Learning from the National Audit of Care at the End of Life (NACEL) 2018

Care of Dying Adults in the last days of life
20\textsuperscript{th} September 2019

Claire Holditch
Director, NHS Benchmarking Network
The first round of NACEL (2018)
Aim and scope of NACEL

- **Aim of NACEL**: to improve the quality of care of people at the end of life in acute, mental health inpatient facilities and community hospitals.


- The audit covered NHS funded end of life care in hospitals.

- Covers 5 priorities for the dying person outlined in "One chance to get it right" and NICE quality standards.

- Acute, mental health inpatient facilities and community hospitals were all in scope of the audit, where they provided inpatient facilities.

- Hospices were excluded.

- NACEL Steering Group, Advisory Group and The Patients Association played a key role in the development of the audit.
NACEL elements

Data for all audit elements was collected between 4th June and 12th October

- **Organisation Level Audit (OLA)**
  - Trust/ UHB and submission level questions
  - Policies, activity, SPC workforce, training

- **Case Note Review (CNR)**
  - Completed by acute and community providers only
  - April 2018 deaths – acute; April – June 2018 community hospitals. Maximum 80 (acute)
  - Audit standards: 5 priorities of care and NICE QS

- **NACEL Quality Survey (QS)**
  - Developed with the assistance of the Patients Association
  - Piloted with bereaved carers
  - Online survey; linked to the Case Note Review
NACEL participation in England and Wales

- 207 English Trusts and 7 UHBs took part
- 207 Trust / UHB overviews
- 302 hospital site submissions
- 11,034 Case Note Reviews (Acute – 10,024, Community – 1,010)
- 790 NACEL Quality Surveys
First round of NACEL key themes and recommendations
Key themes for first round of NACEL

- **The nine themes** below cover the five priorities and the NICE quality standards:

  1. Recognition of imminent death (CNR)
  2. Communication with dying person (CNR)
  3. Communication with families and others (CNR)
  4. Involvement in decision making (CNR)
  5. Individual plan of care (CNR)
  6. Needs of families and other (CNR)
  7. Families and others experience of care (QS)
  8. Governance (OLA)
  9. Workforce/ specialist palliative care (OLA)

- A **summary score** was calculated for each key theme
Recognition of the possibility of imminent death

Case Note Review (CNR) - 89% had documented evidence that patient might die imminently

Median time for the whole sample from first recognition of death to time of death was 36 hours
Recognition of the possibility of imminent death

- CNR – documented evidence that the possibility that the patient may die had been discussed with the patient, or reason why not recorded, 86% of cases

- CNR - Not surprisingly, discussion was more likely to take place with the people important to the dying person, or reason why not recorded, 95% of cases
Recognition of the possibility of imminent death

**Quality Survey (QS):**

- Staff explained to the patient that they were likely to die in **28%** of cases. In **10%** of cases, the patient wasn’t told but could have been.

- **21%** of respondents felt communication with them about the patient’s imminent death either didn’t happen or was unclear, and a further **5%** were only told when asked.
Ensure that staff have an awareness of, acknowledge and communicate, as early and sensitively as possible, the possibility or likelihood of imminent death. Ensure that patients who have signs and symptoms that suggest they may be in the last days of life are monitored for changes. Staff should have an awareness of the importance of recognising uncertainty and communicating uncertain prognosis early in hospital admission and continuing conversations with patients and those important to them at all stages.
Communication with the dying person

- CNR - In around one third of cases a discussion with the patient about the plan of care, medication, hydration and nutrition had not been recorded.

- QS - 22% of respondents reported that communication with the dying person was not sensitive or was ‘mixed’.
Communication with families and others

- **CNR** - 62% had opportunity to discuss patient’s plan of care documented.
- **CNR** - Where death was recognised, 84% of people were notified that the patient was about to die.
- **QS** - In around a quarter of cases, the QS results suggest there was scope for improvement in communication with families and others.

![Bar chart](chart.png)

(CNR) Documented that family/others had opportunity to discuss patient’s plan of care (n=9,993)
Recommendation

Chief Executives should:

6. Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with patients and families in the last days and hours of life. Training for clinicians and other staff who have contact with dying people should focus on supporting the delivery of the *NICE Quality Standards* within the broader context of *One Chance To Get It Right*. National resources to support training are available such as guidance from professional bodies, learning outcomes and e-ELCA.
Involvement in decision making

- CNR - Patients wishes regarding their involvement in discussion of care were not documented in 38% of cases

- QS - Most were involved as much as they wanted to be but 22% of respondents would like to have been more involved in discussion about the patients care

- CNR - An advance care plan existed in 7% of cases

- QS - 31% of patients were admitted to hospital three or more times within the last 12 months of life
Recommendation

Integrated Care Systems/Commissioners, working with providers, should:

1. **Put in place systems and processes to support people approaching the end of life to receive care that is personalised to their needs and preferences.** Health and care systems should work together to agree, and effectively implement, guidelines across primary, community, secondary care, social care and care homes for timely identification of, documentation of, and information sharing regarding people’s wishes.
Needs of families and others

6.1

(CNR) Documented that needs of family/others asked about (n=9,901)

- CNR - 56% had documented that needs of family/others asked about
- Low compliance was highlighted in this area in the previous audit (*End of Life Care Audit – Dying in Hospital, 2016*)
Needs of families and others

- QS - Those close to the patient felt supported by the hospital staff after the patient’s death in 82% of cases, definitely or to some extent.

