







2024 State of the Nations Report

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National Audit of Care at the End of Life 2024

2024 State of the Nations Report

The National Audit of Care at the End of Life (NACEL) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and the Governments of Wales and Jersey as part of the National Clinical Audit and Patient Outcomes Programme.

This report was written by the NACEL programme delivery team at NHS Benchmarking Network.

The NHS Benchmarking Network is a member-led organisation promoting quality improvement in the NHS through benchmarking and sharing good practice. Members are providers and commissioners of NHS services, spanning the acute, community and mental health sectors. The NHSBN team support members in sharing data to compare service provision and performance with the aim of identifying improvement opportunities.

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Resources

Visit the resources at the links below:



NACEL Portal

Audit website providing information, news and resources for the National Audit of Care at the End of Life, supporting healthcare improvements in end of life care across NHS services.



NACEL Data and Improvement Tool for healthcare professionals

Online interactive tool hosting the latest audit findings. Data is published in real time, providing NHS healthcare professionals with up-to-date insights.



NACEL Quality Improvement pages

Quality improvement resources, tools and training available on NACEL Portal. Information available to support organisations to address improvement opportunities.

Introduction

NACEL is a comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission to hospital before death. The aim of NACEL is to improve the quality of care of adults (18+) at the end of life in NHS-funded hospital inpatient settings in England, Wales and publicly-funded care in Jersey.

The information featured in the State of the Nations Report reflects a validated annual position of care delivered from January 2024 – December 2024.

The audit uses data from four sources to review the quality of care:

- 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.
- 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.

This report highlights key audit findings related to the five national recommendations for improving the quality of end of life care in hospitals. Further information on how the audit stimulates improvement at a local, regional and national level can be found in the NACEL Healthcare Improvement Plan. Information on the audit framework and key themes can be found in the NACEL Driver Diagram.

NACEL 2024 sample size



238

Hospital/Site overviews (H/S)



20,954

Case Note Reviews (CNR)



7,354

Bereavement (Quality) Surveys (QS)



14,406

Staff Reported Measures (SRM)

During 2023, 581,363 deaths were reported in England and Wales; 252,037 of these occurred in an NHS hospital (ONS, 2024).

The 2022 report by the UK Commission on Bereavement stated that the 1.2 million deaths in England and Wales during 2020 and 2021 left an estimated 6.8 million people bereaved. Given the wider context, the sample size of the NACEL Case Note Review accounts for 8% of hospital deaths, and the NACEL Bereavement Survey accounts for 3% of hospital deaths in England and Wales.

This report highlights key findings from NACEL 2024. Please note, "not applicable" responses are excluded from the analysis. Participating NHS providers can access the full dataset via the NACEL Data and Improvement Tool.

Hyperlinks



Background, aim and scope

Acknowledgements

Methodology

Recommendations

Annual report datasheet

Driver Diagram

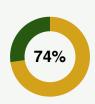
Quality Improvement resources

Key findings at a glance

National Audit of Care at the End of Life 2024



Proportion of hospital/ sites who have shared their end of life care quality improvement plan with the ICB/Health Board.





Hospital/sites with a face-to-face specialist palliative care service (nurse and/or doctor) available 8 hours a day, 7 days a week.





Proportion of deaths expected by clinical staff during the final admission.





Proportion of clinical notes with evidence of communication about hydration with those important to the dying person, or a reason recorded why not.



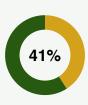


Proportion of bereaved people who agreed that the dying person received sufficient pain relief during their final hospital admission.





Proportion of clinical notes with an assessment of the spiritual, religious and cultural needs of those important to the dying person, or a reason recorded why not.





Proportion of bereaved people that rated the overall care and support given to themselves and others by the hospital as excellent or good.





Proportion of clinical notes with evidence that the patient had participated in personalised care and support planning conversations.







Proportion of people expected to die during the hospital admission with an individualised plan of care addressing their needs at the end of life.





