Royal College of Physicians

Marie Curie Cancer Care

National care of the dying audit for hospitals, England

National report

May 2014

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Foreword

We only have one chance to get end of life care right and sadly sometimes we don't. There are few surprises in the *National care of the dying audit for hospitals (NCDAH) England* report. It reflects many of the issues identified by the Neuberger Review, as well as what needs to be done to improve the quality of hospital care for dying people and their families.

For the first time the report includes the views of over 800 bereaved carers. This provides further insights into relatives' own views about how well hospital staff respond to the physical, emotional and spiritual needs of people in their final days of life, their families, carers and those close to them.

The audit underlines the importance of gathering robust data to enable a regular assessment of the organisational and clinical performance of hospitals against accepted national standards and policies. As the major funder of the audit, Marie Curie is now calling on NHS England to secure continued funding for this important work.

The challenges are broad but the recommendations are clear. We need everyone involved to take decisive action to ensure dying people and their families get the care and support they need and deserve.

I would like to thank the Royal College of Physicians (RCP) and the Marie Curie Palliative Care Institute Liverpool (MCPCIL) for their work in preparing this report.

Dr Jane Collins
Marie Curie Cancer Care

People are tending to live longer, often with a number of potentially life-shortening or debilitating conditions, and despite a move for people to die in the place of their choice a large proportion will continue to die in hospital for the foreseeable future. This report is a timely examination of the current situation with regard to the care people receive in our hospitals and a powerful support for many of the recommendations in the report of the Liverpool Care Pathway Independent Review Panel. It is clear in identifying key areas for improvement whilst recognising the considerable amount of highly effective care that exists already and from which all can learn. In particular, the report's calls for appropriate mandatory training for all staff who care for patients at the end of their lives and for the availability of 7-day face-to-face specialist palliative care teams are to be welcomed, and will provide the basis of sound end of life care.

The report also highlights the need for better communication with patients and relatives, accountability at board level for the quality of end of life care and improved decision making, documentation and communication. At a time when the new NHS Constitution supports patient-centred care and there is an acknowledgement of the need to restore a greater degree of control to both patients and carers, this report represents a major contribution to the drive to achieve the highest standards of end of life care in English hospitals.

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Fundraiser for Macmillan Cancer Support
North Western Champion for the Dying Matters Coalition
Member of the Neuberger Review Panel

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We would also like to thank the Steering Group (see appendix V) for their valuable support and advice throughout the project and Marie Curie Cancer Care and Public Health England for funding this work.

Copies of this executive summary, the full national report and the key performance indicator (KPI) results by site are available from the Royal College of Physicians website at: www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals

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Executive summary

The aim of this report is to contribute to learning that can help to improve the care for dying patients and those close to them in hospital settings.

Background

Around half of all deaths in England occur in hospitals.[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]

The 2013/14 audit represented a departure from previous audits which had been based on the goals of care within the Liverpool Care Pathway for the Dying Patient (LCP). Whilst the standards of care in this audit continued to be based on relevant national policy[2–9] it involved a case note review of a sample of all patients dying in hospital, regardless of whether they were supported by a framework of care in the last hours or days of life. The audit questions were also informed by the 44 recommendations of the Independent Review of the Liverpool Care Pathway undertaken by Neuberger and colleagues in 2013.[10]

This audit comprised the following three sections.

- An organisational audit – key organisational elements that underpin the delivery of care.
- A case note review – a consecutive, anonymised case note review of the all patients who died (excluding sudden unexpected deaths) within participating sites[*] within a defined timeframe.
- An optional local survey of the views of bereaved relatives or friends – using a validated self-completion questionnaire (CODE)[11] to assess care delivery in the last days of life.

Methods

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

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

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[*] 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.

Sample

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

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

Key findings

Organisational element key findings

- Only 21% of sites had access to face-to-face palliative care services 7 days per week, despite a longstanding national recommendation that this be provided; most (73%) provided face-to-face services on weekdays only.
- Mandatory training in care of the dying was only required for doctors in 19% of trusts and for nurses in 28%, despite national recommendations that this be provided. 82% of trusts had provided some form of training in care of the dying in the previous year; 18% had not provided any.
- 53% of trusts had a named board member with responsibility for care of the dying; 47% did not. In 42% of trusts care of the dying had not been discussed formally at trust board in the previous year and only 56% of trusts had conducted a formal audit of such care, despite previous recommendations that this be carried out at least annually.
- Only 47% of trusts reported having a formal structured process in place to capture the views of bereaved relatives or friends prior to this audit.

Case note review element key findings

- Most patients (87%) had documented recognition that they were in the last hours or days of life, but discussion with patients was only documented in 46% of those thought capable of participating in such discussions. Communication with families and friends was recorded in 93% of cases. These discussions occurred on average 31 hours prior to death.
- There was documentation of discussions about spiritual needs in only 21% of patients thought capable of participating in such discussions. In only 25% of cases was it documented that relatives/carers were asked about their own needs.
- In keeping with national guidance, most patients (63-81%) had medication prescribed ’as required’ for the 5 key symptoms which may develop at the end of life. In the last 24 hours of life, 44% received medication for pain and 17% for dyspnoea. 28% had a continuous subcutaneous infusion of medication via a syringe driver.
- An assessment of the need for clinically assisted (artificial) hydration (CAH) was recorded for 59% of patients, but discussions with the patient were recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 36% of cases. CAH was in place in 29% of patients at the time of their death.
- An assessment of the need for clinically assisted (artificial) nutrition (CAN) was recorded for 45% of patients, but discussions with the patient recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 29% of cases. CAN was in place in 7% of patients at the time of their death.

- In keeping with national guidance, most patients (82%) were assessed five or more times in the final 24 hours of life.

Local survey of bereaved relatives' views key findings

- 76% of those completing the questionnaire reported being very or fairly involved in decisions about care and treatment of their family member; 24% did not feel they were involved in decisions at all.
- Only 39% of bereaved relatives reported being involved in discussions about whether or not there was a need for CAH in the last 2 days of the patient's life. For those for whom the question was applicable, 55% would have found such a discussion helpful.
- 63% reported that the overall level of emotional support given to them by the healthcare team was good or excellent. 37% thought it only fair or poor.
- Overall, 76% felt adequately supported during the patient's last 2 days of life; 24% did not.
- Based on their experience, 68% were either likely or extremely likely to recommend their trust to family and friends. 8% were extremely unlikely to do so.

Key recommendations

- Hospitals should provide a face-to-face specialist palliative care service from at least 9am to 5pm, 7 days per week, to support the care of dying patients and their families, carers or advocates.
- Education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training, and skills for supporting families and those close to dying patients.
- All hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually.
- All trusts should have a designated board member and a lay member with specific responsibility for care of the dying. Trust boards should formally receive and discuss the report of local audit at least annually.
- The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient's care. This should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.
- Pain control and other symptoms in dying patients should be assessed at least 4- hourly and medication given promptly if necessary. Interventions should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.
- Decisions about the use of CAN and CAH are complex and should be taken by a senior experienced clinician supported by a multidisciplinary team. They should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.
- Hospitals should have an adequately staffed and accessible pastoral care team to ensure that the spiritual needs of dying patients and those close to them are met.

Future directions

- Education and training for care of the dying should be made a priority by Health Education England.
- Continuous quality improvement for care of the dying should be promoted and monitored by the Care Quality Commission (CQC).
- Future research into the key issues raised by the audit including recognition of dying, hydration and nutrition, symptom control, and communication should be supported by the National Institute for Health Research (NIHR) to enhance the evidence base.
- NHS England and the Healthcare Quality Improvement Partnership (HQIP) should promote and support future national clinical audits to ensure continued improvement in the care of dying patients.

Introduction

Background

National policy context

> *Too many patients will experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from healthcare professionals during the final stages of an illness. This can have a lasting effect on carers and those close to the patient, who often carry the burden of care. The care of all dying patients must improve to the level of the best*.[12]

The Department of Health (DH) Cancer Plan[12] helped to focus much needed attention on the care provided for dying patients, with the ultimate aim that care provision and delivery should 'improve to the level of the best'. Between the years 2004–2007 the government announced the release of £12million to support healthcare professionals in delivering high-quality care to dying patients and their families, and supported the implementation of three initiatives aimed at promoting best practice in caring for dying patients: the Liverpool Care Pathway for the Dying Patient (LCP); the Gold Standards Framework (GSF) and the Preferred Place of Care document (PPC),[13] which has now been restructured as the 'Preferred Priorities for Care'.[14]

The *End of life care strategy*[2] set out key objectives for healthcare providers to further improve the care delivered to dying patients. Out of this came the 'quality markers' document,[3] which has provided key targets and quality indicators that can be used by organisations to monitor themselves in terms of the structures, policies and procedures in place to enhance the care for dying patients, and their families. Similarly, the CQC has outlined their focus for monitoring quality for the care of dying patients in *The Essential Standards of Quality and Safety* document.[7] Furthermore, the National Institute for Clinical Excellence (NICE) has developed quality standards for end of life care.[4] Measures of such standards are also reflected in current DH policies (eg NHS Constitution;[9] NHS Outcomes Framework;[8] The Mandate).[5]

Overarching this framework of improvement in end of life care delivery, the government has outlined the Quality, Improvement, Productivity and Prevention (QIPP) agenda,[15] which has challenged end of life care services to improve the quality of care while maximising the impact of resources. The End of Life Care Programme 'The Route to Success'[16] has advocated the adoption of recognised tools that have already been developed, such as the Liverpool Care Pathway for the Dying Patient (LCP), as a start to address this agenda for the care of patients in the last hours or days of life.

In July 2013 the report of the Independent Review[10] into the LCP was published. The review report acknowledged that whilst the LCP when implemented properly can improve care for dying patients, there are still too many examples of poor care of such patients in the hospital setting. The review made a total of 44 recommendations including phasing the LCP out over the next 6–12 months and replacing it with individual care plans. The recommendations also included the need for further research and improved education and training for healthcare professionals, including regarding hydration, nutrition and sedation in the last hours or days of life and improving communication with patients and families at this challenging time. The review recommendations were mapped against the draft clinical and organisational audit questions to ensure that information pertaining to the findings and recommendations is reflected within this audit.

National care of the dying audit for hospitals, England

Gaining robust, objective data on which to base plans for improvement remains a challenge in palliative care where many examples exist to illustrate the difficulties of successfully implementing robust research methods such as randomised controlled trials.[17–20] Conducting this type of research into patient outcomes in the last hours or days of life represents an even greater challenge. One way of evaluating the level of care provided for patients in the dying phase is to engage in a national audit programme, against which future provision of care can be measured. This process allows clinical teams and the executive trust board, to engage in critical reflection on current clinical practice regarding care of the dying, by measuring themselves against a 'national benchmark' of care for the dying including the last hours or days of life.

The DH 'quality markers' for end of life care[3] have included the submission of data into local and national audits of care of the dying as one of the top 10 markers of quality for organisations caring for dying patients. Participation in the audit will support hospital trusts in this, by giving them the opportunity to report back nationally relevant data regarding care delivered to patients in the dying phase, to their trust boards, and position themselves against the 'national benchmark'. This supports hospital trusts to spotlight areas for improvement, because 'we can only be sure to improve what we can actually measure'.[2] This audit represents a departure from previous audits which have been based on the goals of care within the LCP.

Aims of the audit

The aim of the audit was to contribute to learning that can help to improve the care for dying patients and their relatives or carers in hospital settings.

The standards of care evaluated in the audit were based on the End of Life Care Strategy [2] and reflect recent National Policy guidance, including: Best care for the dying patient;[21] NHS Constitution;[9] NHS Outcomes Framework;[8] The Mandate;[5] National Institute for Health and Clinical Excellence (NICE) Quality Standards;[4] The Care Quality Commission (CQC) Essential Standards of Quality and Safety;[7] End of Life Care Quality Markers;[3] and Guidance for Doctors.[6]

Participation in the audit ensured that ALL eligible NHS acute hospital trusts could participate regardless of the model of care used to support patients in the last hours or days of life.

Audit governance

Delivery and performance of the audit was accountable to Public Health England and Marie Curie Cancer Care. It was managed by the RCP in collaboration with the Marie Curie Palliative Care Institute Liverpool and supported by a multidisciplinary and multi-agency 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 director provided clinical leadership (Appendix V).

Registration

Promotional materials 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. Registration invitation letters were also sent out along with details of the formal registration process for participation. It was then the responsibility of each trust to register their participation. For the case note review and local survey of bereaved relatives views, 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. Participating trusts that wished to make use of the Care of the Dying Evaluation (CODE) questionnaires[11] to ascertain bereaved relatives or friends' perspectives were responsible for ensuring that the conduct of this element complied with their relevant trust quality governance framework.

Sites registered their participation by inputting managerial, clinical, administration and audit representative postal address/ email/ telephone details into a web-based registration data entry tool. A memorandum of understanding was also signed by the chief executive and uploaded into the electronic registration tool for each trust. A username and password to access the web-based data entry tool was automatically generated following registration and was emailed to nominated personnel within each site.

Method

A retrospective audit of organisational and clinical elements of care in the dying phase, and a local survey of bereaved relatives' views, were undertaken in the acute hospital setting.

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 their relatives or friends. This information enabled the assessment of trust performance against key national standards and to contextualise the findings from the case note review.

Case note review

This clinical element was based upon a set of case note review questions which were devised to reflect the best care for the dying patient by consultation with members of the multidisciplinary audit steering group. The case note review entailed a consecutive, anonymised clinical case note audit of all deaths between 1–31 May 2013 (excluding acute, sudden unexpected deaths) regarding care provided to patients and their relatives or carers in the last 'episode of hospital care'. Sites with fewer than 50 cases for May were requested to continue to include consecutive cases from June and July 2013 until they had at least 50 audit cases or had reached 31 July 2013 with fewer than 50 cases, if that was the maximum number of eligible cases available. Sites with 50 or more audit cases from

May 2013 were able to continue to include cases from June and July 2013 if they wished in order to provide themselves with a more robust local sample for benchmarking against national statistics.

Cases were identified for inclusion in the audit using a two-step approach:

Step one: The site quality governance/information team created a list of eligible adult patients aged 18 years or above (at time of death), who died in the acute hospital trust and had been under the care of the hospital trust for ≥ 24 hours prior to death. Deaths in the accident and emergency department, death as a result of an accident/ untoward incident, deaths where suicide was suspected, deaths where overdose (including accidental) was suspected and deaths with unknown cause were excluded.

Step two: Further *exclusion* criteria were applied to all cases containing the following ICD–10 codes, clinically coded in any position within the finished consultant episodes (FCE's) of the last episode of care: acute myocardial infarction – I21, I22; pulmonary embolism – I26; pulmonary aneurysm – I281; sudden cardiac death – I461; aortic aneurysm – I71; injury, poisoning, other consequences of external causes – S00-T98; external causes – V01–Y98.

Local survey of bereaved relatives' views

The local survey of bereaved relatives' views provided an opportunity for trusts to seek perceptions of the delivery of care provided to a consecutive sample of patients in the last 'episode of hospital care' whose death was certified between 1 May 2013 and 30 June 2013 (excluding acute, sudden unexpected deaths), if they did not have existing mechanisms to do so. This data collection period coincided with the first 2 months of the data collection period stipulated for the clinical case note audit.

These views were captured via the use of an anonymised bereaved relative or friend survey, ie the care of the dying evaluation (CODE) questionnaire.[11] Next of kin were invited by sites to complete and return a CODE questionnaire. To avert undue confusion and/or distress to bereaved relatives it was agreed by the steering group that all cases where a complaint was pending should not be sent a CODE questionnaire, given that these views were already being captured and responded to by trusts.

CODE[11] is a 40-item self-completion questionnaire, used with bereaved relatives or friends to assess the quality of care and the level of support provided to individuals and their families in the last days and hours of life. The NHS friends and family test[22] was also included as an additional question within this questionnaire.

CODE[11] represents a shortened and more user-friendly version of the original instrument, 'evaluating care and health outcomes – for the dying' (ECHO-D). [23] ECHO-D[23] has been used with over 700 bereaved relatives within a hospice and hospital setting and has been shown to be valid, reliable and sensitive in detecting inequalities in care and areas of unmet need.[24, 11] Both these instruments are unique from other post-bereavement questionnaires as they specifically link with the key components representing best practice for 'care of the dying' ie the last days of life.[25]

Tools

A web-based data collection tool was designed to capture data pertaining to each audit element (ie organisation, case note review and local survey of bereaved relatives' views). For the local survey of bereaved relatives' views element, this web-based data entry tool also had the facility for bereaved relatives and/or sites to input responses from their completed CODE questionnaires.

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; submit the organisational and case note review data; and make use of the CODE[11] questionnaire process should they wish to do so. 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. A helpline was made available during the data submission period to answer any queries.

Data entry for the organisational audit was between 1 October 2013 and 30 November 2013. Participating trusts were responsible for completing the 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 case note review data entry period was also between 1 October 2013 and 30 November 2013. 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 from either any specific end of life model of care or directly from information held within the patient case notes.

Sites were also requested to provide two independent ratings of the first five patient data sets for the internal inter-auditor reliability study. The second ratings were entered separately via a separate username and password to distinguish them from the original ratings.

Data entry for the local survey of bereaved relatives' views was between 1 October 2013 and 31 January 2014. Unique identifiers were applied to each record by the site and input into the electronic web based data entry tool. The unique identifier input for each record were applied automatically to each CODE[11] questionnaire and printed by the site via the web-based tool. Sites were then responsible for the distribution of these CODE[11] questionnaires, and associated covering letters, to the bereaved relative or friend who was identified as the patient's next of kin contact. By allocating each questionnaire a unique number, it allowed sites to send out reminders to non-responders. To ensure a minimum 3-month period of elapsed time from the death of a patient, sites had to distribute CODE[11] questionnaires to the bereaved relatives or friends in October 2013. Further, it was recommended that one reminder letter be sent to bereaved relatives by participating trusts no later than Friday 22 November 2013, to avoid the Christmas season. Bereaved relatives or friends were able to either complete the CODE[11] questionnaires online or return the hard copy directly to the site for subsequent data entry and reporting purposes.

Confidentiality

Organisational audit and case note review

All data was completely anonymised prior to submission via the web based data entry tool. Sites were allocated a unique identifier for their organisation and, for the patient level data, asked to assign consecutive numbers to the audit forms for each patient in the sample. Audit coordinators accessed the web-based data entry tool via a unique username and password. They were instructed not to pass on their username and password to any unauthorised personnel, nor leave their computer unattended whilst still logged into the web based data entry tool. The web based data entry tool was accessed via a secure https website to ensure that any data submitted was encrypted, and all data submitted was stored on a secure server.

Local survey of bereaved relatives' views

The CODE[11] questionnaire comprises questions with possible response options and offers one opportunity to add additional comments. In the event that free text comments were supplied by a bereaved relative or friend, such comments should have been notated by the relevant participating site for subsequent action in line with their existing quality governance framework. These written comments, therefore, did not form part of the data analysis or reporting.

Participating sites were responsible for the confidential storage and subsequent destruction of the paper-based CODE[11] questionnaires, in line with their existing data protection policies and procedures. Letters to accompany the CODE[11] questionnaire explaining the way in which the data was managed, used and held were developed by the sites, though example templates were provided within the web-based data entry tool.

The national aggregate sample made available to the audit team for analysis was further anonymised to exclude responder and site level identifiers from the dataset of individual responses. The audit team were however aware of which sites used CODE[11] questionnaires and which did not to enable comparison of the two groups of sites in respect of other characteristics (ie organisational /case note review data – appendix III).

Web server

The RCP are the data controllers 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.[26]

Back up of information held on 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 (RCP, 2013).

All data made available for analysis was 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

This audit has been led by the RCP in collaboration with the Marie Curie Palliative Care Institute Liverpool and supported by Public Health England and Marie Curie Cancer Care.

The audit concurs with the definition stipulated by the National Research Ethics Service (NRES), and as such, ethical approval was not required.[27] Participating sites that chose to make use of the CODE[11] questionnaire to ascertain bereaved relatives' or friends' perspectives were responsible for ensuring that the process was compliant with their relevant site quality governance framework.

Data analysis

Organisational audit

Data has been analysed using descriptive statistics and summarised in tabular format to illustrate the national picture of the provision for care delivery for patients in the dying phase. This data also provides useful contextual data with which to interpret the case note review findings. Sites will see their own data benchmarked against national data in associated site level reports. Key performance indicators (KPIs) have been developed to reflect salient elements of provision and care delivery in the dying phase.

Case note review

National data has been analysed using tables of descriptive statistics:

- median and inter quartile ranges (IQR) where appropriate
- percentages relating to each of the question response options within the case note review.

Clinical KPIs have been developed to reflect salient elements of provision and care delivery in the dying phase. Again, sites will see results from their own sample benchmarked against national results in associated site level reports. Between site variations relating to each KPI have also been reported in appendix VII. This has been presented in the form of scatter plots, which take into account variations in sample size, and illustrate site variation to enable sites to interpret their own results.

Local survey of bereaved relatives' views

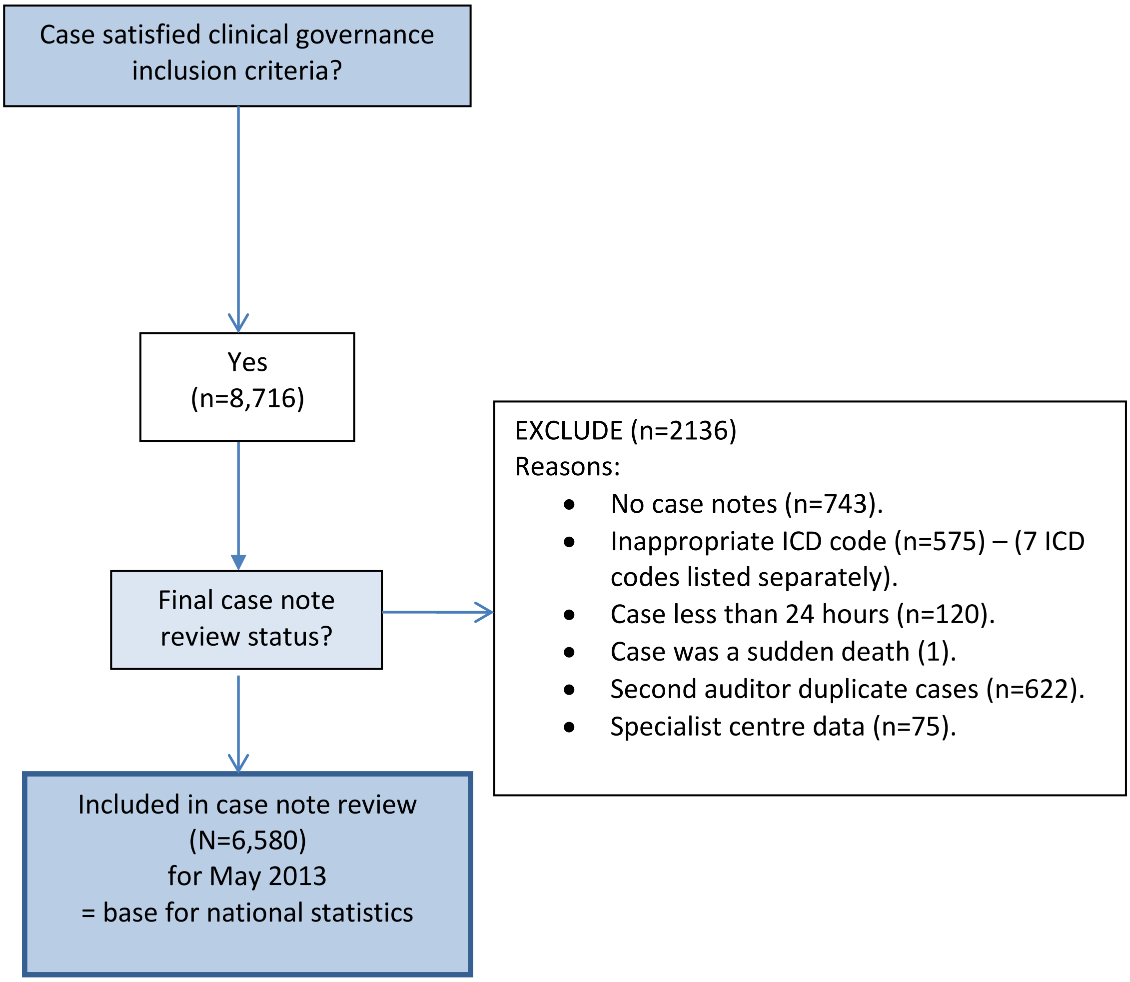
Site level data are only accessible to individual sites in the form of a local report generated by the web-based tool. The dataset, anonymised at patient and site level, has also been aggregated to enable a national perspective. Data have been analysed using descriptive statistics (ie number and proportions) for each of the questions and key outcome measures.

Flowcharts

The case note review and local survey of bereaved relatives' views process flowcharts help to explain the process of case ascertainment and the main denominators for analysis including exclusions. Two CONSORT type flowcharts are shown below, one for the main May 2013 national sample analyses and one for all CODE questionnaire analyses.

