

The Marie Curie
Palliative Care Institute

LIVERPOOL



NATIONAL CARE OF THE DYING AUDIT – HOSPITALS (NCDHAH)

ROUND 2

GENERIC REPORT 2008/2009

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

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

Foreword

If a clinical provider is to thrive in our current economic climate and evolving healthcare landscape it will need to demonstrate that it is best in class. How we care for dying patients is an indicator of the patient experience across our organisations. The recommendations and performance indicators outlined in this national audit give healthcare workers, Chief Executives and Commissioners a clear direction of travel.

We need to build on the success of the Liverpool Care Pathway for the Dying Patient (LCP) as a vehicle to drive up sustainable and measurable quality care, to deliver excellence in care of the dying. This audit is a significant step towards the development of a national benchmark across all other health sectors.

We need to continue to inspire, motivate and truly empower our patients, carers, health care workers and Commissioners. Time is of the essence; care of the dying is everyone's business

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

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. Reassuringly an increasing number of patients, both those with cancer and those with other conditions, are being cared for using the care pathway. The challenge raised by the audit is to ensure that those who should appropriately be on the pathway, are on it.

Aspects of care where much improvement is required within busy hospital schedules are communication with and support for relatives and carers both during the dying phase and after death.

All those that have contributed to the audit are to be congratulated for their efforts in improving the care of the dying.

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Acknowledgements

This report was prepared by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Clinical Standards Department of the Royal College of Physicians (RCP).

We would like to thank all those hospitals that participated in this round of the audit, with particular thanks to members of staff who submitted their data. We would also like to thank the National LCP Reference Group for their valuable support and advice throughout the project and to Marie Curie Cancer Care and the National End of Life Care Programme for funding this National Care of the Dying Audit (NCDAA) – Hospitals Round 2.

A report of the generic results from this audit is available as a separate publication. For details on how to access a copy, please visit the Institute website at www.mcpcil.org.uk

Useful Links:

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

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

Marie Curie Cancer Care. www.mariecurie.org.uk

End of Life Care Programme. www.endoflifecareforadults.nhs.uk

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

EXECUTIVE SUMMARY

Background Fifty-six percent of all deaths in England occur in the hospital sector (ONS, 2005). 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 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 Chair of the End of Life Strategy Advisory Board, Professor Mike Richards commented *“How we care for the dying must surely be an indicator of how we care for all our sick and vulnerable patients. Care of the dying is urgent care with only one opportunity to get it right to create a potential lasting memory for relatives and carers”* (MCPCIL 2007)

The Liverpool Care Pathway for the Dying Patient (LCP) has been recommended for use as a template of best practice in the last hours and days of life in UK 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 first National Care of the Dying Audit in Hospitals (NCDAH) was undertaken in 2006/2007 based on the standards of care within the LCP. The results from the first round provided a picture of care of the dying in our acute hospitals in England for the 2672 patients from 118 acute hospitals that were included in the audit (MCPCIL, 2007).

Building on the first round, the results from this second round of the audit provide a National snapshot of performance against the goals on the LCP against which individual hospital performance is benchmarked. It also focuses on the prescription and administration of medication for agitation and restlessness in the last 24 hours of life, as well as providing more information about variance recording for a proportion of goals. Data driven Key Performance Indicators (KPI) for the delivery of care to dying patients during the last hours and days of their lives have also been developed to promote the appropriate prioritisation of this area of care within Acute Hospital Trusts.

Methods A prospective audit design was used to gather LCP data from up to 30 consecutive deaths in each of the participating hospitals between 1st October 2008 and 31st December 2008. Pertinent hospital organisational data was also gathered to contextualise the data from the LCP and to aid interpretation of the results. 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 has provided advice and support throughout the project.

Sample 155 hospitals from 114 Acute Hospital Trusts participated in the audit and submitted a total of 3893 patient data sets.

Results Inter-auditor reliability was assessed as ‘very good’ (Median Kappa values for goals of care = 0.93, IQR 0.91 – 0.95 and for medication goals = 0.91, IQR 0.86 – 0.95). The results are presented for the following Domains of care **in the** main body of the report:

Domain 1 - Physical comfort of the patient

Domain 2 - Psychosocial and spiritual/religious aspects of care (patients & carers)

Domain 3 - Communication (patient, carer and healthcare colleagues)

Domain 4 - Appropriate information (giving and receiving)

Domain 5 - Compliance with appropriate policies and procedures.

Reports 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.

KEY FINDINGS


Key Performance Indicators

The following are based on data from those 102 hospitals that submitted the full sample size of 30 cases in Round 2. These KPIs are data driven metrics that have been developed to illustrate the performance of all hospitals in three specific areas against which individual hospitals can gauge their relative performance. These KPIs can be usefully included on the ‘corporate performance dashboard’ used in many Trusts to promote continuous quality improvement.

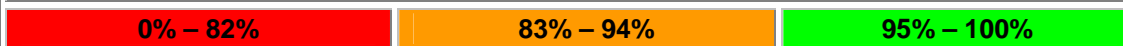
The spread of the performance of hospitals nationally for the 3 KPIs has been divided into 3 sections based on the Inter Quartile Range:

- ‘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

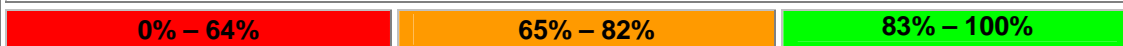
Key Performance Indicator 1: Spread of the LCP

Proportion of wards using the LCP	National Round 2 (n=102)
Median % (IQR)	75% (60% - 93%)
	

Key Performance Indicator 2: Anticipatory prescribing for the key symptoms that may develop in the last hours & days of life

Anticipatory prescribing for key symptoms	National Round 2 (n=101)
Median % (IQR)	88% (83%-94%)
	

Key Performance Indicator 3: Compliance with completion of the LCP or equivalent pathway

% compliance with completion	National Round 2 (n=102)
Median % (IQR)	74% (65 - 82)
	

PART A – ORGANISATIONAL LEVEL KEY FINDINGS

- The National Care of the Dying Audit – Hospitals demonstrates increased spread of the LCP both nationally and within hospitals in Round 2 (2008/2009) compared with Round 1 (2006/2007):
 - The number of participating hospitals has increased in Round 2 by 31% (from 118 to 155). 115 (82%) hospital trusts are represented in the audit and the number of patient data sets submitted has increased by 46% (from 2672 to 3893).
 - The percentage of hospitals that were able to submit the full sample size has increased from 44% to 65%
 - The national percentage of wards reported to be ‘using’ the LCP in Round 2 is 68% compared with 44% in Round 1.
- The LCP has been in use for 42 months on average (median) in comparison to 19 months in Round 1
- 39% of Hospitals have an LCP Facilitator working on average 0.6 wte in comparison with 47% and 0.8 wte in Round 1. The presence of an LCP facilitator (or equivalent) is associated with improved compliance with the LCP in this audit in those domains where the proportion of missing data is especially high (Domains 3, 4 and 5).
- The median number of side rooms has increased from 68 to 74 overall, and from 68 to 79 for those 104 hospitals in both audit rounds
- 99% of hospitals have a Hospital Specialist Palliative Care Team
- 75% of hospitals have a Coping with Dying Leaflet or equivalent available (compared with 58% in Round 1) and there has been an increase in the level of information available in general
- 84% of hospitals have an ongoing education programme for Nurses in care of the dying, and 74% have such a programme for Medical Staff.
- An electronic data collection tool has been developed that enhanced the quality of submitted data and streamlined the process of the audit. The inter-auditor reliability was again ‘very good’ in Round 2 and improved over Round 1 (Round 1: median 0.91, IQR 0.86 – 0.92; Round 2: median 0.93, IQR 0.91 – 0.95).
- There is an increase in the proportion of annual local audits of care of the dying being fed back to Trust Boards in Round 2 - from 48% in Round 1 to 62% in Round 2.

PART B: - PATIENT LEVEL KEY FINDINGS

- The patient level results indicate that there has generally been little demonstrable change in overall hospital performance between Round 1 and Round 2. However, 51 hospitals (just under one third of the sample) are new to the audit this round and for those 104 hospitals in both rounds there has been expansion in the number of wards covered. Hence caution should be exercised when making direct comparisons between rounds. The relatively short period between Round 1 and 2 may be implicated in the lack of demonstrable improvement as there may not have been adequate time for the implementation of Action Plans (ie closing the audit loop). Also, improvement is more difficult to achieve where performance is already at a high level (ie for Domains 1 and 2).
- The proportion of patients who had a diagnosis other than cancer has increased from 55% in Round 1 to 61% in Round 2.
- Percentage achieved for goals concerning the physical aspects of patient comfort (Domain 1) remains high across the board this round. For 92% of patients medications were reviewed and non-essentials discontinued, and for 90% of patients, medication for pain was prescribed for use in the event of the patient developing this symptom.
- Documentation of the four hourly assessments made in the last 24 hours of life illustrates that the vast majority of patients are reported to be comfortable. More variance is recorded on the variance sheets than is documented in the ongoing assessment section. This may, in part, be accounted for by the 20% (on average) missing data in this section, and/or may indicate more frequent assessment of patients in the last 24 hours of life.
- Communication, particularly with patients and primary care remains a challenge, especially for patients with a diagnosis other than cancer – see Part E of your full Report. This may be affected by the relatively high number of patients in this sample who had stroke and dementia (including Alzheimer's).
- Whilst communication regarding the plan of care and recognition that the patient had entered the dying phase was generally undertaken with relatives/carers (achieved in 72% and 76% respectively) there is still room for improvement.
- As in Round 1, a higher percentage of variance was documented for the discontinuation of IV fluids and medications (11% in Round 2). However, the lack of recording of explanations on the variance sheets for this goal precludes a full understanding of the reasons for continuation in this sample.
- The proportion of missing data in the care after death section is high (>50% across all goals).
- Medication: It is of note that drugs prescribed prn for agitation and restlessness were actually given in only 37% of cases. This supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed drug for agitation and restlessness. The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 5mg as a PRN dose. The median doses of haloperidol and levomepromazine were also relatively low.

PART D: RECOMMENDATIONS

1. Key Performance Indicators (KPI's) for care of the dying should be measured, monitored and managed as part of the organisation corporate performance dashboard.
2. All hospitals should have a clear programme for continuous quality improvement for care of the dying to drive up performance and quality. A remedial action plan in response to National Care of the Dying Audit findings should be in place to address poor compliance, Inter Quartile Range (IQR) outliers, variance reporting and improved performance across the key domains of care.
3. A named person within the organisation should take formal responsibility to act as an LCP Facilitator / change agent for care of the dying.
4. Whilst the median doses prescribed and given for agitation and restlessness (both prn and continuous subcutaneous infusion) are relatively low, audit sites that are frequently prescribing outside the 90th percentile need to review practice. Audit sites where morphine and diamorphine have been prescribed for this symptom should also review their practice.
5. All hospitals should have a local audit programme for care of the dying that includes the assessment of the views of bereaved carers.
6. Optimising knowledge transfer is an important aspect of continuous quality improvement. All hospitals should have appropriate information leaflets available in support of care in the last hours / days of life.
7. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with patient insight (both into diagnosis and recognition of dying) and spiritual assessment (for both patients and carers). All health care workers caring for dying patients and their relatives / carers should have access to appropriate ongoing training and education in care of the dying (DH 2009).
8. The use of the Care After Death Section of the LCP for all deaths has been recommended (DH 2009). This audit shows that there is a high proportion of missing data for all goals in the Care After Death Section and it is therefore important that hospitals identify the reasons for this.
9. The Department of Health's Quality Markers and Measures for End of Life Care (DH 2009) document recommends that all hospitals take part in the 2 yearly National Care of the Dying Audit Cycle.
10. All hospitals should have an LCP or equivalent in place (DH 2009) that is compliant with the goals to be included in the new updated version 12 of the LCP to be launched in November 2009.

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INTRODUCTION

Background

The National End of Life Care Strategy (DH, 2008) was published in the summer of 2008 to promote the delivery of high quality care to patients at the end of their lives and their relatives and carers, including care of the dying. Supported by the Department of Health National End of Life Care Programme (<http://www.endoflifecareforadults.nhs.uk/eolc/>) the strategy reinforced the importance of three end of life care tools, which had previously been promoted by the National Institute for Health and Clinical Excellence (NICE, 2004) and the Department of Health (DH, 2006). These tools were felt to provide important mechanisms to underpin care in three specific areas:

- choice around the place of care at the end of life (Preferred Priorities for Care, (<http://www.endoflifecareforadults.nhs.uk/eolc/CS310.htm>);
- co-ordination of care in the last 12 months of life (Gold Standards Framework <http://www.goldstandardsframework.nhs.uk/>)
- care in the final hours and days of life (Liverpool Care Pathway for the Dying Patient (LCP) www.mcpcil.org.uk). The End of Life Care Strategy: Quality Markers and Measures for End of Life Care suggests that the implementation of the LCP could provide important indicators of quality for patients in the last hours and days of their lives (DH, 2009).

Whilst one of the main issues in this area is to enable patients to die in their place of choice, it remains a fact that fifty-six percent of all deaths in England will occur in the hospital sector (ONS, 2005). 'Spotlight on Complaints' (The Healthcare Commission, 2007) highlighted that many of the complaints surrounding care of the dying and their families (particularly in acute trusts) are related not only to the actual care provided but also to the relationships between healthcare staff and family members following a patient's death. In many cases contradictory or confusing information was a contributory factor and the use of ambiguous language or complex clinical terminology had led to misunderstandings. In other cases, family members complained that they had felt unprepared for the patient's death. Sometimes complaints stemmed from a lack of robust record keeping which family members had interpreted as a lack of monitoring of the patient or a failure to provide good care, and the Care Quality Commission continues to recommend regular audit of record keeping systems. It is, therefore, important for hospital 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 carers.

The Liverpool Care Pathway for the dying patient (LCP)

The LCP (Ellershaw and Wilkinson, 2003) is a multi-professional document that provides an evidence-based framework during the last hours and days of life based on the standards of care delivery in the hospice environment. The LCP incorporates:

1 Aim

To improve care of the dying in the last hours / days of life

2 Key Themes

To improve the knowledge related to the process of dying

To improve the quality of care in the last hours / days of life

3 Key Sections

Section 1. The Initial Assessment Section

This section is completed on commencement of the LCP and is primarily concerned with ensuring that the care delivered (both to patients and to carers) is optimum in light of the changing condition of the patient. It includes ensuring that medications are reviewed and appropriate prn medications are available for the 5 key symptoms that may develop in the last hours and days of life. It is also concerned with ensuring that appropriate communication takes place with patients (wherever possible), relatives/carers and other health professionals.

Section 2. The Ongoing Assessment Section

This section documents the patient's condition and level of physical and emotional comfort as assessed by health professionals at a minimum of 4 hourly (or 12 hourly where appropriate) intervals. It also provides information regarding the continued well-being of relatives/carers in this phase.

Section 3. The Care After Death Section

This section documents the care and procedures to be followed after the death of a patient, including following appropriate procedures for the care of the body and giving information and support to bereaved relatives in the period immediately following the death.

The LCP is used when the multidisciplinary team has agreed that the patient is dying and all reversible causes for the current situation have been considered. The focus of care now changes to care of the dying, this includes discussion with the relative/carer and when possible the patient. The current plans of care need to be reviewed and inappropriate interventions stopped when the burden of an intervention or treatment outweighs the benefits.

The LCP therefore provides a useful template to guide the delivery of care for the dying to complement the skill and expertise of the practitioner using it. Once commenced the goals of care prompt staff to consider the continued need for invasive procedures and whether current medications really are conferring benefit, and determine the best model of care of the last hours / days of life. The clinician has the opportunity to follow the LCP guidance or to record the reason for decisions to determine a plan of care that deviates from this pathway; this is recorded as a variance. Using the LCP in any environment requires regular assessment and involves continuous reflection, challenge, critical decision-making and clinical skill.

National Audit

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 (Jordhøy et al 1999; Westcombe et al 2003). Conducting this type of research into outcomes in the last hours and days of life represents an even greater challenge. In addition to providing a template of best practice, the LCP is also designed to allow the easy extraction of data for audit purposes that can be used locally to drive quality care. The standardisation of the documentation enables measurable outcomes of care that can also be used to provide comparative data.

Thus, one way of evaluating the level of care provided for patients dying on an LCP in our acute hospital trusts is to engage in a national audit project against which future provision of care can be measured. The results from the first round provided a picture of care of the dying in our acute hospitals in England (see www.mcpcil.org.uk for the generic report of the results). In the main, the vast majority of the 2672 patients from 118 acute hospitals were included in the audit. Over three quarters of the assessments made in the last 24 hours of life reported patients to be comfortable in terms of their physical needs. However, it also highlighted the need for improved communication, particularly with patients (where possible) and primary care colleagues. The assessment of spiritual and religious needs was often poorly documented and compliance with the goals of care was a point of concern, particularly in the Care after Death section.

The results of this second round of the national audit will inform all those involved of their current level of performance regarding the goals of care on the LCP and will benchmark this performance against other participating hospitals. For the first time, it will also focus on the prescription and administration of medication for agitation and restlessness in the last 24 hours of life, as well as providing more information about variance recording for a proportion of goals. It will allow

comparison with data from the first round, and will provide data driven Key Performance Indicators (KPI) for the delivery of care to dying patients during the last hours and days of their lives, and to their families and carers.

Aim

Building on the results of the first round of the NCDAAH (www.mcpcil.org.uk) the aim of round 2 ultimately remains to improve the standards of care for patients who die in acute hospitals in England on the LCP. The specific objectives are to:

1. Identify the quality of care for dying patients as documented on the LCP
2. Benchmark their performance with other hospitals across England
3. Compare their performance with the results from the first round to assess levels of progression
4. Identify Key Performance Indicators (KPI's) to drive up the quality of care for the dying that can be reflected within the Hospital/Trust corporate performance dashboard
5. To promote the Continuous Quality Improvement of care of the dying

Organisation of the Audit

The audit was coordinated and carried out by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Royal College of Physicians (RCP) London, which has a wealth of experience in undertaking national audits. (eg Wilson et al, 2008), supported by Marie Curie Cancer Care and the National End of Life Care Programme at the Department of Health. A standardised approach to collection of data was employed within each participating hospital, which was overseen by a designated lead clinician and auditor. In general, the appointed auditor was familiar with the LCP programme and the lead clinician was a member of the palliative care team. Contacts within those hospitals that participated in the first round, appropriate contacts held by the LCP Central Team UK and representatives of the palliative care teams within each acute hospital in England were contacted directly with publicity material informing them of the details of the proposed second round of the audit. (Appendix 1 provides a list of all participating hospitals). The National LCP Reference Group (Appendix 2) and a Working Group made up of clinical and research colleagues from MCPCIL and audit colleagues from the RCP guided the project and oversaw the preparation, governance, analysis and reporting phases.