- QS - 61% felt they were given enough emotional support, and 58% enough practical support, during the last two or three days.
6. **Ensure systems are in place to assess and address the needs of the families of dying patients in a timely manner.** Specific senior, strategic and operational responsibility is required. Assessment of needs should cover emotional/psychological, spiritual/religious/cultural, social and practical needs.
CNR - 62% had documented evidence that patient had an individual end of life care plan

Definition of ‘end of life care plan’ has been clarified for second round
11. Ensure that patients who are recognised to be dying have a clearly documented and accessible individual plan of care developed and discussed with the patient and those important to them to ensure the person’s needs and wishes are known and taken into account. The plan will be based on the holistic care standards set out in the five priorities for care (One Chance To Get It Right) and NICE Quality Standards and take into account previously expressed wishes. Documentation for the individual plan of care may vary locally and may be part of standard care plans. Mechanisms to ensure the coordination of this plan must be in place especially at points of handover of care.

Recommendation

Medical Directors and Nursing Directors should:
Individual plan of care – review

- CNR - Review of routine monitoring of vital signs, blood sugar monitoring, administration of oxygen and antibiotics was not recorded to have taken place in between 25% – 33% of cases.
12. Ensure that the intended benefit of starting, stopping or continuing treatment for the individual is clear, with documentation of the associated communication with the patient and/or person important to them. This may include, but is not limited to, discussions regarding assessment and management of food and fluid, the common side effects of medication, the rationale for the use of syringe pumps, the review of routine monitoring of vital signs and blood sugar and the review of ongoing administration of medications e.g. oxygen and antibiotics.
Individual plan of care – eating and drinking

- QS - Around **one in five** of respondents had concerns about support for patients to eat and drink

- CNR - evidence that the patient was supported to drink once death was recognised in 39% of cases, no evidence in 20%, and assessed as not able to drink in 40% of cases

- CNR - evidence that the patient was supported to eat once death was recognised in 27% of cases, no evidence in 23%, and assessed as not able to eat in 49% of cases
Recommendations

Medical Directors and Nursing Directors should:

12. Ensure the dying person is supported to eat and drink if they are able and wish to do so.
Individual plan of care – place of care

- QS - 75% of respondents believed hospital to be right place for the patient to die.

- CNR - Attempts were made to move 11% of patients which were, for some reason, unsuccessful.

- QS - 16% of respondents felt no effort had been made to transfer the person from hospital if that was their wish.

(QS) On balance, do you think that hospital was the right place for him/her to die? (n=773)
Recommendations

2. **Review capability and capacity within primary care, community services and social care, to provide appropriate care at the end of life, and to support families through to bereavement, with the aim of better meeting people’s needs and preferences.** Review should lead to service re-design where potential improvements are identified.

3. **Implement processes to enable rapid discharge to home, care home or hospice, from hospital to die if that is the person’s wish.**
Individual plan of care – location in hospital

(QS) Within the hospital where did the person die? (n=767)

- 32% Bay shared with other patients
- 56% Side room
- 8% Intensive Care/HDU
- 5% Other

(QS) During the last two to three days of the patient’s life, did you feel that they had adequate privacy? (n=737)

- 51% Always
- 23% Most of the time
- 10% Sometimes
- 5% Almost never
- 6% Never
- 1% N/A
- 2% Not sure

(QS) Were you satisfied that this location within the hospital was appropriate? (n=774)

- 75% Yes
- 18% No
- 7% Not sure

- QS - One third of people died on a shared bay
- QS - Location was an issue for 21% of people who felt they had adequate privacy sometimes, almost never or never
- QS - Many comments related to lack of privacy and appropriately quiet environment where person on ward not side room
9. Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and their families. Take into account the wishes of dying people and those important to them, to be cared for in a side room.
Families and others experience of care

- **QS - 80%** of respondents felt the quality of care and support provided to the patient was good, excellent or outstanding.

- **QS - 76%** felt quality of care for families/others was good, excellent or outstanding.

- **QS – 67%** felt staff looking after patient communicated sensitively.

- **QS - 82%** felt that patients were treated with compassion.

- **QS - 78%** felt they had been communicated to by staff in a sensitive and compassionate way.

