National Audit of Care at the End of Life

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

Palliative and End of Life Care conference
14th November 2019

Claire Holditch
Director, NHSBN and NACEL

Aim and scope of NACEL

National Audit of Care at the End of Life

- 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
- Commissioned by HQIP on behalf of NHS England and the Welsh Government in October 2017
- 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

National Audit of Care at the End of Life

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

National Audit of Care at the End of Life

- 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

Key themes for first round of NACEL

National Audit of Care at the End of Life

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

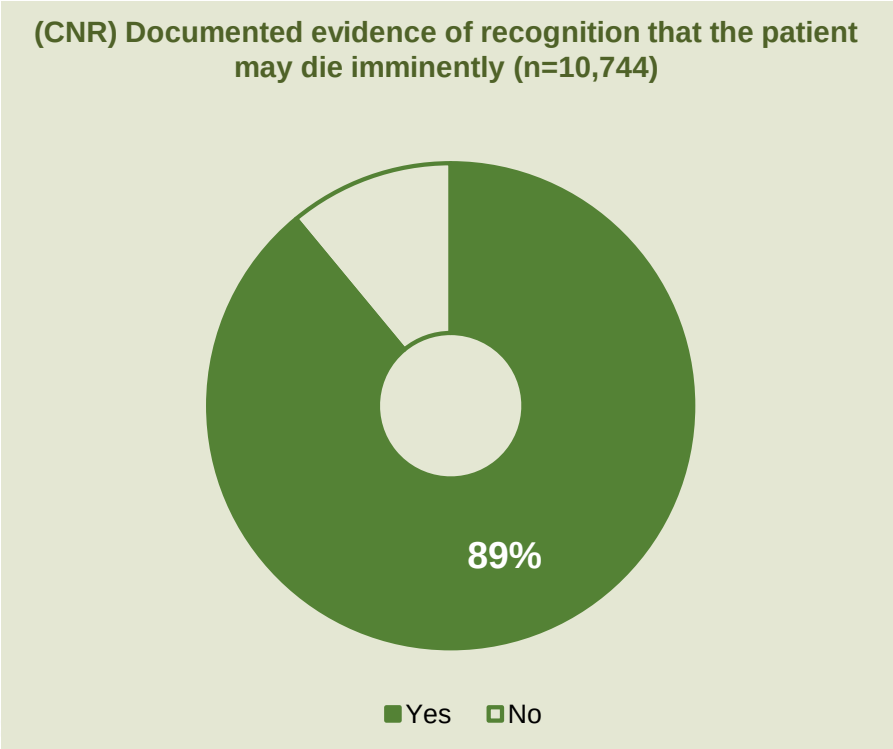
1. Recognition of imminent death (CNR)
2. Communication with dying person (CNR)
3. Communication with families and others(CNR)
4. Involvement in decision making (CNR)
5. Individual plan of care (CNR)
6. Needs of families and other (CNR)
7. Families and others experience of care (QS)
8. Governance (OLA)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

