

The Marie Curie
Palliative Care Institute

LIVERPOOL



Royal College
of Physicians

Setting higher medical standards

NATIONAL CARE OF THE DYING AUDIT – HOSPITALS (NCDHAH)

GENERIC REPORT 2006/2007

The Marie Curie Palliative Care Institute
Liverpool (MCPCIL) in collaboration with the
Royal College of Physicians (RCP) Clinical
Effectiveness & Evaluations Unit (CEEu)

*Supported by Marie Curie Cancer Care and the
DoH End of Life Care Programme*



Forward

More than half of all deaths (56%) in England currently occur in acute hospitals. Although one of the key aims of the forthcoming End of Life Care Strategy will be to enable more patients to die in the place of their choice, and thus reduce the number of hospital deaths, hospitals will almost certainly continue to be the commonest place of death in this country for the foreseeable future. It is therefore imperative that the quality of end of life care provided by hospitals should be given the priority it deserves.

Several observational studies have shown that a proportion of patients dying in hospital experience very poor care. They may not receive optimal symptom control, communication may be poor, and they may not receive the personal and nursing care they need and deserve. Their carers may receive insufficient information and support and may not be enabled to participate in care giving to the extent they would wish. These problems with care are reflected in the high number of complaints from bereaved relatives identified by the Healthcare Commission as being related to care of the dying.

It is therefore paramount that care of the dying is recognised as a core activity with the same rigorous measures and outcomes as applied to other areas of healthcare.

I warmly welcome this first National Audit of Care of the Dying. Ninety four hospital Trusts have participated, providing a total of 2672 patient cases. Importantly the audit was not confined to cancer patients. Over half of all reported cases had non-cancer diagnoses. This demonstrates the applicability of the Liverpool Care Pathway to patients with a wide range of conditions. The audit findings will help hospitals to recognise areas of high achievement and areas where improvements can be made.

The workshops planned for later this year are an excellent opportunity for exchange of best practice between organisations and form part of a Continuous Quality Improvement Programme for Care of the dying that should be reflected at Trust board level in all hospital Trusts.

It is envisaged that this National Audit will be repeated on a two-yearly cycle that will enable Trusts to demonstrate improvements linked with the key recommendations from this audit.

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.



Professor Mike Richards
Chair: End of Life Care Strategy Advisory Board

Acknowledgements

This report was prepared by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) with the support of the Clinical Effectiveness and Evaluations Unit (CEEU) of the Royal College of Physicians (RCP).

We would like to thank all those hospitals that participated in this first round of the audit, with particular thanks to members of staff who completed and submitted the documentation. We would also like to thank the steering group for their valuable support and advice throughout the project and to Marie Curie Cancer Care and the End of Life Care Programme for funding this audit.

A summary of this report 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

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

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

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

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

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Executive Summary

Background

Care of the dying is an important part of hospital care with fifty-six percent of all deaths in England occurring in hospitals (ONS, 2005). The emerging End of Life Strategy will look to strengthen the community support to enable more people to die in the community. However, it is important for hospital trust boards, managers and clinicians to recognize that it is a core responsibility of hospitals to provide a dignified death for patients and adequate support to their carers.

The Liverpool Care Pathway for the Dying Patient (LCP) provides a framework of best practice for the dying phase (Ellershaw & Wilkinson, 2003) that was recommended by the National Institute for Health and Clinical Excellence (NICE, 2004) and the Government White Paper, 'Our Health, Our Care, Our Say: a new direction for community services' (DH, 2006). This integrated care pathway is outcomes based and designed to enable the easy extraction of data for audit purposes. The results of this 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.

Aims of the Audit

Building on the results of two previous pilot phases (Gambles et al, 2005; Gambles et al, 2006), the aim of undertaking this national audit is ultimately to improve the standards of care for patients who die in acute hospitals in England. Specifically it will enable participating hospitals to:

1. Identify the quality of their care for dying patients as documented on the LCP
2. Compare their performance with other hospitals across England

Organisation of the Audit

The audit was coordinated and carried out by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) with the support of the Clinical Effectiveness and Evaluations Unit (CEEu) of the Royal College of Physicians (RCP) London, who have a wealth of experience in undertaking national audits. (eg Hoffman et al, 2004). 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 framework and the lead clinician was a member of the palliative care team. Hospitals were recruited initially by inviting the Chief Executive of each hospital with the potential to

participate to express an interest in participation. A Steering Group (Appendix 1) guided the project and oversaw the preparation, conduct, analysis and reporting of the audit.

Method

A predominantly retrospective audit design was used to gather LCP data from up to 30 deaths in each of the participating hospitals between 1st September 2006 and 30th November 2006 (see Appendix 2 for list of all participating hospitals). Pertinent hospital organisational data was also gathered to contextualise the data from the LCP and to aid interpretation of the results

Sample

Two hundred and nine hospitals from 108 acute Trusts were deemed to have the potential to participate in this round of the audit. Of these, 118 (57%) hospitals from 94 (87%) hospital trusts provided a total of 2672 patient cases. Fifty-two hospitals (44%) were able to provide the full sample size of 30 patient data sets (1560 representing 58% of the total data); 26 hospitals (22%) provided between 20 and 29, 25 hospitals provided between 10 and 19 (21%) and the remaining 15 hospitals (13%) provided 9 or fewer patient data sets.

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 was calculated for each of the goals of care on the LCP. Kappas ranged from 0.75 to 0.96 (Median = 0.91; IQR = 0.86 – 0.92) suggesting a very good level of agreement.

Analysis and Reports

(a further copy of this report and a summary report is available from www.mcpcil.org.uk)

Part A: 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.

Part B: Patient Level Data

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. Percentage 'achieved' (goal met), 'variance' (goal not met), and 'goal not documented' (ie nothing recorded on the LCP) was also calculated for each of the goals on the LCP for the whole sample and for each individual hospital (see Appendix 3 for illustration of goals of care on LCP). A snapshot of the last 24 hours of the patient's life formed the basis for the analysis of Ongoing Care delivered.

Comparative Hospital Performance

A summary of the performance of hospitals in this audit can be achieved by calculating the Inter Quartile Range (IQR) for % 'achieved', 'variance' and 'goal not documented' for each goal. It is then possible to assess individual performance on each of these goals by comparing this with the IQRs which were also included in each table. The IQR of % 'achieved' by each hospital for each of the goals within the five domains was also illustrated graphically as a series of box plots.

Reports

Hospital organisational data is presented in tabular format in 4 sections:

1. Personnel responsible for submitting data for this audit
2. General Hospital Demographics as at September 2006
3. Availability of support for implementation and sustainability
4. Continuing Education, Training and Audit

A commentary on the findings and their wider implications is included after each section.

Patient demographic data is then presented followed by LCP data as a series of tables and boxplots within each of 5 domains and a commentary on the findings and their wider implications is included after each domain:

Domain 1 Physical Comfort of the Patient

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

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

Domain 4 Information (giving and receiving)

Domain 5: Following Appropriate Procedures

Regional Workshops

A series of regional workshops will be held within three/four months of dissemination of the National Hospital Audit Report, to enable discussion of the results, sharing of understanding and action planning for the future. Success in Service Improvement relies on the ability to identify and spread good practice. Thus, in order to begin to collate examples of best practice or 'build on the best', part of the focus of the workshops will be to invite those who have achieved highly on certain elements of the audit to present case histories. Two representatives from each hospital (usually the 'auditor' and/or the named clinician and a representative of the management of the hospital) will be invited to attend, along with End of Life representatives from SHAs.

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 the whole exercise (accessing data, quality and clarity of feedback and workshop element itself) via a study specific questionnaire developed and piloted in the earlier phases (Gambles et al, 2005, 2006).

Recommendations

Part A – Organisational Audit

1. Hospital audit departments should undertake regular formal audits of care delivered to dying patients and their carers within their organisation – ideally ones that incorporate a survey of the views of informal carers. Participation in the planned 2 yearly national audit cycle is also recommended.
2. Audit results should be discussed at least annually by the Trust Board. This will encourage the embedding of care of the dying within the governance structure of the organisation.
3. Hospitals should ensure that healthcare workers (qualified and non qualified clinical staff) caring for dying patients and their carers have access to appropriate ongoing training in care of the dying
4. Hospitals should ensure that appropriate information leaflets are readily available to support care in the last days of life

Part B – Patient Level Audit

5. Hospitals should scrutinise carefully those goals where their performance falls outside of the IQR, particularly where an individual hospital is an outlier on the box plot. Also where, for example, a hospital falls below the IQR for % 'achieved', or above the IQR for % 'variance' or above the IQR for % 'not documented' local work should be undertaken to identify the issues that are likely to underpin this level of performance and to put in place a remedial action plan. The workshops will provide a valuable opportunity to share and discuss these issues and action plan for improvement

6. Where a relatively high percentage of variance has been recorded, hospitals should examine the variance sheets on the LCPs to determine whether a useful explanation for each variance reported was recorded on the variance sheets. This ensures that a full clinical picture was available at the point of delivery of care that promotes high quality.
7. Hospitals should explore the relatively high proportion of missing data (ie goals not documented) in several of the domains to inform best practice and education in care of the dying.
8. 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 ensure that an appropriate education programme is in place that supports health care professionals in their discussions with patients
9. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with the spiritual assessment (for both patients and carers) and ensure that an appropriate education programme is in place that supports health care professionals to engage in these discussions.
10. The perception of the quality of communication and relationships with healthcare professionals immediately after the death of a patient has been linked to complaints (Healthcare Commission, 2007). There is a high proportion of missing data for all goals in the Care after Death Section in this audit and hospitals should identify the reasons for this. Further work should then be undertaken to integrate quality in care after death, including the accurate recording of information, within the hospital system for all deaths.
11. Work needs to be undertaken to ensure that the goals added recently to the LCP (anticipatory prescribing for dyspnoea, discontinuation of cardiac defibrillation) are fully understood by practitioners.

These recommendations can underpin a Continuous Quality Improvement Framework for Care of the Dying that is represented within the Trust Governance and Performance Management Programme

See Appendix 4 for an example of 10 Proposed Core Standards for Care of the Dying

Introduction

This audit will inform all those involved in providing care to dying patients and their families of their current performance against the goals of care on the Liverpool Care Pathway for the dying patient (LCP) and benchmark their performance against other participants in the audit.

Background

The Cancer Plan in 2000 was the first national document to focus on the needs of dying patients and their families stating that:

Too many patients will experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from healthcare professionals during the final stages of an illness. This can have a lasting effect on carers and those close to the patient, who often carry the burden of care. The care of all dying patients must improve to the level of the best.” (DOH, 2000).

The hospice model of care is espoused as a model of excellence in the delivery of high quality care to patients dying in this sector (Ellershaw and Ward, 2003). However, in the United Kingdom, just over two-thirds of patients die in hospital with only a small proportion (4%, mainly cancer patients) dying in the hospice environment (ONS, 2005). A major challenge faced by specialist palliative care services is to transfer best practice from a hospice setting to other care settings and also to non-cancer patients. The End of Life Care Programme (2004-2007 – www.endoflifecare.nhs.uk) has prioritised this issue by supporting the roll out of three frameworks that aim to promote best practice in caring for all dying patients. The Government White Paper ‘Our Health, Our Care, Our Say’ (DH 2006, p104) states

“We will ensure all staff who work with people who are dying are properly trained to look after dying patients and their carers. This will mean extending the roll-out of tools such as the Gold Standard Framework and the Liverpool Care Pathway for the Dying to cover the whole country’ (DOH 2006)

The recent Healthcare Commission Report ‘Spotlight on Complaints (2007) highlighted that many of the complaints surrounding the 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 Healthcare Commission continues to recommend regular audit of record keeping systems.

