# National Audit of Care at the End of Life

Fourth round of the audit (2022/23) report

**England and Wales** 







The National Audit of Care at the End of Life (NACEL) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www hqip.org.uk/national-programmes.

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This report also has a number of appendices, contained in a separate report, which should be read in conjunction with these findings. See <u>NACEL appendices</u> for full details.

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### 1. Foreword

### This report presents the fourth round results of the National Audit of Care at the End of Life (NACEL).

Ongoing and unprecedented pressures on health and social care have continued throughout 2022, with services endeavouring to provide the capacity for treatment and care needed in light of increasing demand and significant staff shortages. The fourth round of NACEL ran whilst healthcare providers were re-building services following the challenges of the pandemic, trying to catch up on waiting lists for elective care, recruiting, re-training and recuperating staff, and managing surges in illnesses from a range of viruses including COVID-19. National COVID-19 rules were lifted, but local restrictions remained in place in certain areas. Global impacts of climate change, and food and fuel shortages, continue to have the greatest impact on the health of the most vulnerable, including those with frailty, long term conditions and at the end of life.

Within this context, we are even more appreciative of all the families and staff who took the time to respond, giving us valuable feedback on the experience of care, and the impact on staff, following the pandemic. Overall data submissions have been high in NACEL round four, with 7,620 Case Note Reviews, 3,600 Quality Survey responses and 11,143 completed Staff Reported Measures. Excellence in end of life care is built on the bedrock of excellent overall care. It follows that if there are insufficient resources and poor staff wellbeing, then care of the dying will suffer. The potential impact of this is evident in the round four findings, along with the detrimental effect of some ongoing visiting restrictions in the audit timeframe of April/May 2022.

However, first let us acknowledge the good and the consistent findings. The improvements in access to specialist palliative care seen in round three have been maintained, with 60% of providers providing seven day a week access to face-face specialist palliative care, with further improvement a priority. Staff are recognising death earlier, with an increase in the median number of hours between the recognition of the possibility of dying and death, from 36 hours in 2018 to 47 hours in 2022. This provides a greater opportunity to realise individual wishes for end of life care, however an improvement in conversations with patients being documented at this crucial time is not yet evident. There has been a modest increase in the number of documented advance care plans, however this also remains an area for improvement across all care settings. There is also a marked improvement in the proportion of staff who felt supported by the specialist palliative care teams and by managers when providing care at the end of life.

Areas where results remain consistent with last year's findings include documented communication with the dying person and those important to them, the proportion of patients with preferred place of death documented, assessment of needs and overall staff confidence to deliver end of life care. Staff survey respondents remain most confident in accessing specialist palliative care, recognising when a patient might be dying and communicating clearly and sensitively with dying patients and those important to them. Despite the confidence to deliver end of life care, this isn't reflected in the overall rating of care and support for families and carers captured in the Quality Survey.

The main areas for improvement are in meeting the needs of families and others, with findings suggesting further deterioration in the support provided to those close to the dying person. Visitation restrictions are likely to have contributed to these results, where 44% of families stated that restrictions were in place to visit the patient in hospital due to COVID-19 (82% in round three). The narrative messages in particular from bereaved carers, families and friends, detailed the frustration around visitation restrictions, unclear policies of when families can come into hospital and reference to the system being too stretched for staff to provide enough support. The feedback from the Quality Survey for individual healthcare providers will be provided to them, so that they can review these accounts and identify lessons to be learnt.





### 1. Foreword

Some aspects of communication with patients and those close to them continue to be in need of improvement. The documentation of conversations about hydration and nutrition needs with those important to the dying person remains documented in only around a half of cases.

We've appreciated hearing examples of how participants have utilised the NACEL results to improve local services. We will be publishing these examples within the NACEL Good Practice Compendium. Examples include using the local results to form successful business cases to expand the specialist palliative care input, highlighting the gaps in practice to contribute to educational programmes, to motivating the team to set up an end of life care forum and increasing system wide awareness of end of life care.

There will be a hiatus on NACEL data collection during 2023. The audit is in the process of being re-designed to allow for real time reporting and a further focus on quality improvement. Further details will be available on the NHS Benchmarking Network webpages when available.

After five years of being NACEL Clinical Leads, we will be stepping down at the end of NACEL round four and handing over leadership to Dr Mary Miller as Clinical Lead, Jess Moss as Quality Improvement Lead and Dr Rosie Bronnert as NACEL Quality Improvement Clinical Advisor. We wish them every success in their new roles to shape the future audits of end of life care.