(National) case note review data for May 2013

Figure 1

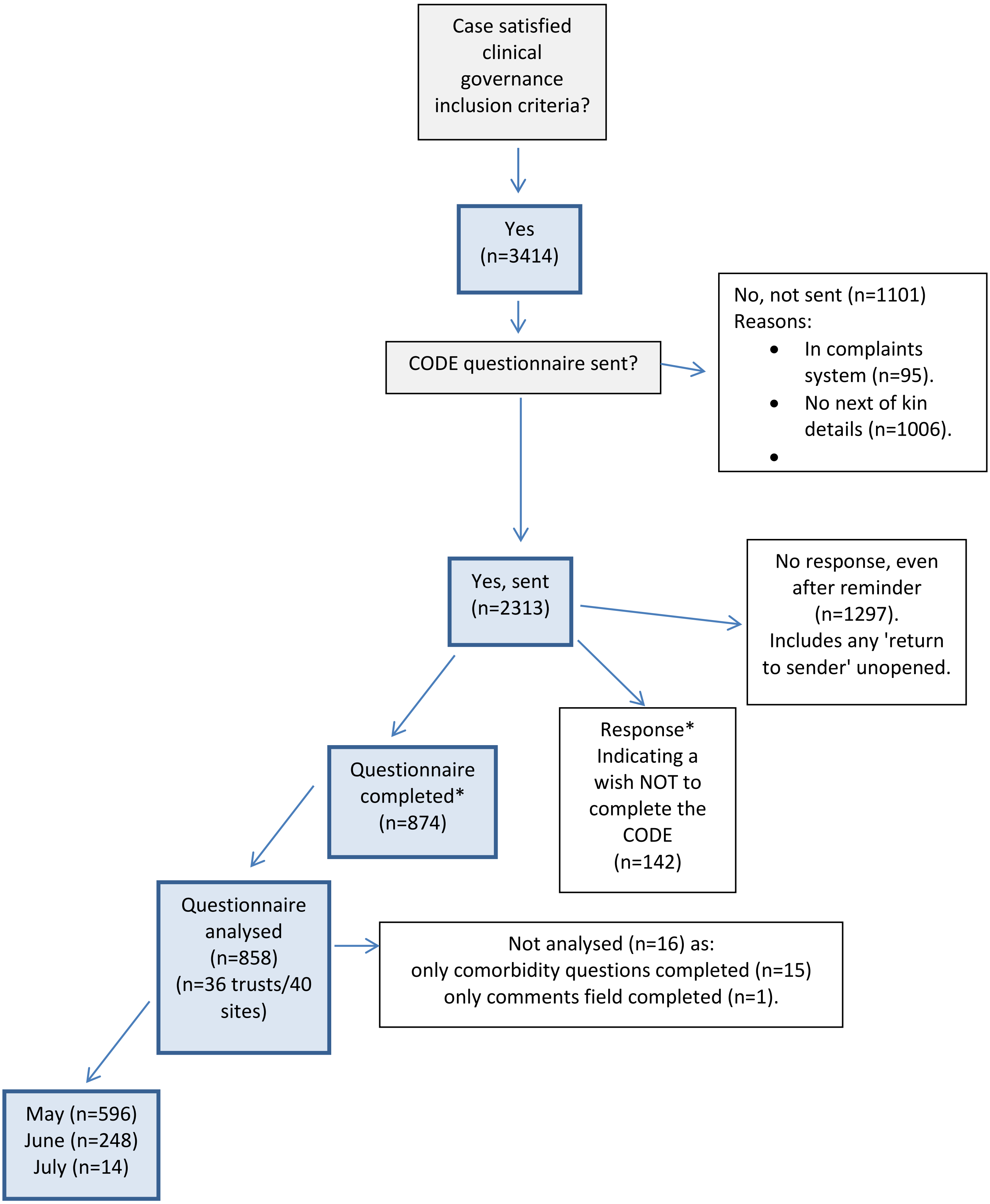


Note: Some sites collected data into June 2013 – and for a smaller number of sites, into July 2013 – for their own benchmark set of results.

The flow chart above, showing the number of cases considered to the number of cases audited, is only available for May 2013.

(National) analysis of code survey questionnaire: 1 May–31 July 2013

Figure 2



*NOTE: The breakdown of online and paper responses is not available.

Main national analysis for patients May 2013

All deaths, (excluding acute, sudden unexpected deaths), within participating sites between 1–31 May 2013 form the denominator for the main national statistics for the case note review. Local case note review results have been benchmarked against the national statistics for May. As a check on seasonality issues the results for May were compared to June/July 2013 in 60 sites with at least 10% of their cases from June/July. There were no notable differences in respect of KPI standards achievement or for any of the individual questions that make up the KPIs. This indicates that national results for May 2013 provide a meaningful benchmark for all audit sites (appendix II).

The CODE[11] results have been analysed in their totality (May and July 2013) at the national level only; sites can obtain their own local CODE report from the web tool. Sites using CODE and sites not using CODE have been compared in other characteristics (ie organisational /case note review KPI data – appendix III).

Key performance indicators (KPI)

The individual audit questions within both the organisational and case note review elements of the audit were derived from current national policy and guidelines. These organisational and case note review questions were then successfully field tested within a small number of registered trusts to promote clarity and validity. The final organisational and case note review questions were ratified by the steering group in August 2013.

Salient questions from each section of the organisational audit element and from each domain of the case note review audit element were identified and incorporated into relevant KPIs for that section/domain. Details of each KPI in terms of question composition, scoring and summary cut off scores were discussed and ratified by the steering group in February 2014. These KPIs will hence forth be referred to as organisational and clinical KPIs within this report, respectively.

Reliability

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. Participating sites were asked to re-audit five cases using a different auditor. Reliability analyses were performed on 641 pairs, these being submitted by 136 sites with 12 sites submitting one to three pairs, 22 submitting four pairs, 95 submitting five pairs and seven submitting six to ten pairs. The total number of pairs analysed differs slightly from the number of duplicate pairs indicated elsewhere in the main report due to differences in the hierarchy used for excluding cases.

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 whilst values of over 0.80 are very good. In practice any value of kappa much below 0.50 will indicate inadequate agreement. The levels of agreement were generally ‘good’ to ‘very good’ with almost all kappa values over 0.60. About two-thirds were over 0.70 and about one in five were over 0.80. Only four were below 0.50 and these were regarding who took part in the multidisciplinary team (MDT) decision (physiotherapists, other personnel) or non-MDT decision (specialist nurses, other personnel) that a patient was expected to die in the coming hours or days. Kappa values for all ten KPI scores were above 0.60, median 0.69, apart from KPI 6 (a review of interventions during the dying phase) with 0.59. Regarding time and date of the death there was exact agreement in 85% of pairs, with two-thirds of discrepancies being within 60 minutes. Further details about the reliability analysis can be found in appendix I.

How to read this report

The audit results are presented via three separate sections, representing the three audit elements: organisational, case note review and local survey of bereaved relatives' views, and prefixed with key statistics, respectively.

The organisational audit element is subdivided into sections one through to eight. Each section begins with a statement to explain its provenance, followed by tables presenting the audit questions, and where applicable (sections four to eight) the questions forming the associated KPIs, together with the KPI scoring system for each relevant question. Subsequent results tables present trust KPI score distributions (number and percentages) and KPI cut off scores. The final table within each section provides the results for each individual question. A commentary about these results is then provided at the end of each section.

The case note review element is subdivided into ten domains representing specific areas of clinical care and is set out in the same way as the organisational element – detailed above. Again, summary commentaries conclude each domain.

The local survey of bereaved relatives' views element is prefixed with a summary background and description of the CODE[11] questionnaire. Demographic statistics pertinent to the bereaved relative that completed the CODE[11] questionnaire and the patient, to whom the CODE questions relate, are then presented. The percentage and number of responses pertinent to each CODE[11] question, within each of the sections, A through to E, is then presented with associated commentary following the data for each section. Section F also represents the key outcome measures pertinent to the CODE[11] questionnaire and it is to this section that the NHS friends and family test[22] has been added. An explanation and the result of the NHS friends and family test score[22] are then presented, followed by commentary to support these key outcome measures.

Notes:

- As a result of data cleaning, the number of responses in the organisational /case note review / local survey of bereaved relatives' view audit elements varies between questions, respectively, which are reflected in the denominator for each question.
- Some questions were subordinate to stem questions and the associated denominator reflects the subpopulation relevant to the question, (for example, questions within case note review domains: 2, 7 and 8 are subordinate to case note review domain 1).

This national report concludes with key recommendations.

Key performance indicators (KPIs)

Organisational KPIs

Table 1

KPI	Description	Trust score range	Summary cut off (≥)	National (n=131)	
				% Trusts achieved KPI	% Trusts not achieved KPI
1	Access to information relating to death and dying.	0–5	5	41% (n=54)	59% (n=77)
2	Access to specialist support for care in the last hours or days of life.	0–5	4	21% (n=28)	79% (n=103)
3	Care of the dying: continuing education, training and audit.	0–20	10	40% (n=52)	60% (n=79)
4	Trust board representation and planning for care of the dying.	0–4	4	28% (n=37)	72% (n=94)
5	Clinical protocols for the prescription of medications for the five key symptoms at the end of life.	0–5	5	98% (n=128)	2% (n=3)
6	Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient.	0–9	9	34% (n=45)	66% (n=86)
7	Formal feedback processes regarding bereaved relatives/friends views of care delivery.	0–4	1	34% (n=44)	66% (n=87)

Clinical KPIs

Table 2

KPI	Description	Cases Score Range	Summary Cut Off (≥)	National (n=6,580) % cases achieved KPI	% cases not achieved KPI
1	Multidisciplinary recognition that the patient is dying.	0–2	2	59% (n=3859)	41% (n=2721)
2 [†]	Health professional's discussions with both the patient and their relatives/friends regarding their recognition that the patient is dying (n=5,722).	0–4	4	74% (n=4210)	26% (n=1512)
3	Communication regarding the patient's plan of care for the dying phase.	0–4	4	57% (n=3773)	43% (n=2807)
4	Assessment of the spiritual needs of the patient and their nominated relatives or friends.	0–4	1	37% (n=2410)	63% (n=4170)
5	Medication prescribed prn[††] for the five key symptoms that may develop during the dying phase.	0–5	5	50% (n=3305)	50% (n=3275)
6	A review of interventions during the dying phase.	0–6	5	55% (n=3650)	45% (n=2930)
7 [2]	A review of the patient's nutritional requirements (n=5,722).	0–8	6	39% (n=2249)	61% (n=3473)
8 [2]	A review of the patient's hydration requirements (n=5,722).	0–8	6	48% (n=2737)	52% (n=2985)
9	A review of the number of assessments undertaken in the patient's last 24 hours of life.	<5 ≥5	≥5	82% (n=5409)	18% (n=1171)
10	A review of the care after death.	0–2	1	56% (n=3701)	44% (n=2879)

[†] NB Only applicable if recognition of dying recorded in Domain 1.

[††] Prn = as needed; as the circumstances require.

Local survey of bereaved relatives' views key outcome measures

Table 3

	Question	National results (n=858)
29a	How much of the time was s/he treated with respect and dignity in the last two days of life? **By doctors** (n=815)	Always 66% (n=535) Never 3% (n=25) NB compared with VOICES[‡]*:* Always *67%*
29b	How much of the time was s/he treated with respect and dignity in the last two days of life? **By nurses** (n=823)	Always 70% (n=577) Never 3% (n=21) NB compared with VOICES*:* Always *63%*
30	Overall, in your opinion, were you adequately supported during his/her last two days of life? (n=802)	Yes 76% (n=610)
31	How likely are you to recommend our trust to friends and family? (n=820)	Extremely likely or likely 68% (n=560) Extremely unlikely or unlikely 12% (n=98) NHS friends and family test score 13

[‡] The Views of Informal Carers – Evaluation of Services (VOICES) questionnaire (ONS, 2011) is a 144 self-completion questionnaire, National Bereavement Survey to assess the quality of care and the level of support provided to bereaved relatives, friends and carers in the last 3 months of life.

Organisational data

Participation figures – organisational audit

- 146 trusts invited to participate in the audit.
- 131 (ie 90%) trusts participated in the audit.
    - 98 trusts participated as a trust.
    - 33 trusts participated individual hospitals.
    - 150 'sites' (trust/hospital).

Section 1:
Personnel responsible for completing the organisational audit element for the trust

Table 4

Question number	Questions	National n=131 trusts % (n)
1.a	Auditor role for completion of organisational proforma:	
	clinical governance/audit staff	14% (18)
	medical staff	24% (32)
	nursing staff	24% (32)
	LCP facilitator	4% (5)
	end of life care facilitator	21% (28)
	data manager	-
	other	12% (16)
1.b	Auditor was a member of the hospital specialist palliative care service	78% (102)

Section 2:
Information regarding the hospital compilation within trusts as well as the use of end of life care frameworks

Table 5

Question number	Questions	National n=131 trusts
2.a	Median number of hospitals within trust (as at 1 May 2013)	2 (IQR 1-3)
2.b	Median number of hospitals within trust that would have been eligible for inclusion into the case note review element (as at 1 May 2013)	1 (IQR 1-2)
2.e	Percentage (and number) of participating trusts who use the following end of life care key 'enablers' (as at 1 May 2013):	% (n)
	i. advance care planning (ACP)	55% (72)
	ii. electronic palliative care co-ordination system (EPaCCS)	21% (28)
	iii. assessment, management, best practice, engagement or patients and carers, for patients whose recovery is uncertain (AMBER) care bundle	19% (25)
	iv. the rapid discharge home to die care pathway	59% (77)
	v. framework for care in the last hours or days of life.	99% (130)
2.f	Percentage (and number) of trusts who have a named member of the trust board for care of the dying (as at 1 May 2013).	53% (70)

Section 2 commentary: information regarding the hospital compilation within trusts as well as the use of end of life care frameworks

Of the five end of life key enablers, as identified in the National Transform Programme, a 'Framework for care in the last hours or days of life' was reported as being the most widely available (ie by 99% (n=130)) of participating trusts). Just over half of the participating trusts reported the use of a 'rapid discharge home to die care pathway' (ie 59%, n=77) and 'anticipatory care planning' (ie 55%, n=72) within their trusts. However, the electronic palliative care coordination system (EPaCCS) and the assessment, management, best practice, engagement of patients and carers, for patients whose recovery is uncertain (AMBER) care bundle (which was part of a research project and therefore not available to all trusts) were reported to be in use by only one-fifth of trusts (ie 21%, (n=28) and 19%, (n=25) respectively).

Seventy of the 131 participating trusts (ie 53%) reported having a named member of their trust board specifically for care of the dying.

Section 3:
Trust demographic data

Table 6

Question number	Questions	National n=131 trusts
3.a	Median number of adults wards within trust (as at 1 May 2013)	26 (IQR 19–38)
3.b	Median number of adult beds within trust (as at 1 May 2013)	595 (IQR 419–850)
3.c	Median number of adult single patient occupancy rooms within trust (as at 1 May 2013)	125 (IQR 72–174)
3.d	Median number of adult deaths within trusts occurring in the financial year (ie 1 April 2012–31 March 2013)	1,311 (IQR 926–1,672)
3.e	Median number of adult deaths within trusts occurring in the national aggregate data collection period (ie 1–31 May 2013)	104 (IQR 72–140)
3.f	Median number of adult deaths within trusts occurring in the national aggregate data collection period (ie 1–31 May 2013) in those hospitals from which data was submitted to the case note review	98 (IQR 59–123)

Section 3 commentary: trust demographic data

Median trust demographic data suggests that participating trusts were relatively large in size, with, on average, 26 (IQR: 19-38) wards, 595 (IQR: 419–850) adult beds, 1,311 (IQR: 926–1,672) annual deaths and 104 (IQR: 72–140) deaths during May 2013.

Section 4: supportive information for relatives or friends

Organisational KPI: access to information relating to death and dying

Table 7

Question number	Question summary	Scoring	Score range
4a 4b 4c 4d 4e	Changes that may occur in patients in the hours before death Facilities available to relatives or friends Grieving process for relatives or friends Local procedures to be undertaken after the death of patient What to do after death	For each question: Yes=1 No=0	0–5

Table 8

Organisational KPI 1 score	National (n=131 trusts)	KPI achieved	KPI not achieved
0	-		59%
1	-		
2	4% (n=5)		
3	18% (n=23)		
4	37% (n=49)		
Cut off score = 5			
5	**41% (n=54)**	**41%**	

Table 9

Question number	Questions	National n=131 trusts % (n)
4.a	A leaflet outlining the changes that may occur in patients in the hours before death.	90% (118)
4.b	A leaflet explaining the facilities that are available for relatives and friends.	60% (78)
4.c	A leaflet explaining the grieving process for relatives and friends.	76% (100)
4.d	A leaflet explaining local procedures to be undertaken after the death of a patient.	99% (130)
4.e	Department of Work and Pensions (DWP) leaflet 1027, *What to Do After A Death in England and Wales* or equivalent.	91% (119)

Organisational KPI 1 commentary: access to information relating to death and dying

Five key information leaflets should exist to support relatives around the time of death and in the immediate aftermath. It is acknowledged that the availability of written information is not a substitute for good communication but should supplement a significant conversation at such a sensitive time. Three of these leaflets were reported by the vast majority of participating trusts to have been available. These included, a leaflet outlining the changes that may occur in patients in the hours before death; one explaining the local procedures to be undertaken after the death of a patient; and the DWP 1027 leaflet *What to Do After A Death in England and Wales* (90% n=118; 99% n=130; and 91% n=119, respectively).

Other supportive information leaflets, however, were reported to be available in between two-thirds and three-quarters of trusts. A leaflet explaining the facilities available to the relatives and friends of patients was reported as being available in 60% (n=78) of participating trusts and a leaflet explaining the grieving process for relatives and friends was reported as being available in 76% (n=100) of participating trusts.

The NHS Constitution[9] stipulates that 'the NHS also commits...to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it'. This pledge supports the generation of organisational KPI 1 and the decision to set the summary cut off score at 5 (ie all five leaflets available) which was achieved by 41% (n=54) of participating trusts.

Section 5: access to end of life care services to support care in the last hours or days of life

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

Table 10

Question number	Question summary	Scoring	Score range
5c	Level of face to face specialist palliative care service within trust		0-5
5ci	9-5; 5 days a week	Yes:5ci=1 No: 5ci=0	
5cii	9-5; 6 days a week	Yes:5cii=2 No: 5cii=0	
5ciii	9-5; 7 days a week	Yes:5ciii=3 No: 5ciii=0	
5civ	24/7 day service	Yes:5civ=4 No: 5civ=0	
	(NB: if 'yes' to 5ciii then always 'yes' to 5d)		
5d	Out-of-hours telephone service	Yes:5d=1 No:5d=0	

Table 11

Organisational KPI 2 score	National (n=131 trusts)	KPI achieved	KPI not achieved
0	-		79%
1	8% (n=10)		
2	67% (n=88)		
3	4% (n=5)		
Cut off score = 4			
4	**19% (n=25)**	**21%**	
5	**2% (n=3)**		

Table 12

Question number	Questions	National n=131 trusts % (n)	
5.a	Access to a Specialist Palliative Care Service (SPCS) in trust (as at 1 May 2013)	100% (131)	
5.b	Median (and IQR) number of whole time equivalent (WTE) or programmed activities (PA) values for the number of contracted and established posts within the trust specialist palliative care service within the trust:	Contracted Median (IQR) (n)	Established Median (IQR) (n)
	consultant in palliative medicine (PA)	10 (6–20) (n=122)	10 (6–21) (n=118)
	other doctor (PA)	10 (6–30) (n=51)	10 (6–24) (n=49)
	clinical nurse specialist in palliative care (WTE)	3.6 (2.3–5.3) (n=124)	3.4 (2.0–5.0) (n=127)
	other nurse (WTE)	1.0 (1.0–2.0) (n=38)	1.0 (1.0–2.0) (n=40)
	social worker (WTE)	1.0 (0.5–1.0) (n=26)	0.9 (0.3–1.0) (n=26)
	psychologist (WTE)	0.5 (0.2–1.0) (n=25)	0.5 (0.2–1.0) (n=24)
	complementary therapist (WTE)	0.3 (0.2–1.0) (n=8)	0.2 (0.2–0.7) (n=10)
	spiritual adviser (WTE)	1.0 (0.2–2.0) (n=41)	0.5 (0.2–2.0) (n=43)
	pharmacist (WTE)	0.5 (0.3–1.0) (n=23)	0.4 (0.2–0.6) (n=23)
	other (WTE).	1.0 (0.8–2.0) (n=38)	1.0 (0.6–2.0) (n=35)
5.c	Level of face-to-face specialist palliative care service available within trust (as at 1 May 2013):	% (n)	
	face to face 9–5 5 day service	73% (96)	
	face to face 9–5 6 day service	5% (7)	
	face to face 9–5 7 day service	19% (25)	
	face to face 24 hour 7 day service.	2% (3)	
5.d	Out of office hours telephone service availability within trust (as at 1 May 2013).	91% (119)	
5.e	One or more end of life care(EOL) /care of the dying facilitators working within the trust (as at 1 May 2013).	55% (72)	
5.f	Median (and IQR) number, or actual value where appropriate, of whole time equivalent (WTE) or programmed activities (PA) values for contracted and established end of life care/care of the dying facilitators within the trust (as at 1 May 2013):	Contracted Median (IQR) /actual value (n)	Established Median (IQR) /actual value (n)
	medical (PA)	1.0 and 1.0 (n=2)	0.3 and 0.7 (n=2)
	nursing (WTE)	1.0 (0.6–1.0) (n=66)	1.0 (0.7–1.0) (n=67)
	other (WTE).	0.4 and 0.5(n=2)	0.4 and 0.5 (n=2)

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

All trusts reported having access to specialist palliative care (SPC) teams which, on average, were most likely to comprise a consultant and/or senior doctor and 3.4 clinical nurse specialists. Each of the remaining staff groupings (ie nurse, social worker, psychologist, spiritual adviser, and pharmacist) were reported to have been individually represented in approximately one-fifth or more of the SPC teams within the participating trusts with the exception being complementary therapists who were reportedly represented in only 10 (8%) of the 131 participating trusts.

Most participating trusts reported operating a 9–5, 5-day face-to-face SPC service (73%, n=96) and the vast majority of trusts reported the availability of an out-of-office-hours telephone service (91%, n=119).

A fifth of the participating trusts reported operating a 7-day face to face SPC service, either 9–5 (19%, n=25) or 24 hour (2%, n=3).

Fifty five per cent of the participating trusts reported having one or more EOL care facilitators (n=72) which were most likely to be a member of the nursing staff working full-time in this post (n=67).

Neuberger[10] recommendation 33 stipulates that:
Funding should be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, 7 days a week.
This recommendation supports the generation of organisational KPI 2 and the decision to set the cut off score at 4 (ie face to face, 9-5, 7 day service supported by an out of hours telephone service), which was achieved by 19% (n=25) of trusts and exceeded by 2% (n=3) of participating trusts.

Recommendation: Hospitals should provide a face-to-face specialist palliative care service from at least 9am to 5pm, 7 days per week, to support the care of dying patients and their families, carers or advocates.

SECTION 6: continuing education, training and audit

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

Table 13

Question number	Question summary	Scoring	Score range
6b	Training availability for medical, nursing (qualified); nursing (non-qualified) and allied health professional via following categories: e-learning; update sessions; session in trust induction programme.	6b: For each training category for each staff group: Yes=1 No=0	0-20
6c	Communication skills training for medical, nursing (qualified); nursing (non-qualified) and allied health professional.	6c: for each staff group: Yes=1 No=0	

Table 14

National (n=131 trusts)					
Organisational KPI 3 score	**% (n)**	**KPI not achieved**	**Organisational KPI 3 score**	**% (n)**	**KPI achieved**
			Cut off score = 10		
0	18% (24)	60%	**10**	**7% (9)**	**40%**
1	0% (0)		**11**	**5% (7)**	
2	1% (1)		**12**	**10% (13)**	
3	2% (2)		**13**	**4% (5)**	
4	5% (7)		**14**	**5% (7)**	
5	5% (7)		**15**	**2% (3)**	
6	5% (7)		**16**	**2% (2)**	
7	8% (11)		**17**	**2% (2)**	
8	9% (12)		**18**	**2% (2)**	
9	6% (8)		**19**	**0% (0)**	
			20	**2% (2)**	

Table 15

Question number	**Questions**	**National n=131 trusts**			
6.a	Formal in-house continuing education programme on the subject of care of the dying during the financial year (ie 1 April 2012–31 March 2013).	82% (n=108)			
6.b	Formal in-house continuing education programme on the subject of care of the dying during the financial year (ie 1 April 2012–31 March 2013) for the following staff groups:	E-learning session	Update session	Mandatory training	Induction training
	medical (n=108)	54% (58)	63% (68)	19% (20)	51% (55)
	nursing (qualified) (n=108)	54% (58)	69% (74)	28% (30)	52% (56)
	nursing (non-qualified) (n=108)	53% (57)	60% (65)	23% (25)	45% (49)
	allied health professionals (n=108).	52% (56)	50% (54)	20% (22)	29% (31)
6.c	Inclusion of communication skills training for the last hours or days of life within the formal in-house continuing education programme on the subject of care of the dying during the financial year (ie 1 April 2012–31March 2013)				
	for the following staff groups:	% (n)			
	medical (n=108)	61% (66)			
	nursing (qualified) (n=108)	69% (75)			
	nursing (non-qualified) (n=108)	56% (60)			
	allied health professionals (n=108).	48% (52)			

Table 16

	Number of Training types provided for each staff group			
	1	**2**	**3**	**4**
Medical (n=94)	32% (30)	48% (45)	13% (12)	7% (7)
Nursing (qualified) (n=98)	29% (28)	47%(46)	16% (16)	8% (8)
Nursing (non-qualified) (n=95)	44% (42)	31% (29)	18% (17)	7% (7)
Allied health professionals(AHP) (n=83)	47% (39)	33% (27)	14% (12)	6% (5)

Organisational KPI 3 commentary: care of the dying: continuing education, training and audit

The importance of access to appropriate, ongoing education and training in care of the dying and more specifically in communication skills training continues to be reinforced in national policy and recommendations (eg the NHS Constitution;[9] Neuberger;[10] NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers;[4] Guidance about compliance. Essential standards of quality and safety section 4K;[7] End of Life Care Strategy: Quality Markers and Measures for End of Life Care.[3]

Eighty two per cent (n=108) of participating trusts reported having a formal in-house continuing education programme on the subject of care of the dying, leaving 18% (n=23) of trusts reporting that they did not have such provision.

Approximately half of these 108 trusts reported access to two out of the four training mediums for their qualified health professionals (ie medical 48% (n=45); qualified nursing 47% (n=46)). Approximately half reported access to one out of the four training mediums for their non-qualified nursing staff (44% (n=44)) and allied health professionals (47%; n=39). This suggests that the main focus for provision is for qualified nurses and doctors. Although there is evidence of room for improvement even here in the provision of training, the importance of such training for non-qualified nursing staff, who are likely to spend time directly supporting care at the bedside of dying patients, should not be neglected.

For these 108 trusts, update sessions were reported as the most popular training type across all qualified and non-qualified health professional staffing groups listed (50%–69%). However, e-learning was also a popular type (52%–54%) and mandatory training (19%–28%) was the least popular training type across all groupings of staff (qualified and non-qualified).

Communication skills training for the last hours or days of life within the formal in-house continuing education programme on the subject of care of the dying was reported to be included in between a half and two thirds of trusts and reportedly more prevalent for qualified nurses (69%, n=75) and medics (61%, n=66) and least prevalent for allied health professionals (48%, n=52).

Within the End of Life Care Strategy[2] (page 14), it stipulates that: 'ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying will be critical to the success of improving end of life care. For this to happen, end of life care needs to be embedded in training curricula at all levels and for all staff groups. End of life care should be included in induction programmes, in continuing professional development and in appraisal systems.' This recommendation supports the generation of organisational KPI 3 and the decision to set the cut off score at 10, which represents at least half of the maximum KPI 3 score. This KPI summary cut off score was achieved or exceeded by 40% (n=52) of participating trusts.

