

The Marie Curie  
Palliative Care Institute

LIVERPOOL



# NATIONAL CARE OF THE DYING AUDIT – HOSPITALS (NCDAH)

## ROUND 2 (2008/2009)

### AUDIT REPORT Northern Ireland Pilot

#### NIa2 Belfast City Hospital

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

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



## Foreword


How well we look after the dying is surely the hallmark of any civilised society. A service which can accommodate an individual's choice of where they wish to die, in a peaceful and dignified manner, is a key performance indicator for the rest of the health and social care system. If we can get this right, then many other aspects of a safe and high quality service will fall into place.

The Minister for Health, Social Services, and Public Safety, Michael McGimpsey, has commissioned a strategy for Palliative and End of Life Care. He has also set out in Priorities for Action (2011) a target for each Trust to have multi-disciplinary palliative care teams and service improvement programmes in place, to support the development of a community facing palliative care model for adult patients.

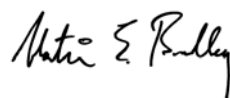
In 2009 we also saw the publication of the N.I. Bereavement Strategy supported by the appointment of a bereavement coordinator in each of the HSC Trusts, and the establishment of the N.I. Bereavement Network.

Clearly there is a wide range of services and information available for the care and support of dying patients and bereaved people, but there are still variations in the standards and organisation of these important services. We need to build on existing good practice and ensure that all who require these services can access them in a timely fashion.

In support of this we welcome the National Care of the Dying Audit Hospitals (NCDAH).



*Dr Michael McBride  
Chief Medical Officer  
Northern Ireland*



*Martin Bradley  
Chief Nursing Officer  
Northern Ireland*

The majority of people who die, die in hospital. It is essential to ensure this aspect of hospital care is of the highest standard. The second round of the national audit of care of the dying demonstrates that, where the Liverpool Care Pathway for the dying patient (LCP) is used, people are receiving high quality clinical care in the last hours and days of life. Reassuringly an increasing number of patients, both those with cancer and those with other conditions, are being cared for using the care pathway. The challenge raised by the audit is to ensure that those who should appropriately be on the pathway, are on it.

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

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

*Jonathan Potter  
Clinical Director,  
Clinical Effectiveness and Evaluation Unit,  
Royal College of Physicians, London.*

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

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

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

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

### **Acknowledgements**

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

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

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

#### **Useful Links:**

Marie Curie Palliative Care Institute Liverpool. [www.mcpcil.org.uk](http://www.mcpcil.org.uk)

Royal College of Physicians. [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

Marie Curie Cancer Care. [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

End of Life Care Programme. [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

National Council for Palliative Care. [www.ncpc.org.uk](http://www.ncpc.org.uk)

Northern Ireland Cancer Network. [www.cancerni.net](http://www.cancerni.net)

## EXECUTIVE SUMMARY

**Background** Fifty-seven percent of all deaths in Northern Ireland in 2005 occurred in the hospital sector (NICAN, 2008). It is, therefore, important for Trust boards, managers and clinicians to recognise that it is a core responsibility of hospitals to provide a dignified death for patients and appropriate support to their carers. Government Policy in England in recent years has reinforced the need to prioritise the delivery of high quality care at the end of life (DH 2006, 2008, 2009). As the Chair of the End of Life Strategy Advisory Board for England, Professor Mike Richards commented *“How we care for the dying must surely be an indicator of how we care for all our sick and vulnerable patients. Care of the dying is urgent care with only one opportunity to get it right to create a potential lasting memory for relatives and carers”* (MCPCIL 2007)

The Liverpool Care Pathway for the Dying Patient (LCP) has been recommended for use as a template of best practice in the last hours and days of life in UK National policy (DH 2006, 2008) and more recently in the National End of Life Care Strategy: Quality Markers and Measures for End of Life Care (2009). The first National Care of the Dying Audit in Hospitals in England (NCDHA) was undertaken in 2006/2007 based on the standards of care within the LCP. The results from the first round provided a picture of care of the dying in our acute hospitals in England for the 2672 patients from 118 acute hospitals that were included in the audit (MCPCIL, 2007).

New to this second round of the NCDHA, In addition to the 155 Hospitals from 114 Acute Hospital Trusts in England, a pilot cohort of hospitals from Northern Ireland (which included 13 Hospitals from 9 Trusts in Northern Ireland) submitted data from completed LCPs. The Northern Ireland Pilot has been analysed separately (please go to [www.mcpcil.org.uk](http://www.mcpcil.org.uk) for details of how to download a copy of the Generic Reports for England and Northern Ireland). This report provides information on the goals of care on the LCP for your hospital benchmarked against the aggregate performance of all participating hospitals in Northern Ireland. It also focuses on the prescription and administration of medication for agitation and restlessness in the last 24 hours of life, as well as providing more information about variance recording for a proportion of goals. Data driven Key Performance Indicators (KPI) for the delivery of care to dying patients during the last hours and days of their lives have also been developed to promote the appropriate prioritisation of this area of care within Acute Hospital Trusts.

**Methods** A prospective audit design was used to gather LCP data from up to 30 consecutive deaths in each of the participating hospitals between 1<sup>st</sup> October 2008 and 31<sup>st</sup> December 2008. Pertinent hospital organisational data was also gathered to contextualise the data from the LCP and to aid interpretation of the results. An electronic data collection tool was developed to enable easy data input and to enhance the quality of the data submitted. The National (UK) LCP Reference Group has provided advice and support throughout the project.

**Sample** 13 hospitals from 5 Acute Hospital Trusts participated in the audit and submitted a total of 274 patient data sets.

### **Results**

The results are presented for the following Domains of care **in the** main body of the report:

Domain 1 - Physical comfort of the patient

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

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

Domain 4 - Appropriate information (giving and receiving)

Domain 5 - Compliance with appropriate policies and procedures.

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

**KEY FINDINGS**

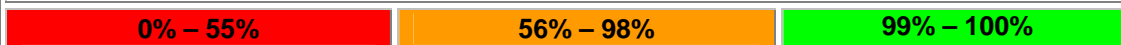
Key Performance Indicators

These KPIs are data driven metrics that have been developed to illustrate the performance of all hospitals in three specific areas against which individual hospitals can gauge their relative performance. They can be usefully included on the ‘corporate performance dashboard’ used in many Trusts to promote continuous quality improvement.

For each KPI, the performance of hospitals has been colour coded (as red, amber and green – see below) based on the Inter Quartile Range of performances using combined data from the 13 hospitals in Northern Ireland and the 155 hospitals in England.

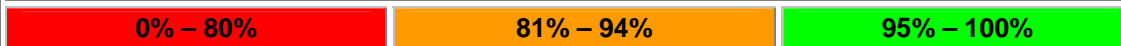
- ‘Red’ Box represents the spread of performance for the bottom 25% of hospitals
- ‘Amber’ Box represents the spread of performance for the middle 50% of hospitals
- ‘Green’ Box represents the spread of performance for the top 25% of hospitals

**Key Performance Indicator 1: Spread of the LCP**

Proportion of wards using the LCP	Your Site (n=30)	Northern Ireland + England Combined Sample (n=165)
Median % (IQR)	<b>100%</b>	75% (56% - 98%)
		

Median % for 13 Northern Ireland Hospitals was 100%, IQR 58% - 100%, Range 37% - 100

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

Anticipatory prescribing for key symptoms	Your Site (n=30)	Northern Ireland + England Combined Sample (n=167)
Median % (IQR – Northern Ireland only)	<b>86%</b>	88% (81%-94%)
		

Median % for 13 Northern Ireland Hospitals was 90%, IQR 87% - 93%, Range 77% - 100%

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

% compliance with completion	Your Site (n=30)	Northern Ireland + England Combined Sample (n=168)
Median % (IQR – Northern Ireland only)	<b>81%</b>	73% (68% - 83%)
<b>0% – 67%</b>	<b>68% - 83%</b>	<b>84% - 100%</b>

Median % for 13 Northern Ireland Hospitals was 83%, IQR 80% - 93%, Range 64% - 99%

## **PART A – ORGANISATIONAL LEVEL KEY FINDINGS**

- 13 hospitals from 5 hospital trusts provided a total of 274 patient cases. Four hospitals submitted the full sample size of 30.
- Data for the audit has been mainly submitted by nurses or those designated as an 'LCP Coordinator'.
- The LCP had been in use for 49 months on average (median).
- 100% of hospitals had a Hospital Specialist Palliative Care Team.
- 38% of hospitals had an LCP Facilitator or equivalent working on average 1.00 wte.
- Only 8% of hospitals had a Coping with Dying Leaflet or equivalent available for use.
- 62% of hospitals had an ongoing education programme for Nurses in care of the dying, and 38% had such a programme for Doctors.
- 77% of hospitals had conducted an audit of LCPs within the last 12 months, but only 40% of these fed the results back to the Trust Board.
- No 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 KEY FINDINGS**

- The proportion of patients with a diagnosis other than cancer (65%) was higher than those with a diagnosis of cancer (35%).
- Assessment of current medication and writing up of anticipatory medication for Pain, Agitation, Respiratory Tract Secretions (RTS) and Nausea and Vomiting were achieved for more than 80% of patients overall in this sample. Prescribing for Pain alone occurred in 94% of cases.
- Documentation for the 4 hourly assessments in the last 24 hours of life illustrate that in the main, patients were found to be comfortable in terms of their physical symptoms.
- There were relatively high levels of 'variance' (23%) being recorded for the discontinuation of IV Fluids/Medications overall in this sample, with much variation across hospital sites in terms of % achieved. However, the relatively poor recording of explanations on the variance sheets for this goal precludes a full understanding of the reasons for continuation.
- The highest levels of variance (patient discomfort) recorded in the ongoing assessment were for RTS (16%), with Pain (10%) and Agitation (9%) the next 2 most common symptoms.
- For the vast majority of carers, it was documented that they were aware of the patients' diagnosis (90%) and that the patient was entering the dying phase (91%). The plan of care was explained in over four fifths of carers (86%), and 93% of those expressed an understanding of that plan.
- Communication with the patient regarding insight into their condition, and that they were entering the dying phase, was less well achieved (63% and 58% respectively). Variance was recorded for 18% and 19% of patients respectively and in a relatively high proportion of patients no information was documented at the point of care delivery (18% and 23% respectively). This suggests that these goals may be challenging to achieve, highlighting a potential need for more education and training.
- Whilst the assessment of the patients' into their diagnosis and prognosis, and of their spiritual/religious needs (42% achieved) appear to be challenging, the dot plots, showing variation across hospitals for these goals, do indicate that levels of good practice can be achieved.
- Communication with colleagues in Primary Care was less well achieved, both prior to and after the patient's death (28% and 45% respectively).
- The vast majority (80%) of carers received hospital information leaflets and information detailing the most appropriate person to be contacted in the event of deterioration was recorded for most cases (88%).

- In the main, the Care After Death section was very well completed, with most goals being achieved in at least 80% of cases. However two goals in this section were less well achieved - giving necessary documentation and advice to the appropriate person (64%) and giving a bereavement leaflet specifically (46%).
- It is of note that drugs prescribed prn for agitation and restlessness were actually given in only 41% of cases. This supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed drug for agitation and restlessness. The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 2.5mg as a PRN dose. The median doses of haloperidol and levomepromazine were also relatively low.

#### **PART D: RECOMMENDATIONS**

1. Key Performance Indicators (KPI's) for care of the dying should be measured, monitored and managed as part of the organisation corporate performance dashboard.
2. All hospitals should have a clear programme for continuous quality improvement for care of the dying to drive up performance and quality.
3. A remedial action plan in response to National Care of the Dying Audit findings should be in place to address poor compliance, Inter Quartile Range (IQR) outliers, variance reporting to improve performance across the key domains of care.
4. A named person within the organisation should take formal responsibility to act as an LCP Facilitator / change agent for care of the dying.
5. All hospitals should have a local audit programme for care of the dying that includes the assessment of the views of bereaved carers.
6. Optimising knowledge transfer is an important aspect of continuous quality improvement. All hospitals should have appropriate information leaflets available in support of care in the last hours / days of life.
7. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with patient insight (both into diagnosis and recognition of dying) and spiritual assessment (for both patients and carers).
8. Whilst this audit shows that the Care After Death Section of the LCP is well completed in the main, hospitals should strive to improve the proportion of carers receiving appropriate information after the death of the patient.
9. All hospitals should take part in the 2 yearly National Care of the Dying Audit Cycle.
10. All hospitals should have an LCP or equivalent in place that is compliant with the goals to be included in the new updated version 12 of the LCP to be launched in November 2009.