Availability of this report in the public domain

- Chief Executives, Clinical Governance Leads and Lead Clinician/Auditors within participating hospitals will have access to their individual hospital reports detailing their performance versus the generic performance of all hospitals.
- The Generic Report, (including the list of participating hospitals) that illustrates the aggregate performance for all patients in the sample (3893 data sets), and the Generic Key Findings and Recommendations Report will be made more widely available in the public domain as separate publications (see Appendix 4 – Reporting Schedule).
- It is intended that articles based on the generic findings will be published in national and international journals and that presentations to national and international conferences will be undertaken.

Inclusion Criteria for the audit

Adult patients (\geq 18 years of age at time of death) who died on a care pathway where the goals of care had remained relatively compliant with Version 11 of the LCP were eligible to participate. As part of the registration process for the audit, hospitals were asked to submit a blank copy of their current pathway and checks were made by the Evaluations Unit at the MCPCIL to establish the level of compliance between this pathway and Version 11 of the LCP. Where goals had been modified such that they no longer meant the same as the corresponding goal on the LCP and /or where goals of care on Version 11 had been removed on a given pathway, they were excluded from analysis in the audit. Each auditor was notified of the goals of care that could be fed back and invited to review their desire to participate.

Hospitals were asked to provide (where possible) a consecutive sample of 30 patients who died on an LCP within the designated time period (1st October 2008 – 31st December 2008). The proposed sample size represented an approach to accommodate statistical rigor within the practicalities of data collection in this challenging area.

Project Methodology

Design

A prospective audit design was used to gather LCP data from up to 30 deaths in each of the participating hospitals between 1st October 2008 and 31st December 2008. Pertinent hospital organisational data was also gathered to contextualise the data from the LCP and to aid

interpretation of the results. For this round, an electronic data submission tool was developed to aid standardised data collection and to improve the quality of data submitted.

Data were collected via a secure website (<https://ncdaudit.rcplondon.ac.uk>). As no patient identifiable information was collected in this audit, Individual patient consent was not required. Auditors were specifically reminded not to input any information in the free text comments boxes that could identify an individual patient.

Data Collection Tools

Organisational Data:

Identification of the organisational elements that are likely to impact on the delivery of care in the last hours and days of life is necessary. The electronic data submission tool was used to gather pertinent data from participating hospitals including information regarding the size, scope and environment in which care was provided to dying patients.

Patient Level Data:

The LCP was developed to incorporate the most salient elements of care in the last hours and days of life for patients and their relatives/carers (Ellershaw & Wilkinson, 2003). As such, the structure and content of the LCP means that the document functions as a template to guide the delivery of care, as a clinical record of the care delivered and as a tool with which to audit that care. Thus, evaluation of each of the goals on the LCP enables a picture of care delivered within each hospital and, subsequently, the hospital sector as a whole to emerge.

In addition to information coded against the goals of care on the LCP, data from the medication charts was also sought for prescribing and administration of medications for agitation and restlessness in the last 24 hours of life, both 'as required' (prn) and via continuous subcutaneous infusion. Information coded onto the variance sheets was also requested for those goals of care that had shown relatively high levels of variance reporting in the first round of the audit (Discontinuation of IV Fluids/Medications; Patient awareness of insight; Assessment of Spiritual/Religious needs of carers; the giving of a bereavement leaflet to carers after the death of the patient). In addition, the number of times that a variance was recorded on the variance sheets for pain, agitation and respiratory tract secretions in the ongoing assessment section was requested.

Procedure

A set of explanatory notes were devised to assist auditors in the completion of the organisational audit and the patient audit, and a helpline was made available during the data coding period to answer any queries. Participating hospitals prospectively submitted data from up to the first 30 patients who died on an LCP within their hospital between 1st October 2008 and 31st December 2008. Participating hospitals were requested to complete the submission of their data by mid January 2009.

Analysis

Key Performance Indicators (KPI)

A series of key performance indicators have been developed in this second round of the audit to provide an 'at a glance' picture of relative performance on some of the key elements in the delivery of care to dying patients and their relatives/carers. These indicators are data driven benchmarks that focus on the following issues:

- **Key Performance Indicator 1: Spread of the LCP**
 - An important indicator of the extent to which the LCP has become embedded within a hospital is the proportion of wards using the LCP and the Department of Health have recognised this as an important indicator of the spread of education and training within a hospital (DH, 2009). Auditors were asked to provide information about the total number of wards in their hospital and the number of wards that were estimated to be using the LCP (ie had used at least 1 LCP in the 3 month period prior to the data collection period). From this information, the proportion of wards 'using' the LCP has been calculated for each hospital. The overall median percentage for those hospitals that gave the full sample size was also calculated to provide a National score.
- **Key Performance Indicator 2: Anticipatory prescribing for the key symptoms that may develop in the last hours and days of life**
 - Goal 2 on the LCP requires the prescription of appropriate drugs for Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting and, more recently, Dyspnoea. It is imperative that appropriate drugs are written up on commencement of the LCP regardless of whether the patient is symptomatic at that point in time. This is to ensure that there is no delay in responding to a symptom if it occurs. As such, goal 2 is an example of a goal that is an overriding duty or principle and has been included as a performance indicator for this reason. As

prescribing for dyspnoea is a relatively new goal on the LCP and many participating hospitals in this round did not have the goal on their pathway, it has been excluded from the scoring system.

- A coding system was developed and applied to the remaining four sub-goals within goal 2. A score of 1 was given for each patient for whom a 'yes' had been coded; a score of 0 was given for each patient for whom 'goal not documented' (missing) had been coded; and a score of 0.25 was given for each patient for whom a 'no' had been coded, in recognition of the fact that a coding of 'no' should result in the supply of information on the variance sheet as to why the goal was not met (eg patient request) which may then be used locally to improve both education and the provision of care in the future.
- The scores across Goal 2 for each patient were added and then converted into a percentage of maximum score. The median percentage for each hospital was then calculated. The National median and IQR were calculated using the hospital median scores for Goal 2.

➤ **Key Performance Indicator 3: Compliance with completion of the LCP or equivalent pathway.**

- It is important that full documentation exists in order to fully understand and support appropriate care delivery in the last hours and days of life. The design and layout of the LCP makes completion of documentation against each goal simple and straightforward and compliance (full completion of the documentation) should, therefore, be easy to achieve.
- The percentage of LCP goals that were documented appropriately (ie coded achieved, variance, not applicable or comatose) was calculated for each patient. The mean of these percentages was then calculated for each hospital and the median and IQR of hospital mean percentages were then calculated to provide the National median.

Organisational Data

Data were analysed using descriptive statistics and are summarised in tabular format to provide useful contextual data with which to interpret the findings. Data from the first round are also included

Patient Level Data – LCP Goals

Data were analysed using descriptive statistics. Median age, number of hours on the pathway, % male/female and % occurrence of different diagnoses were calculated for the whole sample and for each individual hospital. The percentage 'achieved' (goal met), 'variance' (goal not met), and 'goal not documented' was also calculated for each of the goals on the LCP for the whole sample and for each individual hospital (see appendix 3: Glossary for definitions). A snapshot of the last 24 hours of the patient's life formed the basis for the analysis of Ongoing Care delivered.

'Not applicable' or 'comatose' options are available for certain goals on the LCP. For example, where patients were not receiving certain aspects of treatment, or where patients could not enter into communication because they were 'comatose' on commencement of the LCP. Wherever a goal on the LCP was not applicable to a particular patient for any of these reasons, the denominator for the calculation of the percentage was reduced accordingly. Similarly, where a goal could not be included in the audit analysis because it did not conform to the corresponding goal on Version 11 of the LCP, the denominator was also reduced. A statement of the denominator used is included against each goal in the results tables, and on the charts.

Variables New to Round 2 - Medication and Variance

The data from medication charts regarding whether medication was prescribed and given for agitation and restlessness in the last 24 hours of life was also analysed descriptively for the whole sample and for each individual hospital. This information was assessed separately for 'as required medication' and for medications delivered via continuous subcutaneous infusion. The median doses of Midazolam, Haloperidol and Levomepromazine were also calculated, along with the Inter Quartile Range (IQR) (see appendix 3 for a definition) and the 10th and 90th percentiles to illustrate the average dose and the variation in doses across the sample.

Variance reporting for LCP Goals 3.3, 5b1, 6.2 and 18: In order to compare the correspondence between the variance reported against each of these goals on the Initial and Care after Death sections and detailed explanations provided on the variance sheets, the percentage of times that a corresponding variance was recorded for the identified goals was calculated. The written documentation on the variance sheets were then also analysed descriptively using content analysis to identify the 'Top 3' reasons why these goals were not met for the sample as a whole.

Ongoing Assessment Section – Pain, Agitation, Respiratory Tract Secretions (RTS): The number of times that there was written documentation of patient discomfort against these symptoms in the last 24 hours of life was calculated for the sample as a whole and for individual hospitals.

Data Reliability

Participants were asked to re-audit their first 4 patient data sets using a different auditor to assess the level of inter-auditor reliability. The Kappa Coefficient (see Appendix 3 for a definition) was calculated for each of the goals of care on the Initial Assessment and Care after Death sections of the LCP. In addition, variables collected for the first time in this round (medication prescribed and given for agitation and restlessness in the last 24 hours of life) were also included.

Comparative Hospital Performance – Inter Quartile Range (IQR)

A summary of the performance of hospitals in this audit was accomplished by calculating the Inter Quartile Range (IQR – see appendix 3 glossary for definition) for % ‘achieved’, ‘variance’ and ‘goal not documented’ for each goal, making it possible for hospitals to assess their level of performance on each of these goals by comparing it with the IQR. The IQR of % ‘achieved’ by each hospital for each of the goals within the five domains is also illustrated graphically within the report as a series of box plots (see appendix 3 glossary for a definition).

Small Sample Size

It is important to remember that some hospitals within the sample submitted a relatively small number of patient data sets to the audit. For example, whilst 66% of hospitals provided the full sample size of 30, 12% provided between 10 and 19 and 9% provided 9 or fewer. This may be due to several factors including hospitals being relatively early in the implementation process at the time of the audit, or, that it may never be possible for some hospitals to provide the full sample size due to their specific patient and/or service profile. The results for those hospitals with relatively small numbers should be interpreted with caution as the potential for bias is increased. For this reason, the box plots (detailed above) only include those hospitals that provided a sample of 10 or more patients and the KPIs have been calculated using the data provided by those who provided the full sample.

Reporting

Feedback Reports to individual hospitals

Participating hospitals will receive an electronic copy and paper copies of the Individual Hospital Report and the Key Findings and Recommendations Report for their Hospital. Two Powerpoint presentations (Generic Results and Generic Results with the capacity for inclusion of individual hospital results) will also be made available to participating hospitals to promote wider dissemination of the findings to staff within the hospital.

Availability of Generic Reports

An electronic copy of the Generic Report and the Generic Key Findings and Recommendations Report will be made available for download and printing on the MCPCIL website (www.mcpcil.org.uk). Paper copies of these reports will also be disseminated widely - see the reporting schedule (Appendix 4)

Regional Workshops

Three regional workshops will be held in:

- Liverpool (30th September 2009),
- London (7th October 2009)
- Northern Ireland participants only: Belfast (9th October 2009)

The workshops will enable discussion of the results, sharing of understanding and action planning for the future. Representatives from each hospital (usually the 'auditor' and/or the named clinician and a representative of the management / executive team of the hospital) will be invited to attend the workshops. Success in Service Improvement relies on the ability to identify, spread and sustain good practice. In order to begin the process of 'building on the best' participating hospitals will be invited to provide examples of good practice in the delivery of quality care in the last hours and days of life (see example of the best practice proforma in Appendix 5).

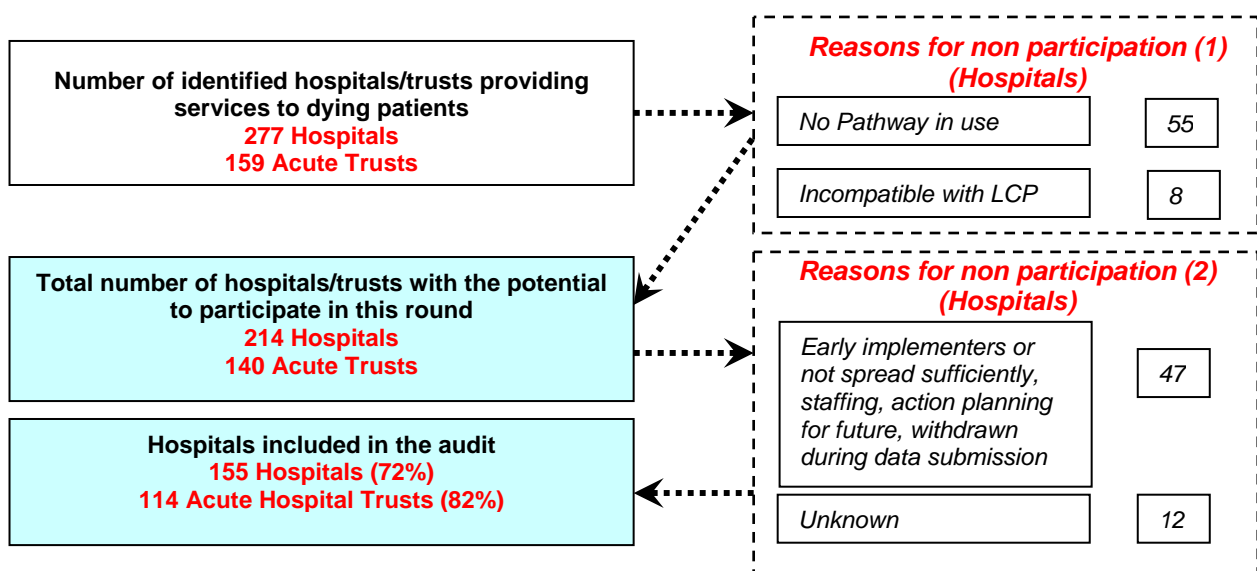
Questionnaire Evaluation

A questionnaire evaluation of the auditing process as a whole will be undertaken as part of the final workshops. The evaluation will attempt to gauge participants' perspectives of participation in the audit (submission of data, quality and clarity of feedback and workshop element) via study specific questionnaire (developed from that used in round 1 - Generic Report, 2007) – using both paper and electronic systems. **RESULTS**

PARTICIPATION

Two hundred and fourteen hospitals from 140 acute Trusts were deemed to have the potential to participate in this round of the audit. Of these, 155 (72%) hospitals from 114 (82%) hospital trusts provided a total of 3893 patient cases. One hundred and two (66%) of participating sites were able to provide the full sample size of 30 patient data sets (3060 representing 79% of the total data); 20 hospitals (13%) provided between 20 and 29, 19 hospitals (12%) provided between 10 and 19 and the remaining 14 hospitals (9%) provided 9 or fewer patient data sets. See Figure 1 below.

Figure 1: Participation



Of note, 104 of these 155 hospitals (67%) also participated in Round 1, with one-third of the sample – 51 (33%) joining for the first time in Round 2.

Data Reliability

In the Initial Assessment and Care after Death Sections, Kappa values ranged from 0.81 to 0.97 (median 0.93, IQR 0.91 – 0.95) and in the Medication Section Kappa values ranged from 0.64 – 1.00 (median 0.91, IQR 0.86 – 0.95) illustrating a very good level of agreement. The level of agreement was higher than that in the first round, which may have been influenced by the use of an electronic data submission tool.

PART A: ORGANISATIONAL AUDIT RESULTS

153 of the 155 hospitals submitted organisational data. The slightly reduced National denominator for some items reflects any further missing data.

Section 1: Personnel responsible for submitting data for this audit

1.1a Auditor Discipline for completion of Organisational Audit Form

	National Round 2 (n=155)		National Round 1 (n=118)	
Medical Team	9%	(14/153)	10%	(12/116)
Nursing Team	67%	(102/153)	74%	(86/116)
Audit Team	5%	(8/153)	7%	(8/116)
*Other	19%	(29/153)	9%	(10/116)

* Other included Care Pathway or LCP facilitators/managers; MDT facilitator, End of Life Team member, Clinical Standards personnel

1.1b Auditor Discipline for completion of Patient Data Audit Form

	National Round 2 (n=155)		National Round 1 (n=118)	
Medical Team	6%	(9/153)	8%	(9/116)
Nursing Team	65%	(100/153)	72%	(83/116)
Audit Team	11%	(17/153)	10%	(12/116)
*Other	18%	(27/153)	10%	(12/116)

*Other included Care Pathway facilitators/managers; MDT facilitator, End of Life Team, Clerical

1.1c Second Auditor Discipline for completion of Patient Data Audit Form (Inter-Auditor Reliability)

	National Round 2 (n=155)		National Round 1 (n=118)	
Medical Team	10%	(16/153)	9%	(11/117)
Nursing Team	58%	(89/153)	59%	(69/117)
Audit Team	17%	(26/153)	18%	(21/117)
*Other	14%	(22/153)	14%	(16/117)

*Other included Care Pathway/LCP facilitators/managers; End of Life Team; Palliative Care Team; Data Manager; Project Assistant; Clinical Governance personnel

Commentary: Personnel Responsible for Submitting Data

- 155 (72%) hospitals from 114 (82%) hospital trusts provided a total of 3893 patient cases. This represents an increase of 31% in the number of participating hospitals in Round 1 (n=118).
- A total of 104 hospitals (67%) participated in both Round 1 and Round 2 with a further 51 (33%) joining the audit for the first time in Round 2
- In addition, 102 hospitals (66%) submitted the full sample size in Round 2 in comparison with 52 hospitals (44%) in Round 1, which suggests greater spread of LCP within participating hospitals.
- In the main, the professionals responsible for coding and submitting data for the organisational and patient level elements of this audit were from the nursing profession, many of whom were also LCP Facilitators.

Section 2: General Hospital Demographics as at October 2008

Hospital Size	National Round 2 (n=155)	National Round 1 (n=118)
Median number of wards (IQR)	23 (15 - 32) n=152	25 (18 - 36) n=113
Median number of beds in hospital (IQR)	478 (341 - 674) n=153	522 (380 - 774) n=113
Median number of side-rooms in hospital (IQR)	74 (53 - 121) n=149	68 (43 - 115) n=116

Number of Deaths	National Round 2 (n=155)	National Round 1 (n=118)
Median number of all deaths occurring in the financial year (Round 1 - 1st April 2006 - 31st March 2007; Round 2 - 1st April 2007 - 31st March 2008) (IQR)	1073 (686 - 1379) n=150	1185 (863 - 1547) n=111
Data Gathering Periods (Round 1 - 01/09/06 - 30/11/06; Round 2 - 01/10/08 - 31/12/08)		
Median number of all deaths occurring in data gathering period (IQR)	277 (180 - 366) n=151	254 (182 - 351) n=111

Estimate of LCP Use	National Round 2 (n=155)	National Round 1 (n=118)
Length of time (in months) that the LCP has been in use in your hospital (median) (IQR)	42 (30 - 57) n=152	19 (10 - 36) n=87
Total percentage of wards estimated to be using an LCP	68% n=152	44% n=114
Total percentage of deaths on an LCP in data gathering periods	21% n=149	15% n=111

Commentary: General Hospital Demographics as at October 2008

- The median number of wards per hospital was 23 and beds 478 compared with 25 wards and 522 beds in Round 1. The median number of side rooms was however higher at 74 compared with 68 in Round 1. For those hospitals in both rounds this increase was greater (79 Vs 68).
- On average participating hospitals had used the LCP for 42 months (median) in comparison with 19 months in Round 1.
- In participating hospitals, the percentage of wards reported to be 'using' the LCP in Round 2 was 68% compared with 44% in Round 1. The increase was from 44% to 72% for those hospitals in both rounds, with 60% for the 51 new hospitals in Round 2. Key Performance Indicator 1 (see Part C) illustrates that for those 102 hospitals that submitted the full sample size in Round 2, the median number of wards using the LCP is estimated to be 75%. This suggests that the LCP is more widely spread throughout participating hospitals.
- 21% of all patients who died between October 1st 2008 and December 31st 2008 were cared for using an LCP compared with 15% in Round 1. For those hospitals in both rounds the increase was from 14% to 22%, for those new in Round 2 the proportion of deaths on an LCP was 19%.