Since its inception, NACEL remains the only national survey of care at the end of life and has distributed over 2,000 local outputs to healthcare providers in the form of local dashboards, infographics, narrative extracts, an online toolkit and good practice case studies. We believe the audit has achieved what it originally set out to do, enabling providers locally and the palliative and end of life care community nationally to assess service provision, to identify where things are going well, where there is room for improvement and to make changes where needed.

The audit continues to contribute to conversations on what good care at the end of life looks like; emphasising the importance of early recognition of possible imminent death, the assessment of needs for both the patient and those important to them, and sensitive communication. National progress against the audit recommendations have been reported since round one of the audit, and continued throughout the COVID-19 pandemic. This includes an increase in the service availability of inpatient specialist palliative care teams, an increase in the assessment of the patient's needs being documented in the case notes and a rise in the delivery of annual end of life care training programmes for inpatient staff. A specific priority for the future audit should be to explore missed opportunities to involve patients directly, and those important to them, earlier in conversations about their care at the end of life.

We would like to thank Professor Bee Wee CBE, Sherree Fagge, the NACEL Steering and Advisory Groups, the Patients Association and all the NHS Benchmarking Network team for your continued enthusiasm and commitment to NACEL and for championing best possible end of life care for our patients and those important to them.

Dr Suzanne Kite

NACEL Co-Clinical Lead

Clinical Lead for Palliative and End of Life Care,

Leeds Teaching Hospitals NHS Trust

Elizabeth Rees

NACEL Co-Clinical Lead

Lead Nurse for Palliative and End of Life Care,

Leeds Teaching Hospitals NHS Trust



# 2. Executive summary

This report sets out the findings of the fourth round of NACEL which took place in 2022. Where possible, the results are compared to previous findings from round three (2021) and round two (2019).

The audit comprised:

- an Organisational Level Audit covering hospital/site (H/S) level questions for 2021/22;
- a Case Note Review (CNR) which reviewed either:
  - 25 consecutive deaths between 1st April 2022 and 14th April 2022 and 25 consecutive deaths between 9th May 2022 and 22nd May 2022 for acute providers
  - or up to 50 consecutive deaths in April and May 2022 for community providers.

The audit included two categories of deaths:

- Category 1: It was recognised that the patient may die.
- **Category 2**: The patient was not expected to die, however clinical staff were not surprised (see Appendix 5 for full definitions);
- a Quality Survey (QS) completed online, or by telephone, by the bereaved person; and
- a Staff Reported Measure (SRM), completed online.

Data for all elements of the audit was collected between June and October 2022.

Each theme receives a summary score out of  $10^1$ ; these scores are calculated from the results of the themes' component metrics (see <u>pg 12</u> for further information).

### **Key findings:**



### Recognising the possibility of imminent death (CNR)

-

- The possibility that the patient may die within the next few hours/days was recognised in 87% of cases audited, consistent with 2021 (pg 13).
- The median time from recognition of dying to death was recorded as 47 hours (41 hours in 2019), providing a greater opportunity to realise individual wishes for end of life care (pg 13).

### Communication with the dying person (CNR)

8.0

- The documentation of conversations with the dying person remained similar to 2021 and pre-pandemic levels (pg 15).
- Results from the Quality Survey show that 13% of families and those important to the dying patient strongly disagreed or disagreed with the statement 'staff communicated sensitively with the dying person' (11% in 2021) (pg 15).

### 

### Communication with families and others (CNR)

7.1

- There was little movement in the recording of conversations with families and others in 2022 when compared to 2019, with continued high compliance on the recording of conversations about the possibility that the person might die and on the individualised plan of care (pg 17).
- Improvement is required on documenting discussions about the risks and benefits of hydration and nutrition options with families and others. This was reported in around a half of cases (pg 18).

# Y

### Involvement in decision making (CNR)

9.2

- A quarter of cases had a documented discussion about the extent to which the patient wished to be involved in their care and 62% had no discussion documented but a reason recorded. This suggests earlier action is required once uncertain recovery is identified to avoid missed opportunities to involve patients, and those important to them.
- From the Quality Survey, 26% of respondents felt they would like to have been more involved in the person's care compared to 23% in 2021 (pg 19).