- A **summary score** was calculated for each key theme

Recognition of the possibility of imminent death

National Audit of Care at the End of Life

9.1



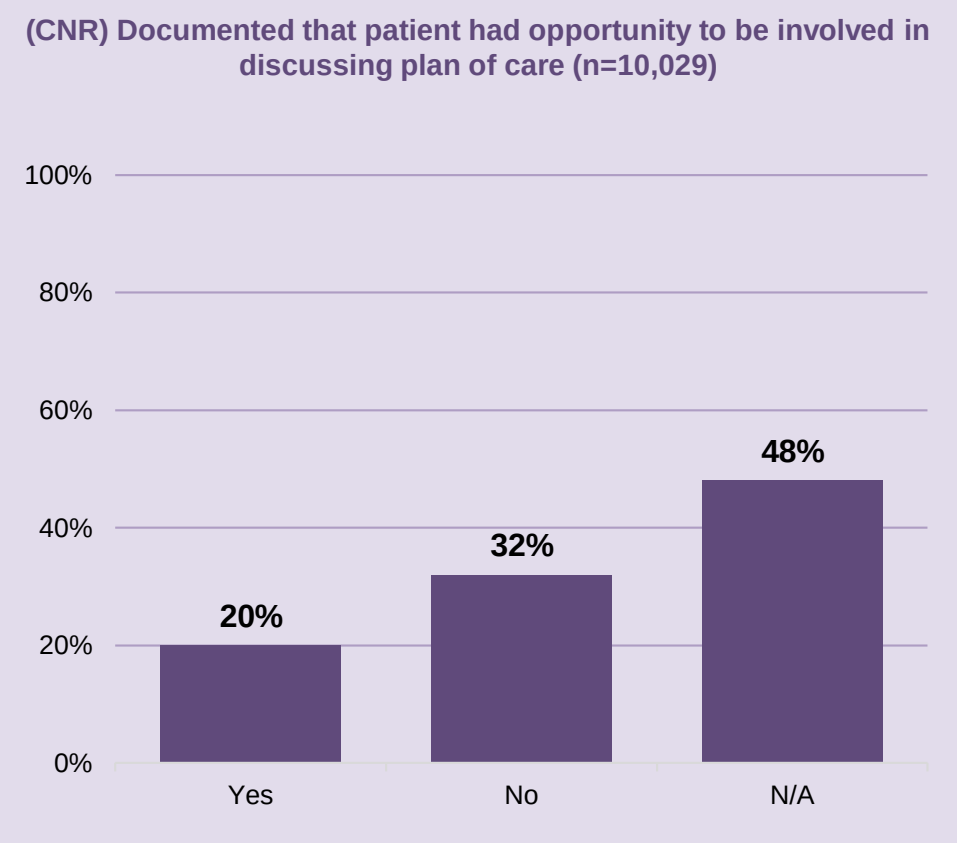
- Case Note Review (CNR) - **89%** had documented evidence that patient might die imminently
- Median time for the whole sample from first recognition of death to time of death was **36 hours**
- **21%** of respondents felt communication with them about the patient's imminent death either didn't happen or was unclear, and a further **5%** were only told when asked

NHS Benchmarking Network

Communication with the dying person

National Audit of Care at the End of Life

6.9



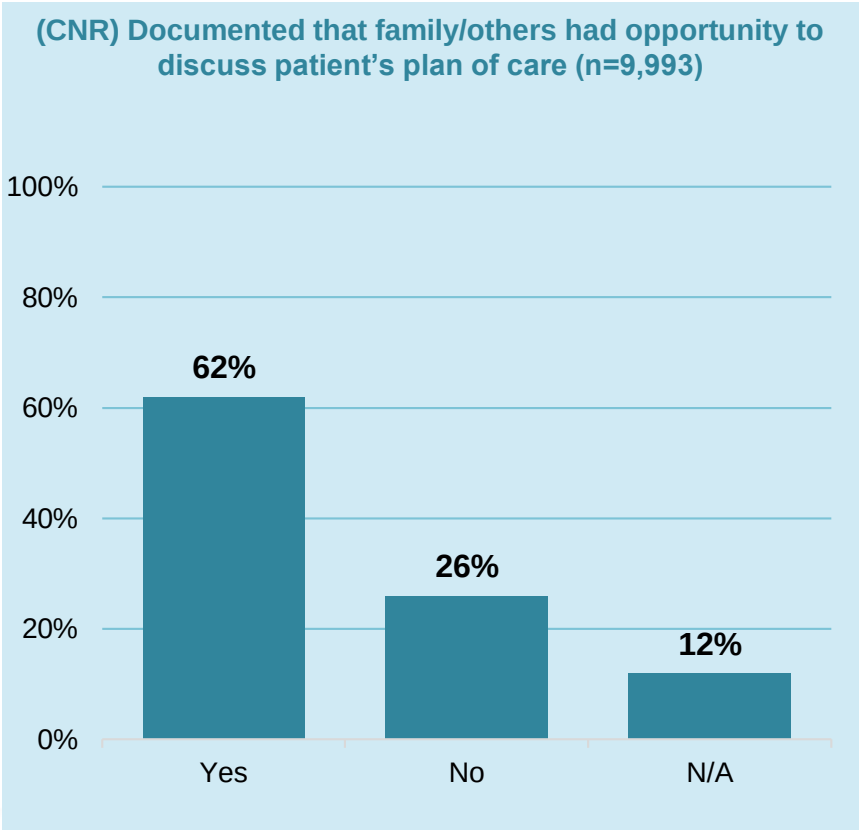
- CNR - In around **one third** of cases a discussion with the patient about the plan of care, medication, hydration and nutrition had not been recorded
- QS - **22%** of respondents reported that communication with the dying person was not sensitive or was 'mixed'

