National Audit of Care at the End of Life (NACEL) submission to the Health & Social Care Committees Expert Panel (Palliative Care)

About NACEL

The National Audit of Care at the End of Life (NACEL) is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Jersey.

NACEL is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) programme run by Healthcare Quality Improvement Partnership (HQIP), and delivered by NHS Benchmarking Network. The audit collected data during 2024 that supports three out of the four policy areas under review by the Health & Social Care Committees Expert Panel in relation to palliative care:

- Commissioning of palliative and end of life care in England;
- Delivery of palliative and end of life care in England;
- Workforce, education and training.

Outside the scope of NACEL is a review of care for under 18's and sudden deaths (including deaths in A&E, within four hours of admission, maternal deaths and death by suicide). Deaths of people with a formal diagnosis of learning disability was not reviewed in 2024, and instead will be audited in 2025. NACEL looks at NHS funded inpatient care only (hospices are outside the scope).

More information can be found at: https://www.nacel.nhs.uk/

Evidence

The evidence provided by NACEL relates to care delivered to adults in NHS funded acute and community hospitals in England. The audit period was from 1st January 2024 – 31st December 2024. Data for Wales and Jersey has been excluded. Furthermore, N/A responses are removed from the evidence shown.

158 English Trusts participated in NACEL 2024, creating a total of 178 submissions for acute hospital providers and 49 community hospital providers. The dataset includes data from the following audit elements:

- 1. **Hospital/Site Overview:** Organisational level questions focusing on service model and quality improvement efforts.
- 2. **Case Note Review:** Data collected from the clinical case notes of adults who died in hospital during 2024.

- 3. **Bereavement (Quality) Survey**: A survey completed by bereaved relatives, carers and those important to the person who died in hospital during 2024.
- 4. **Staff Reported Measure:** A survey completed by staff who are most likely to come into contact with dying people and those important to them.

Sample size: NACEL 2024 data for acute and community hospitals in England	
Hospital/Site Overviews	225
Case Note Reviews	20,140
Bereavement (Quality) Surveys	7,155
Staff Reported Measures	14,049

COMMISSIONING OF PALLIATIVE AND END OF LIFE CARE (PEoLC) IN ENGLAND

Resourcing: To what extent are 24/7 Specialist level palliative care (SLPC) services funded?

- 97% (218/225) of hospital/sites report having access to a Specialist Palliative Care service. This means 3% of hospitals/sites do not have an ability to escalate/seek help when needed. Of this 3%, 86% (6/7) are community hospital providers.
- Only 59% (133/225) of hospital/sites have face-to-face specialist palliative services availability (doctor and/or nurse) 8 hours a day, 7 days a week, which is a NICE QS since 2013.
 - o Reasons for no face-to-face availability, 8 hours a day, 7 days a week include:
 - 34% (29/85) local service model will not support this
 - **32%** (27/85) lack of funding
 - **19**% (16/85) business case in development
 - 5% (4/85) operational issues
 - **7**% (6/85) other
 - **4**% (3/85) recruitment issues
- This means **3**% of hospitals/sites do not have an ability to escalate/seek help when needed. Of this **3**%, **86**% (6/7) are community hospital providers.
- Of the hospital/sites with access to Specialist Palliative Care services, 90% (194/216) of hospital/sites have a telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week.
 - Reasons for no telephone advice availability, 24 hours a day, 7 days a week include:
 - 55% (12/22) local service model will not support this
 - 18% (4/22) lack of funding
 - **18**% (4/22) other
 - 9% (2/22) business case in development
 - **0**% (0/22) operational issues
 - **0**% (0/22) recruitment issues
- The annual number of deaths in the United Kingdom is predicted to rise to 736,000 by mid-2035 (ONS, 2024). Despite an increasing need for specialist palliative care, the NACEL data reports the same level of service provision and a decrease in the average size of the specialist palliative care Consultant workforce from 1.6 WTE per 100 beds in 2021 to 1.5 WTE per 100 beds in 2024. This inequity persists despite national guidance

on access to Specialist Palliative care. (NICE QS13, published 2011. https://www.nice.org.uk/guidance/qs13).

