National Audit of Care at the End of Life (NACEL)

Case Note Review – Data specification 2019. PDF version.

The deadline for submission of data is 11th October 2019

Data should be entered into the online data collection pages (www.nhsbenchmarking.nhs.uk)

Participation is open to all Trusts/Health Boards in England, Wales and Northern Ireland

Please Note:

- If you do not have the data to answer the question, please leave blank.
- Guidance notes to assist with the Case Note Review are available to download from the Network website.
- Definitions are included within the excel Case Note Review data specification and online data collection pages.

Support:

Definitions are provided, however questions on interpretation of data items and any other queries can be submitted to: nhsbn.nacelsupport@nhs.net or telephone 0161 266 2214.
Definitions of deaths to be included in NACEL Case Note Review

1. **Acute hospitals**: Audit up to a maximum of 20 consecutive deaths from 1st April 2019 - 14th April 2019, and up to a maximum of 20 consecutive deaths from 1st May 2019 - 14th May 2019.
   **Community hospitals**: Audit up to a maximum of 40 consecutive deaths from 1st April 2019 - 31st May 2019.

2. Separate submissions should be made for acute and community hospital sites. You will have defined these during the registration process.

3. Please submit up to a maximum of 40 Case Note Reviews from deaths occurring in the audit period.

4. Include only ADULT deaths i.e. if the patient was aged 18+ at the time of death.

5. Include deaths in specialist palliative care beds that are fully managed and funded by the NHS. Hospices are excluded.

6. The Case Note Review will audit deaths which fall into the following two categories:-
   1. **It was recognised that the patient may die** - it had been recognised by the hospital staff that the patient may die imminently (i.e. within hours or days). Life sustaining treatments may still be being offered in parallel to end of life care.
   2. **The patient was not expected to die** - imminent death was not recognised or expected by the hospital staff. However, the patient may have had a life limiting condition or, for example, be frail, so that whilst death wasn't recognised as being imminent, hospital staff were "not surprised" that the patient died.

7. Deaths which are classed as "**sudden deaths**" are excluded from the Case Note Review. These are deaths which are sudden and unexpected; this includes, but is not limited to, the following:-
   - all deaths in Accident and Emergency departments
   - deaths within 4 hours of admission to hospital
   - deaths due to a life-threatening acute condition caused by a sudden catastrophic event, with a full escalation of treatment plan in place. These deaths would not fall into either category 1 or 2 above.

8. Throughout this Case Note Review, the term "**nominated person(s)**" has been used. This relates to the terminology "those identified as important to the dying person" as used in "One chance to get it right". This may not necessarily be the next of kin.
<table>
<thead>
<tr>
<th><strong>PATIENT CASE NOTE REVIEW CODE</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Name of case note reviewer</td>
<td></td>
</tr>
<tr>
<td>2. There are two categories of</td>
<td></td>
</tr>
<tr>
<td>deaths for patients included in</td>
<td></td>
</tr>
<tr>
<td>the audit. Indicate whether for</td>
<td></td>
</tr>
<tr>
<td>this patient:</td>
<td></td>
</tr>
<tr>
<td>□ Category 1. It was recognised</td>
<td></td>
</tr>
<tr>
<td>and documented that the</td>
<td></td>
</tr>
<tr>
<td>patient may die</td>
<td></td>
</tr>
<tr>
<td>□ Category 2. The patient was</td>
<td></td>
</tr>
<tr>
<td>not expected to die</td>
<td></td>
</tr>
<tr>
<td>3. Age at the time of death</td>
<td></td>
</tr>
<tr>
<td>4. Usual place of Residency</td>
<td></td>
</tr>
<tr>
<td>□ Home</td>
<td></td>
</tr>
<tr>
<td>□ Residential Home</td>
<td></td>
</tr>
<tr>
<td>□ Nursing Home</td>
<td></td>
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<tr>
<td>□ Prison</td>
<td></td>
</tr>
<tr>
<td>□ No fixed abode</td>
<td></td>
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<tr>
<td>□ NHS other hospital provider</td>
<td></td>
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<tr>
<td>□ Other</td>
<td></td>
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<tr>
<td>5. Gender</td>
<td></td>
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<tr>
<td>□ Male</td>
<td></td>
</tr>
<tr>
<td>□ Female</td>
<td></td>
</tr>
<tr>
<td>□ Other</td>
<td></td>
</tr>
<tr>
<td>6. Ethnicity</td>
<td></td>
</tr>
<tr>
<td>□ A White: British</td>
<td></td>
</tr>
<tr>
<td>□ B White: Irish</td>
<td></td>
</tr>
<tr>
<td>□ C White: Any other White</td>
<td></td>
</tr>
<tr>
<td>background</td>
<td></td>
</tr>
<tr>
<td>□ D Mixed: White and Black</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
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<tr>
<td>□ E Mixed: White and Black</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td></td>
</tr>
<tr>
<td>□ F Mixed: White and Asian</td>
<td></td>
</tr>
<tr>
<td>□ G Mixed: Any other mixed</td>
<td></td>
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<tr>
<td>background</td>
<td></td>
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<tr>
<td>□ H Asian or Asian British:</td>
<td></td>
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<tr>
<td>Indian</td>
<td></td>
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<td>□ J Asian or Asian British:</td>
<td></td>
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<tr>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>□ K Asian or Asian British:</td>
<td></td>
</tr>
<tr>
<td>Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>□ L Asian or Asian British:</td>
<td></td>
</tr>
<tr>
<td>Any other Asian background</td>
<td></td>
</tr>
<tr>
<td>□ M Black or Black British:</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
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<td>□ N Black or Black British:</td>
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<tr>
<td>African</td>
<td></td>
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<tr>
<td>□ P Black or Black British:</td>
<td></td>
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<tr>
<td>Any other Black background</td>
<td></td>
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<tr>
<td>□ R Other Ethnic Groups:</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>□ S Other Ethnic Groups:</td>
<td></td>
</tr>
<tr>
<td>Any other ethnic group</td>
<td></td>
</tr>
<tr>
<td>□ Z Not stated</td>
<td></td>
</tr>
</tbody>
</table>
7. What was the primary cause of death?