Section 3: Availability of support for implementation and sustainability

Supporting Literature

An important element in the successful implementation and use of the LCP in a given environment is the availability of supporting literature. Several of the goals of care require written information to be given to carers, and generic, national leaflets have been devised by the LCP Central Team UK within the MCPCIL to support the local implementation process. Thus, it was interesting to establish the extent to which these leaflets were generally available in each of the environments.

Supporting Leaflets available for use	National Round 2 (n=155)	National Round 1 (n=118)
Organisation of Facilities	61% (92/152)	67% (78/116)
Local procedures after death	95% (145/153)	91% (107/117)
Bereavement leaflet	92% (140/153)	79% (93/117)
LCP Coping with Dying leaflet	75% (114/153)	58% (68/117)
Leaflet explaining the LCP (patient/carers)	65% (99/153)	37% (43/117)
Leaflet explaining the LCP (health professional)	61% (93/153)	58% (68/117)

Personnel

The LCP Central Team UK suggest that implementation of the LCP should be undertaken in conjunction with the support of the Specialist Palliative Care Team to assist in providing appropriate education (as and when required) and to support the delivery of care in the early phase of implementation. In addition, a facilitator with responsibility for implementation and sustainability is deemed to be an asset (Mellor et al 2004). Such a person or persons help to ensure that the momentum is maintained throughout the period of implementation and beyond, promoting high quality care.

Personnel	National Round 2 (n=155)	National Round 1 (n=118)
Proportion of Hospitals with a Specialist Palliative Care Team	99% (151/153)	97% (113/117)
Proportion of Hospitals with one or more LCP Facilitators or equivalent	39% (59/153)	47% (52/110)
For Hospitals with one or more LCP Facilitator or equivalent (n=52 Round 1, n= 59 Round 2)		
Total number of posts	71 posts*	71 Posts
Median number of posts per hospital (IQR)	1 (1 – 1)	1 (1 – 2)
Median whole time equivalent (WTE) per hospital (n=59) (IQR)	0.6 (0.4 – 1.0)	0.8 (0.5 – 1.1)
Nursing Profession (% YES)	97% (69/70)	99% (69/70)
Medical Profession (% YES)	0% (0/70)	0% (0/70)
Allied Health Professional (% YES)	0% (0/70)	0% (0/70)
Other (% YES)	2% (1/70)	1% (1/70)
Member of Hospital Specialist Palliative Care Team (% YES)	66% (/71)	60% (42/70)

**1 hospital reported having at least one facilitator but did not provide all information requested about those posts. Thus it is known that there is a minimum of 71 facilitators though information is generally only known for 70 of these posts*

The Impact of an LCP Facilitator (or equivalent) on compliance with completion of the LCP or equivalent pathway

The results from the first round of the National Care of the Dying Audit - Hospitals (NCDHAH, 2007) revealed that those hospitals that had an LCP Facilitator at the beginning of the audit period had higher levels of compliance (Gambles et al, 2009). Goals that were coded either 'achieved', 'variance', 'comatose' or 'not applicable' were deemed to represent compliance, only those where nothing was recorded were deemed to represent non compliance. In order to assess the impact of an LCP Facilitator further in this round, domain scores for level of compliance have been analysed separately for those hospitals that took part in both rounds (n=101/104 – 3 sites did not provide data) in 4 groups

- Group 1: Those with a facilitator in both rounds
- Group 2: Those with a facilitator in round 1 but not round 2
- Group 3: Those with a facilitator in round 2 but not round 1
- Group 4: Those with no facilitator in either round

The Impact of an LCP Facilitator (or equivalent) on hospital compliance in Round 2

Table gives median and IQR compliance of hospitals within each group (n=101)	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5
Facilitator in both rounds (n=21 hospitals)	86% (81-88)	72% (62-76)	72% (64-76)	65% (54-73)	56% (41-64)
Facilitator round 1 but not round 2 (n=24 hospitals)	86% (76-92)	72% (64-82)	65% (58-75)	47% (44-64) n=23	38% (30-57) n=23
Facilitator round 2 but not round 1 (n=18 hospitals)	86% (81-91)	74% (63-84)	74% (61-87)	67% (49-83)	54% (38-72)
No Facilitator in either round (n=38 hospitals)	83% (78-92)	68% (60-81)	64% (51-78)	52% (41-70) n=37	44% (28-59) n=35

Domain 1 - Physical comfort of the patient

Domain 2 - Psychosocial and spiritual/religious aspects of care (patients and carers)

Domain 3 - Communication (patient, carer and healthcare colleagues)

Domain 4 - Appropriate information (giving and receiving)

Domain 5 - Compliance with appropriate policies and procedures.

The results of this descriptive analysis showed that there was very little difference in compliance in Domains 1 and 2 for hospitals with or without an LCP Facilitator. However, for Domains 3, 4 and 5, those hospitals with no Facilitator in either round and those with no Facilitator in round 2 had lower levels of compliance.

Commentary: Availability of support for implementation and sustainability

- Appropriate information leaflets were more available in Round 2 particularly for those concerned with bereavement information to relatives (up from 79% to 92%); explanation of the LCP for relatives and carers (37% to 65%) and the LCP coping with dying leaflet (58% to 75%).
- Once again, almost all participating hospitals (99% compared to 97% in Round 1) have a Specialist Palliative Care Team.
- Only 39% of hospitals in Round 2 employed a specific LCP facilitator or equivalent in comparison to 47% in Round 1. For the 104 hospitals in both audits this percentage has decreased from 50% to 39%, and was 37% for hospitals new to round 2. Where such a facilitator is employed the post holder is again most likely to be from the nursing profession but for hospitals in this round the whole time equivalent (WTE) was 0.6 compared to 0.8 for hospitals in the first round.

- The presence of an LCP facilitator appears to be positively associated with the level of compliance, particularly in those domains where the level of compliance is relatively low (Domains 3, 4 and 5) – see Part C. The decrease in personnel and hours worked may, therefore, have a negative impact on levels of compliance with the LCP in the future.

Section 4: Continuing Education, Training and Audit

Education and Training

The provision of ongoing education, training and audit are also important aspects underpinning the delivery of quality care to dying patients and the Department of Health have stated their intention 'to ensure that all staff who work with people who are dying are properly trained to look after dying patients and their carers.' (DH, 2006, p104).

Education and Training for Care of the Dying	National Round 2 (n=155)	National Round 1 (n=118)
Hospitals with an in-house continuing education programme for care of the dying:		
<i>Medical staff (% YES)</i>	74% (113/153)	73% (85/117)
<i>Nursing Staff (% YES)</i>	84% (128/153)	80% (94/117)
<i>Non-Qualified clinical staff (% YES)</i>	58% (89/153)	64% (74/116)

Audit

Audit of Care of the Dying	National Round 2 (n=155)	National Round 1 (n=118)
4.4 Routine collection of all completed LCPs takes place (% YES)	28% (43/153)	38% (45/117)
4.4.1 For all hospitals where routine collection of all LCPs takes place		
<i>Hospital Audit Department Responsible (% YES)</i>	14% (6/43)	9% (4/44)
<i>LCP Facilitator Responsible (% YES)</i>	35% (15/43)	45% (20/44)
<i>Other Responsible (% YES)*</i>	51% (22/43)	45% (20/44)
4.5 Formal audit of LCP taken place in last 12 months (% YES)	45% (69/153)	58% (67/116)
4.5.1 For all hospitals where formal audit has taken place in the last 12 months		
<i>Intention to repeat in next 12 months – 2 years (% YES)</i>	96% (66/69)	85% (57/66)
<i>Results fed back to clinical teams (% YES)</i>	89% (59/66)	92% (61/66)
<i>Results fed back to Trust board (% YES)</i>	62% (41/66)	48% (31/65)
4.6 Report assessing the views of carers re care of the dying produced between 31 st August 2005 and 1 st September 2006 (Round 1) and 31 st August 2007 and 1 st September 2008 (Round 2) (% YES)	11% (16/153)	8% (9/117)

**Other in Round 2 included 26% (11) CNS/Palliative Care Team member; 19% (8) Administration/secretarial; 6% (3) other nursing, Patient Affairs and Bereavement Service*

Commentary: Continuing education, training and audit

- The percentage of hospitals providing ongoing in-house training in care of the dying was higher in this round of the audit for nurses (up from 80 to 84%) and medical staff (73 to 74%), but was lower for non-qualified staff who are often closely involved in such care (64 to 58%).
- A formal audit using LCP documentation has taken place in a smaller percentage of LCP hospitals (down from 58 – 45%) in the previous 12 months. However, a greater proportion of these hospitals in the second round state their intention to repeat the audit within the next 2 years (96% compared to 85% in the first round). The results of audits undertaken are often fed back to healthcare professionals providing the care (89% Round 2; 92% Round 1), and there is an increase in the proportion being fed back to Trust Boards in Round 2 (up from 48% in Round 1 to 62% in Round 2). Finding ways to engage senior management and to embed the LCP within the governance structures of a hospital is an important way to promote sustainability of the LCP and thus to improve care of the dying. The Key Performance Indicators (KPI) developed in this second round of the audit should go some way to provide an effective and meaningful language for this purpose.
- There is general recognition of the need to involve the ‘user’ perspective in the evaluation of services (Daykin et al, 2007). Despite this, the proportion of hospitals that had produced a report assessing the perspectives of informal carers re care of the dying in the previous 12 months has increased little between rounds (up from 8% to 11%).

Section 5: Part A Key Findings

- The National Care of the Dying Audit – Hospitals demonstrates increased spread of the LCP both nationally and within hospitals in Round 2 (2008/2009) compared with Round 1 (2006/2007):
 - The number of participating hospitals has increased in Round 2 by 31% (from 118 to 155). 115 (82%) hospital trusts are represented in the audit and the number of patient data sets submitted has increased by 46% (from 2672 to 3893).
 - The percentage of hospitals that were able to submit the full sample size has increased from 44% to 65%
 - The national percentage of wards reported to be ‘using’ the LCP in Round 2 is 68% compared with 44% in Round 1.
- The LCP has been in use for 42 months on average (median) in comparison to 19 months in Round 1
- 39% of Hospitals have an LCP Facilitator working on average 0.6 wte in comparison with 47% and 0.8 wte in Round 1. The presence of an LCP facilitator (or equivalent) is associated with improved compliance with the LCP in this audit in those domains where the proportion of missing data is especially high (Domains 3, 4 and 5).
- The median number of side rooms has increased from 68 to 74 overall, and from 68 to 79 for those 104 hospitals in both audit rounds
- 99% of hospitals have a Hospital Specialist Palliative Care Team
- 75% of hospitals have a Coping with Dying Leaflet or equivalent available (compared with 58% in Round 1) and there has been an increase in the level of information available in general
- 84% of hospitals have an ongoing education programme for Nurses in care of the dying, and 74% have such a programme for Medical Staff.
- An electronic data collection tool has been developed that enhanced the quality of submitted data and streamlined the process of the audit. The inter-auditor reliability was again ‘very good’ in Round 2 and improved over Round 1 (Round 1: median 0.91, IQR 0.86 – 0.92; Round 2: median 0.93, IQR 0.91 – 0.95).
- There is an increase in the proportion of annual local audits of care of the dying being fed back to Trust Boards in Round 2 - from 48% in Round 1 to 62% in Round 2.

PART B: PATIENT LEVEL AUDIT RESULTS

Comparison between Round 1 and Round 2 Data

Fifty-one of the 155 hospitals are in the audit for the first time in this Round and for those 104 hospitals in both rounds there has been expansion in the number of wards covered. Hence much caution should be exercised when making direct comparisons between rounds. However, the Round 1 data included in the following tables does provide an interesting point of reference for comment on the results.

Section 1: Demographic Data

	National Round 2 (n=3893)	National Round 1 (n=2672)
Patient Gender = Female	55% (2141)	54% (1441/2664)
Median Patient Age (IQR)	81 (73 – 87)	80 (72 – 86)
Median hours on LCP (IQR)	33 (12 – 74)	33 (13 – 79) n=2664

Primary Diagnosis

	National Round 2 (n=3893)	National Round 1 (n=2672)
Cancer	39% (1532)	45% (1190/2647)
Non Cancer	61% (2361)	55% (1457/2647)

Primary Diagnosis Breakdown of 'Top 6' cancer and non-cancer diagnoses (Round 1 and 2)

	National Round 2 (n=3893)	National Round 1 (n=2672)
CANCER		
Lung (small and non-small cell)	6.7% (258)	8.0% (213/2647)
Lymphoid, haematopoietic C81-96	3.6% (141)	4.0% (106/2647)
Breast	3.3% (128)	3.2% (84/2647)
Unknown Primary	3.1% (122)	4.0% (105/2647)
Colon	2.9% (112)	3.9% (103/2647)
Pancreas	2.2% (86)	Not in top 6 round 1 1.9% (51/2647)
Oesophagus	Not in top 6 in Round 2 1.2% (47)	2.3% (61/2647)

NB 4% of patients with a diagnosis of cancer had dementia recorded as a co-morbidity

	National Round 2 (n=3893)	National Round 1 (n=2672)
NON CANCER		
Pneumonia	13.2% (513)	Coded within other non cancer in Round 1
Stroke	12.2% (475)	12.2% (323/2647)
Heart Failure (I50)	6.2% (243)	5.9% (155/2647)
Other Heart and circulatory conditions (excluding I50)	4.2% (162)	3.7% (99/2647)
Chronic Respiratory Disease J40-70	4.0% (154)	2.9% (76/2647)
Dementia including Alzheimer's disease G30 and other F00-3	3.5% (135)	4.1% (109/2647)
Chronic Renal Failure N18	Not in top 6 round 2 2.7% (107)	2.8% (75/2647)

NB 19% of patients with a diagnosis other than cancer either had dementia as a primary diagnosis or recorded as a co-morbidity

Commentary: Demographic Data

- The proportion of patients included in this audit who have a diagnosis other than cancer (61%) has increased in the two years since the last round (55%).
- Dementia is recorded as a co-morbidity in a small proportion of patients with a diagnosis of cancer; in the non-cancer group dementia as a primary diagnosis or a co-morbidity affects nearly a fifth of the sample.
- Females again make up over half of the patients and the average age this round (81 years) has also remained largely unchanged. When the two sets of patients are viewed separately (cancer vs non cancer) the average age of those with a diagnosis other than cancer is significantly higher (76 years vs 84 years) – see Part E
- The median 33 hours that patients spent on an LCP in this audit is identical to that in Round 1.
- Those patients with a diagnosis other than cancer, however, spend around 35 hours on average on the LCP in comparison with those with a diagnosis of cancer, who spend around 30 hours on average – see Part E

Organisation of feedback

The LCP is organised into 3 sections: Initial Assessment, Ongoing Assessment and Care after Death. Whilst each of these sections deals with a discrete element of care specifically linked to appropriate points in time, 5 major domains of care can be highlighted across each of the sections that document the well-being of the patient and family throughout the process:

Domain 1 - Physical comfort of the patient

Domain 2 - Psychosocial and spiritual/religious aspects of care (patients and carers)

Domain 3 - Communication (patient, carer and healthcare colleagues)

Domain 4 - Appropriate information (giving and receiving)

Domain 5 - Compliance with appropriate policies and procedures.

As in round 1, the results from the audit will, therefore, be expressed under these 5 key domains. Each of the following tables includes the National proportion coded as 'achieved', 'variance' and 'not documented' for each goal of care for the whole patient sample regardless of which hospital they died in. Each table includes the Inter Quartile Range (IQR) as a measure of hospital variation in performance in terms of % 'achieved', 'variance' and 'not documented' on each goal of care and the individual result for each hospital (Your Site Round 2). In addition, the National data for Round 1 are also included for comparative reference.

Domain 1: Physical Comfort of the Patient

Comfort Measures

Initial Assessment LCP Goals 1 and 2

Maximising the physical comfort of the patient is a primary focus of care in the last hours and days of life. It is vital that all current medications are reviewed and anything deemed non-essential is discontinued. There is evidence that 5 key symptoms may occur for a sizeable proportion of patients in the last hours and days of life – Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting and Dyspnoea (Lichter & Hunt, 1990; Klinkenberg et al, 2004). Once the multidisciplinary team have agreed that the patient has entered the last hours and days of life, it is important that drugs are written up for these symptoms so that they can be delivered without delay if and when required. Goals 1 and 2 on the LCP address these particular issues:

LCP Goal 1: Current medication assessed and non-essentials discontinued

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
	N						
National Round 2	3864	92	3547	1	47	7	270
Hospital IQR – all (%) (n = 153)		87 – 97%		0 – 3%		0 – 10%	
National Round 1	2633	93	2442	2	55	5	136

LCP Goal 2: PRN subcutaneous medication written up for list below as per protocol

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
	N						
2.1 Pain							
National Round 2	3863	90	3476	3	128	7	259
Hospital IQR - all (%) (n=154)		87 – 97%		0 – 3%		0 – 10%	
National Round 1	2671	91	2418	4	95	6	158

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
	N						
2.2 Agitation							
National Round 2	3863	85	3285	6	250	8	328
Hospital IQR - all (%) (n=154)		77 – 93%		0 – 10%		0 – 13%	
National Round 1	2671	84	2249	8	209	8	213

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.3 RTS							
National Round 2	3863	80	3108	10	373	10	382
Hospital IQR - all (%) (n=154)		73 – 90%		3 – 14%		3 – 13%	
National Round 1	2671	80	2128	11	297	9	246

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.4 Nausea & Vomiting							
National Round 2	3863	81	3147	9	348	10	368
Hospital IQR - all (%) (n=154)		73 – 92%		3 – 13%		0 – 13%	
National Round 1	2670	82	2187	9	253	9	230

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.5 Dyspnoea							
National Round 2	3200	72	2319	14	433	14	448
Hospital IQR - all (%) (n=124)		62 – 87%		3 – 20%		3 – 18%	
National Round 1	1387	67	926	15	214	18	247

Initial Assessment Goal 3

Another very important element in the delivery of appropriate care is the consideration of the need to continue or discontinue invasive interventions for patients in the last hours and days of life. This includes blood tests, antibiotics, IV fluids and medications. There is ongoing debate regarding the use of clinically assisted/artificial nutrition and hydration in palliative care (Thorns and Garrard, 2003, Klee M, 2004, Faisinger and Bruera, 1997, Ganzini, 2006). In particular, reversible causes for the patient's deterioration, including hypercalcaemia, treatable infections and the side effects of medications (eg opioid toxicity), should be excluded by the multidisciplinary team (GMC, 2009). In the dying phase, the team should discontinue invasive interventions that are no longer believed to be of benefit to the patient (Chapman et al, 2007).