The Liverpool Care Pathway for the dying patient (LCP)

The LCP is a multi-professional document that provides an evidence-based framework during the dying phase based on the standards of care delivery in the hospice environment. The goals of care focus on ensuring the physical comfort of the patient, psychosocial (insight) and spiritual aspects (for both patients and carers), communication, information (giving and receiving) and policy and procedure. It is organised into 3 discrete sections:

1. The Initial Assessment Section

This section is completed on commencement of the pathway 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 most common symptoms in the dying phase. It is also concerned with ensuring that appropriate communication takes place with patients (wherever possible), carers and other health professionals.

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 carers in this phase.

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.

Coding of Goals

Achieving the goals on the LCP should ensure that best practice care in the dying phase is undertaken. Wherever an outcome relating to a goal of care has been accomplished, the health care professional should record a tick in the 'achieved' box in sections 1 and 3, and write an 'A' in the appropriate box in section 2. However, there may be times when a goal is

not met – sometimes due to lack of resources in a given area and sometimes because a clinician makes a decision that achieving a given goal is not in the best interests of a particular patient. When this happens the healthcare professional should place a tick in the ‘variance’ box in sections 1 and 3, or place a ‘v’ in the appropriate box in section 2. At the same time, they should complete a section on the variance sheet at the back of the pathway to explain the nature of the variation in care and any actions and further outcomes. This sheet then provides a valuable clinical record of the condition of the patient and the care provided.

The LCP is highlighted in National Institute for health and Clinical Excellence Guidance (NICE, 2004) and its roll out across England was recently promoted by the Department of Health (DH, 2006). To date well over 1,000 organisations in the UK and beyond have registered with the project.

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 randomized 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 standardization 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 across the country is to engage in a national audit project against which future provision of care can be measured. The results of this audit exercise could potentially inform the cancer appraisal and Healthcare Commission audit process.

Aims of the Audit

Building on the results of two previous pilot phases (Gambles et al, 2005; Gambles et al, 2006), the aim of undertaking this national audit is ultimately to improve the standards of care for patients who die in acute hospitals in England. Specifically it will enable participating hospitals to:

1. Identify the quality of their care for dying patients as documented on the LCP
2. Compare their performance with other hospitals across England

Organisation of the Audit

The audit was coordinated and carried out by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) with the support of the Clinical Effectiveness and Evaluations Unit (CEEu) of the Royal College of Physicians (RCP) London, who have a wealth of experience in undertaking national audits. (eg Hoffman et al, 2004). 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 framework and the lead clinician was a member of the palliative care team. Hospitals were recruited initially by inviting the Chief Executive of each hospital with the potential to participate to express an interest in participation. A Steering Group (Appendix 1) guided the project and oversaw the preparation, conduct, analysis and reporting of the audit.

Availability of this report in the public domain

This is the first ever round of a national audit of care of the dying. As such, it was decided that only participating hospitals (Chief Executives, Lead Clinician/Auditor) would have access to the reports detailing their own individual hospital performance. This generic report, however, illustrating the aggregate performance (ie including all 2672 data sets) and a summary report will be made more widely available in the public domain as a separate publication (please visit www.mcpcil.org.uk for details). It is intended that publications and conference presentations building on this work will be undertaken. A list of hospitals that participated in this first round will also be made available to the Healthcare Commission (Appendix 2).

Inclusion Criteria for the audit

Adult patients (>= 18 years of age at time of death) who died on an LCP where the goals of care had remained relatively consistent with Version 11 of the LCP were eligible to participate. As part of the registration process for the audit, hospitals were asked to send in a blank copy of their current pathway and checks were made by the audit team to establish the level of correspondence 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 register only if they felt they would be able to provide a consecutive sample of 30 patients who died on an LCP within the designated time period (1st September 2006 - 30th November 2006). The proposed sample size represented an approach to

accommodate statistical rigor within the practicalities of data collection in this challenging area.

Method

Design

A predominantly retrospective audit design was used to gather data from LCPs used in each of the participating hospitals. Pertinent organisational data was also gathered to contextualise the data from the LCP and to aid interpretation of the results.

Data Collection Tools

Patient Level Data:

The LCP was developed to incorporate the most salient elements of care in the dying phase, for patients and 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. A scannable proforma was developed to aid standardised data collection based on one that has already been used extensively in the national and international dissemination programme for the LCP framework.

Organisational Data:

Identification of the organisational elements that are likely to impact on the delivery of care in the dying phase is necessary. A scannable proforma 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.

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.

Procedure

Participating hospitals prospectively collected all completed LCPs of patients who died within their hospital between 1st September 2006 and 30th November 2006. Data from a maximum of the most recent 30 consecutive pathways was then coded and submitted at the

end of this period. Participating hospitals were given a three month period in which to code and submit the data for analysis.

Analysis

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.

Patient Level Data

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. Percentage 'achieved' (goal met), 'variance' (goal not met), and 'goal not documented' (ie nothing recorded on the LCP) was also calculated for each of the goals on the LCP for the whole sample and for each individual hospital. 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. 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.

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 measure of agreement for each of the goals of care was assessed using the Kappa Coefficient and by calculating the percentage agreement.

Small Sample Size

It is important to remember that a number of hospitals within the sample submitted a relatively small number of patient data sets to the audit. For example, 25 provided between 10 and 19 and 15 provided 9 or fewer. The results for those hospitals with relatively small numbers should be interpreted with caution as the potential for bias is increased.

Comparative Hospital Performance

A summary of the performance of hospitals in this audit can be achieved by calculating the Inter Quartile Range (IQR) for % 'achieved', 'variance' and 'goal not documented' for each goal. It is then possible to assess your individual performance on each of these goals by comparing this with the IQR. Taking goal 1 as an example, the IQR is 90 – 99% for % achieved. This means that half of the hospitals in this sample score between 90 and 99% on this goal and a quarter score above 99% and a quarter score below 90%. Comparing your own score against this IQR allows you to judge how well your hospital has performed in comparison with the others. A second IQR has been calculated using data from only those hospitals that were able to provide 30 sets of patient data. This is because some hospitals included in the overall IQR have provided very small samples, and this may introduce an element of bias in the results.

The IQR of % 'achieved' by each hospital for each of the goals within the five domains is also illustrated graphically 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.

- 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.

Feedback Reports

Each participating hospital has received 2 paper copies of a report detailing their performance in comparison with the aggregate performance of all patients and all hospitals. In addition, electronic copies of that report, a summary report and a powerpoint presentation of the results has been made available in CD format to enable wider dissemination within the hospital. Appendix 4 provides an example of comparative feedback.

Regional Workshops

A series of regional workshops will be held within three/four months of dissemination of the National Hospital Audit Report, to enable discussion of the results, sharing of understanding and action planning for the future. Success in Service Improvement relies on the ability to identify and spread good practice. Thus, in order to begin to collate examples of best practice or 'build on the best', part of the focus of the workshops will be to invite

those who have achieved highly on certain elements of the audit to present case histories. Two representatives from each hospital (usually the 'auditor' and/or the named clinician and a representative of the management of the hospital) will be invited to attend, along with End of Life representatives from SHAs.

Questionnaire Evaluation

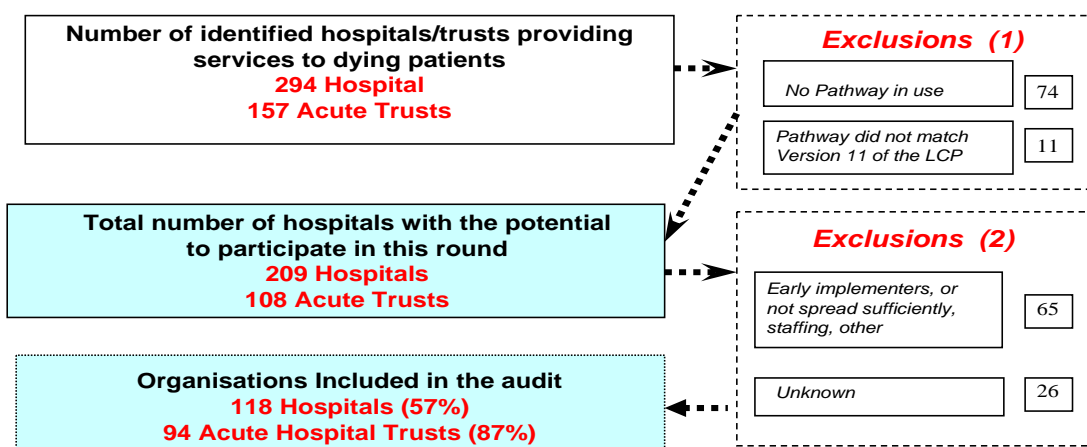
A questionnaire evaluation of the auditing process as a whole will be undertaken as part of the final workshops. The evaluation will attempt to gauge participants' perspectives of the whole exercise (accessing data, quality and clarity of feedback and workshop element itself) via a study specific questionnaire developed and piloted in the earlier phases (Gambles et al, 2005, 2006).

RESULTS

Sample

A total of 118 hospitals from 94 hospital trusts provided a total of 2672 patient cases for this audit – see figure 1 below.

Figure 1: Sample



Therefore, 40% of all hospitals providing services to care for dying patients took part in this audit, which represents 60% of all acute Trusts.

Fifty-two hospitals (44%) were able to provide the full sample size of 30 patient data sets (1560 representing 58% of the total data); 26 hospitals (22%) provided between 20 and 29, 25 hospitals (21%) provided between 10 and 19 and the remaining 15 hospitals (13%) provided 9 or fewer patient data sets. A total of 2672 pathways were submitted for the audit.

Data Reliability

The Kappa Coefficient was calculated to provide a measure of reliability for each of the goals of care on the LCP. Kappas ranged from 0.75 to 0.96 (Median = 0.91; IQR = 0.86 – 0.92) suggesting a very good level of agreement.

PART A: ORGANISATIONAL AUDIT

118 hospitals submitted organisational data. The slightly reduced National denominator for some items reflects any missing data.

Section 1: Personnel responsible for submitting data for this audit

1.1a Auditor Discipline for completion of Organisational Audit Form

	National (118)	
Medical Team	10%	(12/116)
Nursing Team	74%	(86/116)
Audit Team	7%	(8/116)
*Other	9%	(10/116)

* Other included Care Pathway facilitators/managers; MDT facilitator, End of Life team member, Clinical Standards

1.1b Auditor Discipline for completion of Patient Data Audit Form

	National (118)	
Medical Team	8%	(9/116)
Nursing Team	72%	(83/116)
Audit Team	10%	(12/116)
*Other	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 (118)	
Medical Team	9%	(11/117)
Nursing Team	59%	(69/117)
Audit Team	18%	(21/117)
*Other	14%	(16/117)

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

Section 1 Personnel responsible for submitting data for this audit:

Commentary

- 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 providing the primary data on which the results are based were operating in the role of LCP facilitator (or equivalent) and were thus likely to be very familiar with both the LCP itself and the process of auditing.
- The second auditor was, again, primarily from the nursing profession, though there was more involvement from hospitals' audit team in this element.

