

National Audit of Care at the End of Life

Key findings for patients and carers

Third round of the audit (2021/22)
Mental Health Spotlight Audit



What is 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 facilities in England and Wales. NACEL focuses on adult (18+) inpatient care only.

The Mental Health Spotlight Audit was run as part of the third round of NACEL during 2021, at the request of the audit commissioners. The audit was originally planned for 2020, but was delayed due to the Covid-19 pandemic. This report sets out the findings of the Mental Health Spotlight Audit. Results are compared to the acute and community findings, where appropriate.

NACEL round three included four main data collection elements;

1. Organisation Level Audit

Trust/Health Board (T/HB) questions - metrics completed at the Trust/HB level.

Hospital/site (H/S) questions – metrics covering hospital/site level questions. This focused on the specialist palliative care workforce, staff training, anticipatory prescribing and quality and outcomes. Additional questions were asked on the impact of COVID-19.

2. Case Note Review (CNR)

Patient level data collection, where organisations completed an in-depth review of case notes of patients (18+). Mental Health providers were requested to audit consecutive deaths during April to August 2021.

The Case Note Review audited deaths that were categorised as the following:

Category 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.

Category 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.

Deaths classed as "sudden deaths" were excluded from the Case Note Review. These were deaths which were sudden and unexpected, including but not limited to, deaths which occurred within 4 hours of admission. Additional exemptions were deaths by suicide, deaths of patients in a learning disability designated bed, deaths in "addiction beds" and maternal deaths in a mother and baby unit.

3. Quality Survey (QS)

An online survey was completed by relatives, carers and those important to the person who died in hospital, to report their experiences of the care and support received at the end of life. The survey was developed with support from the Patients Association, who also provided a telephone helpline to assist those completing the survey.

4. Staff Reported Measure (SRM)

An online survey was completed by staff members who were most likely to come into contact with dying patients and those important to them. The survey asked questions pertaining to staff confidence and experience in delivering care at the end of life.



What does this report include?

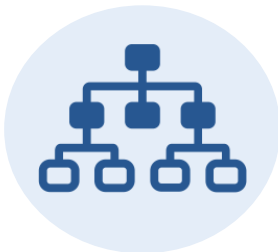
This report provides a summary of the key findings from mental health providers in England and Wales taking part in the third round of the National Audit of Care at the End of Life (NACEL) which took place in 2021. There is a separate report for acute and community providers who also participated in NACEL round three <https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs>.

The results are based on data collected from 49 organisations, comprising 44 English Trusts and 5 Welsh Health Boards (HB). Full details of the findings can be found at <https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs>.

Who took part?

All NHS mental health hospitals with inpatient facilities in England and Wales were eligible to take part in the audit. A letter inviting each organisation to take part in the audit was sent to the Chief Executive, Director of Nursing and, where available, Lead Nurse for End of Life Care.

A total of **49** NHS organisations completed the following....



