

End of Life Care: Clinician Questionnaire

A. Introduction

What is this study about?

To identify and explore areas for improvement in the end-of-life care of patients aged 18 and over with advanced illness, focusing on the last six months of life.

Inclusions

Patients aged 18 and over that have died in hospital between 1st April 2022 - 30th September 2022 inclusive, with one or more of the following conditions; dementia, heart failure, lung cancer and liver disease. Patients aged 18 and over that have been discharged to the community between 1st April 2022 - 30th September 2022 inclusive who have subsequently died within six months with one of the above conditions are also included.

Exclusions

Deaths due to trauma, drowning, suicides, homicides, drug overdose or poisoning

Who should complete this questionnaire?

This questionnaire should be completed by the named consultant, or the most appropriate clinician, responsible for the patients care when they were treated in hospital.

Questions or help

Further information regarding this study can be found here: <https://www.ncepod.org.uk/EndofLifeCare.html>
If you have any queries about this study or this questionnaire, please contact: eolc@ncepod.org.uk or telephone 0207 251 9060.

CPD accreditation

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development (CPD) in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and make recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) - following publication of the 2005 'An Acute Problem' report.

Appointment of a National Clinical Director for Trauma Care - following publication of 'Trauma: Who Cares?' 2007. Development of NICE Clinical Guidelines for Acute Kidney Injury, published in 2013 - 'Adding Insult to Injury' 2009.

Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 - 'On the right trach?' 2014.

Development of guidelines from the British Society of Gastroenterology: diagnosis and Management of acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' 2015.

Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' 2017

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Patient details

1a. Age at time of death

Only patients aged 18 or over are included in the study

 Years

Unknown

Value should be between 18 and 120

1b. Sex

Female Male Other

1c. Ethnicity

- White British/White - other
 Black British/African/Caribbean/Black - other
 Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)
 Mixed/Multiple ethnic groups
 Unknown

If not listed above, please specify here...

2a. Date of death

Unknown

2b. Time of death

Unknown

2c. Location of death

- Hospital Hospice Own Home
 Relatives home Residential Care home Nursing home

If not listed above, please specify here...

Medical Certification of Cause of Death

3a. 1a. Disease or condition directly leading to death

3b. 1b. Other disease or condition, if any, leading to 1a

3c. 1c. Other disease or condition, if any, leading to 1b

3d. 2. Other significant conditions contributing to the death but not related to the disease or condition causing it

3e. Related cause of death

To be included in the study, the patient must have had one or more of the following conditions (please tick all that apply)

Lung Cancer Dementia Heart Failure Liver Disease

Comorbidities

4a. Which of the following physical health comorbidities did the patient have?

Please tick all that apply

- | | | |
|--|--|--|
| <input type="checkbox"/> Lung cancer | <input type="checkbox"/> Chronic liver disease | <input type="checkbox"/> Hypertension |
| <input type="checkbox"/> Ischaemic Heart Disease | <input type="checkbox"/> Heart Failure | <input type="checkbox"/> Previous stroke |
| <input type="checkbox"/> Chronic Kidney Disease | <input type="checkbox"/> COPD | <input type="checkbox"/> Diabetes |
| <input type="checkbox"/> None of the above | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

4b. Which of the following mental health comorbidities did the patient have?

- | | | | |
|--|-------------------------------------|----------------------------------|----------------------------------|
| <input type="checkbox"/> Dementia | <input type="checkbox"/> Depression | <input type="checkbox"/> Anxiety | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> None of the above | | | |

Please specify any additional options here...

4c. Was there a documented learning disability?

- Yes No Unknown

4d. If answered "Yes" to [4c] then:

Please state the documented learning disability

Social support

5a. Please select the patient's usual place of residence (prior to final admission)

- | | | |
|--------------------------------|---|------------------------------------|
| <input type="radio"/> Own Home | <input type="radio"/> Residential care home | <input type="radio"/> Nursing home |
| <input type="radio"/> Hospice | <input type="radio"/> No fixed abode | <input type="radio"/> Prison |
| <input type="radio"/> Unknown | | |

If not listed above, please specify here...