Section 2: General Hospital Demographics as at September 2006

Hospital Size	National (118)
1.2 Median number of wards (IQR)	25 (18 - 36) n=113
1.3 Median number of beds in hospital (IQR)	522 (380 - 774) n=113
1.4 Median number of side-rooms in hospital (IQR)	68 (43 - 115), n=116

Number of Deaths	National (118)
1.5 Median number of all deaths occurring in the year 1st April 2005 - 31st March 2006 (IQR)	1185 (863 - 1547) n=111
3.1 Number of all deaths occurring in data gathering period Median number of all deaths occurring in data gathering period (IQR)	29646 254 (182 - 351) n=111
3.2 Number of deaths on LCP in data gathering period Median number of deaths on LCP in data gathering period (IQR)	4303 32 (17 - 51) n=111

Estimate of LCP Use	National (118)
2.1 Median number of months since the pilot project was undertaken (IQR)	19 (10 - 36) n=87*
2.2 Median estimated number of wards using the LCP (IQR)	9 (5 - 15) n=114

**11 hospitals included their pilot data in the NCDAH; 4 hospitals indicated they had not undertaken a pilot; 7 hospitals were unsure of the month of pilot; data not provided by 9 hospitals*

Section 2 General Hospital Demographics as at September 2006:

Commentary

- On average participants have been using the LCP for 19 months (median) with 25% having less than 10 months experience and 25% having more than three years experience.
- It is estimated that 44% of wards in hospitals in this sample are using the LCP.
- On average, 15% of all patients who died between September 1st 2006 and November 30th 2006 in participating hospitals were cared for using an LCP. When interpreting this statistic, it is important to remember that diagnosing dying remains a clinical challenge and more research is urgently needed to identify those signs and symptoms that indicate approaching death. Also, the LCP was estimated to be in use in fewer than half of all wards in this sample and was not designed for use in sudden death, which will undoubtedly be implicated in this comparatively low level of usage. However, to promote best practice in care after the death of a patient, it may be worthwhile considering the use of Section 3 (Care after Death Section) or an equivalent document for use in all deaths.
- It is intended that a separate comparison will be undertaken to assess the effect of time and spread on the patient level data at a later date, but the potential for difference should be borne in mind when looking at the results for compliance with the goals of care in Part B of this report.

Section 3: Availability of support for implementation and sustainability

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	National (118)
2.3 Supporting leaflets for relatives available for use	
Organisation of Facilities	67% (78/116)
Local procedures after death	92% (107/117)
Bereavement leaflet	80% (93/117)
LCP Coping with Dying leaflet	58% (68/117)
Leaflet explaining the LCP (patient/carers)	37% (43/117)
Supporting leaflets for health professionals available for use	
Leaflet explaining the LCP (health professional)	58% (68/117)

Similarly, 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.

Key Personnel	National (118)
2.4 Proportion of Hospitals with a Specialist Palliative Care Team	97% (113/117)
2.5 Proportion of Hospitals with one or more LCP Facilitators or equivalent	47% (52/110)
2.5.1 For Hospitals (n=52) with one or more LCP Facilitator or equivalent*	
Actual number of posts per hospital (n=51)	71 posts
Median number of posts per hospital (n=51) (IQR)	1 (1 – 2)
Median whole time equivalent (WTE) per hospital (n=51) (IQR)	0.8 (0.5 – 1.1)
Median Length of time in post (months) (IQR)	16 (10 - 29) n= 48
Nursing Profession (% YES)	99% (69/70)
Medical Profession (% YES)	0% (0/70)
Allied Health Professional (% YES)	0% (0/70)
Administrator (% YES)	1% (1/70)
Member of Hospital Specialist Palliative Care Team (% YES)	60% (42/70)

* 2 hospitals 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 72 facilitators though information is generally only known for 70 or 71 of these posts

Section 3 Availability of support for implementation and sustainability: Commentary

- The availability of appropriate information leaflets in the environment is inconsistent. Leaflets regarding procedures after death and bereavement were available in 91% and 79% of hospitals respectively, but leaflets explaining the LCP to healthcare professionals and carers and the LCP Coping with Dying Leaflet were less often available (58%, 37% and 58% respectively). It is important that appropriate information leaflets are readily available to reinforce verbal communication, particularly when such communication is likely to be emotionally charged. For example, the provision of an information leaflet on bereavement as an adjunct high quality verbal communication has been shown to lessen the burden of bereavement (Lautrette et al, 2007).
- A majority of hospitals in this sample (95%) have a Specialist Palliative Care Team, which the Department of Health have deemed essential in every acute Trust (DH, 2004) and which is recommended by the LCP Central Team UK to provide back up and educational support for the successful implementation of the LCP (Ellershaw & Wilkinson, 2003).

- Fewer than half of hospitals (47%) in this audit report having a specific LCP facilitator or equivalent. Where such a facilitator is employed the post holder is most likely to be from the nursing profession and be 0.8 whole time equivalent (WTE). LCP facilitators act as 'change agents' in the environment and are also generally responsible for educating staff in the use of the document and co-ordinating the delivery of palliative care education more generally as and when required. The appointment of a facilitator is thus felt to have a positive effect on the success of the LCP in a given environment (Mellor et al 2004). More work to explore relationships between organisational factors and performance on goals of care in this audit is currently being planned. However, although the methodology used in this audit makes it impossible to establish cause and effect, preliminary results do suggest that the amount of missing data on many of those goals where missing data is relatively high (eg the assessment of spirituality and certain care after death goals) is lower in those hospitals that have an LCP facilitator in post.

Section 4: Continuing Education, Training and Audit

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 (118)
4.1 – 4.3 Hospitals with an in-house continuing education programme for care of the dying:	
<i>Medical staff (% YES)</i>	73% (85/117)
<i>Nursing Staff (% YES)</i>	80% (117)
<i>Non-Qualified clinical staff (% YES)</i>	64% (116)
Audit of Care of the Dying	National (118)
4.4 Routine collection of all completed LCPs (% YES)	39% (45/117)
4.4.1 For all hospitals where routine collection of all LCPs takes place	
<i>Hospital Audit Department Responsible (% YES)</i>	9% (4/44)
<i>LCP Facilitator Responsible (% YES)</i>	45% (20/44)
<i>Other Responsible (% YES)</i>	45% (20/44)
4.5 Formal audit of the LCP taken place in last 12 months (% YES)	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>	85% (57/66)
<i>Results fed back to clinical teams (% YES)</i>	92% (61/66)
<i>Results fed back to Trust board (% YES)</i>	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 (% YES)	8% (9/117)

Section 4 Continuing Education, Training and Audit:

Commentary

- Ongoing in house training in care of the dying appears to be available for nurses in 80% of hospitals and for medical staff in 73% of hospitals, but similar training for non-qualified staff, who are often closely involved in such care, is less often provided (67% of hospitals). The Department of Health (2006) recommends that all staff working with dying patients are properly trained to care for such patients and their carers. (NB It is important to remember that this audit does not provide information regarding the nature or quality of such training).

- A formal audit using LCP documentation has taken place in just over half (58%) of the hospitals in the sample in the previous 12 months and it is the intention of the vast majority of these hospitals (86%) to repeat the audit within the next two years. However, whilst the results of audits undertaken are often fed back to healthcare professionals providing the care (92%), they are less often fed back to the Trust board (48%). 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.
- There is general recognition of the need to involve the 'user' perspective in the evaluation of services (Daykin et al, 2007). Despite this, very few (under 10%) of hospitals had produced a report assessing the perspectives of informal carers regarding care delivered in the dying phase in the previous 12 months.

Part A: Recommendations

1. Hospital audit departments should undertake regular formal audits of care delivered to dying patients and their carers within their organisation – ideally ones that incorporate a survey of the views of informal carers. Participation in the 2 yearly national audit cycle is also recommended.
2. Audit results should be discussed at least annually by the Trust Board. This will encourage the embedding of care of the dying within the governance structure of the organisation.
3. Hospitals should ensure that healthcare workers (qualified and non qualified clinical staff) caring for dying patients and their carers have access to appropriate ongoing training in care of the dying
4. Hospitals should ensure that appropriate information leaflets are readily available to support care in the last days of life

RESULTS

PART B: PATIENT LEVEL AUDIT

Section 1: Demographic Data

	National (2672)
Patient Gender = Female	54% (1441/2664)
Median Patient Age (IQR)	80 (72 – 86)
Median hours on LCP (IQR)	33 (13 – 79)
	N=2664

Primary Diagnosis

	National (2672)
Cancer	45% (1190/2647)
Non Cancer	55% (1457/2647)

Primary Diagnosis - Breakdown of 'Top 6' cancer and non-cancer diagnoses

	National (2672)
CANCER	
Lung (small and non-small cell)	8% (213/2647)
Lymphoid, haematopoietic C81-96	4% (106/2647)
Breast	4% (105/2647)
Colon	3.9% (103/2647)
Unknown Primary	3.2% (84/2647)
Oesophagus	2.3% (61/2647)

NON CANCER	
Stroke	12.2% (323/2647)
Heart Failure (I50)	5.9% (155/2647)
Dementia including Alzheimer's disease G30 and other F00-3	4.1% (109/2647)
Chronic Respiratory Disease J40-70	3.7% (99/2647)
Other Heart and circulatory conditions (excluding I50)	2.9% (76/2647)
Chronic Renal Failure N18	2.8% (75/2647)

Demographic Commentary

- Marginally more females are included in this audit sample, which is similar to the gender split in the two SHA benchmarking pilot phases of this work.
- The average age of 80 years in this sample is somewhat higher than for hospitals in the SHA pilot phases of this work, where it was 75 years in phase 1 (Gambles et al 2005) and 78 years in phase 2 (Gambles et al 2006),
- The median 33 hours that patients spent on an LCP in this audit was also higher than in the previous pilots where the median hours were 28 and 30 respectively (Gambles et al, 2005, 2006).
- For the first time in this type of comparative work the proportion of patients with a diagnosis other than cancer (55%) is higher than the proportion diagnosed with cancer (45%).

LCP PATIENT LEVEL AUDIT

Organisation of feedback

As explained earlier, the LCP is organised into 3 sections: Initial Assessment, Ongoing Assessment and Care after Death. Whilst each of these sections deals with a discrete package 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.

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 place of care. Each table also 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.

Domain 1: Physical Comfort of the Patient

Comfort Measures (Initial Assessment)

Care in the last days of life focuses primarily on interventions aimed at maximising patient comfort. To this end, it is vital that all current medications are reviewed and anything deemed non-essential is discontinued. Evidence points to the presence of 5 common symptoms at the end of life – Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting and Dyspnoea (Lichter & Hunt, 1990; Klinkenberg et al, 2004). It is important, therefore, that drugs to combat the presentation of these symptoms are written up once it has been decided that the patient has entered the dying phase, so that they can be delivered as and when required. Goals 1 and 2 on the LCP address these particular issues:

Goal 1: Current medication assessed and non-essentials discontinued

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2633	93	2442	2	55	6	136
Hospital IQR - all (%) (n = 116)		90 – 99%		0 – 3%		0 – 10%	
Hospital IQR – full sample size only (%) (n = 52)		90 – 97%		0 – 3%		0 – 7%	

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	2671	91	2418	4	95	5	158
Hospital IQR - all (%) (n=118)		87 – 98%		0 – 7%		0 – 10%	
Hospital IQR – full sample size only (%) (n=52)		87 – 97%		0 – 7%		0 – 10%	
2.2 Agitation							
National	2671	84	2249	9	209	8	213
Hospital IQR - all (%) (n=118)		76 – 93%		0 – 13%		0 – 13%	
Hospital IQR – full sample size only (%) (n=52)		80 – 93%		3 – 10%		1 – 13%	
2.3 RTS							
National	2671	80	2128	11	297	9	246
Hospital IQR - all (%) (n=118)		70 – 92%		3 – 17%		3 – 14%	
Hospital IQR – full sample size only (%) (n=52)		77 – 90%		3 – 13%		3 – 13%	

2.4 Nausea & Vomiting							
National	2670	82	2187	10	253	9	230
Hospital IQR - all (%) (n=118)		73 – 93%		0 – 16%		0 – 13%	
Hospital IQR – full sample size only (%) (n=52)		78 – 93%		3 – 13%		3 – 13%	
2.5 Dyspnoea							
National	1387	67	926	15	214	18	247
Hospital IQR - all (%) (n=63)		53 – 80%		3 – 24%		5 – 23%	
Hospital IQR – full sample size only (%) (n=28)		61 – 79%		3 – 20%		4 – 23%	

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 days of life. This includes blood tests, antibiotics, IV fluids and medications. There is ongoing debate regarding the use of artificial feeding 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. In the dying phase, the team should discontinue invasive interventions that are no longer conferring any benefit to the patient (Chapman et al, 2007).