**Contents Page**

	<b>Page (s)</b>
<b>INTRODUCTION</b>	
<b>Background</b>	9
<b>Aim</b>	12
<b>Project Methodology</b>	14
<b>Analysis</b>	15
<b>Reporting</b>	19
<b>Participation</b>	20
<b>Part A: ORGANISATIONAL AUDIT - Results</b>	
Section 1: Personnel responsible for submitting data	21
Section 2: General hospitals demographics (October 2008)	22
Section 3: Availability of support for implementation & sustainability	24
Section 4: Continuing education, training & audit	26
Section 5: Key Findings	27
<b>Part B: PATIENT LEVEL AUDIT - Results</b>	
Section 1: Demographic Data	28
Section 2: Organisation of Feedback	
Domain 1 - Physical comfort of the patient	30
Domain 2 - Psychosocial and spiritual/religious aspects of care (patients and carers)	42
Domain 3 - Communication (patient, carer and healthcare colleagues)	57
Domain 4 - Appropriate information (giving and receiving)	52
Domain 5 - Compliance with appropriate policies and procedures.	55
Section 3: Medication Prescribing	57
Section 4: Variance Reporting	60
Section 5: Key Findings	63
<b>PART C: Key Performance Indicators</b>	65
<b>PART D: Round 2 Recommendations</b>	68
<b>PART E: References</b>	69
<b>Appendices</b>	
Appendix 1: Participating Hospitals	72
Appendix 2: NCDHA Working Group / National LCP Reference Group	73
Appendix 3: Glossary	75
Appendix 4: Reporting Schedule	78
Appendix 5: Best Practice Example Proforma	79
Appendix 6: Goals of care on the LCP	80

## INTRODUCTION

### Background

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

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

In May 2009, the Health Minister for Northern Ireland, Michael McGimpsey, announced that a Strategy for Palliative and End of Life Care for Northern Ireland would be developed by the end of 2010. The aim of this Strategy will be to improve the quality of care for adult patients with advanced progressive illness in Northern Ireland. The Minister said: "I am committed to providing people with the highest quality care at all stages of their treatment, including palliative and end of life care" (Press Briefing Paper, May 2009, <http://www.northernireland.gov.uk/news/news-dhssps/news-dhssps-may-2009/news-dhssps-29052009-health-minister-announces.htm>)

Whilst one of the main issues in end of life care is to enable patients to die in their place of choice (generally in their own homes), fifty-seven percent of all deaths in Northern Ireland in 2005 occurred in the hospital sector (NICAN, 2008). 'Spotlight on Complaints' (The Healthcare Commission, 2007) highlighted that many of the complaints surrounding care of the dying and their families in England (particularly in acute trusts) are related not only to the actual care provided but also to the relationships between healthcare staff and family members following a patient's death. In many cases contradictory or confusing information was a contributory factor and the use of ambiguous language or complex clinical terminology had led to misunderstandings. In other cases, family members complained that they had felt unprepared for the patient's death. Sometimes

complaints stemmed from a lack of robust record keeping which family members had interpreted as a lack of monitoring of the patient or a failure to provide good care, and the Care Quality Commission continues to recommend regular audit of record keeping systems. Providing a dignified death for patients and appropriate support to carers is clearly an important area for clinical governance throughout Health and Social Care Trusts in Northern Ireland. In recognition of this, commitment from managers and clinicians across care settings, particularly within hospitals, is key to enabling the continual improvement in the patient and carer experience of 'end of life care'.

In their position paper 'Defining End of Life Care', the Northern Ireland Cancer Network (NICAN, 2008) recommend that "End of life care tools (such as The Liverpool Care Pathway) should be embedded into practice across all care settings and used effectively on the basis of individual need...". The LCP has now been implemented to varying extents in all acute hospitals in Northern Ireland within the five Health and Social Care Trusts and implementation within primary care and community practice is also slowly evolving.

### *The Liverpool Care Pathway for the dying patient (LCP)*

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

#### **1 Aim**

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

#### **2 Key Themes**

To improve the knowledge related to the process of dying

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

#### **3 Key Sections**

##### **Section 1. The Initial Assessment Section**

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

## **Section 2. The Ongoing Assessment Section**

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

## **Section 3. The Care After Death Section**

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

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

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

### National Audit

Gaining robust, objective data on which to base plans for improvement remains a challenge in palliative care where many examples exist to illustrate the difficulties of successfully implementing robust research methods such as randomised controlled trials (Jordhøy et al 1999; Westcombe et al 2003). Conducting this type of research into outcomes in the last hours and days of life represents an even greater challenge. In addition to providing a template of best practice, the LCP is also designed to allow the easy extraction of data for audit purposes that can be used locally to drive quality care. The standardisation of the documentation enables measurable outcomes of care that can also be used to provide comparative data.

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

A second round of this national audit in England was designed to build on the results of the first round for hospitals in England. In addition, a pilot cohort of hospitals from Northern Ireland was included to assess the feasibility of this approach outside of England. The results from Northern Ireland will inform 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. It will also focus on the prescription and administration of medication for agitation and restlessness in the last 24 hours of life, as well as providing more information about variance recording for a proportion of goals and data driven Key Performance Indicators (KPIs).

## Aim

The aim of this pilot phase in Northern Ireland is to improve the standards of care for patients who die in acute hospitals in Northern Ireland on the LCP. The specific objectives are to:

1. Identify the quality of care for dying patients as documented on the LCP
2. Benchmark performance with other hospitals across Northern Ireland
3. Identify Key Performance Indicators (KPI's) to drive up the quality of care for the dying that can be reflected within the Hospital/Trust corporate performance dashboard

## Organisation of the Audit

The audit was coordinated and carried out by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Royal College of Physicians (RCP) London, which has a wealth of experience in undertaking national audits. (eg Wilson et al, 2008), supported by Marie Curie Cancer Care and the National End of Life Care Programme at the Department of Health. A standardised approach to collection of data was employed within each participating hospital, which was

overseen by a designated lead clinician and auditor. In general, the appointed auditor was familiar with the LCP programme and the lead clinician was a member of the palliative care team. (Appendix 1 provides a list of all participating hospitals). The National LCP Reference Group (Appendix 2) and a Working Group made up of clinical and research colleagues from MCPCIL and audit colleagues from the RCP guided the project and oversaw the preparation, governance, analysis and reporting phases.

Availability of this report in the public domain

- Chief Executives, Clinical Governance Leads and Lead Clinician/Auditors within participating hospitals will have access to their individual hospital reports detailing their performance versus the generic performance of all hospitals.
- The Generic Report, (including the list of participating hospitals) that illustrates the aggregate performance for all patients in the sample (274 data sets), will be made more widely available in the public domain as a separate publication (see Appendix 4 – Reporting Schedule).
- It is intended that articles based on the generic findings will be published in national and international journals and that presentations to national and international conferences will be undertaken.

Inclusion Criteria for the audit

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

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

## Project Methodology

### Design

A prospective audit design was used to gather LCP data from up to 30 deaths in each of the participating hospitals between 1<sup>st</sup> October 2008 and 31<sup>st</sup> December 2008. Pertinent hospital organisational data was also gathered to contextualise the data from the LCP and to aid interpretation of the results. For this round, an electronic data submission tool was developed to aid standardised data collection and to improve the quality of data submitted.

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

### Data Collection Tools

#### **Organisational Data:**

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

#### **Patient Level Data:**

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

In addition to information coded against the goals of care on the LCP, data from the medication charts was also sought for prescribing and administration of medications for agitation and restlessness in the last 24 hours of life, both 'as required' (prn) and via continuous subcutaneous infusion. Information coded onto the variance sheets was also requested for those goals of care that had shown relatively high levels of variance reporting in the first round of the audit (Discontinuation of IV Fluids/Medications; Patient awareness of insight; Assessment of

Spiritual/Religious needs of carers; the giving of a bereavement leaflet to carers after the death of the patient). In addition, the number of times that a variance was recorded on the variance sheets for pain, agitation and respiratory tract secretions in the ongoing assessment section was requested.

### **Procedure**

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

## **Analysis**

### Key Performance Indicators (KPI)

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

- **Key Performance Indicator 1: Spread of the LCP**
  - An important indicator of the extent to which the LCP has become embedded within a hospital is the proportion of wards using the LCP and the Department of Health have recognised this as an important indicator of the spread of education and training within a hospital (DH, 2009). Auditors were asked to provide information about the total number of wards in their hospital and the number of wards that were estimated to be using the LCP (ie had used at least 1 LCP in the 3 month period prior to the data collection period). From this information, the proportion of wards 'using' the LCP has been calculated for each hospital. The overall median percentage for those hospitals that gave the full sample size was also calculated to provide a National score.
- **Key Performance Indicator 2: Anticipatory prescribing for the key symptoms that may develop in the last hours and days of life**
  - Goal 2 on the LCP requires the prescription of appropriate drugs for Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting and, more recently,

Dyspnoea. It is imperative that appropriate drugs are written up on commencement of the LCP regardless of whether the patient is symptomatic at that point in time. This is to ensure that there is no delay in responding to a symptom if it occurs. As such, goal 2 is an example of a goal that is an overriding duty or principle and has been included as a performance indicator for this reason. As prescribing for dyspnoea is a relatively new goal on the LCP and many participating hospitals in this round did not have the goal on their pathway, it has been excluded from the scoring system.

- A coding system was developed and applied to the remaining four sub-goals within goal 2. A score of 1 was given for each patient for whom a 'yes' had been coded; a score of 0 was given for each patient for whom 'goal not documented' (missing) had been coded; and a score of 0.25 was given for each patient for whom a 'no' had been coded, in recognition of the fact that a coding of 'no' should result in the supply of information on the variance sheet as to why the goal was not met (eg patient request) which may then be used locally to improve both education and the provision of care in the future.
- The scores across Goal 2 for each patient were added and then converted into a percentage of maximum score. The mean percentage for each hospital was then calculated. The median and IQR for the combined Northern Ireland and England sample (n=168) was then calculated using the hospital mean scores.

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

- It is important that full documentation exists in order to fully understand and support appropriate care delivery in the last hours and days of life. The design and layout of the LCP makes completion of documentation against each goal simple and straightforward and compliance (full completion of the documentation) should, therefore, be easy to achieve.
- The percentage of LCP goals that were documented appropriately (ie coded achieved, variance, not applicable or comatose) was calculated for each patient. The mean of these percentages was then calculated for each hospital and the median and IQR of hospital mean percentages for the combined Northern Ireland and England sample (n=168) were then calculated.

### Organisational Data

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

### Patient Level Data – LCP Goals

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

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

### Variables New to Round 2 - Medication and Variance

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

Variance reporting for LCP Goals 3.3, 5b1, 6.2 and 18: In order to compare the correspondence between the variance reported against each of these goals on the Initial and Care after Death sections and detailed explanations provided on the variance sheets, the percentage of times that a corresponding variance was recorded for the identified goals was calculated. The written

documentation on the variance sheets were then also analysed descriptively using content analysis to identify the 'Top 3' reasons why these goals were not met for the sample as a whole.

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

#### Data Reliability

Participants were asked to re-audit their first 4 patient data sets using a different auditor to assess the level of inter-auditor reliability. The Kappa Coefficient (see Appendix 3 for a definition) was calculated for each of the goals of care on the Initial Assessment and Care after Death sections of the LCP. In addition, variables collected for the first time in this round (medication prescribed and given for agitation and restlessness in the last 24 hours of life) were also included. The Northern Ireland Sample (n=13) and the England sample (n=155) were combined for this purpose.

#### Comparative Hospital Performance – Inter Quartile Range (IQR)

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

#### Small Sample Size

It is important to remember that some hospitals within the sample submitted a relatively small number of patient data sets to the audit. For example, 5 hospitals (38%) submitted between 8 and 19 patient data sets. This may be due to several factors including hospitals being relatively early in the implementation process at the time of the audit, or, that it may never be possible for some hospitals to provide the full sample size due to their specific patient and/or service profile. The results for those hospitals with relatively small numbers should be interpreted with caution as the potential for bias is increased.

## Reporting

### Feedback Reports to individual hospitals

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

### Availability of Generic Reports

An electronic copy of the Generic Report will be made available for download and printing on the MCPCIL website ([www.mcpcil.org.uk](http://www.mcpcil.org.uk)) - see the reporting schedule (Appendix 4).

### Regional Workshop

A regional workshop for Northern Ireland participants only will be held in Belfast on the afternoon of 9<sup>th</sup> October 2009. The workshop will encourage discussion of the results, sharing of understanding and action planning for the future. Representatives from each hospital (usually the 'auditor' and/or the named clinician and a representative of the management / executive team of the hospital) will be invited to attend the workshops. Success in Service Improvement relies on the ability to identify, spread and sustain good practice. In order to begin the process of 'building on the best' participating hospitals will be invited to provide examples of good practice in the delivery of quality care in the last hours and days of life (see example of the best practice proforma in Appendix 5).

### Questionnaire Evaluation

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

## RESULTS

### Participation

The Northern Ireland Health Sector is organised into 5 Health and Social Care Trusts, within which 28 Hospitals are located. The table below illustrates the spread of hospitals from which the participants were drawn:

<b>Belfast Health and Social Care Trust</b>	<b>Northern Health and Social Care Trust</b>	<b>Western Health and Social Care Trust</b>	<b>Southern Health and Social Care Trust</b>	<b>South Eastern Health and Social Care Trust</b>
Belfast City Hospital*	Antrim Hospital*	Altnagelvin Area Hospital*	Armagh Community Hospital	Ards Community Hospital
Forster Green Hospital	Braid Valley Hospital	Erne Hospital*	Craigavon Area Hospital*	Bangor Community Hospital
Mater Infirmorum Hospital*	Causeway hospital*	Tyrone County Hospital*	Daisy Hill Hospital*	Downe Hospital*
Musgrave Park Hospital	Dalriada Hospital		Lurgan Hospital	Downshire Hospital
Royal Victoria Hospital*	Holywell Hospital		South Tyrone Hospital	Lagan Valley Hospital*
	Mid Ulster Hospital		St Luke's Hospital	Ulster Hospital*
	Moyle Hospital			
	Whiteabbey Hospital			

13 Hospitals (\* above) representing 46% of total hospitals, from 5 Health and Social Care Trusts in Northern Ireland took part and contributed a total of 274 individual patient cases for analysis. Four Hospitals (31%) submitted the full sample size, 4 hospitals (31%) submitted between 20 and 29, and the remaining 5 hospitals (38%) submitted between 8 and 19.

### Data Reliability

Inter-auditor reliability for the combined Northern Ireland and England sample (n=168) was assessed as 'very good' for goals in the Initial Assessment Section and Care After Death Section of the LCP (Range = 0.835 – 0.970, Median Kappa value = 0.936, IQR 0.907 – 0.954) and for medication goals (Range = 0.64 – 1.0; Median Kappa value = 0.889, IQR 0.869 – 0.929).