Effectiveness: What data is there on the effectiveness of current commissioning on PEoLC?

- NACEL data provides evidence on the provision of specialist palliative care services and the proportion of patients who die in hospital reviewed by these teams. In 2024, 55% (11,034/20,024) of patients whose clinical notes were audited were reviewed by a member of the specialist palliative care team/end of life care team during the hospital admission when they died.
- NACEL evidences the interaction between hospital providers and Integrated Care Boards on sharing information on PEoLC. NACEL report that 82% (182/222) of hospital/sites had implemented quality improvement (QI) plans, relating to end of life care in the past 3 years (2021- 2024). Of these hospital/sites 72% (128/177) had shared these with their ICB/Health Board.

Effectiveness: To what extent is there sufficient co-ordination, communication and integration between services to allow for effective delivery of obligations?

- **69**% (4468/6439) of bereaved respondents agreed that there was a co-ordinated care approach by hospital staff during the final admission, including with health and care providers outside the hospital where appropriate.
- **89%** (11,883/13,774) of bereaved respondents agreed that staff work in partnership with the dying person and those important to them in planning and making decisions about their health, treatment, and end of life care.

Impact: How is experience of care measured? And to what extent does this support continuous improvement?

- NACEL measures the experience of care delivered to dying people in hospital and those
 important to them by conducting a national data collection. The collected data
 contributes to a national dataset on the quality of care at the end of life, offering
 valuable insights into best practices at local, regional, and national levels.
- NACEL data is reported via a State of the Nation Report (to be published in August 2025), a public facing tool (to be published in August 2025) and an online interactive reporting tool available to NACEL participants: https://data.nacel.nhs.uk.
- Experience of care is measured by:

Case Note Review:

- The Case Note Review is a retrospective review of medical and nursing records of patients that died in hospital in 2024 to assess the quality of care documentation and adherence to best practices.
- o NACEL uses "documented care" as a proxy for "care delivered".
- The sample size of the NACEL Case Note Review accounts for 8% of hospital deaths in England and Wales (252,037 deaths occurred in an NHS hospital in England and Wales during 2024 (ONS, 2024).
- The Case Note Review process requires clinicians to assess patient records retrospectively. This serves as a learning opportunity, helping to identify both

effective and suboptimal practices, fostering continuous improvement in care delivery.

Bereavement (Quality) Survey:

- The Bereavement (Quality) Survey is a survey used to gather feedback from bereaved people.
- The feedback provides insights from families and loved ones on the care and support offered to the dying person and themselves during the last admission to hospital.
- By analysing and acting on the survey results, healthcare providers can create meaningful improvements that enhance the quality of end-of-life care for future patients and their families
- The sample size of the NACEL Bereavement (Quality) Survey accounts for 3% of national deaths across England and Wales (252,037 deaths occurred in an NHS hospital in England and Wales during 2024 (ONS, 2024).
- o Findings include:
 - **75**% (5,317/7,081) of bereaved respondents rated the care and support given by the hospital to the person who died during the final admission as excellent or good.
 - **72%** (5,121/7,088) of bereaved respondents rated the care and support given by the hospital to themselves and other close relatives or friends during the final admission as excellent or good
 - Bereaved respondents were more likely to rate the care as excellent or good when delivered in a community hospital.
 - Findings from the bereavement survey showed that the overall ratings of care for patients of Asian (64% 111/173), Black (64% 55/86), Mixed (64% 14/22) and Other Minority Ethnic Groups (58% 25/43) were less likely to be recorded as excellent or good by bereaved people, compared to patients of White ethnicity (76% 5,043/6,655)

Staff Survey:

- The NACEL Staff Survey captures feedback from inpatient staff most likely to come into contact with dying people and those important to them. Questions pertain to staff confidence to deliver care at the end of life and what support and training is available to staff.
- The feedback gathered allows insights from healthcare professionals on potential areas for training and education, and areas for improvement.
- Only **63**% (8,214/13,141) of staff respondents had completed training specific to end of life care within the last three years.
- o In contrast, **54**% (120/223) of hospitals/sites report including end of life care in their mandatory or priority training programmes between April 2023 and March 2024.
- Given that hospital remains the most common place of deaths across England and Wales (43%) (ONS, 2024), it is essential for healthcare staff to be equipped with the skills, knowledge and competence to provide effective and compassionate care to dying people and those important to them.

 This, and the variation in staff confidence to deliver care at the end of life and the quality of care, suggests further education and training is needed to support staff to deliver care at the end of life.

Quality improvement is a core aspect of the NACEL model delivered by several differing outputs including resources, events and a community of practice. The NACEL data collection supports continuous improvement by:

- Identifying Strengths and Weaknesses Highlights effective practices and areas needing change within the <u>NACEL Data and Improvement Tool</u>
- Identifying Unwarranted Variation Outliers are identified and managed according to the audit policy. Variation in performance is reported in the online Data and Improvement Tool visible by all NACEL participants.
- **Identifying Health Inequalities –** The <u>Data and Improvement Tool</u> enables users to identify differences in care by patient age, ethnicity and primary language spoken.
- **Drives Policy and Training** Informs staff education, service improvements, and organisational policies.
- **Promotes Accountability** Encourages organisations to maintain high standards and act on feedback.
- **Enhances Patient-Centered Care** Aligns care delivery with the needs and preferences of patients and families.
- Encourages Data-Driven Decisions Supports up to date evidence-based improvements at local, regional, and national levels. Data is reported in real time to enable providers to implement timely changes.
- Share Best Practice and Promotes Networking

 Best practice examples of care delivery at the end of life, and examples of PEoLC quality improvement plans are shared with healthcare professionals via webinars, improvement huddles and the NACEL portal.
- Supports System Reviews NACEL data is shared with CQC to support end of life care
 inspections. Integrated Care Boards, NHS providers, NHS England, Welsh Government
 have access to the NACEL dataset via the <u>Data and Improvement Tool</u>

More information on how NACEL promotes improvement can be found in the NACEL Healthcare Quality Improvement Plan.

Equality and equity: To what extent are available tools, such as ICB dashboards, used to monitor inequalities in outcomes and the commissioning of services to reduce these inequalities?

The NACEL Data Improvement Tool enables hospitals sites and ICBs to review their data based on the ethnicity and age of the person who died. This is a new feature in NACEL 2024 recognising the importance to understand and reduce inequalities. Support to ICBs about how to most effectively use and interpret this is outside of the scope of the NACEL contract but some ICBs attend NACEL events to help their understanding of how to use the data. The data available to the ICBs is for each individual hospital/site -it would be possible to share the NACEL and equity data via ICB dashboards, but this is not commissioned.

DELIVERY OF PALLIATIVE AND END OF LIFE CARE (PEoLC) IN ENGLAND

Resourcing: Is there enough capacity to deliver PEoLC that complies with the standards set in NICE guidance?

NACEL collects data to help illustrate whether care complies with NICE standards, particularly NICE QS 144 and QS13. Gaps in meeting these guidelines are shown in the NACEL 2024 data including:

- Only **68**% (13,415/19,786) of clinical notes audited had documented evidence of a daily review of hydration options in the last days of life
- Less than two thirds **62**% (12,185/19,696) of clinical notes audited had documented evidence that the patient's hydration options had been discussed with those important to the dying person (or where not possible, a reason was recorded).
- Despite this only **8%** (1062/13,015) of staff respondents expressed a lack of confidence in discussing hydration with the patient and those important to them.
- **93%** (15,004/16,176) of people who are recognised as dying have anticipatory medication prescribed so it can be given if they have any of the common symptoms that occur in the last days of life.
- At least **32**% (27/85) of hospitals/sites that did not have 7 day a week palliative care services in line with NICE QS13 did not have this service because of inadequate funding.