Evidence suggests that undertaking cardiopulmonary resuscitation in a patient with advanced chronic disease who is deemed to be in the last days of life is generally viewed as a futile intervention. Therefore, it is imperative that the decision ‘not for cardiopulmonary resuscitation’ has been appropriately recorded once the dying phase 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 implanted cardiac devices is one important element in the improved longevity of cardiac patients. However, Willner (2003) suggests that an ICD can alter unstable cardiac rhythms and “deprive a terminal patient of a timely, mercifully rapid, and “natural” death. In addition, 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 carers) to deactivate such devices when a patient enters the dying phase.

Goals 3.1 – 3.5 on the LCP – Discontinue inappropriate interventions - prompt the consideration and discussion of these important elements of care:

Goal 3: Discontinue inappropriate interventions

	Available & Applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
3.1 Blood Tests							
National	2602	91	2362	4	105	5	135
Hospital IQR - all (%) (n=118)		87 – 97%		0 – 7%		0 – 8%	
Hospital IQR – full sample size only (%) (n=52)		90 – 97%		0 – 3%		0 – 7%	
3.2 Antibiotics							
National	2522	87	2182	8	199	6	141
Hospital IQR - all (%) (n=118)		79 – 96%		0 – 14%		0 – 8%	
Hospital IQR – full sample size only (%) (n = 52)		84 – 97%		0 – 10%		0 – 7%	
3.3 IV Fluids/Medications							
National	2489	79	1955	15	385	6	149
Hospital IQR - all (%) (n=114)		67 – 90%		6 – 24%		0 – 10%	
Hospital IQR – full sample size only (%) (n=50)		70 – 90%		7 – 22%		0 – 10%	
3.4 Not for CPR							
National	2382	93	2210	1	24	6	148
Hospital IQR - all (%) (n=105)		90 – 100%		0%		0 – 10%	
Hospital IQR – full sample size only (%) (n=46)		90 – 100%		0%		0 – 7%	
3.5 De-activate cardiac defibrillators							
National	483	40	191	7	34	53	258
Hospital IQR - all (%) (n=53)		0 – 56%		0 – 15		27 – 83%	
Hospital IQR – full sample size only (%) (n=28)		0 – 66%		0 – 13		31 – 95%	

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:

Certain nursing interventions are deemed to be less appropriate when a patient enters the dying phase and the emphasis of care turns primarily to patient comfort. Taking vital signs and BM monitoring, are nursing interventions that can now either be ceased or the frequency reduced. Goal 3a is used to prompt reconsideration of such interventions.

Goal 3a: Decisions to discontinue inappropriate nursing interventions taken

	Available & applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
National	2423	78	1897	2	45	20	481
Hospital IQR - all (%) (n=107)		70 – 93%		0 – 3%		6 – 27%	
Hospital IQR – full sample size only (%) (n=48)		70 – 93%		0 – 3%		7 – 27%	

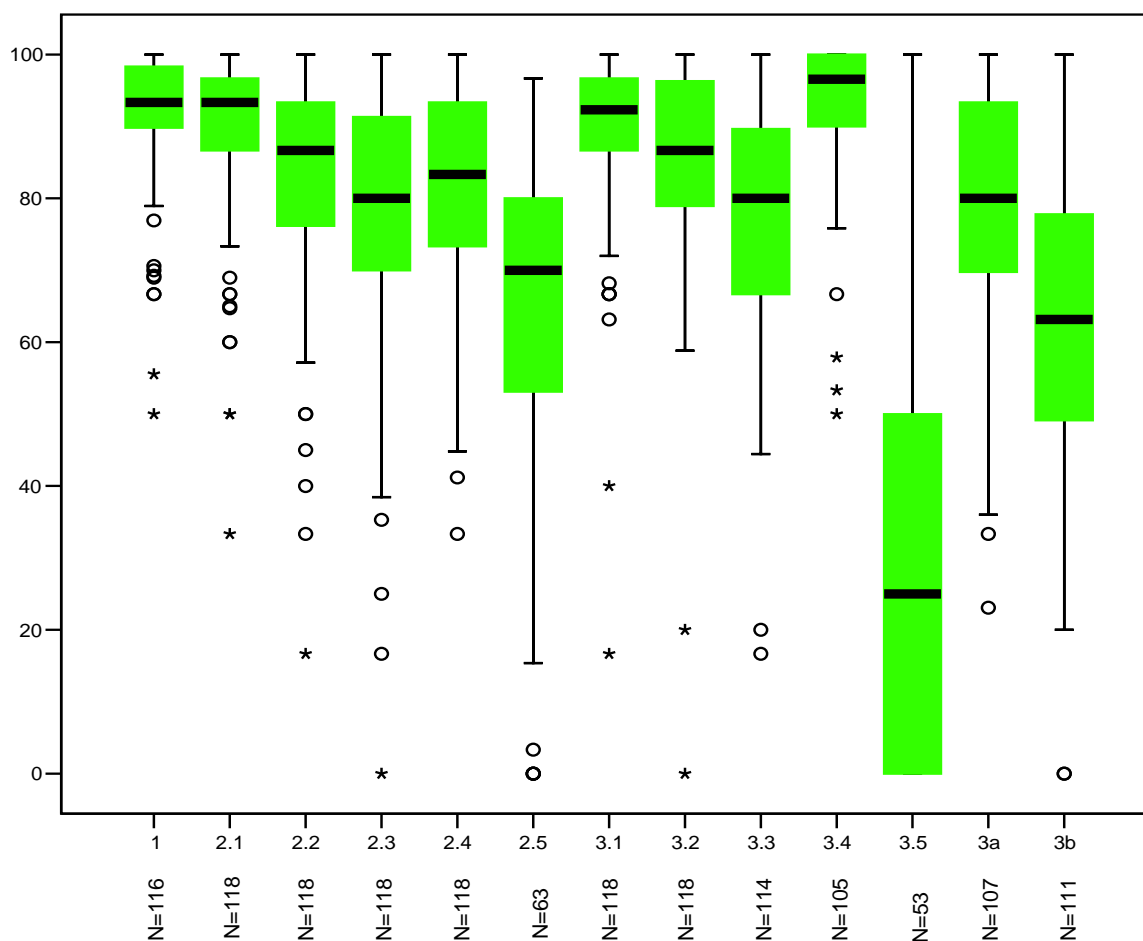
When regular prn medications have been required over a period of time, to promote patient comfort it can be beneficial for patients to receive their medications via subcutaneous continuous infusion pump. Where this need has been identified, it is essential that the pump is set up as quickly as possible 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	1804	61	1100	8	149	31	555
Hospital IQR - all (%) (n=111)		48 – 78%		0 – 12%		13 – 44%	
Hospital IQR – full sample size only (%) (n=52)		48 – 80%		3 – 12%		13 – 45%	

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 to illustrate hospital variation in percentage achieved



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 from the time at which the LCP was commenced to the death of the patient. 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’ (ie the patient is deemed to be comfortable in terms of each indicator) or
- ‘variance’ (ie the patient is deemed not to be comfortable and to require some intervention to improve their condition).

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. Where assessments are made between the minimum 4 hourly assessment times and the patient's condition is deemed 'uncomfortable', this information is also coded onto the variance sheets. In this way, a full record of issues and interventions is available on the variance sheets which clinicians can use to determine future care. 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 the current audit.

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. The following table indicates the proportion of times a patient was deemed 'comfortable' at assessment (achieved), not comfortable at assessment (variance), or where a healthcare professional did not document patient comfort at the allotted time (not documented).

NB: a code of Not Applicable (NA) can be 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 pathway 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 reduced number of assessments is expressed in the 'Eligible Assessments excluding not applicable' section of the above table.

The total number of potential assessments (ie if all 2672 patients were included in the sample all were on the pathway for at least 24 hours) = 16,032 for all 4 hourly assessed goals and 5,344 for 12 hourly assessed goals (ie Mobility and Bowel Care)

Ongoing Assessment of Physical indicators of Comfort

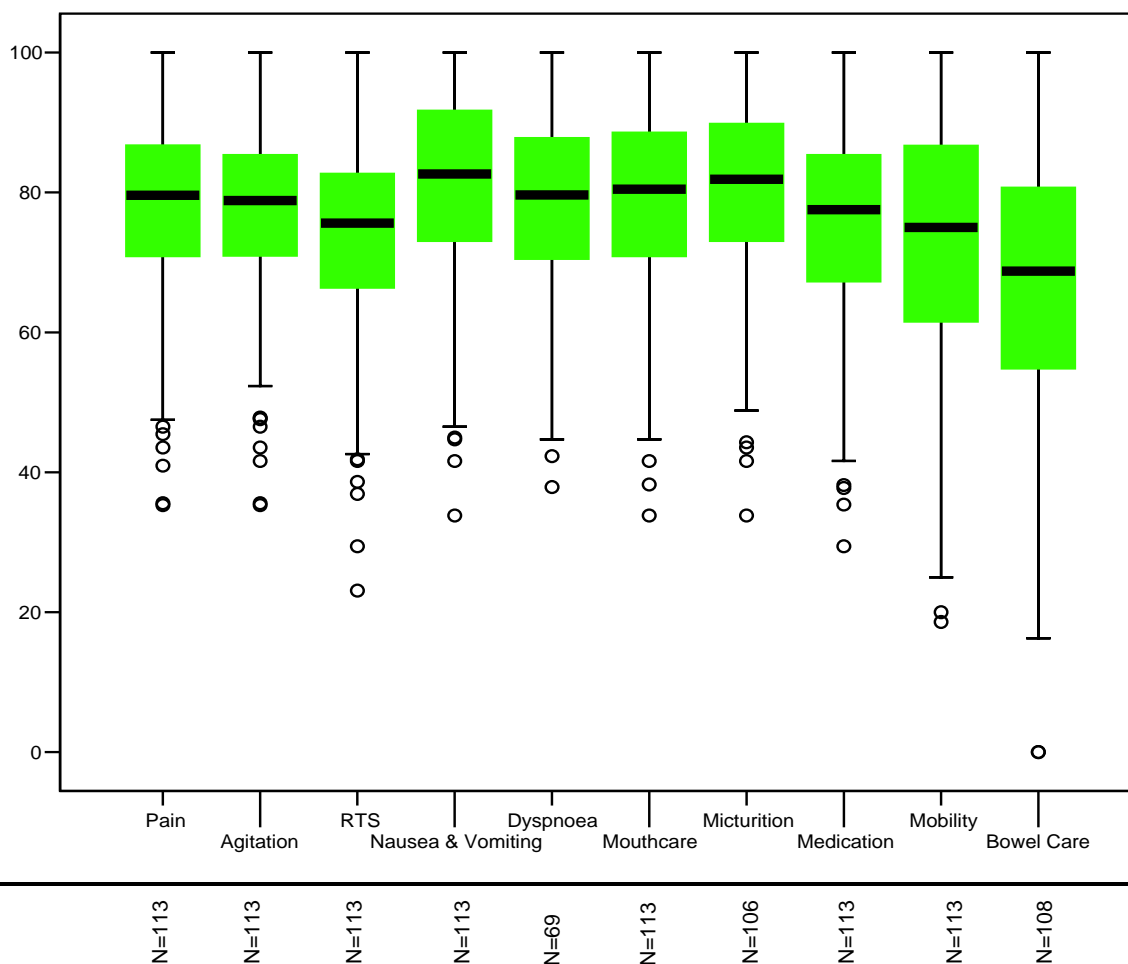
	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Pain							
National	12068	77	9340	4	529	18	2199
Hospital IQR - all (%) (n=113)		70 – 87%		2 – 6%		8 – 26%	
Hospital IQR – full sample size only (%) (n=50)		73 – 87%		2 – 6%		8 – 23%	
Agitation							
National	12069	77	9265	5	594	18	2210
Hospital IQR - all (%) (n=113)		71 – 86%		2 – 7%		8 – 26%	
Hospital IQR – full sample size only (%) (n=50)		72 – 85%		3 – 7%		7 – 23%	
Respiratory Tract Secretions (RTS)							
National	12067	74	8929	7	882	19	2256
Hospital IQR - all (%) (n=113)		66 – 83%		4 – 10%		8 – 27%	
Hospital IQR – full sample size only (%) (n=50)		69 – 83%		4 – 8%		8 – 24%	
Nausea & Vomiting							
National	12067	81	9721	1	85	19	2261
Hospital IQR - all (%) (n=113)		73 – 92%		0 – 2%		8 – 27%	
Hospital IQR – full sample size only (%) (n=50)		75 – 92%		0 – 1%		7 – 25%	
Dyspnoea							
National	7350	78	5741	2	168	20	1441
Hospital IQR - all (%) (n=69)		70 – 88%		0 – 3%		10 – 29%	
Hospital IQR – full sample size only (%) (n=33)		77 – 88%		1 – 4%		10 – 22%	
Mouth Care							
National	12069	78	9429	3	333	19	2307
Hospital IQR - all (%) (n=113)		71 – 89%		0 – 5%		9 – 27%	
Hospital IQR – full sample size only (%) (n=50)		70 – 90%		0 – 4%		8 – 24%	
Micturition							
National	11394	80	9082	1	122	19	2190
Hospital IQR - all (%) (n=106)		73 – 90%		0 – 1%		9 – 27%	
Hospital IQR – full sample size only (%) (n=47)		71 – 90%		0 – 1%		9 – 26%	
Medication							
National	11752	76	8883	1	137	23	2732
Hospital IQR - all (%) (n=113)		67 – 86%		0 – 1%		13 – 32%	
Hospital IQR – full sample size only (%) (n=50)		67 – 88%		0 – 2%		11 – 33%	