A summary score has been calculated for each theme with the exception of 'recognising the possibility of imminent death'.

# 2. Executive summary

### **Key findings continued**



### Individualised plan of care (CNR)

7.6

- Findings from the Case Note Review show 76% of Category 1 patients had documented evidence of an individualised plan of care. A lower proportion of Quality Survey respondents agreed there was a plan of care which took into account the individual's wishes and requirements (54%) (pg 22).
- There remains to be room for improvement in advance care planning. The results from the case notes show that 15% of Category 1 patients had a plan in place prior to admission, 22% had participated in advance care planning during the final admission, 56% had no advance care plan and 7% not applicable (pg 24).



### Needs of families and others (QS)

5.5

- The needs of families and others continue to be significant area for improvement.
- Performance on the consideration of families' and others' needs, from the Quality Survey, has further
  dropped since 2019 and 2021. This may reflect the ongoing impact of the pandemic on the ability of
  visitors to access wards and the capacity of staff to assess and address the needs of families and others
  (pg 25).



### Families' and others' experience of care (QS)

6.3

The overall rating of care and support to the person who died and the overall rating of care and support
provided to families and others are lower than in 2021 (pg 27).



### Workforce / specialist palliative care (H/S)

8.1

 Access to specialist palliative care, in particular face-to-face access 8 hours a day, 7 days a week, remains stable when compared to the 2021 results. This remains available in 60% of hospitals/sites (pg 30).



### Staff confidence (SRM)

7.5

Staff confidence to deliver end of life care remains similar to the 2021 results. Staff expressed most
confidence in recognition of dying, communication, responding to the needs of the dying person and
those important to them, involving people in decision making, accessing specialist palliative care and
managing pain and physical symptoms (pg 32).



### Staff support (SRM)

7.1

- There has been a calculation change to the round four summary score theme 'Staff support', due to the removal of two questions relating to the COVID-19 pandemic. Comparing against past summary scores is therefore caveated, although results for the remaining underlying indicators show an improvement.
- Results show an improvement in staff feeling supported to deliver care at the end of life by the specialist
  palliative care team and by managerial staff (pg 33).
- Training continues to be highlighted as a potential area for improvement with only half of respondents stating they had completed training specific to end of life care within the last three years (pg 33).



### Care and culture (SRM)

7.6

- An increase in the proportion of staff agreeing that deaths are actively reviewed, and action plans implemented, to improve end of life care is reported at 62% (from 54% in 2021) (pg 35).
- Attention is required in ensuring that all staff are able to raise a concern about end of life care (5% of staff disagreed) (pg 35).

# National Audit of Care at the End of Life 2022 Key findings at a glance



214 Hospital/site overviews (H/S)



7,620 Case Note Reviews (CNR)



3,600 Quality Surveys (OS)



11,143 Staff Reported Measures (SRM)



(CNR - Cat 1)

87%

Case notes recorded that the patient might die within hours or days

(CNR- Cat 1)



95%

Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care (CNR - Cat 1)
98%

Case notes recorded a discussion (or reason why not) with families/carers regarding the possibility the patient may die

(CNR – Cat 1)



**87**%

Case notes recorded extent patient wished to be involved in care decisions, or a reason why not

(CNR - Cat 1)



**76**%

(QS)

Case notes recorded an individualised plan of care

(CNR - Cat 1)



**79%** 

Case notes recorded patient's hydration status assessed daily once dying phase recognised

(QS)



54%

Families/carers were asked about their needs

Families/carers felt the quality of care provided was good, excellent or outstanding

66%

Care provided to families/carers

**71**%

Care provided to the patient

×

(H/S)

60%

Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week

-<del>/</del>

85%



82%

Staff feel supported by their specialist palliative care team



22%

(SRM)

Staff feel confident they can recognise when a patient might be dying imminently

Staff feel they work in a culture that prioritises care, compassion, respect and dignity

### 4. Recommendations

The recommendations include those brought forward from the first, second and third rounds of NACEL where evidence has been collected in round four which indicate improvement is still required (recommendations 3, 4, 5, 6, 7 & 8). These are still ongoing recommendations. The audit year when the recommendation was first introduced is indicated below each recommendation in brackets.