NHS Benchmarking Network

Communication with families and others

National Audit of Care at the End of Life

6.6



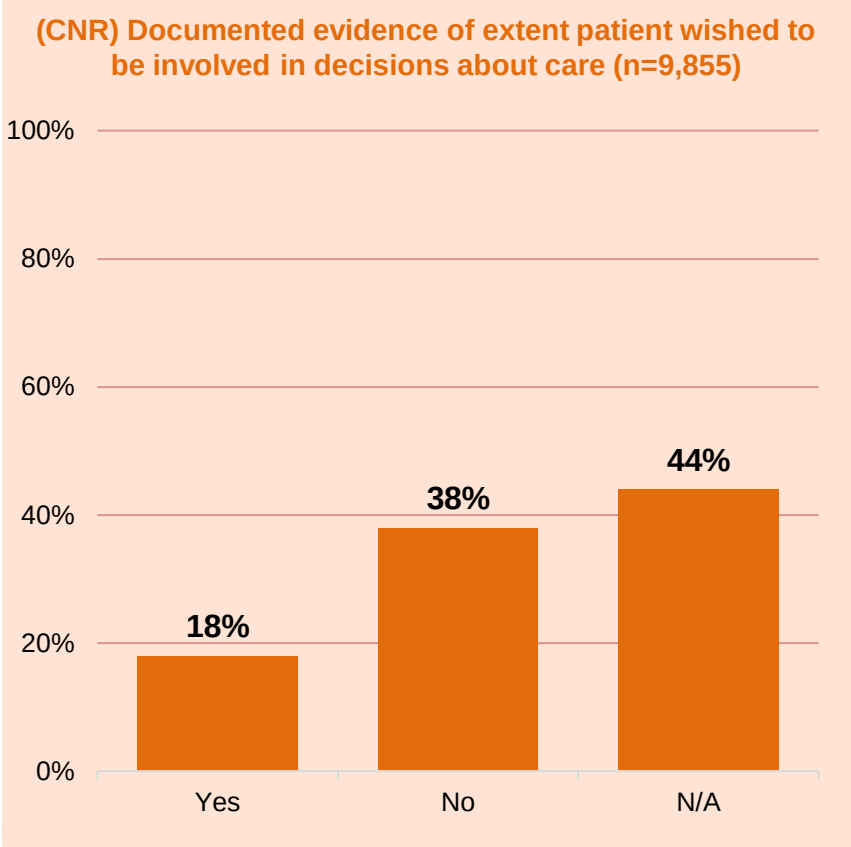
- CNR - **62%** had opportunity to discuss patient's plan of care documented
- CNR - Where death was recognised, **84%** of people were notified that the patient was about to die
- QS - In around a quarter of cases, the QS results suggest there was scope for improvement in communication with families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

