The Marie Curie
Palliative Care Institute
LIVERPOOL

Royal College of Physicians

NATIONAL CARE OF THE DYING AUDIT – HOSPITALS (NCDAH)

ROUND 3

EXECUTIVE SUMMARY 2011/2012

Led by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Royal College of Physicians (RCP)

Supported by Marie Curie Cancer Care & Department of Health End of Life Care Programme

Marie Curie Cancer Care

NHS
End of Life Care Programme

LIVERPOOL Care Pathway
Promoting best practice for care of the dying

Foreword

Fifty-eight percent of all deaths in England occur in the hospital sector (NAO 2008). It is, therefore, important for Trust boards, managers and clinicians to recognise that it is a core responsibility of hospitals to provide a dignified death for patients and appropriate support to their relatives or carers. The National Care of the Dying Audit – Hospitals (NCDAH) Round 3 has been listed in the DH 2011 – 2012 Quality Accounts list of recommended national audits to participate in, and is the only national audit listed under 'End of life Care'.

"How we care for dying patients is an indicator of the patient quality experience across our organisations. Good quality care should be safe, effective, patient centred, timely, efficient and measurable. The recommendations and performance indicators outlined in this third round of the National Care of The Dying Audit – Hospitals (NCDAH) continues to provide healthcare workers, chief executives and commissioners with a clear direction of travel.

Appropriate and timely information regarding the quality of care will assist to improve services and make it easier to share best practice so that organisations remain productive by continually learning and innovating."

Kevin Stewart
Clinical Director, Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, London
NCDAH Working Group / National LCP Reference Group UK Member

"Putting patients and families first requires a focus on dignity and respect, none more so than in care of the dying. To truly achieve value, care needs to be designed and delivered around patient needs, informed by clinical audit data. The National Care of the Dying Audit – Hospitals (NCDAH) Round 3 is an excellent model of continuous quality improvement in support of this agenda".

Thomas Hughes-Hallett
Chief Executive of Marie Curie Cancer Care
Chair, End of Life Care Implementation Advisory Board

"The challenges for end of life care have not diminished, nor have the importance of what we are trying to achieve but there is still a long way to go. This National Care of the Dying Audit - Hospitals (NCDAH) which now includes 83% of Acute Hospital Trusts in England, and is included in the Quality Accounts, continues to drive up quality to ensure that a good death is the norm and not the exception in our society. All those that have contributed to the audit are to be congratulated for their efforts in improving care of the dying."

Professor Sir Mike Richards
National Clinical Director for Cancer and End of Life Care
National LCP Reference Group UK Member

"Everyone will die and, in the United Kingdom, most of us will die in hospital. The great value of a national audit of care of those dying in hospital is to call attention to this time in our lives and to help hospitals to be more attentive to the needs of their dying patients."

Professor David Albert Jones
Director of the Anscombe Bioethics Centre, Oxford
National LCP Reference Group UK Member

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A copy of this report is available from the Marie Curie Palliative Care Institute Liverpool (MCPCIL) website at www.mcpcil.org.uk

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EXECUTIVE SUMMARY

<u>Background</u> Fifty-eight percent of all deaths in England occur in the hospital sector (NAO, 2008). It is, therefore, important for Trust boards, managers and clinicians to recognise that it is a core responsibility of hospitals to ensure a dignified death for patients and to provide appropriate support to their relatives or carers. Government Policy in recent years has reinforced the need to prioritise the delivery of high quality care at the end of life (DH 2006, 2008, 2009). As the previous Clinical Director of the Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, Dr Jonathan Potter commented "The majority of people who die, die in hospital. It is essential to ensure this aspect of hospital care is of the highest standard. The second round of the National Audit of Care of the Dying demonstrates that, where the Liverpool Care Pathway for the dying patient (LCP) is used, people are receiving high quality clinical care in the last hours and days of life." (NCDAH 2009)

The Liverpool Care Pathway for the Dying Patient (LCP) has been recommended for use as a model of best practice in the last hours or days of life in National policy (DH 2006, 2008) and more recently in the End of Life Care Strategy: Quality Markers and Measures for End of Life Care (2009). The NCDAH Round 2 was carried out in 2008/2009, based on the standards of care within the LCP. The results provided a picture of care of the dying in our acute hospitals in England for the 3893 patients from 155 acute hospitals that were included in the audit (MCPCIL, 2009). **The NCDAH Round 3 has been listed in the DH 2011 – 2012 Quality Accounts list of recommended national audits, and is the only national audit listed under 'End of life Care'**.

Building on round 1 and 2, the results from this third round of the audit will provide a National snapshot of performance against the goals of care on the LCP generic version 12 (or 'matched alternative') against which individual hospital performance is benchmarked. Data driven Key Performance Indicators (KPI) for the delivery of care to dying patients during the last hours or days of their lives have also been developed to promote the appropriate prioritisation of this area of care within Acute Hospital Trusts.