Mobility*							
National	4215	74	3116	1	35	25	1064
Hospital IQR - all (%) (n=113)		61 – 87%		0 – 1%		13 – 38%	
Hospital IQR – full sample size only (%) (n=50)		61 – 87%		0 – 2%		12 – 38%	
Bowel Care*							
National	4030	67	2709	1	43	32	1278
Hospital IQR - all (%) (n=108)		55 – 81%		0%		18 – 44%	
Hospital IQR – full sample size only (%) (n=47)		58 – 82%		0%		17 – 42%	

* Goals assessed 12 hourly on the LCP

Domain 1 Physical Comfort of the Patient: Ongoing Assessment

Boxplots to illustrate hospital variation in percentage achieved



Domain 1 Physical Comfort of the Patient: Commentary

- It is encouraging to note that goals of care focusing on the assessment of current medication and writing up of anticipatory medication for pain, agitation, respiratory tract secretions (RTS) and nausea and vomiting were achieved for at least 80% of patients overall in this sample, and three quarters of organisations achieved these goals for at least 70% of their audit patients.
- The percentage achieved was particularly high for anticipatory prescribing for pain (91%).
- The percentage 'achieved' for anticipatory prescribing for dyspnoea (67%), however, was somewhat lower than for all other symptoms and the box plot illustrates much greater variation across hospitals for this goal. It is perhaps worth noting that this goal has only relatively recently been added to the LCP and just under half of the sample have yet to include it on their pathway. Also, as the medication for dyspnoea and pain may be the same, this variation could be due to differences in the way health care professionals are documenting.
- 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 (87%, 91% and 93% respectively). The boxplot and the IQR values reveal that three quarters of hospitals are achieving these goals for at least 80% of their patients.
- In line with the two previous pilots, there is more variation in percentage achieved for the discontinuation of IV fluids/medications where a greater proportion of 'variance' (16%, Hospital IQR = 6% – 24%) is being recorded. This shows individualised decision making and patient care directed by the clinical team.
- Perhaps most strikingly, there is much diversity in the recording of the deactivation of cardiac defibrillators. Again, this goal has been added to the LCP relatively recently - only 53 hospitals had it on their pathway and it was deemed applicable only for a minority of patients (483). Even so, there was missing data for over 50% of those patients deemed eligible for this goal.
- Inappropriate nursing interventions are discontinued in almost 78% of patients, and a syringe driver is set up within 4 hours in 61% of those patients who require one. However, again, the level of missing data is relatively high for these goals.
- In around three quarters of all assessments made in the last hours of their lives, patients were found to be comfortable in terms of all physical symptoms assessed. Unfortunately, in around one fifth of cases, data for assessments that could have been carried out was not documented.

- In line with the results from the two SHA pilots, most variance 'ie patient not comfortable on assessment' was recorded for RTS (7%), with agitation (5%) and pain (4%) the next two most common symptoms.
- The most variation across hospitals is occurring for mobility and bowel care where there is the greatest proportion of missing data (25% and 32% respectively).

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

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. It is very important that health care professionals have an understanding of the level of awareness regarding the patient's diagnosis and recognition of the dying phase to facilitate appropriate future communication and information giving. 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.

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	1677	57	949	21	346	23	382
Hospital IQR - all (%) (n=114)		45 – 72%		6 – 28%		8 – 32%	
Hospital IQR – full sample size only (%) (n=52)		45 – 67%		9 – 29%		10 – 33%	
5a2 Awareness of diagnosis (carer)							
National	2591	84	2166	1	27	15	398
Hospital IQR - all (%) (n=114)		78 – 96%		0%		4 – 21%	
Hospital IQR – full sample size only (%) (n=52)		77 – 93%		0%		7 – 23%	
5b1 Recognition of dying (patient)							
National	1721	45	780	24	407	31	534
Hospital IQR - all (%) (n=116)		33 – 60%		12 – 31%		17 – 42%	
Hospital IQR – full sample size only (%) (n=52)		36 – 58%		13 – 29%		19 – 41%	
5b2 Recognition of dying (carer)							
National	2633	82	2151	1	37	17	445
Hospital IQR - all (%) (n=116)		77 – 93%		0%		6 – 22%	

Hospital IQR – full sample size only (%) (n=52)	77 – 90%	0%	8 – 23%
6.1 Religious and spiritual needs assessed (patient)			
National	1393	34	476
Hospital IQR - all (%) (n=87)	23 – 48%	15 – 36%	20 – 55%
Hospital IQR – full sample size only (%) (n=43)	23 – 48%	14 – 35%	20 – 55%
6.2 Religious and spiritual needs assessed (carer)			
National	2053	53	1085
Hospital IQR - all (%) (n=88)	38 – 67%	8 – 20%	18 – 47%
Hospital IQR – full sample size only (%) (n=43)	37 – 67%	7 – 17%	17 – 50%

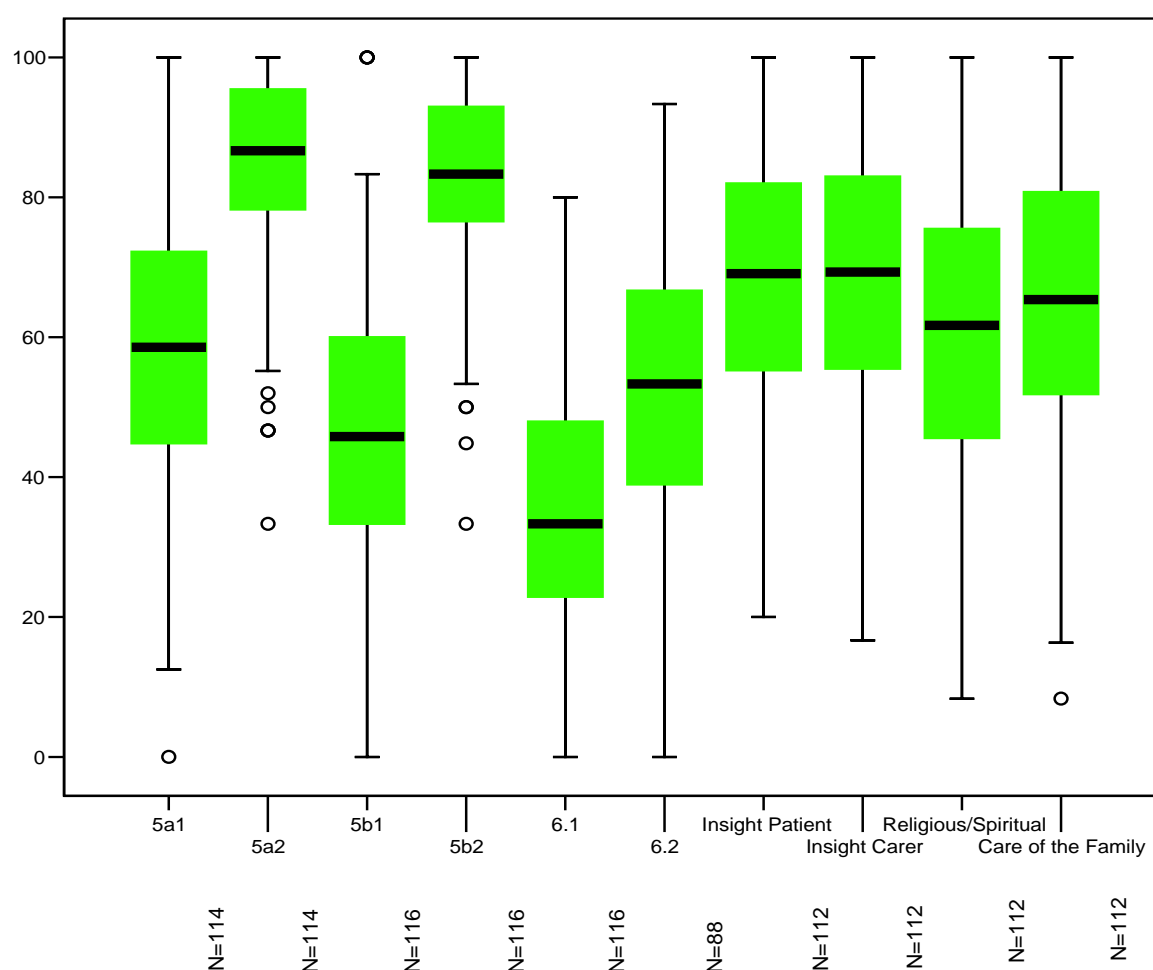
Whilst on the LCP, regular monitoring of issues continues at a minimum of 12 hourly intervals in order that any changes in the situation for patients (where appropriate) and carers can be identified and addressed. It may be that new family members come into the environment over the course of time a patient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

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Psychological Insight support (patient)							
National	4186	69	2883	2	70	29	1233
Hospital IQR - all (%) (n=112)		55 – 82%		0 – 2%		15 – 42%	
Hospital IQR – full sample size only (%) (n=50)		57 – 85%		0 – 2%		13 – 41%	
Psychological Insight support (carer)							
National	4184	69	2887	2	68	29	1229
Hospital IQR - all (%) (n=112)		55 – 83%		0 – 2%		16 – 42%	
Hospital IQR – full sample size only (%) (n=50)		56 – 85%		0 – 2%		13 – 42%	
Religious/Spiritual support (patient)							
National	3970	61	2433	3	109	36	1428
Hospital IQR - all (%) (n=107)		45 – 76%		0 – 4%		21 – 53%	
Hospital IQR – full sample size only (%) (n=49)		50 – 78%		0 – 4%		18 – 50%	
Care of the family							
National	4116	66	2728	1	52	32	1336
Hospital IQR - all (%) (n=110)		51 – 81%		0 – 2%		18 – 47%	
Hospital IQR – full sample size only (%) (n=50)		52 – 83%		0 – 2%		15 – 47%	

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

Boxplots to illustrate hospital variation in percentage achieved



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

- The results clearly illustrate that the patient's insight into their diagnosis (57% achieved) and recognition of the dying phase (45% achieved) is relatively low, and, for the latter, for more than one-third of patients this goal was 'not documented', suggesting that achieving this remains a particular challenge and may highlight a need for further education and training. The box plots illustrate a great deal of variation across hospitals for these goals, with some hospitals (albeit generally those with a relatively small sample size) achieving 100% and others 0%.
- In over 80% of cases it is documented that the carer is aware of the patient's diagnosis, and the fact that they are deemed to be entering the dying phase. There is also evidence of less missing data and considerably less variation

across hospitals for these goals, with three quarters of hospitals achieving them for almost 80% of their carers. This suggests that healthcare professionals are more comfortable in assessing the insight of carers which is encouraging as the Healthcare Commission Report 'Spotlight on Complaints' (2007) illustrates that many complaints arise from carers being unprepared for the patient's death.