Proportion of people who died with their ethnicity documented in their clinical notes.





Proportion of staff who have completed end of life care training within the last three years.

National recommendations

The below recommendations are evidenced by the data collected from January 2024 – December 2024. A line-of-sight table, outlining the data, supplementary information and linked national standards can be found here.

RECOMMENDATION 1:

Oversight of hospital improvement plans

Integrated care boards, health boards and commissioners should ensure system level oversight of provider quality improvement plans relating to end of life care. For example:

- Having named clinical and executive leadership with responsibility for care at the end of life in both provider and commissioner organisations. This may include a system collaborative quality improvement group with oversight assurance of delivery
- Signing up to <u>NACEL Data and Improvement Tool</u> to understand provider performance of the 10 NACEL Key Indicators
- Requesting receipt of the annual NACEL report and recommendations from the provider within 4 weeks of publication
- Requesting sight of the end of life care quality improvement plan and subsequent activity updates from providers at least once a year

RECOMMENDATION 2:

Access to specialist palliative care services

Integrated care boards, health boards and commissioners should ensure that services provide specialist palliative medical and nursing cover face-to-face, 8 hours a day, 7 days a week and a 24-hour, 7 days a week, telephone advice service. For example:

- Understanding existing provision of specialist palliative care in hospital including a gap analysis against <u>NICE Standard QS13</u>
- Working collaboratively with providers to develop and implement time-bound action plans to mitigate gaps in access to palliative care services
- Taking account of the population need to match service provision to ensure high quality end of life care, including specialist palliative care where indicated, is delivered for all dying patients
- Publishing strategic plans about system-wide access to specialist palliative care

RECOMMENDATION 3:

Improve personalised care and support planning

Integrated care boards, health boards and commissioners should lead on collaborative improvement initiatives to increase the number of personalised care and support planning conversations, including advance care planning conversations, offered to patients. Further ensuring planning is shared across the system, including with the inpatient teams. For example:

- Actively seeking and learning from examples of governance and quality improvement initiatives to address unwarranted variation, including reviewing the <u>NACEL Good Practice Compendium</u>
- Monitoring the implementation of improvement work, considering its sustainability along with reviewing the trends in the metrics published by NACEL

RECOMMENDATION 4:

Equitable care being delivered for all dying people

Integrated care boards, health boards and commissioners should ensure that high quality end of life care is equitable and tailored to the needs of the local population by recognising and actively addressing current inequities across the local system. For example:

- Having a comprehensive understanding of the population living in the local area including the
 palliative care and end of life care needs of those with intersectional disadvantage e.g. from a local
 needs analysis, and/or through the use of existing data such as <u>Fingertips</u>
- Understanding the provision of hospital services that can support the local population's end of life care needs e.g. services to support an urgent release of the body
- Identifying gaps in provision and implement action plans to an agreed timescale
- Publishing strategic plans for the delivery of equitable palliative care and end of life care for all dying people

RECOMMENDATION 5:

Training and support

Integrated care boards, health boards and commissioners should consider system level initiatives aimed at increasing the uptake and quality of end of life care training. For example:

- Setting standards and establishing guidance, reflective of the local population need, for palliative care and end of life care training
- NACEL data highlights that training should include, but is not limited to, recognition of dying, pain management, discussions about drinking at the end of life and hydration, and assessment of spiritual, religious and cultural needs
- Seeking annual assurance from providers regarding numbers of staff who are undertaking training e.g. e-ELCA
- Developing strategic plans for staff training in palliative care and end of life care to support the delivery of end of life care

Key findings

KEY FINDING 1:

QUALITY IMPROVEMENT PLANS



Of hospital/sites with quality improvement plans² relating to end of life care in place, 74% had shared these plans with the ICB/Health Board in the past three years.

