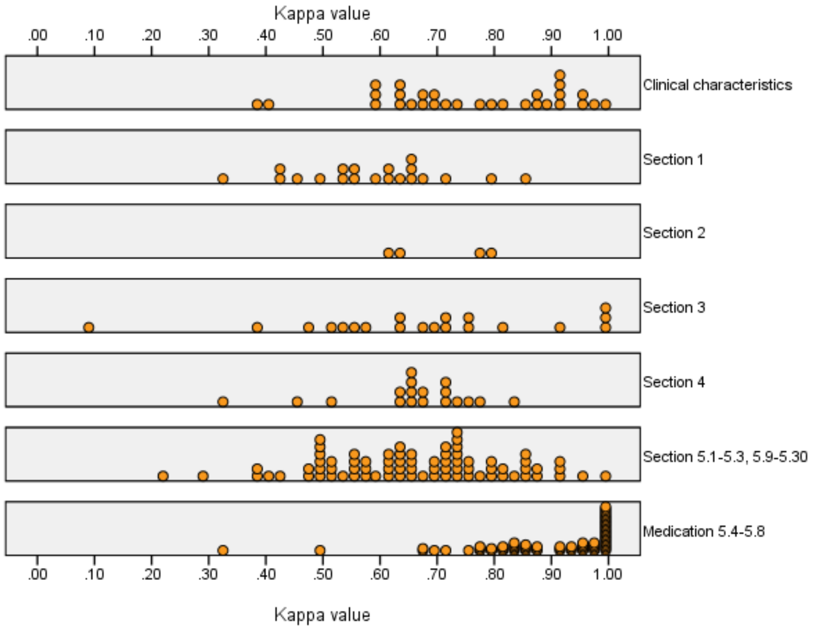
Agreement was strongest in regard to clinical/demographic characteristics and medication prescribing, and least strong within the section relating to the recognition of dying.

In hindsight, it would have been more informative to have asked for five re-audit cases, as has been usual for previous audits, instead of reducing this to three cases.

Table B: Kappa value distribution by section of clinical audit proforma

	Median (IQR) kappa value
Section 1: Clinical/demographic characteristics	0.76 (0.64-0.91), n=30
Section 2: Recognition of dying	0.60 (0.50-0.66), n=20
Section 3: Communication	0.71 (N/C), n=4
Section 4: Dying person and those important to them in decision making	0.69 (0.55-0.81), n=20
Section 5: Needs of families and other	0.67 (0.63-0.72), n=18
Section 6 (non-medication): Individual plan of care	0.66 (0.55-0.72), n=76
Section 6 (medication): Individual plan of care	0.95 (0.83-1.00), n=67

Fig A: Kappa value distribution by section of clinical audit proforma



Summary tables are presented below for categorical data (Table C), dates (Table D), numerical data (Table E) and drug dosage data (Table F), with the data items being organised as much as possible in the way they appeared in the audit proforma. Below these are the main body text of agreement tables and statistics, which provide further detail about the nature of agreement and disagreement.

Items are grouped according to the value of kappa statistic, with the 95% confidence interval (CI) in brackets. Items with kappa values below 0.50 are highlighted. Some CIs could not be computed and in such circumstance the term 'N/C' appears.

Table C: Categorical data

Kappa statistic	Data item: kappa value (95% CI)
K<0.00	• 1.2 Chaplain took part in discussion about recognition: -0.01 (N/C)
0.00≤ K<0.10	• 3.2i If yes to 3.2, was the advance care plan reviewed: 0.09 (0.00-0.61)
0.10≤ K<0.20	•
0.20≤ K<0.30	• 5.1.2I: If yes to 5.1I (pressure area care / relief needs), was care delivered to meet the individual patient requirements: 0.22 (0.00-0.49) • 5.2vi 'Other', In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.29 (0.19-0.39)
0.30≤ K<0.40	• 1.2 Pharmacist took part in discussion about recognition: 0.33 (0.25-0.82) • 1.3 Time of first documented recognition (hh:mm) recorded Yes/No: 0.39 (0.23-0.55) • 3.6 In the last 24 hours – agreement as to whether defibrillator was in place Yes/No: 0.39 (0.23-0.56) • 4.3iv PRACTICAL needs of the person(s) important to the patient – is there documented evidence within the last episode of care that they were addressed: 0.33 (0.01-0.65) • 5.1.2g: If yes to 5.1g (bladder/urinary needs), was care delivered to meet the individual patient requirements: 0.39 (0.07-0.70) • 5.14C Non-consultant career grade doctor made the decision for nil by mouth: 0.38 (0.00-0.93) • 5.8D19 Remifentanil prescribed in IV/PCA: 0.32 (0.00-0.91)
0.40≤ K<0.50	• Time of death (hh:mm) recorded Yes/No: 0.40 (0.00-0.94) • 1.2 Other doctors took part in discussion about recognition: 0.49 (0.40-0.58) • 1.2 'Others' took part in discussion about recognition: 0.46 (0.19-0.73) • 1.4 Is there documented evidence that the recognition that the patient who was dying was regularly reviewed: 0.42 (0.27-0.58) • 1.4a Review included i) The recognition that the patient was dying: 0.43 (0.14-0.72) • 3.8b Questions answered about concerns: 0.47 (0.19-0.75) • 4.3ii SPIRITUAL/RELIGIOUS needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were addressed: 0.45 (0.09-0.81) • 5.1I If yes to 5.1, does this include an assessment of pressure areas: 0.48 (0.28-0.68) • 5.1.2k: If yes to 5.1k (mouth care), was care delivered to meet the individual patient requirements: 0.48 (0.21-0.76) • 5.2iii Nausea/vomiting In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.41 (0.33-0.50) • 5.10 Is there documented evidence (from case notes or prescription charts including electronic systems) that any of the medications the patient received were reviewed in the last 24 hours of life: 0.49 (0.40-0.57) • 5.14A Consultant – palliative medicine made the decision for nil by mouth: 0.49 (0.00-0.99) • 5.24D 'Nothing recorded', If no to 5.24 were reasons documented as to why discussion did not take place: 0.49 (0.36-0.61) • 5.27ii If yes to 5.27 (team aware of individual plan of care), was this reviewed: 0.43 (0.29-0.58)
0.50≤ K<0.60	• Genitourinary comorbidity: 0.59 (0.47-0.71) • Length of stay known to nearest minute Yes/No: 0.59 (0.44-0.75) • Admission time (hh:mm) recorded Yes/No: 0.59 (0.42-0.76) • 1.2 Senior doctor (such as a consultant or GP) took part in discussion about recognition: 0.59 (0.49-0.68) • 1.2 Ward sister took part in discussion about recognition: 0.56 (0.42-0.69) • 1.2 Clinical nurse specialist took part in discussion about recognition: 0.56 (0.42-0.71) • 1.2 Dietician took part in discussion about recognition: 0.53 (0.22-0.83) • 1.2 Those important to the patient took part in discussion about recognition: 0.54 (0.45-0.63) • 3.7ai If yes to 3.7.a, is there documented evidence within the last episode of care of a discussion undertaken by a senior: 0.52 (0.24-0.80) • 3.7aia If 'No' to 3.7.a.i, reasons documented as to why discussion did not take place: 0.56 (0.39-0.82) • 3.7aii If yes to 3.7a, is there documented evidence that the continuation or withdrawal of assisted ventilation was discussed by a senior doctor with the nominated person(s) important to the patient during the last episode of care: 0.54 (0.22-0.87) • 3.9b If yes to 3.9, how often were there recorded discussions with the nominated person(s) important to the patient and a senior healthcare professional during the last 24 hours of care: 0.58 (0.52-0.64) • 4.3iii CULTURAL needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were addressed: 0.51 (0.04-0.99) • 5.1D If yes to 5.1, does this include an assessment of pain: 0.55 (0.39-0.70) • 5.1G If yes to 5.1, does this include an assessment of bladder function: 0.50 (0.35-0.65) • 5.1H If yes to 5.1, does this include an assessment of bowel function: 0.57 (0.46-0.69) • 5.1J If yes to 5.1, does this include an assessment of hygiene requirements: 0.50 (0.34-0.67) • 5.1.2h: If yes to 5.1h (bowel needs), was care delivered to meet the individual patient requirements: 0.52 (0.31-0.72) • 5.1.2j: If yes to 5.1j (hygiene needs), was care delivered to meet the individual patient requirements: 0.52 (0.21-0.83) • 5.2i Agitation/delirium In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.57 (0.49-0.64) • 5.2ii Dyspnoea / breathing difficulty In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.50 (0.42-0.58) • 5.2iv Pain In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.55 (0.48-0.63)

