

---

## **The impact of the Liverpool Care Pathway for the Dying Patient (LCP) on care at the end of life in care homes and ICUs**

### **Project Team:**

*Professor John Ellershaw, Director, Marie Curie Palliative Care Institute  
Liverpool (MCPCIL), University of Liverpool*

*Professor E Perkins, Director, HaCCRU, University of Liverpool*

*Dr Suzanne Hodge, HaCCRU, University of Liverpool*

*Dr Alan Haycox, Reader in Health Economics, Health Economics Unit, University of Liverpool  
Management School*

*Researcher North (to be appointed), HaCCRU & MCPCIL, University of Liverpool*

*Researcher South (to be appointed), Marie Curie Palliative Care Research Unit, University  
College London*

### **Introduction**

The National Institute for Health Research, under the auspices of the Service Delivery and Organisation section, has awarded research funding to the University of Liverpool to undertake a study of the impact of the Liverpool Care Pathway for the Dying Patient (LCP). The study is funded for three years and will be conducted in two diverse care settings: Nursing Homes and Intensive Care Units (ICUs) in England.

This work is ethically and practically challenging and in order to maximise the potential for success, a pilot phase was undertaken. This phase involved a formalised engagement of interested parties to inform the construction of the full project plan.

### **Summary of the Main Study**

The LCP provides a template, based on key principles from the hospice environment, to support the care of patients in the last hours and days of their lives. It aims to provide a structure for the delivery of care in the dying phase and to ensure that patients and their families receive good symptom control, psychosocial and bereavement support. The LCP, underpinned by appropriate education and training within participating organisations, has been cited as good practice by the National Institute for Health and Clinical Excellence (NICE, 2004) and is a major end of life tool within the Department of Health End of Life Care Programme (DH, 2006; DH, 2008; DH, 2009). Currently, more than 1,800 organisations in the UK (including Acute Trusts, PCTs, Hospices and Care Homes) are registered with the LCP Programme and 2 National Care of the Dying Audits in Hospitals have been undertaken in recent years (NCDHAH 2007, NCDHAH 2009; [www.mcpcil.org.uk](http://www.mcpcil.org.uk)). In addition, the LCP is in use in 20 countries outside of the UK.

The research evidence for improvement in care of the dying based on the LCP continues to emerge both nationally (UK) and internationally. Qualitative evidence has demonstrated that it improves the confidence of nurses and doctors in delivering care to imminently dying patients (Jack et al, 2003;

---

Gambles et al 2006). A 'before and after study' (Veerbeek et al, 2008) undertaken in hospitals and care homes in the Netherlands has demonstrated reduced symptom burden and improved documentation of care. The results of a questionnaire study of bereaved relatives (Mayland et al, 2009) in the hospital setting showed that those relatives of patients being cared for on the LCP perceived a higher quality of care than the relatives of those who were not cared for on the LCP. In the care home environment, Hockley et al (2005) reported improved anticipatory prescribing of medication for the five key symptoms that may develop in the last hours/days of life and an improvement in Multi-disciplinary Team working. A cluster randomised controlled trial is also currently underway in Italy to evaluate the effectiveness of care in the final hours and days of life with and without the LCP. However, the research base remains limited regarding how the LCP is used and the impact it has on the care of people who are dying and their relatives and carers because of the challenge of undertaking robust research in this phase of life.

This study aims to explore the impact of the LCP on patients, carers, bereaved relatives and clinicians (including nurses, doctors and other members of the multidisciplinary team) involved in the care of patients in the final hours or days of their lives. The impacts to be studied include the physical, psychosocial, and spiritual care of the patient, the information/ communication needs of carers, and the economic costs of care, including the provision of education and training. The study will take place in Intensive Care Units (ICUs) and in Nursing homes for the elderly as relatively high levels of patient death occur in these areas.

## **Methodology**

The study is a matched case study design including 24 sites in two geographical locations in England. Each nursing home/ICU that has adopted the LCP and has agreed to participate in the study will be matched with another nursing home/ICU in the same geographical area which has not adopted the LCP.