58 Hospital/Site organisational returns



75 Case Note Reviews returned



8 Quality Surveys returned



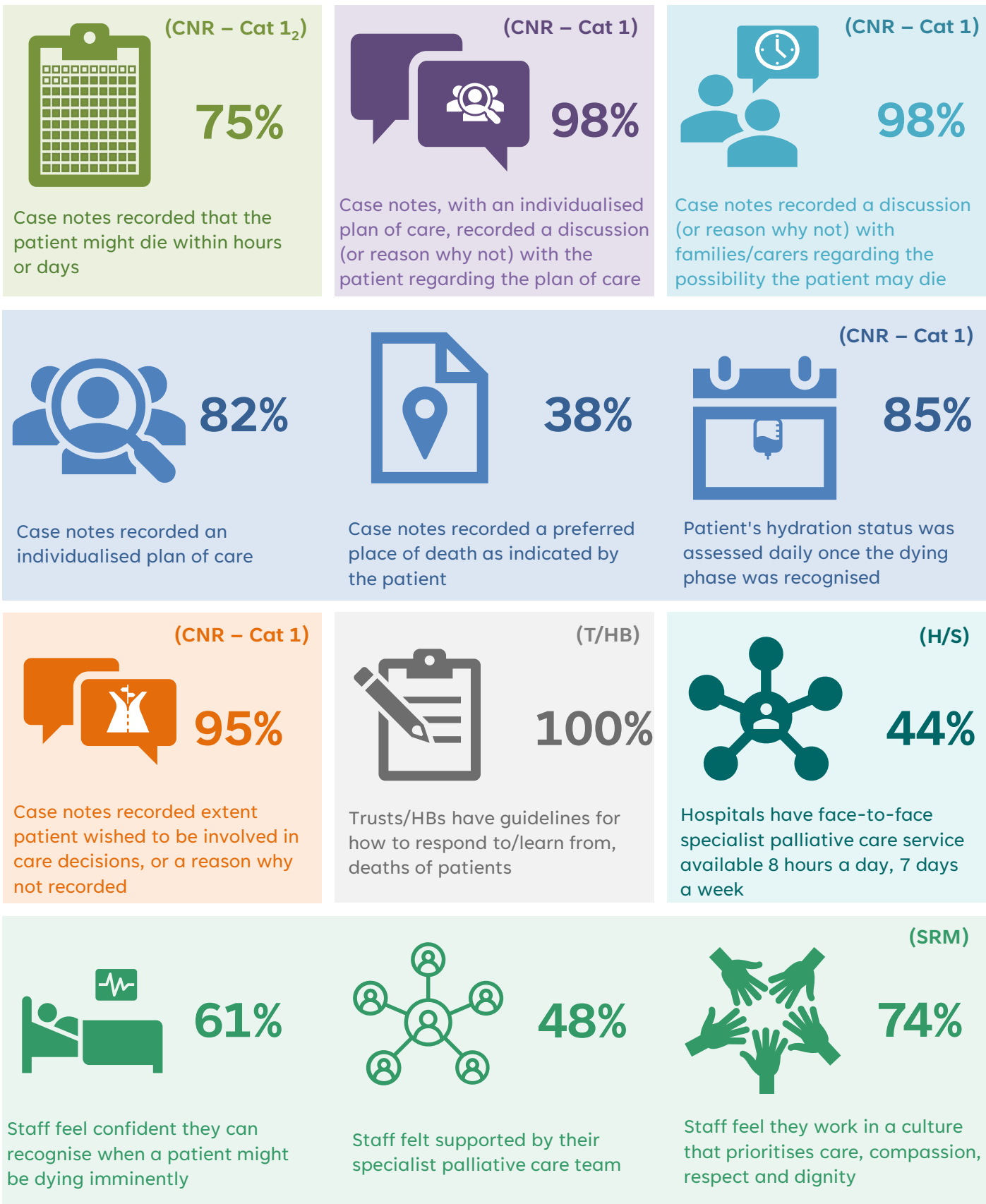
481 Staff Reported Measures returned



National Audit of Care at the End of Life 2021

Mental Health Spotlight Audit

Key findings at a glance



2. Category 1. It was recognised that the patient may die

How the findings are presented

The information in this report is presented thematically in ten sections. As in previous audit rounds, these are derived from the *Five priorities for care* and the *NICE standards and guidelines* on end of life care for adults.

The themes are:

1. **Recognising the possibility of imminent death (CNR)**
2. **Communication with the dying person (CNR)**
3. **Communication with families and others (CNR)**
4. **Involvement in decision making (CNR)** – reintroduced in the third round of NACEL
5. **Individualised plan of care (CNR)**
6. **Governance (T/HB)** – reintroduced in the third round of NACEL
7. **Workforce/specialist palliative care (H/S)**
8. **Staff confidence (SRM)** – new for the third round of NACEL
9. **Staff support (SRM)** – new for the third round of NACEL
10. **Care and culture (SRM)** – new for the third round of NACEL

Case Note Review metrics included in this report refer to Category 1 deaths only:

Category 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.

As in previous rounds, each summary score only uses indicators for one element of the audit, and uses evidence from Category 1 deaths only. The following key is used to show the source of each theme:

- T/HB – Trust/Health Board Organisational Level Audit
- H/S – Hospital/Site Organisational Level Audit
- CNR – Case Note Review
- SRM – Staff Reported Measure

A theme was not devised from the Quality Survey findings due to the low number of responses received.

Key themes

Recognising the possibility of imminent death (CNR)

Timeliness in recognising imminent death is important in ensuring that appropriate discussions and planning can take place, in line with the wishes of the dying person and of those close to them. This underpins all priorities for improving the experience of end of life care in the last few days and hours of the dying person's life.

 **75%** of case notes recorded that the patient might die imminently (CNR)
(87% for acute and community providers)

 **117 hours** is the median time between recognition of dying and death (CNR)
(44 hours for acute and community providers)



Key themes

Communication with the dying person (CNR)

Guidance emphasises the need for sensitive communication with the dying person. High compliance with key end of life care quality standards, may be due to the nature of mental health care, which tends to be longer-term and have longer lengths of stay than that offered in acute and community hospitals, allowing staff to develop a closer relationship with the patient and those important to them.



95% of case notes recorded a discussion (or reason why not) with the patient regarding the possibility that they may die (90% for acute and community providers)



98% of case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care (95% for acute and community providers)

Communication with the families and others (CNR)

Open and honest communication with families and others close to the dying person is crucially important to high quality end of life care.



98% of case notes recorded a discussion (or reason why not) with families and others regarding the possibility that they may die (98% for acute and community providers)



96% of case notes, with an individualised plan of care, recorded a discussion (or reason why not) with families and others regarding the plan of care (94% for acute and community providers)



62% of case notes recorded a discussion with families and others regarding hydration options (52% for acute and community providers)

Involvement in decision making (CNR)

The right to be involved in decisions about one's health and care is enshrined in the NHS Constitution for England in addition to *the Five priorities for care*.

