

The Marie Curie
Palliative Care Institute

LIVERPOOL



Royal College
of Physicians
Setting higher medical standards

NATIONAL CARE OF THE DYING AUDIT – HOSPITALS (NCDHAH)

SUMMARY 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*



Foreword

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

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

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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 appropriate 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 copy of the full generic report can be obtained from www.mcpcil.org.uk)

Part A: Organisational Data

Data were analysed using descriptive statistics and were 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 was 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 was 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 was included after each section.

Patient demographic data was 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 was 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

A CD containing:

- an electronic version of the individual hospital report,
- a summary report
- a powerpoint presentation of the results was also made available to each participating hospital (see appendix 4 for an example of the powerpoint slides).

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).

Major Findings and Commentary

Part A - Organisational information:

- On average participants have been using the LCP for 19 months, 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. This percentage is dependent on the number of expected deaths and the level of implementation. 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.
- 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. For example, the provision of an information leaflet on bereavement alongside 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 have 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.

- 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 be 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 B – Patient Level Audit

Demographics

- 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%).

Domain 1 Physical Comfort of the Patient

- 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):

- 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)

- 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)

- 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% on each of the goals).

Domain 5: Following Appropriate Procedures

- 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.

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 5 for an example of 10 Proposed Core Standards for Care of the Dying

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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

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'*)
- 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

(LCP, Version 11, www.mcpcil.org.uk)




Appendix 4 – 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

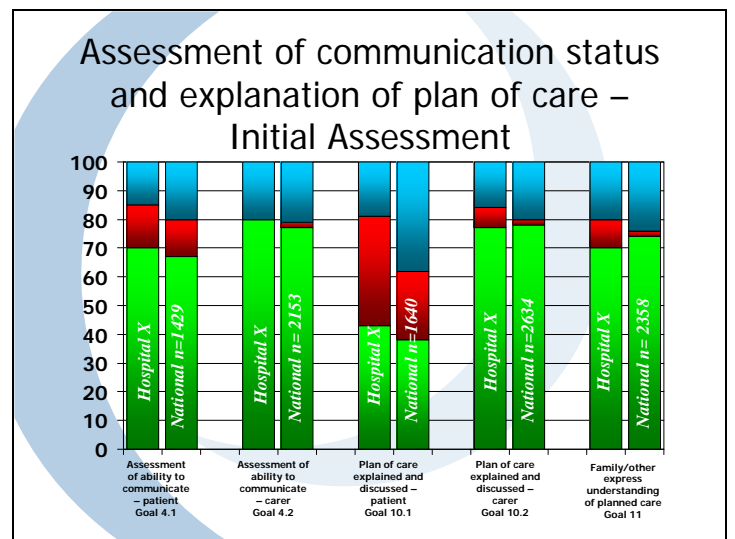
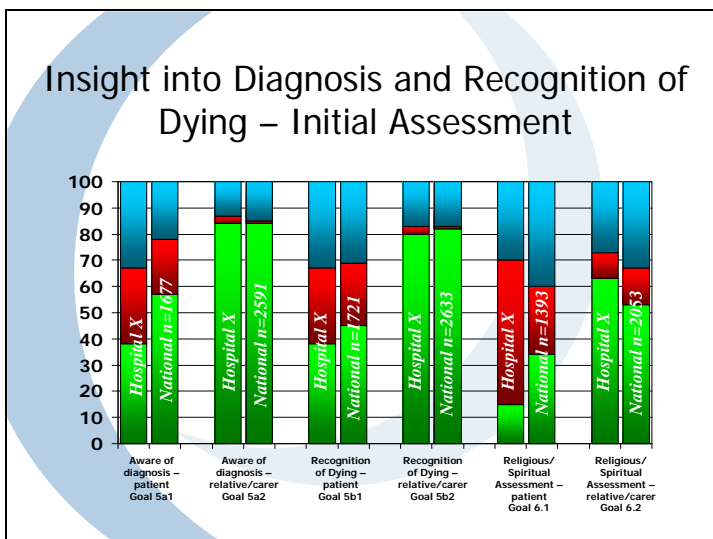
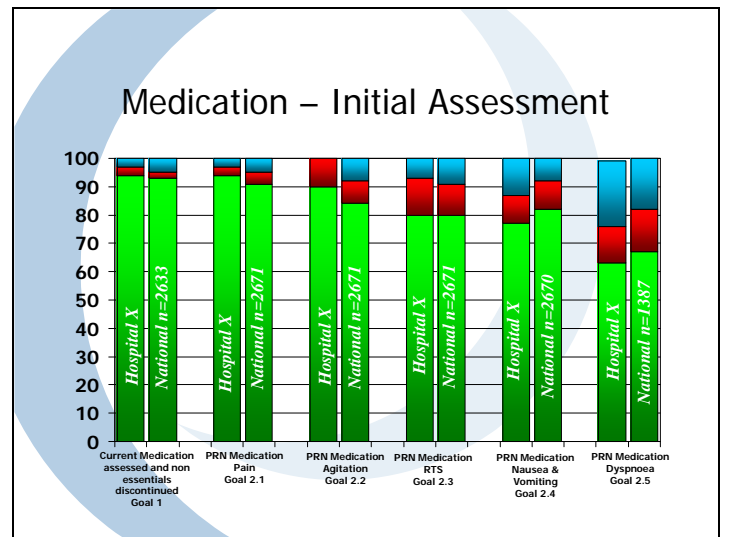
Primary Diagnosis

	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



Appendix 5 – 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)