Undertaking cardiopulmonary resuscitation in a patient with advanced chronic disease who is deemed to be in the last hours and days of life is generally viewed as a futile intervention. Therefore, it is important that the decision 'not for cardiopulmonary resuscitation' has been appropriately recorded once the last hours and days has been diagnosed in order that unnecessary distress to both patients and carers can be avoided.

Advances in cardiac care mean that people are living for longer with chronic disease and the use of implantable Cardioverter Defibrillators (ICD) is one important element in the improved longevity of cardiac patients. However, Willner (2003) suggests that an ICD can alter unstable cardiac rhythms and he suggests that “the ICD discharges can be physically and emotionally distressing to patients”. It is important, therefore, that a defined process is followed (including making information available to patients and relatives/carers) to deactivate such devices when a patient enters the last hours and days of life. Goals 3.1 – 3.5 on the LCP – Discontinue inappropriate interventions - prompt the consideration and discussion of these important elements of care:

LCP Goal 3: Discontinue inappropriate interventions

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.1 Blood Tests							
National Round 2	3292	91	2993	4	126	5	173
Hospital IQR - all (%) (n=131)		87 – 97%		0 – 7%		0 – 7%	
National Round 1	2602	91	2362	4	105	5	135

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.2 Antibiotics							
National Round 2	3657	89	3255	6	209	5	193
Hospital IQR - all (%) (n=149)		83 – 96%		0 – 8%		0 – 8%	
National Round 1	2522	87	2182	8	199	6	141

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.3 IV Fluids/Medications							
National Round 2	3693	83	3049	11	405	6	239
Hospital IQR - all (%) (n=148)		75 – 93%		3 – 15%		0 – 10%	
National Round 1	2489	79	1955	15	385	6	149

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.4 Not for CPR							
National Round 2	3544	94	3317	1	33	5	194
Hospital IQR - all (%) (n=139)		90 – 100%		0 – 0%		0 – 10%	
National Round 1	2382	93	2210	1	24	6	148

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.5 De-activate cardiac defibrillators							
National Round 2	944	33	309	11	108	56	527
Hospital IQR - all (%) (n=115)		0 – 50%		0 – 20%		33 – 83%	
National Round 1	483	40	191	7	34	53	258

NB: a code of Not Applicable (NA) can be applied **only** when a patient was not receiving a given intervention. These patients have been removed from the analysis and the reduced number of patients is expressed in the 'available and applicable' section of the table

LCP Goals 3a and 3b

Routine nursing interventions should be reviewed and a clear plan of care put in place so that inappropriate interventions are discontinued when a patient enters the last hours and days of life and the emphasis of care turns primarily to patient comfort. Taking vital signs and blood sugar monitoring, are nursing interventions that can now either be ceased or the frequency reduced. Goal 3a is used to prompt reconsideration of such interventions.

LCP Goal 3a: Decisions to discontinue inappropriate nursing interventions taken

	Available & applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
National Round 2	3825	75	2852	1	50	24	923
Hospital IQR – all (%) (n=151)		63 – 90%		0 – 0%		10 – 33%	
National Round 1	2423	78	1897	2	45	20	481

When regular prn medications have been required over a period of time, to promote patient comfort it can be beneficial for patients to receive their medications via a continuous subcutaneous infusion pump. Where this need has been identified, it is essential that the pump is set up as quickly as possible and goal 3b records how often this has been achieved within 4 hours of the decision.

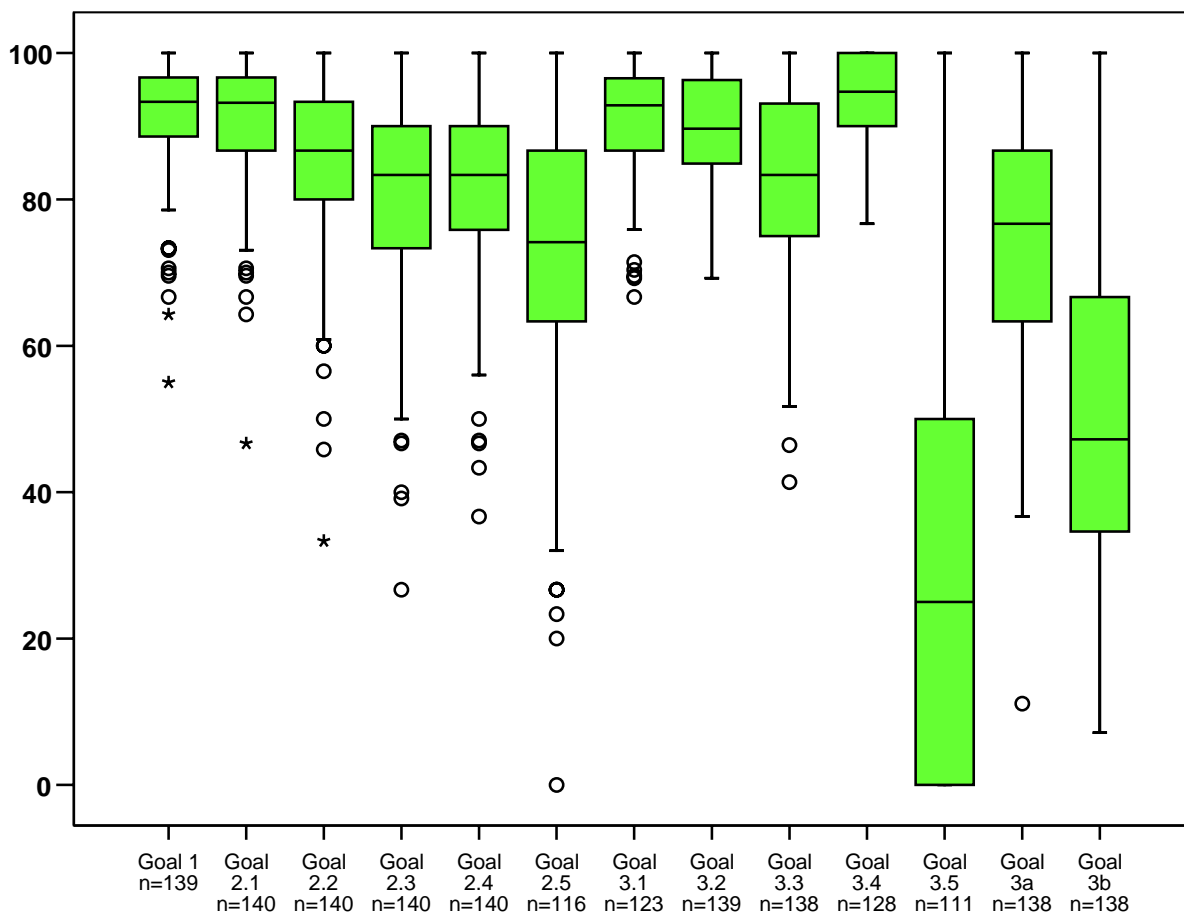
Goal 3b: Syringe driver set up within 4 hours of doctor's order

	Available & applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
National Round 2	2725	49	1336	8	230	43	1159
Hospital IQR - all (%) (n=149)		33 – 68%		0 – 15%		22 – 58%	
National Round 1	1804	61	1100	8	149	31	555

NB: a code of Not Applicable (NA) can be applied **only** when a patient was not receiving a given intervention. These patients have been removed from the analysis and the reduced number of patients is expressed in the 'available and applicable' section of the table

Domain 1 Physical Comfort of the Patient: Initial Assessment

Boxplots (see appendix 4 for a definition)



NB: The median of the hospital variation in results (represented by the black line within the boxes on the box plots) is unlikely to be exactly the same as the overall National percentage – it is more likely to be out of step when the hospital variation is skewed – most notable here with goals 2.5 and 3.5

Ongoing Assessment of Physical Condition

An important feature of the LCP is the requirement for regular assessment and monitoring of the patient's condition. In the ongoing assessment section, health care professionals are tasked to assess the patient in terms of important indices of their physical wellbeing at a *minimum* of every 4 hours. The outcome of these assessments may be coded achieved and variance (see appendix 3: Glossary for definition). Variance can also be reported at any other point in time when a patient is deemed to be uncomfortable because of a specific symptom/issue. Information about the nature of the issue, steps taken to resolve it and the outcome of that intervention are documented onto the variance sheets held within the LCP. The ongoing assessment section itself provides a summary of the patient's condition at 6 four hourly time-points in each 24 hour period. A 'snapshot' of care

(based solely on the 4 hourly coding of 'achieved' and 'variance' in the last 24 hours approximately of each patient's life) has been examined within this current section.

These results differ in nature from results of the goals discussed so far in that they provide information regarding the condition of the patient at particular points in time rather than providing evidence of care delivery.

NB: a code of Not Applicable (NA) is applied in this section of the pathway when a patient was not on the LCP at the time that a particular assessment should have been made (ie for those patients who were not on the LCP (or equivalent) for at least 24 hours). It is also possible to code N/A for 'medication' when a patient was not receiving any medication. These assessments have been removed from the following analysis and the applicable number of assessments is expressed in the 'Eligible Assessments' section of the following tables.

The total number of potential assessments (ie if all 3893 patients were included in the sample and all were on the LCP (or equivalent) for at least 24 hours) = 3893x6=23358 for all 4 hourly assessed goals and 3893x2=7786 for 12 hourly assessed goals (ie Mobility and Bowel Care).

Ongoing Assessment of Physical indicators of Comfort

	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Pain							
National Round 2	16475	77	12622	4	656	19	3197
Hospital IQR - all (%) (n= 135)		68 – 85%		1 – 6%		11 – 28%	
National Round 1	12068	77	9340	4	529	18	2199

	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Agitation							
National Round 2	16475	76	12539	4	699	20	3237
Hospital IQR - all (%) (n=135)		68 – 84%		2 – 6%		11 – 29%	
National Round 1	12069	77	9265	5	594	18	2210

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Respiratory Tract Secretions (RTS)							
National Round 2	16475	75	12408	5	794	20	3273
Hospital IQR - all (%) (n=135)		67 – 84%		2 – 7%		11 – 30%	
National Round 1	12067	74	8929	7	882	19	2256

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Nausea & Vomiting							
National Round 2	16475	79	13052	1	98	20	3325
Hospital IQR - all (%) (n=135)		70 – 89%		0 – 1%		11 – 29%	
National Round 1	12067	81	9721	1	85	19	2261

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Dyspnoea							
National Round 2	15343	76	11661	2	246	22	3436
Hospital IQR - all (%) (n=125)		68 – 88%		0 – 2%		11 – 30%	
National Round 1	7350	78	5741	2	168	20	1441

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Mouth Care							
National Round 2	16475	79	12967	2	249	20	3259
Hospital IQR - all (%) (n=135)		69 – 88%		0 – 2%		11 – 28%	
National Round 1	12069	78	9429	3	333	19	2307

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Micturition							
National Round 2	16324	78	12665	1	98	22	3561
Hospital IQR - all (%) (n=133)		69 – 88%		0 – 1%		11 – 30%	
National Round 1	11394	80	9082	1	122	19	2190

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Medication							
National Round 2	15571	75	11715	1	172	24	3684
Hospital IQR - all (%) (n=135)		66 – 86%		0 – 1%		11 – 31%	
National Round 1	11752	76	8883	1	137	23	2732

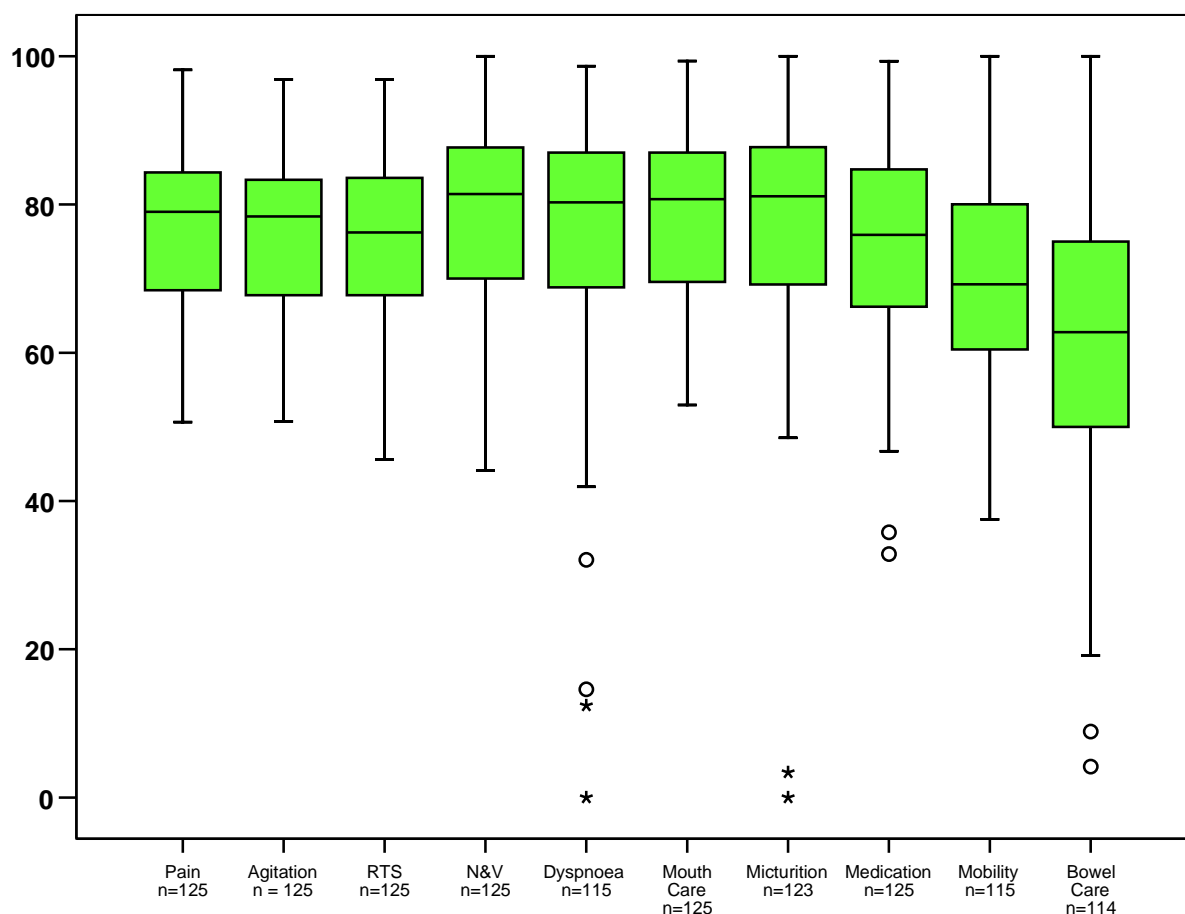
	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Mobility*							
National Round 2	5270	70	3699	1	47	29	1524
Hospital IQR - all (%) (n=125)		60 – 80%		0 – 2%		18 – 40%	
National Round 1	4215	74	3116	1	35	25	1064

	Eligible Assessments	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
Bowel Care*							
National Round 2	5206	62	3212	1	24	38	1970
Hospital IQR - all (%) (n=124)		49 – 75%		0 – 0%		23 – 50%	
National Round 1	4030	67	2709	1	43	32	1278

* Goals assessed 12 hourly on the LCP

Domain 1 Physical Comfort of the Patient: Ongoing Assessment

Boxplots



Commentary: Domain 1 Physical Comfort of the Patient

- As in Round 1, goals of care involving the assessment of medications and the anticipatory prescription of medication for 4 of the 5 key symptoms that may occur in the last hours and days of life were achieved for over 80% of patients. Three quarters of organisations achieved each of these goals for at least 73% of their audit patients. The percentage achieved was again particularly high for anticipatory prescribing for pain (90%)
- The exception was the lower 72% percentage 'achieved' for anticipatory prescribing for dyspnoea though this was up slightly from the 67% reported in Round 1. For those 104 hospitals in both rounds the rise was 63% to 74%. One recommendation from Round 1 was that hospitals pay particular attention to goals that are relatively new to the pathway and, therefore, this apparent improvement between rounds is encouraging.
- The discontinuation of blood tests and antibiotics, and particularly the recording of 'not for Cardiopulmonary Resuscitation (CPR)' are being achieved in an overwhelming majority of patients (91%, 89% and 94% respectively). The boxplot and the IQR values reveal that

three quarters of hospitals are achieving each of these goals for over 80% of their patients.

- In line with the results of Round 1, there is more variation in percentage achieved for the discontinuation of IV fluids/medications where a greater proportion of 'variance' (11%, Hospital IQR = 3% – 15%) is being recorded. This shows individualised decision making and patient care directed by the clinical team.
- There is again much diversity in the recording of the deactivation of implantable cardioverter defibrillators (ICD). The level of missing data rose from 53% in Round 1 to 56% in Round 2 which suggests that some ambiguity still exists regarding this goal that should be addressed in Version 12 of the LCP which is currently under development.
- Inappropriate nursing interventions are discontinued in three quarters of patients in Round 2 which is similar to the results for Round 1. When a syringe driver was deemed to be necessary, the percentage of times that it was set up within 4 hours has decreased from 61% in Round 1 to 49% in Round 2. Missing data is again relatively high for this goal and any ambiguity around the wording of this goal will be addressed in Version 12 of the LCP.
- As in Round 1, patients were observed to be comfortable in terms of all physical symptoms for around three quarters of all possible assessments in the last hours and days of their lives. Unfortunately, documentation was missing for around one fifth of cases where assessments could have been carried out.
- The most variation across hospitals is occurring for mobility and bowel care where there is the greatest proportion of missing data (29% and 38% respectively). The frequency of these assessments will be reviewed in Version 12 of the LCP

Domain 2: Psychosocial (Insight) and Spiritual aspects of care (patient and carer)

Assessment of insight into diagnosis and prognosis and assessment of spiritual needs of patients and carers – Initial Assessment LCP Goals 5 and 6

In addition to ensuring the patient's physical comfort, it is vital to take into account the emotional and psychological comfort of both patients and carers. Appropriate communication and information giving is very important in the last hours and days of life, and therefore understanding the level of insight and awareness the patient has into their diagnosis and recognition of the dying phase is crucial in facilitating this process.

Similarly, it is important that both patients and carers have the opportunity to raise any spiritual or religious issues that may arise specifically in this phase. Evidence from the communication skills literature (Wilkinson et al, 2002) illustrates that there are challenges in undertaking such sensitive communication with patients (and families) who are unlikely to raise these issues with health care professionals even when they would welcome a discussion. The goals of care on the LCP prompt health care professionals to identify the current situation regarding patient and carer awareness and to revisit religious and spiritual affiliation and needs.