95% of case notes recorded the extent to which the patient wished to be involved in decisions about their care (86% for acute and community providers)



93% of case notes recorded discussions with families and others regarding cardiopulmonary resuscitation (CPR) (100% for acute and community providers)



93% of case notes recorded discussions with the patient regarding the use of life sustaining treatments (94% for acute and community providers)



Individualised plan of care (CNR)

Every dying person should have an individualised end of life care plan. The Spotlight Audit has demonstrated good documentation of person-centred care planning. This may be due to a longer time period to assess patients in a mental health inpatient setting, with admission protocols covering holistic assessment of mental and physical health care, with food and fluid protocols routinely carried out on admission to an inpatient setting. High compliance with quality standards concerning anticipatory medication would suggest that mental health providers have robust policies in this area of end of life care.

 **82%** of case notes recorded an individualised plan of care (73% for acute and community providers)

 **91%** of case notes had documented evidence of the assessment of the patient's spiritual/religious/cultural needs (78% for acute and community providers)

 **38%** of case notes document a preferred place of death as indicated by the patient (30% for acute and community providers)

 **93%** of case notes recorded anticipatory medication prescribed for symptoms likely to occur in the last days of life (89% for acute and community providers)

Governance (T/HB)

Local leadership and robust governance arrangements are essential to ensuring continuous improvement in the experiences of those at end of life, and those close to them. Mental health providers reported they had implemented a process whereby mortality is managed and reviewed in a systematic way according to national guidance. The evidence suggests that the systematic scrutiny of deaths in mental health settings is well embedded with a learning from deaths culture noted.

 **97%** of Trusts/HBs have an identified member of the board with responsibility for end of life care (97% for acute and community providers)

 **99%** of Trusts/HBs have guidelines for how it respond to and learns from, deaths of patients who die under its management care (99% for acute and community providers)

Workforce/Specialist Palliative Care (H/S)

National guidance reinforces the need for providers to work with commissioners to ensure access to an adequately resourced specialist palliative care (SPC) workforce. As might be expected, given that end of life care is not a primary function of mental health providers, they report less specialist palliative care availability compared to acute and community providers.

 **89%** of hospitals/sites have access to a specialist palliative care service (99% for acute and community providers)

 **44%** of hospitals/sites have a face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week (60% for acute and community providers)



Key themes

For the third round of NACEL, a new Staff Reported Measure (SRM) was introduced to collect data from both clinical and non-clinical staff working in hospitals where they may be expected to come into contact with the dying person, and those close to them. New themes of **staff confidence**, **staff support** and **care and culture** are introduced in this section. In reviewing the results, it should be noted that the group of staff completing the survey were self-selected. 96% of those responded were clinical staff.

Staff confidence (SRM)

Mental health staff reported that they felt less confident communicating and responding to the needs of patients who are dying, than those in acute and community providers. This may well be due to the fact that end of life care is not a primary focus of staff within mental health hospitals.

 **61%** of staff respondents feel confident they can recognise when a patient might be dying imminently (85% for acute and community providers)

 **62%** of staff respondents feel confident they have the skills to involve the dying patient and those important to them in decisions about end of life care in line with their wishes and preferences (79% for acute and community providers)

Staff support (SRM)

Training availability and managerial support was identified as a potential area for improvement for the staff support theme.

 **30%** of staff respondents have completed training specific to end of life care within the last three years (49% for acute and community providers)

 **64%** of staff respondents feel managerial support is available to help provide care at the end of life (66% for acute and community providers)

Care and culture (SRM)

Potential areas of improvement highlighted in the care and culture theme include staff feeling confident enough to raise complaints regarding end of life care in their organisation. There is also potential to improve engagement with review of deaths.

 **74%** of staff respondents feel able to raise a concern about end of life care (83% for acute and community providers)

 **75%** of staff respondents feel they work in a culture that prioritises care, compassion, respect and dignity (80% for acute and community providers)

 **50%** of staff respondents agree deaths are actively reviewed and action plans implemented to improve end of life care (54% for acute and community providers)



Recommendations

The findings from this first Mental Health Spotlight Audit (2021/22) have been reviewed by the NACEL Mental Health Reference Group who have formulated the following recommendations.

Integrated Care Systems/Health Boards, working with providers, should:

1. **Review local pathways of care for mental health patients with complex physical co-morbidities to ensure access to the right care in the right environment at the right time when they reach the end of life.** Mental health providers should work with their ICS and Health Boards to jointly develop pathways of care for those who are in mental health inpatient beds to ensure equity of access to specialist palliative care services.

Trust/Health Boards should:

2. **Ensure policies and guidelines are in place to support care planning for the *Five Priorities for Care of the Dying Person*. Processes should be put in place to link policies and guidelines to frontline practice.** In particular, staff should feel able to raise a concern about end of life care within their Trust/Health Board.

Chief Executives should:

3. **Ensure health and care staff, on wards more likely to care for patients at the end of life, have the appropriate training, managerial and emotional support to develop the competence and confidence to; recognise imminent death, communicate with the dying person and people important to them as early and sensitively as possible, and deliver end of life care.**





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