## PART A: ORGANISATIONAL AUDIT RESULTS

All 13 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

	Your Site	NI Whole Sample (n=13)	
Medical Team	Nursing Team	38%	(5/13)
Nursing Team		62%	(8/13)
Audit Team		0%	(0/13)
*Other		0%	(0/13)

#### 1.1b Auditor Discipline for completion of Patient Data Audit Form

	Your Site	NI Whole Sample (n=13)	
Medical Team	Nursing Team	0%	(0/13)
Nursing Team		38%	(5/13)
Audit Team		15%	(2/13)
*Other		46%	(6/13)

\*Other included LCP Audit Coordinator

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

	Your Site	NI Whole Sample (n=12)	
Medical Team	Secretarial and Nursing	17%	(2/12)
Nursing Team		17%	(2/12)
Audit Team		8%	(1/12)
*Other		58%	(7/12)

\*Other included Secretarial; Palliative Care Education facilitators

**Commentary: Personnel Responsible for Submitting Data**

- 13 hospitals from 5 hospital trusts provided a total of 274 patient cases.
- In the main, the professionals responsible for coding and submitting data for the organisational level elements of this audit were from the nursing profession. The patient level elements were coded and submitted mainly by nurses and also those from ‘Other’ professions, including LCP Audit Co-ordinators who were likely to be very familiar with both the LCP itself and the process of auditing against the LCP.
- The second auditor was primarily from an ‘Other’ profession.

**Section 2: General Hospital Demographics as at October 2008**

Hospital Size	Your Site	NI Whole Sample (n=13)
1.2 Median number of wards (IQR)	<b>26</b>	13 (8 - 23)
1.3 Median number of beds in hospital (IQR)	<b>579</b>	268 (195 - 529)
1.4 Median number of side-rooms in hospital (IQR)	<b>149</b>	43 (30 - 107)

Number of Deaths	Your Site	NI Whole Sample (n=13)
Median number of all deaths occurring in the financial year (Round 1 - 1st April 2006 - 31st March 2007: Round 2 – 1st April 2007 – 31st March 2008) (IQR)	<b>876</b>	452 (245 - 688)
Data Gathering Periods (Round 1 – 01/09/06 – 30/11/06; Round 2 – 01/10/08 – 31/12/08)		
Median number of all deaths occurring in data gathering period (IQR)	<b>226</b>	122 (67 - 164)

Estimate of LCP Use	Your Site	NI Whole Sample (n=13)
Length of time (in months) that the LCP has been in use in your hospital (median) (IQR)	56	49 (22 - 56)
Data Gathering Periods (Round 1 – 01/09/06 – 30/11/06; Round 2 – 01/10/08 – 31/12/08)		
Total percentage of wards estimated to be using an LCP	100%	79%
Total percentage of deaths on an LCP in data gathering period	23%	20%

### Commentary: General Hospital Demographics as at October 2008

- On average participating hospitals have been using the LCP for 49 months (median) with 4 hospitals having less than 22 months experience and 4 hospitals having more than five years experience.
- The ‘Northern Ireland Whole Sample’ proportion of wards reported to be ‘using’ the LCP was **79%**. This suggests that the LCP is quite widely spread throughout participating hospitals.
- On average, **20%** of all patients who died between October 1st 2008 and December 31st 2008 in participating hospitals were cared for using an LCP. When interpreting this statistic, it is important to remember that the LCP is not applicable for all deaths in the hospital environment (eg sudden/unexpected death). Diagnosing dying remains a clinical challenge and more research is urgently needed to identify those signs and symptoms that indicate approaching death.

### Section 3: Availability of support for implementation and sustainability

### Supporting Literature

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

Supporting Leaflets available for use	Your Site	NI Whole Sample (n=13)
Organisation of Facilities	Yes	62% (8/13)
Local procedures after death	Yes	85% (11/13)
Bereavement leaflet	Yes	69% (9/13)
LCP Coping with Dying leaflet	No	8% (1/13)
Leaflet explaining the LCP (patient/carers)	No	23% (3/13)
Leaflet explaining the LCP (health professional)	No	38% (5/13)

### Personnel

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

Key Personnel	Your Site	NI Whole Sample (n=13)
2.4 Proportion of Hospitals with a Specialist Palliative Care Team	Yes	100% (13/13)
2.5 Proportion of Hospitals with one or more LCP Facilitators or equivalent	No	39% (5/13)

2.5.1 For Hospitals with one or more LCP Facilitator or equivalent (n=5)		
Total number of posts	<b>0</b>	5 posts
Median number of posts per hospital		1
Median whole time equivalent (WTE) per hospital (n=59) (IQR)	<b>0</b>	1.0 (0.3 – 1.0)
Nursing Profession (% YES)	-	100% (5/5)
Medical Profession (% YES)		0% (0/5)
Allied Health Professional (% YES)		0% (0/5)
Other (% YES)		0% (0/5)
Member of Hospital Specialist Palliative Care Team (% YES)	-	100% (5/5)

### Commentary: Availability of support for implementation and sustainability

- The availability of appropriate information leaflets in the environment is inconsistent. Leaflets regarding procedures after death and bereavement were available most often (85% and 69% of hospitals respectively), but leaflets explaining the LCP to healthcare professionals and carers were less often available (38% & 23% respectively). The LCP Coping with Dying Leaflet was only available in 8% of hospitals. 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 to high quality verbal communication has been shown to lessen the burden of bereavement (Lautrette et al, 2007).
- 100% of all participating hospitals had a Specialist Palliative Care Team (SPCT). The SPCT 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).
- Only 38% of hospitals employed an LCP Facilitator or equivalent. Where such a facilitator is employed the post holder is always from the nursing profession, and most likely to be working full-time.

## Section 4: Continuing Education, Training and Audit

### Education and Training

The provision of ongoing education, training and audit are also important aspects underpinning the delivery of quality care to dying patients and Recommendation 10 of the NICAN position paper 'Defining end of life care' suggests that "End of life care, should become a core element of all pre-registration, post registration and clinical education programmes. Further opportunities for multi-disciplinary and multi-professional learning should be developed. Such learning should enable professionals to develop sound knowledge, skills and competencies around palliative and end of life care." (NICAN 2008,p22).

Education and Training for Care of the Dying	Your Site	NI Whole Sample (n=13)
4.1 – 4.3 Hospitals with an in-house continuing education programme for care of the dying:		
Medical staff (% YES)	No	38% (5/13)
Nursing Staff (% YES)	No	62% (8/13)
Non-Qualified clinical staff (% YES)	No	23% (3/13)

### Audit

Audit of Care of the Dying	Your Site	NI Whole Sample (n=13)
4.4 Routine collection of all completed LCPs takes place (% YES)	No	23% (3/13)
4.4.1 For all hospitals where routine collection of all LCPs takes place		
Hospital Audit Department Responsible (% YES)	-	0% (0/3)
LCP Facilitator Responsible (% YES)		100% (3/3)
Other Responsible (% YES)*		0% (0/3)
4.5 Formal audit of LCP taken place in last 12 months (% YES)	Yes	77% (10/13)
4.5.1 For all hospitals where formal audit has taken place in the last 12 months		
Intention to repeat in next 12 months – 2 years (% YES)	Don't Know	30% (3/10)
Results fed back to clinical teams (% YES)	Yes	80% (8/10)
Results fed back to Trust board (% YES)	Yes	40% (4/10)
4.6 Report assessing the views of carers re care of the dying produced between 31st August 2007 and 1st September 2008 (% YES)	No	0% (0/13)

### Commentary: Continuing education, training and audit

- Ongoing in house training in care of the dying for qualified nursing staff was available in 62% of hospitals, but provision for medical and non-qualified staff was less often available (38% and 23% respectively).
- Over three quarters (77%) of hospitals conducted a formal audit using LCP documentation in the last 12 months, however only 30% stated that it is likely to be repeated within the next 2 years. The results of audits undertaken are often (80%) fed back to healthcare professionals providing the care, but are less likely (40%) to be fed back to the Trust Board. 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), however none of the participating hospitals had produced a report assessing the perspectives of informal carers regarding care delivered in the dying phase in the previous 12 months.

### Section 5: Part A Key Findings

- 13 hospitals from 5 hospital trusts provided a total of 274 patient cases. Four hospitals submitted the full sample size of 30.
- Data for the audit has been mainly submitted by nurses or those designated as an 'LCP Coordinator'
- The LCP had been in use for 49 months on average (median)
- 100% of hospitals had a Hospital Specialist Palliative Care Team
- 39% of hospitals had an LCP Facilitator or equivalent working on average 1.0 wte
- Only 8% of hospitals had a Coping with Dying Leaflet or equivalent available for use
- 62% of hospitals had an ongoing education programme for Nurses in care of the dying, and 38% had such a programme for Doctors.
- 77% of hospitals had conducted an audit of LCPs within the last 12 months, but only 40% of these fed the results back to the Trust Board
- No 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 RESULTS**

**Section 1: Demographic Data**

	<b>Your Site (n=30)</b>	<b>NI Whole Sample (n=274)</b>
Patient Gender = Female	<b>57% (17/30)</b>	53% (144/274)
Median Patient Age (IQR)	<b>72 (59 - 81)</b>	80 (73 – 87)
Median hours on LCP (IQR)	<b>38 (7 - 134)</b>	36 (12 – 82)

Primary Diagnosis

	<b>Your Site (n=30)</b>	<b>NI Whole Sample (n=274)</b>
Cancer	<b>43% (13/30)</b>	35% (97/274)
Non Cancer	<b>57% (17/30)</b>	65% (177/274)

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

	<b>Your Site (n=30)</b>	<b>NI Whole Sample (n=274)</b>
CANCER		
Lung (small and non-small cell)	<b>7% (2/30)</b>	7% (19/274)
Breast	<b>3% (1/30)</b>	4% (10/274)
Colon	<b>0% (0/30)</b>	4% (10/274)
Lymphoid, haematopoietic C81-96	<b>7% (2/30)</b>	4% (10/274)
Brain	<b>10% (3/30)</b>	2% (6/274)
Oesophagus	<b>0% (0/30)</b>	2% (6/274)

	<b>Your Site (n=30)</b>	<b>NI Whole Sample (n=274)</b>
NON CANCER		
Pneumonia	<b>30% (9/30)</b>	23% (63/274)
Stroke	<b>3% (1/30)</b>	11% (29/274)
Heart Failure (I50)	<b>3% (1/30)</b>	7% (20/274)
Chronic Respiratory Disease J40-70	<b>3% (1/30)</b>	6% (17/274)
Chronic Renal Failure	<b>7% (2/30)</b>	5% (14/274)
All Other Non Cancer	<b>3% (1/30)</b>	5% (14/274)

### Commentary: Demographic Data

- Just under two thirds of patients in the sample (65%) had a primary diagnosis other than cancer.
- Females made up over half of the sample, and the average age at death for both males and females was 80 years.
- Patients were cared for on an LCP for a median of 36 hours.

### 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.

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

## Domain 1: Physical Comfort of the Patient

### Comfort Measures

#### Initial Assessment LCP Goals 1 and 2

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

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	92	252	1	2	7	20
Hospital IQR – all (%) (n = 13)		86 – 100%		0 – 0%		0 – 12%	
<b>Your Site</b>	<b>30</b>	<b>90</b>	<b>27</b>	<b>0</b>	<b>-</b>	<b>10</b>	<b>3</b>

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
2.1 Pain							
NI Whole Sample	274	94	258	3	9	3	7
Hospital IQR - all (%) (n=13)		90 – 100%		0 – 6%		0 – 5%	
<b>Your Site</b>	<b>30</b>	<b>97</b>	<b>29</b>	<b>0</b>	<b>-</b>	<b>3</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
2.2 Agitation							
NI Whole Sample	274	89	245	8	21	3	8
Hospital IQR - all (%) (n=13)		84 – 95%		2 – 13%		0 – 5%	
<b>Your Site</b>	<b>30</b>	<b>87</b>	<b>26</b>	<b>10</b>	<b>3</b>	<b>3</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.3 RTS							
NI Whole Sample	274	82	225	14	38	4	11
Hospital IQR - all (%) (n=13)		77 – 90%		5 – 20%		0 – 8%	
<b>Your Site</b>	<b>30</b>	<b>73</b>	<b>22</b>	<b>23</b>	<b>7</b>	<b>3</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.4 Nausea & Vomiting							
NI Whole Sample	274	82	225	14	38	4	11
Hospital IQR - all (%) (n=13)		77 – 88%		7 – 20%		0 – 6%	
<b>Your Site</b>	<b>30</b>	<b>73</b>	<b>22</b>	<b>23</b>	<b>7</b>	<b>3</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
2.5 Dyspnoea							
NI Whole Sample	274	32	87	7	19	61	168
Hospital IQR - all (%) (n=13)		0 – 77%		0 – 13%		8 – 100%	
<b>Your Site</b>	<b>30</b>	<b>0</b>	<b>-</b>	<b>0</b>	<b>-</b>	<b>100</b>	<b>30</b>

Initial Assessment Goal 3

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

Undertaking cardiopulmonary resuscitation in a patient with advanced chronic disease who is deemed to be in the last hours and days of life is generally viewed as a futile intervention.

Therefore, it is important that the decision ‘not for cardiopulmonary resuscitation’ has been appropriately recorded once the 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 implantable Cardioverter Defibrillators (ICD) is one important element in the improved longevity of cardiac patients. However, Willner (2003) suggests that an ICD can alter unstable cardiac rhythms and he suggests that “the ICD discharges can be physically and emotionally distressing to patients”. It is important, therefore, that a defined process is followed (including making information available to patients and carers) to deactivate such devices when a patient enters the last hours and days of life.