Resourcing: To what extent are service providers equipped and able to provide support to families and carers at each stage of the PEoLC journey?

- **89**% (12,064/13,543) of staff respondents who frequently care for people at the end of life agreed that they are confident that the team they work with is able to provide good end of life care.
- **88%** (11,979/13,643) of staff agreed that they have a culture that prioritises compassion and support as fundamental in all interactions with dying patients and those important to them.
- **91**% (12,233/13,448) of staff agreed that they are supported to deliver compassionate and respectful care to dying patients and those important to them.

Equality and equity. Are the holistic PEoLC needs of all communities addressed in the application of these statements?

A key objective of NACEL is to understand and reduce health inequalities in relation to care at the end of life. NACEL has an extensive dataset on holistic PEoLC needs including physical, emotional, social, spiritual, religious and cultural needs, whereby the data can be reviewed by patient ethnicity, religion and language spoken. More detailed findings about equity of care will be included in the National Audit of Care at the End of Life 2024: State of the Nations Report when it is published in summer 2025, and can be presented to the Health and Social Care Committee if requested

NACEL 2024 findings for England showed that care is not equitable in all areas.

For NACEL 2024, patient ethnicity has been used as a proxy to assess whether care at the end of life was provided equitably.

Findings for England include:

- People of Other Minority Ethnic Groups were less likely to have the recognition that they were expected to die during their final admission to hospital (**79**% 350/443) compared to the national average of **83**% (16,638/20,053)
- An assessment of the emotional/psychological needs of the patient (or where not possible, a reason was recorded) was least prevalent in the clinical notes of patients of Asian ethnicity (76% 583/767) than the national average (82% 16,236/19,800).

Care delivered to patients with a formal diagnosis of learning disability was not included in NACEL 2024, however care delivered to these patients will be reviewed in NACEL 2025.

WORKFORCE, EDUCATION AND SKILLS

Resourcing: Under current models and systems of staffing, to what extent is 24/7 availability of a healthcare professional achievable?

- Of the **225** hospital/sites with access to Specialist Palliative Care services, **39%** (85/218) do not have face-to-face availability (doctor and/or nurse) 8 hours a day, 7 days a week.
 - Reasons being include:
 - 34% (29/85) local service model will not support this
 - **32%** (27/85) lack of funding
 - 19% (16/85) business case in development
 - **5**% (4/85) operational issues
 - **7**% (6/85) other
 - 4% (3/85) recruitment issues
- Of the **225** hospital/sites with access to Specialist Palliative Care services, **10**% (22/216) do not have telephone availability (doctor and/or nurse) 24 hours a day, 7 days a week.
 - Reasons being include:
 - 55% (12/22) local service model will not support this
 - **18%** (4/22) lack of funding
 - **18%** (4/22) other
 - 9% (2/22) business case in development
 - 0% (0/22) operational issues
 - **0**% (0/22) recruitment issues

Resourcing: Do current funding models support an effective PEoLC workforce across sectors?

- **86**% (11,572/13,414) of staff respondents agreed that they know how to access specialist palliative care advice, if required, when addressing specific end of life care needs for dying patients.
- **88%** (11,663/13,262) of staff respondents agreed that they are supported by the specialist palliative care team that the hospital has access to, when addressing specific end of life care needs for dying patients.

Resourcing: Are non-specialist health and care staff delivering PEoLC sufficiently supported and trained to carry out holistic needs assessments?"

- **79**% (10,328/13,078) of staff respondents agreed that managerial support is available to help provide care at the end of life.

- NACEL data suggests that there are gaps in the systematic training of staff -the information about education is in section below.

