

# End of Life Care: Reviewer Assessment Form

## A. Case Reviewer Details

### 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

---

### 2a. Date of Case Reviewer meeting

### 2b. Case Reviewer Initials

### 2c. Was a completed clinician questionnaire available at the time of case review?

Yes

No

### 2d. NCEPOD site ID

## 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. Location of death

Hospital  Community

### 2c. If answered "Community" to [2b] then: Location of death (community)

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

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*

Lung Cancer  Dementia  Heart Failure  Liver Disease

**4a. Which of the following physical health co-morbidities 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 co-morbidities 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...

---

**5a. Was there a documented learning disability?**

- Yes                       No                       Unknown

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

**Please state the documented learning disability**

---

**Social support**

**6a. Please select the patient's usual place of residence (prior to final admission)**

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

If not listed above, please specify here...

**6b. Was organised domicillary/ home care in place for this patient?**

- Yes                       No                       Not applicable                       Unknown

**6c. If answered "Yes" to [6b] 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"/> Adhoc     |
| <input type="radio"/> Unknown   |  |                                 |

If not listed above, please specify here...

---

**7a. Was any family/ informal support recorded as being provided?**

- Yes                       No                       Not applicable                       Unknown

**7b. If answered "Yes" to [7a] then:**

**Who provided the informal support?**

*Please tick all that apply*

- |   |  |                                       |
|---|--|---------------------------------------|
| <input type="checkbox"/> By partner/ spouse | <input type="checkbox"/> By other relative | <input type="checkbox"/> By friend(s) |
|---|--|---------------------------------------|

Please specify any additional options here...

**8a. Did this patient have a Health and Welfare Power of Attorney documented?**

Yes

No

Not Applicable

Unknown

**8b. If answered "Yes" to [8a] then:**

**Please provide further details as what was documented (power)**

---

**9a. Prior to the index admission, was the patient in receipt of any healthcare services/support in the community?**

Yes

No

Unknown

**9b. If answered "Yes" to [9a] then:**

**Which services in the community?**

C. Previous hospital contact

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

*If you answer No or Unknown please go to the next section*

- Yes                       No                       Unknown

**1b. If answered "Yes" to [1a] then:  
What type of contact(s)?**

*Please tick all that apply*

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

Please specify any additional options here...

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

**How many ED attendances did the patient have in the 6 months prior to the index admission?**

*All ED attendances whether or not the patient was admitted*

- Unknown

---

**Review of the patient's hospital contact prior to index admission**

Please answer the following questions based on the contact the patient had with this hospital in the 6 months prior to the index admission

**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                       Unable to answer

**2b. If answered "Yes" to [1a] and "Yes" to [2a] then:  
Which areas could have been improved?**

- 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  
 Allied healthcare professional input

Please specify any additional options here...

**2c. If answered "Yes" to [1a] and "Yes" to [2a] then:  
Please expand your answer: (areas for improvement)**

**Key dates when EoLC could have been improved/there were missed opportunities**

Please indicate when the contact(s) with the hospital were for which there was room to improve the patients EoLC

**2d. If answered "Yes" to [1a] and "Specialist palliative/end of life care input" to [2b] then:  
Date of presentation/admission (EoLC team input)**

Unknown

**2e. If answered "Yes" to [1a] and "Treatment/intervention limitation decisions" to [2b] then:  
Date of presentation/admission (treatment/intervention)**

Unknown

**2f. If answered "Yes" to [1a] and "Investigation limitation decisions" to [2b] then:  
Date of presentation/admission (investigations)**

Unknown

**2g. If answered "Yes" to [1a] and "Medicines management" to [2b] then:  
Date of presentation/admission (medicines)**

Unknown

**2h. If answered "Yes" to [1a] and "Discharge arrangements for support in the community" to [2b] then:  
Date of presentation/admission (discharge arrangements)**

Unknown

**2i. If answered "Yes" to [1a] and "Communication with patient/family" to [2b] then:  
Date of presentation/admission (communication)**

Unknown

**2j. If answered "Yes" to [1a] and "Allied healthcare professional input" to [2b] then:  
Date of presentation/admission (AHP)**

Unknown

**2k. If answered "Yes" to [1a] and to [2b] then:  
Date of presentation/admission (other)  
(Prior to the final admission)**

Unknown

---

**3a. If answered "Yes" to [1a] then:  
Were the patient's preferences asked, recorded and communicated appropriately regarding end of life care?**

Yes                       No                       Not applicable                       Unknown

**3b. If answered "Yes" to [1a] then:  
During previous contact with this hospital, at any point was it recorded that the patient was in the last 12 months of their life?**