LCP Goal 5 – Insight into condition assessed – aware of diagnosis, recognition of dying

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5a1 Awareness of diagnosis (patient)							
National Round 2	2374	50	1178	19	459	31	737
Hospital IQR - all (%) (n=151)		38 – 65%		10 – 27%		13 – 42%	
National Round 1	1677	57	949	21	346	23	382

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5a2 Awareness of diagnosis (carer)							
National Round 2	3809	79	3016	1	37	20	756
Hospital IQR - all (%) (n=150)		70 – 90%		0 – 0%		9 – 27%	
National Round 1	2591	84	2166	1	27	15	398

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5b1 Recognition of dying (patient)							
National Round 2	2352	40	944	21	490	39	918
Hospital IQR - all (%) (n=151)		26 – 50%		10 – 29%		23 – 52%	
National Round 1	1721	45	780	24	407	31	534

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5b2 Recognition of dying (carer)							
National Round 2	3863	76	2951	2	58	22	854
Hospital IQR - all (%) (n=154)		67 – 87%		0 – 3%		10 – 33%	
National Round 1	2633	82	2151	1	37	17	445

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
6.1 Religious and spiritual needs assessed (patient)							
National Round 2	2351	30	712	22	508	48	1131
Hospital IQR - all (%) (n=138)		15 – 42%		12 – 30%		32 – 62%	
National Round 1	1393	34	476	26	363	40	554

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
6.2 Religious and spiritual needs assessed (carer)							
National Round 2	3554	50	1790	11	408	38	1356
Hospital IQR - all (%) (n=139)		37 – 63%		7 – 16%		24 – 50%	
National Round 1	2053	53	1085	14	281	33	687

Ongoing Psychological, Religious/Spiritual/Care of the Family goals

Whilst on the LCP, regular monitoring of issues continues at a minimum of 12 hourly intervals in order that any changes in the situation for patients (where appropriate) and carers can be identified and addressed. It may be that new family members come into the environment over the course of time a patient is on the LCP and that these issues need to be addressed again. The following table illustrates the results for these elements of care.

Ongoing (12 hourly) Assessment of psychosocial and spiritual comfort (patient and carer)

	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Psychological Insight support (patient)							
National Round 2	5105	66	3351	1	62	33	1692
Hospital IQR - all (%) (n=122)		55 – 78%		0 – 2%		20 – 43%	
National Round 1	4186	69	2883	2	70	29	1233

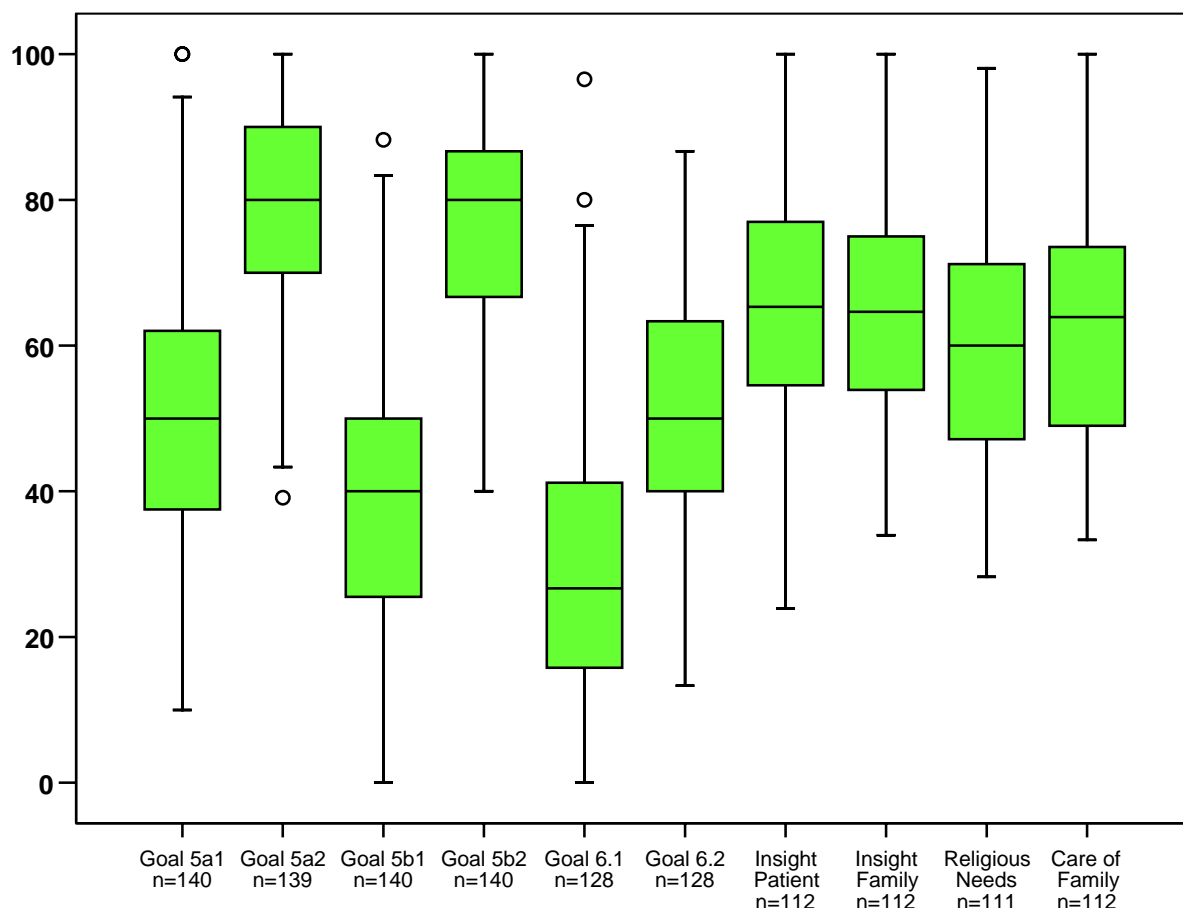
	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Psychological Insight support (carer)							
National Round 2	5105	65	3309	1	71	34	1725
Hospital IQR - all (%) (n=122)		53 – 77%		0 – 2%		21 – 46%	
National Round 1	4184	69	2887	2	68	29	1229

	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Religious/Spiritual support (patient)							
National Round 2	5053	59	3004	2	110	38	1939
Hospital IQR - all (%) (n=121)		46 – 72%		0 – 4%		25 – 52%	
National Round 1	3970	61	2433	3	109	36	1428

	Eligible Assessments	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Care of the family							
National Round 2	5105	63	3235	1	67	35	1803
Hospital IQR - all (%) (n=122)		49 – 76%		0 – 2%		23 – 50%	
National Round 1	4116	66	2728	1	52	32	1336

Domain 2: Psychosocial (Insight) and Spiritual aspects of care (patient and carer)

Box Plots



Commentary: Domain 2 Psychosocial (Insight) and Spiritual aspects of care (patient /carer)

- It is documented that almost four fifths of carers are aware of both the patient's diagnosis and that the multidisciplinary team feel that the patient has entered the final hours and days of life. Around three-quarters of hospitals are achieving these goals for about 70% of their carers.
- The patients' insight into their diagnosis and recognition that they have entered the last hours and days of life is relatively low (50% and 40% respectively). This is lower than for Round 1, particularly for those 104 hospitals in both rounds. Patients with a diagnosis other than cancer are also less likely to have insight into this information than those with a diagnosis of cancer (Goal 5a1 35% vs 65% achieved; Goal 5b1 29% vs 54% achieved) – see Part E.

- The box plots illustrate a great deal of variation across hospitals for these communication goals with patients, with some hospitals achieving 100% and others 0%.
- Though the LCP does not involve undertaking an in-depth spiritual assessment, it does require healthcare professionals to raise the issue with both patients and carers to ensure that appropriate support can be made available if required. An initial spiritual assessment of carers took place in only one half of the cases submitted, and this goal was achieved for less than one third of patients. This remains a challenging goal and efforts will be made in Version 12 of the LCP to ensure clarity of purpose.
- As in Round 1, comparatively high levels of 'variance' were recorded for patients' insight and the spiritual assessment of both patients and carers. Local analysis of the variance sheets should allow hospitals to gain a more complete understanding of why these goals were not met. However, there was a general lack of supporting documentation on the variance sheets for LCP goals 5b1 and 6.2 – see section 4 for further information.
- The two twelve hourly assessments of psychological and spiritual well-being, for both patients and carers were deemed to be 'achieved' in around two-thirds of cases.

Domain 3: Communication (Patient, Carer and other Health Care Professionals)

Assessing ability to communicate, explanation and understanding of the plan of care (patient and carer) and informing primary care of the patient's deterioration and death – Initial Assessment and Care After Death Sections

Patients and Carers – LCP Goal 4

Meaningful communication is dependent on the ability of both patients and carers to understand and communicate effectively. Some may require the services of an interpreter, or may have learning difficulties or hearing impairments. Goal 4 on the LCP prompts consideration of these issues for both patients and carers:

LCP Goal 4: Ability to communicate in English assessed as adequate

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
4.1 Patient							
National Round 2	2354	59	1398	13	315	27	641
Hospital IQR – all (%) (n=145)		46 – 77%		4 – 20%		11 – 39%	
National Round 1	1429	68	965	13	180	20	284

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
4.2 Carer							
National Round 2	3615	73	2633	1	48	26	934
Hospital IQR – all (%) (n=142)		63 – 83%		0 – 3%		13 – 34%	
National Round 1	2153	77	1655	2	35	22	463

LCP Goals 10 and 11

It is important that the plan of care for the patient is discussed with the patient (where possible and appropriate) and with relatives/carers and that healthcare professionals are sure that there is full understanding. Goals 10 and 11 on the LCP prompt appropriate communication in this regard.

LCP Goals 10 and 11

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
10.1 Plan of care explained and discussed with patient							
National Round 2	2386	30	723	19	447	51	1216
Hospital IQR – all (%) (n=149)		18 – 43%		9 – 25%		34 – 65%	
National Round 1	1640	38	617	24	392	38	631

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
10.2 Plan of care explained and discussed with carer							
National Round 2	3815	72	2736	2	60	27	1019
Hospital IQR - all (%) (n=152)		60 – 86%		0 – 3%		13 – 37%	
National Round 1	2634	78	2043	2	62	20	529

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
11 Family/other express understanding of plan of care							
National Round 2	3619	68	2473	2	68	30	1078
Hospital IQR - all (%) (n=142)		57 – 80%		0 – 3%		18 – 40%	
National Round 1	2358	73	1730	2	54	24	574

Primary Care – LCP Goals 9 and 12

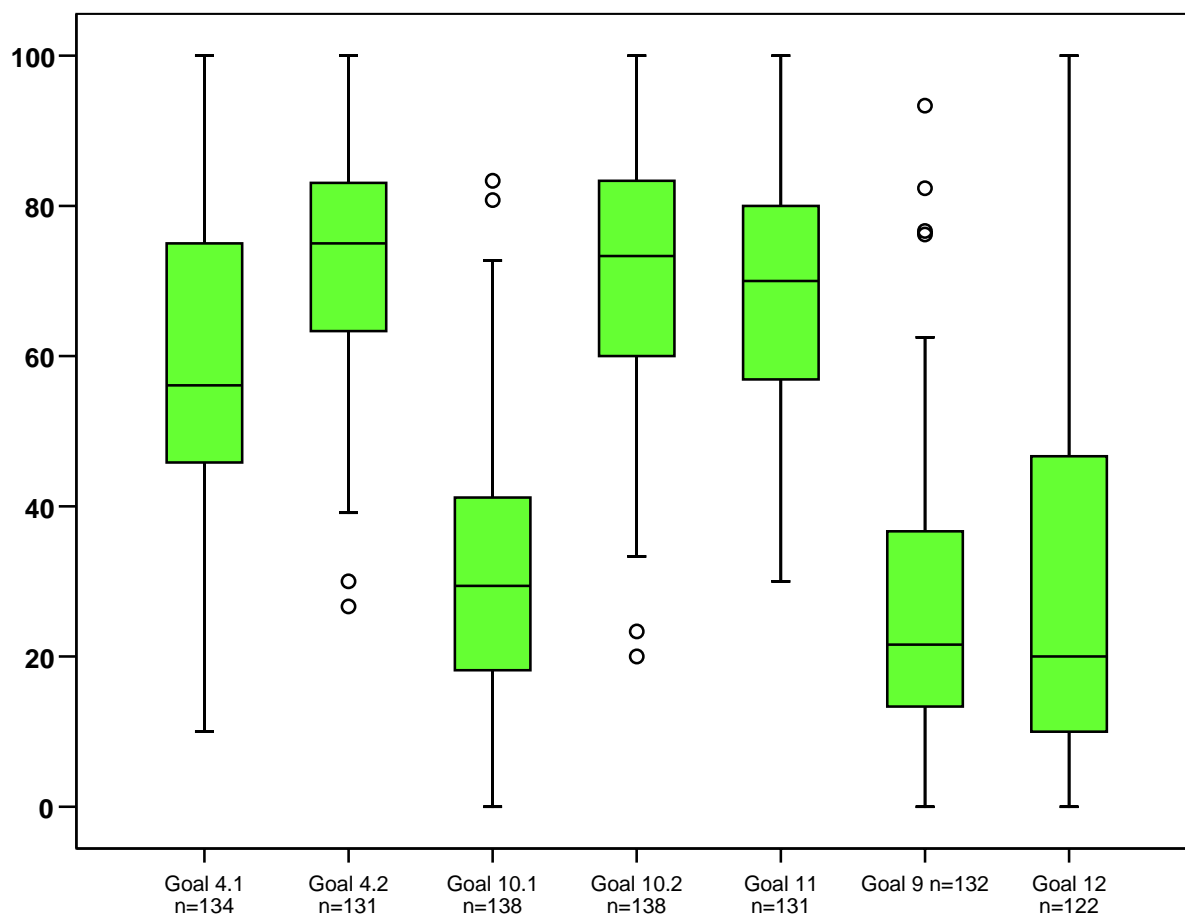
Communication with primary care colleagues regarding the changing prognosis and revised aims of care for patients on the LCP is of paramount importance. It may be that the GP has cared for the patient throughout their illness and would welcome the opportunity to visit them during their last hours and days of life. Often, the patient's GP is also responsible for the care of other members of the family and needs to have up to date information available to him/her if they are called upon to provide care for the patient's relatives at this time. Goal 9 on the LCP prompts the healthcare professional to ensure that the GP practice is fully aware of the situation. Similarly, Goal 12 prompts contact with the GP Practice when the patient has died.

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
9 GP aware of patient's deteriorating condition							
National Round 2	3664	26	940	27	1006	47	1718
Hospital IQR - all (%) (n=141)		13 – 37%		17 – 37%		33 – 59%	
National Round 1	2458	29	705	27	662	44	1091

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
12 GP informed of patient's death							
National Round 2	3355	31	1044	14	460	55	1851
Hospital IQR - all (%) (n=133)		10 – 50%		2 – 20%		33 – 77%	
National Round 1	2507	35	885	14	353	51	1269

Domain 3: Communication (Patient, Carer and other Health Care Professionals)

Boxplots



Commentary: Domain 3 Communication (Patient, Carer & Health Care Professionals)

- Communication with the patient regarding the plan of care is undertaken in only just under one-third of patients who were not comatose at the time the LCP was commenced, though for 19% of patients a variance was recorded.
- Explanation of the plan of care to carers, however, is achieved in just under three quarters of the sample, and 68% express their understanding of a plan of care. Interestingly, understanding of the plan of care was expressed in 90% of the 2736 carers that had a plan of care explained which is encouraging as carers' complaints are often the result of misunderstandings arising from the use of ambiguous language or complex clinical terminology (Healthcare Commission, 2007).

- Communication with colleagues in primary care, particularly prior to but also after the patient's death, occurs only between one quarter and just under one third of cases. The box plot and IQRs illustrate that there is also much variation in % achieved across hospitals with a few hospitals indicating it is possible to achieve highly on Goal 9.
- Despite the fact that there are relatively high levels of missing data in this domain, variance recording is also relatively high for goals pertaining to communication with patients and primary care. Local analysis of variance sheets may, therefore, enable better insight as to why such communication was not undertaken.

Domain 4: Information (giving and receiving)

LCP Goal 7 - establishing contact information

Information that was appropriate and accurate at any other time in this episode of care may not be accurate now that the focus of care has changed to care of the dying. Establishing how relatives or carers wish to be told of the patient's impending death is also very important. In some situations the next of kin may not be the most appropriate person to be contacted at the time of impending death or a list of people may be given or mobile numbers may be needed. Goal 7 on the LCP prompts health care professionals to collect and document appropriate information

LCP Goal 7: Identify how family/other are to be informed of patient's impending death

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3779	73	2747	1	47	26	985
Hospital IQR - all (%) (n=149)		63 – 85%		0 – 0%		13 – 37%	
National Round 1	2616	79	2076	2	40	19	500

LCP Goal 8 – information about hospital facilities

It is also important that written information is given to back up any conversation about facilities available to carers. This ensures that they are able to take full advantage during the last hours and days of the patient's life, particularly since a more flexible approach to visiting is now likely to be appropriate. Goal 8 on the LCP prompts health care professionals to give an information leaflet to carers:

LCP Goal 8: Family/other given hospital information

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3809	53	2006	8	319	39	1484
Hospital IQR - all (%) (n=150)		40 – 67%		0 – 10%		24 – 51%	
National Round 1	2569	59	1511	8	212	33	846

Important information on procedures and points of contact for carers after the death of their loved one – LCP Goals 15, 17 and 18.