5b. Was organised domicillary/ home care in place for this patient?

- Yes No Unknown

5c. If answered "Yes" to [5b] then:

Please select the number of daily care visits

- | | | |
|---------------------------------|--|---------------------------------|
| <input type="radio"/> 1 x daily | <input type="radio"/> 2 x daily | <input type="radio"/> 3 x daily |
| <input type="radio"/> 4 x daily | <input type="radio"/> Full time Live in care | <input type="radio"/> Unknown |

If not listed above, please specify here...

5d. If answered "Yes" to [5b] then:

How was this funded?

Please tick all that apply

- | | | | |
|--|----------------------------------|---|----------------------------------|
| <input type="checkbox"/> Social Services | <input type="checkbox"/> Patient | <input type="checkbox"/> Fast track funding | <input type="checkbox"/> Unknown |
|--|----------------------------------|---|----------------------------------|

Please specify any additional options here...

6a. Was any family/ informal support recorded as being provided?

- Yes No Unknown

**6b. If answered "Yes" to [6a] then:
Who provided the informal support?**

Please tick all that apply

- By partner/ spouse By other relative By friend(s)

Please specify any additional options here...

7. Did this patient have a Health and Welfare Power of Attorney documented?

- Yes No Unknown

8. In the community, prior to the final admission, which of the following services was the patient in receipt of?

Please tick all that apply

- | | |
|--|---|
| <input type="checkbox"/> District nursing | <input type="checkbox"/> Domiciliary care |
| <input type="checkbox"/> Befriending | <input type="checkbox"/> Day hospice |
| <input type="checkbox"/> Community matron | <input type="checkbox"/> Specialist palliative care |
| <input type="checkbox"/> Specialist dementia nurse | <input type="checkbox"/> Heart Failure nurse specialist |
| <input type="checkbox"/> Hospice @ home | <input type="checkbox"/> Care navigators |
| <input type="checkbox"/> Frailty nurse | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Speech and Language Therapy |
| <input type="checkbox"/> Dietetics | <input type="checkbox"/> Family support |
| <input type="checkbox"/> Psychology | <input type="checkbox"/> Social workers |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> None of the above |

Please specify any additional options here...

9a. What was the patient's preferred place of death?

- Hospital Home Hospice Care home
 Not documented

If not listed above, please specify here...

9b. Date preferred place of death first documented

- Not Applicable Unknown

10a. Was the patient on a palliative care register?

- Yes No Unknown

**10b. If answered "Yes" to [10a] then:
Was this (register)?**

Please tick all that apply

- Primary care Secondary care

Please specify any additional options here...

**10c. If answered "Yes" to [10a] then:
When was the patient added to the register?**

DD/MM/YYYY or approximation if unknown

C. Previous hospital contact

1a. Did the patient have contact with this hospital in the 6 months prior to the index admission?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

What type of contact(s)?

Please tick all that apply

- Emergency (non-elective) admission(s) Elective admission(s)
 Emergency department attendance (not admitted)
 Outpatient appointment(s)

Please specify any additional options here...

**1c. If answered "Emergency (non-elective) admission(s)" to [1b] then:
Please state the number of emergency admissions:**

in the 6 months prior to the index admission

Unknown

**1d. If answered "Emergency (non-elective) admission(s)" to [1b] then:
Date of most recent emergency admission**

(Prior to the final admission)

Unknown

1e. If answered "Elective admission(s)" to [1b] then:

Please select the reason(s) for the elective admission(s)

Please tick all that apply

- Chemotherapy/ Immunotherapy Blood transfusion
 Dialysis Endoscopy
 Pleural aspiration/ drainage Abdominal aspiration/ drainage
 Surgery

Please specify any additional options here...

**1f. If answered "Surgery" to [1e] then:
Please provide details of the surgery undertaken**

**1g. If answered "Elective admission(s)" to [1b] then:
Date of most recent elective admission**

Unknown

**1h. If answered "Outpatient appointment(s)" to [1b] then:
Please state the number of outpatient appointments the patient attended:**

in the 6 months prior to the index admission

Unknown

**1i. If answered "Outpatient appointment(s)" to [1b] then:
Date of most recent outpatient consultation**

Unknown

2a. If answered "Yes" to [1a] then:

After retrospectively reviewing the patient's prior contacts with this hospital, were there any missed opportunities for improving the patients end of life care in the 6 months prior to the index admission?