Recommendation: Education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training and skills for supporting families and those close to dying patients.

Organisational KPI 4: trust board representation and planning for care of the dying

Table 17

Question number	Question summary	Scoring	Score range
2f	A named member of the trust board for care of the dying.	Yes:2i=1; No:2i=0	0–4
6j	Formal discussion and reporting processes regarding care of the dying within trust clinical or quality governance structure trust board level reporting regarding care of the dying.	Yes:6j=1;No:6j=0	
6k	Public and patient representation within trust.	Yes:6k=1; No:6k=0	
6l	Discussions/reporting.	Yes:6l=1; No:6l=0	

Table 18

Organisational KPI 4 score	National (n=131 Trusts)	KPI achieved	KPI not achieved
0	18% (n=24)		72%
1	18% (n=24)		
2	15% (n=19)		
3	21% (n=27)		
KPI cut off score = 4			
4	**28% (n=37)**	**28%**	

Table 19

Question number	Questions	National n=131 trusts % (n)
6.d	A formal audit of care delivery for patients in the last hours or days was undertaken between 1 April 2012–31 March 2013 (n=131).	56% (74)
6.e	If 'yes', results of audit (above) fed back to clinical teams (n=74).	88% (65)
6.f	If 'yes', results of audit (above) fed back to trust board teams (n=73).	68% (50)
6.g	Action plan produced in the financial year (ie 1 April 2012–31 March 2013) to promote improvement in care of the dying within trust (n=131).	72% (94)
6.h	If 'Yes', action plan fed back to clinical teams (n=94).	89% (84)
6.i	If 'yes', action plan fed back to trust board (n=94).	70% (66)
6.j	A formal process exists within trust clinical or quality governance structure for discussing and reporting on care of the dying (ie between 1 April 2012–31 March 2013) (n=131).	69% (90)
6.k	Care of the Dying was reported on at least annually at trust board level (ie between 1 April 2012–31 March 2013) (n=131).	58% (76)
6.l	Patient and public representation within these discussions/reporting processes (ie between 1 April 2012–31 March 2013) (n=76).	72% (55)

Organisational KPI 4 commentary: trust board representation and planning for care of the dying

Just over half (56%, n= 74) of trusts reported having undertaken a formal audit of care delivery for patients in the last hours or days of life (Apr 2012–Mar 2013). Their audit results were reported to have been more likely to be fed back to clinical teams (88%, n= 65) than trust boards (68%, n= 50).

Seventy two per cent (n= 94) of all participating trusts reported that they had produced action plans to promote improvement in care of the dying within their trust (Apr 2012–Mar 2013). Again, these action plans were reported to have been more likely fed back to clinical teams (89%, n=84) than trust boards (70%, n=66).

A formal process for discussing and reporting on care of the dying was reported to exist within trust clinical or quality governance structures in 69% (n=90) of trusts.

Care of the dying was evidenced as being at least annually reported upon, at trust board level (April 2012–March 2013), by 58% (n=76) of trusts. Patient and public representation within these discussions/reporting processes was reported as being in place in 72% (n=55).

Fifty three per cent of trusts reported having a named member of their trust board for care of the dying (please refer to Question 2f).

Neuberger,[10] recommendation 28 stipulates that: 'The boards of healthcare providers providing care for the dying should give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals.'

Further the End of Life Care Strategy[2] stipulates that 'Measurement of end of life care provision is a key lever for change and is essential if we are to monitor progress. This will require measurement of structure, process and outcomes of care. Structures and processes will largely be measured through self-assessment by organisations against the quality standards' (pages 14-15)′ and 'Boards will wish to formally review progress on improving end of life care in acute hospitals at least once a year' (page 81). This recommendation and guidance supports the generation of the organisational KPI 4 and the decision to cut off score of four, representing the existence of formal audit processes and appropriate representation. This was achieved by 28% (n=37) of participating trusts.

Recommendation: All hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually.

All trusts should have a designated board member and a lay member with specific responsibility for care of the dying. Trust boards should formally receive and discuss the report of local audit at least annually.

Section 7: availability of trust-wide clinical provisions and protocols promoting patient comfort, dignity and privacy, up to and including the death of the patient

Organisational KPI 5: clinical protocols for the prescription of medications for the five key symptoms at the end of life

Table 20

Question number	Question summary	Scoring	Score range
7a	Protocols for the prescription of medications for five key symptoms:		0–5
7ai	pain		
7aii	agitation	Yes:7ai-7av:=1	
7aiii	noisy breathing		
7aiv	nausea and vomiting	No:7ai-7av:=0	
7av	dyspnoea.		

Table 21

Organisational KPI 5 score	National (n=131 trusts)	KPI achieved	KPI not achieved
0	2% (n=2)		2%
1	-		
2	-		
3	-		
4	1% (n=1)		
KPI cut off score = 5			
5	**98% (n=128)**	**98%**	

Table 22

Question number	Questions	National n=131 trusts
7.a	Protocols for the prescription of medications for patients for the following symptoms: pain agitation noisy breathing nausea and vomiting dyspnoea.	99% (n=129) 99% (n=129) 99% (n=129) 99% (n=129) 98% (n=128)

Organisational KPI 5 commentary: clinical protocols for the prescription of medications for the five key symptoms at the end of life

Almost all participating trusts reported having protocols in place for the anticipatory prescribing of medications for the key symptoms in the dying phase (ie pain, agitation, noisy breathing (ie excessive respiratory tract secretions); nausea and vomiting and dyspnoea). This may be due to the fact that 99% (n=130) of trusts reported using a framework (such as the LCP), which routinely include protocols for the prescription and use of medications for these symptoms. End of Life Care Strategy[2], point 1.34 stipulates that 'pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life'. This recommendation supports the generation of the organisational KPI 5 and the decision to set the cut off score at 5 (ie protocols for all five potential symptoms in place) which was achieved by 98% (n=128) of participating trusts.

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

Table 23

Question number	Question summary	Scoring	Score range
7b	MDT decision making process for diagnosing dying.	Yes:7b-7j:=1 No:7b-7j:=0	0–9
7c	Regular mortality meetings.		
7d	Guidelines for mouth care.		
7e	Pastoral care/chaplaincy.		
7f	Policy regarding DNACPR.		
7g	Policy for deactivation of ICDs.		
7h	Policy for carrying out care of the body after death.		
7i	Policy for providing guidance to relatives or friends re: verification/ certification of the patient's death.		
7j	Policy for viewing the body.		

Table 24

National (n=131 trusts)		**KPI achieved**	**KPI not achieved**
Organisational KPI 6 score	**% (n)**		
0	-		66%
1	-		
2	1% (1)		
3	2% (2)		
4	4% (5)		
5	8% (10)		
6	11% (14)		
7	23% (30)		
8	18% (24)		
KPI cut off score = 9			
9	**34% (45)**	**34%**	

Table 25

Question number	Questions	National n=131 trusts % (n)
7.b	Formal multidisciplinary decision-making process for diagnosing dying.	74% (97)
7.c	Designated regular mortality meetings to review recent deaths.	83% (109)
7.d	Guidelines for the assessment and delivery of mouth care.	74% (97)
7.e	Guidelines for referral to pastoral care/chaplaincy team.	70% (92)
7.f	Policy for the decision and documentation of a 'do not attempt cardiopulmonary resuscitation (DNACPR) order'.	100% (131)
7.g	Policy for the deactivation of implantable cardioverter defibrillators' (ICDs).	75% (98)
7.h	Policy for carrying our care of the body in the immediate time after the death of a patient.	96% (126)
7.i	Policy for providing relatives/friends regarding the verification and certification of the patient's death.	85% (111)
7.j	Policy for viewing the body in the immediate time after the death of a patient.	82% (108)
7.k	Designated formal quiet spaces available for relatives/friends.	64% (84)
7.l	Designated religious/spiritual rooms.	100% (131)

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

All participating trusts reported having a policy for the decision and documentation of a DNACPR order and access to religious /spiritual rooms and 96% (n=126) reported having a policy for carrying out care of the body in the immediate time after the patient's death.

Over 80% of trusts reported designated mortality meetings, a policy for providing information for relatives or friends about verification and certification of the patient's death and for viewing the body immediately after the death of a patient. Seventy to 75% of participating trusts reported having guidelines for: the deactivation of ICDs; 'mouth care'; formal MDT decision making processes for diagnosing dying; and for referral to pastoral care/chaplaincy teams. Just under two-thirds of trusts (64%, n=84) reported having formal quiet spaces for relatives.

General Medical Council Guidance[6], guidance within the End of Life Care Strategy[2] as well as recommendations 12, 39 and 42 from Neuberger[10] stipulate guidance and recommendations pertinent to the required clinical provisions and protocols listed above. These support the generation of the organisational KPI 6 and the decision to set the cut off score at 9 (ie all listed protocols /guidelines in place), which was achieved by 34% (n=45) of participating trusts.

Section 8: formal feedback processes to capture bereaved relatives views

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

Table 26

Question number	Question summary	Scoring	Score range
8d	Did trust seek bereaved relatives views in last two financial years?	Yes:8d=1;No:8d=0	0–4
8g	Were results shared with clinical teams?	Yes:8g=1;No:8g=0	
8i	Were action plans developed based upon these results?	Yes:8i=1;No:8i=0	
8j	Was action plan shared with trust board?	Yes:8j=1;No:8j=0	

Table 27

Organisational KPI 7 score	National (n=129 trusts)	KPI achieved	KPI not achieved
0	66% (n=87)		66%
KPI cut off score = 1			
1	**5% (n=6)**	**34%**	
2	**10% (n=13)**		
3	**11% (n=14)**		
4	**8% (n=11)**		

Table 28

Question number	Questions	National n=131 trusts % (n)
8.a	Existing processes in place to capture bereaved relatives or friends views, prior to the audit.	47% (61)
8.b	If yes, which specific feedback process (n=61): specific questionnaire focus group public involvement group other.	 84% (51) 11% (7) 11% (7) 11% (7)
8.c	Minimum period of elapsed time following the death of a patient that bereaved relatives/friends views were sought (n=61): <= 1 month >1 month but <=3 months >3 month but <=6 months >6 months other.	 56% (34) 25% (15) 13% (8) 5% (3) 2% (1)
8.d	Bereaved relatives/friends views sought during the last two financial years (ie 1 April 2011–31 March 2013) (n=131).	34% (44)
8.e	If yes, which specific feedback process (n=44): specific questionnaire focus group public involvement group other.	 82% (36) 7% (3) - 11% (5)
8.ei	Median number of survey questionnaires distributed by trusts to bereaved relatives (n=25).	160 (IQR 51-807)
8.eii	Median number of survey questionnaires returned by bereaved relatives to Trusts (n=29).[§]	57 (IQR 14-116)
8.eiii	Number of people involved within focus group interviews (n=2).	10 and 18
8.eiv	Median (and IQR) number of people involved in public involvement group discussions.	-
8.g	Results shared with clinical teams (n=44).	82% (36)
8.i	Action plans developed based upon these results (n=44).	61% (27)
8.j	Action plans shared with trust board (n=27) Yes. No but this is intended within the next 6 months. No – there is no plan to share it with the trust board.	 41% (11) 33% (9) 26% (7)

[§] Note: Four trusts had recorded the number of returned questionnaires but hadn't recorded the number of questionnaires that had been originally distributed to bereaved relatives, hence the lack of continuity in the denominator statistics between questions 8.ei and 8.eii.

Organisational KPI 7 commentary: formal feedback processes regarding bereaved relatives/friends views of care delivery

Forty seven per cent (n=61) of trusts reported having existing processes in place to capture bereaved relatives' views prior to the audit. Eighty four per cent (n=51) of these were via specific questionnaires. Bereaved relatives' views were reported to have been sought within one month of the patient's death by 56% (n=34) of trusts and between 1 and 3 months by 25% (n=15) of trusts.

Thirty four per cent (n=44) of trusts reported having sought bereaved relatives views within the last two financial years. Eighty two per cent (n=36) of these were via specific questionnaires. Results from these initiatives were reported to have been shared with clinical teams in 82% of trusts (n=36). Resultant action plans were reportedly developed by 61% of trusts (n=27) and shared with the trust board by 41% of those trusts (n=11).

Whilst nationally driven mechanisms, (eg CODE[11] questionnaire) support feedback mechanisms between trusts and patients and relatives who use their service, it is important that more regular trust specific mechanisms are created and maintained in order to inform trust action plans and drive their continuing quality improvement programmes.

An NHS value, as detailed within The NHS Constitution[9] relates to a commitment to quality of care and stipulates that, 'We encourage and welcome feedback from patients, families, carers, staff and the public.' A resultant NHS pledge is therefore to 'encourage and welcome feedback on your health and care experiences and use this to improve services'. Further, within the End of Life Care Strategy[2], it stipulates that 'your experience will help inform the care of future patients, leading to year on year improvements in quality' (page 19). These statements support the generation of the organisational KPI 7 and the decision to set the cut off score at 1 (as a minimum trusts had formally sought the views of bereaved relatives in the last two years), which was achieved or exceeded by 34% (n=44) of participating trusts.

Recommendation: All hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually.

Case note review data

Participation figures – case note review

- 10,386 clinical cases were entered into the audit data entry web tool.
- 2,532 clinical cases were excluded (ie reliability cases/ case notes not found for detailed audit / sudden deaths/ cancer centre site data).
- 6,580 cases were included in the national dataset (ie May 2013).
- 1,274 cases were included in the local site datasets (ie June/July 2013).
- 149[**] 'Sites' (trust/hospital) provided clinical case note information. Median 50 cases, IQR 45-56 cases per site, range 4-119 cases.

Demographic data

Table 29

		National (n=6580)
Patient gender	Female	51% (n=3,332)
Age	Median patient age	82 (IQR 73-88)
Primary diagnosis:		%age (n)
Non-cancer 77% (5,034)	Pneumonia	23% (1,483)
	Stroke	8% (537)
	Heart failure	8% (499)
	Chronic respiratory disease	7% (439)
	Other	32% (2,076)
Cancer 23% (1,546)	Lung	6% (370)
	Colorectal	2% (143)
	Upper gastrointestinal	2% (141)
	Prostate	2% (103)
	Other	12% (789)
Co-morbidities:		% (n)
	None	17% (1,146)
	1 co-morbidity	47% (3,123)
	2 co-morbidities	24% (1,558)
	3 co-morbidities	9% (607)
	4 or more co-morbidities	2% (146)
Co-morbidity by diagnosis*: _*NB: more than one co-morbidity may be coded per patient_	Heart failure	19% (1,222)
	Renal failure	17% (1,138)
	Diabetes	15% (999)
	Dementia	13% (867)
	Falls and accidents	8% (497)
	Other	60% (3,940)
Ethnicity	White British	89% (5,870)
	Other	11% 710)
Religion _*NB: includes 'none' and 'not documented'_	Christian	65% (4,252)
	Other	7% (446)
	None *	28% (1,882)

[**] one site provided data only for the organisational element of the audit.

Case note information

	National (n=6,580)
Median length of the last episode of care (days) (IQR)	9 (4–19)
Percentage (and number) of patients whose care was supported by a framework of care for the last hours or days of life	% (n) 48% (3,139)
Percentage (and number) of patients whose wishes and preferences for their preferred place of death were documented within the last episode of care	24% (1,602)
Preferred place of death for patients for whom documentation was recorded **(n=1,602):**	
hospital	40% (648)
own home	29% (472)
hospice	15% (233)
care home	11% (175)
with relatives/friends	4% (61)
other.	1% (13)
Percentage (and number) of patients in which discussions and/or activities were documented to initiate hospital discharge planning during the last episode of care (where a category other than 'hospital' was documented as being the preferred place of death) **(n=954).**	84% (797)
Documented reason for the patient not achieving their preferred place of death **(n=954):**	% (n)
patient too ill to transfer	37% (357)
patient died before being able to transfer	35% (338)
family unable to accommodate care at home	6% (60)
insufficient Hospice beds	5% (48)
inadequate resources in the community	2% (17)
awaiting equipment	1% (5)
other	10% (95)
not documented.	4% (34)
Acute hospital department in which the patient's death took place:	% **(n=6,527)**
medical	75% (4,865)
surgical	8% (546)
critical care	8% (507)
acute medical assessment unit	5% (307)
high dependency	3% (175)
specialist palliative care unit.	2% (127)

Domain 1: health professional's recognition that the patient is dying

To enable a refocus of care and an adjustment of the patient and nominated relatives or friends' expectations.

Table 30

Question number	Question	Response options	KPI component
1a	Is there documented evidence within the last episode of care of a decision within the MDT that the patient was expected to die in the coming hours or days?	Yes/No	Yes
1b	If the answer is 'yes' to question 1a: who took part in the MDT decision.	List of possible health professionals	
1c	If the answer to question 1a is 'no': Is there documented evidence within the last episode of care by at least one health professional that the patient was expected to die in the coming hours or days?	Yes/No	Yes
1d	If the answer to question 1c is 'yes': what was the grade of the health professional who documented that the patient was expected to die in the coming hours or days?	List of possible health professionals	
1e	If the answer to questions 1a or 1c is 'yes': what was the date and time of the first documented evidence of the recognition that the patient was expected to die in the coming hours or days?	Date/Time	

Clinical KPI 1: multidisciplinary recognition that the patient is dying

Table 31

Question number	Scoring	Score range
1a 1c	1a: Yes=2; 1a: No=0 1c: Yes=1; 1c: No=0	0–2

Table 32

Clinical KPI 1 score	National (n=6,580)	KPI achieved	KPI not achieved
0	13% (n=858)		41%
1	28% (n=1,863)		
KPI cut off score = 2			
2	**59% (n=3,859)**	**59%**	

Table 33

Question number	Questions	National (n=6,580)
1.	Documented health professional recognition that the patient was expected to die in the coming hours or days:	% (n)
	1.a decision undertaken by a multi-disciplinary team (MDT)	59% (3,859)
	1.c decision undertaken by at least one health professional *	28% (1,863)
	No recognition documented.	13% (858)
1.b	Median number of documented personnel who took part in a MDT decision	3 (IQR: 2-4)
	Percentage (and number) where at least one of the following personnel were recorded as being involved within an MDT:	
	consultant (n=3,815)	75% (2,869)
	staff nurse (n=3,794)	60% (2,272)
	junior doctor (n=3,801)	62% (2,345)
	specialist registrar (n=3,809)	54% (2,041)
	palliative care nurse (3,792)	17% (663)
	ward sister (n=3,792)	16% (620)
	specialist nurse (n=3,791)	9% (354)
	speech and language therapist (n=3,792)	2% (70)
	dietician (n=3,792)	2% (66)
	physiotherapist (3,792)	3% (127)
	occupational therapist (n=3,792)	2% (65)
	chaplain (n=3,792)	1% (44)
	social worker (3,791)	1% (27)
	pharmacist (n=3,792)	0.2% (7)
	other (n=3,792).	4% (137)
1.d	Median number of documented personnel who took part in a non-MDT decision.	2 (IQR:1-2)
	Percentage (and number) where at least one of the following personnel were recorded as being involved within a non-MDT*:	49% (907)
	consultant (n=1,845)	44% (804)
	specialist registrar (n=1,845)	48% (878)
	junior doctor (n=1,844)	10% (186)
	palliative care nurse (n=1,845)	17% (305)
	staff Nurse (n=1,845)	3% (55)
	specialist nurse (n=1,845)	3% (62)
	ward sister (n=1,845)	2% (34)
	other (n=1,845).	
1.e	Median number of hours between the first documented evidence of the recognition that the patient was expected to die and actual death	35.5
	(IQR)	(11.5-88.7)
	(n)	(4,562)

* Please note that upon further scrutiny of the data provided by participating trusts, 19% (n=353) of the 1,864 cases that reported recognition by at least one health professional, could have been classified as an MDT (ie a minimum of a specialist registrar (or above) and a participating nurse).

Clinical KPI 1 commentary: multidisciplinary recognition that the patient is dying

Recognition of death by an MDT (ie a minimum of a specialist registrar (or above) and a participating nurse) was reported in 59% (n=3,859) of cases. The MDT most likely included three health professionals from the following staff groupings: consultant (49%, n=907) /specialist registrar (44%, n=804)/junior doctor (48%, n=878)/staff nurse (17%, n=305).

Recognition of death by at least one health professional was reported in 28% (n=1,864) of cases.*
The decision regarding this recognition most likely included two health professionals and for 71% (n=1,318) of cases was undertaken by doctors only.

The median number of hours between the first documented evidence of the recognition that the patient was expected to die and actual death was 35.5 hours (IQR: 11.5-88.7).

No recognition of death was reported in 13% of cases.

Neuberger,[10] recommendation 12 stipulates that ‘Clear guidance should be issued by the National Institute of Health and Care Excellence on: ....the necessity for multidisciplinary decision-making’. This recommendation supports the generation of the clinical KPI 1 summary cut off score of 2 which reflects the audit recommendation for MDT decision making regarding recognition of dying. This KPI summary cut off score was achieved in 59% (n=3,985) of cases.

Recommendation: The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient’s care. This should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.

Domain 2: communication regarding health professional's awareness that the patient is expected to die in the coming hours or days, with both the patient and the nominated relative, friend or advocate

Table 34

Question number	Question	Response options	KPI component
2a	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?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient did want bad news.	Yes
2b	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?	Yes No No but: • attempts to contact them were unsuccessful • Independent Mental Capacity Adviser (ie IMCA) unavailable.	Yes

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

Table 35

Question number	Scoring	Score range
2a 2b	2a: Yes=2; 2a: No but=2; 2a: No=0 2b: Yes=2; 2b: No but=1; 2b: No=0	0–4

Table 36

Clinical KPI 2 score	National (n=5,722)	KPI achieved	KPI not achieved
0	2% (n=142)		26%
1	0.3% (n=19)		
2	22% (n=1,270)		
3	1% (n=81)		
Summary cut off score = 4			
4	**74% (n=4,210)**	**74%**	

Table 37

Question number	Questions	National (n=5,722)*
2.a	Discussions regarding awareness of patients imminent death held with patients who were capable of participating in such discussions (41%, n=2,327):	% (n)
	yes	46% (1,063)
	no	54% (1,264)
	status of patients who were incapable of participating in such discussions (59%, n=3,395):	
	no as patient lacked mental capacity	40% (1,342)
	no as patient unconscious	58% (1,959)
	no as patient didn't want to receive bad news.	3% (94)
2.b	Discussions regarding awareness of patients imminent death held with relatives:	% (n)
	yes	93% (5,313)
	no	5% (309)
	no as attempts to contact them were unsuccessful	2% (91)
	no as IMCA unavailable.	0.2% (9)

*NB Only applicable if recognition recorded in domain 1a or 1c above

Clinical KPI 2 commentary: health professional's discussions with both the patient and their relatives/friends regarding their recognition that the patient is dying

The following commentary pertains only to the 87% (n=5722) of patients for whom recognition of dying had been documented (either by and MDT or other means). These patients were generally recorded as being incapable of participating in such discussions (59%, n=3,395). However, 41% (n=2,327) of patients were recorded as having been assessed as capable of participating in discussions regarding recognition of dying. Of these patients, such discussions between health professionals and patients were reportedly undertaken in 46% of cases.

Discussions regarding recognition of dying were reported to be more likely to have been undertaken with relatives or representatives of the patients (eg IMCA) (93%, n=5,313). These results suggest opportunities for trusts to engage more fully with patients regarding recognition of dying.

Within The NHS Constitution[9] it stipulates that health professionals should, '*involve patients, their families, carers or representatives' fully in decisions about prevention, diagnosis, and their individual care and treatment*'. Additionally, recommendation 32: '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'. This health professional responsibility supports the generation of the clinical KPI 2 summary cut off score of four, which reflects the audit recommendation that discussions regarding recognition of dying should be undertaken with the patient, where possible, and always with the nominated relative or friend. This KPI summary cut off score was achieved in 74% (n=4,210) of cases.

Recommendation: The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient's care. This should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.

Domain 3: communication regarding the plan of care for the dying phase with the patient and the nominated relative or friends

Table 38

Question number	Question	Response options	KPI component
3a	Is there documented evidence within the last episode of care that a plan of care specifically for the last hours or days of life was discussed with the patient?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient didn't want bad news.	Yes
3b	If the answer is 'yes' to question 3a: within the discussion was information regarding treatment options for symptom control recorded?	Yes/No	
3c	If the answer is 'yes' to question 3b: was specific information regarding the following symptoms recorded: pain agitation nausea noisy breathing dyspnoea.	Yes/No	
3d	Is there documented evidence within the last episode of care that a plan of care specifically for the last hours or days of life was discussed with the nominated relative or friend or the nominated IMCA?	Yes No No but: • attempts to contact them were unsuccessful • IMCA unavailable.	Yes
3e	If the answer is 'yes' to question 3d: within the discussion with the relative or friend or IMCA was information regarding treatment options for symptom control recorded?	Yes/No	
3f	If the answer is 'yes' to question 3e: was specific information regarding the following symptoms recorded: pain agitation nausea noisy breathing dyspnoea.	Yes/No	
3g	If the answer is 'yes' to question 3d: within the last episode of care, what was the date and time of the first discussion with the nominated relative or friend, regarding a plan of care for the dying phase?	Date/Time	

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

Table 39

Question number	Scoring	Score Range
3a	3a: Yes=2; 3a: No but=2; 3a:No=0	0–4
3c	3c: Yes=2; 3c: No but=1; 3c: No=0	

Table 40

Clinical KPI 3 score	National (n=6,580)	KPI achieved	KPI not achieved
0	17% (n=1,099)		43%
1	0.4% (n=29)		
2	24% (n=1,585)		
3	1% (n=94)		
KPI cut off score = 4			
4	57% (n=3,773)	**57%**	

Table 41

Question number	Questions	National (n=6,580)
3.a	Discussions regarding the plan of care for the dying phase held with patients who were capable of participating in such discussions (45%, n=2,975):	% (n=6,577)
	yes	28% (843)
	no.	72% (2,132)
	Status of patients incapable of participating in such discussions (55% ,n=3,602):	
	no as patient lacked mental capacity	40% (1,431)
	no as patient unconscious	58% (2,098)
	no as patient didn't want to receive bad news	2% (73)
3.b	Discussions with the patient regarding a plan of care for the dying phase included general treatment options for symptom control (n=843)	66% (557)
3.c	Discussions with the patient regarding a plan of care for the dying phase included specific information for the following symptoms (n=557):	% (n)
	pain	80% (446)
	agitation	58% (321)
	nausea	53% (297)
	noisy breathing	47% (264)
	dyspnoea.	57% (320)
3.d	Discussions regarding the plan of care for the dying phase held with relative/friends or IMCA:	% (n=6,577)
	yes	73% (4,780)
	no	25% (1,674)
	no as attempts to contact them were unsuccessful	2% (102)
	no as IMCA unavailable.	0.3% (21)
3.e	Discussions with the relative/friend or IMCA regarding a plan of care for the dying phase included general treatment options for symptom control (n=4,780).	59% (2,807)
3.f	Discussions with the relative/friend or IMCA regarding a plan of care for the dying phase included specific information for the following symptoms (n=2,807):	% (n)
	pain	71% (1,988)
	agitation	62% (1,736)
	nausea	46% (1,296)
	noisy breathing	51% (1,430)
	dyspnoea.	52% (1,458)
3.g	Median number of hours between the date and time of the first discussion with the relative/friend or IMCA regarding the plan of care for the dying phase and the date and time of death.	31.0 median (IQR 10.3 – 76.6) (n=3,855)

Clinical KPI 3 commentary: communication regarding the patient’s plan of care for the dying phase

Patients were generally recorded as being incapable in participating in such discussions (55%, n=3,602). However, 45% (n=2,975) of patients were recorded as having been assessed as capable of participating in discussions regarding the patient’s plan of care at the end of life. Of these patients, such discussions between health professionals and patients were reportedly undertaken in only 28% (n=843) of cases.