After the death of the patient, important written information should be given to carers around any local and national procedures that may need to be followed. It is important that such information is available in a written format, as carers may be too upset to receive and retain verbal instructions and information at this very distressing time. For example, local information booklets regarding collection of the death certificate as well as any nationally available documents should be given. In addition, written information about bereavement support (local and/or national) should also be given. Goals 15, 17 and 18 prompt health care professionals in this regard:

LCP Goal 15: Family/other given information on hospital procedures

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3607	46	1671	2	75	52	1861
Hospital IQR - all (%) (n=142)		30 – 65%		0 – 3%		33 – 69%	
National Round 1	2422	54	1309	2	52	44	1061

LCP Goal 17: Necessary documentation and advice is given to the appropriate person

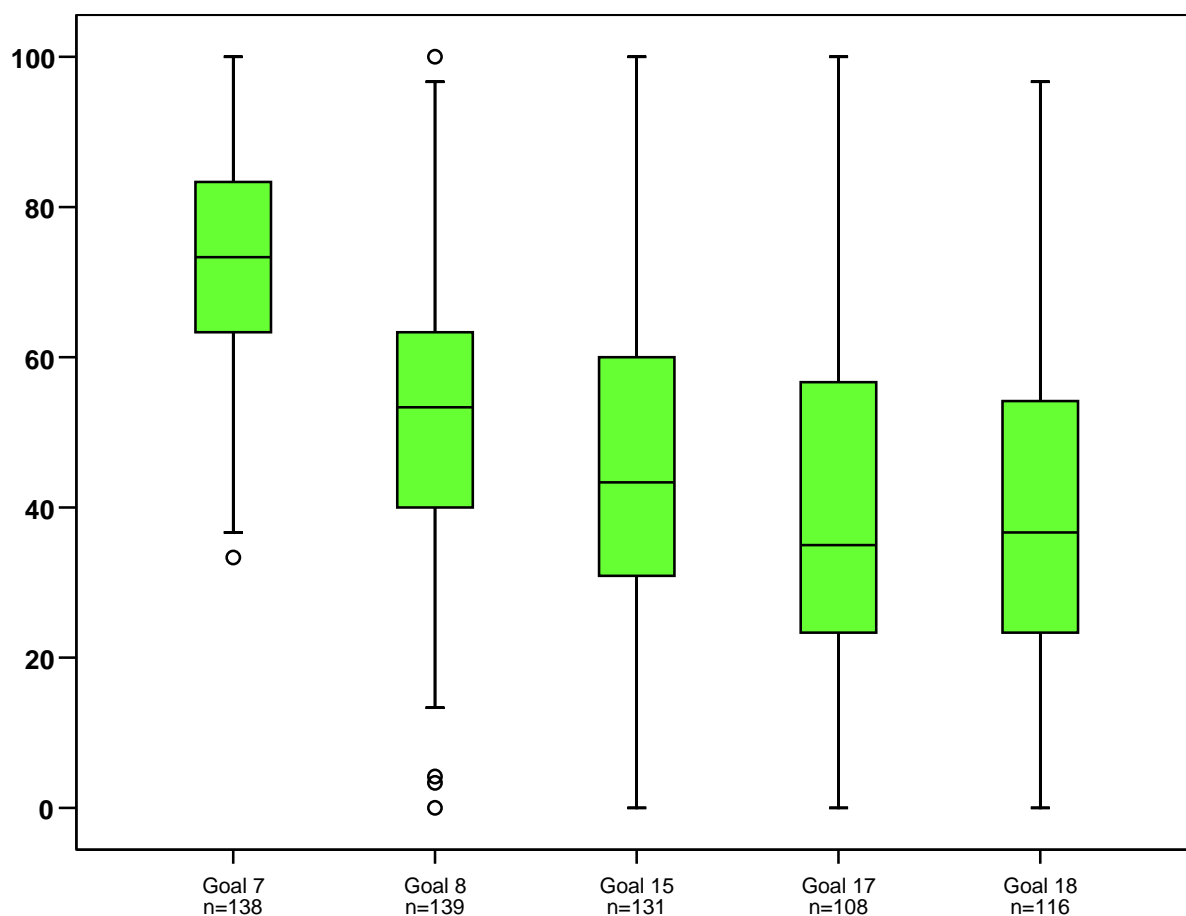
	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	2985	41	1222	6	191	53	1572
Hospital IQR - all (%) (n=116)		23 – 57%		0 – 7%		37 – 70%	
National Round 1	2174	51	1106	5	111	44	957

LCP Goal 18: Bereavement leaflet given

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3213	40	1294	7	231	53	1688
Hospital IQR - all (%) (n=126)		23 – 55%		3 – 10%		33 – 71%	
National Round 1	2264	50	1122	7	156	44	986

Domain 4: Information (giving and receiving)

Boxplots



Commentary: Domain 4 Information (giving and receiving)

- Gaining important contact information from the most appropriate person to contact in the event of deterioration was achieved in just under three-quarters of patients. There is a fairly wide variation in hospital performance highlighting some areas of good practice where hospitals have achieved this goal 100% of the time.
- As in Round 1, information leaflets detailing hospital facilities are given out relatively inconsistently
- The proportion of missing data for information given *after* the death of the patient is comparatively high across the board (over 50% for all of the goals in this domain).

Domain 5: Following appropriate procedures after death

Last Offices – LCP Goal 13

It is important to ensure that the dead body is treated with dignity and respect and appropriately in line with relevant faiths/beliefs. Each hospital will have a policy for laying out patients (last offices) and this should be consulted and followed. It is vital that all specific religious/spiritual/cultural needs are also considered at this time. Goal 13 on the LCP prompts health care professionals to consider these issues:

LCP Goal 13: Procedures for laying out followed according to hospital policy

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3637	46	1671	1	31	53	1935
Hospital IQR - all (%) (n=142)		29 – 60%		0 – 0%		40 – 71%	
National Round 1	2486	52	1292	1	35	47	1159

Consideration of procedures for appropriate care of the body – LCP Goal 14

When the patient dies certain procedures need to be considered. For example, it is often important that mortuary viewing is discussed with the family/carer as family members not present at the time of death may wish to view the deceased. If the patient has a cardiac device or pacemaker the family need to be made aware that this should be removed prior to cremation. In addition, there are some circumstances in which a post mortem will need to be carried out. Goal 14 on the LCP prompts health care professionals to consider and discuss these procedures where appropriate:

LCP Goal 14: Procedures following death discussed or carried out

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3286	40	1328	4	131	56	1827
Hospital IQR - all (%) (n=129)		27 – 53%		0 – 3%		40 – 70%	
National Round 1	2346	45	1064	5	112	50	1170

Care of valuables – LCP Goal 16

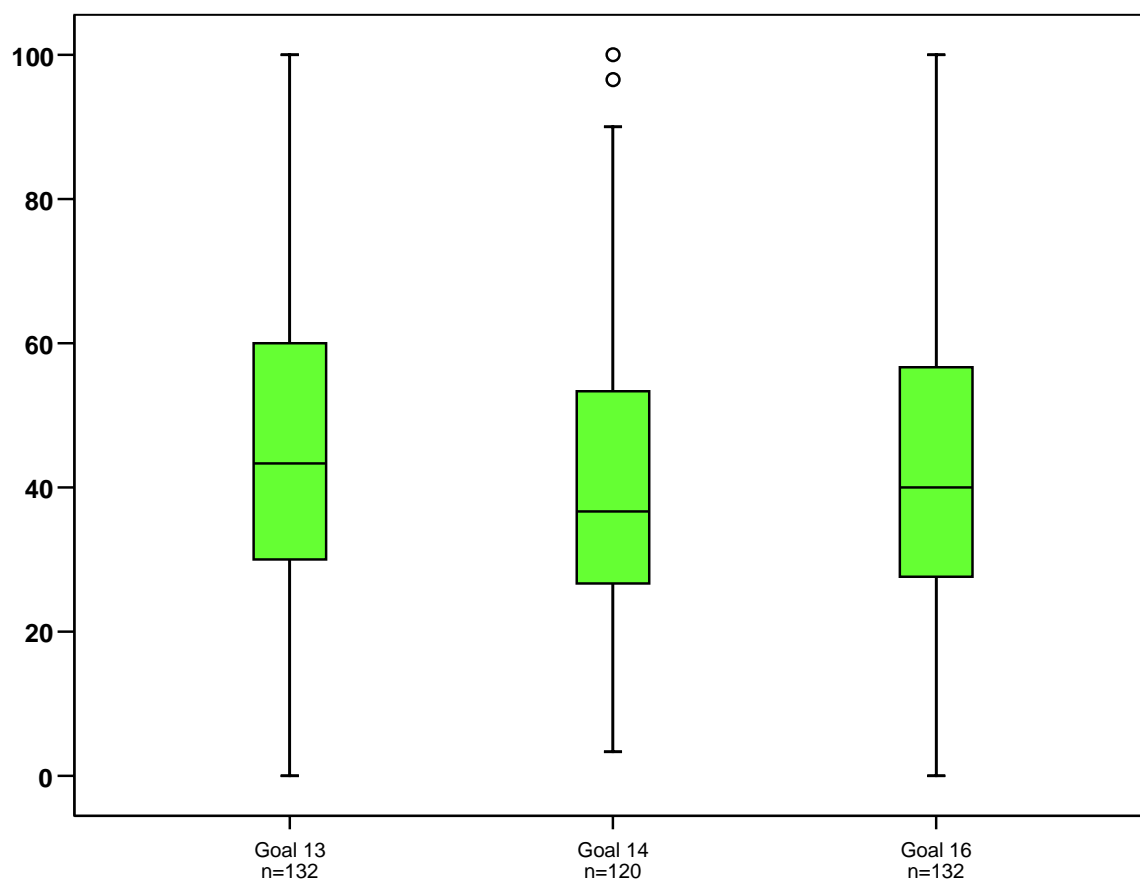
It is important that all items belonging to the patient are collected and stored appropriately, according to the hospital policy, until the family are able to collect them. Goal 16 on the LCP specifically addresses this:

LCP Goal 16: Hospital Policy followed for patient’s valuables & belongings

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National Round 2	3653	43	1589	2	59	55	2005
Hospital IQR - all (%) (n=143)		27 – 57%		0 – 3%		43 – 71%	
National Round 1	2462	52	1287	2	58	45	1117

Domain 5: Following Appropriate Procedures

Boxplots



Commentary: Domain 5 Following Appropriate Procedures after death

- The median score for Domain 5 'goal not documented' is high (55%) and, as such is consistent with other goals in Section 3 of the LCP - Care after Death Section and with the results from the 1st Round
- However, the box plots and IQRs clearly illustrate that whilst there is much variation in the performance of individual hospitals in terms of achievement of these goals, some examples of good practice do exist.
- Generally performance (% achieved) is 5-9% lower in Round 2 for all Domain 5 goals. This is also true for those 104 hospitals participating in both audits. The performance of those new to the audit in Round 2 was worst however, being 5-6% lower than the other hospitals in Round 2.
- An in-depth discussion of the reasons for high levels of missing data will be undertaken in the workshops to underpin the further development of Version 12 of the LCP.

Section 3: Medication Prescribing

This section is concerned with the prescription and administration of medications for agitation and restlessness in the last 24 hours of life and variance reporting for a selection of goals from the LCP against which relatively higher levels of variance was recorded in the first round. This data was only collected in Round 2.

Agitation can be a distressing symptom for both patient and family at end of life and potential reversible causes should be considered for example urinary retention and constipation. The National Council for Palliative Care (NCPC) in collaboration with the Marie Curie Palliative Care institute Liverpool has produced a document containing guidelines to support care delivery in the last days and hours of life for adult patients (NCPC, 2006). This document suggests midazolam as the drug of choice for the treatment of agitation at the end of life. It suggests initial doses of 2.5-5mg of midazolam by subcutaneous injection 2-4 hourly when required. If two or more prn doses have been required then a syringe driver with 5-10mg of midazolam should be considered. Where midazolam has not been successful, the NCPC guidelines suggest that levomepromazine is a useful second line treatment option which can be used alone or in combination with midazolam. NCPC suggest levomepromazine in initial doses of 12.5mg by subcutaneous injection 8-12hourly when required or doses of 25-50mg if considering adding to a syringe driver. Haloperidol is also recommended as a useful treatment option if delirium or hallucinations felt to a factor in contributing to agitation. Non-pharmacological treatment of agitation such as a quiet environment should be provided where possible.

The table below provides a summary of the medications prescribed in the National Audit and administered for agitation and restlessness in the last 24 hours of life – both prn and via continuous subcutaneous infusion. In addition, it details the average doses given along with information about the variation in dose across patients within the samples.

Medications for Agitation and Restlessness prescribed and given in the last 24 hours of life (prn and subcutaneous infusion)

PRN Medications in the last 24 hours of life	National Round 2	
PRN medication prescribed for Agitation or Restlessness)	82%	(3188/3893)
If PRN Medication was prescribed for Agitation or Restlessness		
PRN medication given (%Yes)	37%	(1180/3188)
Drugs prescribed and given PRN in the last 24 hours of life		
Midazolam (% Yes)	94%	(1110/1180)
Midazolam Median dose (mg)	5	
(IQR) (mg)	(2.5 – 7.5)	
10th – 90th percentile (mg)	(2.5 – 10)	
Min – Max (mg)	(0.5 – 60)	
Haloperidol (% Yes)	4%	(52/1180)
Haloperidol Median dose (mg)	1.5	
(IQR) (mg)	(1.1 – 3)	
10th – 90th percentile (mg)	(0.5 - 5)	
Min – Max (mg)	(0.5 – 12.5)	
Levomepromazine (% Yes)	5%	(55/1180)
Levomepromazine Median dose	12.5	
(IQR) (mg)	(6.25 – 25)	
10th – 90th percentile (mg)	(6.25 – 50)	
Min – Max (mg)	(3.75 – 100)	

Other drugs were given for agitation in 108 patients (9% of the 1180 for whom information was submitted). The two most popular drugs given were: morphine (50 patients) and diamorphine (27 patients).

Continuous Subcutaneous Infusion Medications in the last 24 hours of life	National Round 2	
Any medication prescribed for continuous subcutaneous infusion (%Yes)	54%	(2106/3893)
Medication for <i>Agitation or Restlessness</i> prescribed for continuous subcutaneous infusion (%Yes)	69%	(1460/2106)
If medication for Agitation and Restlessness was prescribed via continuous subcutaneous infusion		
Medication for Agitation or Restlessness given via continuous subcutaneous infusion (% Yes)	94%	(1370/1460)
Drugs prescribed and given via continuous subcutaneous infusion for Agitation or Restlessness		
Midazolam (% Yes)	88%	(1208/1370)
Midazolam – median total dose in driver in last 24 hours (mg)	10	
(IQR) (mg)	(7.5 – 15)	
10th – 90th percentile (mg)	(5 – 20.5)	
Min – Max (mg)	(0.10 – 100)	
Haloperidol (% Yes)	15%	(206/1370)

Haloperidol – median total dose in driver in last 24 hours (mg)	3	
(IQR) (mg)	(2.5 – 5)	
10th – 90th percentile (mg)	(1.5 – 5)	
Min – Max (mg)	(1 – 15)	
Levomepromazine (% Yes)	12%	(166/1370)
Levomepromazine – median total dose in driver in last 24 hours (mg)	12.5	
(IQR) (mgs)	(6.25 – 20.3)	
10th – 90th percentile (mg)	(5 – 50)	
Min – Max (mg)	(2.40 – 225)	

Other drugs were given for agitation in 166 patients (12% of the 1370 for whom information was submitted). The two most popular drugs given were: morphine (73 patients) and diamorphine (55 patients).

Commentary: Medication Prescribing

- Anticipatory prescribing in care of the dying is important if the patient is to receive the right drug for the right symptom at the right time. It is of note that prescribing a drug does not mean all patients receive the drug; this supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed drug for agitation and restlessness. The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 5mg as a PRN dose. The median doses of haloperidol and levomepromazine were also relatively low. Audit sites who are frequently prescribing outside the 90th percentile need to review practice.
- In a small proportion of patients morphine or diamorphine were given, it is not clear from the data if this was predominantly for pain control. These drugs would not normally be prescribed for agitation and restlessness therefore these audit sites need to review practice.

Section 4: Variance Reporting

Variance reporting is an important element of any integrated care pathway (see appendix 4 for definition). A variance is reported when a goal on the LCP is not met and the information recorded on the variance sheet provides invaluable information as to the reason why. This information can be used clinically to facilitate better continuity of care and for audit purposes to highlight areas of inconsistency. The table below shows the proportion of times an entry was made on the variance sheets in response to a goal being coded 'no' on the LCP for the following goals:

- Discontinue inappropriate IV fluids/medications
- Patient recognition of dying
- Family/other religious and/or spiritual needs assessed
- Bereavement leaflet given to family/other after the death of the patient

These goals were chosen, in the main, because relatively higher levels of 'no' (variance) had been recorded in Round 1 of the National Audit.

Proportion of time variance written up	National Round 2	
Discontinue Inappropriate Interventions – IV Fluids/Medications	17%	(69/405)
Recognition of Dying - Patient	12%	(58/490)
Religious/Spiritual Needs assessed – Family/Other	19%	(76/408)
Bereavement Leaflet Given (after the death of the patient)	50%	(115/231)

The table below provides a summary of the content analysis performed on the limited number of reasons reported on the variance sheets for these goals for the whole sample.

	Top 3
LCP Goal 3.3: Discontinue Inappropriate Interventions – IV Fluids/Medications (n=69/405)	<ol style="list-style-type: none"> 1. Medical decision to continue (43) <i>(Continue current IV fluid bag then stop, continue fluids until cannula tissues, continue for 24 hours and review)</i> 2. Continue to treat potentially reversible conditions (13) <i>(e.g. Hypoglycaemia, Clinical Dehydration, Elevated calcium / sodium)</i> 3. Family expressed a wish to continue (12)
LCP Goal 5b1: Recognition of Dying – Patient (n=58/490)	<ol style="list-style-type: none"> 1. Patient unable to communicate (42) <i>(Patient unable to comprehend due to confusion / dementia / stroke / general condition / drowsy)</i> 2. Patient comatose (5) 3. Issue not raised (5) <i>(Patient denial / relatives do not wish patient to know)</i>
LCP Goal 6.2: Religious/Spiritual Needs assessed – Family/Other (n=76/408)	<ol style="list-style-type: none"> 1. Next of Kin not present at time of assessment (36) 2. Restatement that this was not undertaken only (12) 3. Next of Kin refusing discussion / too distressed to have discussion (7)

LCP Goal 18: Bereavement Leaflet Given (after the death of the patient) (n=115/231)	<ol style="list-style-type: none"> 1. Next of Kin / family not present (53) 2. Next of Kin / family not present but contact made via the telephone and information given (37) 3. Family request no leaflet / are too distressed to accept (10)
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It was clear that there were occasions when variance was recorded inappropriately. Either the description on the variance sheet was not appropriate to the goal in question (irrelevant), or the goal should have been coded 'achieved' (incorrect):

LCP Goal - 3.3 – 1 irrelevant; LCP Goal 5b1 – 3 irrelevant; LCP Goal 6.2 – 6 irrelevant, 9 incorrect; LCP Goal 18 – 3 irrelevant, 1 incorrect.

Commentary: Variance Reporting

Clearly, information about the reason that a goal was not met is written up only in a minority of appropriate circumstances. This means that a clear picture (clinical and audit) is unavailable to improve our understanding as to why these goals were not met.

- Version 12 of the LCP will enable the recording of variance directly beneath the goals in an attempt to increase documentation

Ongoing Assessment of the patient in the last 24 hours

Variance reporting in the Ongoing Assessment Section of the LCP is generally completed more comprehensively than for other sections of the LCP. In this section, variance is recorded in response to the condition of the patient on regular assessment, and allows healthcare professionals to highlight when patient and/or relative/carer comfort (physical, emotional) has not been met.

The table below compares the number of times a variance was recorded on the variance sheet in the last 24 hours of life and the number of times a 'V' was recorded in the 4 hourly assessment section in the last 24 hours of life for 3 goals (Pain, Agitation, RTS) that had the highest proportion of variance reported in Round 1 of the National Audit.

Each time a 'V' is recorded in the 4 hourly assessment section, information about the action taken in response should be reported on the variance sheet. However, if healthcare professionals attend to the needs of the patient more often than the minimum 4 hourly required by the LCP and find that the patient is not comfortable, then information should also be reported on the variance sheet, even though it is not articulated in the 4 hourly assessment section.