<u>Methods</u> A retrospective audit design was used to gather data on the provision of care (organisational element) within each Hospital Trust. In addition, clinical data from a *minimum* of 30 consecutive deaths in each of the individual participating hospitals between 1st April and 30th June 2011 was collected prospectively. An electronic data collection tool was developed to enable easy data input and to enhance the quality of the data submitted. The National LCP Reference Group UK has provided advice and support throughout the project. In round 3, data from the goals of care were analysed in two ways: compliance with the documentation, to illustrate the proportion of times that information was documented at the point of delivery of care; performance (proportion of achieved and variance recorded) for each goal where data were documented.

<u>Sample</u> 131 Hospital Trusts provided data for the organisational element, and 178 individual hospitals (from 127 Trusts) submitted a total of 7058 patient data sets for the Clinical element. *(see Appendix 1 in the main report www.mcpcil.org.uk)*

<u>Reports</u> Each participating hospital has received a full individual report detailing their performance against that of the whole sample. A Report of the generic results (for the sample as a whole) is also available to download. Please go to www.mcpcil.org.uk for information regarding how to access these reports.

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KEY FINDINGS

PART A – ORGANISATIONAL LEVEL KEY FINDINGS

It is encouraging to see a 13% increase in trust participation between NCDAH Round 2 and Round 3, with 131 Hospital Trusts submitting data into the organisational element of the audit this time. Within participating Trusts, it appears that the use of the LCP is relatively well spread throughout each individual trust, with almost all wards (90%) having the LCP in use to some extent, and on average Hospital Trusts have been using the LCP for 5 years. Further spread of the LCP within Trusts is evident in the proportion of all patients whose care was supported by LCP national core document or 'matched alternative'. This has increased since NCDAH round 2 (R2 21%; R3 31%) which suggests that the LCP is becoming more embedded in practice within each participating Hospital Trust. Although data were collected per Hospital Trust in this audit (and not per hospital as in Round 2), we can see an increase between Round 2 and Round 3 in the amount of education and training offered in care of the dying for Medical staff (R2: 74%; R3: 90%). Two thirds (67%) of all Hospital Trusts produce routine action plans to improve care of the dying in their organisation, to support continuous quality improvement.

PART B: - PATIENT LEVEL KEY FINDINGS – CLINICAL DATA

Trust participation in the clinical element has also increased by 13% between NCDAH Round 2 and Round 3, with 178 hospitals (from 127 Trusts) submitting a total of 7058 individual patient data sets this time. Results show that senior healthcare professional endorsement of the LCP was more likely to occur where this element of practice had a clear process and space to document on the LCP paperwork, as is the case on LCP generic version 12. In terms of patient outcomes, for the ongoing assessment of the patient where assessments were recorded in the last 24 hours, the majority of patients were documented as comfortable for those goals relating to symptom control. When looking at current interventions, for those patients receiving it, clinically assisted (artificial) hydration was more likely to be continued after the multidisciplinary/multiprofessional team discussion than clinically assisted (artificial) nutrition, with around a sixth (16%) of patients still receiving clinically assisted (artificial) hydration after the initial assessment.

There is wide variation in hospital performance (coded achieved) for goals relating to conversations with the patient regarding awareness of dying, and addressing cultural, spiritual or religious needs at this time. This indicates practice across different hospitals may be very different, which should be a point of discussion when interpreting these results. The documentation of the multidisciplinary/multiprofessional team 3 day review also has one of the widest examples of hospital variation. It is encouraging however, that some hospitals are achieving this on 100% of occasions, which could highlight an opportunity for lower performing hospitals to learn from other services.

Compliance with regards to document completion should be addressed by all hospitals, although compliance in some areas is relatively high, certain other areas are a specific point for comment. For example, communication with the Primary Healthcare Team/GP and appropriate services across the organisation both prior to and after the death of the patient have the highest recordings of missing data, as do goals of care relating to significant conversations with the patient and relatives or carers. Low compliance may indicate a lack of confidence in certain areas of care delivery, and could point towards further education and training needs.

Key Performance Indicators (KPI's)

These KPIs are data driven metrics that have been developed to illustrate performance of participating Hospital Trusts (Organisational KPI's) and hospitals (Clinical KPI's) against specific 'themes' of care provision and delivery, with which individual hospitals can gauge their relative performance. Appendix 2 provides more information on how these KPIs were constructed. They can be usefully included on the 'corporate performance dashboard' used in many Trusts to promote continuous quality improvement.