Where these discussions were documented as having taken place, treatment options for symptom control were discussed in general terms in 66% (n=557) of cases. However, specific treatment options for pain management (80%, n=446) were reportedly more likely to have been included in these discussions. Least likely reported specific treatment options to be included in these discussions were the management of noisy breathing (47%, n=264).

Discussions regarding the patient’s plan of care were reportedly more likely undertaken with relatives (73%, n=4,780). Where these discussions were documented as having taken place, treatment options for symptom control were discussed in general terms in 59% (n=2,807) of cases. Again, it was reported that specific treatment options for pain management (71%, n=1,988) were more likely to be included in these discussions. Least likely specific treatment options to be reportedly included in these discussions were the management of nausea (46%, n=1,296).

The median elapsed time between the first documented discussions between health professionals and the relative/friend or IMCA regarding the plan of care for the dying phase and the documented date and time of the patient’s death was 31.0 hours (IQR:10.3-76.6).

These results suggest opportunities for trusts to engage more fully with both patients and nominated relative or friends and to ensure that specific treatment options are discussed and documented.

Within The NHS Constitution[9] it stipulates that patients should, ‘have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers’. This right supports the generation of the clinical KPI 3 summary cut off score of 4, which reflects the audit recommendation that discussions regarding the patient’s plan of care for the dying phase should be undertaken with the patient, where possible, and always with the nominated relative or friend. This KPI summary cut off score was achieved in 57% (n=3,773) of cases.

Recommendation*:* Pain control and other symptoms in dying patients should be assessed at least four hourly and medication given promptly if necessary. Interventions should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.

Domain 4 spirituality: to enable patients, where possible and deemed appropriate and nominated relatives or friends to visit/revisit their spiritual needs (ie wishes, feelings, faith, beliefs and values)

Table 42

Question number	Question	Response options	KPI component
4a	Is there documented evidence within the last episode of care that a discussion took place with the patient regarding their spiritual needs?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient didn't want bad news	Yes
4b	If the answer is 'no' or' no but.' to question 4a: is there documented evidence within the last episode of care that discussion took place with the nominated relative or friend, regarding the patient's spiritual needs?	Yes No No but: • attempts to contact them were unsuccessful.	Yes
4c	If the answer to 4a or 4b is yes: What was the date and time of the **latest** documented discussion with the patient and/or the nominated relative or friend regarding the patient's spiritual needs?	Date (DD/MMM/YYYY); unknown Time (HH:MM); unknown	
4d	Is there documented evidence within the last episode of care that the patient was seen by a spiritual adviser?	Yes/No	
4e	Is there documented evidence within the last episode of care that a discussion took place with the nominated relative or friend regarding their own spiritual needs (wishes, feelings, faith, beliefs, and values)?	Yes No No but: • attempts to contact them were unsuccessful • IMCA unavailable.	Yes
4f	If the answer to 4e is yes: What was the date and time of the **latest** documented discussion with the relative or friend regarding their spiritual needs?	Date (DD/MM/YYYY); unknown Time (HH:MM); unknown	

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

Table 43

Question number	Scoring	Score range
4a 4b 4e	4a: Yes=2; 4a: No but=0; 4a: No=0 4b: Yes=2; 4b: No but=1; 4b: No=0 4e: Yes=2; 4e: No but=1; 4e: No=0	0-4 (*NB: 4b is only available to answer if the answer to 4a is 'no' or 'no but' – hence the maximum score is 4 for this KPI*).

Table 44

Clinical KPI 4 score	National (n=6,580)	KPI achieved	KPI not achieved
0	63% (n=4,170)		63%
KPI cut off score = 1			
1	**0.4% (n=24)**	**37%**	
2	**15% (n=1,002)**		
3	**0.2% (n=12)**		
4	**21% (1,372)**		

Table 45

Question number	Questions	National (n=6,580)
4.a	Discussions regarding the patient’s spiritual needs were held with patients who were capable of participating in such discussions (52%, n=3,391): Yes No Status of patients who were incapable of participating in such discussions (48%’n=3,185): no as patient lacked mental capacity no as patient unconscious no as patient didn’t want to receive bad news.	% (n=6,576) 21% (715) 79% (2,676) 38% (1,211) 61% (1,935) 1% (39)
4.b	Discussions regarding the patient’s spiritual needs were held with the nominated relative/friend: yes no no as attempts to contact them were unsuccessful.	% (n=5,862) 23% (1,342) 75% (4,424) 2% (95)
4.c	Median number of hours between the date and time of the first discussion with the relative or friend regarding the patient’s spiritual needs and the date and time of death (IQR) (n)	28.0 (10.2 – 72.8) (1,273)
4.d	Documented evidence that patient was seen by a spiritual adviser (n=6,576)	9% (595)
4.e	Discussions regarding the relatives spiritual needs were held with the relative: yes no no as attempts to contact them were unsuccessful.	% (n=6,575) 25% (1,623) 74% (4,855) 1% (97)
4.f	Median number of hours between the date and time of the first discussion with the relative or friend regarding their personal spiritual needs and the date and time of the patient’s death (IQR) (n)	26.8 (10.2 – 69.4) (1,537)

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

Patients were frequently recorded as being incapable of participating in such discussions (48%, n=3,185). However, 52% (n=3391) of patients were reportedly assessed as being capable of participating in discussions regarding their spiritual needs. Of these patients, such discussions between health professionals and patients were reported to have been undertaken in 21% (n=715) of cases. (This equates to 11% of the whole sample).

Relatives were reportedly used as a proxy for the patient in 23% of cases (n=1,342). Of these cases, the median elapsed time between the first documented discussions involving health professionals and the relative or friend regarding the patient's spiritual needs was 28.0 hours (IQR: 10.2-72.8).

Documentation that the patient had been seen by a spiritual adviser was recorded in only 9% (n=595) of cases from the whole sample.

Discussions between health professionals and the relative or friend regarding their personal spiritual needs were recorded in 25% (n=1,623) of cases. The median elapsed time between the first documented discussions involving Health Professionals and the relative or friend regarding their personal spiritual needs was 26.8 hours (IQR:10.2-69.4).

These results suggest opportunities for trusts to engage more fully with both patients and nominated relative or friends regarding their spiritual needs.

Statement 6 within the NICE quality standards for end of life care[4] stipulates, 'People approaching the end of life are offered spiritual and/or religious support appropriate to their needs and preferences.' This quality standard supports the generation of the clinical KPI 4 summary cut off score of 1. Given the current gap between aspirational and actual standards of care relating to the documentation of spiritual needs of both the patient and the nominated relative or friend, the audit recommendation purports that at the very least, where it is not possible to discuss the patient's spiritual needs directly with the patient, then discussions should be undertaken with the nominated relative or friend, as proxy for the patient, and documented accordingly. This KPI summary cut off score was achieved in 37% (n=2,410) of cases.

Recommendation: Hospitals should have an adequately staffed and accessible pastoral care team to ensure that the spiritual needs of dying patients and those close to them are met.

Domain 5: medication prescribed ‘prn’ to support the five key symptoms that may develop in the last hours or days of life

Table 46

Question number	Question	Response options		KPI component
5a	At the time of the patient’s death, is there documented evidence that medication was prescribed (prn) for the 5 key symptoms that may develop in the last hours or days of life? I. Pain II. Agitation III. Nausea IV. Noisy breathing V. Dyspnoea	Prescribed *prn* Yes No	Administered Yes No	Prescribed *prn* - Yes
5b	At the time of the patient’s death, is there documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place?	Yes No		
5c	If the answer to 5b is **Yes**: Please list the medication and the **last** prescribed dosage in the CSCI prior to the patient’s death:	Drug name – free text Dosage – free text		

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

Table 47

Question number	Scoring	Score range
5a, 5ai, 5aii, 5aiii, 5aiv and 5av	5ai-5av: Yes=1 5ai-5av: No=0	0-5

Table 48

Clinical KPI 5 score	National (n=6,580)	KPI achieved	KPI not achieved
0	15% (n=986)		50%
1	7% (n=455)		
2	7% (n=478)		
3	7% (n=465)		
4	14% (n=891)		
KPI cut off score = 5			
5	**50% (n=3,305)**	**50%**	

Table 49

Question number	Questions	National (n=6,580)
5.i	At the time of the patient's death there was documented evidence that medication was prescribed (prn) for the five key symptoms that may develop in the last hours or days of life:	% (n=6,575)
	pain	81% (5,314)
	agitation	72% (4,730)
	nausea	68% (4,479)
	noisy breathing	65% (4,258)
	dyspnoea.	63% (4,114)
5.ii	At the time of the patient's death there was documented evidence that medication was administered for the 5 key symptoms that may develop in the last hours or days of life:	% (n=6,575)
	pain	44% (2,875)
	agitation	34% (2,203)
	nausea	12% (776)
	noisy breathing	25% (1,636)
	dyspnoea.	17% (1,114)
5.b	At time of patient's death there was documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place (n=6,575)	28% (1,850)

5c. Table 50 presents the medication and the **last** prescribed dosage in the CSCI prior to the patient's death (all dosages are in milligrams).

Table 50

Opioids	(National n=1850) Number administered	%	Median dose	n*	IQR	10th	90th
						Percentile	
Morphine	760	41	10	756	10-20	5	36
Diamorphine	459	25	10	449	10-20	5	30
Oxycodone	217	12	15	216	5-30	5	60
Alfentanyl	137	7	1.1	134	1-3	0.5	7
Sedatives							
Midazolam	1171	63	10	1159	5-15	5	20
Antipsychotics							
Levomepromazine	274	15	12	271	6-12	6	25
Haloperidol	193	10	2	192	1-3	1	5
Antiemetics							
Cyclizine	235	13	150	234	150-150	75	150
Metoclopromide	82	4	30	82	30-40	30	60
Anticholinergic							
Hyoscine hydrobromide	294	16	1	293	1-1	0.8	2.4
Glycopyrronium	233	13	1	231	0.6-1.2	0.4	1.2
Hyoscine butylbromide	231	12	60	228	40-80	20	120

*NB: The 'n' in the tables above have been reduced wherever a patient was given the drug but the dosage was not recorded in the data collection tool.

Clinical KPI 5 commentary: medication prescribed prn for the five key symptoms that may develop during the dying phase

At the time of the patient's death, medication was reported to have been prescribed prn more often for pain (81%, n=5,314) and less often for dyspnoea (63%, 4,114).

At the time of the patient's death, medication was reported to have been administered prn during the last 24 hours of the patient's life in fewer cases than those where the medication had been prescribed (eg for the whole sample, pain: prescribed in 81% (n=5,314); administered to 44% (n=2,875) / dyspnoea: prescribed=63% (n=4,114); administered to 17% (n=1,114).

A continuous subcutaneous infusion (CSCI) of medication via a syringe driver was recorded as having been in place at the time of the patient's death in 28% (n=1,850) of cases. Whereas, as reported above, dying is recognised in hospital by the MDT (59%) or by at least one healthcare professional (a further 28%), most patients dying in hospital are not found to have a syringe driver in place and prescriptions of drugs prn for symptom control are frequently not used. These results call into question the perception that the recognition of dying automatically leads to the administration of drugs, and / or the use of a syringe driver regardless of patient symptomatology.

As highlighted, at the time of the patients death there was documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place in 28% (1850 of 6575 patients). Drugs used in the last 24 hours of life in these 1850 patients were examined in more detail.

The medications were categorised into 5 groups namely: opioids; sedatives; antipsychotics; antiemetics; and anticholinergics. The types of drugs prescribed were as expected. Midazolam was the most extensively used drug in this cohort with 63% (n=1171) of cases with a median dose of 10 mg (IQR: 5-15mg) over 24 hours. The most commonly used opioid was morphine, used in 41% (n=760) of cases, followed by diamorphine, used in 25% (n=459) and oxycodone, used in 12% (n=217) of cases.

The medications prescribed and the dosages reported were within the expected ranges as indicated by the IQR and the 10th and 90th percentiles.

Statement 11 within the National Institute for Health and Clinical Excellence (ie NICE)[4] stipulates that, 'people in the last days of life are identified and receive care according to their care plan, which takes into account their needs and preferences, and ensures they can have rapid access to all the support they need, including equipment (such as a pressure-relieving mattress) and medication.' This statement supports the generation of the clinical KPI 5 summary cut off score of five which, which reflects the audit recommendation that anticipatory prescribing of medication to alleviate the five key symptoms that may occur in the last hours or days of life (ie pain, agitation, nausea, noisy breathing (ie excessive respiratory secretions) and dyspnoea) should be standard practice, to ensure that patients receive timely and appropriate care. This KPI summary cut off score was achieved in 50% (n=3,305) of cases.

Domain 6: the review of required interventions during the last 24 hours of the patient's life, in the best interests of the patient

Table 51

Question number	Question	Response options	KPI component
6a	In the last 24 hours, were any of the following interventions still included within the patient's plan of care? • Routine recording of vital signs. • Routine blood tests. • Blood sugar monitoring. • The administration of oxygen. • The administration of antibiotics.	Yes – Continued Yes – Commenced No – Discontinued No – Never in place	
6b	Is there documented evidence that a decision by a senior doctor regarding ardiopulmonary resuscitation (CPR) was undertaken during the last episode of care?	Yes No	Yes
6c	Is there documented evidence that a discussion regarding the CPR decision was undertaken with the patient during the last episode of care?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient didn't want bad news.	Yes
6d	Is there documented evidence that a discussion regarding the CPR decision was undertaken with the nominated relative or friend or IMCA during the last episode of care?	Yes No No but: • attempts were made to contact a nominated relative/friend but they were unsuccessful • IMCA unavailable.	Yes
6e	At the time of the patient's death was there a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place?	Yes No	

Clinical KPI 6: a review of interventions during the dying phase

Table 52

Question number	Scoring	Score range
6b 6c 6d	6b: Yes=2; 6b: No=0 6c: Yes=2; 6c: No but =2; 6c: No=0 6d: Yes=2; 6d: No but =1; 6d: No=0	0-6

Table 53

Clinical KPI 6 score	National (n=6,580)	KPI achieved	KPI not achieved
0	3% (n=218)		45%
1	0.3% (n=2)		
2	11% (n=704)		
3	0.5% (n=34)		
4	30% (n=1,972)		
KPI cut off score = 5			
5	**2% (n=116)**	**55%**	
6	**54% (n=3,534)**		

Table 54

Question number	Questions	National (n=6,580)
6.a	In the last 24 hours the following interventions were still included within the patient's plan of care? (ie Yes = Yes Continued and Yes Commenced for each intervention.) Routine recording of vital signs. Routine blood tests. Blood sugar monitoring. The administration of oxygen. The administration of antibiotics.	% (n=6,575) 45% (2,949) 34% (2,242) 17% (1,089) 58% (3,832) 30% (1,999)
6.b	A decision by a senior doctor regarding CPR had been documented as being undertaken during the last episode of care. (n=6,575)	95% (6,223)
6.c	Discussions regarding the senior doctor's decision about CPR were held with patients who were capable of participating in such discussions (50%, n=3,309): yes no. Status of patients who were incapable of participating in such discussions (50% ,n=3,267): no as patient lacked mental capacity no as patient unconscious no as patient didn't want to receive bad news.	% (n=6,576) 41% (1,369) 59% (1,940) 46% (1,516) 51% (1,663) 3% (88)
6.d	Discussions regarding the senior doctor's decision about Cardiopulmonary Resuscitation (CPR) were held with the relative/friend or IMCA: yes no no as attempts to contact them were unsuccessful no as the nominated IMCA was unavailable within the timeframes.	% (n = 6,576) 71% (4,657) 27% (1,767) 2% (117) 0.5% (35)
6.e	At the time of the patient's death a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order was in place (n=6,576).	96% (6,290)

Clinical KPI 6 commentary: a review of interventions during the dying phase

The administration of oxygen was reported as most likely to be included within the patient's plan of care in the last 24 hours (58%, n=3,832). Blood sugar monitoring was reported as least likely to be included (17%, n=1,089). The remaining interventions were recorded within the patient's plan of care in the last 24 hours for between 30% (n=1,999) and 45% (n=2,949) of cases.

A decision by a senior doctor regarding CPR was recorded in 95% (n=6,223) of cases.

Patients were recorded as being incapable of participating in such discussions in 50% of cases (n=3,267). However, 50% (n=3,309) of patients were reportedly assessed as being capable of participating in discussions regarding Cardiopulmonary Resuscitation (CPR). Of these patients, such discussions between health professionals and patients were reportedly undertaken in 41% (n=1,369) of cases.

Discussions regarding this decision were reportedly more likely to have been undertaken with relatives (71%, n=4,657).

A DNACPR order was recorded as being in place in 96% (n=6,290) of cases.

These results show that interventions are neither commenced nor stopped routinely and are consistent with the tailoring of interventions according to patient needs. Further, decisions regarding CPR are routinely undertaken and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders are commonplace within patients' plan of care. However, there are opportunities for trusts to engage more fully with both patients and their nominated relatives or friends and ensure that such decisions are discussed appropriately.

Paragraph 129 within the General Medical Council (GMC) Guidelines[6] stipulates that 'If cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient dies in a dignified and peaceful manner..... if a patient has an existing condition that makes cardiac or respiratory arrest likely, establishing a management plan in advance will help to ensure that the patient's wishes and preferences about treatment can be taken into account and that, if appropriate, a DNACPR decision is made and recorded'. This guidance supports the generation of the Clinical KPI 6 summary cut off score of five, which reflects the audit recommendation that decisions regarding CPR are routinely undertaken and communicated with both the patient and their nominated relative or friend, where possible. This KPI summary cut off score was achieved in 55% (n=3,650) of cases.

Domain 7: patient's nutritional needs during the dying phase

(Note: questions 7a – 7e inclusive, were only applicable to clinical cases in which recognition of the patient's imminent death had been documented with the last episode of care).

Table 55

Question number	Question	Response options	KPI component
7a	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?	Yes No	Yes
7b	Is there documented evidence that an assessment regarding the patient's need for Clinically Assisted (artificial) Nutrition (CAN) was made following recognition that the patient was expected to die in the coming hours or days?	Yes No	Yes
7c	If the answer to question 7b is 'yes': What was the date and time of the **latest** documented decision regarding the patient's need for Clinically Assisted (artificial) Nutrition (CAN)?	Date (DD/MM/YYYY); unknown Time (HH:MM); unknown	
7d	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?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient didn't want bad news.	Yes
7e	Is there documented evidence that a discussion regarding nutrition options/care was undertaken with the nominated relative or friend or the nominated Independent Mental Capacity Advocate, following recognition that the patient was expected to die in the coming hours or days?	Yes No No but: • attempts to contact them were unsuccessful • IMCA unavailable.	Yes
7f	***The following question should be answered for ALL cases:*** At the time of the patient's death was clinically assisted (artificial) Nutrition (CAN) in place?	Yes No	

Clinical KPI 7: a review of the patient's nutrition requirements

Table 56

Question number	Scoring	Score range
7a	7a: Yes=2; 7a: No=0	0-8
7b	7b: Yes=2; 7b: No=0	
7d	7d: Yes=2; 7d: No but=2; 7d: No=0	
7e	7e: Yes=2; 7e: No but=1; 7e: No=0	

Table 57

Clinical KPI 7 score	National (n=6,580) (n=5722)	KPI achieved	KPI not achieved
0	17% (n=999)		61%
1	0.1% (n=6)		
2	25% (n=1411)		
3	0.7% (n=39)		
4	17% (n=992)		
5	0.5% (n=26)		
KPI cut off score = 6			
6	**19% (n=1113)**	**39%**	
7	**0.5% (n=30)**		
8	**19% (n=1106)**		

Table 58

Question number	Questions	National (n=6,580)
7.a	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 (n=5,722).	59% (3,398)
7.b	An assessment regarding the patient's need for Clinically Assisted (artificial) Nutrition (CAN) was made following recognition that the patient was expected to die in the coming hours or days (n=5,722).	45% (2,563)
7.c	Median number of hours between the date and time of the last decision regarding the patient's need for CAN and the date and time of the patient's death. (IQR) (n)	32.7 (11.5 – 79.7) (2,033)
7.d	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 patients who were capable of participating in such discussions (42%, n=2,422):	% (n=5,722)
	yes	17% (420)
	no.	83% (2,002)
	Status of patients who were incapable of participating in such discussions (58% n=3,300):	
	no as patient lacked mental capacity	38% (1,243)
	no as patient unconscious	62% (2,019)
	no as patient didn't want to receive bad news.	1% (38)
7.e	A discussion regarding nutrition options/care was undertaken with the relative/friend or IMCA, following recognition that the patient was expected to die in the coming hours or days:	% (n=5,722)
	yes	29% (1,658)
	no	69% (3,963)
	no as attempts to contact them were unsuccessful	2% (86)
	no as the nominated IMCA was unavailable within the timeframes.	0.3% (15)
7.f	At the time of the patient's death clinically assisted (artificial) Nutrition (CAN) was in place (n=6,579).	7% (441)

Clinical KPI 7 commentary: a review of the patient’s nutrition requirements

An assessment of the patient’s ability to take oral nutrition following recognition that the patient was expected to die in the coming hours or days was recorded in 59% (n=3,398) of cases.

An assessment of the patient’s need for Clinically Assisted (artificial) Nutrition (CAN) following recognition that the patient was expected to die in the coming hours or days was recorded in 45% (n=2,563) of cases. The median elapsed time between the first documented CAN decision and the patient’s death was 32.7 hours (IQR: 11.5-79.7).

Patients were generally recorded as being incapable of participating in such discussions (58%, n=3,300). However, 42% (n=2,422) of patients were reportedly assessed as being capable of participating in discussions regarding nutritional options. Of these patients, such discussions between health professionals and patients were reported to have been undertaken in only 17% (n=420) of cases.

Discussions with relatives occurred relatively infrequently in this instance and were recorded in 29% (n=1,658) of cases.

CAN was recorded as being in place at the time of the patient’s death in 7% (n=441) of cases.

These results suggest opportunities for trusts to improve in health professionals’ assessment of patients ability and need of nutrition options and subsequent discussions with the patient, where possible, and the nominated relative or friend. Further, trusts should ensure that such decisions and discussions are documented appropriately.

Paragraphs 109–127 within the General Medical Council (GMC) Guidelines[6] stipulate that ‘You must assess the patient’s nutrition and hydration needs separately. If you judge that the provision of clinically assisted nutrition or hydration would not be of overall benefit to the patient, you may conclude that the treatment should not be started at that time or should be withdrawn. You should explain your view to the patient, if appropriate, and those close to them, and respond to any questions or concerns they express’. This guidance supports the generation of the Clinical KPI 7 summary cut off score of six, which reflects the audit recommendation that decisions regarding patients ability and need of nutrition options are routinely undertaken and communicated with both the patient, where possible, and their nominated relative or friend. This KPI summary cut off score was achieved in 39% of cases.

Recommendation: Decisions about the use of clinically assisted (artificial) nutrition and hydration are complex and should be taken by a senior experienced clinician supported by a multidisciplinary team. They should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.

Domain 8: patient's hydration needs during the dying phase

(Note: questions 8a – 8e inclusive, were only applicable to clinical cases in which recognition of the patient's imminent death had been documented with the last episode of care).

Table 59

Question number	Question	Response options	KPI component
8a	Is there documented evidence that an assessment regarding the patient's ability to take oral hydration was made following recognition that the patient was expected to die in the coming hours or days?	Yes No	Yes
8b	Is there documented evidence that an assessment regarding the patient's need for Clinically Assisted (artificial) Hydration (CAH) was made following recognition that the patient was expected to die in the coming hours or days?	Yes No	Yes
8c	If the answer to question 8b is 'yes': What was the date and time of the **latest** documented decision regarding the patient's need for Clinically Assisted (artificial) Hydration (CAH)?	Date (DD/MM/YYYY); unknown Time (HH:MM); unknown	
8d	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?	Yes No No but: • patient lacked mental capacity • patient unconscious • patient didn't want bad news.	Yes
8e	Is there documented evidence that a discussion regarding hydration options/care was undertaken with the nominated relative or friend or the nominated Independent Mental Capacity Advocate, following recognition that the patient was expected to die in the coming hours or days?	Yes No No but: • attempts to contact them were unsuccessful. • IMCA unavailable.	Yes
8f	**The following questions should be answered for all cases:** In the last 24 hours of the patient's life is there documented evidence that the patient received: • oral fluids • mouth care.	Yes No	
8g	At the time of the patient's death was clinically assisted (artificial) Hydration (CAH) in place?	Yes No	

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

Table 60

Question number	Scoring	Score range
8a	8a: Yes=2; 8a: No=0	0-8
8b	8b: Yes=2; 8b: No=0	
8d	8d: Yes=2; 8d: No but=2; 8d: No=0	
8e	8e: Yes=2; 8e: No but=1;8e: No=0	

Table 61

Clinical KPI 8 score	National (n=6,580) (n=5722)	KPI achieved	KPI not achieved
0	13% (n=760)		52%
1	0.1% (n=6)		
2	20% (n=1139)		
3	0.7% (n=42)		
4	18% (n=1018)		
5	0.3% (n=20)		
KPI cut off score = 6			
6	**23% (n=1297)**	**48%**	
7	**0.8% (n=43)**		
8	**24% (n=1397)**		

Table 62

Question number	Questions	National (n=6,580)
8.a	An assessment regarding the patient's ability to take oral hydration was made following recognition that the patient was expected to die in the coming hours or days (n=5,722).	64% (3,634)
8.b	An assessment regarding the patient's need for Clinically Assisted (artificial) Hydration (CAH) was made following recognition that the patient was expected to die in the coming hours or days (n=5,722).	59% (3,351)
8.c	Median number of hours between the date and time of the last decision regarding the patient's need for CAH and the date and time of the patient's death.	23.3 median (IQR 7.8 – 64.0) (n=2,655)
8.d	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 who were capable of participating in such discussions (40%, n=2,291): yes no status of patients incapable of participating in such discussions (60%, n=3,431): no as patient lacked mental capacity no as patient unconscious no as patient didn't want to receive bad news.	% (n=5,722) 17% (398) 83% (1,893) 37% (1,263) 62% (2,126) 1% (42)
8.e	A discussion regarding hydration options/care was undertaken with the relative, following recognition that the patient was expected to die in the coming hours or days: yes no no as attempts to contact them were unsuccessful no as the nominated IMCA was unavailable within the timeframes.	% (n=5,722) 36% (2,051) 62% (3,560) 2% (100) 0.2% (11)
8.f	In the last 24 hours of the patient's life there was documented evidence that the patient received: i. oral fluids ii. mouth care.	% (n=6,579) 37% (2,455) 65% (4,262)
8.g	At the time of the patient's death clinically assisted (artificial) hydration (CAH) was in place (n=6,579).	29% (1,916)

Clinical KPI 8 commentary: A review of the patient’s hydration requirements

An assessment of the patient’s ability to take oral hydration following recognition that the patient was expected to die in the coming hours or days was recorded in 64% (n=3,634) of cases.