**LCP Goal 3: Discontinue inappropriate interventions**

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
<b>3.1 Blood Tests</b>							
NI Whole Sample	262	96	251	2	6	2	5
Hospital IQR - all (%) (n=13)		93 – 100%		0 – 5%		0 – 3%	
<b>Your Site</b>	<b>30</b>	<b>97</b>	<b>29</b>	<b>0</b>	<b>-</b>	<b>3</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
<b>3.2 Antibiotics</b>							
NI Whole Sample	238	75	179	3	7	22	52
Hospital IQR - all (%) (n=13)		76 – 94%		0 – 4%		2 – 18%	
<b>Your Site</b>	<b>25</b>	<b>96</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>4</b>	<b>1</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
<b>3.3 IV Fluids/Medications</b>							
NI Whole Sample	258	74	192	23	59	3	7
Hospital IQR - all (%) (n=13)		67 – 86%		13 – 29%		0 – 4%	
<b>Your Site</b>	<b>29</b>	<b>66</b>	<b>19</b>	<b>28</b>	<b>8</b>	<b>7</b>	<b>2</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.4 Not for CPR							
NI Whole Sample	274	96	262	0.4	1	4	11
Hospital IQR - all (%) (n=13)		89 – 100%		0 – 0%		0 – 10%	
<b>Your Site</b>	<b>30</b>	<b>93</b>	<b>28</b>	<b>0</b>	<b>-</b>	<b>7</b>	<b>2</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3.5 De-activate cardiac defibrillators (ICD's)							
NI Whole Sample	77	51	39	30	23	19	15
Hospital IQR - all (%) (n=11)		13 – 100%		0 – 17%		0 – 33%	
<b>Your Site</b>	<b>10</b>	<b>80</b>	<b>8</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>2</b>

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

#### LCP Goals 3a and 3b

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

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

	Available & applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3a							
NI Whole Sample	274	89	244	1	3	10	27
Hospital IQR – all (%) (n=13)		79 – 96%		0 – 2%		4 – 18%	
<b>Your Site</b>	<b>30</b>	<b>87</b>	<b>26</b>	<b>0</b>	<b>-</b>	<b>13</b>	<b>4</b>

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

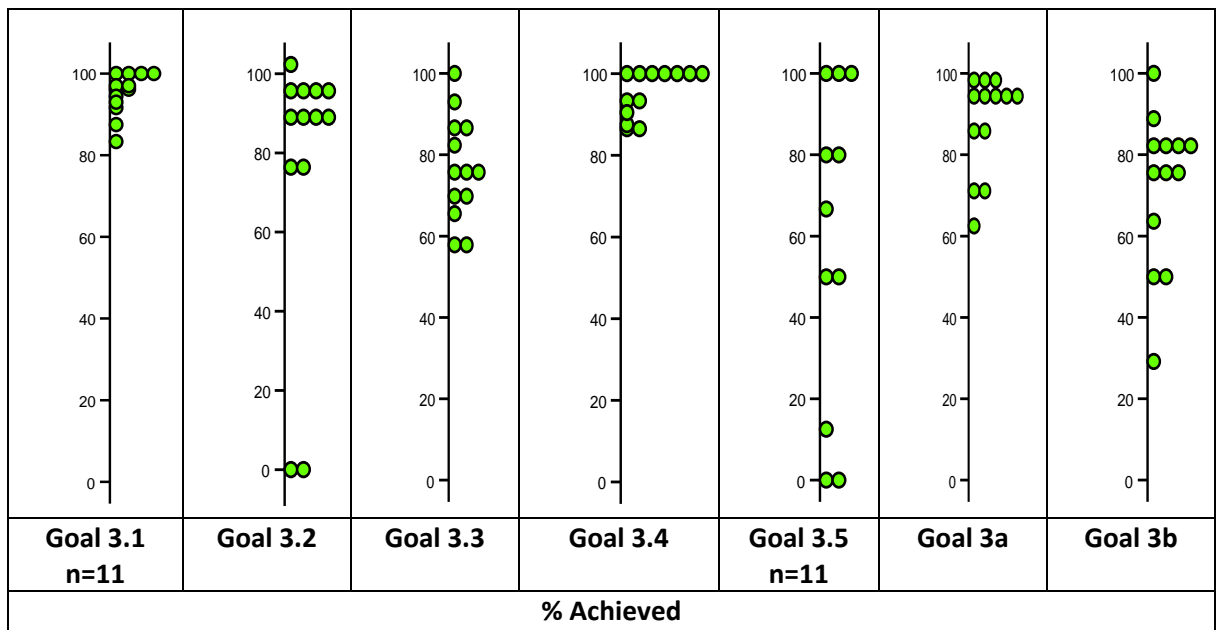
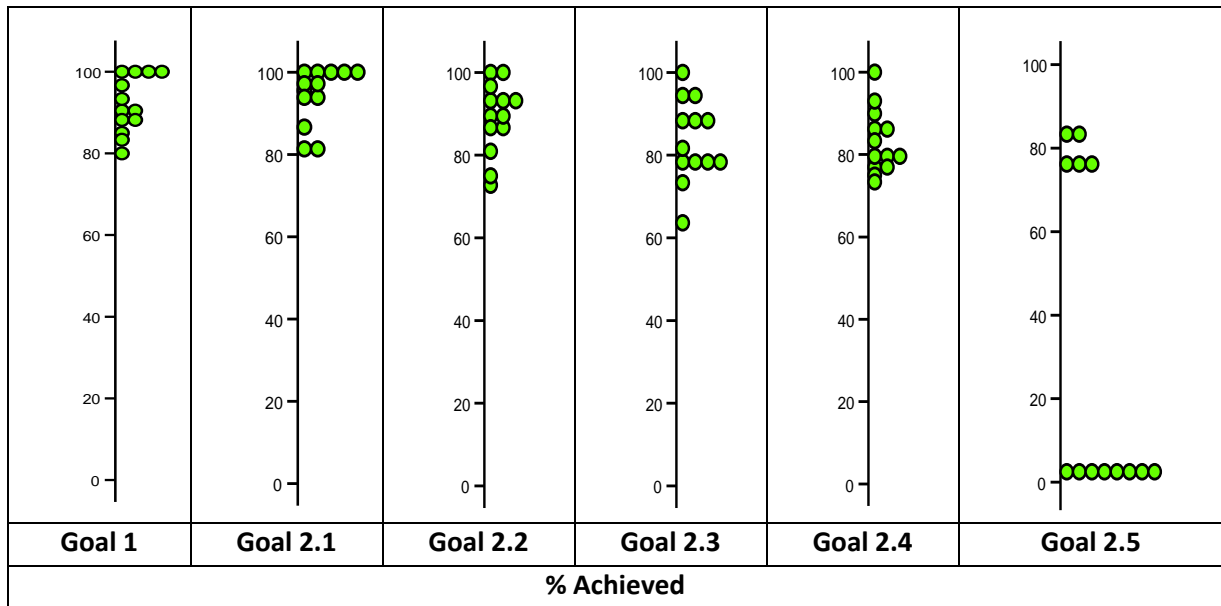
quickly as possible and goal 3b records how often this has been achieved within 4 hours of the decision.

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

	Available & applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
3b							
NI Whole Sample	200	72	144	4	8	24	48
Hospital IQR - all (%) (n=13)		57 – 85%		0 – 7%		11 – 38%	
<b>Your Site</b>	<b>26</b>	<b>73</b>	<b>19</b>	<b>4</b>	<b>1</b>	<b>23</b>	<b>6</b>

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  
Dotplots (n=13)



### **Ongoing Assessment of Physical Condition**

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

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

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

The total number of potential assessments (ie if all 274 patients were included in the sample and all were on the pathway for at least 24 hours) =  $274 \times 6 = 1644$  for all 4 hourly assessed goals and  $274 \times 2 = 548$  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	%
<b>Pain</b>							
NI Whole Sample	1351	80	1086	10	135	10	130
Hospital IQR - all (%) (n= 13)		73 – 87%		6 – 15%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>80</b>	<b>121</b>	<b>11</b>	<b>17</b>	<b>9</b>	<b>13</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
<b>Agitation</b>							
NI Whole Sample	1351	81	1095	9	128	9	128
Hospital IQR - all (%) (n=13)		73 – 89%		4 – 15%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>83</b>	<b>125</b>	<b>9</b>	<b>13</b>	<b>9</b>	<b>13</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
<b>Respiratory Tract Secretions (RTS)</b>							
NI Whole Sample	1351	74	1005	16	215	10	131
Hospital IQR - all (%) (n=13)		64 – 85%		13 – 22%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>77</b>	<b>116</b>	<b>15</b>	<b>22</b>	<b>9</b>	<b>13</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
<b>Nausea &amp; Vomiting</b>							
NI Whole Sample	1351	89	1205	1	17	10	129
Hospital IQR - all (%) (n=13)		80 – 96%		0 – 2%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>91</b>	<b>138</b>	<b>0</b>	<b>0</b>	<b>9</b>	<b>13</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Dyspnoea							
NI Whole Sample	1351	67	911	8	110	24	330
Hospital IQR - all (%) (n=13)		56 – 89%		1 – 17%		6 – 31%	
<b>Your Site</b>	<b>151</b>	<b>77</b>	<b>116</b>	<b>16</b>	<b>24</b>	<b>7</b>	<b>11</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Mouth Care							
NI Whole Sample	1351	87	1172	4	48	10	131
Hospital IQR - all (%) (n=13)		78 – 93%		1 – 7%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>87</b>	<b>131</b>	<b>4</b>	<b>6</b>	<b>9</b>	<b>14</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Micturition							
NI Whole Sample	1351	90	1211	1	11	10	129
Hospital IQR - all (%) (n=13)		82 – 97%		0 – 1%		3 – 17%	
<b>Your Site</b>	<b>151</b>	<b>89</b>	<b>135</b>	<b>2</b>	<b>3</b>	<b>9</b>	<b>13</b>

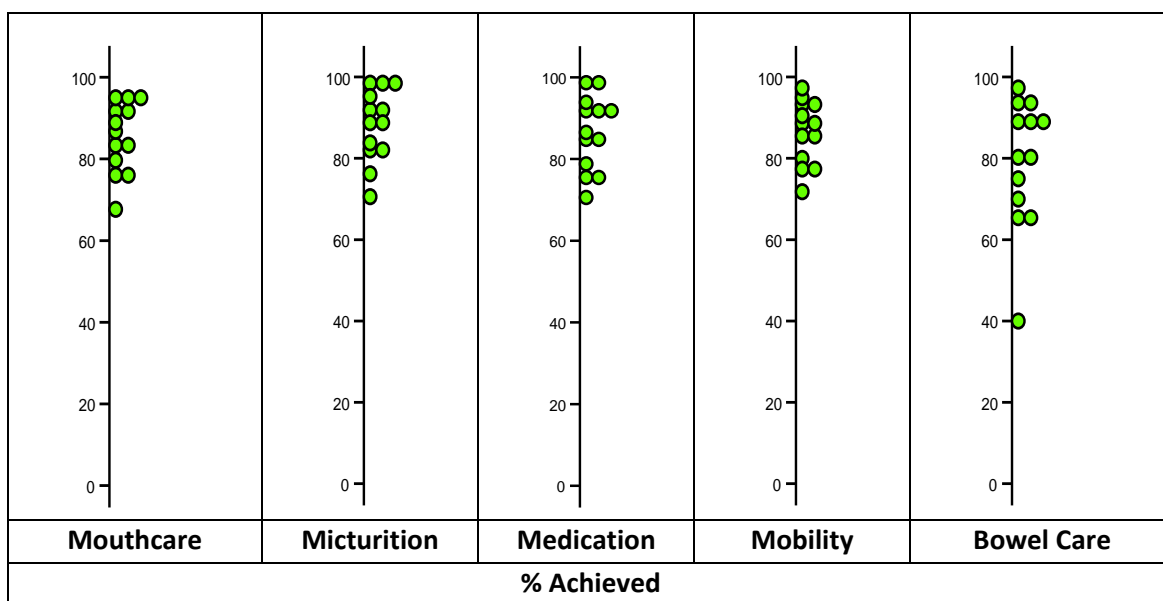
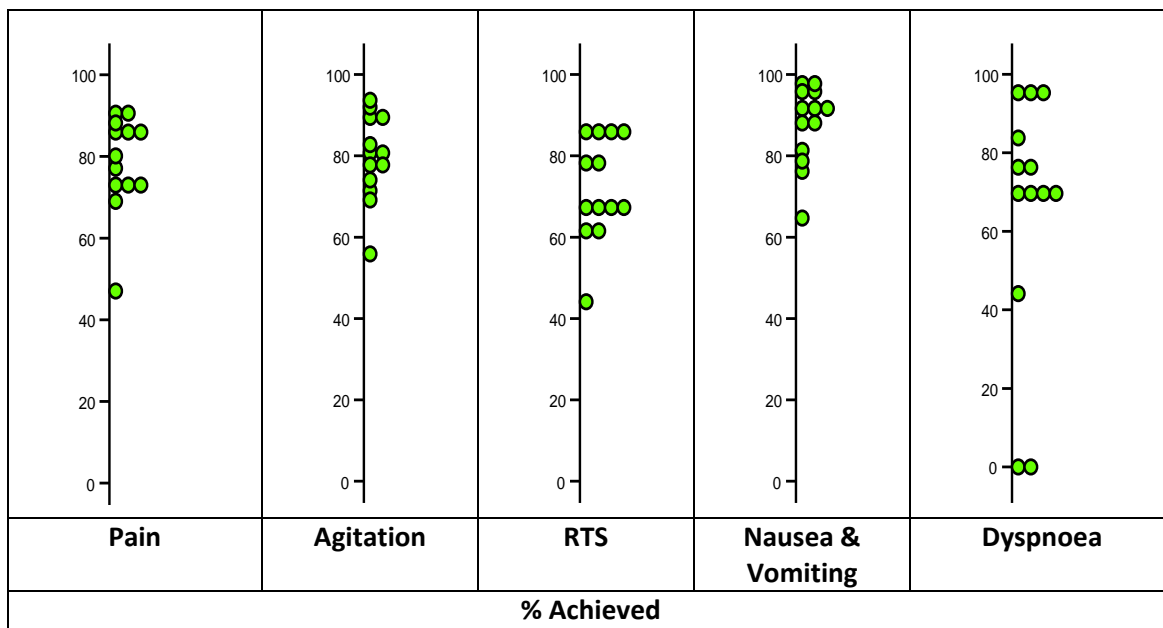
	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Medication							
NI Whole Sample	1263	88	1106	1	13	11	144
Hospital IQR - all (%) (n=13)		77 – 93%		0 – 1%		6 – 20%	
<b>Your Site</b>	<b>146</b>	<b>86</b>	<b>125</b>	<b>3</b>	<b>4</b>	<b>12</b>	<b>17</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Mobility*							
NI Whole Sample	448	87	390	0.4	2	13	56
Hospital IQR - all (%) (n=13)		79 – 93%		0 – 0%		7 – 20%	
<b>Your Site</b>	<b>50</b>	<b>86</b>	<b>43</b>	<b>0</b>	<b>0</b>	<b>14</b>	<b>7</b>