- Yes No
 Not applicable death not anticipated Unknown

2b. If answered "Yes" to [1a] and "Yes" to [2a] then:

What areas could have been improved?

Please tick all that apply

- Specialist palliative/end of life care input
- Treatment/intervention limitation decisions
- Investigation limitation decisions
- Medicines management
- Discharge arrangements for support in the community
- Communication with patient/family

Please specify any additional options here...

2c. If answered "Yes" to [1a] and "Yes" to [2a] then:

Please provide details (areas for improvement)

2d. If answered "Yes" to [1a] then:

After retrospectively reviewing the patient's prior contacts with this hospital, were there areas of good practice regarding End of life care you wish to highlight?

- | | |
|---|-------------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No |
| <input type="radio"/> Not applicable, death not anticipated | <input type="radio"/> Unknown |

2e. If answered "Yes" to [1a] and "Yes" to [2d] then:

Please provide details (good practice):

1a. Where did this patient die?

- In hospital In the community

1b. Date of final admission to hospital

Unknown

1c. What was the route of admission?

- | | |
|---|--|
| <input type="radio"/> Ambulance | <input type="radio"/> Self presented |
| <input type="radio"/> GP referral | <input type="radio"/> Via community heart failure team |
| <input type="radio"/> Hospital transfer | <input type="radio"/> Unknown |

If not listed above, please specify here...

Please make an estimation of the patient's functional status in the two weeks prior to the admission:

2a. Rockwood Clinical Frailty score in the two weeks prior to the admission:

https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2022/02/rockwood-frailty-scale_.pdf

- | | | |
|---|--|---|
| <input type="radio"/> 1. Very Fit | <input type="radio"/> 2. Well | <input type="radio"/> 3. Managing Well |
| <input type="radio"/> 4. Vulnerable | <input type="radio"/> 5. Mildly Frail | <input type="radio"/> 6. Moderately Frail |
| <input type="radio"/> 7. Severely Frail | <input type="radio"/> 8. Very Severely Frail | <input type="radio"/> 9. Terminally Ill |
| <input type="radio"/> Unable to ascertain | | |

2b. Karnofsky performance score in the two weeks prior to the admission:

<https://www.stlukes-hospice.org.uk/wp-content/uploads/2017/06/30-Karnofsky-Performance-Status.pdf>

- 100 - Normal with no complaints
- 90 - Able to carry on normal activity
- 80 - Normal activity with effort
- 70 - Cares for self; unable to carry on normal activity
- 60 - Requires occasional assistance, but able to care for themself
- 50 - Requires considerable assistance and frequent medical care
- 40 - Disabled; requires special care and assistance
- 30 - Severely disabled; hospital admission is indicated although death is not imminent
- 20 - Very sick - hospital admission and active supportive treatment necessary
- 10 - Moribund; fatal processes progressing rapidly
- Unable to ascertain

3a. Was this final admission to hospital appropriate?

- Yes No Unknown

3b. If answered "No" to [3a] then:

Please explain your answer (admission):

4a. Could this final admission have been avoided?

Yes No Unknown

**4b. If answered "Yes" to [4a] then:
Please expand on your answer**

5a. On review of the case notes, were any relevant investigations omitted?

Yes No Unknown

**5b. If answered "Yes" to [5a] then:
Please give further details:**

6a. On review of the case notes, were any investigations done that should have been omitted?

Yes No Unknown

**6b. If answered "Yes" to [6a] then:
Please give further details:**

7a. On review of the case notes, were any relevant interventions/treatments omitted?

Yes No Unknown

**7b. If answered "Yes" to [7a] then:
Please expand on your answer:**

8a. On review of the case notes, were any interventions/treatments given that should have been omitted?