Yes                       No                       Unknown

**3c. If answered "Yes" to [1a] and "Yes" to [3b] then:  
Was the GP alerted on the discharge summary to the patient being in the last year of life?**

Yes                       No                       Unknown

---

**4a. If answered "Yes" to [1a] then:  
How would you rate the discharge planning for end of life care?**

Good                       Adequate                       Poor                       Unacceptable  
 Not applicable                       Unable to rate

**4b. If answered "Yes" to [1a] and "Good", "Adequate", "Poor" or "Unacceptable" to [4a] then:  
Please provide reasons for your rating (discharge)**

---

**5a. If answered "Yes" to [1a] then:  
Based on your review of the patients previous hospital contact, are you surprised that they died within 6 months of the last contact?**

Yes                       No                       Unable to answer

**5b. If answered "Yes" to [1a] and "Yes" to [5a] then:  
Please expand on your answer (surprised)**

---

**6. If answered "Yes" to [1a] then:  
If you would like to add anything else about the patient's previous hospital contact please use this space**

**1a. Where did this patient die?**

- In hospital                       In the community

**1b. Date of final admission to hospital**

**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:**

**1d. Rockwood Clinical Frailty score in the two weeks prior to the admission:**

*Please refer to the Rockwood clinical frailty scale score on the definitions page*

- |   |  |   |
|---|--|---|
| <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 |  |   |

**1e. Karnofsky performance score in the two weeks prior to the admission:**

*Please refer to the definitions page*

- 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

---

**2a. Please state the reason for the admission:**

**2b. Was this final admission to hospital appropriate?**

- Yes                       No                       Unknown

**2c. If answered "No" to [2b] then:**

**Please explain your answer:**



---

**3a. Could this final admission have been avoided?**

Yes                       No                       Unknown

**3b. If answered "Yes" to [3a] then:  
Please explain your answer (avoided)**

---

**4a. On review of the case notes, were any relevant investigations omitted?**

Yes                       No                       Unknown

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

**4c. On review of the case notes, were any relevant investigations done that should have been omitted?**

Yes                       No                       Unknown

**4d. If answered "Yes" to [4c] then:  
Please give further details: (should've limited)**

---

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

Yes                       No                       Unknown

**5b. If answered "Yes" to [5a] then:  
Please expand on your answer (omitted treatment)**

**5c. On review of the case notes, were any treatments given that should have been omitted?**

Yes                       No                       Unknown

**5d. If answered "Yes" to [5c] then:  
Please give further details (shouldve)**

---

### Hospital Deaths

**6a. If answered "In hospital" to [1a] then:  
During the final admission, was there any evidence that recovery was uncertain?**

Yes                       No                       Unknown

**6b. If answered "In hospital" to [1a] then:  
Was the death anticipated?**

Yes                       No                       Unclear

**6c. If answered "In hospital" to [1a] then:  
In your opinion, was there a delay in recognising the patient was dying?**

Yes                       No                       Unknown

**6d. If answered "In hospital" to [1a] then:  
Was there an aim to discharge the patient from hospital?**

Yes                       No                       Unclear

**6e. 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                       Not applicable

**6f. If answered "In hospital" to [1a] then:  
Was there any evidence of delay in discharge?**

Yes                       No                       Unclear

**6g. If answered "In hospital" to [1a] then:  
In your opinion, could death in a location other than hospital have been achieved?**

Yes                       No                       Unclear

**6h. If answered "In hospital" to [1a] and "Yes" to [6g] then:  
Please explain your answer (death location)**

---

**7a. If answered "In hospital" to [1a] then:  
Was specific end of life documentation used?**

Yes                       No                       Unknown

**7b. If answered "Yes" to [7a] and "In hospital" to [1a] then:  
Please state the date this was first started:**

Unknown

---

**8a. If answered "In hospital" to [1a] then:  
Is there documented evidence that the patient was offered information that they were dying?**

Yes                       No                       Unknown

**8b. 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

---

**9a. If answered "In hospital" to [1a] then:  
Was the patient under the care of a palliative care team before this admission?**

Yes                       No                       Unknown

**9b. 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

**9c. If answered "In hospital" to [1a] and "Yes" to [9b] 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

**10a. Did this patient have a RESPECT (or equivalent) form in place?**

Yes                       No                       Unknown

**10b. If answered "Yes" to [10a] then:  
How was this documented?**

Paper form                       Electronic form

**11a. Did the patient have a Treatment Escalation Plan (TEP) in place?**

- Yes                       No                       Unknown

**11b. If answered "Yes" to [11a] then:**

**Please state the date that the TEP was first documented:**

Unknown

**11c. Was a capacity assessment undertaken in relation to the advance care planning (RESPECT and TEP)**

- Yes                       No                       Unknown

**11d. If answered "Yes" to [11c] then:**

**Did the patient have capacity?**

- Yes                       No                       Unknown

---

**Medications**

**12a. Were all appropriate medications given to control symptoms?**

- Yes                       No                       Not applicable                       Unknown