	• 5.2v Noisy breathing / death rattle In the last 24 hours, was there evidence documented that the symptoms the patient had were PRESENT: 0.53 (0.45-0.60) • 5.11 Was there a documented assessment of the patient's ability to drink in the last 24 hours of life: 0.52 (0.43-0.60) • 5.14F Junior (trainee) doctor made the decision for nil by mouth: 0.55 (0.09-0.99) • 5.15 Is there documented evidence that an assessment regarding the patient's need for clinically assisted (artificial) hydration (CAH) was made at any time between the time of the final admission and death: 0.56 (0.48-0.64) • 5.16i If no to 5.16, reasons documented as to why discussion regarding drinking and need for assisted forms of hydration did not take place: 0.59 (0.53-0.65) • 5.26i Were the spiritual/cultural/religious/practical needs of the patient, as identified from the discussion in question 5.26, met: 0.57 (0.40-0.75) • 5.4D19 Fentanyl prescribed prn (info obtained from free-text comment): 0.50 (0.00-0.99)
0.60≤ K <0.70	• Ethnicity known Yes/No: 0.64 (0.53-0.74) • Ethnicity group (if known) : 0.67 (0.53-0.81) • Number of comorbidities including other: 0.66 (0.61-0.72) • Number of comorbidities excluding other: 0.67 (0.61-0.72) • Malignancy comorbidity: 0.69 (0.57-0.81) • Musculoskeletal comorbidity: 0.63 (0.51-0.76) • 'Other' comorbidity: 0.63 (0.55-0.72) • 1.2 Staff nurse took part in discussion about recognition: 0.62 (0.54-0.70) • 1.2 Speech and language therapist took part in discussion about recognition: 0.66 (0.42-0.90) • 1.2 Physiotherapist took part in discussion about recognition: 0.63 (0.43-0.83) • 1.2 Occupational therapist took part in discussion about recognition: 0.66 (0.35-0.97) • 1.2 Social worker took part in discussion about recognition: 0.67 (0.05-0.99) • 1.2 Patient took part in discussion about recognition: 0.66 (0.55-0.76) • 1.4b Review included ii) That the patient was recovering: 0.61 (0.42-0.80) • 2.1i If no to 2.1, reasons as to why discussion did not take place: 0.62 (0.55-0.68) • If no to 2.2, reasons as to why discussion did not take place: 0.64 (0.48-0.82) • If no to 3.3, were any of the following reasons documented as to why discussion did not take place: 0.68 (0.61-0.74) • 3.5 At the time of the patient's death was there a cardiopulmonary resuscitation decision in place: 0.63 (0.46-0.81) • 3.8a: if 'No But' to 3.8, why so: 0.63 (0.53-0.73) • 4.2i PSYCHOLOGICAL needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were assessed: 0.63 (0.49-0.77) • 4.2iv PRACTICAL needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were assessed: 0.68 (0.48-0.89) • 4.3i PSYCHOLOGICAL needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were addressed: 0.66 (0.21-0.99) • 4.4 Is there documented evidence within the last episode of care of discussion regarding the patient's spiritual/religious/cultural/practical needs with the nominated person(s) important to the patient: 0.65 (0.59-0.72) • 4.5 Were those important to the patient notified of the patient's imminent death: 0.63 (0.54-0.71) • 4.5ii Was anyone else recorded as being with the patient at the time of death: 0.66 (0.58-0.74) • 4.6 Is there documented evidence of care and support of the patient's family and those important to them at the time of and immediately after death: 0.65 (0.58-0.72) • 4.6i Is there documented evidence that the family and those people that are important to the deceased were given any culturally appropriate verbal information following the death of the patient: 0.68 (0.61-0.75) • 5.1A If yes to 5.1, does this include an assessment of agitation/delirium: 0.68 (0.57-0.78) • 5.1B If yes to 5.1, does this include an assessment of dyspnoea / breathing difficulty: 0.66 (0.54-0.78) • 5.1F If yes to 5.1, does this include an assessment of anxiety/distress: 0.61 (0.50-0.72) • 5.1K If yes to 5.1, does this include an assessment of mouth care: 0.64 (0.52-0.76) • 5.2ii Dyspnoea / breathing difficulty In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.65 (0.55-0.76) • 5.2iv Pain In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.63 (0.49-0.77) • 5.12 Is there evidence that the patient was supported to drink in the last 24 hours of life: 0.66 (0.60-0.73) • 5.14M Dietician made the decision for nil by mouth: 0.64 (0.26-0.99) • 5.16 Is there documented evidence that a discussion regarding drinking and need for assisted forms of hydration was undertaken with the patient in the time between the final date of admission and of death: 0.64 (0.54-0.73) • 5.19 Was there a documented assessment of the patient's ability to eat in the last 24 hours of life: 0.63 (0.56-0.70) • 5.23i If no to 5.23, were any of the following reasons documented as to why discussion regarding eating and need for assisted forms of nutrition did not take place: 0.61 (0.54-0.67) • 5.24E Other, If no to 5.24 were reasons documented as to why discussion did not take place: 0.65 (0.51-0.79) • 5.27i If yes to 5.27, was this followed: 0.62 (0.40-0.85) • 5.29 Is there documented evidence of care of the patient immediately prior to or at the time of death: 0.61 (0.53-0.68) • 5.4D3 Clonazepam prescribed prn: 0.67 (0.05-0.99) • 5.4D18 Remifentanil prescribed prn: 0.67 (0.05-0.99) • 5.8D18 Propofol prescribed in IV/PCA: 0.69 (0.37-0.99)
0.70≤ K <0.80	• Religious affiliation known Yes/No: 0.71 (0.64-0.78) • Central nervous system comorbidity: 0.70 (0.59-0.81) • Endocrine comorbidity: 0.77 (0.70-0.85) • Sudden unexpected death: 0.74 (0.65-0.84) • 1.2 Member of the specialist palliative care team took part in discussion about recognition: 0.71 (0.62-0.79)