Recommendations for Integrated Care Boards/Health Boards, working with Provider Executive Boards:

1. Advance care planning: Ensure patients have the opportunity for advance care planning conversations, enabling their wishes or preferences for future care and support to be documented and shared. The sharing of these documented advance care plans across the whole system should be enabled by ICBs/Health Boards with a responsibility to measure how well this is being achieved. This may include decisions about hospital/hospice readmission, treatment escalation plans, preferred location of care and who should be involved in decisions, following guidance in NHSE's 'Universal Principles for Advance Care Planning (ACP)', March 2022.

[New for NACEL 2022]

### **Recommendations for Executive Boards:**

1. Involvement in decisions: Ensure conversations are undertaken with the patient at the earliest opportunity once it is identified that they are sick enough to die, to establish the extent to which they wish to be involved in decisions about their care, and who else they want to be involved. Those that the patient wishes to be involved, must be consulted and their views properly considered. In the event of uncertain recovery, parallel planning, ahead of the last few days and hours of life, should be encouraged to allow the patient to contribute to decisions, and systems should be in place to support this.

[New for NACEL 2022]

2. Specialist Palliative Care: All providers should have adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management. 'Adequate' means specialist palliative medical and nursing cover face-to-face, 9am-5pm, 7 days a week and a 24 hour telephone advice service (One Chance To Get It Right, 2014). This would most often be provided by palliative care nurse specialists face-to-face supported by specialist palliative care 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.

[NACEL 2018, 2019 & 2021 Recommendation 4, 3 & 2 - updated for 2022]

3. Training and support: Ensure all health and care staff have the appropriate training and ongoing support to develop the competence and confidence to care for people at the end of life, and those important to them, including when to seek advice. As a minimum, training should be provided at induction and included as part of the mandatory training programme at least every three years. This includes recognising when someone is likely to die in the next few days or hours, recognising their symptoms, communicating with the dying person and people important to them as early, clearly and sensitively as possible, and continuing appropriate conversations with patients and those important to them at all stages. Mechanisms should be in place to ensure that all staff who may be involved with the person or those important to them are made aware when someone has been recognised as likely to die in the next few days.

[NACEL 2018, 2019 & 2021 Recommendations 9, 6 & 3 – updated 2022]



### 4. Recommendations

5. Individualised plan of care: Ensure that all people who are recognised to be dying have a clearly documented and accessible individualised plan of care developed and discussed with the dying person 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, 2014) and NICE Quality Standards and take into account previously expressed wishes. Documentation for the individualised plan of care may vary locally and may be part of standard care plans. Mechanisms to ensure the timely communication and coordination of this plan must be in place, especially at points of handover of care.

[NACEL 2018, 2019 & 2021 Recommendation 11 & 4 - updated 2022]

 Individualised plan of care: Ensure the individualised plan of care includes how the emotional, psychological, practical, spiritual, religious, and cultural needs of the dying person will be met to ensure effective, holistic, and compassionate support during the last days and hours of life.

[NACEL 2021 Recommendation 5]

7. Hydration and nutrition: Ensure the dying person is supported to eat and drink if they are able and wish to do so. Professional guidance from the GMC, 'Treatment and care towards the end of life: good practice in decision making' 2022, and the NMC's 'The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates' 2018, should be implemented. The risks and benefits of hydration and nutrition options should be clearly and sensitively communicated to the patient and those important to them, with documentation of the communication in the patient's care records. This should include documenting regular reviews of the dying person's hydration and nutrition needs.

[NACEL 2018 & 2019 Recommendation 13 – updated 2022]

8. Needs of others: Ensure the needs of people important to the dying person are identified, assessed, and addressed in a timely manner, both before and after death. Those important to the dying person should be kept well informed, involved and always treated with compassion. Specific senior, strategic and operational responsibility is required to ensure there is capability and capacity within the Trust to care for those important to the dying person and to support them through to bereavement. Assessment of needs should cover emotional, practical, spiritual, religious, and cultural needs to understand and deliver effective support.