Yes No Unknown

**8b. If answered "Yes" to [8a] then:
Please give further details:**

Hospital Deaths

**8c. If answered "In hospital" to [1a] then:
During the final admission, was there any evidence that recovery was uncertain?**

Yes No Unknown

**8d. If answered "In hospital" to [1a] then:
Was the death anticipated?**

Yes No Unclear

**9a. If answered "In hospital" to [1a] then:
Was there an aim to discharge the patient from hospital?**

Yes No Unclear

**9b. If answered "In hospital" to [1a] then:
Was there evidence of dual pathway planning?
*i.e. planning discharge alongside preparing for death in hospital?***

Yes No Unknown

**9c. If answered "In hospital" to [1a] then:
Was there any evidence of delay in discharge?**

Yes No Unclear

**9d. If answered "In hospital" to [1a] then:
In your opinion, could death in a location other than hospital have been achieved?**

Yes No Unclear

**9e. If answered "In hospital" to [1a] and "Yes" to [9d] then:
Please explain your answer**

**10a. If answered "In hospital" to [1a] then:
Was specific end of life documentation used?**

Yes No Unknown

**10b. If answered "In hospital" to [1a] and "Yes" to [10a] then:
Please state the date this was first started:**

Unknown

**11a. If answered "In hospital" to [1a] then:
Is there documented evidence that the patient was offered information that they were dying?**

Yes No Unknown

**11b. If answered "In hospital" to [1a] then:
Is there documented evidence that the patient's NOK/ family were told that they were dying?**

Yes No Unknown

**11c. If answered "In hospital" to [1a] then:
Was a nominated lead person documented?**

Yes No Unknown

**11d. If answered "In hospital" to [1a] then:
Was the palliative/end of life care team involved in the patient's care during the admission?**

Yes No Unknown

**11e. If answered "In hospital" to [1a] and "Yes" to [11d] then:
Please state the date of the first palliative/end of life care review during the admission**

Unknown

Hospital and community deaths

Advance Care Planning

12a. Did this patient have a RESPECT (or equivalent) form in place?

Yes No Unknown

**12b. If answered "Yes" to [12a] then:
How was this documented?**

Paper form Electronic form

13a. Did the patient have a Treatment Escalation Plan (TEP) in place?

Yes No Unknown

**13b.If answered "Yes" to [13a] then:
Please state the date that the TEP was first documented:**

Unknown

14a.Was a capacity assessment undertaken in relation to the advance care planning (RESPECT and TEP)?

Yes No Unknown

**14b.If answered "Yes" to [14a] then:
Did the patient have capacity?**

Yes No Unknown

Community deaths

**15a.If answered "In the community" to [1a] then:
Date of discharge of from hospital**

Unknown

**15b.If answered "In the community" to [1a] then:
Discharge location**

Own home Relatives home Residential care home
 Nursing home Hospice

If not listed above, please specify here...

**15c. If answered "In the community" to [1a] then:
When the patient was discharged, was it anticipated that they would die in the community?**

Yes No Unknown

**15d.If answered "In the community" to [1a] then:
Please explain your answer**

**15e.If answered "In the community" to [1a] and "Yes" to [15c] then:
Which of the following were put in place to facilitate discharge?**

District Nursing Domiciliary care Befriending
 Day Hospice Specialist Nurse support Hospice @ Home
 Care Navigators Frailty Nurse OT / Physio
 Family Support Psychology Social workers
 Unknown

Please specify any additional options here...

**15f. If answered "In the community" to [1a] and "Yes" to [15c] then:
Was continuing healthcare funding (or equivalent) used to facilitate the discharge?**

Yes No Unknown

**15g.If answered "In the community" to [1a] and "Yes" to [15c] then:
Are there any examples of good practice that enabled the discharge?**

Yes No Unknown

**15h.If answered "In the community" to [1a] and "Yes" to [15c] and "Yes" to [15g] then:
Please provide details**

Organisation of end of life care services (not specifically related to this case)

**16a.If there are particular organisational aspects of end of life care that you feel work well,
please use this space to provide details:**

**16b.If there are particular organisational aspects of end of life care that you feel need
improving, please use this space to provide details:**

End of questionnaire

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in winter 2024