The spread of the performance of hospitals nationally for the KPIs has been divided into three; Red, Amber and Green (RAG) coded sections based on the Inter Quartile Range:

- 'Red' Box represents the spread of performance for the bottom 25% of hospitals
- 'Amber' Box represents the spread of performance for the middle 50% of hospitals
- 'Green' Box represents the spread of performance for the top 25% of hospitals

These KPI's have been developed to provide Hospital Trusts with an indication of how their individual performance compares with that of the whole sample (Trust level for the Organisational KPI's and individual hospital level for the Clinical KPI's). Whilst an absolute target of 100% would always be recommended as a point to aim and strive for, these KPI's have been constructed to illustrate the spread of performance across participating Hospital Trusts, and can provide a valuable yardstick against which to measure improvement into the future.

Further work is planned to develop patient related outcome measures (PROM's) (DH 2011) from the collection of the national audit dataset.

Organisational Key Performance Indicators (KPI's)

131 NHS Trusts took part in the organisational element of the NCDAH Round 3, and these KPI's contain information derived from responses given against specific elements of care provision for each trust.

Clinical Key Performance Indicators (KPI's)

It is important to remember that some hospitals within the sample submitted a relatively small number of patient data sets to the audit. For this reason, the KPI's only include those 121 hospitals that submitted *at least a minimum* of 30 patient cases into the clinical section of the NCDAH Round 3.

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Key Performance Indicators (KPI)

	NCDAH ROUND 3 - KEY PERFORMANCE INDICATORS (KPI)	
NCDAH Round 3 Organisational Key Performance Indicators		National Round 3 (n=131)
	KPI 1: Access to Information relating to death and dying: to support care in the last hours or days of life	Median 71% IQR (57% - 71%)
	KPI 2: Access to specialist support (Specialist Palliative Care Services, LCP Facilitator) for care in the last hours or days of life	Median 63% IQR (50% - 75%)
	KPI 3: Care of the Dying: Continuing Education, Training and Audit	Median 67% IQR (50% - 83%)
	KPI 4: Care of the dying: Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient	Median 78% IQR (67% - 89%)
NCDAH Round 3 Clinical Key Performance Indicators		National Round 3 (n=121)
	KPI 5: Anticipatory prescribing for the 5 key symptoms that may develop in the last hours or days of life (Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting, Dyspnoea)	Median 83% IQR (73% - 92%)
	KPI 6: Communication with the relatives or carers regarding the plan of care (LCP), to promote understanding	Median 71% IQR (65% - 80%)
	KPI 7: Ongoing, Routine Assessment of the patient, relatives or carers	Median 76% IQR (69% - 84%) N=120*
	KPI 8: Compliance with completion of the LCP	Median 67% IQR (59% - 76%)

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Recommendations

	NCDAH ROUND 3 - RECOMMENDATIONS FOR CONTINUOUS QUALITY IMPROVEMENT FOR CARE OF THE DYING IN HOSPITALS
1.	Education and training in care of the dying should be mandatory for all staff caring for dying patients and their families.
2.	Hospital specialist palliative care teams should operate a seven day 9am to 5pm face to face service to support healthcare professionals caring for dying patients.
3.	Hospitals should have an LCP facilitator to support education and training, support care of the dying and to increase compliance with completion of documentation.
4.	The decision that a patient is dying and in the last hours or days of life should be made by the multidisciplinary/multiprofessional team and documented by the senior doctor who is ultimately responsible for the patient's care.
5.	The decision that a patient is dying and in the last hours or days of life should always be discussed with the patient where possible and deemed appropriate but always with the relatives or carers and appropriate written information should be available to support significant conversations at this time.
6.	The patient's condition should be reassessed regularly and formally documented four hourly. A full multidisciplinary/multiprofessional team review should be undertaken every 72hours or earlier as appropriate.
7.	All Hospital Trusts should have a best practice model of care in place for patients in the last hours or days of life, including up to and after the death of the patient, such as the LCP generic version 12 (DH 2009).
8.	Attention should be given to the three key areas of greatest variation between hospitals in the National Audit A: The provision of written information to support conversations (Initial Assessment Goals 9.2a and 9.3)) B: The provision of written information to support bereaved relatives (Care after Death Goal 11b) C: Communication with GP/Primary Healthcare Team (Initial Assessment Goal 9.4 and Care after Death Goal 12.1)
9.	Attention should be given to the three key areas of poor completion of documentation in the National Audit A: Senior Healthcare Endorsement B: Giving and Receiving of Information (Initial Assessment Goal 1.5 and Care after Death Goal 11 and 11a) C: Communication with GP/Primary Healthcare Team (Initial Assessment Goal 9.4 and Care after Death Goal 12.1)
10.	Care of the dying should be included within the Hospital Trust audit programme including participation in the National Care of the Dying Audit Hospitals (NCDAH) every 2 years.

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