	Eligible Assessments excluding not applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
Bowel Care*							
NI Whole Sample	448	82	366	1	3	18	79
Hospital IQR - all (%) (n=13)		68 – 91%		0 – 0%		9 – 28%	
<b>Your Site</b>	<b>50</b>	<b>80</b>	<b>40</b>	<b>0</b>	<b>0</b>	<b>20</b>	<b>10</b>

\* Goals assessed 12 hourly on the LCP

**Domain 1 Physical Comfort of the Patient: Ongoing Assessment**  
 Dotplots (n=13)



**Commentary: 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 more than 80% of patients overall in this sample, and three quarters of organisations achieved these goals for at least 75% of their patients.

- The percentage achieved was particularly high for anticipatory prescribing for pain (94%).
- The percentage 'achieved' for anticipatory prescribing for dyspnoea was 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.
- The discontinuation of blood tests and the recording of 'not for Cardiopulmonary Resuscitation (CPR)' were achieved in an overwhelming majority (96%) of patients, with three quarters of hospitals achieving each of these goals for over 85% of their patients.
- There was more variation across hospitals in percentage achieved for the discontinuation of IV fluids/medications, and there was a greater proportion of 'variance' (23%, Hospital IQR = 13% – 29%) recorded. This shows individualised decision making and patient care directed by the clinical team.
- There is much diversity in the recording of the deactivation of Implantable Cardioverter Defibrillators (ICD's). Again, this goal has been added to the LCP relatively recently (2 hospitals did not have this goal on their pathway) and it was deemed applicable only for a minority of patients (77). Even so, there was missing data for one fifth of patients deemed eligible for this goal.
- Nursing interventions were assessed, and those agreed to be inappropriate and potentially cause discomfort at the end of life, were discontinued in 89% of patients, and a syringe driver was set up within 4 hours in 72% of those patients who required one. However, again, the level of missing data was relatively high for these goals.
- In the last hours of their lives, documentation for the 4 hourly assessment goals indicated that patients were found to be comfortable in terms of their physical symptoms for 80% – 90% assessments, except for Dyspnoea (67%) and RTS (74%).
- The highest proportion of variance 'ie patient not comfortable on assessment' was recorded for RTS (16%), with Pain (10%) and Agitation (9%) the next 2 most common symptoms.
- The levels of 'goal not documented' (missing) were relatively low for the majority of the goals assessed 4 hourly (9% - 13% of assessments), apart from Dyspnoea (24%) and Bowel Care (18%).

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

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

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

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

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

	Available & Applicable		Achieved		Variance		Not documented	
	N	%	N	%	N	%	N	
5a1 Awareness of diagnosis (patient)								
NI Whole Sample	147	63	93	18	27	18	27	
Hospital IQR - all (%) (n=13)		51 – 79%		0 – 30%		4 – 26%		
<b>Your Site</b>	<b>22</b>	<b>77</b>	<b>17</b>	<b>0</b>	<b>-</b>	<b>23</b>	<b>5</b>	

	Available & Applicable		Achieved		Variance		Not documented	
	N	%	N	%	N	%	N	
5a2 Awareness of diagnosis (carer)								
NI Whole Sample	274	90	247	1	3	9	24	
Hospital IQR - all (%) (n=13)		85 – 100%		0 – 2%		0 – 13%		
<b>Your Site</b>	<b>30</b>	<b>83</b>	<b>25</b>	<b>0</b>	<b>-</b>	<b>17</b>	<b>5</b>	

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5b1 Recognition of dying (patient)							
NI Whole Sample	144	58	83	19	28	23	33
Hospital IQR - all (%) (n=13)		45 – 71%		3 – 24%		8 – 32%	
<b>Your Site</b>	<b>19</b>	<b>63</b>	<b>12</b>	<b>5</b>	<b>1</b>	<b>32</b>	<b>6</b>

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
5b2 Recognition of dying (carer)							
NI Whole Sample	274	91	248	1	3	8	23
Hospital IQR - all (%) (n=13)		85 – 98%		0 – 2%		0 – 13%	
<b>Your Site</b>	<b>30</b>	<b>83</b>	<b>25</b>	<b>0</b>	<b>-</b>	<b>17</b>	<b>5</b>

**LCP Goal 6 – Spiritual and Religious Needs Assessed**

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
6.1 Spiritual and religious needs assessed (patient)							
NI Whole Sample	151	42	63	28	43	30	45
Hospital IQR - all (%) (n=13)		27 – 63%		4 – 39%		20 – 40%	
<b>Your Site</b>	<b>21</b>	<b>52</b>	<b>11</b>	<b>24</b>	<b>5</b>	<b>24</b>	<b>5</b>

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
6.2 Religious and spiritual needs assessed (carer)							
NI Whole Sample	274	80	218	4	10	17	46
Hospital IQR - all (%) (n=13)		74 – 87%		0 – 8%		9 – 24%	
<b>Your Site</b>	<b>30</b>	<b>67</b>	<b>20</b>	<b>7</b>	<b>2</b>	<b>27</b>	<b>8</b>

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

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

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

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Psychological Insight support (patient)							
NI Whole Sample	448	82	366	1	3	18	79
Hospital IQR - all (%) (n=13)		72 – 91%		0 – 1%		9 – 28%	
<b>Your Site</b>	<b>50</b>	<b>78</b>	<b>39</b>	<b>0</b>	<b>0</b>	<b>22</b>	<b>11</b>

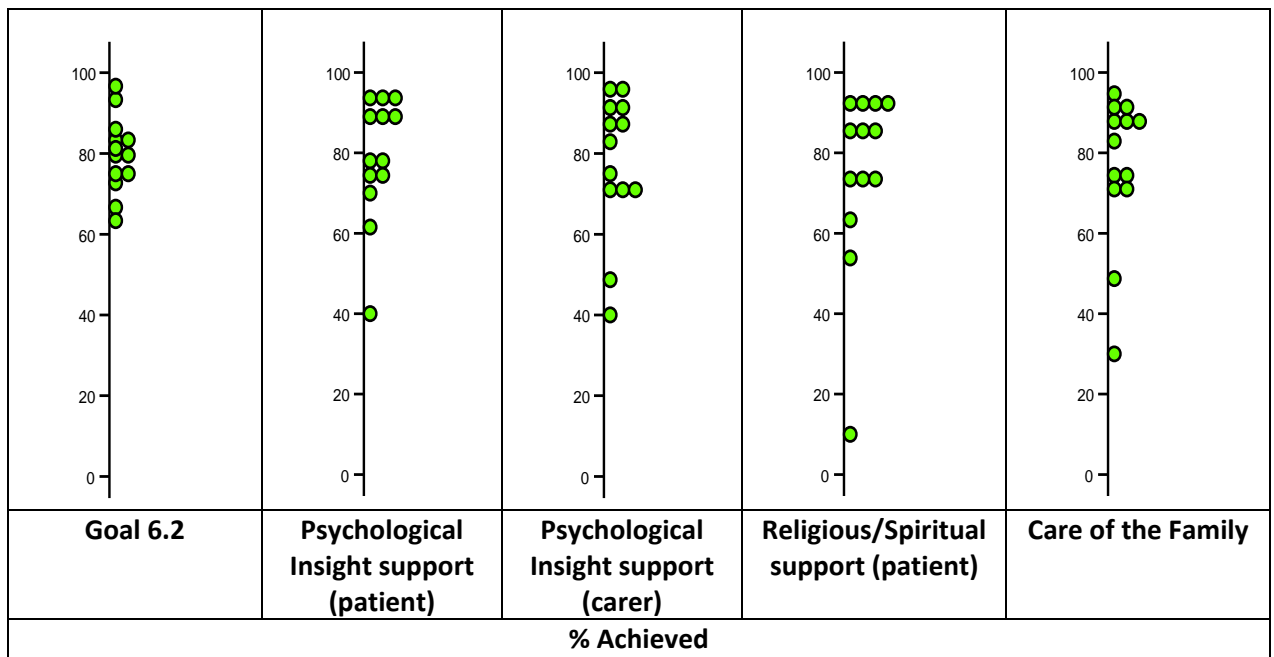
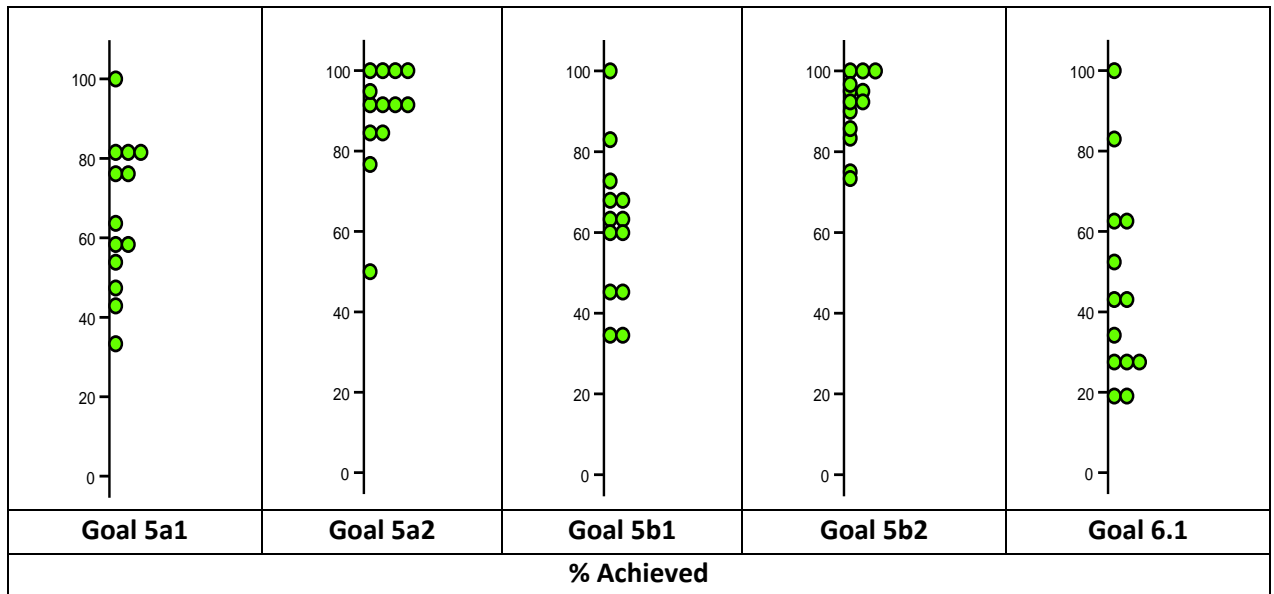
	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Psychological Insight support (carer)							
NI Whole Sample	448	80	359	2	7	19	82
Hospital IQR - all (%) (n=13)		71 – 91%		0 – 2%		9 – 28%	
<b>Your Site</b>	<b>50</b>	<b>72</b>	<b>36</b>	<b>2</b>	<b>1</b>	<b>26</b>	<b>13</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Religious/Spiritual support (patient)							
NI Whole Sample	448	79	355	1	6	19	87
Hospital IQR - all (%) (n=13)		68 – 91%		0 – 4%		9 – 32%	
<b>Your Site</b>	<b>50</b>	<b>72</b>	<b>36</b>	<b>0</b>	<b>0</b>	<b>28</b>	<b>14</b>

	Available & Applicable	Achieved		Variance		Not Documented	
	N	%	N	%	N	%	N
Care of the family							
NI Whole Sample	448	79	356	1	5	19	87
Hospital IQR - all (%) (n=13)		71 – 90%		0 – 1%		10 – 28%	
<b>Your Site</b>	<b>50</b>	<b>72</b>	<b>36</b>	<b>2</b>	<b>1</b>	<b>26</b>	<b>13</b>

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

Dot Plots (n=13)



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

- The results illustrate that 63% of patients were aware of their diagnosis and 58% were aware that they had entered the dying phase. In five cases nothing was documented at the point of delivery of care for these goals, and a similarly high proportion of 'variance' was documented. This suggests achieving these goals may be challenging, and may highlight a need for further education and training.
- In contrast to the insight of the patient, in the vast majority of cases it is documented that the carer was aware of the patient's diagnosis (90%), and the fact that they were deemed to be entering the dying phase (91%). There is also evidence of less missing data (goal not documented) and considerably less variation across hospitals for these goals, with three quarters of hospitals achieving them in at least 85% of cases. 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 patients was only achieved for just 42% of patients, whereas in contrast for the carers, this was achieved for 80%. 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 with patients 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.
- Whilst the assessment of patients' awareness of their diagnosis and prognosis, and their spiritual/religious needs appear to be challenging, the dot plots, showing variation across hospitals for these goals, do indicate that levels of good practice can be achieved.
- It is interesting to note, however, that some of the highest levels of 'variance' were recorded for patients' insight (diagnosis and recognition of dying) and the spiritual assessment of patients (18%, 19% and 28% respectively). Local analysis of the variance sheets should, therefore, lead to better understanding of why these goals were not met.
- The twelve hourly assessments of psychological and spiritual well-being, for both patients and carers were deemed to be 'achieved' in around four fifths of cases, with almost all other cases being 'not documented'.