NHS Benchmarking Network

Involvement in decision making

8.4

National Audit of Care at the End of Life



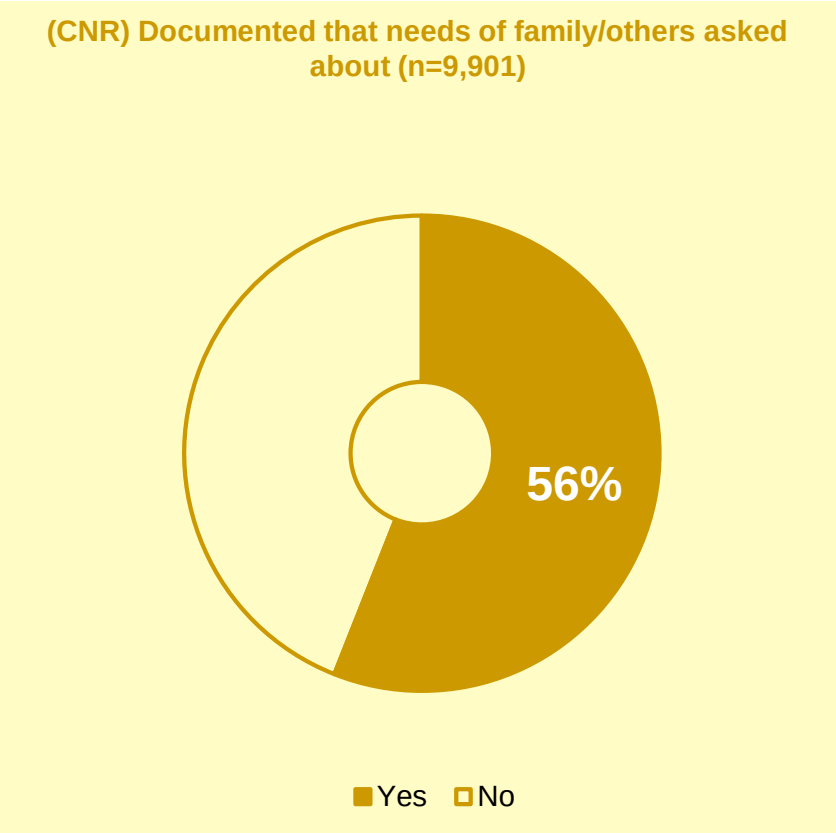
- CNR - Patients wishes regarding their involvement in discussion of care were not documented in **38%** of cases
- QS - Most were involved as much as they wanted to be but **22%** of respondents would like to have been more involved in discussion about the patients care
- QS - **31%** of patients were admitted to hospital three or more times within the last 12 months of life

NHS Benchmarking Network

Needs of families and others

6.1

National Audit of Care at the End of Life



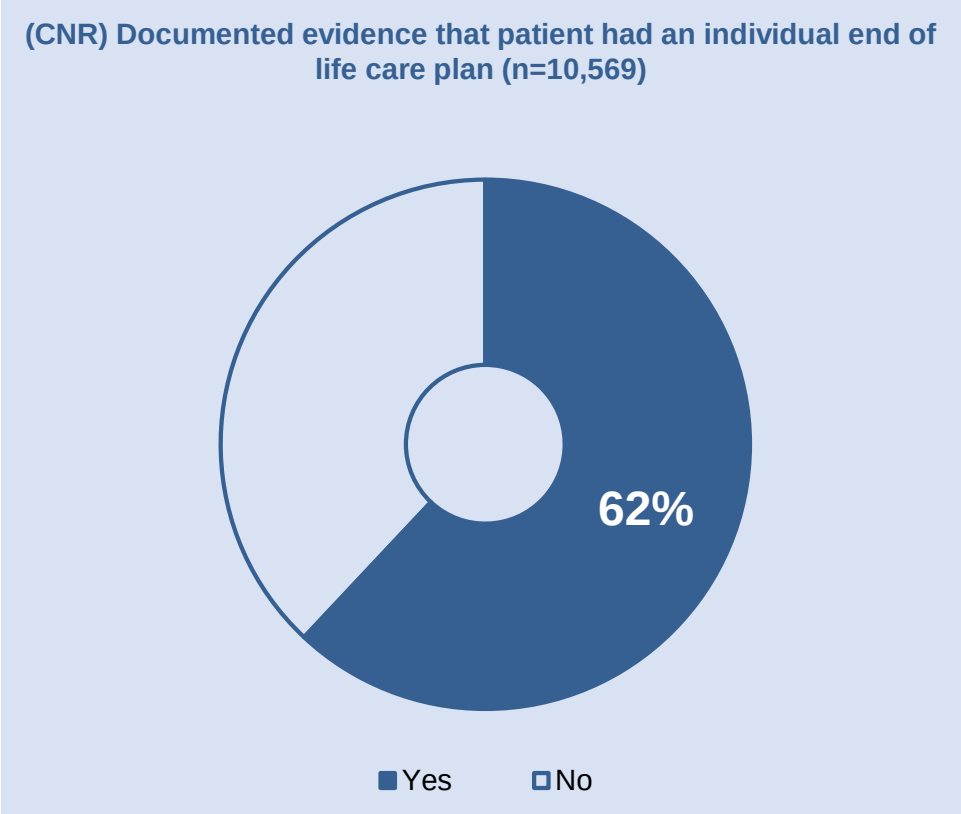
- CNR - **56%** had documented that needs of family/others asked about
- Low compliance was highlighted in this area in the previous audit (*End of Life Care Audit – Dying in Hospital, 2016*)
- QS - Those close to the patient felt supported by the hospital staff after the patient's death in **82%** of 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