**12b. If answered "No" to [12a] then:**

**Please expand on your answer**

**12c. Were medications stopped appropriately as the patient deteriorated?**

- Yes                       No                       Not applicable                       Unknown

**12d. If answered "No" to [12c] then:**

**Please expand on your answer (meds stopped)**

**12e. Were end of life/ anticipatory medications prescribed?**

- Yes                       No                       Unknown

**12f. If answered "Yes" to [12e] then:**

**Were end of life/ anticipatory medications administered?**

- Yes                       No                       Unknown

**12g. In your opinion was there room for improvement in the the use of end of life/ anticipatory medications?**

- Yes                       No                       Unknown

**12h.If answered "Yes" to [12g] then:  
Please expand on your answer (meds)**

---

**Community Deaths**

**13a.If answered "In the community" to [1a] then:  
Date of discharge from hospital**

Unknown

**13b.If answered "In the community" to [1a] then:  
Discharge location**

- |                                    |                                      |   |
|------------------------------------|--------------------------------------|---|
| <input type="radio"/> Own home     | <input type="radio"/> Relatives home | <input type="radio"/> Residential care home |
| <input type="radio"/> Nursing home | <input type="radio"/> Hospice        | <input type="radio"/> Unknown               |

If not listed above, please specify here...

**13c.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

**13d.If answered "In the community" to [1a] and "Yes" to [13c] then:  
Please explain your answer (death anticipated in the community)**

**13e.If answered "In the community" to [1a] and "Yes" to [13c] then:  
Was continuing healthcare funding (or equivalent) used to facilitate the discharge?**

- Yes                       No                       Unknown

---

**14a.If answered "In the community" to [1a] then:  
How would you rate the discharge planning for end of life care (com)?**

- |                                      |                                      |                            |                                    |
|--------------------------------------|--------------------------------------|----------------------------|------------------------------------|
| <input type="radio"/> Good           | <input type="radio"/> Adequate       | <input type="radio"/> Poor | <input type="radio"/> Unacceptable |
| <input type="radio"/> Unable to rate | <input type="radio"/> Not applicable |                            |                                    |

**14b.If answered "In the community" to [1a] and "Good", "Adequate", "Poor" or "Unacceptable" to [14a] then:  
Please explain your answer (discharge rating)**

## E. Overall quality of care

### Please use the following grading to rate the overall quality of care received by this patient

GOOD PRACTICE: A standard that you would accept from yourself, your trainees and your institution

ROOM FOR IMPROVEMENT: Aspects of CLINICAL care that could have been better

ROOM FOR IMPROVEMENT: Aspects of ORGANISATIONAL care that could have been better

ROOM FOR IMPROVEMENT: Aspects of CLINICAL AND ORGANISATIONAL care that could have been better

LESS THAN SATISFACTORY: Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution.

INSUFFICIENT DATA: Insufficient information submitted to NCEPOD to assess the quality of care

#### 1a. Please rate the overall quality of care using the grading system provided

- Good practice
- Room for improvement in clinical aspects of care
- Room for improvement in organisational aspects of care
- Room for improvement in clinical AND organisational aspects of care
- Less than satisfactory
- Insufficient data to grade

#### 1b. If answered "Good practice", "Room for improvement in clinical aspects of care", "Room for improvement in organisational aspects of care", "Room for improvement in clinical AND organisational aspects of care" or "Less than satisfactory" to [1a] then: Please provide reasons for assigning this grade

---

#### 2a. Are there any themes/ issues from this case you feel should be highlighted in the final report?

- Yes                       No

#### 2b. If answered "Yes" to [2a] then: Please expand on your answer (vignette)

---

#### Cause for concern

Occasionally NCEPOD will refer cases that have been identified as 'LESS THAN SATISFACTORY' when it is felt that further feedback to the Trust/ Health Board concerned is warranted. This is usually due to an area of concern to the hospital or clinician involved, and not for issues highlighted across the body of case notes.

This process has been agreed by the NCEPOD Steering Group and the GMC. The medical director of the

Trust/ Health Board is written to by the Chief Executive of NCEPOD explaining our concerns. This process has been in operation for 10 years and the responses received have always been positive

**3. If answered "Less than satisfactory" to [1a] then:  
Do you feel that this case should be considered for such action?**

Yes

No