**Domain 3: Communication (Patient, Carer and other Health Care Professionals)****Assessing ability to communicate, explanation and understanding of the plan of care (patient and carer) and informing primary care of the patient's deterioration and death – Initial Assessment and Care After Death Sections**Patients and Carers – LCP Goal 4

Good communication with patients, carers and other health professionals is vital at all times during the patient's journey, particularly when the patient is entering the dying phase. Meaningful communication is dependent on the ability of both patients and carers to understand and communicate effectively. Some may require the services of a translator, or may have learning difficulties or hearing impairments. Goal 4 on the LCP prompts consideration of these issues for both patients and carers:

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

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
4.1 Patient							
NI Whole Sample	157	69	108	14	22	17	27
Hospital IQR – all (%) (n=13)		61 – 80%		0 – 23%		9 – 22%	
<b>Your Site</b>	<b>21</b>	<b>71</b>	<b>15</b>	<b>5</b>	<b>1</b>	<b>24</b>	<b>5</b>

	Available & Applicable	Achieved		Variance		Not documented	
		%	N	%	N	%	N
4.2 Carer							
NI Whole Sample	274	89	245	1	3	9	26
Hospital IQR – all (%) (n=13)		83 – 97%		0 – 2%		2 – 17%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

LCP Goals 10 and 11

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 and that healthcare professionals are sure that carers fully understand. Goals 10 and 11 on the LCP prompt appropriate communication in this regard.

**LCP Goals 10 and 11**

	Available & Applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
10.1 Plan of care explained and discussed with patient							
NI Whole Sample	138	49	68	28	38	23	32
Hospital IQR – all (%) (n=13)		38 – 71%		14 – 36%		4 – 32%	
<b>Your Site</b>	<b>18</b>	<b>56</b>	<b>10</b>	<b>11</b>	<b>2</b>	<b>33</b>	<b>6</b>

	Available & Applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
10.2 Plan of care explained and discussed with carer							
NI Whole Sample	274	86	237	1	3	12	34
Hospital IQR - all (%) (n=13)		80 – 95%		0 – 2%		4 – 18%	
<b>Your Site</b>	<b>30</b>	<b>83</b>	<b>25</b>	<b>0</b>	<b>-</b>	<b>17</b>	<b>5</b>

	Available & Applicable	Achieved		Variance		Not Documented	
		N	%	N	%	N	%
11 Family/other express understanding of plan of care							
NI Whole Sample	274	83	228	1	4	15	42
Hospital IQR - all (%) (n=13)		78 – 91%		0 – 5%		8 – 22%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>.</b>	<b>20</b>	<b>6</b>

Primary Care – LCP Goals 9 and 12

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

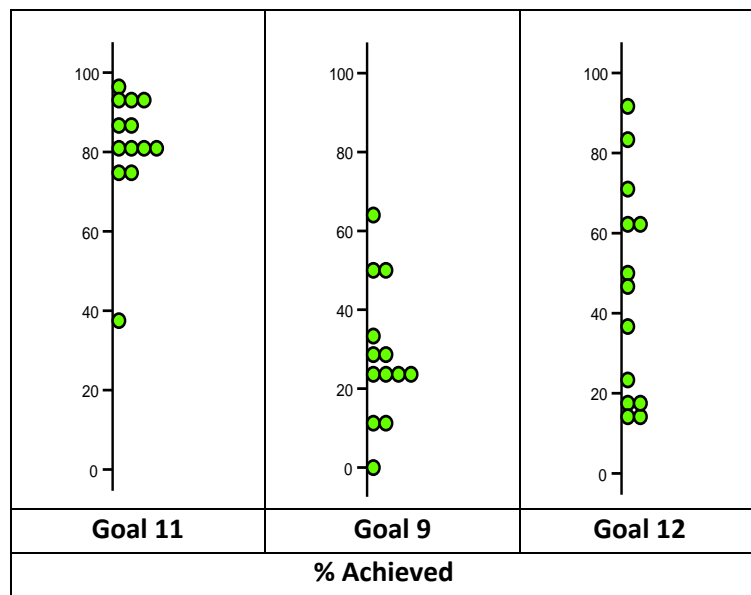
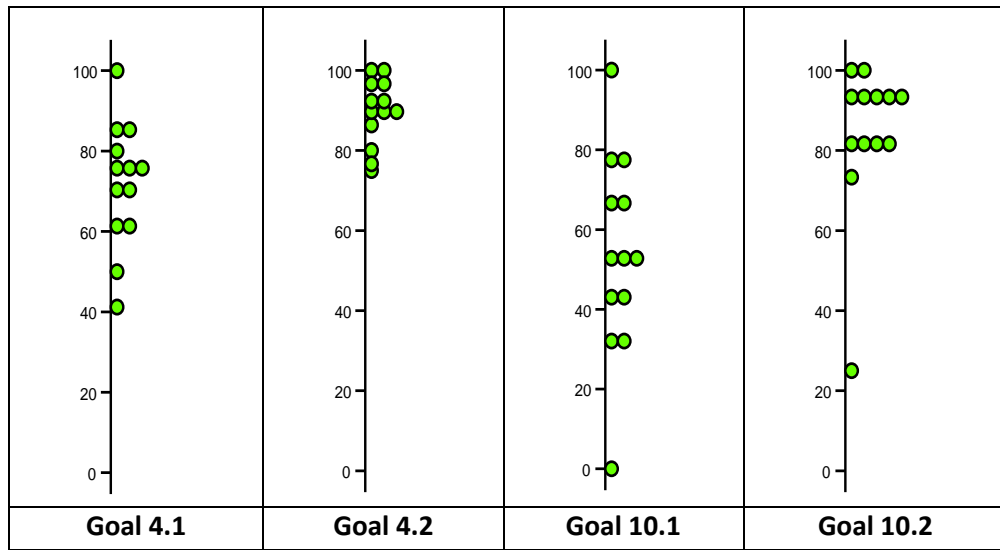
**LCP Goals 9 and 12**

	Available & Applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
9 GP aware of patient's deteriorating condition							
NI Whole Sample	274	28	76	35	97	37	101
Hospital IQR - all (%) (n=13)		17 – 42%		25 – 40%		18 – 59%	
<b>Your Site</b>	<b>30</b>	<b>30</b>	<b>9</b>	<b>37</b>	<b>11</b>	<b>33</b>	<b>10</b>

	Available & Applicable	Achieved		Variance		Not Documented	
		%	N	%	N	%	N
12 GP informed of patient's death							
NI Whole Sample	274	45	122	18	48	38	104
Hospital IQR - all (%) (n=13)		17 – 66%		2 – 24%		13 – 62%	
<b>Your Site</b>	<b>30</b>	<b>23</b>	<b>7</b>	<b>3</b>	<b>1</b>	<b>73</b>	<b>22</b>

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

Dot Plots (n=13)



**% Achieved**

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

- Communication with the patient regarding the plan of care is undertaken in just 49% of patients who were not comatose at the time the LCP was commenced. The box plot shows quite wide variation between hospitals, but there is evidence of good practice from some hospitals.
- Explanation of the plan of care to carers, however, was achieved in an overwhelming 86% of cases and for 83% of cases the plan of care was said to be understood. Interestingly, understanding of the plan of care was expressed in 93% (220) of the 237 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 was less well achieved, particularly prior to but also after the patient's death (28% and 45% respectively). 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 were relatively high levels of missing data in this domain for communication with patients and primary care, variance recording was also relatively high for these goals. Local analysis of variance sheets should, therefore, enable better insight as to why such communication was not undertaken.

**Domain 4: Information (giving and receiving)**LCP Goals 7 - establishing contact information

It is important when communicating information of a sensitive nature around a patient's deteriorating condition/impending death that the most appropriate person is contacted at a suitable 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. Establishing how relatives or carers wish to be told of the patient's impending death is also very important. In some situations the next of kin may not be the most appropriate person to be contacted at the time of impending death or a list of people may be given or mobile numbers may be needed. Goal 7 on the LCP prompts health care professionals to collect and document appropriate information

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	88	240	0.4	1	12	33
Hospital IQR - all (%) (n=13)		79 – 94%		0 – 0%		6 – 21%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

LCP Goal 8 – information about hospital facilities

It is also important that written information is given to back up any conversation about facilities available to carers. This ensures that they are able to take full advantage during the last 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:

**LCP Goal 8: Family/other given hospital information**

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	80	218	4	10	17	46
Hospital IQR - all (%) (n=13)		73 – 90%		0 – 4%		8 – 24%	
<b>Your Site</b>	<b>30</b>	<b>83</b>	<b>25</b>	<b>3</b>	<b>1</b>	<b>13</b>	<b>4</b>

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

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

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	248	80	199	2	4	18	45
Hospital IQR - all (%) (n=13)		67 – 93%		0 – 3%		3 – 33%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

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

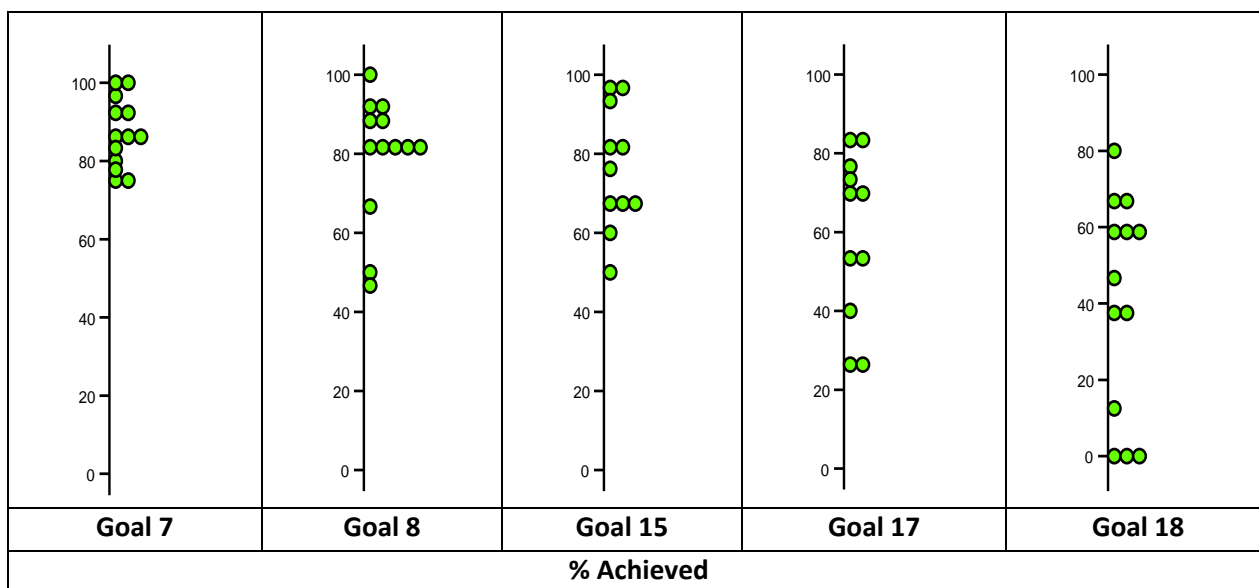
	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	248	64	159	11	28	25	61
Hospital IQR - all (%) (n=13)		40 – 77%		5 – 23%		17 – 44%	
<b>Your Site</b>	<b>30</b>	<b>77</b>	<b>23</b>	<b>3</b>	<b>1</b>	<b>20</b>	<b>6</b>

**LCP Goal 18: Bereavement leaflet given**

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	46	127	32	89	21	58
Hospital IQR - all (%) (n=13)		6 – 63%		10 – 68%		8 – 39%	
<b>Your Site</b>	<b>30</b>	<b>60</b>	<b>18</b>	<b>13</b>	<b>4</b>	<b>27</b>	<b>8</b>

**Domain 4: Information (giving and receiving)**

Dot plots (n=13)



**Commentary Domain 4 Information (giving and receiving):**

- Identifying and recording who to contact in the event of deterioration was achieved in the vast majority (88%) of cases and the dot plot and IQR show little variation between hospitals, with three quarters of hospitals achieving this goal for at least 4 in 5 cases.
- Hospital information leaflets were utilised and given out regularly, with 80% of relatives and carers being given information about hospital facilities and also about procedures.
- The proportion of missing data (12 – 25%) still remains an issue for these goals.

