Royal College of Physicians

Marie Curie

Care and support through terminal illness

End of Life Care Audit – Dying in Hospital

Executive summary 2016

Commissioned by:

Healthcare Quality Improvement Partnership

Acknowledgements

The End of Life Care Audit – Dying in Hospital was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote the use of clinical audit to help drive quality improvement in healthcare.

This report was prepared by the Royal College of Physicians (RCP). We would like to thank all the hospitals and trusts that participated in this audit, with particular thanks to members of staff who submitted their data. We would also like to thank the audit Steering Group (see Appendix III of the full report) for their valuable support and advice throughout the project. Particular thanks also go to the national report writing sub-group: Sam Ahmedzai, Bee Wee, David Brooks, David Jones, Ann Heaton and Amanda Cheesley.

We also acknowledge and thank Marie Curie for contributing additional funding to assist with the dissemination and usage of these audit results for quality improvement purposes.

Useful links

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

Citation for this document: Royal College of Physicians. *End of Life Care Audit – Dying in Hospital: executive summary*. London: RCP, 2016.

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ISBN: 978-1-86016-608-2
e-ISBN: 978-1-86016-609-9

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Registered Charity No 210508

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Foreword

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

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

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

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

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

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

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Executive summary

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

Background

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

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

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

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

This audit comprised the following two sections.

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

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

Progress since the last audit

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

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

Methods

Registration

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

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

Organisational element

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

Clinical case note review element

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

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

Submission of data

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

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

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

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

Sample

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

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

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

Each participating site received an individual report of their performance against the national sample for the organisational and case note review elements of the audit. In addition, individual site results were downloadable separately from within the audit web tool.

Quality indicators for end of life care

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

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

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

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

Key findings

Clinical patient case note review key findings

Recognition of dying

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

Communication and treatment decisions

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

Communication with people important to the patient

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

Individual plan of care

Symptom control

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

Drinking and eating

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

Spiritual care

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

Organisational element key findings

Staffing and training

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

Guidance and policies

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

Using relative's views and auditing care

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

Key recommendations

Clinical case note review element recommendations

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

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

Organisational element recommendations

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

Future opportunities and challenges

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

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

References

1. Office for National Statistics (ONS) mortality statistics. Deaths registered in England and Wales (Series DR): 2014. Tables 1–4 and tables 6–14 (Excel sheet 1051 Kb) (table 12). Deaths registered by age, sex and selected underlying cause of death , 2015. www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015-11-09/relateddata [Accessed 7 March 2016]
2. Department of Health. *End of life care strategy: promoting high quality care for all adults at the end of life*. London: DH, 2008. www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [Accessed 26 January 2014]
3. Department of Health. *End of life care strategy: quality markers and measures for end of life care*. London: DH, 2009. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf [Accessed 26 January 2014]
4. National Institute for Health and Clinical Excellence. *NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers*. London: NICE, 2011. www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-436888045 [Accessed 2 February 2016]
5. Department of Health. *The Mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015*. London: DH, 2013. www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf [Accessed 26 January 2016]
6. Neuberger J. *More care less pathway; a review of the Liverpool Care Pathway*. 2013. www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 7 January 2016]
7. Leadership Alliance for the Care of Dying People. *One chance to get it right – Improving people's experience of care in the last few days and hours of life*, 2014. www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Accessed 26 January 2016]
8. Royal College of Physicians. *National care of the dying audit for hospitals, England – National report*. London: RCP, 2014. www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals [Accessed 26 January 2016]
9. National Institute for Health and Care Excellence. *Care of dying adults in the last days of life* – NICE Guideline. London: NICE, 2015. www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-1837387324357 [Accessed 7 January 2016]

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