NHS Benchmarking Network

Individual plan of care

National Audit of Care at the End of Life

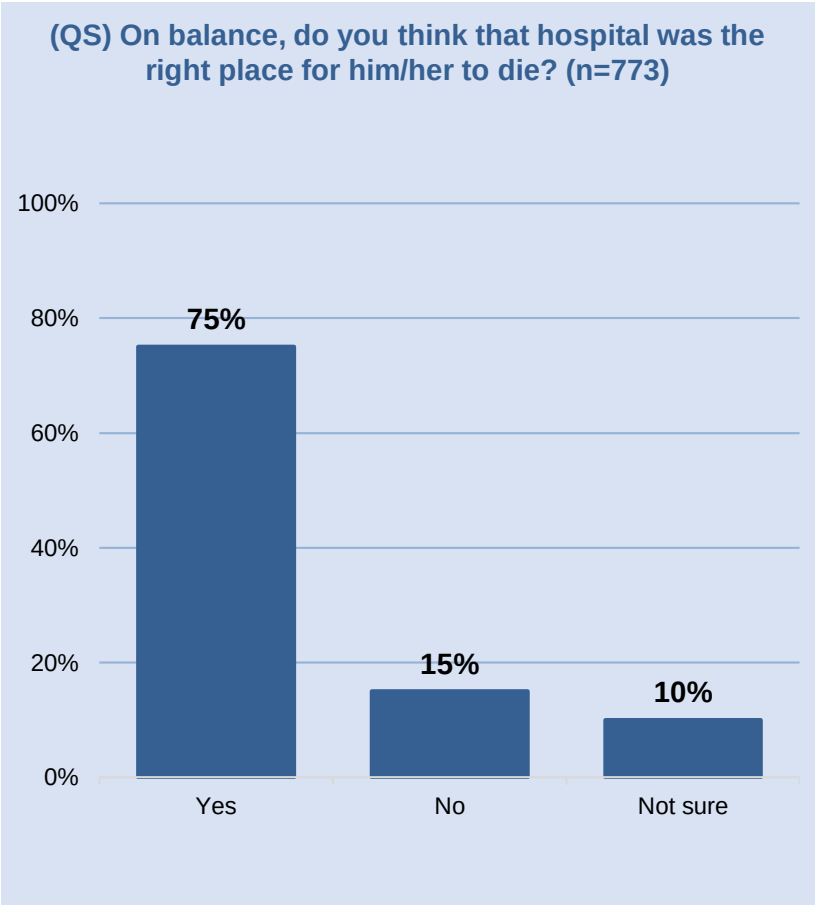
7.4



- CNR - **62%** had documented evidence that patient had an individual end of life care plan
- 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
- QS - Around **one in five** of respondents had concerns about support for patients to eat and drink