(QS) Overall quality of care and support provided to the patient (n=752)

- Outstanding: 32%
- Excellent: 30%
- Good: 18%
- Fair: 8%
- Poor: 11%
- Not sure: 2%
5. Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and the people who are important to them. Support all staff to have awareness, communicate sensitively and behave appropriately, when it is recognised that a person may be dying. See also Annex E of One Chance To Get It Right.
Organisational Level Audit (Trust level):

- 94% of trusts/UHBs have an identified member of the trust/UHB board with a responsibility/role for End of Life Care

- 98% of trusts/UHBs have policies in place which include how it responds to and learns from, deaths of patients who die under its management and care

- 92% of trusts/UHBs have specific care arrangements to enable rapid discharge home to die, if this is the person’s preference

- 97% of trusts/UHBs have a care plan to support the five priorities for care for the dying person
End of Life Care Lead (Board member with accountability for end of life care) should:

8. As part of a strong governance framework for end of life care, report annually to the Board with a performance report and action plan. The report and plan should build on the learning from NACEL, other audits, Learning from Deaths, complaints and feedback from surveys, including those from bereaved people.
Organisational Level Audit (Hospital/Site level):

- **97%** of hospitals have access to a specialist palliative care service and more than a third of patients were reviewed by a palliative care specialist.

- **52%** of hospitals have specialist palliative care nurses available 9-5 7 days a week for face to face contacts (or better/equivalent).

- **61%** of hospitals have end of life care training included in their induction programme and **47%** in their mandatory/priority training.
3. Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management. ‘Adequate’ means specialist palliative medical and nursing cover 9am-5pm, 7 days a week and a 24 hour telephone advice service (*One Chance To Get It Right*). This would most often be provided by nurse specialists face-to-face supported by medical telephone advice. Where this service does not exist, an action plan committing to provision of such services within a specified timeline should be developed.
### National Audit of Care at the End of Life 2018 – Key findings at a glance

#### Recognising the possibility of imminent death
- **36 hours**
  - Median time between recognition and death
- **89%**
  - Case notes recorded that the patient might die imminently

#### Communication with the dying person
- **68%**
  - Case notes recorded discussions with patients about medication, nutrition and hydration, or a reason why these did not take place
- **67%**
  - Families/carers reported communication was sensitive ‘definitely’, or ‘to some extent’

#### Communication with families and others
- **62%**
  - Case notes recorded that families/carers had the opportunity to discuss the patient’s plan of care
- **84%**
  - Case notes recorded families/carers were notified of the patient’s imminent death

#### Involvement in decision making
- **81%**
  - Families/carers reported that the patient was either involved in decision making as much as they wanted to be or were unable to be involved
- **80%**
  - Case notes recorded discussions by a senior clinician regarding CPR with families/carers

#### Individual plan of care
- **62%**
  - Case notes recorded an individualised plan of care
- **75%**
  - Families/carers felt hospital was the right place for the patient to die

#### Needs of families and other
- **56%**
  - Case notes recorded that the families/carers needs were asked about

#### Families’ and others’ experience of care
- **80%**
  - Families/carers felt the quality of care provided to the patient was good, excellent or outstanding
- **76%**
  - Families/carers felt the quality of care provided to themselves was good, excellent or outstanding

#### Governance
- **94%**
  - Organisations have an identified member of the board with responsibility for end of life care
- **92%**
  - Organisations have specific care arrangements to enable rapid discharge home to die
- **97%**
  - Hospitals have access to a specialist palliative care service
- **52%**
  - Hospitals have specialist palliative care nurses available 9-5, 7 days a week for face to face contacts
Looking forward to the second round

Scope and content

- **Aimed to:**
  - Reduce data burden significantly
  - Increase uptake of QS

- **Trust level audit - remove for one year**

- **Hospital/Site level - focus on specialist workforce**

- **Case Note Review**
  - Reduced specification to approx. 25% size of round 1
  - Focus on recognition of dying and individual plan of care
  - Address anticipatory prescribing
  - Reduce number of CNRs to 40 (from 80)

- **Quality Survey**
  - Unlinked from CNR to increase numbers
  - Use for needs of family summary score

- **Mental health inpatient facilities**
  - To complete all elements of the audit in round 2

- **Staff Reported Measure**
  - Developed and piloted in 2019
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<th>Timetable – key dates</th>
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<tr>
<td>Data collection opened</td>
<td>3rd June 2019</td>
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<tr>
<td>Staff Reported Measure pilot</td>
<td>August 2019</td>
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<td>Data collection closes</td>
<td>11th October 2019</td>
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<td>Validation and analysis</td>
<td>October - November 2019</td>
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<td>Toolkit published</td>
<td>December 2019</td>
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<td>February 2020</td>
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<td>National report published</td>
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Thank you – any questions?

Contact:  
nhsbn.nacelsupport@nhs.net