- Cancer
- Chronic respiratory disease
- Dementia
- Heart failure
- Neurological conditions (such as motor neurone disease)
- Pneumonia
- Renal failure
- Stroke
- Other
- No access to death certificate

**RECOGNITION OF THE POSSIBILITY OF IMMINENT DEATH**

1. What was the date of the final admission? .................................................................

2. What was the time of the final admission? .................................................................

3. What was the date of the first documented evidence of the recognition that the patient might die within the next few days and hours? *(Category 1 deaths only)*

4. What was the time of the first documented evidence of the recognition that the patient might die within the next few days and hours? *(Category 1 deaths only)*

5. What was the date of death? .................................................................

6. What was the time of death? .................................................................

7. Is there documented evidence that the possibility that the patient may die has been discussed with the patient? *(Category 1 deaths only)*
   - Yes
   - No – Patient was semi – conscious or unconscious
   - No – Patient lacked capacity to understand
   - No – Patient had asked not to be involved in this discussion
   - No – Other reason recorded
   - No- No reason recorded

8. Is there documented evidence the possibility that the patient may die had been discussed with the nominated person(s)? *(Category 1 deaths only)*
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person(s)
   - No – Patient had not consented for these discussions to take place with the nominated person(s)
   - No – Independent Mental Capacity Adviser (IMCA ) unavailable
   - No – Other reason recorded
   - No- No reason recorded
9. Is there documented evidence that the nominated person(s) were notified that the patient was about to die? (Category 1 deaths only)
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person
   - No – Insufficient time
   - No – Nominated person already present
   - No – Other reason recorded
   - No - No reason recorded

INDIVIDUALISED END OF LIFE CARE PLANNING

ADVANCE CARE PLANNING

1. Is there documented evidence that the patient had participated in advance care planning prior to the recognition that the patient might die, and had their wishes recorded?
   - Yes, prior to admission
   - Yes, during the final admission
   - No advance care plan
   - N/A

2. Was there documented evidence of the preferred place of death as indicated by the patient?
   - Yes
   - No

THE PATIENT

3. Is there documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs?
   - Yes
   - No

4. Is there documented evidence that the patient and their individualised plan of care were reviewed regularly? (Only answer if Yes to Q3)
   - Yes
   - No
   - Patient died before a review was necessary

5. Is there documented evidence that the patient was involved in discussing the individualised plan of care? (Only answer if Yes to Q3)
   - Yes
   - No – Patient was semi-conscious or unconscious
   - No – Patient lacked capacity to understand
   - No – Patient had asked not to be involved in this discussion
   - No – Other reason recorded
   - No- No reason recorded
6. Is there documented evidence that the nominated person(s) was involved in discussing an individualised plan of care for the patient? (Only answer if Yes to Q3)
   - ☐ Yes
   - ☐ No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person(s)
   - ☐ No – Patient had not consented for these discussions to take place with the nominated person(s)
   - ☐ No – Independent Mental Capacity Adviser (IMCA) unavailable
   - ☐ No – Other reason recorded
   - ☐ No- No reason recorded

7. Is there documented evidence of an assessment of the following needs:

<table>
<thead>
<tr>
<th>Need</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>agitation / delirium</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>dyspnoea / breathing difficulty</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>nausea / vomiting</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pain</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>noisy breathing / death rattle</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>anxiety / distress</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>bladder function</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>bowel function</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>pressure areas</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>hygiene requirements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>mouth care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>emotional / psychological needs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>spiritual / religious/ cultural needs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>social and practical needs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

CARE OF PLANNING OF TREATMENTS

8. Was the benefit of starting, stopping or continuing the following interventions documented as being reviewed in the patient’s plan of care? (Category 1 deaths only)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>routine recording of vital signs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>blood sugar monitoring</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>the administration of oxygen</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>the administration of antibiotics</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>routine blood tests</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>other medication</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
SYMPTOM MANAGEMENT