	• 2.1 Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with the patient: 0.78 (0.71-0.84) • 2.2 Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with a nominated person(s) important to the patient: 0.79 (0.71-0.87) • 3.1 Is there documented evidence that the patient had made an advance care plan prior to admission: 0.71 (0.56-0.86) • 3.4 Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior doctor was discussed with the nominated person(s) important to the patient during the last episode of care: 0.76 (0.69-0.83) • 3.6 In the last 24 hours, (where both auditors agreed defibrillator was in place) was deactivation of an implanted defibrillator recorded: 0.75 (0.31-0.99) • 3.8 Is there documented evidence that the patient was given an opportunity to have: (a) Concerns listened to: 0.70 (0.64-0.75) • 3.9 Is there documented evidence that the nominated person(s) important to the patient during the last episode of care was given regular opportunities to discuss the patient’s condition with a senior healthcare professional: 0.71 (0.62-0.79) • 4.1 Is there documented evidence that the needs of the person(s) important to the patient were asked about: 0.73 (0.67-0.79) • 4.1i If ‘Yes’ to 4.1, were any needs identified: 0.72 (0.62-0.82) • 4.1ia If ‘Yes’ to 4.1i, what was the outcome of identifying these needs: 0.71 (0.60-0.83) • 4.2ii SPIRITUAL/RELIGIOUS needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were assessed: 0.78 (0.68-0.89) • 4.2iii CULTURAL needs of the person(s) important to the patient is there documented evidence within the last episode of care that they were assessed: 0.71 (0.57-0.84) • 4.5i Were those important to the patient present at the time of the patient’s death: 0.76 (0.70-0.83) • 5.1 Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient’s needs regarding an individual plan of care: 0.73 (0.66-0.80) • 5.1C If yes to 5.1, does this include an assessment of nausea/vomiting: 0.74 (0.66-0.82) • 5.1E If yes to 5.1, does this include an assessment of noisy breathing / death rattle: 0.71 (0.63-0.80) • 5.2i Agitation/delirium In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.72 (0.61-0.83) • 5.2iii Nausea/vomiting In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.77 (0.64-0.90) • 5.2v Noisy breathing / death rattle In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.70 (0.58-0.82) • 5.13 Was the patient drinking in the last 24 hours of life: 0.74 (0.68-0.80) • 5.14 Was there a ‘nil by mouth’ order in place in the last 24 hours of life: 0.74 (0.66-0.83) • 5.14I Ward sister made the decision for nil by mouth: 0.79 (0.40-0.99) • 5.14R Was there a documented reason for the nil by mouth decision: 0.73 (0.38-0.99) • 5.17 Is there documented evidence that a discussion regarding hydration needs was undertaken with the nominated relative or friend or the nominated independent mental capacity advocate (IMCA), or LPA personal welfare at any time between the time of the final admission and death: 0.70 (0.63-0.76) • 5.17i If no to 5.17, reasons documented as to why discussion did not take place: 0.75 (0.63-0.87) • 5.20 Is there evidence that the patient was supported to eat in the last 24 hours of life: 0.72 (0.65-0.79) • 5.21 Was the patient eating in the last 24 hours of life: 0.75 (0.69-0.82) • 5.22 Is there documented evidence that an assessment regarding the patient’s need for clinically assisted (artificial) nutrition (CAN) was made at any time between the time of the final admission and death: 0.71 (0.64-0.77) • 5.23 Is there documented evidence that a discussion regarding eating and need for assisted forms of nutrition was undertaken with the patient in the time between the final date of admission and of death: 0.70 (0.61-0.79) • 5.24 Is there documented evidence that a discussion regarding nutrition needs was undertaken with the nominated relative or friend or the nominated independent mental capacity advocate (IMCA), or LPA personal welfare at any time between the time of the final admission and death: 0.74 (0.67-0.81) • 5.26 Is there documented evidence within the last episode of care of discussion regarding the patient’s spiritual/cultural/religious/practical needs with patients who were capable of participating in such discussions: 0.75 (0.70-0.81) • 5.27 Is there documented evidence that the team were aware of an individual plan of care for the person that is dying: 0.74 (0.68-0.80) • 5.30 Is there documented evidence of care of the patient immediately after death: 0.72 (0.65-0.78) • 5.4B Is there documented evidence (in case notes or in prescription chart) that anticipatory medication ‘prn’ was prescribed for dyspnoea / breathing difficulty in the last hours or days of life: 0.79 (0.73-0.85) • 5.4 Analgesics (painkillers) prescribed prn: 0.77 (0.67-0.87) • 5.5 In the last 24 hours of life, was the patient taking prescribed oral medications: 0.72 (0.66-0.79) • 5.6 In the last 24 hours of life, was the patient prescribed any transdermal medications (skin patches): 0.77 (0.64-0.90) • 5.7D9 Hyoscine hydrobromide prescribed in CSCI: 0.77 (0.60-0.95) • 5.8 In the last 24 hours of life is there documented evidence that a continuous intravenous infusion of medication was in place (includes patient controlled analgesia (PCA)): 0.76 (0.64-0.89)
0.80≤ K<0.90	• Religious affiliation group (if known): 0.87 (0.80-0.94) • Primary diagnosis group: 0.87 (0.83-0.91) • Cardiovascular comorbidity: 0.81 (0.75-0.86) • Respiratory comorbidity: 0.80 (0.73-0.87) • Place of death group: 0.86 (0.82-0.91) • Time of day of death: 0.89 (0.86-0.92) • 1.1 Is there documented evidence within the last episode of care that it was recognised that the patient would probably

	die in the coming hours or days: 0.86 (0.79-0.93) • 1.2 Healthcare assistant took part in discussion about recognition: 0.80 (0.57-0.99) • 3.3 Is there documented evidence that a discussion regarding cardiopulmonary resuscitation (CPR) was undertaken by a senior doctor with the patient that was relevant to the last episode of care: 0.82 (0.76-0.87) • 4.6ii Is there documented evidence that the family and those people that are important to the deceased were given any culturally appropriate written information, in the appropriate language, following the death of the patient: 0.84 (0.79-0.89) • 5.2vi Other In the last 24 hours, was there evidence documented that the symptoms the patient had were CONTROLLED: 0.80 (0.60-0.99) • 5.9 In the last 24 hours of life is there documented evidence that any rectal medication was prescribed: 0.85 (0.69-0.99) • 5.14B Consultant – other specialty made the decision for nil by mouth: 0.84 (0.70-0.97) • 5.14E Specialist registrar made the decision for nil by mouth: 0.88 (0.64-0.99) • 5.14J Staff nurse made the decision for nil by mouth: 0.81 (0.61-0.99) • 5.14L Speech and language therapist made the decision for nil by mouth: 0.81 (0.65-0.97) • 5.14OTHER 'Other' made the decision for nil by mouth: 0.85 (0.56-0.99) • 5.14Reason What was the reason for the nil by mouth decision: 0.85 (0.73-0.97) • 5.18 In the last 24 hours before the patient's death, was clinically assisted (artificial) hydration (CAH) in place: 0.80 (0.74-0.85) • 5.18i If yes to 5.18, what was the route: 0.88 (0.78-0.98) • 5.25 At the time of the patient's death was clinically assisted (artificial) nutrition (CAN) in place: 0.86 (0.76-0.95) • 5.4C Is there documented evidence (in case notes or in prescription chart) that anticipatory medication 'prn' was prescribed for nausea/vomiting in the last hours or days of life: 0.86 (0.81-0.91) • 5.4D Is there documented evidence (in case notes or in prescription chart) that anticipatory medication 'prn' was prescribed for pain in the last hours or days of life: 0.85 (0.79-0.91) • ANY OF 5.4A to 5.4E: 0.83 (0.76-0.90) • 5.4D4 Cyclizine prescribed prn: 0.87 (0.81-0.92) • 5.4D8 Hyoscine butylbromide prescribed prn: 0.85 (0.79-0.91) • 5.4D13 Metoclopromide prescribed prn: 0.80 (0.65-0.96) • 5.4D14 Midazolam prescribed prn: 0.84 (0.77-0.91) • 5.4D17 Oxycodone prescribed prn: 0.88 (0.82-0.95) • 5.4 Antiemetics (for nausea and vomiting) prescribed prn: 0.82 (0.74-0.89) • 5.4 Sedatives prescribed prn: 0.83 (0.76-0.91) • 5.4 Noise respiratory secretions ('death rattle') prescribed prn: 0.85 (0.79-0.91) • 5.7D8 Hyoscine butylbromide prescribed in CSCI: 0.83 (0.68-0.97) • 5.8D1 Alfentanil prescribed in IV/PCA: 0.83 (0.51-0.99) • 5.8D15 Midazolam prescribed in IV/PCA: 0.88 (0.64-0.99) • 5.8 Analgesics (painkillers) prescribed in IV/PCA: 0.81 (0.55-0.99) • 5.8 Sedatives prescribed in IV/PCA: 0.81 (0.56-0.99)
K ≥0.90	• Gender: 0.98 (0.97-0.99) • Age group: 0.99 (0.98-0.99) • Primary cancer diagnosis group: 0.91 (0.84-0.97) • Dementia comorbidity: 0.92 (0.87-0.97) • Day of admission: 0.91 (0.88-0.94) • Day of admission group: 0.95 (0.93-0.98) • Day of death: 0.96 (0.94-0.98) • Length of stay <24hr ≥24hr): 0.92 (0.85-0.99) • 3.2 If yes to 3.1, is there documented evidence that the team took into account the contents of the advance care plan when making decisions: 1.00 (N/C) • If no but (3.4) during the last episode of care, why?: 1.00 (N/C) • 3.7a In the last 24 hours, was the patient having assisted ventilation: 0.91 (0.84-0.97) • 3.9a If 'No but' (3.9) during the last episode of care, why so: 1.00 (N/C) • 5.3A Was the patient reviewed by a member of a specialist palliative care team: i) In this last admission: 0.96 (0.94-0.99) • 5.3B Was the patient reviewed by a member of a specialist palliative care team: ii) In the last 24 hours of the patient's life: 0.91 (0.86-0.95) • 5.14P Patient made the decision for nil by mouth: 1.00 (N/C) • 5.24A Attempts to contact them were unsuccessful, If no to 5.24 were reasons documented as to why discussion did not take place: 0.91 (0.73-0.99) • 5.25i If yes to 5.25 (CAN in place), what was the route: 0.92 (0.76-0.99) • 5.4A Is there documented evidence (in case notes or in prescription chart) that anticipatory medication 'prn' was prescribed for agitation/delirium in the last hours or days of life: 0.93 (0.89-0.96) • 5.4E Is there documented evidence (in case notes or in prescription chart) that anticipatory medication 'prn' was prescribed for noisy breathing / death rattle in the last hours or days of life: 0.94 (0.91-0.97) • 5.4D1 Alfentanil prescribed prn: 1.00 (N/C) • 5.4D5 Diamorphine prescribed prn: 0.96 (0.92-0.99) • 5.4D6 Glycopyrronium bromide prescribed prn: 0.94 (0.90-0.98) • 5.4D7 Haloperidol prescribed prn: 0.95 (0.92-0.99) • 5.4D9 Hyoscine hydrobromide prescribed prn: 0.91 (0.85-0.96) • 5.4D11 Levomepromazine prescribed prn: 0.91 (0.86-0.96) • 5.4D15 Morphine prescribed prn: 0.92 (0.88-0.96) • 5.6i If yes to 5.6 Buprenorphine transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Fentanyl transdermal medication administered: 1.00 (N/C)