Individual plan of care – place of care

National Audit of Care at the End of Life

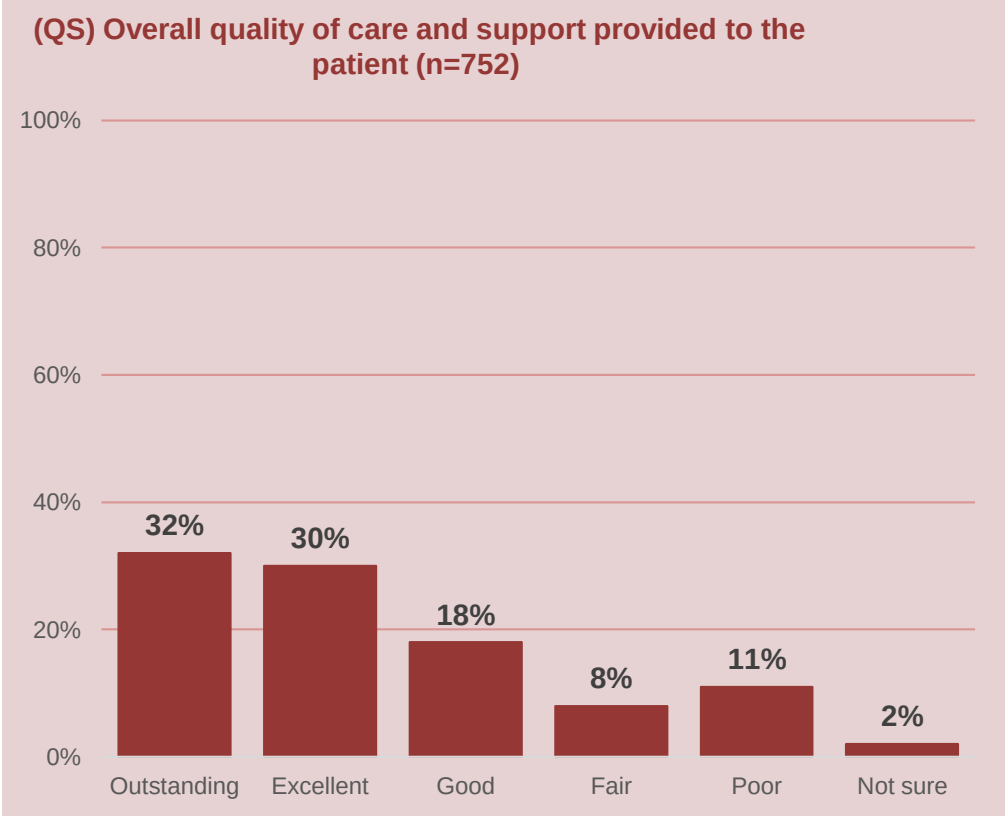


- QS - **75%** of respondents believed hospital to be right place for the patient to die
- CNR - Attempts were made to move **11%** of patients which were, for some reason, unsuccessful
- QS - **16%** of respondents felt no effort had been made to transfer the person from hospital if that was their wish
- QS - Location was an issue for 21% of people who felt they had adequate privacy sometimes, almost never or never

Families and others experience of care

National Audit of Care at the End of Life

7.1



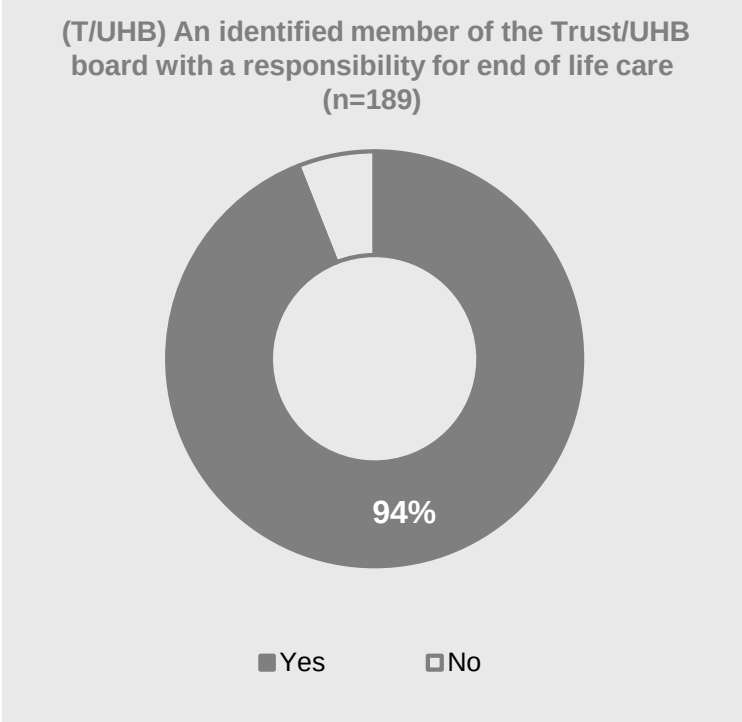
- QS - **80%** of respondents felt the quality of care and support provided to the patient was good, excellent or outstanding
- QS - **76%** felt quality of care for families/others was good, excellent or outstanding
- QS – **67%** felt staff looking after patient communicated sensitively
- QS - **82%** felt that patients were treated with compassion
- QS - **78%** felt they had been communicated to by staff in a sensitive and compassionate way