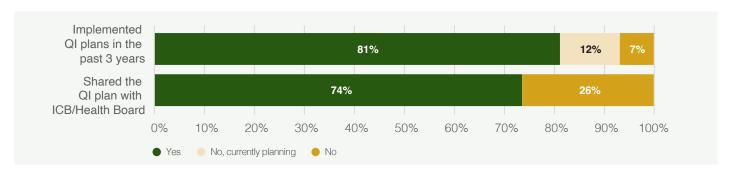


Figure 1: (HSO) Proportion of hospital/sites that have implemented a quality improvement (QI) plan relating to end of life care and shared this with their ICB/Health Board

Increasing the quality of palliative and end of life care services is a key role for commissioning, (NHS England, 2022). However, ICBs, health boards and commissioners require accurate up to date data to help the commissioning, delivery and improvement of services.

This relies on Trusts/Health Boards sharing information on the quality of care at the end of life with ICBs, health boards and commissioners, including existing quality improvement plans.

KEY FINDING 2:

ACCESS TO SPECIALIST PALLIATIVE CARE SERVICES



97% of hospital providers have access to specialist palliative care services. Yet of those providers, 61% have access to a face-to-face specialist palliative care service (nurse and/or doctor) 8 hours a day, 7 days a week.

Furthermore, there are **10%** of hospital providers without access to a telephone specialist palliative service (nurse and/or doctor) 24 hours a day, 7 days a week, with little increase in service availability over the past 3 years. In 2011, NICE outlined the need for adults approaching the end of their life and their carers to have access to support, including specialist palliative care, 24 hours a day, 7 days a week. NACEL data shows a failure to meet this standard during 2024.

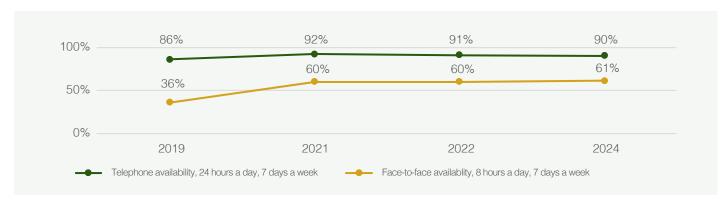


Figure 2: (HSO) The proportion of hospital/sites with specialist palliative service availability (nurse and/or doctor) over four rounds of NACEL

²A quality improvement plan refers to a detailed proposal for improving the service quality for those who use it e.g. patients and those important to them (safe, effective & caring service) and/or for those providing services (well-led, sustainable and equitable service).

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 stagnating service availability (Figure 2) and a slight decrease in the average size of the specialist palliative care workforce from **1.6 WTE** per 100 beds in 2021 to **1.5 WTE** per 100 beds in 2024.

The audit reports an increase in the proportion of dying people reviewed by a member of the specialist palliative care team/end of life care team during the final hospital admission. This has increased from **47%** in 2022 to **55%** in 2024. Whilst this has increased across acute hospitals and community hospitals, a lower proportion of patients are reported to be seen by specialist teams in community hospitals (**40%**) than in acute hospitals (**56%**).

KEY FINDING 3:

RECOGNITION OF DYING



Of the patients audited by the Case Note Review, 83% were expected to die during their final hospital admission. For these patients, the median time between first recognition that the patient might die (within days or hours) and death was 56 hours (2.3 days).

Recognising as early as possible that a patient is dying is key to providing high quality end of life care. Early recognition of dying allows more opportunity to have key conversations with both the patient and those important to them, and additional time to meet their needs.

Of the **17%** of patients who were not expected to die during their last hospital admission, **69%** were recognised as being 'sick enough to die'³. This cohort of patients suggests a clinical opportunity to identify the dying phase earlier.