- An initial spiritual assessment of carers took place in around one half of the cases submitted, and this goal was achieved for only around one third of patients. 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. These results suggest that this is an area of communication that remains challenging and may highlight a need for further education and training. Indeed, these results appear to support the findings of Wilkinson et al (2002) who illustrated that prior to undertaking communication skills training, nurses generally did not routinely include psychological or spiritual issues within their nursing assessments.
- It is interesting to note, however, that some of the highest levels of 'variance' were recorded for patients' insight and the spiritual assessment of both patients and carers. Local analysis of the variance sheets should, therefore, lead to better understanding of why these goals were not met.
- 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

Good communication with patients, carers and other health professionals is vital at all times during the patient's journey, but arguably even more so when it is believed that a patient is entering the dying phase. Before meaningful communication about the patient's current condition and the revised plan of care can be engaged in, it is vital that checks are made regarding patients' and carers' ability to communicate in English. For example, patients may require the services of a translator, or they may have learning difficulties or may have a hearing impairment and all may require the services of specialist colleagues. Goal 4 on the LCP prompts consideration of these issues for both patients and carers:

Goal 4: Ability to communicate in English assessed as adequate

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
4.1 Patient							
National	1429	68	965	13	180	20	284
Hospital IQR - all (%) (n=95)		59 – 80%		4 – 20%		0 – 29%	
Hospital IQR – full sample size only (%) (n=44)		60 – 78%		5 – 20%		4 – 29%	
4.2 Carer							
National	2153	77	1655	2	35	22	463
Hospital IQR - all (%) (n=94)		67 – 90%		0 – 3%		8 – 31%	
Hospital IQR – full sample size only (%) (n=44)		67 – 87%		0 – 3%		10 – 30%	

Once a level of understanding has been assessed and appropriate support gained to promote successful communication, it is important that the plan of care for the patient for this specific phase is discussed with the patient (where possible and appropriate) and with carers. The Healthcare Commission (2007) highlight the potentially negative effects of the use of euphemisms and jargon when explaining complex healthcare issues with patients and carers. This, they suggest, can lead to a lack of shared understanding of the situation. It is vital, therefore, that the carers' understanding of the communication is checked. Goals 10 and 11 on the LCP prompt healthcare professionals to undertake such communication and to check that the communication has been fully understood.

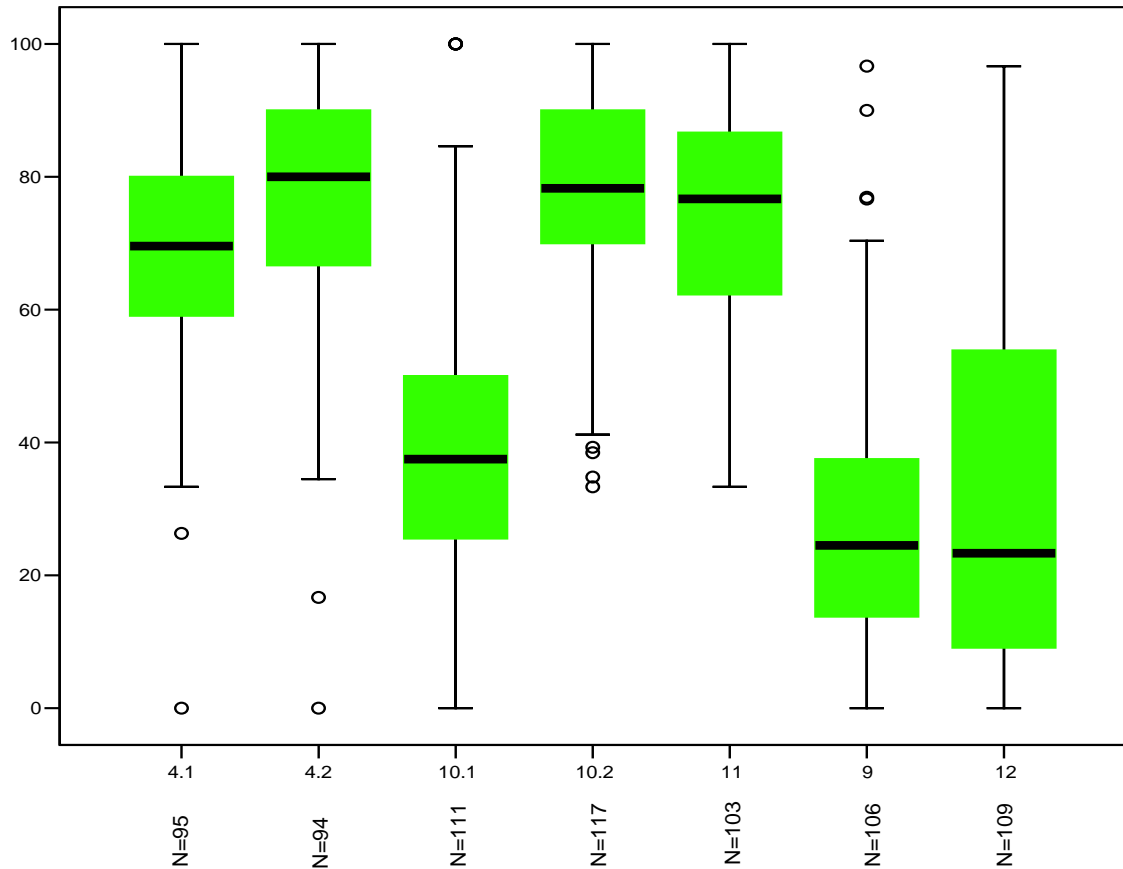
	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
10.1 Plan of care explained and discussed with patient							
National	1640	38	617	24	392	38	631
Hospital IQR – all (%) (n=111)		25 – 50%		13 – 33%		18 – 52%	
Hospital IQR – full sample size only (%) (n=49)		25 – 50%		13 – 34%		23 – 51%	
10.2 Plan of care explained and discussed with carer							
National	2634	78	2043	2	62	20	529
Hospital IQR - all (%) (n=117)		70 – 90%		0 – 3%		7 – 28%	
Hospital IQR – full sample size only (%) (n=52)		70 – 89%		0 – 3%		10 – 30%	
11 Family/other express understanding of plan of care							
National	2358	73	1730	2	54	24	574
Hospital IQR - all (%) (n=103)		62 – 87%		0 – 3%		10 – 35%	
Hospital IQR – full sample size only (%) (n=49)		60 – 87%		0 – 3%		10 – 38%	

Primary Care

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 days/hours 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 assure themselves that the GP practice are aware that the patient is now deemed to be in the last days of life. If the healthcare professional knows that the GP is aware because of previous conversations or because the GP referred the patient because it was felt that they were dying, the health professional can code goal achieved. However, if they are unsure, they should make contact with the GP surgery as quickly as possible to inform them of the situation. Similarly, Goal 12 prompts the healthcare professional to contact 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	2458	29	705	27	662	44	1091
Hospital IQR - all (%) (n=106)		14 – 38%		16 – 37%		26 – 56%	
Hospital IQR – full sample size only (%) (n=51)		13 – 40%		20 – 33%		27 – 57%	
12 GP informed of patient's death							
National	2507	35	885	14	353	51	1269
Hospital IQR - all (%) (n=109)		9 – 54%		3 – 23%		28 – 74%	
Hospital IQR – full sample size only (%) (n=49)		12 – 68%		3 – 17%		23 – 73%	

Domain 3: Communication (Patient, Carer and other Health Care Professionals)
Boxplots to illustrate hospital variation in percentage achieved



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

- Communication with the patient regarding the plan of care is undertaken in only just over one-third of patients who were not comatose at the time the LCP was commenced.
- Explanation of the plan of care to carers, however, is achieved in 78% of the sample, and 73% of the whole sample express their understanding of a plan of care. Interestingly, understanding of the plan of care was expressed in 90% of the 2043 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 in only around one-third of cases. However, the box plot and IQRs illustrate that there is much variation in % achieved across hospitals. These findings support the notion that the "establishment of

effective interprofessional collaboration requires a major cultural change in the NHS” (Pollard et al, 2005, p.339).

- 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 should, therefore, enable better insight as to why such communication was not undertaken.

Domain 4: Information (giving and receiving)

It is important when communicating information of a sensitive nature around patients deteriorating condition/impending death that the appropriate person is contacted at an appropriate time. 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. Some carers may be working, elderly or indeed not want to be contacted until the following day irrespective of the patient's condition. Establishing how relatives / carers wish to be told of patients 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

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

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
National	2616	79	2076	2	40	19	500
Hospital IQR - all (%) (n=115)		68 – 93%		0 – 3%		7 – 27%	
Hospital IQR – full sample size only (%) (n=51)		73 – 93%		0 – 3%		7 – 27%	

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 days and hours 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:

Goal 8: Family/other given hospital information

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
National	2569	59	1511	8	212	33	846
Hospital IQR - all (%) (n=113)		47 – 77%		0 – 12%		17 – 45%	
Hospital IQR – full sample size only (%) (n=50)		46 – 70%		3 – 13%		17 – 47%	

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. For example, local information booklets regarding collection of the death certificate as well as nationally available documents such as the Department of Social Security (DSS) Leaflet D49 'What to do after a death' in England and Wales should be given. In addition, written information about grieving and any support available locally or nationally should be given. 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 what can be a very distressing time. Goals 15, 17 and 18 prompt health care professionals in this regard:

Goal 15: Family/other given information on hospital procedures

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2422	54	1309	2	52	44	1061
Hospital IQR - all (%) (n=107)		33 – 77%		0 – 3%		23 – 67%	
Hospital IQR – full sample size only (%) (n=49)		34 – 73%		0 – 3%		22 – 64%	

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

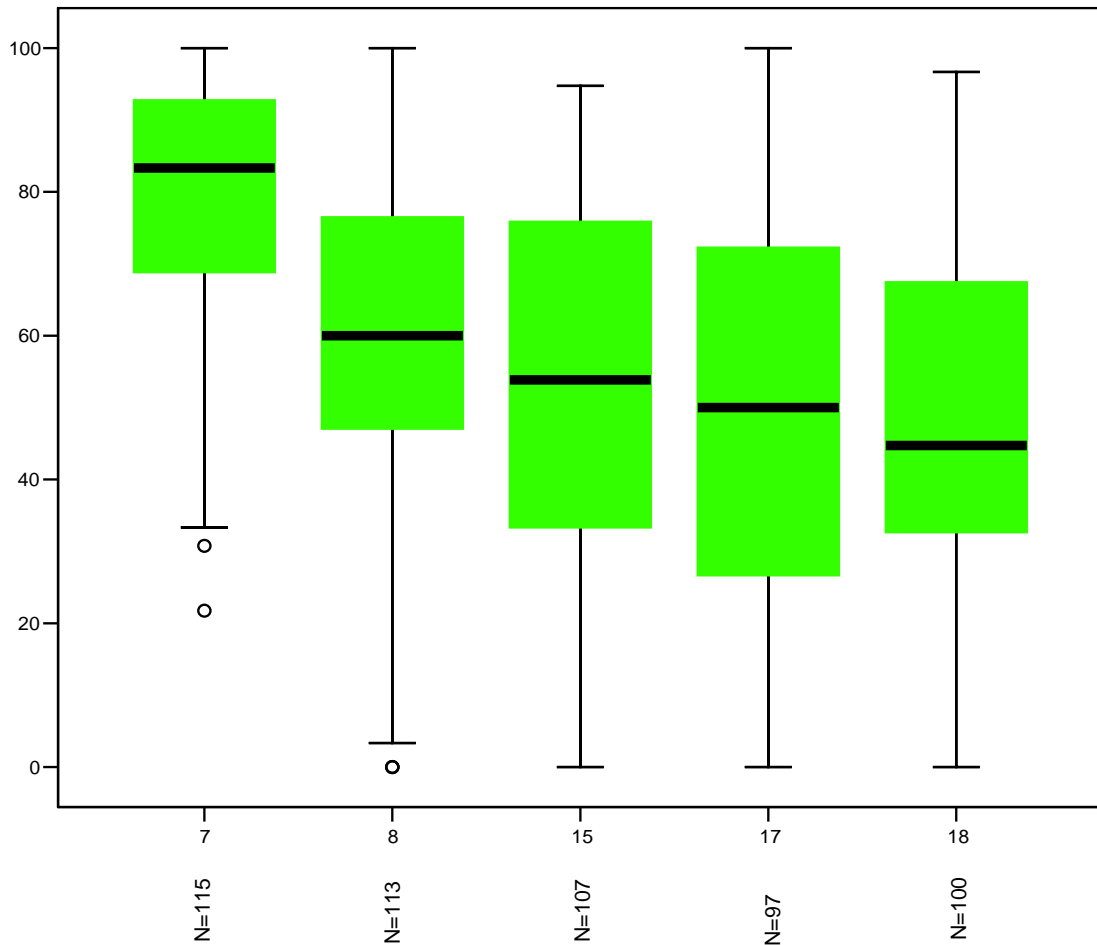
	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2174	51	1106	5	111	44	957
Hospital IQR - all (%) (n=97)		26 – 73%		0 – 10%		21 – 70%	
Hospital IQR – full sample size only (%) (n=45)		25 – 80%		0 – 10%		15 – 67%	