NHS Benchmarking Network

Governance

9.5

National Audit of Care at the End of Life



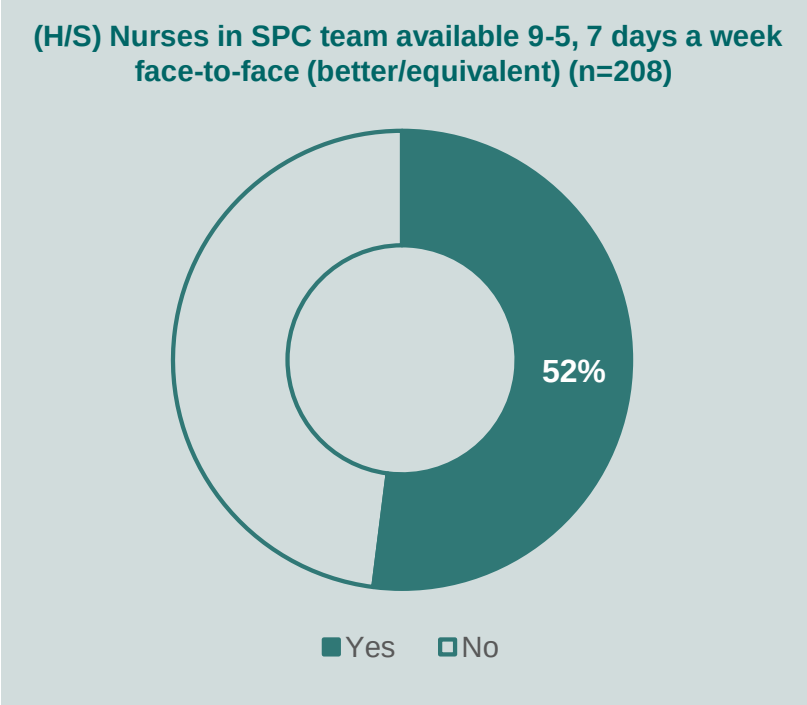
Organisational Level Audit (Trust level):

- **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

Workforce/specialist palliative care

7.6

National Audit of Care at the End of Life



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

National Audit of Care at the End of Life 2018 – Key findings at a glance

Recognising the possibility of imminent death

9.1

36 hours
Median time between recognition and death

89%
Case notes recorded that the patient might die imminently

Involvement in decision making

8.4

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

302
Organisational audits

11,034
Case Note Reviews

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

Communication with the dying person

6.9

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'

Individual plan of care

7.4

62%
Case notes recorded an individualised plan of care

75%
Families/carers felt hospital was the right place for the patient to die

Governance

9.5

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

7.6

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

Communication with families and others

6.6

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

Needs of families and other

6.1

56%
Case notes recorded that the families/carers needs were asked about

NHS
Benchmarking Network

NACEL 2018 outputs

- First round of audit report is available on the public facing Network website:

  https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs

- Report includes 13 recommendations for the improvement of care at the end of life

- Participants also receive bespoke PDF reports and access to an online toolkit

Future rounds of NACEL

National Audit of Care at the End of Life

- For round 2 (NACEL 2019) aimed to:
  - Reduce data burden significantly
  - Increase uptake of QS
- Data collection now closed and analysis underway
- Trust level reporting February 2020
- National report July 2020
- Staff Reported Measure
  - Developed and piloted in 2019 for roll out in NACEL 2020
- Mental health trusts will take part in the full audit in 2020
- A community feasibility study has been undertaken

Benchmarking Network

Thank you – any questions?

Contact:

nhsbn.nacelsupport@nhs.net