[NACEL 2018, 2019 & 2021 Recommendation 7, 7 & 6 - updated 2022]



# 5. How the findings are presented

### 5.1 National results

Section 6-7 of this report contain results from acute and community hospitals in England and Wales taking part in round four of NACEL (2022). This round was open to all acute and community organisations who provide inpatient services to adults (18+), including community services integrated with acute trusts, Community Interest Companies (CICs), standalone Community Services providers and Community Services integrated with Mental Health providers. Hospices are excluded from NACEL

### 5.2 Key themes and summary scores

The information in this report is presented thematically in eleven 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)
- 5. Individualised plan of care (CNR)
- 6. Needs of families and others (QS)
- 7. Families' and others' experience of care (QS)
- 8. Workforce/specialist palliative care (H/S)
- 9. Staff confidence (SRM)
- 10. Staff support (SRM)
- 11. Care and culture (SRM)

A summary score system was originally designed in round one of NACEL to summarise the large dataset into concise findings. The scoring methodology was updated during round two of NACEL, following feedback from audit participants and the Steering and Advisory Group. A similar summary score methodology was then adopted for rounds three and four. A number of component indicators are used to develop the summary scores. As in previous rounds, each summary score only uses indicators from one element of the audit. The following key is used to show the source of each theme:

- H/S Hospital/Site Organisational Level Audit
- CNR Case Note Review
- QS Quality Survey
- SRM Staff Reported Measure

The Case Note Review includes two categories of deaths; where dying was recognised (Category 1) and where dying was not recognised but staff were not surprised (Category 2) (see Appendix 5 for full definitions).

With the exception of 'recognising the possibility of imminent death', a national summary score has been developed and calculated for each theme and, where possible, for each hospital. The mean summary scores across all participants for round four can be found in the Executive Summary on pages 7 - 8. Summary scores using metrics from the Case Note Review only include Category 1 deaths<sup>2</sup>. Appendix 16 explains the process undertaken to select the eleven key themes and their component indicators, together with an explanation of how the scores are calculated. The maximum possible value for a summary score is ten. A box and whisker chart is shown at the start of each theme to show the range of summary scores for participating hospitals.

The round four results are displayed against each key theme in a range of charts. A selection of comments from those close to the dying person via the Quality Survey are shown throughout the report to evidence against the key themes. Where possible, comparisons have been made between the findings from round four (2022), round three (2021) and round two (2019) of NACEL.



# 6.0 Recognising the possibility of imminent death



**Priority 1:** This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly (*One Chance To Get It Right*, 2014).

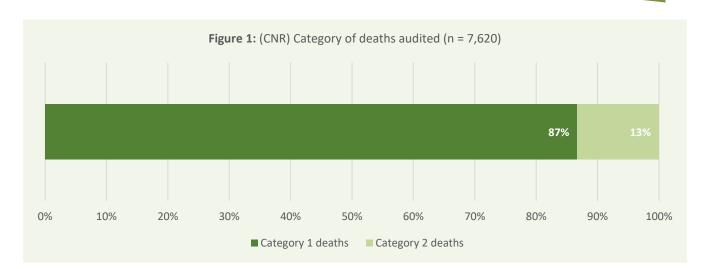
**NICE QS144:** Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering (*Statement 1, NICE Quality Standard 144*).

Timeliness in recognising imminent death 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. Given the importance of recognising imminent death, NACEL requested auditors to classify deaths between Category 1, where it had been recognised by the hospital staff that the patient may die (i.e. within hours or days), and Category 2, where the patient was not expected to die but the hospital staff were "not surprised". Findings to support the theme 'Recognising the possibility of imminent death' are taken from the Case Note Review.

- Figure 1 shows that 87% of patients audited in the Case Note Review were classified as Category 1 deaths.
   The results remain consistent across the four rounds of NACEL.
- Figure 2 shows that 28% of patients were in hospital for over two weeks before being recognised as dying.
- The median time from first recognition of imminent death to the time of death was 47 hours (44 hours in round three).
- A third of patients (33%) died within one day of death being recognised (Figure 4).
- A selection of comments submitted to the Quality Survey reference the failure of hospitals to notify family and others that their loved one was dying.
- Of the Quality Survey results, 8% of respondents felt that staff missed an opportunity to explain to the person that they were likely to die in the next few days (6% in round three). 11% of respondents felt that staff missed an opportunity to explain to friends and family that the person was likely to die in the next few days, 14% felt that they were told but not clearly or only when asked.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"The visiting restrictions should have been lifted given that staff must have known she was towards the end of her life, but no-one said anything to us and we were restricted to the 1 hour a day (shared between 2 people)."