Goal 18: Bereavement leaflet given

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2264	50	1122	7	156	44	986
Hospital IQR - all (%) (n=100)		32 – 68%		0 – 10%		19 – 66%	
Hospital IQR – full sample size only (%) (n=46)		33 – 70%		0 – 10%		17 – 63%	

Domain 4: Information (giving and receiving)

Boxplots to illustrate hospital variation in percentage achieved



Domain 4 Information (giving and receiving):

Commentary

- Gaining important contact information from the most appropriate person to contact in the event of deterioration is achieved in 79% of patients, though there is a fairly wide variation in hospital performance
- Hospital information leaflets are given out relatively inconsistently (ie in 59% of cases with 33% missing data)
- The proportion of missing data for information given *after* the death of the patient is relatively high across the board (over 40% for all of the goals).

Domain 5: Following appropriate procedures

It is important to ensure that the body is treated with dignity and respect and appropriately in line with any appropriate rituals for followers of particular 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 in this regard:

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2486	52	1292	1	35	47	1159
Hospital IQR - all (%) (n=107)		33 – 73%		0%		23 – 67%	
Hospital IQR – full sample size only (%) (n=51)		31 – 70%		0 – %3		27 – 67%	

When the patient dies certain procedures need to be considered. For example, it is important that mortuary viewing is discussed with the family/carer as there may be family members who were not present at the time of death who 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, where appropriate, these procedures:

Goal 14: Procedures following death discussed or carried out

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2346	45	1064	5	112	50	1170
Hospital IQR - all (%) (n=109)		24 – 62%		0 – 7%		29 – 71%	
Hospital IQR – full sample size only (%) (n=51)		23 – 60%		0 – 7%		30 – 72%	

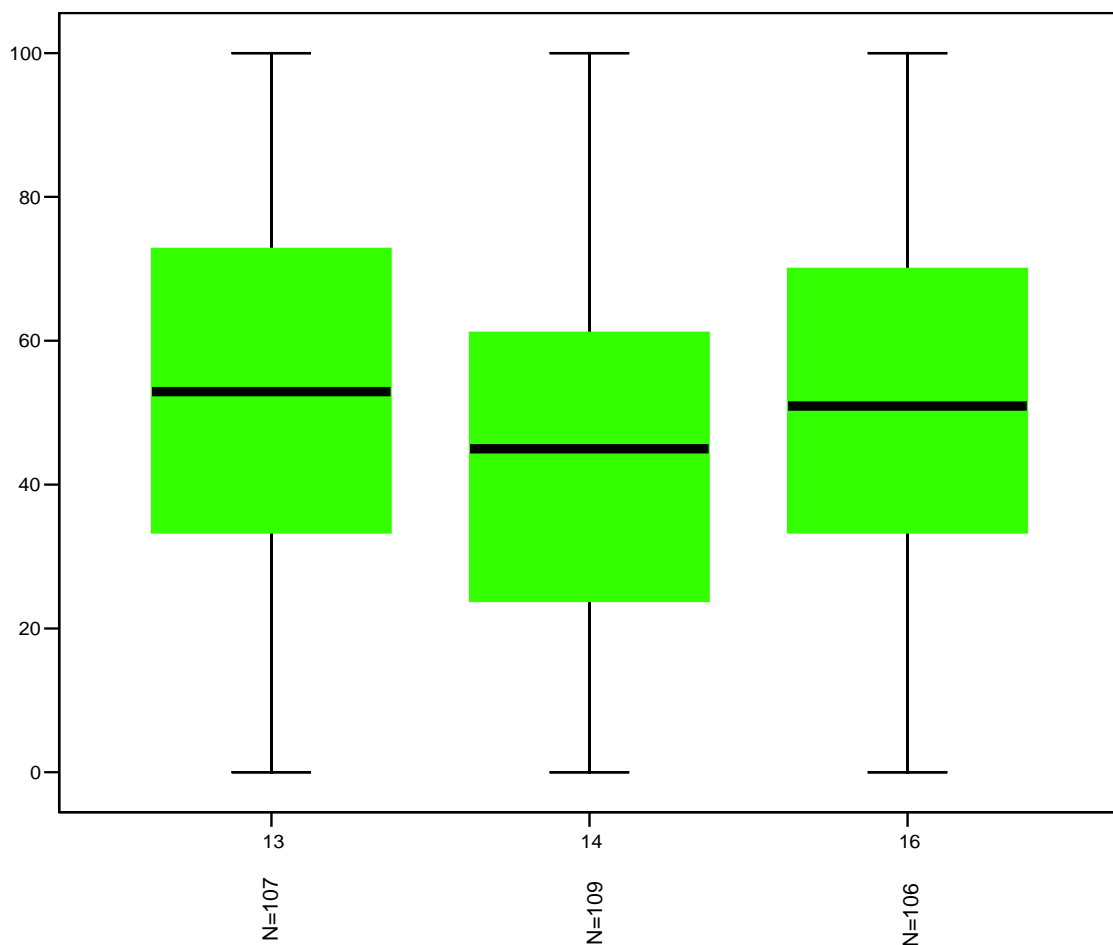
It is important that all items belonging to the patient are collected and stored appropriately, according to the hospital policy, until the family are able to collect them. Goal 16 on the LCP specifically addresses this:

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
National	2462	52	1287	2	58	45	1117
Hospital IQR - all (%) (n=106)		33 – 70%		0 – 3%		25 – 67%	
Hospital IQR – full sample size only (%) (n=49)		33 – 70%		0 – 3%		22 – 66%	

Domain 5: Following Appropriate Procedures

Boxplots to illustrate hospital variation in percentage achieved



Domain 5: Following Appropriate Procedures

Commentary

- The level of missing data for the goals of care within this domain is relatively high (47, 50, 45%) and as such is consistent with other goals in Section 3 of the LCP - Care after Death Section.
- However, the box plots and IQRs clearly illustrate that whilst there is much variation in the performance of individual hospitals, some examples of good practice do exist.

PART B RECOMMENDATIONS

5. Hospitals should scrutinise carefully those goals where their performance falls outside of the IQR, particularly where an individual hospital is an outlier on the box plot. Also where, for example, a hospital falls below the IQR for % 'achieved', or above the IQR for % 'variance' or above the IQR for % 'not documented' local work should be undertaken to identify the issues that are likely to underpin this level of performance and to put in place a remedial action plan. The workshops will provide a valuable opportunity to share and discuss these issues and action plan for improvement
6. Where a relatively high percentage of variance has been recorded, hospitals should examine the variance sheets on the LCPs to determine whether a useful explanation for each variance reported was recorded on the variance sheets. This ensures that a full clinical picture was available at the point of delivery of care that promotes high quality.
7. Hospitals should explore the relatively high proportion of missing data (ie goals not documented) in several of the domains to inform best practice and education in care of the dying.
8. 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 ensure that an appropriate education programme is in place that supports health care professionals in their discussions with patients

9. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with the spiritual assessment (for both patients and carers) and ensure that an appropriate education programme is in place that supports health care professionals to engage in these discussions.
10. The perception of the quality of communication and relationships with healthcare professionals immediately after the death of a patient has been linked to complaints (Healthcare Commission, 2007). There is a high proportion of missing data for all goals in the Care after Death Section in this audit and hospitals should identify the reasons for this. Further work should then be undertaken to integrate quality in care after death, including the accurate recording of information, within the hospital system for all deaths.
11. Work needs to be undertaken to ensure that the goals added recently to the LCP (anticipatory prescribing for dyspnoea, discontinuation of cardiac defibrillation) are fully understood by practitioners.

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<http://www.mcw.edu/display/displayFile.asp?docid=2463&filename=/User/jrehm/Case23.pdf>

Appendix 1: List of Steering 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 Palliative Care – Specialist
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 & Senior Research Fellow, MCPCIL
Sian Edwards	Programme Administrator - MCPCIL
Tamsin McGlinchey	Research Assistant - MCPCIL
Kate Richardson	Research Assistant - MCPCIL
Maria Bolger	National LCP Facilitator - MCPCIL
Dame Gill Oliver, DBE	Advisor to MCPCIL
Prof Mike Pearson	Professor of Clinical Evaluation, University of Liverpool; Consultant Physician, University Hospital Aintree

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

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

National Representation

Prof Mike Richards, CBE	National Cancer Director, Department of Health Chair of End of Life Care Strategy Advisory Board
Prof Jane Maher	Chief Medical officer for Macmillan Cancer Support; Consultant Clinical Oncologist , Lynda Jackson Macmillan Centre
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
Sue Hawkett OBE	Nursing Adviser / Team Leader (Supportive & Palliative Care) Cancer Policy Team, Department of Health

Eve Richardson	Chief Executive, National Council for Palliative Care
Maggie Boyle Talib Yaseen	Chief Executive / Acting 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 Anne Naysmith	Consultant in Palliative Medicine, Pembridge Unit, St Charles Hospital; Representative of the Joint Colleges of Physicians and General Practitioners
Celia Manson	Nurse Adviser - Complementary Therapies, Pain & Palliative Care, Royal College of Nursing
Andrea Mostyn-Jones	Cancer Network Lead Nurse, Dorset Cancer Network
Mary Casey	Joint Professional Advisor (Palliative Care), Healthcare Commission / CSCI
Pam Fenner	Head of Nursing & Clinical Governance, Essex Strategic Health Authority, linked with the End of Life Care Programme
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
Paul Cann	Director of Policy, Research and International, Help the Aged

Observers from Wales, Northern Ireland and Scotland

Dr Andrew Fowell	Consultant in Palliative Medicine, Bangor Hospital, Wales
Dr Jenny Gingles	Consultant in Public Health, Ard Hospital, Northern Ireland
Jill Nelson	Head, Clinical Effectiveness Coordination Unit, NHS - Quality Improvement Scotland

Appendix 2 – Participating Hospitals (by SHA and Trust)

EAST MIDLANDS SHA

Derby Hospitals NHS Foundation Trust
Derby City General Hospital

Northampton General Hospital NHS Trust
Northampton General Hospital

Nottingham City Hospital NHS Trust
City Campus
QMC Campus

United Lincolnshire Hospitals NHS Trust
Lincoln County Hospital

University Hospitals of Leicester NHS Trust
Glenfields Hospital
Leicester Royal Infirmary