	• 5.6i If yes to 5.6 Granisetron transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Hyoscine transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Rigotidine transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Analgesics (painkillers) transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Antiemetics (for nausea and vomiting) transdermal medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Noise respiratory secretions (‘death rattle’) medication administered: 1.00 (N/C) • 5.6i If yes to 5.6 Miscellaneous medication administered: 1.00 (N/C) • 5.7 In the last 24 hours of life is there documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place: 0.97 (0.94-0.99) • 5.7D1 Alfentanil prescribed in CSCI: 1.00 (N/C) • 5.7D3 Clonazepam prescribed in CSCI: 1.00 (N/C) • 5.7D4 Cyclizine prescribed in CSCI: 1.00 (N/C) • 5.7D5 Diamorphine prescribed in CSCI: 1.00 (N/C) • 5.7D6 Glycopyrronium bromide prescribed in CSCI: 0.97 (0.92-0.99) • 5.7D7 Haloperidol prescribed in CSCI: 1.00 (N/C) • 5.7D11 Levomepromazine prescribed in CSCI: 0.97 (0.92-0.99) • 5.7D12 Methadone prescribed in CSCI: 1.00 (N/C) • 5.7D13 Metoclopromide prescribed in CSCI: 1.00 (N/C) • 5.7D14 Midazolam prescribed in CSCI: 0.97 (0.92-0.99) • 5.7D15 Morphine prescribed in CSCI: 0.98 (0.96-0.99) • 5.7D16 Octreotide prescribed in CSCI: 1.00 (N/C) • 5.7D17 Oxycodone prescribed in CSCI: 1.00 (N/C) • 5.7 Analgesics (painkillers) prescribed in CSCI: 0.96 (0.87-0.99) • 5.7 Antiemetics (for nausea and vomiting) prescribed in CSCI: 0.97 (0.93-0.99) • 5.7 Sedatives prescribed in CSCI: 0.96 (0.90-0.99) • 5.7 Noise respiratory secretions (‘death rattle’) prescribed in CSCI: 1.00 (N/C) • 5.8D6 Glycopyrronium bromide prescribed in IV/PCA: 1.00 (N/C) • 5.8D14 Morphine prescribed in IV/PCA: 1.00 (N/C) • 5.8D20 Fentanyl prescribed in IV/PCA (info obtained from free-text comment): 1.00 (N/C) • 5.8 Noise respiratory secretions (‘death rattle’) prescribed in IV/PCA: 1.00 (N/C)
Kappa not computable	• 3.2ii If no to 3.2, was the reason it was not taken into account recorded • 3.7a11a If ‘No but’ to 3.7a.ii • 3.8bi If ‘No but’ (3.8b), why so • 5.14D Palliative medicine doctor – Other made the decision for nil by mouth • 5.14G CNS – palliative care nurse made the decision for nil by mouth • 5.14H CNS – other specialty made the decision for nil by mouth • 5.14K Healthcare assistant made the decision for nil by mouth • 5.14N Pharmacist made the decision for nil by mouth • 5.24B IMCA unavailable, If no to 5.24, were reasons documented as to why discussion did not take place • 5.24C LPA personal welfare, If no to 5.24, were reasons documented as to why discussion did not take place • 5.4D2 Apomorphine prescribed prn • 5.4D9 Hyoscine hydrobromide prescribed prn • 5.4D10 Ketamine prescribed prn • 5.4D12 Methadone prescribed prn • 5.4D16 Octreotide prescribed prn • 5.7D2 Apomorphine prescribed in CSCI • 5.7D10 Ketamine prescribed in CSCI • 5.7D18 Remifentanil prescribed in CSCI • 5.7D19 Fentanyl prescribed in CSCI (information obtained from free-text comment) • 5.7 Miscellaneous prescribed in CSCI • 5.8D2 Clonazepam prescribed in IV/PCA • 5.8D3 Cyclizine prescribed in IV/PCA • 5.8D4 Diamorphine prescribed in IV/PCA • 5.8D5 Granisetron prescribed in IV/PCA • 5.8D7 Haloperidol prescribed in IV/PCA • 5.8D8 Hyoscine Butylbromide prescribed in IV/PCA • 5.8D9 Hyoscine Hydrobromide in IV/PCA • 5.8D10 Ketamine prescribed in IV/PCA • 5.8D11 Levomepromazine prescribed in IV/PCA • 5.8D12 Methadone prescribed in IV/PCA • 5.8D13 Metoclopromide prescribed in IV/PCA • 5.8D16 Ondansetron prescribed in IV/PCA • 5.8D17 Oxycodone prescribed in IV/PCA • 5.8 Antiemetics (for nausea and vomiting) prescribed in IV/PCA

Table D: Dates

Denominators reflect both auditors knowing the date and time and, in the case of recognition, both auditors agreeing there was recognition.