**Domain 5: Following appropriate procedures**Last Offices – LCP Goal 13

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

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	84	229	0.4	1	16	44
Hospital IQR - all (%) (n=13)		69 – 95%		0 – 0%		5 – 31%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

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

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

**LCP Goal 14: Procedures following death discussed or carried out**

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	272	82	222	1	4	17	46
Hospital IQR - all (%) (n=13)		66 – 95%		0 – 0%		5 – 32%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

Care of valuables – LCP Goal 16

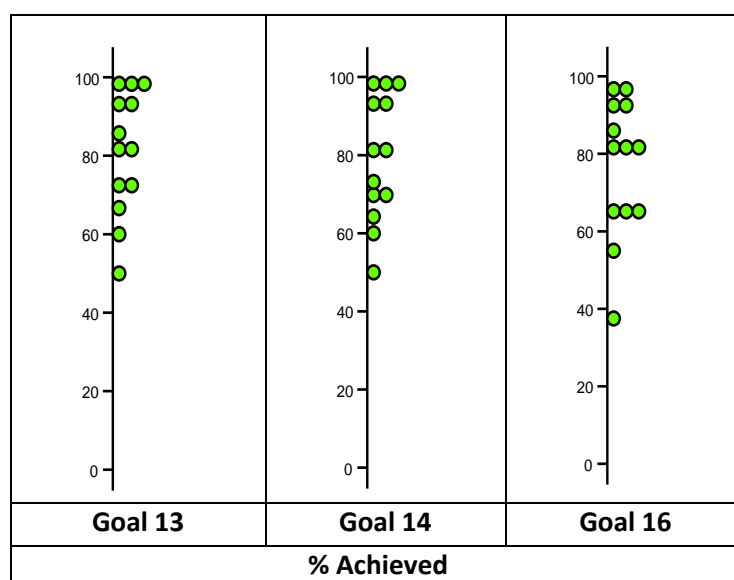
It is important that all items belonging to the patient are collected and stored appropriately, according to the hospital policy, until the family are able to collect them. Goal 16 on the LCP specifically addresses this:

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

	Available & Applicable	Achieved		Variance		Not documented	
	N	%	N	%	N	%	N
NI Whole Sample	274	80	220	1	4	18	50
Hospital IQR - all (%) (n=13)		65 – 93%		0 – 2%		6 – 33%	
<b>Your Site</b>	<b>30</b>	<b>80</b>	<b>24</b>	<b>0</b>	<b>-</b>	<b>20</b>	<b>6</b>

**Domain 5: Following Appropriate Procedures**

Dot plots (n=13)



**Commentary Domain 5: Following Appropriate Procedures**

- The ‘NI Whole Sample’ percentage achieved for this Domain is high, with at least 80% achieved for all goals.
- The dot plots and IQRs illustrate considerable variation in the performance of individual hospitals in terms of percentage ‘achieved’ for this domain, however three quarters of hospitals achieved this goal for at least 65% of their cases.

### Section 3: Medication Prescribing

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

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

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

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

PRN Medications	Your Site		NI Whole Sample	
PRN medication prescribed for Agitation or Restlessness (%Yes)	<b>97%</b>	<b>(29/30)</b>	87%	(239/274)
If PRN Medication was prescribed for Agitation or Restlessness				
PRN medication given (%Yes)	<b>52%</b>	<b>(15/29)</b>	41%	(99/239)
Drugs prescribed and given PRN				
Midazolam (% Yes)	<b>87%</b>	<b>(13/15)</b>	96%	(95/99)
Midazolam Median dose (mgs) (IQR) (mgs) 10th – 90th percentile (mgs)	<b>5</b> <b>(2.5 - 5)</b> <b>(1.75 - 8)</b>		2.5 (2.5 – 5) (2.5 – 10)	
Haloperidol (% Yes)	<b>0%</b>	<b>(0/15)</b>	0%	(0/99)
Haloperidol Median dose (mgs) (IQR) (mgs) 10th – 90th percentile (mgs)	-		-	
Levomepromazine (% Yes)	<b>13%</b>	<b>(2/15)</b>	2%	(2/99)
Levomepromazine Median dose (IQR) (mgs) 10th – 90th percentile (mgs)	<b>12.5</b> <b>-</b> <b>(12.5 - 12.5)</b>		12.5 - -	

Continuous Subcutaneous Infusion Medications	Your Site		NI Whole Sample	
Any medication prescribed for continuous subcutaneous infusion (%Yes)	<b>83%</b>	<b>(25/30)</b>	68%	(187/274)
Medication for Agitation or Restlessness prescribed for continuous subcutaneous infusion (%Yes)	<b>88%</b>	<b>(22/25)</b>	75%	(140/187)
If medication for Agitation and Restlessness was prescribed via continuous subcutaneous infusion				
Medication for Agitation or Restlessness given via continuous subcutaneous infusion (% Yes)	<b>100%</b>	<b>(22/22)</b>	100%	(140/140)
Drugs prescribed and given via continuous subcutaneous infusion for Agitation or Restlessness				
Midazolam (% Yes)	<b>77%</b>	<b>(17/22)</b>	89%	(125/140)
Midazolam – median total dose in driver in last 24 hours (mgs) (IQR) (mgs) 10th – 90th percentile (mgs)	<b>10</b> <b>(5 - 11.25)</b> <b>(2.5 - 36)</b>		10 (5 – 10) (5 – 15)	
Haloperidol (% Yes)	<b>23%</b>	<b>(5/22)</b>	8%	(11/140)
Haloperidol – median total dose in driver in last 24 hours (mgs) (IQR) (mgs) 10th – 90th percentile (mgs)	<b>1.5</b> <b>(1.5 - 4)</b> <b>(1.5 - 5)</b>		1.5 (1.5 – 3) (1 – 4.6)	

Levomepromazine (% Yes)	<b>18%</b>	<b>(4/22)</b>	11%	(16/140)
Levomepromazine – median total dose in driver in last 24 hours (mgs)	<b>6.25</b>		10	
(IQR) (mgs)	<b>(6.25 - 10.9375)</b>		(6.25 – 12.5)	
10th – 90th percentile (mgs)	<b>(6.25 - 12.5)</b>		(5.87 – 16.25)	

### Commentary: Medication Prescribing

- Anticipatory prescribing in care of the dying is important if the patient is to receive the right drug for the right symptom at the right time. It is of note that prescribing a drug does not mean that all patients receive the drug (41% - 99 of the 239 patients who were prescribed a drug). This supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed and administered drug for agitation and restlessness (96% - of the 99 patients prescribed and given a drug prn for this symptom; 89% of the 140 patients prescribed and given a drug for this symptom via continuous subcutaneous infusion).
- The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 2.5mg as a PRN dose over 24 hours. The median doses of haloperidol and levomepromazine were also relatively low. Audit sites who are frequently prescribing outside the 90<sup>th</sup> percentile need to review their practice.

## Section 4: Variance Reporting

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

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

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

Proportion of time variance written up	Your Site	NI Whole Sample	
Discontinue Inappropriate Interventions – IV Fluids/Medications	<b>(3/8)</b>	51%	(30/59)
Recognition of Dying - Patient	<b>(1/1)</b>	21%	(6/28)
Religious/Spiritual Needs assessed – Family/Other	<b>(0/2)</b>	10%	(1/10)
Bereavement Leaflet Given (after the death of the patient)	<b>(3/4)</b>	22%	(20/89)

The table below provides a summary of the content analysis performed on the limited number of reasons reported on the variance sheets for these goals. These data should be interpreted with caution as the sample sizes are very small

	Top 3
Discontinue Inappropriate Interventions – IV Fluids/Medications	<b>Medical Decision (21/30)</b> – including reducing rate or volume of fluids; continue until venflon tissues; continue until current bag is empty; <b>Family or Patient Reason (5/30)</b> – including family not available; family discussing the issue; continuation desired by family x 2; <b>Restatement of non-discontinuation only (4/30)</b> – no real explanation why given
Recognition of Dying - Patient	<b>Confusion – including Dementia (n=3/6)</b> <b>Unresponsive (n=2)</b> <b>Family request (n=1)</b>
Religious/Spiritual Needs assessed – Family/Other	<b>Family unavailable (n=1/1)</b>
Bereavement Leaflet Given (after the death of the patient)	<b>Leaflet not available (n=6/20);</b> <b>No Family in attendance (n=4/20)</b> <b>Leaflet offered but declined (n=4/20)</b>

### Commentary: Variance Reporting

Clearly, apart from the decision to continue IV Fluids/Medications where something was recorded on the variance sheets in over half of cases, information about the reason that a goal was not met was written up only in a minority of appropriate circumstances. This means that a clear picture (clinical and audit) is unavailable to improve our understanding as to why these goals were not met.

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

### **Ongoing Assessment of the patient in the last 24 hours**

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

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

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

Symptom	Your Site		NI Whole Sample	
	Variance Sheet	Variance Sheet	Variance Sheet	4 hourly Assessment Section
Pain	<b>17</b>	<b>16</b>	138	135
Agitation	<b>22</b>	<b>13</b>	138	128
RTS	<b>13</b>	<b>20</b>	237	215

#### Commentary: Variance Reporting Ongoing Assessment

The results illustrate that relatively similar amounts of variance is being recorded on the variance sheet and documented in the 4 hourly assessment section for Pain, however more variances were recorded on the variance sheets than were documented in the 4 hourly assessment section, for Agitation and RTS.

## SECTION 5: PART B KEY FINDINGS

- The proportion of patients with a diagnosis other than cancer (65%) was much higher than those with a diagnosis of cancer.
- Assessment of current medication and writing up of anticipatory medication for Pain, Agitation, RTS and Nausea and Vomiting were achieved for more than 80% of patients overall in this sample. Prescribing for Pain alone occurred in 94% of cases.
- Documentation for the 4 hourly assessments in the last 24 hours of life illustrate that in the main, patients were found to be comfortable in terms of their physical symptoms.
- There were relatively high levels of 'variance' (23%) being recorded for the discontinuation of IV Fluids/Medications overall in this sample, with much variation across hospital sites in terms of % achieved. However, the relatively poor recording of explanations on the variance sheets for this goal precludes a full understanding of the reasons for continuation.
- The highest levels of variance (patient discomfort) recorded in the ongoing assessment were for RTS (16%), with Pain (10%) and Agitation (9%) the next 2 most common symptoms.
- For the vast majority of carers, it was documented that they were aware of the patients' diagnosis (90%) and that the patient was entering the dying phase (91%). The plan of care was explained in over four fifths of carers (86%), and 93% of those expressed an understanding of that plan.
- Communication with the patient regarding insight into their condition, and that they are entering the dying phase, was less well achieved (63% and 58% respectively). Variance was recorded for 18% and 19% of patients respectively and in a relatively high proportion of patients no information was documented at the point of care delivery (18% and 23% respectively). This suggests that these goals may be challenging to achieve, highlighting a potential need for more education and training.
- Whilst the assessment of the patients' awareness into their diagnosis and prognosis, and of their spiritual/religious needs (42% achieved) appear to be challenging, the dot plots, showing variation across hospitals for these goals, do indicate that levels of good practice can be achieved.
- Communication with colleagues in Primary Care was less well achieved, both prior to and after the patient's death (28% and 45% respectively).
- The vast majority (80%) of carers received hospital information leaflets and information detailing the most appropriate person to be contacted in the event of deterioration was recorded for the majority of cases (88%).
- In the main, the Care After Death section was very well completed, with most goals being achieved in at least 80% of cases. However two goals in this section were less well achieved -

giving necessary documentation and advice to the appropriate person (64%) and giving a bereavement leaflet specifically (46%).

- It is of note that drugs prescribed prn for agitation and restlessness were actually given in only 41% of cases. This supports the use of the LCP in clinical decision-making and promoting individualisation of care for each patient.
- Midazolam was the most frequently prescribed drug for agitation and restlessness. The median dose of midazolam given as a continuous subcutaneous infusion medication was 10mg over 24 hours and 2.5mg as a PRN dose. The median doses of haloperidol and levomepromazine were also relatively low.

**PART C: KEY PERFORMANCE INDICATORS (KPI)**

These KPIs are data driven metrics that have been developed to illustrate the performance of all hospitals in three specific areas against which individual hospitals can gauge their relative performance. They can be usefully included on the ‘corporate performance dashboard’ used in many Trusts to promote continuous quality improvement.

For each KPI, the performance of hospitals has been colour coded (as red, amber and green – see below) based on the Inter Quartile Range of performances using combined data from the 13 hospitals in Northern Ireland and the 155 hospitals in England.

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

Key Performance Indicator 1: Spread of the LCP

An important indicator of the extent to which the LCP has become embedded within a hospital is the proportion of wards using the LCP. The Department of Health have specifically highlighted this metric as an important indicator of the spread of education and training in care of the dying within a hospital (DH, 2009). The table below illustrates the data from ‘Your Site’ compared with the National median proportion of wards using the LCP based on the 13 hospitals from Northern Ireland and the 155 Hospitals from England.

**Key Performance Indicator 1: Spread of the LCP**

Proportion of wards using the LCP	Your Site (n=30)	Northern Ireland + England Whole Sample (n=165)
Median % (IQR)	100%	75% (56% - 98%)

Median % for 13 Northern Ireland Hospitals was 100%, IQR 58% - 100%, Range 37% - 100



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

% compliance with completion	Your Site (n=30)	Northern Ireland + England Whole Sample (n=168)
Median % (IQR – Northern Ireland only)	<b>81%</b>	73% (68% - 83%)
<b>0% – 67%</b>	<b>68% - 83%</b>	<b>84% - 100%</b>

**Median % for 13 Northern Ireland Hospitals was 83%, IQR 80% - 93%, Range 64% - 99%**

## PART D: RECOMMENDATIONS

1. Key Performance Indicators (KPI's) for care of the dying should be measured, monitored and managed as part of the organisation corporate performance dashboard.
2. All hospitals should have a clear programme for continuous quality improvement for care of the dying to drive up performance and quality.
3. A remedial action plan in response to National Care of the Dying Audit findings should be in place to address poor compliance, Inter Quartile Range (IQR) outliers, variance reporting and improved performance across the key domains of care.
4. A named person within the organisation should take formal responsibility to act as an LCP Facilitator / change agent for care of the dying.
5. All hospitals should have a local audit programme for care of the dying that includes the assessment of the views of bereaved carers.
6. Optimising knowledge transfer is an important aspect of continuous quality improvement. All hospitals should have appropriate information leaflets available in support of care in the last hours / days of life.
7. Hospitals need to identify the reasons for the relatively poorer performance on goals that deal with patient insight (both into diagnosis and recognition of dying) and spiritual assessment (for both patients and carers).
8. Whilst this audit shows that the Care After Death Section of the LCP is well completed in the main, hospitals should strive to improve the proportion of carers receiving appropriate information after the death of the patient.
9. All hospitals take part in the 2 yearly National Care of the Dying Audit Cycle.
10. All hospitals should have an LCP or equivalent in place that is compliant with the goals to be included in the new updated version 12 of the LCP to be launched in November 2009.