EAST OF ENGLAND SHA

Bedford Hospital NHS Trust
Bedford Hospital

East and North Hertfordshire NHS Trust
Lister Hospital
Queen Elizabeth II Hospital

Essex Rivers Healthcare NHS Trust
Essex County Hospital
Colchester General Hospital

Hinchingbrooke Health Care NHS Trust
Hinchingbrooke Hospital

Ipswich Hospital NHS Trust
Ipswich Hospital

James Paget Healthcare NHS Trust
James Paget Hospital

Luton and Dunstable Hospitals NHS Trust
Luton and Dunstable Hospital

Norfolk and Norwich University Hospital NHS Trust
Norfolk and Norwich University Hospital

West Hertfordshire Hospitals NHS Trust
Watford General Hospital
Hemel Hempstead General Hospital

West Suffolk Hospitals NHS Trust
West Suffolk Hospital

LONDON SHA

Barking, Havering and Redbridge Hospitals NHS Trust
Oldchurch Hospital

Barnet and Chase Farm Hospitals NHS Trust
Chase Farm Hospital
Barnet Hospital

Chelsea and Westminster Healthcare NHS Trust
Chelsea and Westminster Hospital

Epsom and St Helier University Hospitals NHS Trust
St Helier Hospital

Hammersmith Hospitals NHS Trust
Charing Cross Hospital

King's College Hospital NHS Trust
King's College Hospital

North Middlesex University Hospital NHS Trust
North Middlesex Hospital

Queen Mary's Sidcup NHS Trust
Queen Mary's Hospital

Royal Free Hampstead NHS Trust
Royal Free Hospital

St Mary's NHS Trust
St Mary's Hospital

The Whittington Hospital NHS Trust
The Whittington Hospital

University College London NHS Foundation Trust
University College London

NORTH EAST SHA

County Durham and Darlington Acute Hospitals NHS Trust
University Hospital of North Durham

Gateshead Health NHS Foundation Trust
Queen Elizabeth Hospital

Northumbria Healthcare NHS Trust
Wansbeck Hospital
North Tyneside General Hospital

South Tees Hospitals NHS Trust
The James Cook University Hospital
Friarage Hospital

South Tyneside NHS Foundation Trust
South Tyneside District General Hospital

The Newcastle upon Tyne Hospitals NHS Trust
Royal Victoria Infirmary
Newcastle General Hospital
Freeman Hospital

NORTH WEST SHA

Aintree Hospitals NHS Trust
Aintree Hospital

Bolton Hospitals NHS Trust
Royal Bolton Hospital

Central Manchester and Manchester Children's University NHS Trust
Manchester Royal Infirmary

Christie Hospital NHS Trust
Christie Hospital

Clatterbridge Centre for Oncology NHS Trust
Clatterbridge Centre for Oncology

East Cheshire NHS Trust
Macclesfield District General Hospital

East Lancashire Hospitals NHS Trust
Blackburn Royal Hospital
Burnley General Hospital

Lancashire Teaching Hospitals NHS Trust
Chorley District General Hospital
Royal Preston Hospital

North Cheshire Hospitals NHS Trust
Warrington Hospital

Pennine Acute Hospitals NHS Trust
Fairfield General Hospital
North Manchester General Hospital
Royal Oldham Hospital
Rochdale Infirmary

Royal Liverpool and Broadgreen University Hospitals NHS Trust
Royal Liverpool University Hospital

Salford Royal NHS Foundation Trust
Hope Hospital

Southport and Ormskirk Hospital NHS Trust
Southport and Formby District General Hospital

St Helens and Knowsley Hospitals NHS Trust
Whiston Hospital

Stockport Foundation Trust
Stepping Hill Hospital

Tameside and Glossop Acute Services NHS Trust
Tameside General Hospital

The Mid Cheshire Hospitals NHS Trust
Leighton Hospital

Trafford Healthcare NHS Trust
Trafford General Hospital

University Hospital of South Manchester NHS Foundation Trust
Wythenshawe Hospital

University Hospitals of Morecambe Bay NHS Trust
Royal Lancaster Infirmary

Wirral Hospital NHS Trust
Arrowe Park Hospital

Wrightington, Wigan and Leigh NHS Trust
Royal Albert Edward Infirmary

SOUTH CENTRAL SHA

Portsmouth Hospitals NHS Trust
Queen Alexandra Hospital
Queen Mary's Hospital

Royal Berkshire NHS Foundation Trust
Royal Berkshire Hospital

Southampton University Hospitals NHS Trust
Southampton General Hospital

Winchester and Eastleigh Healthcare NHS Trust
Royal Hampshire County Hospital

SOUTH EAST COAST SHA

East Kent Hospitals NHS Trust
Queen Elizabeth the Queen Mother Hospital

East Sussex Hospitals NHS Trust
Conquest Hospital
Eastbourne District General Hospital

Frimley Park Hospital NHS Trust
Frimley Park Hospital

Maidstone and Tunbridge Wells NHS Trust
Maidstone Hospital
Kent and Sussex Hospital

Medway NHS Trust
Medway Maritime Hospital

Royal Surrey County Hospital NHS Trust
Royal Surrey County Hospital

Royal West Sussex NHS Trust
St Richards Hospital

Surrey and Sussex Healthcare NHS Trust
East Surrey Hospital

SOUTH WEST SHA

Gloucestershire Hospitals NHS Foundation Trust
Cheltenham General Hospital
Gloucestershire Royal Hospital

North Bristol NHS Trust
Frenchay Hospital
Southmead Hospital

Northern Devon Healthcare NHS Trust
North Devon District Hospital

Plymouth Hospitals NHS Trust
Derriford Hospital

Poole Hospitals NHS Trust
Poole Hospital

Royal Bournemouth and Christchurch Hospitals NHS Trust
Royal Bournemouth Hospital

Royal Cornwall Hospitals NHS Trust
Royal Cornwall Hospital
West Cornwall Hospital

Royal Devon and Exeter NHS Foundation Trust
Royal Devon and Exeter Hospital

Salisbury Healthcare NHS Trust
Salisbury District Hospital

South Devon Healthcare NHS Trust
Torbay District General Hospital

Taunton and Somerset NHS Trust
Musgrove Park Hospital

Weston Area Health NHS Trust
Weston General Hospital

Yeovil NHS Foundation Trust
Yeovil District Hospital

WEST MIDLANDS SHA

Burton Hospitals NHS Trust

Queens Hospital Burton

Hereford Hospitals NHS Trust

Hereford County Hospital

The Royal Wolverhampton Hospitals NHS Trust

Newcross Hospital

University Hospital of North Staffordshire NHS Trust

University Hospital of North Staffordshire

University Hospitals Coventry and Warwickshire NHS Trust

University Hospitals Coventry and Warwickshire

Walsall Hospitals NHS Trust

Walsall Manor Hospital

Worcestershire Acute Hospitals NHS Trust

Worcestershire Royal Hospital

YORKSHIRE AND THE HUMBER SHA

Barnsley Hospital NHS Trust

Barnsley Hospital

Bradford Teaching Hospitals NHS Foundation Trust

Bradford Royal Infirmary

Doncaster and Bassetlaw Hospitals NHS Foundation Trust

Doncaster Royal Infirmary

Bassetlaw Hospital

Hull and East Yorkshire Hospitals NHS Trust

Princess Royal Hospital

Leeds Teaching Hospitals NHS Trust

St James' University Hospital

Leeds General Infirmary

Cookridge Hospital

Scarborough and North East Yorkshire Healthcare NHS Trust

Scarborough General Hospital

ISLE OF MAN

Nobles Hospital

Appendix 3 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', cardiac defibrillators*)
- 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

Appendix 4 – An example of 10 Proposed Core Standards for Care of the Dying

CORE STANDARD 1	The Hospital has an identified Specialist Palliative Care Team (HSPCT)
RATIONALE: Every Acute Trust should have a Hospital Specialist Palliative Care Team (HSPCT) in place. HSPCT working with generalist teams will drive the best practice model of care in the last days of life (<i>Quality Measure for Peer review 2004</i>)	
CORE STANDARD 2	The Hospital collates & reports annually on the demographics of dying patients
RATIONALE: National data indicates that 56% of patients die in hospital (<i>Higginson, I (2003) Priorities and Preferences for End of Life Care</i>). Each Trust needs to be able to monitor this level of activity.	
CORE STANDARD 3	There is a framework for care of the dying that incorporates an ongoing educational programme
RATIONALE: All staff who work with the dying are properly trained to look after dying patients and their carers. (<i>Dept of Health, Our Health, Our Care, Our Say: a new direction for community services, London DoH</i>)	
CORE STANDARD 4	Care of the Dying is discussed annually at Trust Board Level
RATIONALE: We believe care of the dying should be a key indicator of best practice in the acute environment (<i>End of Life Care Programme, 2004</i>)	
CORE STANDARD 5	Within the framework for Care of the Dying the LCP goals are identifiable in association with the NICE Guidance and the White Paper
RATIONALE: In response to best practice in national guidance – key indicators/goals in support of care of the patient, carer, staff in the last days of life are clearly defined. (<i>NICE Guidance, 2004; 'Our Health, Our Care, Our Say' - White Paper 2006</i>)	
CORE STANDARD 6	Percentage of deaths in the Hospital using the Framework for Care of the Dying e.g. LCP is recorded including location of death in Hospital & Demographic Data
RATIONALE: It is important to be able to demonstrate the use of a recommended best practice model for care in the last days of life and be able to audit care process including demographics and care delivery (<i>End of Life Care Programme, 2004</i>)	
CORE STANDARD 7	The Hospital participates in a Continuous Quality Improvement Programme incorporating the National Audit for Care of the Dying
RATIONALE: The Trust should be able to measure the quality of documentation and care delivery in the last days of life against a national benchmark as part of a Continuous Quality Improvement Programme (<i>End of Life Care Programme, 2004</i>)	
CORE STANDARD 8	The Trust monitors its performance against a national scoring system
RATIONALE: We believe that care of the dying should be a quality indicator at Trust level as part of the Trust Performance Management Mainstream agenda. All staff who work with the dying are properly trained to look after dying patients and their carers. (<i>End of Life Care Programme 2004, White Paper 2006</i>)	

CORE STANDARD 9	There is a current Service Improvement Plan for Improving Care of the Dying within the Trust
RATIONALE: A strategy for care of the dying and care after death is outlined using service improvement methodology that supports the Trusts Governance agenda (<i>End of Life Care Programme 2004</i>)	
CORE STANDARD 10	Care of the Dying is a key element of Performance Management for Hospital Trusts at Board Level
RATIONALE: A strategy for care of the dying and care after death is presented as part of the Trust's Performance Management Mainstream Processes at local, clinical and Trust Board level (<i>End of Life Care Programme 2004</i>)	

(LCP Central Team UK, Marie Curie Palliative Care Institute Liverpool)




Appendix 5 – Example Powerpoint Presentation Slides

Summary as at 1 st September 2006	Hospital X (n=30)	National Median (IQR)
Months since Pilot	113	19 10 – 36 Includes data from 87 hospitals
Number of Beds	924	522 380 – 774 Includes data from 113 hospitals
Number of Wards	50	24 18 – 36 Includes data from 113 hospitals
Estimated proportion of wards using LCP	70%	44% 23% - 73% Includes data from 110 hospitals
Number of deaths on LCP 1 st Sept – 30 th Nov 2006	50	32 17 - 51 Includes data from 111 hospitals

Primary Diagnosis

	Hospital X (n=30)	National (n=2647)
Cancer	50% (15)	45% (1190)
Non-Cancer	50% (15)	55% (1457)

Key to Graphs

- Achieved 
- Variance 
- Not Documented 

- 'N' on column for particular goals = number left in sample after not applicable/comatose/not on pathway have been removed
- Where individual organisation sample sizes are significantly reduced after the removal of not applicable and comatose, please interpret findings with caution