An assessment of the patient’s need for Clinically Assisted (artificial) Hydration (CAH) following recognition that the patient was expected to die in the coming hours or days was recorded in 59% (n=3,351) of cases. The median elapsed time between the first documented CAH decision and the patient’s death was 23.3 hours (IQR: 7.8-64.0).

Patients were generally recorded as being incapable of participating in such discussions (60%, n=3,431). However, 40% (n=2,291) of patients were reportedly assessed as being capable of participating in discussions regarding hydration options. Of these patients, such discussions between health professionals and patients were reported as having been undertaken in 17% (n=398) of cases.

Discussions with relatives occurred relatively infrequently in this instance and were reported in only 36% (n=2,051) of cases.

Patients were recorded as more likely to receive mouth care (65%, n=4,262) than oral fluids (37%, n=2,455) during the last 24 hours of life.

CAH was recorded as being in place at the time of the patient’s death in 29% (n=1,916) of cases (which is a higher rate than that of CAN (ie 7%, n=441).

These results suggest opportunities for trusts to improve in health professionals’ assessment of patients ability and need of hydration options and subsequent discussions with the patient, where possible, and the nominated relative or friend. Trusts should also ensure that such decisions and discussions are documented appropriately. Further, the provision of ‘mouth care’ should be standard practice regardless of the hydration needs or status of the patient and these results show that there are further opportunities for improvement in providing this care routinely.

Paragraphs 109–127 within the General Medical Council (GMC) Guidelines[6] stipulate that: ‘You must assess the patient’s nutrition and hydration needs separately. If you judge that the provision of clinically assisted nutrition or hydration would not be of overall benefit to the patient, you may conclude that the treatment should not be started at that time or should be withdrawn. You should explain your view to the patient, if appropriate, and those close to them, and respond to any questions or concerns they express’. This guidance supports the generation of the Clinical KPI 8 summary cut off score of six, which reflects the audit recommendation that decisions regarding patients ability and need of hydration options are routinely undertaken and communicated with both the patient, where possible, and their nominated relative or friend. This KPI summary cut off score was achieved in 48% of cases.

Recommendation: Decisions about the use of clinically assisted (artificial) nutrition and hydration are complex and should be taken by a senior experienced clinician supported by a multidisciplinary team. They should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.

Domain 9: number of regular patient assessments during last 24 hours of the patient's life

Table 63

Question number	Question	Response options	KPI component
9a	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?	Number of assessments	Yes

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

Table 64

Question number	Scoring	Score range
9a	<5 assessments ≥5 assessments	Report number and percentages for each category

Table 65

Clinical KPI 9 score	National (n=6,580)	KPI achieved	KPI not achieved
<5	18% (n=1,171)		18%
KPI cut off score ≥ 5			
≥5	**82% (n=5, 409)**	**82%**	

Table 66

Question number	Questions	National (n=6,580)
9.a	The number of clinical cases in which clinical assessments were undertaken during the final 24 hour timeframe:	
	≤4 assessments	18% (1,171)
	5–10 assessments	57% (3,769)
	11–15 assessments	15% (965)
	16–20 assessments	5% (343)
	21–25 assessments	3% (169)
	26–30 assessments	1% (86)
	31–36 assessments	1% (77)

Clinical KPI 9 commentary: Review of the number of assessments undertaken in the patient's last 24 hours of life

Five or more assessments of the patient were reported as being undertaken during the final 24 hour timeframe in 82% (n=5,409) of cases. In just over half of cases (57% (n=3,769)) between 5 and 10 assessments were recorded during the last 24 hours of the patient's life. Between 11 and 15 assessments were recorded in 15% (n=965) of cases whilst more than 15 assessments were recorded in 10% (n=675) of cases. These results suggest that patients were being monitored very regularly during the last 24 hours of their lives.

Within the End of Life Care Strategy[2], recommendations stipulate that 'end of life care should include: assessment, care planning and review'. This guidance supports the generation of the Clinical KPI 9 summary cut off score of ≥ 5 assessments within the last 24 hours of life, which reflects the audit recommendation that patient assessments should be undertaken and documented at least 4-hourly over a 24 hour timeframe. This KPI summary cut off score was achieved in 82% (n=5,409) of cases.

Domain 10: care of the patient and the nominated relative/friend immediately after the patient’s death to ensure dignity and respect

Table 67

Question number	Question	Response options	KPI component
10a	Is there documented evidence that the care of the body of the deceased was undertaken?	Yes No	Yes
10b	Is there documented evidence that the nominated relative/friend was given any written information following death of the patient?	Yes No	Yes

Clinical KPI 10: a review of the care after deat*h*

Table 68

Question number	Scoring	Score range
10a 10b	10a: Yes = 1; 10a: No = 0 10b: Yes = 1; 10b: No = 0	0-2

Table 69

Clinical KPI 10 score	National (n=6,580)	KPI achieved	KPI not achieved
0	44% (n=2,879)		44%
KPI cut off score = 1			
1	**22% (n=1,416)**	**56%**	
2	**35% (n=2,285)**		

Table 70

Question number	Questions	National (n=6,580)
10.a	Care of the body of the deceased was documented as having been undertaken (n=6,579).	46% (3,037)
10.b	The nominated relative or friend was given any written information following the death of the patient (n=6,579).	45% (2,949)

Clinical KPI 10 commentary: a review of the care after death

Information about the care of the body was recorded in 46% (n=3,037) of cases. Documented evidence that the relative was given written information following the death of the patient was recorded in 45% (n=2,949) of cases. These results suggest that, at the very least, there are further opportunities for trusts to improve the documentation of care after death for both the patient and their nominated relative or friend.

Paragraph 3.68 within the End of Life Care Strategy[2] stipulates that ‘Good end of life care does not stop at the point of death. When a person dies, all staff need to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes and cultural or religious and spiritual needs’. Paragraph 3.94 within the End of Life Care Strategy[2] stipulates that ‘people need.....information of a variety of subjects and issues such as....practical advice on what to do when someone dies’ This guidance supports the generation of the Clinical KPI 10 summary cut off score of one, which reflects the audit recommendation that given the current gap between aspirational and actual care provision following the patients’ death, at the very least documentary evidence of care of the body after death should be maintained.

Local survey of bereaved relatives' views

General commentary: local survey of bereaved relatives' views (ie Care of the Dying Evaluation (CODE) questionnaire national dataset responses)

Within the NHS constitution,[9] point 3.b stipulates a number of patient and public responsibilities and a plea for patients to '... give feedback – both positive and negative – about your experiences and the treatment and care you have received ..... If a family member or someone you are a carer for is a patient and unable to provide feedback, you are encouraged to give feedback about their experiences on their behalf. Feedback will help to improve NHS services for all.' This plea supported the inclusion of this audit element into the audit, which was well received by Trusts and for which 82% (n=112) of the then participating Trusts (n=135) registered to take part in this element of the audit.

CODE[11] is a 40-item self-completion questionnaire, used with bereaved relatives or friends to assess the quality of care and the level of support provided to individuals and their families in the last days and hours of life. The NHS Friends and Family Test[22] was also included as an additional question within this questionnaire. CODE[11] represents a shortened and more user-friendly version of the original instrument, 'Evaluating Care and Health Outcomes - for the Dying' (ECHO-D).[23] ECHO-D[23] has been used with over 700 bereaved relatives within a hospice and hospital setting and has been shown to be valid, reliable and sensitive in detecting inequalities in care and areas of unmet need.[24] Both these instruments are unique from other post-bereavement questionnaires as they specifically link with the key components representing best practice for 'care of the dying' ie the last days of life.[25]

Participation figures: local survey of bereaved relatives' views

Although the audit protocol and guidance stipulated a data collection period spanning May and June 2013, a number of patient cases relating to patient deaths registered in July 2013 were entered into the audit web tool. The decision was ratified by the Steering Group in February 2014 to include all cases entered by participating sites into the national dataset which was made available for data analysis.

3,414 patient cases were reported to match the local survey of bereaved relatives' views eligibility criteria at the clinical governance level as described for the case note review element in the protocol. 95 patient cases were subsequently removed from the local survey of bereaved relatives' views as the patient cases were being managed within the trust complaints system. 1,006 cases were then excluded as the next of kin details, for example full postal addresses were unavailable.

2,313 CODE[11] questionnaires were therefore mailed to bereaved relatives by trusts, from which information regarding 858 CODE[11] questionnaires was entered into the audit web tool (by either the bereaved relative or the registered trust on their behalf) and available for data analysis. These data came from 36 trusts (40 Sites) and represented 596, 248 and 14 patient deaths' during May, June and July 2013, respectively.

Demographic information for bereaved relative or friend

Table 71

Demographic information for bereaved relative or friend: National (n=858)	%	n
Relationship to patient? (n=825)		
Husband/Wife/Partner	47	(387)
Son/Daughter	44	(366)
Brother/Sister	3	(24)
Son-in-law/Daughter-in-law	1	(6)
Parent	1	(11)
Friend	0.1	(1)
Neighbour	0.1	(1)
Staff in nursing or residential home	0	(0)
Warden (sheltered accommodation)	0.1	(1)
Other	3	(28)
Age in years (n=822)		
18–19	0	(0)
20–29	1	(5)
30–39	1	(8)
40–49	10	(80)
50–59	24	(194)
60–69	30	(248)
70–79	22	(179)
80+	13	(108)
Ethnicity (n=817)		
White British	97	(794)
Mixed white/black Caribbean	0.2	(2)
White Irish	1	(6)
Mixed white/black African	0.1	(1)
White other	1	(7)
Mixed white/Asian	0.1	(1)
Indian	0.1	(1)
Mixed other	0	(0)
Pakistani	0	(0)
Black Caribbean	0.2	(2)
Bangladeshi	0	(0)
Black African	0.1	(1)
Asian other	0.1	(1)
Black other	0	(0)
None of these	0.1	(1)
Gender (n=801)		
Male	35	(278)
Female	65	(523)
Religious affiliation (n=806)		
None	15	(117)
Christian	84	(676)
Hindu	0	(0)
Buddhist	0.4	(3)
Jewish	1	(5)
Muslim	0.1	(1)
Sikh	0.1	(1)
Any other religion	0.4	(3)

Demographic information for patient

Table 72

Demographic information for patient: National (n=858)		
	%	n
Diagnosed Illnesses during the last days of life (n=858)		
Cancer (including leukaemia and lymphoma)	31	(265)
Heart failure	27	(228)
COPD	19	(162)
End-stage renal (or kidney) disease	14	(118)
Dementia	13	(114)
Motor neurone disease	0.5	(4)
Don’t know	3	(30)
Something else	27	(235)
Age in years (n=816)		
18–19	0	(0)
20–29	0.1	(1)
30–39	0.1	(1)
40–49	1	(6)
50–59	4	(32)
60–69	13	(102)
70–79	27	(218)
80+	56	(456)
Ethnicity (n=809)		
White British	96	(780)
Mixed white/black Caribbean	0	(0)
White Irish	1	(8)
Mixed white/black African	0.1	(1)
White other	2	(14)
Mixed white/Asian	0	(0)
Indian	0.1	(1)
Mixed other	0	(0)
Pakistani	0	(0)
Black Caribbean	0	(0)
Bangladeshi	0	(0)
Black African	0.2	(2)
Asian other	0.1	(1)
Black other	0	(0)
None of these	0.2	(2)
Gender (n=782)		
Male	51	(395)
Female	49	(387)
Religious affiliation (n=805)		
None	14	(109)
Christian	84	(678)
Hindu	0	(0)
Buddhist	0.2	(2)
Jewish	1	(5)
Muslim	0.1	(1)
Sikh	0.1	(1)
Any other religion	1	(9)

Demographic data commentary:

The bereaved relative or friend who completed the CODE[11] questionnaire was most likely to be: female (65%), aged between 60 and 69 (30%) or 50 and 59 (24%), of white British ethnicity (97%), and Christian religion (84%), and a spouse/partner (47%) or son/daughter (44%).

The patient to which the CODE[11] questionnaire responses relate were: male (in 51% of cases), most likely to be aged 80+ (56%) or between 70 and 79 years of age (27%), of white British ethnicity (96%) and Christian religion (84%).

Section A: the care received from the nurses and doctors

Table 73

Section A: Care received from the nurses and doctors: National (n=858)	%	n
1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs (n=851)		
Strongly agree	32	(272)
Agree	51	(430)
Neither agree or disagree	6	(54)
Disagree	7	(57)
Strongly disagree	4	(38)
Missing data		(7)
2. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed (n=848)		
Strongly agree	36	(306)
Agree	45	(384)
Neither agree or disagree	7	(62)
Disagree	7	(56)
Strongly disagree	5	(40)
Missing data		(10)
3. The bed area and surrounding environment was comfortable for him/her (n=851)		
Strongly agree	32	(275)
Agree	50	(429)
Neither agree or disagree	8	(72)
Disagree	5	(45)
Strongly disagree	4	(30)
Missing data		(7)
4. The bed area and surrounding environment had adequate privacy for him/her (n=850)		
Strongly agree	36	(308)
Agree	41	(351)
Neither agree or disagree	10	(83)
Disagree	8	(66)
Strongly disagree	5	(42)
Missing data		(8)
5. In your opinion, how clean was the ward area that s/he was in? (n=848		
Very clean	68	(577)
Fairly clean	30	(258)
Not at all clean	2	(13)
Missing data		(10)
6. Did you have confidence and trust in the nurses who were caring for him/her? (n=842)		
Yes, in all of them	67	(561)
Yes, in some of them	30	(251)
No, not in any of the nurses	4	(30)
Missing data		(16)
7. Did you have confidence and trust in the doctors who were caring for him/her? (n=841)		
Yes, in all of them	68	(575)
Yes, in some of them	25	(212)
No, not in any of the doctors	6	(54)
Missing data		(17)
8. The nurses had time to listen and discuss his/her condition with me (n=847)		
Strongly agree	34	(290)
Agree	40	(336)
Neither agree or disagree	11	(90)
Disagree	10	(82)
Strongly disagree	6	(49)
Missing data		(11)
9. The doctors had time to listen and discuss his/her condition with me (n=832)		
Strongly agree	34	(284)
Agree	39	(326)
Neither agree or disagree	12	(101)
Disagree	9	(78)
Strongly disagree	5	(43)
Missing data		(26)

Section A commentary: the care received from doctors and nurses

The majority of bereaved relatives responded that they ‘agreed (ie ‘Strongly agreed’ or ‘Agreed’) to the following aspects of care: there was enough help available to meet the patient’s personal care needs (82%, n=702); enough help with nursing care (81%, n=690) the bed area and surrounding environment was comfortable for the patient (83%, n=704); and the bed area and surrounding environment had adequate privacy for the patient (77%; n=659). However, a small minority – between 4% and 5% (ie n=30-42) – of these bereaved relatives responded ‘strongly disagree’ to these questions.

The majority of bereaved relatives also considered the ward area to be ‘very clean’ (68% n=577) whilst 2% (n=13) responded that the environment was ‘not at all clean’.

Two thirds of bereaved relatives reported that they had confidence and trust in all the nurses (67%, n=561) and doctors (68%, n=575) caring for the patient. However, 4% (n=30) and 6% (n=54) reported that they did not have any confidence or trust in either the nurses or doctors caring for the patient, respectively.

There were generally positive perceptions by bereaved relatives that both the nurses (74% (n=626) and doctors (73% (n=610) had time to listen and discuss the patient’s condition with them. However, 6% (n=49) and 5% (n=43) of bereaved relatives responded ‘strongly disagree’ to this statement for both nurses and doctors, respectively. It is also worth remembering that the views of 95 bereaved relatives were not sought as part of this exercise as their cases were within hospital complaints systems. It could be argued that because of this more negative perspectives remain absent.

Section B: the control of pain and other symptoms

Table 74

Section B: The control of pain and other symptoms: National (n=858)		
	%	n
10. In your opinion, during the last two days, did s/he appear to be in pain? (n=845)		
Yes, all of time	9	(76)
Yes, some of time	40	(335)
No, s/he did not appear to be in pain	51	(434)
Missing data		(13
11. In your view, did the doctors and nurses do enough to help relieve the pain? (n=833)		
Yes, all of time	52	(437)
Yes, some of time	23	(193)
No, not at all	4	(34)
Not applicable, s/he was not in pain	20	(169)
Missing data		(25)
12. In your opinion, during the last two days, did s/he appear to be restless? (n=844)		
Yes, all of time	13	(112)
Yes, some of time	47	(399)
No, s/he did not appear to be restless	39	(333)
Missing data		(14)
13. In your view, did the doctors and nurses do enough to help relieve the restlessness? (n=830)		
Yes, all of time	34	(282)
Yes, some of time	31	(255)
No, not at all	7	(54)
Not applicable, s/he was not restless	29	(239)
Missing data		(28)
14. In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing? (n=833)		
Yes, all of time	16	(130)
Yes, some of time	33	(274)
No, s/he did not have a 'noisy rattle' to the breathing	52	(429)
Missing data		(25)
15. In your view did the doctors and nurses do enough to help relieve the 'noisy rattle' to his/her breathing? (n=807)		
Yes, all of time	23	(188)
Yes, some of time	21	(169)
No, not at all	7	(59)
Not applicable, s/he was not restless	48	(391)
Missing data		(51)

Section B commentary: The control of pain and other symptoms

A relatively high proportion of patients were deemed not to have had pain and other symptoms at all in the last 2 days of life (ie no pain 51% (n=434); not restless 39% (n=333); no noisy breathing 52% (n=429)). However, a proportion were perceived to have had symptoms all of the time (ie pain 9% (n=76); restless 13% (n=112); noisy breathing 16% (n=130)). Such experiences are unexpected given that between 98% and 99% of participating trusts reported having clinical protocols in place for the anticipatory prescribing of medications for the key symptoms in the dying phase.

Overall, relatives reported that healthcare professionals had responded to the symptom control needs of the patient. However, for a minority of patients, relatives reported that the healthcare team had 'not at all' done enough to help to relieve these symptoms (ie pain 4% (n=34); restless 7% (n=54); noisy breathing 7% (n=59)).

Section C: communication with the healthcare team

Table 75

Section C: Communication with the healthcare team: National (n=858)	%	n
16. During the last two days how involved were you with the decisions about his/her care and treatment? (n=839)		
Very involved	48	(402)
Fairly involved	28	(237)
Not involved	24	(200)
Missing data		(19)
17. Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last 2 days of life? (n=818)		
Yes	39	(323)
No	50	(411)
Don't know	10	(84)
Missing data		(40)
18. Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful? (n=791)		
Yes	35	(279)
No	29	(230)
Not applicable we had these types of discussion	36	(282)
Missing data		(67)
19. Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand? (n=842)		
Very easy	50	(418)
Fairly easy	32	(268)
Fairly difficult	4	(37)
Very difficult	2	(20)
They did not explain his/her condition or treatment to me	12	(99)
Missing data		(16)

Section C commentary: communication with the healthcare team

Bereaved relatives considered themselves to either be 'very involved' (ie 48% (n=402)) or 'fairly involved' (ie 28% (n=237)) in the decisions about the patient's care and treatment. This is similar in proportion to the discussions regarding the patient's plan of care that were recorded within the case note review element, between health professionals and nominated relatives or friends (ie 73% (n=4,780). Again, however, a significant minority of bereaved relatives considered themselves to have not been involved in such discussions (ie 24% (n=200)).

39% (n=323) of bereaved relatives confirmed that the healthcare team had discussed whether giving fluids through a drip would be appropriate for the patient. Again these results reflect the results within the case note review whereby 36% (n=2,051) of cases recorded discussions regarding hydration options between health professionals and nominated relatives or friends. It is noteworthy that whilst 35% (n=279) of bereaved relatives reported that they would have found such discussions helpful, 29% (n=230) reported that they would not have found them helpful.[††]

The majority of bereaved relatives considered that the health care team explanations regarding the patient's condition and/or treatment were either 'very easy' (ie 50% (n=418)) or 'fairly easy' (ie 32% (n=268) to understand. However, 2% (n=20) bereaved relatives reported that they found such explanations 'very difficult' to understand.

[††] Note that the 39% from Q17 and the 35% and 29% from Q18 don't add to 100% – in part a consequence of the information coming from two separate questions with different known denominators.

Section D: the emotional and spiritual support provided by the healthcare team

Table 76

Section D: The emotional and spiritual support provided by the healthcare team: National (n=858)	%	n
20. How would you assess the overall level of emotional support given to you by the healthcare team? (n=830)		
Poor	17	(140)
Fair	20	(170)
Good	33	(275)
Excellent	30	(245)
Missing data		(28)
21. Overall, his/her religious or spiritual needs were met by the healthcare team (n=779)		
Strongly agree	13	(103)
Agree	26	(203)
Neither agree or disagree	50	(387)
Disagree	6	(50)
Strongly disagree	5	(36)
Missing data		(79)
22. Overall, my religious or spiritual needs were met by the healthcare team (n=766)		
Strongly agree	12	(95)
Agree	22	(172)
Neither agree or disagree	51	(393)
Disagree	8	(61)
Strongly disagree	6	(45)
Missing data		(92)

Section D commentary: The circumstances surrounding the patient's death

Two-thirds of bereaved relatives reported that they perceived the level of emotional support provided to them by the healthcare team was either 'excellent' (ie 30% (n=245)) or 'good' (ie 33% (N=275)). However, a significant minority (17%, n=140) of bereaved relatives reported emotional support to be 'poor'.

Just over a third of bereaved relatives either responded 'strongly agree' (ie 13% (n=103)) or 'agree' (ie 26% (n=203)) when asked whether the patient's spiritual needs were met by the healthcare team. A similar proportion of bereaved relatives either responded 'strongly agree' (ie 12% (n=95)) or 'agree' (ie 22% (n=172)) when asked whether their own spiritual needs were met by the healthcare team. Again, these results resonate with those within the clinical element of the audit where the documentation of discussions between health professionals and the nominated relative or friend were limited in relation to both the patient's spiritual needs (ie 23% (n=1.342) and those of the relative (ie 25% (n=1.623)).

Again, a significant minority of bereaved relatives reported 'strongly disagree' when asked either whether the patient's (ie 5% (n=36)) or their own (ie 6% (n=45)) spiritual needs were met by the healthcare team.

More strikingly, however, was that at least half of respondents recorded that they 'neither agreed not disagreed' that either the patient's (ie 50% (n=387)) or their own (ie 51% (n=393)) spiritual needs were met by the healthcare team. It could be argued that this suggests some lack of understanding and interpretation regarding 'spiritual needs'.

Section E: the circumstances surrounding his/her death

Section E: The circumstances surrounding his/her death: National (n=858)		
	%	**n**
23. Before s/he died, were you told s/he was likely to die soon? (n=835)		
Yes	74	(616)
No	26	(219)
Missing data		(23)
24. Did a member of the healthcare team talk to you about what to expect when s/he was dying (eg symptoms that may arise)? (n=815)		
Yes	46	(377)
No	54	(438)
Missing data		(43)
25. Would a discussion about what to expect when s/he was dying have been helpful? (n=810)		
Yes	44	(355)
No	17	(141)
Not applicable we had these types of discussions	39	(314)
Missing data		(48)
26. In your opinion did s/he die in the right place? (n=837)		
Yes it was the right place	72	(606)
No it was not the right place	16	(134)
Not sure	9	(72)
Don't know	3	(25)
Missing data		(21)
27. I was given enough help and support by the healthcare team at the actual time of his/her death (n=829)		
Strongly agree	38	(311)
Agree	35	(288)
Neither agree or disagree	14	(114)
Disagree	7	(61)
Strongly disagree	7	(55)
Missing data		(29)
28. After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner? (n=822)		
Yes	83	(686)
No	8	(64)
Not applicable I didn't have any contact with the healthcare team	9	(72)
Missing data		(36)

Section E commentary: the circumstances surrounding the patient's death

Seventy four per cent (n=616) of bereaved relatives reported being told that the patient was likely to die soon, whilst 26% (n=219) of relatives reported that they were not told that the patient was likely to die soon. In contrast, the results reported within the clinical data indicated that in 93% (n=5,313) of cases discussions were undertaken between health professionals and nominated relatives or friends regarding awareness that the patient was dying. It is impossible to draw any firm conclusions regarding these observed differences in proportions, however, as the method undertaken for this audit makes it impossible to match individual cases from the larger clinical sample with those from the more limited CODE[11] questionnaire responses. Further, perceptions regarding the content and/or quality of such conversations may differ between bereaved relatives and health professionals, which again are not captured within the audit.

Forty six per cent of relatives (n=377) recalled being told what to expect (eg symptoms that might arise) when the patient was dying, whilst 44% (n=355) reportedly felt that such discussions would have been helpful.[‡‡] Comparing these results to the case note review results, discussions between health professionals and the nominated relative or friend regarding treatment options for symptom control were reportedly included within discussions regarding the patient's plan of care for the dying phase in 66% of cases. Again, this demonstrates a slight disconnect between documented discussions for the larger clinical sample and bereaved relatives perceptions in the smaller CODE sample. This reinforces the need for competent health care professionals to undertake these conversations and provide written material if appropriate.