The study will involve six components, some of which will be undertaken concurrently:

1. Documentary analysis – including scrutiny of the stated end of life care priorities of relevant SHAs and the policies and procedures in place within each of the sites.
2. A retrospective analysis of case notes relating to deaths experienced in each of the locations will be undertaken. We propose to analyse up to 30 sets of case notes drawn from each case study site.
3. Interviews with staff - Semi structured interviews with key clinical and administrative staff will be undertaken at two time points in each of the sites
  - a. Interviews will be arranged with key individuals in each participating organisation involved in the management and provision of care to patients in the last hours or days of their lives. All interviews will be recorded and transcribed.
  - b. Observations of patients in the dying phase will be undertaken (see 4 below). Key staff involved in the care of patients observed in this stage of the research will be interviewed regarding care delivery both in relation to the observed patient and in general.
4. Observation of interactions with dying patients will take place in blocks of four hours. It is proposed that a sample of mornings, afternoons, evenings and night times are observed. Flexibility will be paramount to take account of each individual's circumstances, changes in clinical indicators and the needs and wishes of patients and their family members. The purpose of these observations is to record the nature and content of interactions between

---

patients, relatives and staff and, in particular, to record interventions including the administration of drugs, fluid and food as well as their withdrawal.

5. Case note analysis of each patient observed will be undertaken. Case note data recorded during the period of observation will be matched for consistency with the observational data. In addition, data will be extracted from these notes for periods in which an observer was not present using a structured proforma.
6. Interviews with bereaved relatives will be undertaken which will provide an important insight into how the care of a dying relative was perceived. They will focus on the perceptions and experiences of bereaved relatives on the care of the dying patient and their own care during the final days and hours of their relatives' lives. They will be in-depth interviews which will be tape recorded and transcribed

### **Ethical Challenges in undertaking this study**

It is recognised that there are complex practical, moral and ethical challenges involved in successfully undertaking this study. The research team has a track record in studies relating to care of the dying and is ideally placed to conduct this work. However, the five main ethical and design challenges that need to be addressed are:

1. Identification of the dying phase
2. Recruiting patients who are dying and their family and friends to the study
3. Recruiting staff to the study
4. Observing care in a potentially distressing environment
5. Providing support for researchers undertaking the study

### **Pilot Study**

In view of these ethical challenges, a pilot study was undertaken with staff in ICU and Nursing Homes and with patient/relative representatives. The aim of the pilot study was to learn from the perspective of these stakeholders how best to sensitively translate the proposed research into practice. The pilot study involved focus groups in a convenience sample of one local Intensive Care Unit and 2 local Nursing Homes:

- 2 focus groups of nursing and medical staff
- 3 focus groups of managers, nursing staff, health care assistants and non-clinical support staff

Also, 5 telephone interviews were undertaken with representatives of key patient groups recruited through the National Council for Palliative Care (NCPC) and locality and partnerships groups locally.

The findings from the pilot study have been summarised and recommendations made and used to refine the approach to the recruitment of patients, their relatives and staff and to the conduct of the study in general.

### **References**

Department of Health (2008). The English End of Life Care Strategy: London: DH

---

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

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

Gambles, M, Stirzaker, S, Jack B and Ellershaw JE (2006) The Liverpool Care Pathway in Hospices: An exploratory study of doctor and nurse perceptions. *International Journal of Palliative Nursing*. 12 (9), p. 414-421

Hockley J, Dewar B, Watson J (2005) Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *J Res Nurs*. 10:135–152.

Jack B, Gambles M, Murphy D, Ellershaw JE. (2003) Nurses' perceptions of the Liverpool Care Pathway for the Dying Patient in the acute hospital setting. *International Journal of Palliative Nursing*. 9 (9):375-381

Mayland CR, Williams EMR, Addington Hall, J, Ellershaw JE (2009) Does the Liverpool Care Pathway have an impact on the quality of care for dying patients: the views of bereaved relatives. Poster presented to the European Association for Palliative Care 11<sup>th</sup> Congress. Vienna. 2009.  
<http://www.eapcnet.org/congresses/Vienna2009/Viena2009ScProg.html>

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

Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ, de Vogel-Voogt E, van der Rijt CC, van der Heide A (2008) The effect of the Liverpool Care Pathway for the dying: a multi centre study. *Palliative Medicine*. 22(2): 145-51