Symptom against which a recording was made	National Round 2	
	Variance Sheet	4 hourly Assessment Section
Pain (3197 assessments 'not documented')	1066	656
Agitation (3237 assessments 'not documented')	1063	699
RTS (3273 assessments 'not documented')	1217	794

Commentary: Variance Reporting Ongoing Assessment

- The results for the ongoing assessment goals illustrate that more variances were recorded on the variance sheets than were documented in the 4 hourly assessment section. It is possible that this difference is accounted for by the relatively high level of 'assessment not documented' (around 20%) for these goals of care – ie it is possible that the missing data should have been coded 'variance' in the ongoing assessment section. It is also possible that healthcare professionals were assessing the needs of the patient more frequently than 4 hourly.

SECTION 5: PART B PATIENT LEVEL KEY FINDINGS

- The patient level results indicate that there has generally been little demonstrable change in overall hospital performance between Round 1 and Round 2. However, 51 hospitals (just under one third of the sample) are new to the audit this round and for those 104 hospitals in both rounds there has been expansion in the number of wards covered. Hence caution should be exercised when making direct comparisons between rounds. The relatively short period between Round 1 and 2 may be implicated in the lack of demonstrable improvement as there may not have been adequate time for the implementation of Action Plans (ie closing the audit loop). Also, improvement is more difficult to achieve where performance is already at a high level (ie for Domains 1 and 2).
- The proportion of patients who had a diagnosis other than cancer has increased from 55% in Round 1 to 61% in Round 2.
- Percentage achieved for goals concerning the physical aspects of patient comfort (Domain 1) remains high across the board this round. For 92% of patients medications were reviewed and non essentials discontinued, and for 90% of patients, medication for pain was prescribed for use in the event of the patient developing this symptom.
- Documentation of the four hourly assessments made in the last 24 hours of life illustrates that the vast majority of patients are reported to be comfortable. More variance is recorded on the variance sheets than is documented in the ongoing assessment section. This may, in part, be accounted for by the 20% (on average) missing data in this section, and/or may indicate more frequent assessment of patients in the last 24 hours of life.
- Communication, particularly with patients and primary care remains a challenge, especially for patients with a diagnosis other than cancer – see Part E of your full Report. This may be affected by the relatively high number of patients in this sample who had stroke and dementia (including Alzheimer's).
- Whilst communication regarding the plan of care and recognition that the patient had entered the dying phase was generally undertaken with relatives/carers (achieved in 72% and 76% respectively) there is still room for improvement.
- As in Round 1, a higher percentage of variance was documented for the discontinuation of IV fluids and medications (11% in Round 2). However, the lack of recording of explanations on the variance sheets for this goal precludes a full understanding of the reasons for continuation in this sample.
- The proportion of missing data in the care after death section is high (>50% across all goals).

- Medication: It is of note that drugs prescribed prn for agitation and restlessness were actually given in only 37% of cases. This supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed drug for agitation and restlessness. The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 5mg as a PRN dose. The median doses of haloperidol and levomepromazine were also relatively low.

PART C: KEY PERFORMANCE INDICATORS (KPI)

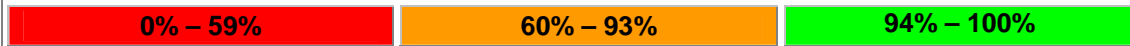
These KPIs are metrics that can be used to illustrate performance on the 'corporate performance dashboard' (see Appendix 3: glossary) in the Trust. They are based on data for those 102 hospitals that submitted the full sample size of 30 cases in Round 2. The spread of the performance of hospitals nationally for the 3 KPIs has been divided into 3 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

Key Performance Indicator 1: Spread of the LCP

An important indicator of the extent to which the LCP has become embedded within a hospital is the proportion of wards using the LCP. The Department of Health have specifically highlighted this metric as an important indicator of the spread of education and training in care of the dying within a hospital (DH, 2009). The table below illustrates the data from 'Your Site' compared with the National median proportion of wards using the LCP based on those 102 hospitals that submitted the full sample size.

Key Performance Indicator 1: Spread of the LCP

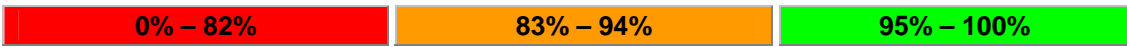
Proportion of wards using the LCP	National Round 2 (n=102)
Median % (IQR)	75% (60% - 93%)
	

Key Performance Indicator 2: Anticipatory prescribing for the key symptoms that may develop in the last hours and days of life

Goal 2 on the LCP requires the prescription of appropriate drugs for Pain, Agitation, Respiratory Tract Secretions, Nausea and Vomiting and, more recently, Dyspnoea. It is imperative that appropriate drugs are written up on commencement of the LCP regardless of whether the patient is symptomatic at that point in time. This is to facilitate a prompt response in the event of the patient becoming symptomatic. As such, goal 2 is an example of a goal that is an overriding duty or principle and has been included as a performance indicator for this reason. As prescribing for dyspnoea is a relatively new goal on the LCP and many participating hospitals in this round did not

have the goal on their pathway, it has been excluded from the key performance indicator. The table below illustrates the data from 'Your Site' compared with the National median percentage:

Key Performance Indicator 2: Anticipatory prescribing for the key symptoms that may develop in the last hours & days of life

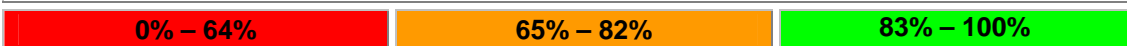
Proportion of wards using the LCP	National Round 2 (n=101)
Median % (IQR)	88% (83%-94%)
	

* 1 hospital did not have this goal

Key Performance Indicator 3: Compliance with completion of the LCP or equivalent pathway.

Documenting the care delivered in the last hours / days of life appropriately and consistently is very important. Good documentation not only provides a wealth of information that is important to other colleagues involved in caring for the particular patient and family, it also allows scrutiny of the care that was delivered after the event. The design and layout of the LCP makes completion of documentation against each goal simple and straightforward and compliance (full completion of the documentation) should, therefore, be achievable. The table below illustrates the data from 'Your Site' compared with the National median percentage for those 102 hospitals that provided the full sample.

Key Performance Indicator 3: Compliance with completion of the LCP or equivalent pathway

Proportion of wards using the LCP	National Round 2 (n=102)
Median % (IQR)	74% (65 - 82)
	

The Impact of an LCP Facilitator (or equivalent) on compliance with completion of the LCP or equivalent pathway

The results from the first round of the National Care of the Dying Audit - Hospitals (NCDHA, 2007) revealed that those hospitals that had an LCP Facilitator at the beginning of the audit period had higher levels of compliance (Gambles et al, 2009). Goals that were coded either 'achieved', 'variance', 'comatose' or 'not applicable' were deemed to represent compliance, only those where nothing was recorded were deemed to represent non compliance. In order to assess the impact of an LCP Facilitator further in this round, domain scores for level of compliance have been analysed separately for those hospitals that took part in both rounds (n=101/104 – 3 sites did not provide data) in 4 groups

- Group 1: Those with a facilitator in both rounds
- Group 2: Those with a facilitator in round 1 but not round 2
- Group 3: Those with a facilitator in round 2 but not round 1
- Group 4: Those with no facilitator in either round

The Impact of an LCP Facilitator (or equivalent) on hospital compliance in Round 2

Table gives median and IQR compliance of hospitals within each group (n=101)	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5
Facilitator in both rounds (n=21 hospitals)	86% (81-88)	72% (62-76)	72% (64-76)	65% (54-73)	56% (41-64)
Facilitator round 1 but not round 2 (n=24 hospitals)	86% (76-92)	72% (64-82)	65% (58-75)	47% (44-64) n=23	38% (30-57) n=23
Facilitator round 2 but not round 1 (n=18 hospitals)	86% (81-91)	74% (63-84)	74% (61-87)	67% (49-83)	54% (38-72)
No Facilitator in either round (n=38 hospitals)	83% (78-92)	68% (60-81)	64% (51-78)	52% (41-70) n=37	44% (28-59) n=35

Domain 1 - Physical comfort of the patient

Domain 2 - Psychosocial and spiritual/religious aspects of care (patients and carers)

Domain 3 - Communication (patient, carer and healthcare colleagues)

Domain 4 - Appropriate information (giving and receiving)

Domain 5 - Compliance with appropriate policies and procedures.

The results of this descriptive analysis showed that there was very little difference in compliance in Domains 1 and 2 for hospitals with or without an LCP Facilitator. However, for Domains 3, 4 and 5, those hospitals with no Facilitator in either round and those with no Facilitator in round 2 had lower levels of compliance.

PART D: ROUND 2 RECOMMENDATIONS

1. Key Performance Indicators (KPI's) for care of the dying should be measured, monitored and managed as part of the organisation corporate performance dashboard.
2. All hospitals should have a clear programme for continuous quality improvement for care of the dying to drive up performance and quality. A remedial action plan in response to National Care of the Dying Audit findings should be in place to address poor compliance, Inter Quartile Range (IQR) outliers, variance reporting and improved performance across the key domains of care.
3. A named person within the organisation should take formal responsibility to act as an LCP Facilitator / change agent for care of the dying.
4. Whilst the median doses prescribed and given for agitation and restlessness (both prn and continuous subcutaneous infusion) are relatively low, audit sites who are frequently prescribing outside the 90th percentile need to review practice. Audit sites where morphine and diamorphine have been prescribed for this symptom should also review their practice.
5. All hospitals should have a local audit programme for care of the dying that includes the assessment of the views of bereaved carers.
6. Optimising knowledge transfer is an important aspect of continuous quality improvement. All hospitals should have appropriate information leaflets available in support of care in the last hours / days of life.
7. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with patient insight (both into diagnosis and recognition of dying) and spiritual assessment (for both patients and carers). All health care workers caring for dying patients and their relatives / carers should have access to appropriate ongoing training and education in care of the dying (DH 2009).
8. The use of the Care After Death Section of the LCP for all deaths has been recommended (DH 2009). This audit shows that there is a high proportion of missing data for all goals in the Care After Death Section and it is therefore important that hospitals identify the reasons for this.
9. The Department of Health's Quality Markers and Measures for End of Life Care (DH 2009) document recommends that all hospitals take part in the 2 yearly National Care of the Dying Audit Cycle.
10. All hospitals should have an LCP or equivalent in place (DH 2009) that is compliant with the goals to be included in the new updated version 12 of the LCP to be launched in November 2009.

PART E: COMPARISON OF PATIENTS WITH A DIAGNOSIS OF CANCER AND A DIAGNOSIS OTHER THAN CANCER

The following data are presented to illustrate important differences in the demographics and the percentage of goals coded 'achieved' on the LCP (or equivalent) for patients with a diagnosis of cancer and those with a diagnosis other than cancer. These differences are highlighted, where appropriate, in the commentaries in the Part A and B of this report.

	Cancer		Non Cancer	
Patient Demographics	N = 1532		N = 2361	
Age (median/IQR)	76	67 - 83	84	77 - 89
Gender (% Female/number)	49	744	59	1397
Hours on LCP (median/IQR)	30	12 - 65	35	12 - 84

	Cancer		Non Cancer	
Domain 1				
Initial Assessment	%	N	%	N
1. Current medication assessed and non-essentials discontinued	91	1386	92	2161
2. PRN subcutaneous medication written up for list below as per protocol				
2.1 Pain	92	1395	89	2081
2.2. Agitation	88	1335	83	1950
2.3. RTS	82	1232	80	1876
2.4. Nausea and Vomiting	85	1283	79	1864
2.5. Dyspnoea	75	937	71	1382
3. Discontinue inappropriate interventions				
3.1. Blood Tests	91	1185	91	1808
3.2. Antibiotics	88	1257	90	1998
3.3. IV Fluids/Medications	82	1189	83	1860
3.4. Not for CPR	94	1290	94	2027
3.5. Deactivate Cardiac Defibrillators	30	102	34	207
3a. Decisions to discontinue inappropriate nursing interventions taken	74	1122	75	1730
3b. Syringe driver set up within 4 hours of doctor's order	62	725	39	611
Ongoing Assessment				
Assessment of Physical indicators of Comfort (4 hourly)				
Pain	75	4985	77	7637
Agitation	75	4964	77	7575
RTS	75	4943	76	7465
Nausea and Vomiting	80	5268	79	7784

Dyspnoea	76	4754	76	6907
Mouth Care	79	5248	78	7719
Micturition	78	5108	77	7557
Medication	78	4938	74	6777
(12 hourly)				
Mobility	72	1534	69	2165
Bowel Care	62	1315	61	1897

	Cancer		Non Cancer	
Domain 2				
Initial Assessment	%	N	%	N
5. Insight into condition assessed				
5a1. Awareness of diagnosis (patient)*	65	736	35	442
5a2. Awareness of diagnosis (family)	81	1209	78	1807
5b1. Recognition of Dying (patient)*	54	574	29	370
5b2. Recognition of Dying (family)	78	1182	76	1769
6. Religious and Spiritual Needs Assessed				
6.1. Patient*	37	390	25	322
3.2. Family/carer	54	764	48	1026
Ongoing Assessment				
Assessment of Physical indicators of Comfort (12 hourly)				
Psychological Insight – Patient	68	1422	64	1929
Psychological Insight – Family	67	1407	63	1902
Religious/Spiritual support - Patient	62	1294	57	1710
Care of the Family	66	1384	61	1851

*5a1 - Comatose = 26% Cancer; 45% Non Cancer; Variance = 10% Cancer; 28% Non Cancer; Missing = 24% Cancer; 37% Non Cancer

*5b1 - Comatose = 29% Cancer; 44% Non Cancer; Variance = 14% Cancer; 27% Non Cancer; Missing = 32% Cancer; 45%

*6.1 – Comatose = 24% Cancer; 36% Non Cancer; Variance = 22% Cancer; 22% Non Cancer; Missing = 42% Cancer; 54% Non Cancer

NB comatose taken out of sample prior to analysis of proportions

	Cancer		Non Cancer	
Domain 3				
Initial Assessment	%	N	%	N
4. Ability to communicate in English assessed as adequate				
4.1. Patient	68	738	52	660
4.2. Family	76	1106	71	1527
10. Plan of Care Explained and Discussed				
10.1. Patient*	42	441	21	282
10.2. Family/carer	74	1107	71	1629
11. Family/other express understanding of plan of care	70	1014	67	1459
9. GP aware of patient's deteriorating condition	29	414	23	526
Care After Death Section				
12. GP informed of patient's death	34	437	30	607

10.1 – Comatose = 29% Cancer, 41% Non cancer; Variance = 16% Cancer, 21% Non Cancer;
Missing = 42% Cancer, 58% Non Cancer

NB comatose taken out of sample prior to analysis of proportions

	Cancer		Non Cancer	
Domain 4				
Initial Assessment	%	N	%	N
7. Identify how family/other are to be informed of patient's impending death	75	1131	71	1616
8. Family/other given hospital information	58	880	49	1126
Care After Death Section				
15. Family/other given information on hospital procedures	50	719	44	952
17. Necessary documentation and advice is given to the appropriate person	47	549	37	673
18. Bereavement leaflet given	47	602	36	692

	Cancer		Non Cancer	
Domain 5				
Care after Death	%	N	%	N
13. Procedures for laying out followed out according to hospital policy	48	701 (n=1451)	44	970 (n=2186)
14. Procedures following death discussed or carried out	44	569 (n=1296)	38	759 (n=1990)
16. Hospital policy followed for patients' valuables and belongings	47	682 (n=1460)	41	907 (n=2193)

PART F: REFERENCES

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Appendix 1 – Participating Hospitals (by SHA and Trust)

EAST MIDLANDS SHA	
Derby Hospitals NHS Foundation Trust Derby City General Hospital	Nottingham City Hospital NHS Trust City Campus QMC Campus
Northampton General Hospital NHS Trust Northampton General Hospital	University Hospitals of Leicester NHS Trust Glenfields Hospital Leicester Royal Infirmary Leicester General Hospital
EAST OF ENGLAND SHA	
Bedford Hospital NHS Trust Bedford Hospital	Luton and Dunstable Hospitals NHS Trust Luton and Dunstable Hospital
Cambridge University Hospital NHS Trust Addenbrookes Hospital	Mid Essex Hospital Services NHS Trust Broomfield Hospital
East and North Hertfordshire NHS Trust Lister Hospital Queen Elizabeth II Hospital	Norfolk and Norwich University Hospital NHS Trust Norfolk and Norwich University Hospital
Essex Rivers Healthcare NHS Trust Essex County Hospital Colchester General Hospital	Peterborough and Stamford Hospitals NHS Foundation Trust Edith Cavell Hospital Peterborough District Hospital Stamford and Rutland Hospital
Hinchingbrooke Health Care NHS Trust Hinchingbrooke Hospital	The Queen Elizabeth Hospital Kings Lynn NHS Trust The Queen Elizabeth Hospital
Ipswich Hospital NHS Trust Ipswich Hospital	West Hertfordshire Hospitals NHS Trust Watford General Hospital Hemel Hempstead General Hospital
James Paget Healthcare NHS Trust James Paget Hospital	West Suffolk Hospitals NHS Trust West Suffolk Hospital
LONDON SHA	
Barking, Havering and Redbridge Hospitals NHS Trust Queens Hospital King George Hospital	Newham University Hospital NHS Trust Newham General Hospital
Barnet and Chase Farm Hospitals NHS Trust Chase Farm Hospital Barnet Hospital	North Middlesex University Hospital NHS Trust North Middlesex Hospital
Barts and the London NHS Trust St Bartholomew's Hospital The Royal London Hospital	North West London Hospitals NHS Trust Northwick Park Hospital Central Middlesex Hospital
Bromley Hospitals NHS Trust Princess Royal University Hospital	Queen Elizabeth Hospital NHS Trust Queen Elizabeth Hospital
Chelsea and Westminster Healthcare NHS Trust Chelsea and Westminster Hospital	Queen Mary's Sidcup NHS Trust Queen Mary's Hospital
Epsom and St Helier University Hospitals NHS Trust St Helier Hospital Epsom Hospital	Royal Free Hampstead NHS Trust Royal Free Hospital
Guy's and St Thomas' NHS Foundation Trust	Lewisham University Hospital NHS Trust

Guy's Hospital St Thomas' Hospital	Lewisham University Hospital
Homerton University Hospital NHS Foundation Trust Homerton Hospital	The Royal Marsden Hospital NHS Trust The Royal Marsden Hospital
Imperial College Healthcare NHS Trust St Mary's Hospital Charing Cross Hospital	The Whittington Hospital NHS Trust The Whittington Hospital
King's College Hospital NHS Trust King's College Hospital	University College London NHS Foundation Trust University College London
Kingston Hospital NHS Trust Kingston Hospital	Mayday Hospital NHS Trust Mayday University Hospital
NORTH EAST SHA	
City Hospitals Sunderland NHS Foundation Trust Sunderland Royal Hospital	Northumbria Healthcare NHS Trust North Tyneside Hospital Wansbeck Hospital Hexham General Hospital Haltwhistle War Memorial Hospital
County Durham and Darlington Acute Hospitals NHS Trust University Hospital of North Durham Darlington Memorial Hospital Bishop Auckland General Hospital	South Tees Hospitals NHS Trust The James Cook University Hospital Friarage Hospital
Gateshead Health NHS Foundation Trust Queen Elizabeth Hospital	South Tyneside NHS Foundation Trust South Tyneside District General Hospital
North Tees and Hartlepool NHS Trust University Hospital of North Tees University Hospital of Hartlepool	
NORTH WEST SHA	
Aintree Hospitals NHS Trust Aintree Hospital	Pennine Acute Hospitals NHS Trust Fairfield General Hospital North Manchester General Hospital Royal Oldham Hospital Rochdale Infirmary
Blackpool, Fylde and Wyre Hospitals NHS Trust Blackpool Victoria Hospital	Royal Liverpool and Broadgreen University Hospitals NHS Trust Royal Liverpool University Hospital Broadgreen Hospital
Bolton Hospitals NHS Trust Royal Bolton Hospital	Salford Royal NHS Foundation Trust Hope Hospital
Central Manchester and Manchester Children's University NHS Trust Manchester Royal Infirmary	Southport and Ormskirk Hospital NHS Trust Southport and Ormskirk District General Hospital
Christie Hospital NHS Trust	St Helens and Knowsley Hospitals NHS Trust

