



NCEPOD End of Life Care Study

Information for Local Reporters

Introduction

End of life care is relevant to all of us. How it is delivered, however, varies considerably. People frequently do not die in their place of choice, and the quality of care they receive, although sometimes excellent, frequently is not. The population is ageing and through improved treatment of many chronic diseases means that many more people are living longer with these conditions. The incidence of dementia is also increasing. There will be an increasing number of deaths where there are limited options for treatment of the underlying condition and death is expected. Excellence in palliative care is therefore becoming of increasing importance.

Each year over 500,000 people die in England and Wales, around half of these as an inpatient in hospital and approximately 75% die from long term health conditions that often follow a predictable course, with death anticipated well in advance of the event. Providing the highest quality end of their life care has a positive impact on the experience of dying for patients and their families, whilst the inverse is also true.

Previous national audits have generally looked at deaths in acute hospitals of any cause, excluding sudden death. The review would focus on 4 exemplar conditions: heart failure, dementia, lung cancer and liver disease. These conditions were among the most common causes of death in 2019 which all have a reasonably predictable course with death often anticipated. Peer review of the care delivered, focussing on the whole end of life care pathway in and out of hospital, will provide an in-depth understanding of areas that require improvement. The NCEPOD study will complement the work of the national audit. Recommendations from this report will have the potential to improve the quality of care of large numbers of patients and their families.

Overall aim:

To identify and explore areas for improvement in the end of life care of adults with advanced illness, focussing on the last 6 months of life.

Organisational objectives:

To explore the organisational structures in place to deliver high quality end of life care in hospital and within the community with particular focus on the following:

- Communication between the healthcare providers
- The multi-disciplinary team approach
- Equity of access to palliative care services
- The management of the 'acute' end of life pathway and ceilings of treatment including appropriateness of interventions

Clinical objectives

To explore remediable factors in the process of care of patients at the end of life with particular focus on the following:

- Prompt recognition of dying patients
- Management of multiple admissions

- Recording and communicating patient's wishes across primary, secondary, community teams.
- Adequate communications with patients, families and carers
- Evidence to support advanced care planning in achieving key quality outcomes

Participating hospitals

Data will be collected from all hospitals in England, Wales and Northern Ireland, which admit patients with dementia, heart failure, lung cancer or liver disease.

Method of Data collection

Data collection spreadsheet

To identify the patient sample, an excel spreadsheet has been sent out for Local Reporters to complete.

We are looking to identify patients aged 18 and over, who have died in the hospital setting between **1st April 2022 - 30th September 2022** inclusive, with an ICD10 diagnosis code on discharge in any position of one or more of the following conditions, dementia (F01, F03 and G30), heart failure (I11, I20 – I25.9, 142.9, I50 – I50.9), lung cancer (C33 – C34.9) and liver disease (K70 -K77.9). Deaths in the emergency department are included in this study.

We also want to identify a group of patients who have been discharged from hospital to the community between **1st April 2022 - 30th September 2022** inclusive, who have subsequently died within six months of discharge with one or more of the previously listed conditions. We appreciate that this group may be harder to identify from the main patient administration system, and therefore suggest liaising with the Palliative Care/Oncology/Liver and Heart failure teams (if you have them) to confirm the relevant community deaths. You may also have a palliative care register that identifies deaths in the community. Your pharmacy department colleagues may also have a list of patients in the community who received anticipatory medicines, and subsequently died.

Clinician questionnaire – To be disseminated

A questionnaire will be sent to the named consultant responsible for the patient's care during their final admission to hospital. Instructions will be provided, to pass the questionnaire on to most appropriate clinician should it not be the named person.

Data collected will include information on any previous admissions that the patient had including discharge and follow up, the involvement of the (specialist) palliative care team, treatments and investigations the patient received in hospital, specialist reviews, use of protocols and clinical pathways. The questionnaire will also ask about the use of treatment escalation plans and ReSPECT (or equivalent) forms and conversations with patients, families and carers. Case notes extracts will also be requested.

Hospital organisational questionnaire – To be disseminated

An organisational questionnaire will be disseminated via the online system. Local reporters will be able to invite multiple clinicians to complete the questionnaire. Data collected will include information around the organisation of services, networks of care, multidisciplinary team working, the use of guidelines/protocols and training.

National data opt out: From 1st August 2022 organisations in England need to comply with the national data opt-out. If you are returning a spreadsheet to NCEPOD after this date, please check the patient list against SPINE, and remove the details of any patients who have 'opted-out' prior to returning the data.

We would be grateful if you could return the **completed password protected patient identifier spreadsheet** to ncepod@nhs.net by **7th July 2023**. Please then phone the office with the password to open the spreadsheet.

Further information about the study and the protocol, including frequently asked questions, can be found on our website: <https://www.ncepod.org.uk/EndofLifeCare.html> or please contact the office on **0207 251 9060** or by email at eolc@ncepod.org.uk.