Seventy two per cent (n=606) of bereaved relatives considered that the patient had died in the right place. Interestingly, in a proportion of the case note review sample (n=1,602) for whom the patient's preferred place of care had been documented within the case notes, Hospital had been recorded for only 40% (n=648) of cases. This data suggests caution regarding claims that people wish to die at home, as it may be that perceptions shift in support of hospital, which comes to be seen as the best place.

Bereaved relatives either responded 'strongly agree' (ie 38% (n=311)) or 'agree' (ie 35% (n=288)) when asked whether the healthcare team had given them enough help and support at the time of the patient's death. However, 7% (n=55) of bereaved relatives 'strongly disagreed' with this view.

Whilst 83% (n=686) bereaved relatives reportedly felt that the healthcare team dealt with them in a sensitive manner when the patient died, 8% (n=64) of bereaved relatives recorded that they did not agree with this statement and 9% (n=72) of bereaved relatives reported that they did not have any contact with the team at that time.

[‡‡] Note that the 44% helpful comes from Q25 whilst the 46% comes from Q24. These do not sum to 100% as Q24 and Q25 have different known denominators.

Key outcome measures – section F: overall impressions

Table 77

Key outcome measures – section F: overall impressions: National (n=858)	%	n
29a. How much of the time was s/he treated with respect and dignity in the last 2 days of life? – By doctors (n=815)		
Always	66	(535)
Most of the time	13	(105)
Some of the time	8	(63)
Never	3	(25)
Don't know	11	(87)
Missing data		(43)
29b. How much of the time was s/he treated with respect and dignity in the last 2 days of life? – By nurses (n=823)		
Always	70	(577)
Most of the time	16	(131)
Some of the time	9	(76)
Never	3	(21)
Don't know	2	(18)
Missing data		(35)
30. Overall, in your opinion, were you adequately supported during his/her last 2 days of life? (n=802)		
Yes	76	(610)
No	24	(192)
Missing data		(56)
31. How likely are you to recommend our trust to friends and family? (n=820)		
Extremely likely	40	(328)
Likely	28	(232)
Neither likely or unlikely	16	(132)
Unlikely	4	(32)
Extremely unlikely	8	(64)
Don't know	4	(32)
Missing data		(38)

Key outcome measure	Question item	Scale range	Friends and family test score
NHS Friends and family test[22] How likely are you to recommend our trust to friends and family? Represents a simple, comparable test which, when combined with follow-up questions, provides a mechanism to identify both good and bad performance and encourage staff to make improvements where services do not live up to expectations.	F31 Proportion of respondents who would be extremely likely to recommend (response category: 'extremely likely') Less Proportion of respondents who would not recommend (response categories: 'neither likely nor unlikely', 'unlikely' and 'extremely unlikely'). (NB: It is important to highlight that, while "likely" responses are not mentioned in the calculation, they will of course form part of the total (the denominator for both parts of the calculation) and the numbers of 'likely' responses are therefore highly influential on the final score.)	**-100 - +100**	The NHS Friends and Family Test score for May – July 2013 for the National Care of the Dying Audit for Hospitals is 13. This is based on 820 responses.

Table 78

Section F key outcome measures commentary: overall impressions

Three key outcome measures were included within the questionnaire to give an overview of the perception of care received.

Sixty six per cent (n=535) and 70% (n=577) of bereaved relatives perceived that the patient was 'always' treated with dignity and respect in the last two days of life by doctors and nurses respectively. These figures are comparative with the results of the most recent VOICES results (ie 67% and 63% for doctors and nurses, respectively). However 3% of bereaved relatives perceived that the patient was 'never' treated with dignity and respect in the last two days of life by either doctors (n=25) or nurses (n=21).

Although 76% (n=610) of bereaved relatives perceived that they themselves were adequately supported during the patient's last 2 days of life, 24% (n=192) did not consider themselves to have been adequately supported during this time.

From the 858 CODE[11] questionnaire responses analysed which related to patient care delivered between May 2013 and July 2013, 68% (n=560) of bereaved relatives were reportedly either 'extremely likely' or 'likely' to recommend the trust to friends and family. This equates to an NHS Friends and Family Test[22] score of 13, for which there is no comparator within the existing NHS Friends and Family Test[22] scores, as determined by care provision category. However, 8% (n=64) of respondents reported being 'extremely unlikely' to recommend the trust to friends and family.

Whilst much of the data suggests that the majority of bereaved relatives' views are positive regarding all measured aspects of end of life care provided by acute hospital trusts to the patients and themselves, a significant minority of bereaved relatives have reported negative perceptions of this care. The challenge is therefore to improve the standard of care, including the level of communication in order to meet the needs of patients and their relatives at this critical time.

Recommendations

Hospitals should provide a face-to-face specialist palliative care service from at least 9am to 5pm, 7 days per week, to support the care of dying patients and their families, carers or advocates.

Rationale	Audit context
Neuberger[10]: Recommendation 33, 'Funding should be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, 7 days a week'. In addition: NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers[4]; Guidance about compliance. Essential standards of quality and safety. Section 4K[7]; End of Life Care Strategy: Quality Markers and Measures for End of Life Care[3].	Whilst all participating trusts reported having access to Specialist Palliative Care teams, most operate a 9–5, 5-day face to face specialist palliative care (SPC) service (73% of participating trusts) supported by an out of office hours telephone service (91% of participating trusts). A fifth of participating trusts reported operating a 7-days face to face SPC service (21% of participating trusts) as at 1 May 2013 (organisational section 5, KPI 2).

Education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training and skills for supporting families and those close to dying patients.

Rationale	Audit context
Within The NHS Constitution[9] – patients' '**have the right** to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality'. In addition: Neuberger;[10] NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers[4]; Guidance about compliance. Essential standards of quality and safety. Section 4K.[7]; End of Life Care Strategy: Quality Markers and Measures for End of Life.[3]	Fifty nine per cent of participating trusts reported having less than half the recommended education and training opportunities available to staff, with the least provision via mandatory training and with allied health professionals and non-qualified nurses receiving the least training (organisational section 6, KPI 3).

All hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually.	
Rationale	**Audit context**
DH Quality Markers[3] 3.14 '[hospitals] have mechanisms for auditing and reviewing quality of end of life care provided by the hospital (p28)'. End of Life Care Strategy[2] stipulates that: 'your experience will help inform the care of future patients, leading to year on year improvements in quality (page 19)'. Neuberger (2013): Recommendation 33: 'The CQC and the Health Quality Improvement Partnership, should conduct fully independent assessments of the role of healthcare professionals in end of life care in England, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying'. Also: The NHS Constitution;[9] The Mandate.[5]	Care of the dying was at least annually reported upon, at trust board level (April 2012–March 2013), by 58% (n=76) of trusts. Patient and public representation within these discussions/reporting processes was in place in 72% (n=55). Forty seven per cent (n=61) of trusts reported having existing processes in place to capture bereaved relatives' views prior to this audit. 34% (n=44) of Trusts reported having sought bereaved relatives views within the last two financial years. 82% (n=36) of these were via specific questionnaires.

All trusts should have a designated board member and a lay member with specific responsibility for care of the dying. Trust boards should formally receive and discuss the report of local audit at least annually.	
Rationale	**Audit context**
Neuberger[10]: Recommendation 28: 'The boards of healthcare providers providing care for the dying should give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals.'	A formal process existed within trust clinical or quality governance structures for discussing and reporting on care of the dying in 69% (n=90) of trusts. Fifty three per cent of trusts reported having a named member of their trust board for care of the dying.

<table>
<tr><th colspan="2">The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient’s care. This should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.</th></tr>
<tr><th>Rationale</th><th>Audit context</th></tr>
<tr><td>Neuberger[10]: Recommendation 29: ‘Guidance should specify that the senior clinician writes in the patient’s notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient’s relatives or carers’ and Recommendation 29: ‘Guidance should specify that the senior clinician writes in the patient’s notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient’s relatives or carers. The record of that conversation must include the following: that the clinician explained that the patient is now dying and when and how death might be expected to occur’.
In addition: GMC Guidance;[6] End of Life Strategy;[2] Guidance about compliance. Essential standards of quality and safety. Section 4K.[7]</td><td>Recognition of dying was reported by a multidisciplinary team in 59% of cases and by at least one health professional in 28% of cases. No recognition of dying was reported in 13% of cases. (Clinical Domain 1, KPI 1).
In patients for whom there was recognition of dying, 59% were recorded as being unable to take part in such discussions. For the remaining 41% such discussions were undertaken in just under half of cases (46%). Such discussions were more likely to be undertaken with relatives (93%). (Clinical Domain 2, KPI 2).
However, bereaved relatives in 74% of cases, via CODE questionnaire responses, reported that they were told the patient was likely to die soon and in 26% of cases they reported that they were not told this (CODE question 23).</td></tr>
</table>

Pain control and other symptoms in dying patients should be assessed at least four hourly and medication given promptly if necessary. Interventions should be discussed with the patient where possible and appropriate, and with family, carers or other advocate	
Rationale	**Audit context**
Statement 11 within the NICE quality standards for end of life care[4]: 'People in the last days of life are identified and receive care according to their care plan, which takes into account their needs and preferences, and ensures they can have rapid access to all the support they need, including equipment (such as a pressure-relieving mattress) and medication.' In addition: Recommendations 23 Neuberger;[10] The NHS Constitution;[9] End of Life Strategy.[2]	Ensuring appropriate medication is available as and when required (prn) is an important element within the care plan for imminently dying patients. 99% of participating trusts reported having a protocol for the prescription of prn medication to alleviate pain. However, actual prn prescriptions recorded at the time of the patient's death were documented in 81% of cases. Of the 557 cases in which symptom control was discussed with patients, 80% of such discussions included specific information relating to the control of pain. Of the 2,807 cases in which symptom control was discussed with a relative/friend or Independent Mental Capacity Advocate (IMCA), 71% of such discussions included specific information relating to the control of pain (organisational section 7 and clinical domains 5 and 3). Bereaved relatives, via CODE questionnaire responses, indicated that 9% appeared to be in pain 'all of the time', 40% of patients appeared to be in pain 'some of the time', whilst 51% 'did not appear to be in pain'. Further, in a separate question, bereaved relatives considered that health professionals had done enough to relieve pain for 52% 'all of the time', 23% of patients 'some of the time' and 4% 'not at all'.[§§]

[§§] NB There is an unexplained discrepancy between the proportion of patients deemed not to be in pain in CODE question 10 (51%) and those coded such in CODE question 11 (20%).

Decisions about the use of clinically assisted (artificial) nutrition and hydration are complex and should be taken by a senior experienced clinician supported by a multidisciplinary team. They should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.	
Rationale	**Audit context**
Neuberger[10]: Recommendation 22: 'Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life.' In addition: GMC Guidance.[6]	In patients for whom there was recognition of dying, 58% of cases (nutrition) and 60% (hydration) were recorded as being unable to take part in such discussions. For the remaining 42% and 40% of cases respectively, such discussions were undertaken with the patient in 17% of these sub-populations of cases. Such discussions were undertaken with relatives for nutrition in 29% of cases and for hydration in 36% of cases (clinical domains 7 and 8, KPIs 7 and 8). Bereaved relatives, via CODE questionnaire responses indicated that in 39% of cases the healthcare team discussed whether giving fluids through a drip would be appropriate. (CODE Question 17). In 35% of cases relatives responded that they would have found such a discussion helpful, whilst 29% would not (CODE Question 18).[***]

Hospitals should have an adequately staffed and accessible pastoral care team to ensure that the spiritual needs of dying patients and those close to them are met.	
Rationale	**Audit context**
Statement 6 within the NICE quality standards for end of life care[4] stipulates: 'People approaching the end of life are offered spiritual and/or religious support appropriate to their needs and preferences.' In addition: The NHS Constitution[9]; End of Life Strategy.[3]	Patients were recorded as being unable to take part in such discussions in 48% of cases. For the remaining 52%, discussions regarding their spiritual needs were undertaken in 21% of cases. Relatives were used as a proxy for the patient in 23% of cases where discussions were not held with the patient. (See clinical domain 4, KPI 4). Bereaved relatives views, via CODE questionnaire responses, suggest that 39%

[***] Note that the 39% from Q17 and the 35% & 29% from Q18 don't add to 100% - in part a consequence of the information coming from two separate questions with different known denominators.

	agreed or strongly agreed that the spiritual needs of the patient had been met whilst 35% agreed or strongly agreed that their own needs had been met. However, half of bereaved relatives reported that they neither agreed nor disagreed that the spiritual needs of either the patients (50%) or themselves (51%) had been met. (CODE Questions 21 and 22).

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Appendix I: inter-auditor 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. Participating sites were asked to re-audit five cases using a different auditor. A total of 684 pairs (original and duplicate) of data were submitted. Of these, 27 pairs were excluded because of a lack of data for both auditors as either no case notes could be found or the ICD code was inappropriate; a further 5 were excluded when this affected one of the two auditors only and 11 were excluded because both auditors recorded the episode as being under 24 hours. Reliability analyses were performed on 641 pairs, these being submitted by 136 sites with 12 sites submitting 1–3 pairs, 22 submitting 4 pairs, 95 submitting 5 pairs and 7 submitting 6-10 pairs. The total number of pairs analysed differs slightly from the total number of duplicate pairs indicated in the main report due to differences in the hierarchy used for excluding cases.

Regarding time and date of the death there was exact agreement in 85% of pairs, with two-thirds of discrepancies being within 60 minutes. For the six other sets of times and dates satisfactory kappa agreement values (range 0.69-0.74) were found for auditors being able to find a date +/- a time, and for those finding both a date and time the rates of exact agreement ranged from 69% to 78% of pairs. There was exact agreement (in hours) on the length of the last episode of care for 64% of pairs, with half of discrepancies being within 6 hours. During the last 24 hours of the patient’s life there was exact agreement for 57% of pairs on the number of documented clinical assessments made by a doctor or nurse regarding the patient’s condition, with half of the discrepancies being by one or two sessions. There was exact agreement of age in years of the patient for 94% of pairs.

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 whilst values of over 0.80 are very good. In practice any value of kappa much below 0.50 will indicate inadequate agreement. 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.

Often the overall kappa value, computed over all cases (n=641 here), gives an assessment of agreement that 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 the codes/categories of responses when both auditors have found information to cases they regard as relevant. The kappa statistics given in the summary tables below are both overall (based on 641 cases) and specific (to when both auditors found information that was relevant).

In brief: The levels of agreement were found to be generally ‘good’ to ‘very good’ with almost all kappa values over 0.60. About two thirds were over 0.70 and about one in five over 0.80. Only four were below 0.50. The 10 KPI scores were all above 0.60, median 0.70, apart from KPI 6 (a review of interventions during the dying phase) with 0.59.

Item-specific kappa values of below 0.60 were computed for the following items:

Item:	Kappa
Comorbidity: other	0.58
f. If hospital was not the preferred place was the discharge planning process commenced to attempt to move the patient to their preferred place of care during the last episode of care?	0.59
Q1b Who took part in the multidisciplinary decision:	
• no. of staff nurses	0.59
• No. of social workers	0.50
• No. of physiotherapists	0.49
• No. of other personnel.	0.30
Q1d. Who took part in the non-multidisciplinary decision:	
• no. of specialist nurses	0.47
• no. of ward sisters	0.53
• no. of staff nurses	0.52
• no. of other personnel.	0.42
Q6b Is there documented evidence that a decision by a senior doctor regarding cardiopulmonary resuscitation (CPR) was undertaken during the last episode of care?	0.53

There will be a need to exercise caution when performing analyses that correlate one variable with another when one or both variables has less than good inter-auditor reliability – associations between them may dilute as a consequence.

Summary key performance indicator (KPI) scores

Unweighted kappa does not take account of the ordinal nature of the KPI scores, and regards one kind of discrepancy as serious as another. A weighted version of kappa can be calculated which takes account of how far apart any disagreements are. An obvious choice for weights would be 0 for agree, 1 for a disagreement by one points in the score, 2 for a disagreement of two points etc. These are known as linear weights.

Score	Descriptor	Unweighted Kappa value	Kappa with linear weighting
KPI 1	Health Professionals recognition that patient is dying	0.74	0.78
KPI 2 (if KPI 1 >0)	Communication regarding the Health Professionals awareness that the patient is dying	0.62	0.63
KPI 3	Communication regarding the patients plan of care for the dying phase	0.60	0.66
KPI 4	Visit/revisit spiritual needs of the patient and their nominated relatives or friends	0.72	0.78
KPI 5	A review of medication prescribed prn for the 5 key symptoms that may develop during the dying phase	0.72	0.78
KPI 6	A review of interventions during the dying phase	0.56	0.59
KPI 7 (if KPI 1 >0)	A review of the patient's nutrition requirements	0.57	0.70
KPI 8 (if KPI 1 >0)	A review of the patient's hydration requirements	0.55	0.68
KPI 8	A review of the number of assessments taken in the patient's last 24 hours of life	0.63	x
KPI 9	A review of the care after death	0.81	0.84

In the tables that follow, the KPI scores of the original auditor are described on the left vertical side of the table and the KPI scores of the repeat independent auditor are described across the top horizontal. The variable descriptor for the repeat auditor is denoted by an ‘R’ at the end of the descriptor. The values in the table show how many agreements and disagreements there were between auditors in scores.

KPI1: domain 1: health professionals recognition that patient is dying

		KP1R			Total
		0	1	2	
KP1	0	64	4	4	72
	1	7	117	34	158
	2	3	33	375	411
Total		74	154	413	641

Unweighted Kappa coefficient, k=0.74, 95% CI: 0.69-0.79,

Kappa with linear weighting, k=0.78, 95% CI: 0.74-0.83

KPI2: domain2: communication regarding health professionals awareness that patient is dying

		KP2R					Total
		KP1=0	0	2	3	4	
KP2	KP1=0	64	2	2	-	4	72
	0	-	11	1	-	1	13
	2	5	4	90	1	29	129
	3	-	-	1	5	2	8
	4	5	6	43	3	362	419
Total		74	23	137	9	398	641

Overall (n=641) unweighted kappa, k=0.68. In 3% (18/641) there was disagreement as to whether KPI2 was relevant.

This KPI2 is dependent on KPI1 in that it only applies if KPI1>0.
Both auditors agreed that KPI2 was relevant in 559 cases (shaded area of table):

Unweighted Kappa coefficient, k=0.62, 95% CI: 0.54-0.69

Kappa with linear weighting, k=0.63, 95%CI: 0.56-0.70

KPI3: domain 3: communication regarding the patients plan of care for the dying phase

		KP3R					Total
		0	1	2	3	4	
KP3	0	74	1	16	-	4	95
	1	1	1	1	1	1	5
	2	12	-	100	1	42	155
	3	1	-	4	4	-	9
	4	14	-	50	-	313	377
Total		102	2	171	6	360	641

Unweighted Kappa coefficient, k=0.60, 95% CI: 0.54-0.66

Kappa with linear weighting, k=0.66, 95% CI: 0.61-0.71

KPI4: domain 4: visit/revisit spiritual needs of the patient and their nominated relatives or friends

		KP4R					Total
		0	1	2	3	4	
KP4	0	376	-	20	-	4	400
	1	2	1	-	-	-	3
	2	24	-	67	-	16	107
	3	-	-	-	2	-	2
	4	14	1	13	-	101	129
Total		416	2	100	2	121	641

Unweighted Kappa coefficient, k=0.72, 95% CI: 0.67-0.78
Kappa with linear weighting, k=0.78, 95% CI: 0.73-0.82

KPI5: domain 5: a review of medication prescribed prn for the five key symptoms that may develop during the dying phase

		KP5R						Total
		0	1	2	3	4	5	
KP5	0	60	13	3	4	2	-	82
	1	8	35	7	1	-	-	51
	2	1	4	28	5	1	1	40
	3	4	1	6	24	6	5	46
	4	3	-	1	8	71	8	91
	5	1	3	2	9	25	291	331
Total		77	56	47	51	105	305	641

Unweighted Kappa coefficient, k=0.72, 95% CI: 0.67-0.78
Kappa with linear weighting, k=0.78, 95%CI: 0.73-0.82

KPI6: domain 6: a review of interventions during the dying phase

		KP6R						Total
		0	2	3	4	5	6	
KP6	0	9	1	-	-	-	-	10
	2	1	39	1	18	-	9	68
	3	-	1	-	-	-	1	2
	4	7	19	1	127	1	48	203
	5	-	2	-	-	7	3	12
	6	5	10	-	41	-	290	346
Total		22	72	2	186	8	351	641

Unweighted Kappa coefficient, k=0.56, 95% CI: 0.50-0.62
Kappa with linear weighting, k=0.59, 95%CI: 0.54-0.65

KPI7: domain 7: a review of the patient's nutrition requirements

This has the same applicable denominator as KPI2:

		KP7R										Total
		KP1=0	0	1	2	3	4	5	6	7	8	
KP7	KP1=0	64	1	0	3	0	3	0	0	0	1	72
	0	3	76	1	18	0	6	0	1	1	1	107
	2	1	17	0	69	1	17	0	10	1	1	117
	3	0	0	0	1	3	0	0	0	0	0	4
	4	4	3	0	13	1	62	0	20	0	3	106
	5	0	0	0	1	0	0	2	0	0	0	3
	6	1	4	0	9	0	14	0	74	0	9	111
	7	0	0	0	0	0	0	0	1	0	0	1
	8	1	1	0	6	0	10	0	21	0	81	120
Total		74	102	1	120	5	112	2	127	2	96	641

Overall (n=641 table) unweighted kappa, k=0.61

Applicable denominator (n=559, shaded area, both auditors have KP1>0):

Unweighted Kappa coefficient, k=0.57, 95% CI: 0.53-0.62

Kappa with linear weighting, k=0.70, 95%CI: 0.66-0.74

KPI8: domain 8: a review of the patient's hydration requirements

This has the same applicable denominator as KPI2:

		KP8R										Total
		KP1=0	0	1	2	3	4	5	6	7	8	
KP8	KP1=0	64	2	-	4	-	1	-	1	-	-	72
	0	4	53	-	15	1	4	-	4	-	3	84
	1	-	1	-	-	-	-	-	-	-	-	1
	2	1	18	-	59	1	10	-	7	-	4	100
	3	-	-	1	1	2	-	-	-	-	-	4
	4	3	5	-	15	-	60	-	16	-	7	106
	5	-	-	-	-	-	1	1	-	-	-	2
	6	1	5	-	6	-	15	-	80	-	20	127
	7	-	-	-	-	-	-	-	-	1	-	1
	8	1	-	-	6	-	12	-	22	-	103	144
Total		74	84	1	106	4	103	1	130	1	137	641

Overall (n=641 table) unweighted kappa, k=0.59

Applicable denominator (n=559, shaded area, both auditors have KP1>0):

Unweighted Kappa coefficient, k=0.55, 95% CI: 0.50-0.60

Kappa with linear weighting, k=0.68, 95%CI: 0.63-0.72

KPI9: domain 9: a review of the number of assessments taken in the patient's last 24 hours of life

		KP8R		
		1	2	Total
KP8	1 <5	79	29	108
	2 >=5	41	492	533
Total		120	521	641

Kappa coefficient, k=0.63, 95% CI: 0.54-0.71

KPI10: domain 10: a review of the care after death

		KP9R			
		0	1	2	Total
KP9	0	250	24	7	281
	1	9	120	18	147
	2	7	16	190	213
Total		266	160	215	641

Unweighted Kappa coefficient, k=0.81, 95% CI: 0.77-0.85

Kappa with linear weighting, k=0.84, 95%CI: 0.81-0.88

Summary: categorical questions within the audit tool

The full range of tables that specifically cross-relate auditors responses for each question can be found at www.rcplondon.ac.uk

Question	Variable label	Overall Kappa value (n=641)	Kappa value (relevant subgroup)
	Gender	0.97	x
	Ethnicity	0.77	x
	Religious affiliation	0.80	x
	Comorbidity: dementia	0.84	x
	Comorbidity: heart failure	0.73	x
	Comorbidity: renal failure	0.68	x
	Comorbidity: diabetes	0.76	x
	Comorbidity: falls and accidents	0.66	x
	Comorbidity: other	0.58	x
	Comorbidity: none	0.65	x
b	Was care supported by the Liverpool Care pathway for the Dying patient (LCP) or equivalent framework for the last hours or days of life?	0.96	x
d	Were the patient's wishes and preferences for their preferred place of death documented in the last episode of care?	0.85	x
e	A documented preferred place of death	0.83	0.90
f	If hospital was not the preferred place was the discharge planning process commenced to attempt to move the patient to their preferred place of care during the last episode of care?	0.98	0.59
g	What was the reason for the patient not being cared for in their preferred place prior to death?	0.76	0.77
h	In which hospital department did the patient's death take place	0.87	x
DOMAIN 1	RECOGNITION OF DYING		
Q1a	Is there documented evidence within the last episode of care of a decision within the multidisciplinary team (MDT) (a minimum of a senior doctor and a trained nurse) that the patient was expected to die in the coming hours or days?	0.74	x
Q1b	Who took part in the multidisciplinary decision; no. of:		
	Consultants	0.71	0.73
	Specialist registrars	0.68	0.68
	Junior doctors	0.67	0.65
	Palliative care nurses	0.73	0.76
	Specialist nurses	0.70	0.62
	Ward sisters	0.71	0.70
	Staff nurses	0.64	0.59
	Chaplains	0.74	0.66
	Social workers	0.74	0.50
	Occupational therapists	0.74	0.66
	Physiotherapists	0.73	0.49
	Pharmacists	0.75	1.00
	Dieticians	0.75	0.80
	Speech and language therapists	0.74	0.61
	Other personnel	0.71	0.30
Q1c	If Q1a is 'no': Is there documented evidence within the last episode of care by at least one health professional that the patient was expected to die in the coming hours or days?	0.74	0.88
Q1d	If Q1c is 'yes', the No. of health professionals involved were:		
	Consultants	0.63	0.72
	Specialist Registrars	0.62	0.71
	Junior doctors	0.63	0.75
	Palliative care nurses	0.65	0.71
	Specialist nurses	0.64	0.47
	Ward sisters	0.65	0.53
	Staff nurses	0.61	0.52

	Other personnel	0.63	0.42
Q1e.	Auditor agreement on finding a date and/or time for Q1e	0.72	x
DOMAIN 2	COMMUNICATION RE: AWARENESS OF DYING		
Q2a	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?	0.70	0.68
Q2b	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?	0.78	0.64
DOMAIN 3	COMMUNICATION RE: PLAN OF CARE FOR THE DYING PHASE		
Q3a	Is there documented evidence within the last episode of care that a plan of care specifically for the last hours or days of life was discussed with the patient?	0.67	x
Q3bi	If the answer to Q3a is ‘yes’: Within the discussion with the patient about their plan of care was information for treatment options for symptom control recorded:	0.72	0.66
Q3bii	If the answer to Q3bi is ‘yes’: Was specific information on the following symptoms recorded:		
	Pain	0.75	0.80
	Agitation	0.75	0.87
	Nausea	0.74	0.79
	Noisy breathing	0.75	0.83
	Dyspnoea	0.75	0.87
Q3c	Is there documented evidence within the last episode of care that a plan of care specifically for the last hours or days of life was discussed with the nominated relative or friend or the nominated Independent Mental Capacity Advocate?	0.73	x
Q3di	If the answer to Q3c is ‘yes’: Within the discussion with the relative or friend or Independent Mental Capacity Advocate about the patient’s plan of care, was information for treatment options for symptom control recorded?	0.72	0.71
Q3dii	If the answer to Q3di is ‘yes’: Was specific information on the following symptoms recorded:		
	Pain	0.70	0.73
	Agitation	0.71	0.77
	Nausea	0.70	0.73
	Noisy breathing	0.70	0.76
	Dyspnoea	0.69	0.73
Q3e	Auditor agreement on finding a date and/or time for Q1e	0.69	x
DOMAIN 4	SPIRITUALITY		
Q4a	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)?	0.64	x
Q4b	If the answer to question 4a is ‘No’ or ‘No but’: Is there documented evidence within the last episode of care that a discussion took place with the nominated relative or friend, regarding the patient’s spiritual needs (wishes, feelings, faith, beliefs, and values)?	0.77	0.81
Q4c	Auditor agreement on finding a date and/or time for Q4c	0.74	x
Q4d	Is there documented evidence within the last episode of care that the patient was seen by a spiritual adviser?	0.77	x
Q4e	Is there documented evidence within the last episode of care that a discussion took place with the nominated relative or friend regarding their own spiritual needs (wishes, feelings, faith, beliefs, and values)?	0.75	x
Q4f	Auditor agreement on finding a date and/or time for Q4f	0.70	x
DOMAIN 5	MEDICATION		
Q5a	At the time of the patient’s death, is there documented evidence that medication was prescribed (prn) for the 5 key symptoms that may develop in the last hours or days of life?		