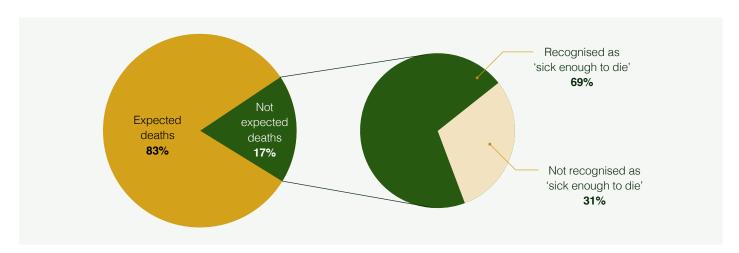


Figure 3: (CNR) The proportion of clinical case notes where it was expected that the person would die during the final admission, or recognised as being sick enough to die

KEY FINDING 4:

HYDRATION OPTIONS



Less than two thirds (62%) of the clinical case notes sampled 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%** of staff respondents expressed a lack of confidence in discussing hydration with the patient and those important to them. There is further work to be done to deliver conversations about hydration options at the end of life, in line with <u>NICE Quality Standard (QS144)</u>, and for organisations to encourage documentation of conversations.

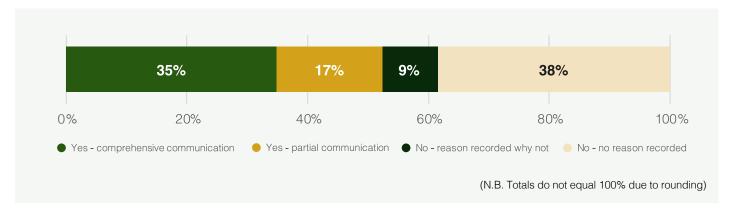


Figure 4: (CNR) The proportion of clinical case notes with documented evidence of communication about hydration with those important to the dying person (n=20,478)

KEY FINDING 5:

PAIN RELIEF



77% of bereaved respondents agreed that the dying person received sufficient pain relief during their final hospital admission, while 12%* disagreed with this statement.

NACEL data continues to reflect public concern around pain relating to dying and care at the end of life (BMA, 2015). Best practice of care of dying adults in the last days of life outlines that pain should be managed promptly, effectively and any reversible causes of pain should be treated once identified (NICE, 2015).

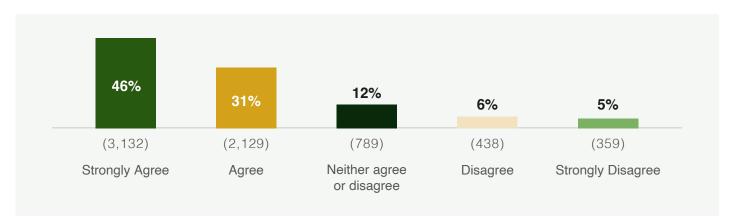


Figure 5: (QS) The proportion of bereaved people that agreed that the person was given enough pain relief (n= 6,847)

^{*}The combined percentage for "Strongly Disagree" and "Disagree" equates to 12% due to rounding.

KEY FINDING 6:

SPIRITUAL, RELIGIOUS AND CULTURAL NEEDS



Spiritual, religious and cultural needs were least assessed and addressed when compared to other needs (communication, emotional/psychological and social/practical needs). An assessment of those important to the dying person's spiritual, religious and cultural needs was documented in 41% of cases (or where not possible, a reason was recorded).

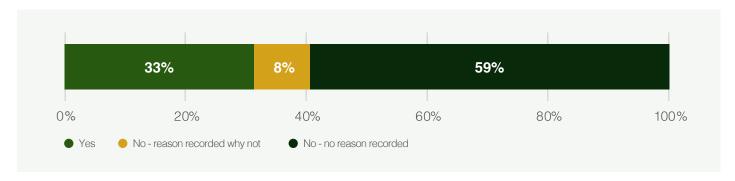


Figure 6: (CNR) The proportion of clinical notes with documented evidence of an assessment of the spiritual/religious/cultural needs of those important to the patient (n=20,577)

Of those identified as having spiritual, religious, or cultural needs, there was evidence that staff sought to address these in **97%** of the case notes sampled. From the bereavement survey, **46%** of respondents who required spiritual, religious or cultural support agreed that their needs were met, whilst **31%** disagreed. Although 'Not applicable' responses have been removed from the analysis in this report, it is important to note that **42%** of total respondents for this metric selected 'Not applicable', suggesting that just under half of all respondents felt that spiritual, religious or cultural support was not required.