	Exact agreement (to the minute)	Nature of disagreement
Date and time of admission (hh:mm)	71% (309/434)	17 (within 10 min), 13 (10-29 min), 11 (30-59 min), 12 (60-119 min), 27 (120-239 min), 27 (4-24 hrs), 18 (>24 hrs)
Date and time of death (hh:mm)	82% (379/464)	12 (within 10 min), 15 (10-29 min), 16 (30-59 min), 15 (60-119 min), 7 (120-239 min), 12 (4-24 hrs), 8 (>24 hrs)
Date and time of first documented recognition (hh:mm)	54% (225/350)	8 (within 10 min), 9 (10-29 min), 5 (30-59 min), 9 (60-119 min), 16 (120-239 min), 31 (4-24 hrs), 7 (>24-48 hrs), 20 (>48 hrs)
Time from admission to first documented recognition	53% (174/327)	33 (within 60 min), 12 (60-119 min), 22 (120-239 min), 35 (4-24 hrs), 23 (>24-48 hrs), 28 (>48 hrs)
Time from recognition to death	56% (193/347)	35 (within 60 min), 26 (60-119 min), 8 (120-239 min), 36 (4-24 hrs), 26 (>24-48 hrs), 23 (>48 hrs)
Length of stay from admission to discharge	62% (268/430)	60 (within 60 min), 17 (60-119 min), 28 (120-239 min), 33 (4-24 hrs), 4 (>24-48 hrs), 20 (>48 hrs)

Table E: Numerical data

	Exact agreement	Nature of disagreement
Age in years	95% (443/468)	21 (within one year), and 4 (more than one year – range 2-50).
Number of comorbidities excluding other	74% (347/468)	90 (one), 14 (two), 14 (three), 3 (four)
Number of comorbidities including other	75% (351/468)	89 (one), 16 (two), 9 (three), 3 (four)
If 'yes' to 3.9, how often were there recorded discussions with the nominated person(s) important to the patient and a senior healthcare professional during the last 24 hours of care?	66% (247/373)	75 (one), 30 (two), 17 (three to five), 4 (six to ten)
During the last 24 hours of the patient's life, how many times was it documented that the patient's condition was reviewed by a doctor or nurse?	51% (241/468)	63 (one), 45 (two), 61 (three to five), 38 (six to ten), 17 (eleven to nineteen), 3 (twenty or more)

Table F: Drug dosage data

Denominators reflect both auditors agreeing the drug was prescribed (or administered depending on the question) and that a dose was stated by both auditors.

	Exact agreement on dosage prescribed	Exact agreement on dosage administered
Prn dosage (5.4)		
Alfentanil (mcg)	86% (6/7)	100% (4/4)
Apomorphine (mcg)	-	-
Clonazepam (mcg)	100% (1/1)	100% (1/1)
Cyclizine (mg)	96% (97/101)	93% (13/14)
Diamorphine (mg)	79% (65/82)	75% (41/55)
Glycopyrronium bromide (mcg)	89% (103/116)	81% (42/52)
Haloperidol (mg)	89% (81/91)	82% (18/22)
Hyoscine butylbromide (mg)	96% (82/85)	91% (30/33)
Hyoscine hydrobromide (mg)	90% (56/62))	92% (23/25)
Ketamine (mg)	-	-
Levomepromazine (mg)	89% (72/81)	80% (12/15)
Methadone (mg)	-	-
Metoclopromide (mg)	100% (13/13)	100% (4/4)
Midazolam (mg)	91% (267/295)	83% (109/132)
Morphine (mg)	89% (174/196)	75% (79/105)
Octreotide (mcg)	-	-
Oxycodone (mg)	82% (40/49)	71% (24/34)
Remifentanil (mcg)	100% (1/1)	100% (1/1)
Transdermal medications dosage ADMINISTERED in last 24 hours (5.6)		
Buprenorphine (mcg)	X	100% (7/7)
Fentanyl (mcg)	X	100% (5/5)
Granisetron (mg)	X	-
Hyoscine (mg)	X	100% (2/2)
Lidocaine (mg)	X	100% (1/1)
Rigototine (mg)	X	100% (6/6)
In the CSCI in the last 24 hours prior to the patient's death (5.7)		
Alfentanil (mcg)	100% (11/11)	91% (10/11)
Apomorphine (mcg)	-	-
Clonazepam (mcg)	100% (2/2)	100% (2/2)
Cyclizine (mg)	100% (19/19)	89% (17/19)
Diamorphine (mg)	97% (29/30)	80% (24/30)
Glycopyrronium bromide (mcg)	91% (20/22)	85% (17/20)
Haloperidol (mg)	90% (9/10)	78% (7/9)
Hyoscine butylbromide (mg)	93% (13/14)	86% (12/14)
Hyoscine hydrobromide (mg)	100% (12/12)	92% (11/12)
Ketamine (mg)	-	-
Levomepromazine (mg)	90% (19/21)	75% (15/20)
Methadone (mg)	100% (1/1)	100% (1/1)
Metoclopromide (mg)	100% (9/9)	100% (7/7)
Midazolam (mg)	96% (81/84)	80% (64/80)
Morphine (mg)	98% (58/59)	89% (49/55)
Octreotide (mcg)	100% (1/1)	100% (1/1)
Oxycodone (mg)	94% (17/18)	94% (15/16)
Remifentanil (mcg)	-	-
In the IV/PCA in the last 24 hours prior to the patient's death (5.8)		
Alfentanil (mcg)	0% (0/1)	0% (0/1)
Clonazepam (mcg)	-	-
Cyclizine (mg)	-	-
Diamorphine (mg)	-	-
Granisetron (mgs)	-	-
Glycopyrronium bromide (mg)	100% (1/1)	100% (1/1)
Haloperidol (mg)	-	-
Hyoscine butylbromide (mg)	-	-
Hyoscine hydrobromide (mg)	-	-
Ketamine (mg)	-	-
Levomepromazine (mg)	-	-
Methadone (mg)	-	-
Metoclopromide (mg)	-	-
Midazolam (mg)	100% (4/4)	75% (3/4)
Morphine (mg)	75% (3/4)	50% (2/4)

Ondansetron (mg)	-	-
Oxycodone (mg)	-	-
Propofol (mg)	60% (3/5)	60% (3/5)
Remifentanil (mcg)	100% (1/1)	100% (1/1)

Appendix V: Participation / non-participation

Participating sites

(Please note that where sites have entered 10 cases or fewer, these results have been omitted from the Appendix VI table.)