Christie Hospital	Whiston Hospital St Helens Hospital
Clatterbridge Centre for Oncology NHS Trust Clatterbridge Centre for Oncology	Stockport Foundation Trust Stepping Hill Hospital
Countess of Chester Hospital NHS Trust Countess of Chester Hospital	Tameside and Glossop Acute Services NHS Trust Tameside General Hospital
East Cheshire NHS Trust Macclesfield District General Hospital	Trafford Healthcare NHS Trust Trafford General Hospital
East Lancashire Hospitals NHS Trust Blackburn Royal Hospital Burnley General Hospital	University Hospital of South Manchester NHS Foundation Trust Wythenshawe Hospital
Lancashire Teaching Hospitals NHS Trust Chorley District General Hospital Royal Preston Hospital	Wirral Hospital NHS Trust Arrowe Park Hospital
North Cheshire Hospitals NHS Trust Warrington Hospital	Wrightington, Wigan and Leigh NHS Trust Royal Albert Edward Infirmary
SOUTH CENTRAL SHA	
Basingstoke and North Hampshire NHS Trust Basingstoke and North Hampshire Hospital	Royal Berkshire NHS Foundation Trust Royal Berkshire Hospital
Heatherwood and Wexham Park NHS Trust Wexham Park Hospital	Southampton University Hospitals NHS Trust Southampton General Hospital
Portsmouth Hospitals NHS Trust Queen Alexandra Hospital	Winchester and Eastleigh Healthcare NHS Trust Royal Hampshire County Hospital
Milton Keynes General Hospital NHS Trust Milton Keynes Hospital	
SOUTH EAST COAST SHA	
Ashford and St Peters Hospitals NHS Trust St Peters Hospital	Medway NHS Trust Medway Maritime Hospital
Brighton and Sussex University Hospitals NHS Trust Princess Royal Hospital Royal Sussex County Hospital	Royal Surrey County Hospital NHS Trust Royal Surrey County Hospital
East Kent Hospitals NHS Trust Queen Elizabeth the Queen Mother Hospital Kent and Canterbury Hospital William Harvey Hospital	Royal West Sussex NHS Trust St Richards Hospital
East Sussex Hospitals NHS Trust Conquest Hospital Eastbourne District General Hospital	Surrey and Sussex Healthcare NHS Trust East Surrey Hospital
Frimley Park Hospital NHS Trust Frimley Park Hospital	Worthing and Southlands Hospitals NHS Trust Worthing Hospital
Maidstone and Tunbridge Wells NHS Trust Maidstone Hospital Kent and Sussex Hospital	
SOUTH WEST SHA	
Gloucestershire Hospitals NHS Foundation Trust Cheltenham General Hospital	Royal Devon and Exeter NHS Foundation Trust Royal Devon and Exeter Hospital

Gloucestershire Royal Hospital	
North Bristol NHS Trust Frenchay Hospital Southmead Hospital	Salisbury Healthcare NHS Trust Salisbury District Hospital
Northern Devon Healthcare NHS Trust North Devon District Hospital Plymouth Hospitals NHS Trust Derriford Hospital	South Devon Healthcare NHS Trust Torbay District General Hospital
Poole Hospitals NHS Trust Poole Hospital	Taunton and Somerset NHS Trust Musgrove Park Hospital
Royal Bournemouth and Christchurch Hospitals NHS Trust Royal Bournemouth Hospital	Weston Area Health NHS Trust Weston General Hospital
Royal Cornwall Hospitals NHS Trust Royal Cornwall Hospital West Cornwall Hospital	Yeovil NHS Foundation Trust Yeovil District Hospital
WEST MIDLANDS SHA	
Burton Hospitals NHS Trust Queens Hospital Burton	University Hospitals Coventry and Warwickshire NHS Trust University Hospitals Coventry and Warwickshire
Hereford Hospitals NHS Trust Hereford County Hospital	Walsall Hospitals NHS Trust Walsall Manor Hospital
The Royal Wolverhampton Hospitals NHS Trust Newcross Hospital	Worcestershire Acute Hospitals NHS Trust Worcestershire Royal Hospital
University Hospital of North Staffordshire NHS Trust University Hospital of North Staffordshire	
YORKSHIRE AND THE HUMBER SHA	
Bradford Teaching Hospitals NHS Foundation Trust Bradford Royal Infirmary	Northern Lincolnshire and Goole Hospitals NHS Trust Diana Princess of Wales Hospital Goole and District Hospital Scunthorpe General Hospital
Doncaster and Bassetlaw Hospitals NHS Foundation Trust Doncaster Royal Infirmary Bassetlaw Hospital	Scarborough and North East Yorkshire Healthcare NHS Trust Scarborough General Hospital
Hull and East Yorkshire Hospitals NHS Trust Castle Hill Hospital	The Rotherham NHS Foundation Trust Rotherham General Hospital
Leeds Teaching Hospitals NHS Trust St James' University Hospital Leeds General Infirmary	

Appendix 2: List of NCDAA Round 2 Working Group Members

Marie Curie Palliative Care Institute Liverpool (MCPCIL)

Prof John Ellershaw	Professor of Palliative Medicine, University of Liverpool, Director – MCPCIL Clinical Director, Specialist Palliative Care Directorate, The Royal Liverpool & Broadgreen University Hospitals NHS Trust; Medical Director, The Marie Curie Hospice Liverpool; National Clinical Lead - LCP
Deborah Murphy	Associate Director - MCPCIL Directorate Manager, Specialist Nurse, Specialist Palliative Care Directorate, The Royal Liverpool & Broadgreen University Hospitals NHS Trust; National Lead Nurse - LCP
Maureen Gambles	Project Co-ordinator Research and Development Lead MCPCIL
Tamsin McGlinchey	Research Assistant - MCPCIL
Rachel Abbott	Audit Assistant - MCPCIL
Maria Bolger	National LCP Facilitator - MCPCIL
Emer McKenna	Specialist Registrar In Palliative Medicine, MCPCIL

Royal College of Physicians Clinical Effectiveness and Evaluations Unit (RCP, CEEU)

Dr Jonathan Potter	Director, CEEU
Jane Ingham	Director of Clinical Standards, CEEU
Derek Lowe	Medical Statistician, CEEU
Katharine Young	Clinical Standards Facilitator, CEEU

List of National LCP Reference Group Members

Prof Mike Richards, CBE	National Cancer Director, Department of Health Chair of End of Life Care Strategy Advisory Board
Prof Mike Pearson	Professor of Clinical Evaluation, University of Liverpool; Consultant Physician, University Hospital Aintree
Prof Jane Maher	Chief Medical officer for Macmillan Cancer Support; Consultant Clinical Oncologist , Lynda Jackson Macmillan Centre
Dame Gill Oliver	Partnership Board Member, MCPCIL
Reverend Peter Wells	Senior Chaplain / Bereavement Offices Manager, Brighton & Sussex University Hospitals NHS Trust
Dr Stephanie Gomm	Consultant in Palliative Medicine, Trafford General Hospital; National Clinical Champion (LCP)
Dr Teresa Tate	Medical Advisor, Marie Curie Cancer Care; Consultant in Palliative Medicine, Barts & The London NHS Trust
Claire Henry	National Programme Director – End of Life Care, End of Life Care Programme
Eve Richardson	Chief Executive, National Council for Palliative Care

Isobel Quinn	National Manager, End of Life Care Programme
Lucy Sutton	National Policy Lead, National Council for Palliative Care
Elizabeth Spragg	Senior Analyst, Care Quality Commission
Tessa Ing	Head of End of Life Care, Department of Health, London
Susan Thomas	Long Term Conditions Advisor, RCN
Talib Yaseen	Deputy Chief Executive, The Royal Liverpool & Broadgreen University Hospitals NHS Trust
Dr Martine Meyer	Consultant in Palliative Medicine, Epsom & St Helier University Hospitals NHS Trust; Representative of the Association of Palliative Medicine (APM)
Dr Miriam Johnson	Consultant in Palliative Medicine, St Catharine's Hospice, Scarborough
Dr Pauline Wilkinson	Consultant in Palliative Medicine Belfast City Hospital
Celia Manson	Nurse Adviser and Royal College of Nursing Member
Pam Fenner	Strategic Lead for Palliative and End of Life Care, SHA East of England
Mary Holland	Committee member – RCN Palliative Nursing Forum
Suzy Croft	Chair, National Association of Hospice & Specialist Palliative Care Social Workers
Prof John Lumley	Royal College of Surgeons Representative
Prof David Albert Jones	Director of the Centre for Bioethics and Emerging Technologies, St Mary's University College Twickenham
Dr John Wiles	Consultant in Palliative Care, Bromley Hospitals
Prof Ian Gilmore	President, Royal College of Physicians
Linda Kerr	Nurse Specialist Training Office for Palliative Care
Paul Cann	Chief Executive of Age Concern, Oxfordshire
Clive Bowman	Medical Director, BUPA
Helga Goutcher	Head of Operational Compliance, BUPA
David Whitmore	Senior Clinical Advisor to the Medical Director, London Ambulance Service
Dr Andrew Fowell	Consultant in Palliative Medicine, Bangor Hospital, Wales
Dr Jenny Gingles	Consultant in Public Health, South Eastern Health and Social Care Trust, Northern Ireland
Jill Nelson	Head, Clinical Effectiveness Coordination Unit, NHS - Quality Improvement Scotland

Statistical Terminology	
Interquartile Range (IQR)	<p>The IQR, which is presented within the tables for % achieved, % variance and % data not documented, divides the given sample into 3 ranges. Twenty-five percent of hospitals score below the first stated value, 50% of hospitals have a score that lies between the two values, and 25% have a score that lies between the higher value and 100%.</p> <p>Taking goal 1 as an example, the IQR is 87 – 97% for % achieved. This means that half of the hospitals in this sample score between 87 and 97% on this goal and a quarter score above 97% and a quarter score below 87%. Comparing one’s own score against this IQR allows a judgement of how well an individual hospital has performed in comparison with the others.</p>
Box Plots	<p>The IQR of % ‘achieved’ by each hospital for each of the goals within the five domains is illustrated graphically within the report as a series of box plots. The highest and lowest values (that are not defined as ‘outliers’) are represented by the ‘whiskers’ above and below the green boxes. The green boxes incorporate 50% of the data (ie that which falls between the 25th and the 75th percentiles) and the thick black line within each box represents the median value.</p> <ul style="list-style-type: none"> ▪ An outlier is so defined if it falls more than one and a half box lengths above or below the box. This is marked with a ‘circle’ on the charts ▪ An extreme outlier is so defined if it falls 3 box lengths above or below the box. This is marked with a ‘star’ on the charts. <p>These box plots contain hospitals that were able to submit a sample size of equal to or greater than 10 patients, as it was felt that including hospitals with fewer patients would unduly distort the findings.</p>
Cohen’s Kappa Co-efficient	<p>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 is always less than or equal to 1. A value of 1 implies perfect agreement and values less than 1 imply less than perfect agreement (perfect agreement is rare).</p>

	<p>Altman DG (1991) suggests one possible interpretation of Kappa.</p> <ul style="list-style-type: none"> • 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. This enables an assessment of the accuracy of the submitted data.
Median	One type of average, found by arranging the values in order and then selecting the one in the middle
Integrated Care Pathway (ICP) Definition and Terminology	
Definition	<p>The European Pathway Association offers the following definition:</p> <p>Care pathways are a methodology for the mutual decision making and organization of care for a well-defined group of patients during a well-defined period. The aim of a care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources. Defining characteristics of care pathways include:</p> <p>An explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations;</p> <p>The facilitation of the communication, coordination of roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives;</p> <p>The documentation, monitoring, and evaluation of variances and outcomes; and</p> <p>The identification of the appropriate resources.</p>
Achieved	<p>Goals 1 – 18</p> <p>When a goal of care is achieved within the Initial Assessment and Care After Death sections, a yes is recorded on the LCP or equivalent at the point of delivery of care.</p> <p>Ongoing Assessment Section:</p> <p>A recording of 'A' on the LCP or equivalent means that the patient is deemed to be comfortable in terms of each indicator</p>
Variance	Variance is a specific Integrated Care Pathway term for exception reporting. When a clinical decision is made that achieving a goal on a

	<p>pathway is not in an individual patient’s best interest, or where it was impossible for any other reason not to follow the goal, variance is recorded and an explanation provided which includes any action taken and outcome.</p> <p>Goals 1 – 18</p> <p>When a goal is ‘varianced’ on the Initial and Care after Death Section, a no is recorded on the LCP or equivalent.</p> <p>Ongoing Assessment Section</p> <p>‘variance’ = the patient is deemed not to be comfortable and to require some intervention to improve their condition</p>
Management Terminology	
<p>Key Performance Indicator (KPI)</p>	<p>KPI's are quantitative measurements / metrics that enable an organisation measure progress towards goals and identify areas for improvement.</p> <p>They can be used to focus activities, assess, tune, performance and model / modify processes.</p>
<p>Corporate Performance Dashboard</p>	<p>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</p>

Appendix 4: Reporting Schedule

Stage 1: July/August 2009

The following up-loaded on to the secure, password protected website into which data for the audit were originally input:

- Individual Hospital Reports
- Individual Key Findings and Recommendations
- Powerpoint presentation – Generic Results
- Powerpoint presentation – Generic Results adapted to allow input of individual results by hospitals

These presentations can only be accessed by means of a unique identifier and password. In order to promote the security of the data, the number of personnel within the Hospital/Trust that have access to the password will be restricted, as follows:

Chief Executives receive an email alerting them to the publication of the results which includes the passwords for access to the data of all participating hospitals within their Trust.

NCDAAH Audit Co-ordinators receive an email alerting them to the publication of the results which includes the password for access to the data for their individual hospital.

Clinical Governance Leads and NCDAAH Audit Clinical Leads receive an email alerting them to the publication of the results and which personnel have received the unique identifier and passwords for access to the reports.

Stage 2: September 2009

Chief Executives and NCDAAH Audit Co-ordinators receive a paper copy (2 per Hospital) of the Individual Hospital Report and 10 paper copies (per hospital) of the Generic Key Findings and Recommendations Report.

Copies of the Generic Key Findings and Recommendations Report uploaded onto the MCPCIL website for wider dissemination (www.mcpcil.org.uk)

Press Release to coincide with the wider dissemination of the Generic Key Findings and Recommendations Report

Stage 3: October 2009

Paper copies of the Full Generic Report and Generic Key Findings and Recommendations Report sent to Presidents/ Directors/Chief Executives and Key Personnel in organisations that have an interest in care in the last hours and days of life. These include (but are not restricted to): The Care Quality Commission, the Department of Health End of Life Care Programme, Marie Curie Palliative Care Institute Liverpool, Marie Curie Cancer Care, the Royal College of Physicians, The National Council for Palliative Care, The National LCP Reference Group, Strategic Health Authorities, National End of Life Care Charities.

The Full Generic Report uploaded onto the MCPCIL website (www.mcpcil.org.uk)

APPENDIX 5: BEST PRACTICE EXAMPLE PROFORMA

Trust Name: *Trust X*

Hospital Name: Hospital X

Example of good practice description: (Please include, where appropriate, what made you think of the idea? What you did? Who was involved? Details of any education and training undertaken or delivered.)

Raising a high profile regarding end of life care within the Trust. A key factor in the success of the LCP within our Trust has been executive level support for the project. This has enabled the change to be positively embraced at all levels within the organisation. Audit results are presented to Trust Board, and an annual report is produced and disseminated to key leaders within the Trust. Progress regarding the LCP is also shared with staff at ward level to encourage a feeling of involvement and ownership. This is achieved by producing articles for the staff magazine, and circulating flyers to ward areas detailing the achievements of the LCP. The project has been guided by a steering group of experienced professionals, and this group has been instrumental in providing ideas and guidance for the LCP facilitator. Involvement with a local Cancer Services User group has also enabled the facilitator to improve the experience of families of dying patients, for example by providing a free car parking permit for families of patients on the LCP, and developing written information.

Has this example been evaluated? If yes, please explain the method used, and whether it indicated a change in practice:

This example has not been formally evaluated, however the level of awareness within the Trust regarding the LCP indicates that the above methods are successful in raising the profile of end of life care.

Additional Comments:

Appendix 6 Goals of Care on the LCP

INITIAL ASSESSMENT

- Goal 1** Current medication assessed and non-essentials discontinued
- Goal 2** As required subcutaneous drugs written up according to protocol (*pain, agitation, respiratory tract secretions, nausea & vomiting, dyspnoea*)
- Goal 3** Discontinue inappropriate interventions (*blood tests, antibiotics, IV fluids/medications, document 'not for CPR'*)
- Goal 3a** Discontinue inappropriate nursing interventions
- Goal 3b** Syringe driver set up within 4 hours of doctor's order
- Goal 4** Ability to communicate in English assessed as adequate (*patient/carer*)
- Goal 5** Insight into condition assessed in patient and/or carer:
- 5a1** Diagnosis Patient
 - 5a2** Diagnosis Carer
 - 5b1** Prognosis Patient
 - 5b2** Prognosis Carer
- Goal 6** Religious and spiritual needs assessed with patient and carers
- Goal 7** How family/other to be informed of patient's impending death
- Goal 8** Family or other people involved given relevant hospital information leaflets (accommodation, car parking, dining room facilities etc)
- Goal 9** General Practitioner is aware of patient's condition
- Goal 10** Plan of care explained to patient and carer
- Goal 11** Family/other understanding of plan of care

ONGOING ASSESSMENT

- 4 hourly** Pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnoea, mouth care, micturition, medication given safely and accurately, syringe driver checked (where appropriate),
- 12 hourly** Mobility, Bowels, Psychological, Religious/Spiritual, Care of the Family

CARE AFTER DEATH

- Goal 12** GP informed of patient's death
- Goal 13** Procedure for laying out followed
- Goal 14** Procedure following death discussed or carried out
- Goal 15** Family/other given information on procedures
- Goal 16** Policy followed re collection of valuables
- Goal 17** Documentation and advice given to the appropriate person
- Goal 18** Bereavement leaflet/information given