9. Is there documented evidence that anticipatory medication was prescribed for symptoms likely to occur in the last days of life? (Category 1 deaths only)
   - Yes, anticipatory medicine prescribed but not used
   - Yes, anticipatory medicines prescribed and administered
   - No
   - N/A

10. Is there documented evidence that an indication for the use of the medication was included within the prescription? (Only answer if Yes to Q9)
    - Yes, for all medicine prescribed
    - Yes, for some medicines prescribed
    - No

11. Is there documented evidence that a discussion about the use of anticipatory medication was undertaken with the patient? (Only answer if Yes to Q9)
    - Yes
    - No – Patient was semi-conscious or unconscious
    - No – Patient lacked capacity to understand
    - No – Patient had asked not to be involved in this discussion
    - No – Other reason recorded
    - No- No reason recorded

12. Is there documented evidence that a discussion about the use of anticipatory medication was undertaken with the nominated person(s)? (Only answer if Yes to Q9)
    - Yes
    - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person
    - No – Patient had not consented for these discussions to take place with the nominated person(s)
    - No – Independent Mental Capacity Adviser (IMCA ) unavailable
    - No – Other reason recorded
    - No- No reason recorded

13. Is there documented evidence that the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with the patient?
    - Yes
    - No – Patient was semi-conscious or unconscious
    - No – Patient lacked capacity to understand
    - No – Patient had asked not to be involved in this discussion
    - No – Other reason recorded
    - No- No reason recorded
    - N/A
14. Is there documented evidence that the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with the nominated person(s)?
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person
   - No – Patient had not consented for these discussions to take place with the nominated person(s)
   - No – Independent Mental Capacity Adviser (IMCA) unavailable
   - No – Other reason recorded
   - No – No reason recorded
   - N/A

15. Is there documented evidence that the patient had a continual infusion of medications, for example via syringe pump?
   - Yes
   - No

16. Is there evidence of a documented discussion with the patient on the need for a syringe pump? (Only answer if Yes to Q15)
   - Yes
   - No – Patient was semi-conscious or unconscious
   - No – Patient lacked capacity to understand
   - No – Patient had asked not to be involved in this discussion
   - No – Other reason recorded
   - No – No reason recorded
   - N/A

17. Is there evidence of a documented discussion with the nominated person on the need for a syringe pump? (Only answer if Yes to Q15)
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person
   - No – Patient had not consented for these discussions to take place with the nominated person(s)
   - No – Independent Mental Capacity Adviser (IMCA) unavailable
   - No – Other reason recorded
   - No – No reason recorded
   - N/A

**DRINKING AND ASSISTED HYDRATION**

18. Is there documented evidence that the patient’s hydration status was assessed daily once the dying phase was recognised? (Category 1 deaths only)
   - Yes
   - No
19. Is there documented evidence that a discussion about the risks and benefits of hydration options was undertaken with the patient once the dying phase was recognised? (Category 1 deaths only)
   - Yes
   - No – Patient was semi-conscious or unconscious
   - No – Patient lacked capacity to understand
   - No – Patient had asked not to be involved in this discussion
   - No – Other reason recorded
   - No– No reason recorded
   - N/A

20. Is there documented evidence that a discussion about the risks and benefits of hydration options was undertaken with the nominated person(s)? (Category 1 deaths only)
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person
   - No – Patient had not consented for these discussions to take place with the nominated person(s)
   - No – Independent Mental Capacity Adviser (IMCA) unavailable
   - No – Other reason recorded
   - No– No reason recorded
   - N/A

21. Is there documented evidence that the patient was supported to drink as long as they were able and wished to do so? (Category 1 deaths only)
   - Yes
   - No
   - N/A

**EATING AND ASSISTED NUTRITION**

22. Is there documented evidence that the patient’s nutrition status was reviewed regularly once the dying phase was recognised? (Category 1 deaths only)
   - Yes
   - No

23. Is there documented evidence that a discussion about the risks and benefits of nutrition options was undertaken with the patient once the dying phase was recognised? (Category 1 deaths only)
   - Yes
   - No – Patient was semi-conscious or unconscious
   - No – Patient lacked capacity to understand
   - No – Patient had asked not to be involved in this discussion
   - No – Other reason recorded
   - No– No reason recorded
   - N/A
24. Is there documented evidence that a discussion about the risks and benefits of nutrition options was undertaken with the nominated person(s)? (Category 1 deaths only)
   - Yes
   - No – Attempts to contact the nominated person(s) were unsuccessful/ no nominated person(s)
   - No – Patient had not consented for these discussions to take place with the nominated person(s)
   - No – Independent Mental Capacity Adviser (IMCA) unavailable
   - No – Other reason recorded
   - No – No reason recorded
   - N/A

25. Is there documented evidence that the patient was supported to eat as long as they were able to and wished to do so? (Category 1 deaths only)
   - Yes
   - No
   - N/A

OTHER

1. If the following areas were identified when reviewing the case notes, please supply further detail:
   a. areas of excellent practice
      ..................................................................................................................................................
      ..................................................................................................................................................
      ..................................................................................................................................................
   b. learning points
      ..................................................................................................................................................
      ..................................................................................................................................................
      ..................................................................................................................................................