Impact: To what extent does current available training support non-specialist health and social care professionals to deliver holistic needs assessments for patients with PEoLC needs, and their carers/families

- **76**% (15,135/19,927) of clinical notes audited had documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs.
- **82**% (16,295/19,879) of clinical notes audited had documented evidence of an assessment of the emotional/psychological needs of the patient (or where not possible, a reason was recorded).
- **64**% (12,749/19,892) of clinical notes audited had documented evidence of an assessment of the spiritual/religious/cultural needs of the patient (or where not possible, a reason was recorded).
- **74**% (14,726/19,803) of clinical notes audited had documented evidence of an assessment of the emotional/psychological needs of those important to the dying person (or where not possible, a reason was recorded).
- **42**% (8,330/19,769) of clinical notes audited had documented evidence of an assessment of the spiritual/religious/cultural needs of those important to the dying person (or where not possible, a reason was recorded).

NACEL data is available about whether there is a record that these holistic needs were met if they had been assessed.

- **57**% (2,943/5,164) of bereaved respondents agreed that staff tried to provide care for the dying person's emotional needs (e.g., feeling low, feeling worried, feeling anxious).
- **64**% (4,341/6,753) of bereaved respondents agreed that staff tried to provide me with emotional help and support.
- **46**% (1,875/4,089) of bereaved respondents agreed that staff tried to provide spiritual/religious/cultural support to meet their needs.
- **78**% (5,428 /6,964) of bereaved respondents agreed that they were supported by hospital staff after the person had died (e.g., signposting to bereavement services, offered emotional/cultural/spiritual support).
- **82%** (5,792 /7,066) of bereaved respondents agreed that staff behaved with compassion and care.
- **76**% (5,316 /7,000) of bereaved respondents agreed that staff looking after the person had the skills to care for someone at the end of their life.

Appropriateness: To what degree is the current framework of workforce education and skills appropriate to deliver care in different care settings?

- **65**% (146 /223) of hospital/sites included end of life care training in their induction programme from 1st April 2023 31st March 2024.
- **54%** (120 /223) of hospital/sites included end of life care training in their mandatory/priority training from 1st April 2023 31st March 2024.

- **75**% (168 /223) of hospital/sites included communication skills training specifically addressing end of life care from 1st April 2023 31st March 2024.
- **96**% (2,15/223) of hospital/sites included other training in relation to end of life care from 1st April 2023 31st March 2024.
- **63**% (8,214 /13,141) of staff respondents agreed that they had completed training specific to end of life care within the last three years (2021- 2024).

Conclusion

Commissioning of palliative and end of life care in hospitals in England

Despite progress, 24/7 access to specialist palliative and end-of-life care services across England is still lacking, the main barriers being local service models and funding. Closer collaboration between hospitals, sites, and commissioners is essential, with Integrated Care Boards (ICBs) playing a key role in supporting improvement plans through better data sharing and strategic development.

Delivery of palliative and end of life care in hospitals in England;

Action is needed to expand the workforce and meet rising care demands. Additional resource is needed to increase the size and availability of specialist palliative care teams to ensure organisations are able to provide care in line with NICE QS13 (published 2011 https://www.nice.org.uk/guidance/qs13).

Shifting to community

There is currently a lack of evidence on the movement of PEoLC from hospitals to a community setting.

The National Audit of Care at the End of Life (NACEL) examines the quality of care delivered to patients dying in acute, community and mental health care hospitals in England, Wales and Jersey. Hospital is the most common place of death (43.4%) but more than half of deaths (56.6%) occur in other settings (ONS, 2024). The quality of care delivered to 56.6% of dying patients is not evaluated or understood at a national level.

Workforce, education and training in hospitals in England

NACEL 2024 reveals that only 62% of staff respondents have completed end-of-life care training in the past three years. With hospitals being the most common place of death in England and Wales (43%) (ONS, 2024), this gap highlights a need for more comprehensive and regular training. Ensuring healthcare staff are fully equipped with the necessary skills, knowledge, and competence is critical to delivering high-quality, compassionate care to dying individuals and those important to them.