Prescribed	Pain	0.78	x
	Agitation	0.86	x
	Nausea	0.83	x
	Noisy breathing	0.89	x
	Dyspnoea	0.77	x
Administered	Pain	0.78	x
	Agitation	0.81	x
	Nausea	0.68	x
	Noisy breathing	0.81	X
	Dyspnoea	0.60	x
Q5b	At the time of the patient’s death, is there documented evidence that a continuous subcutaneous infusion (CSCI) of medication was in place?	0.94	x
DOMAIN 6	INTERVENTIONS		
Q6a	In the last 24 hours, were any of the following interventions still included within the patient’s plan of care?		
	Routine recording of vital signs	0.81	x
	Routine blood tests	0.76	x
	Blood sugar monitoring	0.72	x
	The administration of Oxygen	0.73	x
	The administration of Antibiotics	0.75	x
Q6b	Is there documented evidence that a decision by a senior doctor regarding Cardiopulmonary Resuscitation (CPR) was undertaken during the last episode of care?	0.53	x
Q6c	Is there documented evidence that a discussion regarding the Cardiopulmonary Resuscitation (CPR) decision was undertaken with the patient during the last episode of care?	0.64	x
Q6d	there documented evidence that a discussion regarding the Cardiopulmonary Resuscitation (CPR) decision was undertaken with the nominated relative or friend or Independent Mental Capacity Advocate during the last episode of care?.	0.69	x
Q6e	At the time of the patient’s death was there a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place?	0.62	x
DOMAIN 7	CLINICALLY ASSISTED (ARTIFICIAL) NUTRITION ie CAN		
Q7a	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?	0.74	0.70
Q7b	Is there documented evidence that an assessment regarding the patient’s need for Clinically Assisted (artificial) Nutrition (CAN) was made following recognition that the patient was expected to die in the coming hours or days?	0.80	0.79
Q7c	Auditor agreement on finding a date and/or time for Q7c	0.73	x
Q7d	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?	0.69	0.67
Q7e	Is there documented evidence that a discussion regarding nutrition options/care was undertaken with the nominated relative or friend or the nominated Independent Mental Capacity Advocate, following recognition that the patient was expected to die in the coming hours or days?	0.74	0.71
Q7f	At the time of the patient’s death was clinically assisted (artificial) Nutrition (CAN) in place?	0.66	x
DOMAIN 8	CLINICALLY ASSISTED (ARTIFICIAL) HYDRATION ie CAH		
Q8a	Is there documented evidence that an assessment regarding the patient’s ability to take oral hydration was made following recognition that the patient was expected to die in the coming hours or days?	0.71	0.67
Q8b	Is there documented evidence that an assessment regarding the patient’s need for Clinically Assisted (artificial) Hydration (CAH) was made following recognition that the patient was expected to die in the coming hours or days?	0.74	0.71

Q8c	Auditor agreement on finding a date and/or time for Q8c	0.69	x
Q8d	Q8d. 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?	0.67	0.64
Q8e	Is there documented evidence that a discussion regarding hydration options/care was undertaken with the nominated relative or friend or the nominated Independent Mental Capacity Advocate, following recognition that the patient was expected to die in the coming hours or days?	0.74	0.71
Q8f	In the last 24 hours of the patient's life is there documented evidence that the patient received:		
	Oral fluids	0.66	x
	Mouth care	0.77	x
Q8g	At the time of the patient's death was clinically assisted (artificial) Hydration (CAH) in place?	0.78	x
DOMAIN 9	REGULAR ASSESSMENT		
Q9a	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? Range 0-36 recoded into 7 categories	Unweighted 0.62 Weighted 0.70	
DOMAIN 10	CARE AFTER DEATH		
Q10a	Is there documented evidence that the care of the body of the deceased was undertaken?	0.83	x
Q10b	Is there documented evidence that the nominated relative or friend was given any written information following the death of the patient?	0.83	x

Summary: dates and times within the audit tool

	Date/time	Exact agreement	Further details about nature of disagreement
	Date and time of DEATH	85% (546/641)	32 (<5 minutes), 23 (6-30 minutes), 11 (31-60 minutes), 12 (61-240 minutes), 8 (241-895 minutes), 6 (1 day exactly), 3 (>1 day).
Q1e.	If Q 1a or Q1c is 'yes': What was the date and time of the first documented evidence of the recognition that the patient was expected to die in the coming hours or days?	69% (296/431) where both auditors found a time and date	25 (within 60 minutes), 22 (61-240 minutes), 36 (241-1440 minutes), 52 (> 1 day)
		72% (68/94) where one or both auditors found a date but no time	15 (by 1 day), 5 (2 days), 5 (3-5 days), 1 (19 days)
Q3e	Within the last episode of care, what was the date and time of the first discussion of a plan of care specifically for the last hours or days of life with the nominated relative or friend or Independent Mental Capacity Advocate?	74% (257/346) where both auditors found a time and date	29 (within 60 minutes), 18 (61-240 minutes), 18 (241-1440 minutes), 24 (> 1 day)
		76% (58/76) where one or both auditors found a date but no time	11 (by 1 day), 4 (2 days), 2 (3 days), 1 (4 days)
Q4c	If the answer to 4a or 4b is yes: What was the date and time of the latest documented discussion with the patient and/or the nominated relative or friend regarding the patient's spiritual needs?	78% (98/126) where both auditors found a time and date	9 (within 60 minutes), 2 (61-240 minutes), 8 (241-1440 minutes), 9 (> 1 day)
		91% (29/32) where one or both auditors found a date but no time	3 (by 1 day)
Q4f	If the answer to 4e is yes: What was the date and time of the latest documented discussion with the relative or friend regarding their spiritual needs?	76% (75/99) where both auditors found a time and date	8 (within 60 minutes), 5 (61-240 minutes), 5 (241-1440 minutes), 6 (> 1 day)
		90% (19/21) where one or both auditors found a date but no time	1 (by 1 day), 1 (4 days)
Q7c	If the answer to question 7b is 'yes': What was the date and time of the latest documented decision regarding the patient's need for Clinically Assisted (artificial) Nutrition (CAN)?	76% (135/177) where both auditors found a time and date	16 (within 60 minutes), 7 (61-240 minutes), 7 (241-1440 minutes), 12 (> 1 day)
		81% (38/47) where one or both auditors found a date but no time	5 (by 1 day), 5 (2-6 days), 1 (27 days)
Q8c	If the answer to question 8b is 'yes': What was the date and time of the latest documented decision regarding the patient's need for Clinically Assisted (artificial) Hydration (CAH)?	74% (163/219) where both auditors found a time and date	12 (within 60 minutes), 10 (61-240 minutes), 19 (241-1440 minutes), 15 (> 1 day)
		86% (65/76) where one or both auditors found a date but no time	6 (by 1 day), 4 (2-6 days), 1 (28 days)

SUMMARY: Numerical questions within the audit tool

	Exact agreement	Further details about nature of disagreement
Age	94% (603/641)	29 (1 yr.), 3 (2-4 yr.), 5 (5-9 yr.), 1 (10yr)
a. What was the length of the last episode of care (number of days/hours – converted into hours)?	64% (408/641)	110 (1-6 hours), 27 (7-12 hours), 47 (13-24 hours), 24 (25-48 hours), 10 (49-96 hours), 15 (>96 hours).
Q9a 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? Range 0-36	57% (360/635)	81 (by 1), 65 (by 2), 78 (by 3-5), 29 (by 6-10), 18 (by 11-20) and 4 (by more than 20).

Appendix II: seasonality check for case note review results

The set of national results against which local results are compared come from those dying in May 2013. Some sites collected a sizeable proportion of cases from June and July which together with cases from May make up their local result. The question arose as to how reasonable it is to use May results as a benchmark for local results involving data from June and July. As a check on seasonality issues the results for May were compared to June/July in 60 sites with at least 10% of their cases from June/July. There were 1,595 cases in May and 1,239 in June/July for these 60 sites.

There were no notable differences in respect of KPI standards achievement (see table below) nor for any of the individual questions that make up the KPIs (results not shown). This indicates that national results for May provide a meaningful benchmark for all audit sites.

Case note review KPIs: % achieved (% with KPI score ≥ cut-off score)

Case note review KPI	May	June/July
KPI 1	64% (1016/1595)	59% (726/1239)
KPI 2	74% (1060/1433)	77% (838/1083)
KPI 3	59% (945/1595)	61% (752/1239)
KPI 4	35% (562/1595)	36% (440/1239)
KPI 5	51% (808/1595)	52% (642/1239)
KPI 6	54% (858/1595)	57% (701/1239)
KPI 7	43% (610/1433)	47% (509/1083)
KPI 8	52% (744/1433)	54% (587/1083)
KPI 9	82% (1305/1595)	84% (1045/1239)
KPI 10	59% (947/1595)	61% (758/1239)

Appendix III: A comparison of 36 trusts (40) sites submitting bereaved relative survey data with other trusts (sites)

Only a minority of sites submitted bereaved family questionnaire data (CODE) and the question arose as to how representative are these sites in relation to the whole. An answer to this question would help in the wider interpretation of results across the various modes of data collection (organisational audit, case note review, survey of bereaved relatives). The 36 trusts (40 hospital sites) with CODE survey data were compared to those without CODE data with regard to key indicators (KPIs) from the organisational and case note reviews. There were some differences in organisational KPI data but not for clinical KPI data and overall the two groups did not appear too dissimilar.

Organisational audit KPIs: % achieved (% with KPI score ≥ cut-off score)

Case note review KPI	36 trusts with CODE survey data	95 trusts without CODE survey data
KPI 1	19% (7)	49% (47)
KPI 2	25% (9)	20% (19)
KPI 3	39% (14)	40% (38)
KPI 4	31% (11)	27% (26)
KPI 5	97% (35)	98% (93)
KPI 6	25% (9)	38% (36)
KPI 7	25% (9)	37% (35)

There were no notable differences in respect of organisational KPIs 2, 3, 4 and 5 achievement (see table above) nor in component questions. Looking at the questions that make up KPI 1, the discrepancy in KPI achievement was in large part down to less use in CODE trusts of leaflets explaining the facilities available for relatives or friends (44% vs. 65%). Discrepancy in KPI 6 was mainly due to CODE trusts having fewer designated regular mortality meetings to review recent deaths (75% vs. 86%) and less use of guidelines for the assessment and delivery of mouth care (64% vs. 78%). Discrepancy in KPI 7 was mainly due to fewer CODE trusts having sought bereaved friends or relatives' views during the previous two financial years (25% vs. 37%).

CODE and non-CODE trusts appeared similar in size – number of adult wards (median 26 vs. 27), adult beds (median 571 vs. 623), adult single occupancy (median 126 vs. 124), adult deaths in financial year (median 1306 vs. 1316), adult deaths in national aggregate data collection period (median 103 vs. 106), adult deaths occurring in the national aggregate data collection period in those hospitals entered into the case note review (median 96 vs. 98).

Case note review KPIs: % achieved (% with KPI score ≥ cut-off score)

Case note review KPI	40 sites with CODE survey data	109 sites without CODE survey data
KPI 1	58% (1251/2171)	59% (2608/4409)
KPI 2	71% (1336/1887)	75% (2874/3835)
KPI 3	54% (1180/2171)	59% (2593/4409)
KPI 4	36% (785/2171)	37% (1625/4409)
KPI 5	49% (1058/2171)	51% (2247/4409)
KPI 6	52% (1137/2171)	57% (2513/4409)
KPI 7	38% (722/1887)	40% (1527/3835)
KPI 8	46% (869/1887)	49% (1868/3835)
KPI 9	83% (1799/2171)	82% (3610/4409)
KPI 10	51% (1116/2171)	59% (2585/4409)

There were no notable differences in respect of KPI achievement (see table above for deaths occurring in May 2013) nor for any individual question making up the KPIs (results not shown).

Appendix IV: a list of sites that participated in the audit and registered as either a trust or as individual hospitals within a trust

Registration Type T=Trust; H=Hospital

Site	Trust	County	T/ H
Aintree University Hospitals NHS Foundation Trust	Aintree University Hospitals NHS Foundation Trust	Merseyside	**T**
Airedale NHS Foundation Trust	Airedale NHS Foundation Trust	West Yorkshire	**T**
Alexandra Hospital	Worcestershire Acute Hospitals NHS Trust	Worcestershire	**H**
Ashford and St Peter's Hospitals NHS Foundation Trust	Ashford and St Peter's Hospitals NHS Foundation Trust	Surrey	**T**
Barnet and Chase Farm Hospitals NHS Trust	Barnet and Chase Farm Hospitals NHS Trust	Middlesex	**T**
Barnsley Hospital NHS Foundation Trust	Barnsley Hospital NHS Foundation Trust	South Yorkshire	**T**
Basildon and Thurrock University Hospitals NHS Foundation Trust	Basildon and Thurrock University Hospitals NHS Foundation Trust	Essex	**T**
Bassetlaw District General Hospital	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	South Yorkshire	**H**
Bedford Hospital	Bedford Hospital NHS Trust	Bedfordshire	**H**
Blackpool Teaching Hospitals NHS Foundation Trust	Blackpool Teaching Hospitals NHS Foundation Trust	Lancashire	**T**
Bolton NHS Foundation Trust	Bolton NHS Foundation Trust	Greater Manchester	**T**
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Teaching Hospitals NHS Foundation Trust	West Yorkshire	**T**
Brighton and Sussex University Hospitals NHS Trust	Brighton and Sussex University Hospitals NHS Trust	East Sussex	**T**
Buckinghamshire Healthcare NHS Trust	Buckinghamshire Healthcare NHS Trust	Buckinghamshire	**T**
Burton Hospitals NHS Foundation Trust	Burton Hospitals NHS Foundation Trust	Staffordshire	**T**
Calderdale and Huddersfield NHS Foundation Trust	Calderdale and Huddersfield NHS Foundation Trust	West Yorkshire	**T**
Central Manchester University Hospitals NHS Foundation Trust	Central Manchester University Hospitals NHS Foundation Trust	Greater Manchester	**T**
Chelsea and Westminster Hospital NHS Foundation Trust	Chelsea and Westminster Hospital NHS Foundation Trust	London	**T**
Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital NHS Foundation Trust	Derbyshire	**T**
Chorley & South Ribble DGH	Lancashire Teaching Hospitals NHS Foundation Trust	Lancashire	**H**
Christie NHS Foundation Trust	Christie NHS Foundation Trust	Greater Manchester	**T**
Churchill Hospital	Oxford University Hospitals NHS Trust	Oxfordshire	**H**
City Hospitals Sunderland NHS Foundation Trust	City Hospitals Sunderland NHS Foundation Trust	Tyne & Wear	**T**
Clatterbridge Cancer Centre NHS Foundation Trust	Clatterbridge Cancer Centre NHS Foundation Trust	Merseyside	**T**
Colchester General Hospital	Colchester Hospital University Hospitals NHS Trust	Essex	**H**
Countess Of Chester Hospital NHS Foundation Trust	Countess Of Chester Hospital NHS Foundation Trust	Cheshire	**T**
County Durham and Darlington NHS Foundation Trust	County Durham and Darlington NHS Foundation Trust	County Durham	**T**
Croydon University Hospital	Croydon Health Services NHS Trust	Surrey	**H**
Dartford and Gravesham NHS Trust	Dartford and Gravesham NHS Trust	Kent	**T**
Doncaster Royal Infirmary	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	South Yorkshire	**H**
Dorset County Hospital NHS Foundation Trust	Dorset County Hospital NHS Foundation Trust	Dorset	**T**
Dudley Group of Hospitals NHS Foundation	Dudley Group of Hospitals NHS Foundation	West Midlands	**T**

Site	Trust	County	T/ H
Trust	Trust		
Ealing Hospital NHS Trust	Ealing Hospital NHS Trust	Middlesex	**T**
East and North Hertfordshire NHS Trust	East and North Hertfordshire NHS Trust	Essex	**T**
East Cheshire NHS Trust	East Cheshire NHS Trust	Cheshire	**T**
Epsom and St Helier University Hospitals NHS Trust	Epsom and St Helier University Hospitals NHS Trust	Surrey	**T**
Essex County Hospital	Colchester Hospital University Hospitals NHS Trust	Essex	**H**
Fairfield General Hospital	The Pennine Acute Hospitals NHS Trust	Greater Manchester	**H**
Frimley Park Hospital NHS Foundation Trust	Frimley Park Hospital NHS Foundation Trust	Surrey	**T**
George Eliot Hospital NHS Trust	George Eliot Hospital NHS Trust	Warwickshire	**T**
Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire	**T**
Grantham & District Hospital	United Lincolnshire Hospitals NHS Trust	Lincolnshire	**H**
Great Western Hospital	Great Western Hospitals NHS Foundation Trust	Wiltshire	**H**
Guy's and St Thomas' NHS Foundation Trust	Guy's and St Thomas' NHS Foundation Trust	London	**T**
Hampshire Hospitals NHS Foundation Trust	Hampshire Hospitals NHS Foundation Trust	Hampshire	**T**
Harrogate and District NHS Foundation Trust	Harrogate and District NHS Foundation Trust	North Yorkshire	**T**
Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Berkshire	**T**
Hexham General Hospital	Northumbria Healthcare NHS Foundation Trust	Tyne & Wear	**H**
Hillingdon Hospitals NHS Foundation Trust	Hillingdon Hospitals NHS Foundation Trust	Middlesex	**T**
Hinchingbrooke Hospital	Hitchingbrooke Health Care NHS Trust	Cambridgeshire	**H**
Homerton University Hospital NHS Foundation Trust	Homerton University Hospital NHS Foundation Trust	London	**T**
Horton General Hospital	Oxford University Hospitals NHS Trust	Oxfordshire	**H**
Hull Royal Infirmary	Hull and East Yorkshire Hospitals NHS Trust	East Yorkshire	**H**
Imperial College Healthcare NHS Trust	Imperial College Healthcare NHS Trust	London	**T**
Ipswich Hospital NHS Trust	Ipswich Hospital NHS Trust	Suffolk	**T**
Isle Of Wight NHS Trust	Isle Of Wight NHS Trust	Isle of Wight	**T**
James Paget University Hospitals NHS Foundation Trust	James Paget University Hospitals NHS Foundation Trust	Norfolk	**T**
John Radcliffe Hospital	Oxford University Hospitals NHS Trust	Oxfordshire	**H**
Kettering General Hospital NHS Foundation Trust	Kettering General Hospital NHS Foundation Trust	Northamptonshire	**T**
King George Hospital	Barking, Havering and Redbridge University Hospitals NHS Trust	Essex	**H**
King's College Hospital	Kings College Hospital NHS Foundation Trust	Greater London	**H**
Kingston Hospital NHS Trust	Kingston Hospital NHS Trust	Surrey	**T**
Leeds Teaching Hospitals NHS Trust	Leeds Teaching Hospitals NHS Trust	West Yorkshire	**T**
Leighton Hospital	Mid Cheshire Hospitals NHS Foundation Trust	Cheshire	**H**
Lewisham Healthcare NHS Trust	Lewisham Healthcare NHS Trust	London	**T**
Lincoln County Hospital	United Lincolnshire Hospitals NHS Trust	Lincolnshire	**H**
Luton and Dunstable Hospital NHS Foundation Trust	Luton and Dunstable Hospital NHS Foundation Trust	Bedfordshire	**T**
Maidstone and Tunbridge Wells NHS Trust	Maidstone and Tunbridge Wells NHS Trust	Kent	**T**
Medway Maritime Hospital	Medway NHS Foundation Trust	Kent	**H**
Mid Essex Hospital Services NHS Trust	Mid Essex Hospital Services NHS Trust	Essex	**T**
Mid Staffordshire NHS Foundation Trust	Mid Staffordshire NHS Foundation Trust	Staffordshire	**T**
Mid Yorkshire Hospitals NHS Trust	Mid Yorkshire Hospitals NHS Trust	West Yorkshire	**T**
Milton Keynes Hospital NHS Foundation	Milton Keynes Hospital NHS Foundation	Buckinghamshire	**T**

Site	Trust	County	T/ H
Trust	Trust		
Musgrove Park Hospital	Taunton and Somerset NHS Foundation Trust	Somerset	**H**
New Cross Hospital	The Royal Wolverhampton NHS Trust	West Midlands	**H**
Newcastle upon Tyne Hospitals NHS Foundation Trust	Newcastle upon Tyne Hospitals NHS Foundation Trust	Tyne & Wear	**T**
Newham University Hospital	Barts Health NHS Trust	London	**H**
Nobles Hospital	Isle of Man	Isle of Man	**H**
Norfolk and Norwich University Hospitals NHS Foundation Trust	Norfolk and Norwich University Hospitals NHS Foundation Trust	Norfolk	**T**
North Bristol NHS Trust	North Bristol NHS Trust	Avon	**T**
North Manchester General Hospital	The Pennine Acute Hospitals NHS Trust	Greater Manchester	**H**
North Middlesex University Hospital NHS Trust	North Middlesex University Hospital NHS Trust	London	**T**
North Tees and Hartlepool NHS Foundation Trust	North Tees and Hartlepool NHS Foundation Trust	Stockton-on-Tees	**T**
North Tyneside General Hospital	Northumbria NHS Trust	Tyne & Wear	**H**
North West London Hospitals NHS Trust	North West London Hospitals NHS Trust	Middlesex	**T**
Northampton General Hospital NHS Trust	Northampton General Hospital NHS Trust	Northamptonshire	**T**
Northern Devon Healthcare NHS Trust	Northern Devon Healthcare NHS Trust	Devon	**T**
Northern General Hospital	Sheffield Teaching Hospitals NHS Foundation Trust	South Yorkshire	**H**
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	North East Lincolnshire	**T**
Nottingham University Hospitals NHS Trust	Nottingham University Hospitals NHS Trust	Nottinghamshire	**T**
Pilgrim Hospital	United Lincolnshire Hospitals NHS Trust	Lincolnshire	**H**
Plymouth Hospitals NHS Trust	Plymouth Hospitals NHS Trust	Devon	**T**
Poole Hospital NHS Foundation Trust	Poole Hospital NHS Foundation Trust	Dorset	**T**
Portsmouth Hospitals NHS Trust	Portsmouth Hospitals NHS Trust	Hampshire	**T**
Princess Alexandra Hospital NHS Trust	Princess Alexandra Hospital NHS Trust	Essex	**T**
Princess Royal Hospital	Kings College Hospital NHS Foundation Trust	Greater London	**H**
Queen Elizabeth Hospital	Gateshead Health NHS Foundation Trust	Tyne & Wear	**H**
Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Norfolk	**T**
Queens Hospital	Barking, Havering and Redbridge Hospitals NHS Trust	Essex	**H**
Rotherham NHS Foundation Trust	Rotherham NHS Foundation Trust	South Yorkshire	**T**
Royal Albert Edward Infirmary	Wrightington, Wigan and Leigh NHS Foundation Trust	Lancashire	**H**
Royal Berkshire NHS Foundation Trust	Royal Berkshire NHS Foundation Trust	Berkshire	**T**
Royal Blackburn Hospital	East Lancashire Hospitals NHS Trust	Lancashire	**H**
Royal Bournemouth Hospital	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Dorset	**H**
Royal Derby Hospital	Derby Hospitals NHS Foundation Trust	Derbyshire	**H**
Royal Devon and Exeter (Wonford)	Royal Devon and Exeter NHS Foundation Trust	Devon	**H**
Royal Free London	Royal Free London NHS Foundation Trust	London	**H**
Royal Hallamshire Hospital	Sheffield Teaching Hospitals NHS Foundation Trust	South Yorkshire	**H**
Royal Liverpool University Hospital	Royal Liverpool and Broadgreen University Hospitals NHS Trust	Merseyside	**H**
Royal London Hospital	Barts Health NHS Trust	London	**H**
Royal Marsden NHS Foundation Trust	Royal Marsden NHS Foundation Trust	London	**T**
Royal Oldham Hospital	The Pennine Acute Hospitals NHS Trust	Greater Manchester	**H**
Royal Preston Hospital	Lancashire Teaching Hospitals NHS	Lancashire	**H**