These findings highlight the importance of assessing spiritual, religious and cultural needs to ensure opportunities to meet these needs are not missed. Recommendation 4 is reinforced by the need for spiritual, religious and cultural competency and communication skills training for healthcare professionals, as outlined by the <u>Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK report (2013)</u>.

KEY FINDING 7:

CARE AND SUPPORT



The care and support provided to the dying person was rated as excellent or good by 75% of bereaved respondents, whilst 73% of bereaved respondents rated the care and support given to themselves and others as excellent or good. Bereaved respondents were more likely to rate the care as excellent or good when delivered in a community hospital.

Figure 7 demonstrates the difference in the rating of care when delivered in acute hospitals and community hospitals to the dying person and to those important to them.

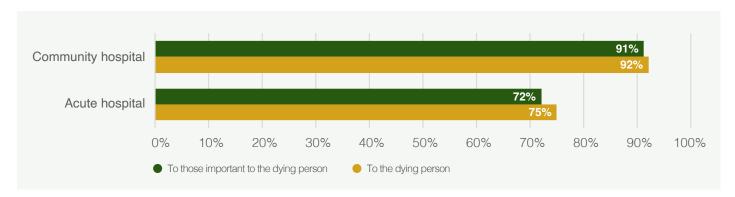


Figure 7: (QS) The proportion of bereaved people that rated the care and support given by the hospital to the dying person and those important to them as excellent or good.

KEY FINDING 8:

PERSONALISED CARE AND SUPPORT PLANNING



From the Case Note Review, 44% of patients whose clinical notes were sampled had evidence that they had participated in personalised care and support planning, including advance care planning, conversations.

Of the patients who had participated in personalised care and support planning conversations, **41%** first participated prior to the admission and **59%** first occurred during the final admission.

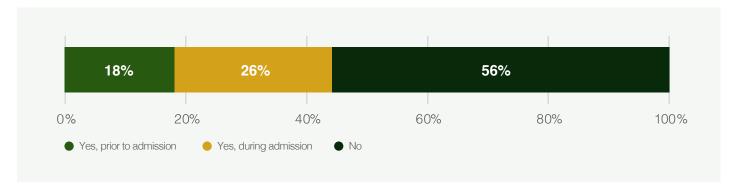


Figure 8: (CNR) The proportion of clinical case notes with documented evidence that the patient participated in personalised care and support planning (advance care planning) conversations (n=20,684)

Personalised care and support planning provides patients the opportunity to outline what matters to them within the context of their health and wellbeing. Results from the Case Note Review show underperformance against NHS England Guidance.

Inpatient teams should have access to previous personalised care and support planning conversations, to support timely, person-centred end of life care that aligns with the patient's wishes and preferences during their hospital admission.

KEY FINDING 9:

INDIVIDUALISED PLAN OF CARE



Of the people expected to die during the hospital admission, 84% had an individualised plan of care addressing their needs at the end of life. Of these, 63% were documented on a standalone template and 37% within the general clinical notes.

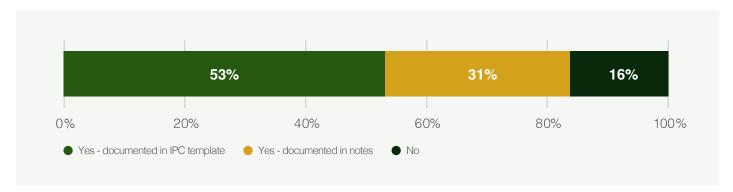


Figure 9: (CNR) The proportion of clinical case notes with documented evidence that the patient who was expected to die had an individualised plan of care addressing their end of life care needs (n=17,171)

Every person nearing the end of their life should have an individual plan of care that supports staff deliver comprehensive care at the end of life (<u>One Chance to Get It Right, 2014</u>). The results suggest that **16%** of patients did not receive individualised care addressing their end of life care needs during their final admission.

