



Royal College
of Physicians

Marie Curie
Cancer Care



National care of the dying audit for hospitals, England

Executive summary

May 2014

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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Royal College of Physicians: www.rcplondon.ac.uk

Marie Curie Palliative Care Institute Liverpool: www.mcpcil.org.uk

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National Council for Palliative Care: www.ncpc.org.uk

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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 policy²⁻⁹ 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 sites¹ 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.

¹ 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.

References

- 1 Office for National Statistics (ONS) Mortality Statistics. Deaths registered in 2012 (Series DR) Tables 1–4 and tables 6–14 (excel sheet 1051Kb) (table 12) deaths: place of occurrence and sex by underlying cause and age group, 2012. www.ons.gov.uk/ons/search/index.html?newquery=number-of-deaths+in+hospital [Accessed 21 March 2014]
- 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 7 March 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 7 April 2014]
- 4 National Institute for Health and Clinical Excellence (NICE). *NICE Quality Standards: Information for adults who use NHS end of life care services and their families and carers*. London: NICE, 2011. www.nice.org.uk/nicemedia/live/13845/60322/60322.pdf [Accessed 7 April 2014]
- 5 Department of Health. *The Mandate: a mandate from the government to the NHS commissioning Board: April 2013 to March 2015*. London: DH, 2012. www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf [Accessed 7 March 2014]
- 6 General Medical Council. *Treatment and care towards the end of life: good practice in decision making – guidance for doctors*. London: GMC, 2010. www.gmc-uk.org/static/documents/content/End_of_life.pdf [Accessed 7 March 2014]
- 7 Care Quality Commission. *Guidance about compliance. Essential standards of quality and safety. Section 4K*. London: CQC, 2010. [www.cqc.org.uk/sites/default/files/media/documents/gac - dec 2011 update.pdf](http://www.cqc.org.uk/sites/default/files/media/documents/gac_-_dec_2011_update.pdf) [Accessed 7 March 2014]
- 8 Department of Health. *The NHS Outcomes Framework 2013/14*. London: DH, 2012. www.gov.uk/government/uploads/system/uploads/attachment_data/file/134662/dh_131723.pdf.pdf [Accessed 7 March 2014]
- 9 Department of Health. *The NHS Constitution – the NHS belongs to us all*. London: DH, 2013. www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf [Accessed 7 March 2014]
- 10 Neuberger J. More care less pathway; a review of the Liverpool Care Pathway. 2013. http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 7 March 2014]
- 11 Mayland CR, Lees C, Germain A *et al*. Caring for those who die at home: the use and validation of ‘Care Of the Dying Evaluation’ (CODE) with bereaved relative. *BMJ Support Palliat Care* doi:10.1136/bmjspcare-2013-000596 (published online first 28th March 2014).

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