Aintree University Hospitals NHS Foundation Trust
Airedale NHS Foundation Trust
Ashford and St Peter's Hospitals NHS Foundation Trust
Barking, Havering and Redbridge University Hospitals NHS Trust
Barnsley Hospital NHS Foundation Trust
Barts Health NHS Trust
Basildon and Thurrock University Hospitals NHS Foundation Trust
Bedford Hospital NHS Trust
Blackpool Teaching Hospitals NHS Foundation Trust
Bolton NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Brighton and Sussex University Hospitals NHS Trust
Buckinghamshire Healthcare NHS Trust
Burton Hospitals NHS Foundation Trust
Calderdale and Huddersfield NHS Foundation Trust
Cambridge University Hospitals NHS Foundation Trust
Central Manchester University Hospitals NHS Foundation Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Chesterfield Royal Hospital NHS Foundation Trust
City Hospitals Sunderland NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust
Countess of Chester Hospital NHS Foundation Trust
Croydon Health Services NHS Trust
Dartford and Gravesham NHS Trust
Derby Hospitals NHS Foundation Trust
Doncaster and Bassetlaw NHS Foundation Trust
Dorset County Hospital NHS Foundation Trust
Dudley Group of Hospitals NHS Foundation Trust
Ealing Hospital
East and North Hertfordshire NHS Trust
East Cheshire NHS Trust
East Kent Hospitals University NHS Foundation Trust
East Lancashire Hospitals NHS Trust
East Sussex Healthcare NHS Trust
Epsom and St Helier University Hospitals NHS Trust
Frimley Health NHS Foundation Trust
Gateshead Health NHS Foundation Trust
George Eliot Hospital NHS Trust
Gloucestershire Hospitals NHS Foundation Trust
Great Western Hospital (Community sites)
Great Western Hospitals NHS Foundation Trust
Guy’s and St Thomas’ NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust
Harefield
Harrogate & District NHS Foundation Trust

Heart of England NHS Foundation Trust
Hinchingbrooke Healthcare NHS Trust
Homerton University Hospital NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
Imperial College Healthcare NHS Trust
Ipswich Hospital NHS Trust
Noble Hospital, Isle of Man
Isle of Wight NHS Trust
James Paget University Hospitals NHS Foundation Trust
Kent Community Health NHS Foundation Trust
Kettering General Hospital NHS Foundation Trust
King’s College Hospital NHS Foundation Trust
Kingston Hospital NHS Trust
Lancashire Teaching Hospitals NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Lewisham and Greenwich NHS Trust
London North West Healthcare NHS Trust
Luton and Dunstable Hospital NHS Foundation Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Mid Cheshire Hospitals NHS Foundation Trust
Mid Essex Hospital Services NHS Trust
Mid Yorkshire Hospitals NHS Trust
Milton Keynes Hospital NHS Foundation Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
North Bristol NHS Trust
North Cumbria University Hospitals NHS Trust
North Middlesex University Hospital NHS Trust
North Tees and Hartlepool NHS Foundation Trust
Northampton General Hospital NHS Trust
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
Nottingham University Hospitals NHS Trust
Oxford University Hospitals NHS Trust
Pennine Acute Hospitals NHS Trust
Peterborough and Stamford Hospitals NHS Foundation Trust
Plymouth Hospitals NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Princess Alexandra Hospital NHS Trust
Royal Berkshire NHS Foundation Trust
Royal Brompton
Royal Devon & Exeter NHS Foundation Trust
Royal Free London NHS Foundation Trust
Royal Liverpool and Broadgreen University Hospital NHS Trust
Royal Surrey County Hospital NHS Foundation Trust
Royal United Hospitals Bath NHS Foundation Trust
Salford Royal NHS Foundation Trust
Salisbury NHS Foundation Trust
Sandwell and West Birmingham Hospitals NHS Trust

Sheffield Teaching Hospitals NHS Foundation Trust
Sherwood Forest Hospitals NHS Foundation Trust
Solent NHS Trust
South Tees Hospitals NHS Foundation Trust
South Tyneside NHS Foundation Trust
South Warwickshire NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
Southport and Ormskirk Hospital NHS Trust
St George’s University Hospitals NHS Foundation Trust
St Helens & Knowsley NHS Trust
Stockport NHS Foundation Trust
Surrey and Sussex NHS Trust
Tameside Hospital NHS Foundation Trust
Taunton and Somerset NHS Foundation Trust
The Christie NHS Foundation Trust
The Clatterbridge Cancer Centre NHS Foundation Trust
The Hillingdon Hospitals NHS Foundation Trust
The Newcastle upon Tyne Hospitals NHS Foundation Trust
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
The Rotherham NHS Foundation Trust
The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust
The Royal Marsden NHS Foundation Trust
The Royal Wolverhampton NHS Trust
The Shrewsbury and Telford Hospital NHS Trust
Torbay and South Devon Healthcare NHS Foundation Trust
United Lincolnshire Hospitals NHS Trust
University College London Hospitals NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
University Hospital of South Manchester NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
University Hospitals of Coventry and Warwickshire NHS Trust
University Hospitals of Leicester NHS Trust
University Hospitals of Morecambe Bay
University Hospitals of North Midlands – County Hospital Stafford
University Hospitals of North Midlands – Royal Stoke University Hospital
Walsall Healthcare NHS Trust
Warrington and Halton Hospitals NHS Foundation Trust
West Hertfordshire Hospitals NHS Trust
West Middlesex University Hospital NHS Trust
West Suffolk NHS Foundation Trust
Western Sussex Hospitals NHS Trust
Weston Area Health NHS Trust
Whittington Health NHS Trust
Wirral University Teaching Hospital NHS Foundation Trust
Worcestershire Acute Hospitals NHS Trust
Wrightington, Wigan and Leigh NHS Foundation Trust
Wye Valley NHS Trust
Yeovil District Hospital NHS Foundation Trust
York Teaching Hospital NHS Foundation Trust

Non-participating sites

County Durham and Darlington NHS Foundation Trust
North Devon Healthcare NHS Trust
Royal Cornwell Hospitals NHS Trust

Appendix VI: Site-level end of life care quality indicator data

(Please note that where sites have entered 10 cases or fewer, these results have been omitted from the following national table.)

	CLINICAL AUDIT						ORGANISATIONAL AUDIT							
INDICATOR		1	2	3	4	5	6	7	8A	8B	8C	8D	9	10
	Cases in clinical audit	Is there documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days? **%YES**	Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with a nominated person(s) important to the patient? **%YES**	Is there documented evidence that the patient was given an opportunity to have Concerns listened to? **%YES or NO BUT**	Is there documented evidence that the needs of the person(s) important to the patient were asked about? **%YES or NO BUT**	Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient's needs regarding an individual plan of care? **%YES**	Is there a lay member on the Trust board with a responsibility/role for End of Life Care?	Did your Trust seek bereaved relatives' or friends' views during the last two financial years (i.e. from 1st April 2013 to 31st March 2015)?	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Medical staff**	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Nursing (registered) staff**	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Nursing non-registered) staff**	Between 1st April 2014 and 31st March 2015 did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **Allied Health professional staff**	Access to **face-to-face** specialist palliative care for at least 9-5 Mon-Sun	Does your trust have 1 or more End of Life Care Facilitators as of 1st May 2015?
NATIONAL RESULT (% of cases for clinical audit, % of sites for organisational audit)	**9302**	**83%**	**79%**	**84%**	**56%**	**66%**	**49%**	**80%**	**63%**	**71%**	**62%**	**49%**	**37%**	**59%**
Aintree University Hospitals NHS Foundation Trust	71	96	92	93	52	80	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Airedale NHS Foundation Trust	36	83	81	86	58	83	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ashford and St Peter's Hospitals NHS Foundation Trust	79	78	77	90	59	59	Yes	Yes	No	No	No	No	Yes	No
Barking, Havering and Redbridge University Hospitals NHS Trust	80	85	85	89	64	93	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Barnsley Hospital NHS Foundation Trust	54	94	89	63	76	81	No	Yes	No	No	No	No	No	Yes
Barts Health NHS Trust	61	85	80	79	44	36	No	Yes	No	No	No	No	No	No
Basildon and Thurrock University Hospitals NHS Foundation Trust	80	76	75	86	43	54	No	Yes	Yes	Yes	Yes	Yes	Yes	No
Bedford Hospital NHS Trust	51	65	67	65	49	24	Yes	No	No	No	No	No	No	No
Blackpool Teaching Hospitals NHS Foundation Trust	80	88	88	91	89	89	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Bolton NHS Foundation Trust	79	86	85	86	56	10	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bradford Teaching Hospitals NHS Foundation Trust	78	82	77	68	38	37	Yes	Yes	Yes	Yes	No	No	No	Yes
Brighton and Sussex University Hospitals NHS Trust	95	85	60	76	54	32	No	No	No	No	No	No	No	Yes
Buckinghamshire Healthcare NHS Trust	58	81	83	91	67	84	Yes	Yes	No	No	No	No	Yes	No
Burton Hospitals NHS Foundation Trust	80	75	69	91	61	99	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Calderdale and Huddersfield NHS Foundation Trust	80	71	68	75	53	45	No	Yes	Yes	Yes	Yes	No	No	No
Cambridge University Hospitals NHS Foundation Trust	78	85	85	82	58	69	No	Yes	No	Yes	No	No	No	Yes
Central Manchester University Hospitals NHS Foundation Trust	80	81	80	94	88	75	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Chelsea and Westminster Hospital NHS Foundation Trust	25	88	84	88	60	80	Yes	Yes	Yes	No	No	No	Yes	No
Chesterfield Royal Hospital NHS Foundation Trust	72	75	72	76	19	97	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
City Hospitals Sunderland NHS Foundation Trust	62	73	74	90	50	50	No	No	No	No	No	No	No	Yes
Colchester Hospital University NHS Foundation Trust	79	81	72	78	38	73	Yes	Yes	No	No	No	No	Yes	Yes
Countess of Chester Hospital NHS Foundation Trust	77	71	71	69	40	9	No	Yes	No	No	No	No	No	No
Croydon Health Services NHS Trust	50	72	64	86	50	86	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Dartford and Gravesham NHS Trust	22	91	73	64	9	59	-	-	-	-	-	-	-	-
Derby Hospitals NHS Foundation Trust	80	81	76	89	45	80	Yes	Yes	Yes	No	No	No	Yes	Yes
Doncaster and Bassetlaw NHS Foundation Trust	80	73	81	84	71	74	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes

Dorset County Hospital NHS Foundation Trust	49	82	65	59	20	27	Yes	No	No	No	No	No	No	No
Dudley Group of Hospitals NHS Foundation Trust	80	84	81	96	59	80	Yes	Yes	No	Yes	Yes	Yes	No	No
Ealing Hospital	40	73	70	88	45	53	Yes	No	Yes	No	No	No	No	No
East and North Hertfordshire NHS Trust	50	78	80	90	80	76	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
East Cheshire NHS Trust	45	84	76	84	53	64	Yes	Yes	Yes	Yes	No	Yes	No	Yes
East Kent Hospitals University NHS Foundation Trust	80	80	76	60	29	50	Yes	Yes	Yes	Yes	Yes	No	Yes	No
East Lancashire Hospitals NHS Trust	80	85	79	95	63	25	Yes	Yes	No	Yes	Yes	No	Yes	Yes
East Sussex Healthcare NHS Trust	81	79	77	95	36	91	No	Yes	No	No	No	No	No	Yes
Epsom and St Helier University Hospitals NHS Trust	80	76	74	74	44	25	Yes	Yes	Yes	Yes	Yes	No	No	Yes
Frimley Health NHS Foundation Trust	80	80	78	88	76	73	No	Yes	Yes	Yes	Yes	No	Yes	Yes
Gateshead Health NHS Foundation Trust	77	82	82	81	71	88	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
George Eliot Hospital NHS Trust	52	75	73	85	58	52	No	Yes	Yes	Yes	No	No	No	Yes
Gloucestershire Hospitals NHS Foundation Trust	71	83	85	79	30	54	No	Yes	Yes	No	No	No	No	No
Great Western Hospitals NHS Foundation Trust	80	78	75	71	16	4	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Guy’s and St Thomas’ NHS Foundation Trust	80	84	80	94	86	79	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hampshire Hospitals NHS Foundation Trust	80	93	93	90	75	75	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Harefield	15	87	87	80	67	80	No	Yes	Yes	Yes	Yes	No	No	No
Harrogate & District NHS Foundation Trust	45	96	87	91	69	69	No	Yes	No	No	No	No	No	Yes
Heart of England NHS Foundation Trust	27	78	78	59	37	78	-	-	-	-	-	-	-	-
Hinchingbrooke Healthcare NHS Trust	31	90	90	94	39	58	No	No	No	Yes	Yes	Yes	No	No
Homerton University Hospital NHS Foundation Trust	34	91	85	88	74	44	Yes	Yes	No	No	No	No	No	No
Hull and East Yorkshire Hospitals NHS Trust	80	86	83	80	49	45	No	Yes	Yes	Yes	Yes	Yes	No	No

Imperial College Healthcare NHS Trust	80	88	83	94	81	81	Yes	No	No	No	No	No	No	No
Ipswich Hospital NHS Trust	79	80	77	63	18	29	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Noble Hospital, Isle of Man	27	78	78	100	89	89	No	No	Yes	Yes	Yes	Yes	No	No
Isle of Wight NHS Trust	24	92	88	42	46	92	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
James Paget University Hospitals NHS Foundation Trust	69	86	84	88	45	96	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Kettering General Hospital NHS Foundation Trust	80	75	71	73	41	41	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
King’s College Hospital NHS Foundation Trust	85	88	84	95	68	78	Yes	Yes	Yes	Yes	Yes	No	No	No
Kingston Hospital NHS Trust	44	86	84	100	70	93	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Lancashire Teaching Hospitals NHS Foundation Trust	80	83	78	86	55	58	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Leeds Teaching Hospitals NHS Trust	80	81	75	94	80	93	No	Yes	No	No	No	No	No	Yes
Lewisham and Greenwich NHS Trust	70	73	74	77	54	80	Yes	No	No	Yes	Yes	No	No	No
London North West Healthcare NHS Trust	45	71	71	76	11	20	Yes	Yes	Yes	Yes	Yes	No	No	No
Luton and Dunstable Hospital NHS Foundation Trust	67	78	84	76	64	67	No	Yes	Yes	Yes	Yes	Yes	Yes	No
Maidstone and Tunbridge Wells NHS Trust	44	64	64	70	45	48	No	No	Yes	Yes	Yes	Yes	No	Yes
Medway NHS Foundation Trust	80	85	83	93	61	60	No	Yes	No	No	No	No	No	Yes
Mid Cheshire Hospitals NHS Foundation Trust	73	89	82	88	62	73	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Mid Essex Hospital Services NHS Trust	78	91	87	81	47	42	Yes	No	Yes	No	No	No	Yes	Yes
Mid Yorkshire Hospitals NHS Trust	80	85	85	98	54	63	Yes	Yes	No	Yes	No	No	No	Yes
Milton Keynes Hospital NHS Foundation Trust	50	92	86	88	58	52	No	Yes	Yes	Yes	Yes	No	Yes	No
Norfolk and Norwich University Hospitals NHS Foundation Trust	81	88	80	83	48	72	No	Yes	Yes	Yes	Yes	Yes	No	Yes
North Bristol NHS Trust	52	79	77	98	58	71	No	No	Yes	Yes	No	No	No	Yes
North Cumbria University Hospitals NHS Trust	79	85	82	77	35	44	Yes	No	Yes	Yes	Yes	Yes	No	No