KEY FINDING 10:

EQUITABLE CARE



When reviewing patient ethnicity, 86% of the clinical case notes included documentation of the patient's ethnicity and 14% reported ethnicity as either not stated or unknown.

Accurate and standardised documentation of patient demographic information is required to be able to address disparities in care at the end of life. High variation was reported across providers, suggesting further work is needed in some services to embed the recording of this information. Patient ethnicity data was reviewed to assess whether care was provided equitably.

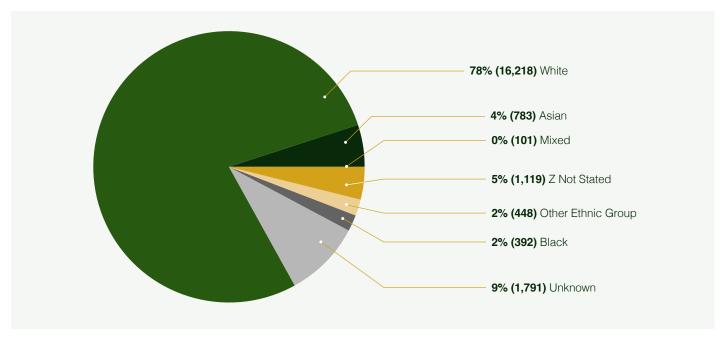


Figure 10: (CNR) The proportion of people who died with ethnicity documented in their clinical case notes (n=20,852)

A chi-square test of independence was performed to examine the relationship between care delivered at the end of life and patient ethnicity. The relationship between these variables was significant for several areas of care, including the below:

- The clinical case notes sampled often showed the largest difference in care for patients whose ethnicity was reported as 'Unknown'. For example, key finding 4 showed that discussions about hydration options were documented less often for patients of Unknown ethnicity (51%) compared to the national average (62%), or where not possible a reason was recorded (p<0.01).
- Key finding 7 showed that the overall rating of care for patients of Asian (64%), Black (64%), Mixed (64%), Other Minority Ethnic Groups (58%) and Unknown ethnicity (59%) were less likely to be recorded as excellent or good by bereaved people, compared to patients of White ethnicity (76%) (p<0.01).
- The bereavement survey feedback showed that hospital staff were least likely to communicate sensitively with those important to the dying person, when the dying person was of Asian ethnicity (69%), Undisclosed ethnicity (61%) or Other Minority Ethnic Groups (56%), compared to the national average of 83% (p<0.01).

More information on the differences in care based on the patient's ethnicity can be found in the <u>annual report datasheet</u>.

In England, it is a statutory duty of ICBs to ensure action is taken to improve equity of access and outcomes for PEoLC (NHS England, 2022).

KEY FINDING 11:

END OF LIFE CARE TRAINING



Only 62% of staff respondents had completed training specific to end of life care within the last three years.

In contrast, **51%** 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.

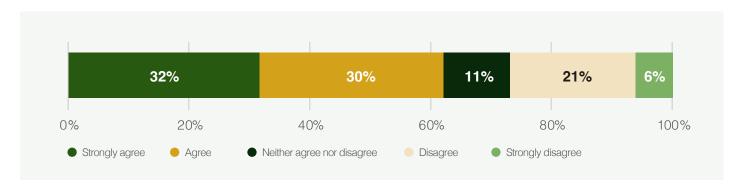


Figure 11: (SRM) The proportion of staff that agreed they had completed training specific to end of life care within the last three years (n=13,460)

Recommended end of life care training includes specific attention to the topics of nutrition and hydration, symptom management and communication skills (<u>One Chance to Get It Right, 2014</u>). Example programmes available to train and support frontline staff in caring for people at the end of life include: <u>Health Education England's e-Learning for health e-learning programme on end of life care (e-ELCA)</u> and <u>The Gold Standards Framework (GSF)</u>.

Find out more about this audit

For more information about the audit, please visit the NACEL Portal.



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