**Part E: REFERENCES**

Altman DG (1991) *Practical Statistics for Medical Research*. Chapman and Hall London England

Chapman S, Sutton L, Richardson E (2007) *Artificial Nutrition and Hydration – Summary Guidance*. National Council for Palliative Care . ISBN 978-1-898915-54-6

Daykin N, Evans D, Petsoulas C, Sayers A (2007) The impact of patient and public involvement initiatives on UK health services: a literature review. *Evidence and Policy* 3 (1): 47-65

Department of Health (2006) *Our Health, Our Care, Our Say: a new direction for community services*. London. DH

Department of Health (2008) *End of Life Care Strategy - promoting high quality care for all adults at the end of life*. DH London

Department of Health (2009) *End of Life Care Strategy: Quality Markers and Measures for End of Life Care*. DH. London

Ellershaw and Wilkinson Eds (2003) *Care of the Dying: A Pathway to Excellence*. Oxford. OU Press

Fainsinger RL, Bruera E. (1997) When to treat dehydration in a terminally ill patient? *Supportive Care Cancer*. 5(3):205-11.

Ganzini L. (2006) Artificial nutrition and hydration at the end of life: ethics and evidence. *Palliative and Supportive Care*. 4(2):135-43.

General Medical Council (2009) *End of Life Treatment and Care: a draft for consultation*. GMC.

Healthcare Commission (2007) *Spotlight on Complaints: A report on second-stage complaints about the NHS in England*.

[www.healthcarecommission.org.uk/db/documents/spotlight\\_on\\_complaint.pdf](http://www.healthcarecommission.org.uk/db/documents/spotlight_on_complaint.pdf) (last accessed July 2007)

Jordhøy MS, Kaasa S, Fayers P, Ovreness T, Underland G, Ahlner-Elmqvist M. (1999) Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial. *Palliative Medicine* 13(4):299-310.

Klinkenberg M, Willems DL, van der Wal G, Deeg DJ. (2004) Symptom burden in the last week of life *Journal of Pain and Symptom Management* 27(1):5-13.

Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, Barnoud D, Bleichner G, Bruel C, Choukroun G, Curtis JR, Fieux F, Galliot R, Garrouste-Orgeas M, Georges H, Gldgran-Toledano D, Jourdain M, Loubert G, Regnier J, Saidi F, Souweine B, Vincent F, Barnes NK, Pochard F, Schlemmer B, Azoulay E (2007) A communication strategy and brochure for relatives of patients dying in the ICU. *New England Journal of Medicine*. 1: 356(5) 469-78

Lichter I, Hunt E. (1990) The last 48 hours of life *Journal of Palliative Care*. 6(4):7-15.

Mellor F, Foley T, Connolly M, Mercer V, Spanswick M (2004) Role of the Clinical Facilitator in introducing and Integrated Care Pathway for the Care of the Dying. *International Journal of Palliative Nursing* 10, 10 497-501

MCPCIL (2007) National Care of the Dying Audit Hospitals Generic Report Round 1.  
[www.mcpcil.org.uk](http://www.mcpcil.org.uk)

National Institute for Health and Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer* London, London: NICE

Northern Ireland Cancer Network (2008) *Defining End of Life Care For People with Cancer and Non Cancer Diagnoses: A Position paper*, NICAN

Pollard, K.C., Ross, K., and Means, R. (2005) Nurse leadership, interprofessionalism and the modernization agenda. *British Journal of Nursing*, Vol. 14 (6),p.339-344

The National Council for Palliative Care (2006) *Changing Gear: guidelines for managing the last days of life in adults*. NCPC. London

Thorns A, Garrard E (2003) *Ethical Issues in Care of the Dying* in Ellershaw J & Wilkinson S (eds) *Care of the Dying: a pathway to excellence*. Oxford: OUP

Westcombe AM, Gambles MA, Wilkinson SM, Barnes K, Fellowes D, Maher EJ,

Young T, Love SB, Lucey RA, Cubbin S, Ramirez AJ. (2003) Learning the hard way! Setting up an RCT of aromatherapy massage for patients with advanced cancer. *Palliative Medicine*. 17(4):300-7.

Wilkinson S, Gambles M, Roberts A (2002) The essence of cancer care: the impact of training on nurses' ability to communicate effectively. *Journal of Advanced Nursing* 40 (6): 731-8

Willner (2003) Keeping Pace with Technology: Implantable Cardiac Devices in Palliative Care  
<http://www.mcw.edu/display/displayFile.asp?docid=2463&filename=/User/jrehm/Case23.pdf>

Wilson D, Lowe D, Hoffman A, Rudd A, Wagg A (2008) Urinary incontinence in stroke: results from the UK National Sentinel Audits of Stroke 1998-2004. *Age & Ageing*: 37(5):542-6. Epub 2008 Aug 7.

### Appendix 1 – Participating Hospitals (by Trust)

The Northern Ireland Health Sector is organised into 5 Health and Social Care Trusts, within which 28 Hospitals are located. The table below illustrates the spread of hospitals from which the participants were drawn:

<b>Belfast Health and Social Care Trust</b>	<b>Northern Health and Social Care Trust</b>	<b>Western Health and Social Care Trust</b>	<b>Southern Health and Social Care Trust</b>	<b>South Eastern Health and Social Care Trust</b>
Belfast City Hospital*	Antrim Hospital*	Altnagelvin Area Hospital*	Armagh Community Hospital	Ards Community Hospital
Forster Green Hospital	Braid Valley Hospital	Erne Hospital*	Craigavon Area Hospital*	Bangor Community Hospital
Mater Infirmorum Hospital*	Causeway hospital*	Tyrone County Hospital*	Daisy Hill Hospital*	Downe Hospital*
Musgrave Park Hospital	Dalriada Hospital		Lurgan Hospital	Downshire Hospital
Royal Victoria Hospital*	Holywell Hospital		South Tyrone Hospital	Lagan Valley Hospital*
	Mid Ulster Hospital		St Luke's Hospital	Ulster Hospital*
	Moyle Hospital			
	Whiteabbey Hospital			

13 Hospitals (\* above) representing 46% of total hospitals, from 5 Health and Social Care Trusts in Northern Ireland took part and contributed a total of 274 individual patient cases for analysis. Four Hospitals (31%) submitted the full sample size, 4 hospitals (31%) submitted between 20 and 29, and the remaining 5 hospitals (38%) submitted between 8 and 19.

**Appendix 2: 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 - LCP
Deborah Murphy	Associate Director - MCPCIL Directorate Manager, Specialist Nurse, Specialist Palliative Care Directorate, The Royal Liverpool & Broadgreen University Hospitals NHS Trust; National Lead Nurse - LCP
Maureen Gambles	Project Co-ordinator Research and Development Lead MCPCIL
Tamsin McGlinchey	Research Assistant - MCPCIL
Rachel Abbott	Audit Assistant - MCPCIL
Maria Bolger	National LCP Facilitator - MCPCIL
Emer McKenna	Specialist Registrar In Palliative Medicine, MCPCIL

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

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

## List of National LCP Reference Group Members

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

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

## Appendix 3 – Glossary

Statistical Terminology	
Interquartile Range (IQR)	<p>The IQR, which is presented within the tables for % achieved, % variance and % data not documented, divides the given sample into 3 ranges. Twenty-five percent of hospitals score below the first stated value, 50% of hospitals have a score that lies between the two values, and 25% have a score that lies between the higher value and 100%.</p> <p>Taking goal 1 as an example, the IQR is 87 – 97% for % achieved. This means that half of the hospitals in this sample score between 87 and 97% on this goal and a quarter score above 97% and a quarter score below 87%. Comparing one's own score against this IQR allows a judgement of how well an individual hospital has performed in comparison with the others.</p>
Dot Plots	<p>A dot chart or dot plot is a statistical chart consisting of group of data points plotted on a simple scale. Dot plots are one of the simplest statistical plots, and are suitable for small to moderate sized data sets. They are useful for highlighting clusters and gaps, as well as outliers.</p>
Cohen's Kappa Co-efficient	<p>When two individuals attempt to code the same information, Cohen's Kappa (often simply called Kappa) can be used as a measure of agreement between the two individuals. Kappa adjusts for the amount of agreement that could be expected due to chance alone. Kappa is always less than or equal to 1. A value of 1 implies perfect agreement and values less than 1 imply less than perfect agreement (perfect agreement is rare). Altman DG (1991) suggests one possible interpretation of Kappa.</p> <ul style="list-style-type: none"> <li>• Poor agreement = Less than 0.20</li> <li>• Fair agreement = 0.20 to 0.40</li> <li>• Moderate agreement = 0.40 to 0.60</li> <li>• Good agreement = 0.60 to 0.80</li> <li>• Very good agreement = 0.80 to 1.00</li> </ul>
Inter-auditor Reliability	<p>The second coding of a number of audit proformas by an independent auditor to assess the level of agreement in coding. This enables an assessment of the accuracy of the submitted data.</p>
Median	<p>One type of average, found by arranging the values in order and then selecting the one in the middle</p>

Integrated Care Pathway (ICP) Definition and Terminology	
Definition	<p>The European Pathway Association offers the following definition:</p> <p>Care pathways are a methodology for the mutual decision making and organization of care for a well-defined group of patients during a well-defined period. The aim of a care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources. Defining characteristics of care pathways include:</p> <p>An explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations;</p> <p>The facilitation of the communication, coordination of roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives;</p> <p>The documentation, monitoring, and evaluation of variances and outcomes; and</p> <p>The identification of the appropriate resources.</p>
Achieved	<p>Goals 1 – 18</p> <p>When a goal of care is achieved within the Initial Assessment and Care After Death sections, a yes is recorded on the LCP or equivalent at the point of delivery of care.</p> <p>Ongoing Assessment Section:</p> <p>A recording of 'A' on the LCP or equivalent means that the patient is deemed to be comfortable in terms of each indicator</p>
Variance	<p>Variance is a specific Integrated Care Pathway term for exception reporting. When a clinical decision is made that achieving a goal on a pathway is not in an individual patient's best interest, or where it was impossible for any other reason not to follow the goal, variance is recorded and an explanation provided which includes any action taken and outcome.</p> <p>Goals 1 – 18</p> <p>When a goal is 'varianced' on the Initial and Care after Death Section, a no is recorded on the LCP or equivalent.</p> <p>Ongoing Assessment Section</p> <p>'variance' = the patient is deemed not to be comfortable and to require some intervention to improve their condition</p>

Management Terminology	
Key Performance Indicator (KPI)	<p>KPI's are quantitative measurements / metrics that enable an organisation measure progress towards goals and identify areas for improvement.</p> <p>They can be used to focus activities, assess, tune, performance and model / modify processes.</p>
Corporate Performance Dashboard	<p>A dashboard is a graphical easy to read and interpret user interface that shows at a glance metrics and KPI's in a single overview about performance that aligns strategy, processes, tools and culture around corporate objectives. Reports are REAL, relevant, engaging, actionable and lean. A dashboard facilitates the dissemination of the KPI's throughout the organisation</p>

## Appendix 4: Reporting Schedule

### Stage 1: September 2009

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

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

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

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

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

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

### Stage 2: September/October 2009

Chief Executives and NCDAH Audit Co-ordinators receive a paper copy (2 per Hospital) of the Individual Hospital Report.

### Stage 3: October 2009

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

**APPENDIX 5: Best PRACTICE EXAMPLE PROFORMA**

<p>Trust Name: Trust X</p> <p>Hospital Name: Hospital X</p>
<p>Example of good practice description: (Please include, where appropriate, what made you think of the idea? What you did? Who was involved? Details of any education and training undertaken or delivered.)</p> <p>Raising a high profile regarding end of life care within the Trust. A key factor in the success of the LCP within our Trust has been executive level support for the project. This has enabled the change to be positively embraced at all levels within the organisation. Audit results are presented to Trust Board, and an annual report is produced and disseminated to key leaders within the Trust. Progress regarding the LCP is also shared with staff at ward level to encourage a feeling of involvement and ownership. This is achieved by producing articles for the staff magazine, and circulating flyers to ward areas detailing the achievements of the LCP. The project has been guided by a steering group of experienced professionals, and this group has been instrumental in providing ideas and guidance for the LCP facilitator. Involvement with a local Cancer Services User group has also enabled the facilitator to improve the experience of families of dying patients, for example by providing a free car parking permit for families of patients on the LCP, and developing written information.</p>
<p>Has this example been evaluated? If yes, please explain the method used, and whether it indicated a change in practice:</p> <p>This example has not been formally evaluated, however the level of awareness within the Trust regarding the LCP indicates that the above methods are successful in raising the profile of end of life care.</p>
<p>Additional Comments:</p>

## Appendix 6 Goals of Care on the LCP

### INITIAL ASSESSMENT

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

### ONGOING ASSESSMENT

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

### CARE AFTER DEATH

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