North Middlesex University Hospital NHS Trust	63	76	71	89	16	40	Yes	No	Yes	No	No	No	No	No
North Tees and Hartlepool NHS Foundation Trust	80	70	74	73	60	70	Yes	Yes	Yes	Yes	No	Yes	No	Yes
Northampton General Hospital NHS Trust	80	70	65	84	46	50	Yes	No	No	Yes	Yes	No	No	Yes
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	77	82	79	79	34	83	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Northumbria Healthcare NHS Foundation Trust	58	93	90	91	60	59	Yes	Yes	No	Yes	Yes	No	Yes	No
Nottingham University Hospitals NHS Trust	80	88	84	91	78	84	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Oxford University Hospitals NHS Trust	81	78	75	73	41	89	No	Yes	No	No	No	No	No	No
Pennine Acute Hospitals NHS Trust	78	81	82	81	36	60	No	Yes	Yes	No	No	No	No	Yes
Peterborough and Stamford Hospitals NHS Foundation Trust	80	85	83	86	68	66	No	Yes	No	No	No	No	Yes	No
Plymouth Hospitals NHS Trust	78	85	85	81	28	35	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Poole Hospital NHS Foundation Trust	66	86	85	94	91	88	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Portsmouth Hospitals NHS Trust	80	85	81	90	64	69	No	Yes	Yes	Yes	Yes	Yes	Yes	No
Princess Alexandra Hospital NHS Trust	58	78	72	84	53	67	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Royal Berkshire NHS Foundation Trust	84	86	82	96	90	92	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Royal Devon & Exeter NHS Foundation Trust	79	89	89	85	51	68	No	No	Yes	Yes	Yes	No	No	Yes
Royal Free London NHS Foundation Trust	79	86	76	76	62	90	No	Yes	Yes	Yes	No	No	No	No
Royal Liverpool and Broadgreen University Hospital NHS Trust	69	77	77	91	86	68	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Royal Surrey County Hospital NHS Foundation Trust	60	92	90	85	63	63	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Royal United Hospitals Bath NHS Foundation Trust	80	81	81	94	78	86	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Salford Royal NHS Foundation Trust	80	88	83	99	79	96	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Salisbury NHS Foundation Trust	42	83	86	81	40	76	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Sandwell and West Birmingham Hospitals NHS Trust	80	98	93	96	85	94	No	Yes	Yes	Yes	Yes	No	Yes	Yes

Sheffield Teaching Hospitals NHS Foundation Trust	80	86	80	74	30	24	No	Yes	No	No	No	No	Yes	Yes
Sherwood Forest Hospitals NHS Foundation Trust	81	85	84	91	69	95	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
South Tees Hospitals NHS Foundation Trust	79	91	89	95	87	81	Yes	Yes	No	No	No	No	No	No
South Tyneside NHS Foundation Trust	53	75	75	87	75	26	No	Yes	No	No	No	No	No	Yes
South Warwickshire NHS Foundation Trust	46	89	89	87	70	43	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Southend University Hospital NHS Foundation Trust	80	85	78	83	46	65	Yes	Yes	No	Yes	Yes	Yes	No	No
Southport and Ormskirk Hospital NHS Trust	34	82	79	97	68	50	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
St George's University Hospitals NHS Foundation Trust	35	86	83	89	94	63	No	Yes	Yes	Yes	No	No	Yes	No
St Helens & Knowsley NHS Trust	67	88	84	82	76	72	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Stockport NHS Foundation Trust	80	78	76	100	88	90	Yes	Yes	No	No	No	No	Yes	Yes
Surrey and Sussex NHS Trust	79	80	76	73	34	48	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Tameside Hospital NHS Foundation Trust	66	67	64	100	68	92	Yes	Yes	No	Yes	Yes	No	Yes	Yes
Taunton and Somerset NHS Foundation Trust	80	83	83	76	43	33	No	Yes	No	No	No	No	No	No
The Christie NHS Foundation Trust	22	100	100	100	95	91	Yes	No	Yes	Yes	Yes	Yes	Yes	No
The Clatterbridge Cancer Centre NHS Foundation Trust	19	95	95	95	95	100	No	Yes	No	Yes	No	No	Yes	Yes
The Hillingdon Hospitals NHS Foundation Trust	59	98	95	97	69	36	No	Yes	No	Yes	Yes	Yes	No	No
The Newcastle upon Tyne Hospitals NHS Foundation Trust	80	90	88	99	93	100	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	60	77	72	95	72	88	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
The Rotherham NHS Foundation Trust	80	83	78	94	65	58	No	No	Yes	Yes	No	No	Yes	No
The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust	80	88	80	83	51	84	No	Yes	No	Yes	No	No	No	Yes
The Royal Marsden NHS Foundation Trust	17	100	94	88	76	100	No	Yes	Yes	Yes	Yes	Yes	Yes	No
The Royal Wolverhampton NHS Trust	80	71	69	99	85	96	Yes	Yes	Yes	Yes	Yes	Yes	No	No

The Shrewsbury and Telford Hospital NHS Trust	81	78	70	65	30	56	No	No	No	No	No	No	No	Yes
Torbay and South Devon Healthcare NHS Foundation Trust	80	95	93	98	80	96	Yes	Yes	No	No	No	No	No	No
United Lincolnshire Hospitals NHS Trust	80	76	70	89	35	84	No	No	No	No	No	No	No	No
University College London Hospitals NHS Foundation Trust	36	97	97	97	81	94	Yes	No	Yes	Yes	Yes	No	Yes	Yes
University Hospital Birmingham NHS Foundation Trust	76	86	88	97	82	86	No	Yes	Yes	Yes	Yes	Yes	No	Yes
University Hospital of South Manchester NHS Foundation Trust	80	89	84	96	79	96	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
University Hospital Southampton NHS Foundation Trust	75	81	80	85	63	76	Yes	No	Yes	Yes	No	No	Yes	Yes
University Hospitals Bristol NHS Foundation Trust	61	75	80	97	64	85	No	Yes	No	No	Yes	No	No	No
University Hospitals of Coventry and Warwickshire NHS Trust	81	73	69	68	58	42	Yes	Yes	No	No	No	No	No	Yes
University Hospitals of Leicester NHS Trust	80	74	68	58	35	19	No	Yes	No	No	No	No	Yes	Yes
University Hospitals of Morecambe Bay	79	89	86	78	49	61	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
University Hospitals of North Midlands – County Hospital Stafford	15	80	67	53	47	80	Yes	No	Yes	Yes	Yes	Yes	No	No
University Hospitals of North Midlands – Royal Stoke University Hospital	51	80	71	53	51	86	Yes	No	Yes	Yes	Yes	Yes	No	No
Walsall Healthcare NHS Trust	71	86	79	86	45	86	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Warrington and Halton Hospitals NHS Foundation Trust	71	76	75	90	73	80	No	Yes	No	No	No	No	Yes	Yes
West Hertfordshire Hospitals NHS Trust	81	91	86	83	36	27	No	Yes	Yes	Yes	Yes	No	Yes	No
West Middlesex University Hospital NHS Trust	30	70	73	73	57	73	Yes	No	Yes	Yes	Yes	Yes	No	No
West Suffolk NHS Foundation Trust	68	87	87	85	68	51	Yes	No	Yes	Yes	Yes	Yes	No	Yes
Western Sussex Hospitals NHS Trust	79	84	75	84	38	59	Yes	Yes	No	No	No	No	No	No
Weston Area Health NHS Trust	54	85	89	63	19	33	No	Yes	No	Yes	Yes	No	No	No
Whittington Health NHS Trust	18	94	94	94	28	94	No	No	No	No	No	No	No	No
Wirral University Teaching Hospital NHS Foundation Trust	80	81	83	76	30	91	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Worcestershire Acute Hospitals NHS Trust	84	83	80	92	48	60	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wrightington, Wigan and Leigh NHS Foundation Trust	63	65	65	41	35	32	No	Yes	No	No	No	No	Yes	Yes
Wye Valley NHS Trust	46	96	87	89	30	93	No	Yes	Yes	Yes	Yes	Yes	No	No
Yeovil District Hospital NHS Foundation Trust	52	79	75	92	60	81	No	Yes	No	No	No	No	No	Yes
York Teaching Hospital NHS Foundation Trust	80	80	76	70	50	55	Yes	Yes	No	Yes	Yes	No	No	Yes

End of Life Care Audit – Dying in Hospital

National report for England 2016

Royal College
of Physicians