Site	Trust	County	T/H
	Foundation Trust		
Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey County Hospital NHS Foundation Trust	Surrey	**T**
Royal United Hospital Bath NHS Trust	Royal United Hospital Bath NHS Trust	Somerset	**T**
Salford Royal NHS Foundation Trust	Salford Royal NHS Foundation Trust	Manchester	**T**
Salisbury NHS Foundation Trust	Salisbury NHS Foundation Trust	Wiltshire	**T**
Sandwell and West Birmingham Hospitals NHS Trust	Sandwell and West Birmingham Hospitals NHS Trust	West Midlands	**T**
Scarborough Hospital	York Teaching Hospital NHS Foundation Trust	North Yorkshire	**H**
Sherwood Forest Hospitals NHS Foundation Trust	Sherwood Forest Hospitals NHS Foundation Trust	Nottinghamshire	**T**
Shrewsbury and Telford Hospital NHS Trust	Shrewsbury and Telford Hospital NHS Trust	Shropshire	**T**
South Tees Hospitals NHS Foundation Trust	South Tees Hospitals NHS Foundation Trust	Cleveland	**T**
South Tyneside NHS Foundation Trust	South Tyneside NHS Foundation Trust	Tyne & Wear	**T**
Southend University Hospital NHS Foundation Trust	Southend University Hospital NHS Foundation Trust	Essex	**T**
Southport and Ormskirk Hospital NHS Trust	Southport and Ormskirk Hospital NHS Trust	Merseyside	**T**
St. Bartholomew's Hospital	Barts Health NHS Trust	London	**H**
Stepping Hill Hospital	Stockport NHS Foundation Trust	Cheshire	**H**
Surrey and Sussex Healthcare NHS Trust	Surrey and Sussex Healthcare NHS Trust	Surrey	**T**
Tameside Hospital NHS Foundation Trust	Tameside Hospital NHS Foundation Trust	Lancashire	**T**
University College London Hospitals NHS Foundation Trust	University College London Hospitals NHS Foundation Trust	Camden	**T**
University Hospital of North Staffordshire NHS Trust	University Hospital of North Staffordshire NHS Trust	Staffordshire	**T**
University Hospital of South Manchester NHS Foundation Trust	University Hospital of South Manchester NHS Foundation Trust	Lancashire	**T**
University Hospital Southampton NHS Foundation Trust	University Hospital Southampton NHS Foundation Trust	Hampshire	**T**
University Hospitals Coventry and Warwickshire NHS Trust	University Hospitals Coventry and Warwickshire NHS Trust	West Midlands	**T**
University Hospitals of Leicester NHS Trust	University Hospitals of Leicester NHS Trust	Leicestershire	**T**
University Hospitals of Morecambe Bay NHS Foundation Trust	University Hospitals of Morecambe Bay NHS Foundation Trust	Cumbria	**T**
Walsall Healthcare NHS Trust	Walsall Healthcare NHS Trust	West Midlands	**T**
Wansbeck General Hospital	Northumbria NHS Trust	Tyne & Wear	**H**
Warrington and Halton Hospitals NHS Foundation Trust	Warrington and Halton Hospitals NHS Foundation Trust	Cheshire	**T**
West Hertfordshire Hospitals NHS Trust	West Hertfordshire Hospitals NHS Trust	Hertfordshire	**T**
West Middlesex University Hospital NHS Trust	West Middlesex University Hospital NHS Trust	Middlesex	**T**
Western Sussex Hospitals NHS Trust	Western Sussex Hospitals NHS Trust	West Sussex	**T**
Whipps Cross University Hospital	Barts Health NHS Trust	London	**H**
Whiston Hospital	St Helens and Knowsley NHS Trust	Merseyside	**H**
Whittington Hospital NHS Trust	Whittington Hospital NHS Trust	London	**T**
Wirral University Teaching Hospital NHS Foundation Trust	Wirral University Teaching Hospital NHS Foundation Trust	Wirral	**T**
Worcestershire Royal Hospital	Worcestershire Acute Hospitals NHS Trust	Worcestershire	**H**
Wye Valley NHS Trust	Wye Valley NHS Trust	Herefordshire	**T**
Yeovil District Hospital NHS Foundation Trust	Yeovil District Hospital NHS Foundation Trust	Somerset	**T**
York Teaching Hospital	York Teaching Hospital NHS Foundation Trust	North Yorkshire	**H**

Appendix V: Steering Group membership

Name	Title
Dr Kevin Stewart **(CHAIR)**	Clinical Director, Clinical Effectiveness and Evaluations Unit (CEEU), Royal College of Physicians (RCP)
Janet Husk	Patient Safety and Quality Improvement Programme Manager, CEEU, RCP
Helen Mulholland	Research Assistant, MCPCIL
Tony Bonser	Trustee for the National Council for Palliative Care Chair of the NCPC People in Partnership User Group Local (North Western) Champion for the Dying Matters Consortium. Fund-raiser and spokesperson for Macmillan Cancer Support.
Dr Sally Briggs	Consultant, Manchester. British Geriatrics Society representative
Dr David Brooks	President of the Association of Palliative Medicine
Rhona Buckingham	Operations Director, CEEU, RCP
Simon Chapman	Director of Public and Parliamentary Engagement
Linda Cuthbertson	Communications Lead, RCP
Professor John Ellershaw (CO-CHAIR)	Professor of Palliative Medicine, University of Liverpool, Director The Marie Curie Palliative Care Institute Liverpool (MCPCIL), Clinical Director, Specialist Palliative Care Directorate, The Royal Liverpool and Broadgreen University Hospitals NHS Trust; Medical Director, The Marie Curie Hospice Liverpool
Maureen Gambles	Service Innovation and Improvement Operational Lead, MCPCIL
Tom Gentry	Policy adviser, Age UK
Professor David Jones	Director Bio ethics
Derek Lowe	Medical Statistician, Clinical Standards, RCP
Olwen Minford	Member of RCN Pain and Palliative Care Forum steering committee
Deborah Murphy	Associate Director – MCPCIL, Directorate Manager, Specialist Nurse, Specialist Palliative Care Directorate, The Royal Liverpool and Broadgreen University Hospitals NHS Trust
Dr Philippa Nicholson	Consultant, University Hospitals Birmingham Foundation Trust
Dr Bill Noble (replaced Dr Teresa Tate in this role on 1/7/2013)	Medical Director, Marie Curie
Ben O’Brien	Communications Lead, MCPCIL.
Dr Liz Sampson	Senior Clinical Lecturer, Marie Curie Palliative Care Research Unit, University College, London
Professor Julia Verne	Director for Knowledge and Intelligence (South West) and Clinical Lead – National End of Life Care Intelligence Network
Dr Bee Wee	National Clinical Director, End of Life Care, NHS England
Heather Richardson	Help the Hospices

Appendix VI: glossary

Statistical terminology	
Interquartile range (IQR)	Where appropriate, the IQR, is presented within the tables. Twenty-five percent 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.
Scatter plots	For each clinical KPI, the percentage of cases for each site with a KPI score that was greater than or equal to the KPI cut off score was plotted against the number of cases submitted by the site. For each clinical KPI, the KPI cut off score for the national dataset (ie May 2013) was presented as a dotted line within each scatter plot to enable sites to compare their performance with that of others as well as against the national benchmark.
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[28] suggests one possible interpretation of Kappa. • Poor agreement = Less than 0.20. • Fair agreement = 0.20 to 0.40. • Moderate agreement = 0.40 to 0.60. • Good agreement = 0.60 to 0.80. • Very good agreement = 0.80 to 1.00.

Inter-auditor reliability	The second coding of a number of audit proformas 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.
Median	One type of average, found by arranging the values in order and then selecting the one in the middle.

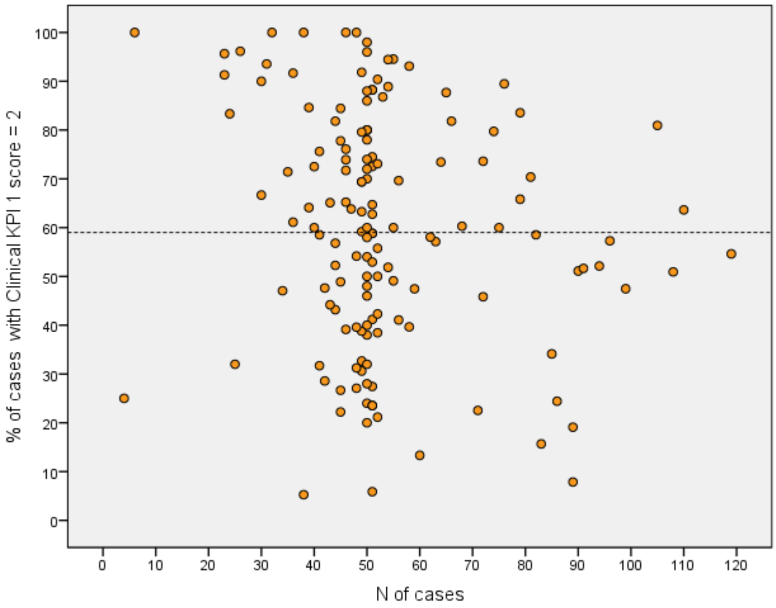
Terminology	
Key performance indicator (KPI)	KPI's are quantitative measurements / metrics that enable an organisation measure progress towards goals and identify areas for improvement. They can be used to focus activities, assess, tune, performance and model / modify processes.
Corporate performance dashboard	A dashboard is a graphical easy to read and interpret user interface that shows at a glance metrics and KPI's in a single overview about performance that aligns strategy, processes, tools and culture around corporate objectives. Reports are REAL: relevant, engaging, actionable and lean. A dashboard facilitates the dissemination of the KPI's throughout the organisation
General terminology	
Independent mental capacity adviser (IMCA)	Neuberger[10] 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.'

Appendix VII: scatter plot graphs showing site level variation in clinical kpi scores plotted against the number of cases submitted by each site.

Clinical KPI 1: Multidisciplinary recognition that the patient is dying

Site variation: % of cases with a clinical KPI1 score ≥ cut-off plotted against number of cases submitted by site.

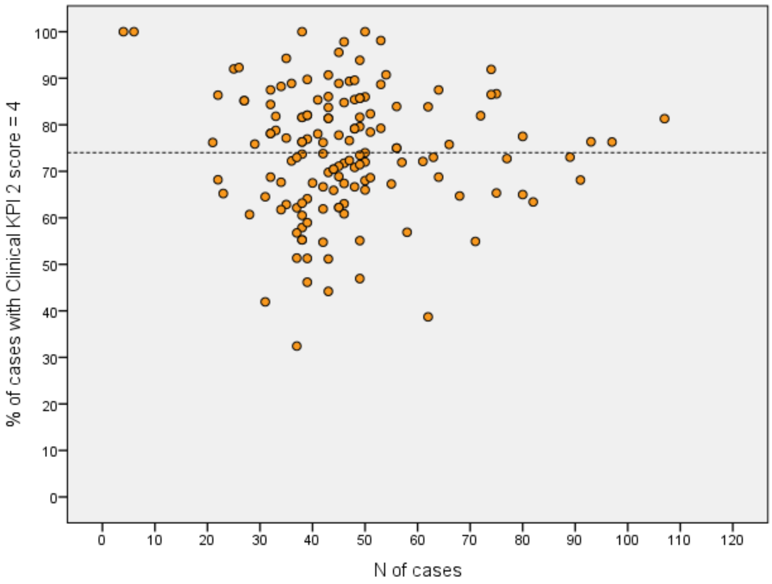
Median site: 60%, IQR of sites 43-80%. The dotted line depicts the 59% (3,859/6,580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 2: health professional's discussions with both the patient and their relatives/friends regarding their recognition that the patient is dying.

Site variation: % of cases with a clinical KPI2 score ≥ cut-off plotted against number of cases submitted by site.

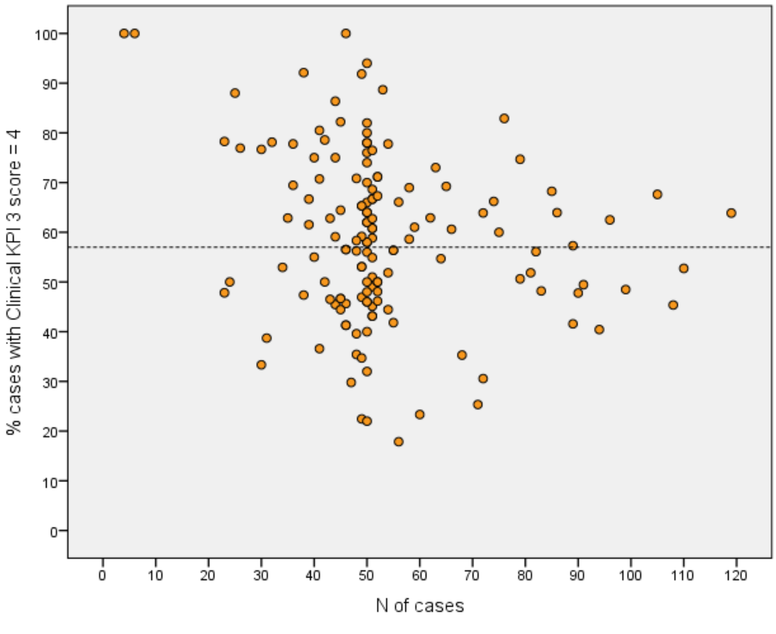
Median site: 76%, IQR of sites 66–85%. The dotted line depicts the 74% (4210/5722) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 3 communication regarding the patient's plan of care for the dying phase.

Site variation: % of cases with a clinical KPI3 score ≥ cut-off plotted against number of cases submitted by site.

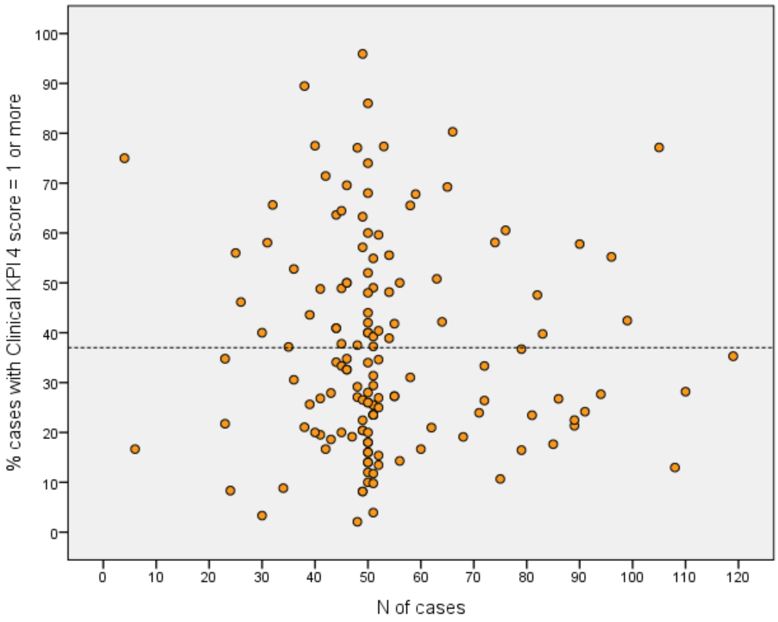
Median site: 59%, IQR of sites 48–71%. The dotted line depicts the 57% (3773/6580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 4: assessment of the spiritual needs of the patient and their nominated relatives or friends.

Site variation: % of cases with a clinical KPI4 score ≥ cut-off plotted against number of cases submitted by site.

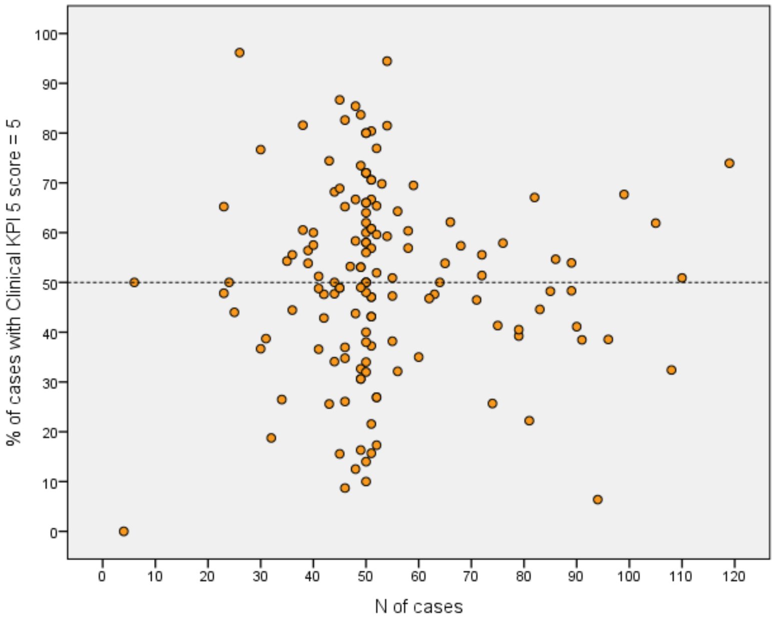
Median site: 33%, IQR of sites 21–50%. The dotted line depicts the 37% (2,410/6,580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 5: medication prescribed prn for the five key symptoms that may develop during the dying phase.

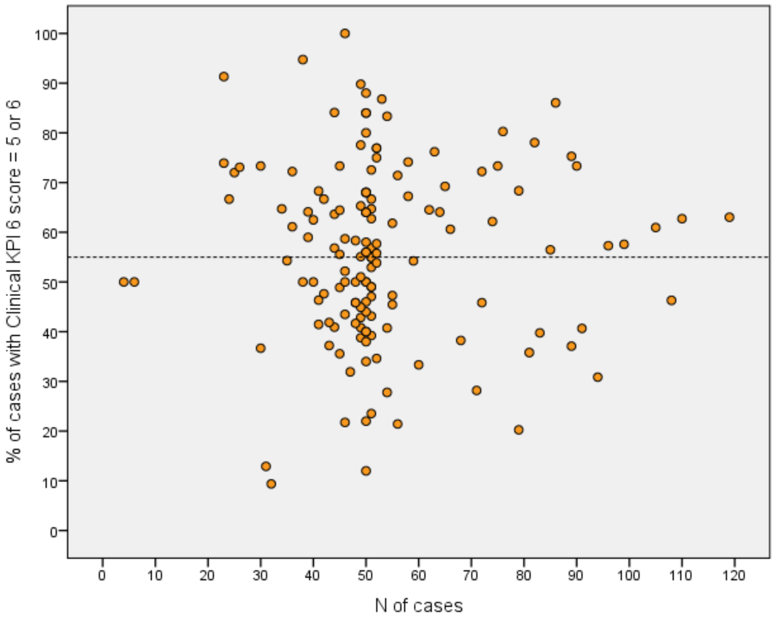
Site variation: % of cases with a clinical KPI5 score ≥ cut-off plotted against number of cases submitted by site.

Median site: 50%, IQR of sites 39–63%. The dotted line depicts the 50% (3,305/6,580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



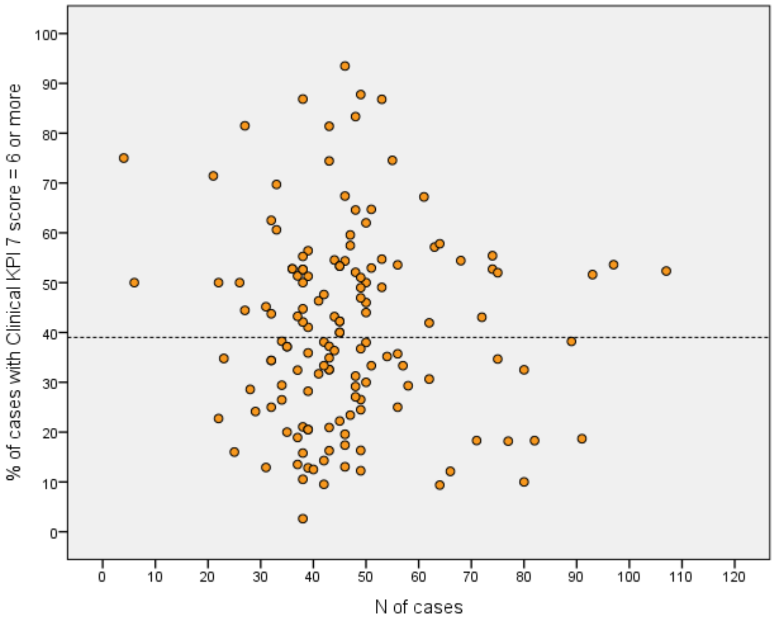
Clinical KPI 6: a review of interventions during the dying phase.

Site variation: % of cases with a clinical KPI6 score ≥ cut-off plotted against number of cases submitted by site.
Median site: 55%, IQR of sites 44–68%. The dotted line depicts the 55% (3,650/6,580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 7: a review of the patient's nutrition requirements

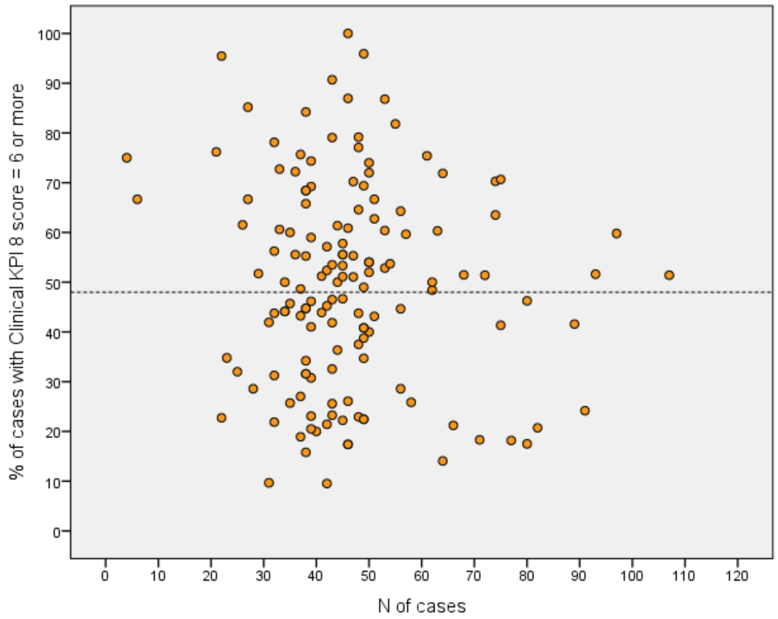
Site variation: % of cases with a clinical KPI7 score ≥ cut-off plotted against number of cases submitted by site.
Median site: 40%, IQR of sites 26–53%. The dotted line depicts the 39% (2,249/5,722) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 8: a review of the patient’s hydration requirements

Site variation: % of cases with a clinical KPI8 score ≥ cut-off plotted against number of cases submitted by site.

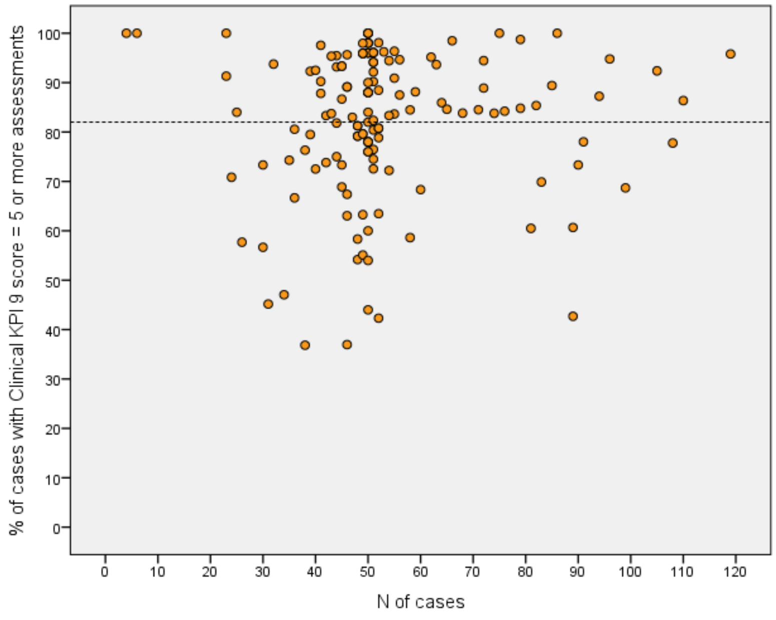
Median site: 51%, IQR of sites 3365%. The dotted line depicts the 48% (2,737/5,722) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 9 a review of the number of assessments undertaken in the patient’s last 24 hours of life.

Site variation: % of cases with a clinical KPI9 score ≥ cut-off plotted against number of cases submitted by site.

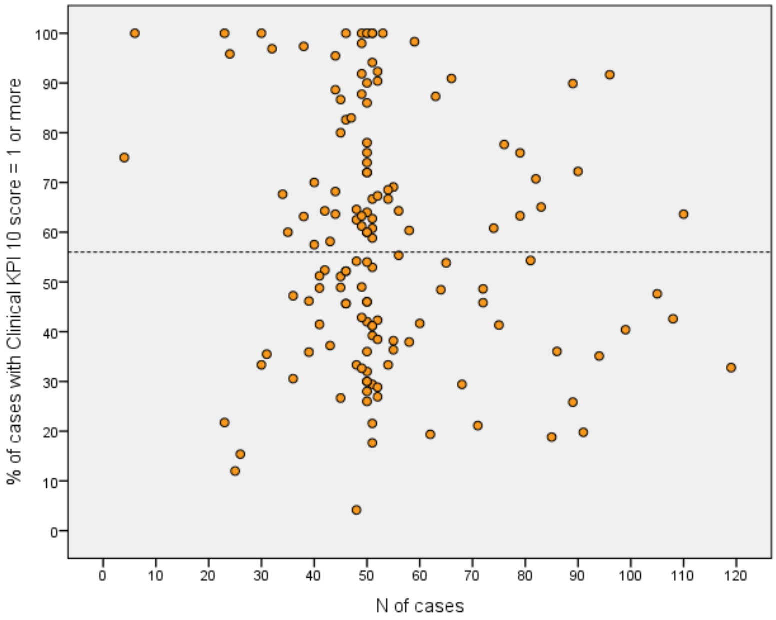
Median site: 85%, IQR of sites 76–95%. The dotted line depicts the 82% (5,409/6,580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



Clinical KPI 10: a review of the care after death

Site variation: % of cases with a clinical KPI10 score ≥ cut-off plotted against number of cases submitted by site.

Median site: 59%, IQR of sites 39–76%. The dotted line depicts the 56% (3701/6580) national statistic for May 2013. Site level data includes all their cases for May, June and July 2013.



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