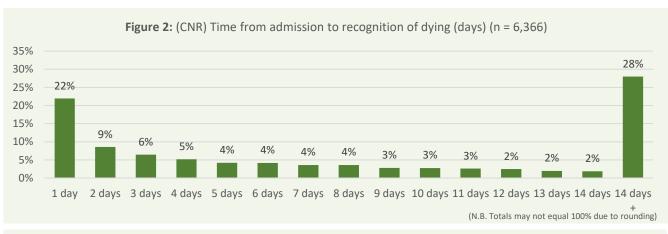
"The nurse on duty when my mother died was great at explaining the likely timescale, and calling me when I needed to be there for my mother's last hour."

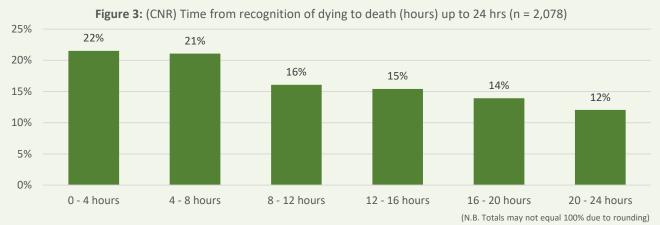




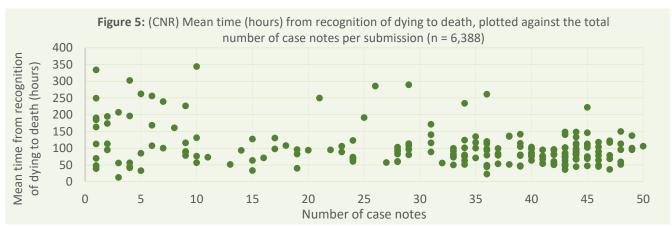
# 6.0 Recognising the possibility of imminent death













# 6.1 Communication with the dying person



**Priority 2:** Sensitive communication takes place between staff and the dying person, and those identified as important to them (*One Chance To Get It Right*, 2014).

**NICE QS144:** Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan (*Statement 2, NICE Quality Standard 144*).

Guidance emphasises the need for open, honest and sensitive communication between staff and the dying person, where communication must be regular and proactive. The round four summary score taken from the Case Note Review for 'Communication with the dying person' (8.0) shows very little change from round three (7.9).

- The documentation of conversations with the dying person appears to have been upheld in 2022, with results on all key metrics in this theme similar to 2021 and pre-pandemic levels.
- Figure 7 shows that 10% of cases had no documented discussion with the patient about the possibility they may die, or a reason why there was no discussion recorded.
- Results from the Quality Survey show an increase in the proportion of respondents that strongly disagreed or disagreed with the statement 'staff communicated sensitively with the dying person'. This is reported as 13%, compared to 7% in 2019 (Figure 46, Section 6.6).
- Evidence from the Staff Reported Measure suggests that staff feel most confident in their skills to communicate clearly and sensitively to dying patients and those important to them compared to delivering other aspects of care. (86% agreeing, Figure 57, Section 6.8).
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"My grandad was never spoken to about his health, he was never asked questions. There was no person centred care."

"Despite him being in hospital over 5 weeks, at no point did anyone communicate the fact that he was going to die." "I would like to send an extra special thank you to the end of life nurses who looked after my wife in the last few days. They were all so patient, compassionate and took time to speak directly to my wife as well as to me and my children. They took the time to explain everything that they were doing, how it would effect [sic] my wife and what we should expect."

Figure 6: Range of hospital mean

Table 1. Communication with the dying person (CNR)	Yes or a reason why not recorded		
Documented evidence (Category 1 only):	2022	2021	2019
Possibility that the patient may die had been discussed with the patient	90%	90%	89%
Patient was involved in discussing the individualised plan of care	95%	95%	94%
Possibility of drowsiness as a result of prescribed medications discussed with the patient	76%	73%	74%
Risks and benefits of hydration options discussed with the patient	82%	81%	80%
Risks and benefits of nutrition options discussed with the patient	81%	81%	78%

summary scores: Communication with the dying person (n submissions = 154) (n CNR = 6,414)

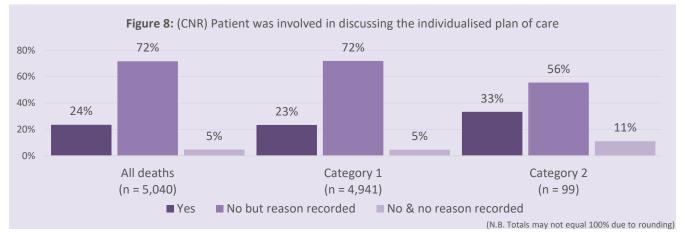
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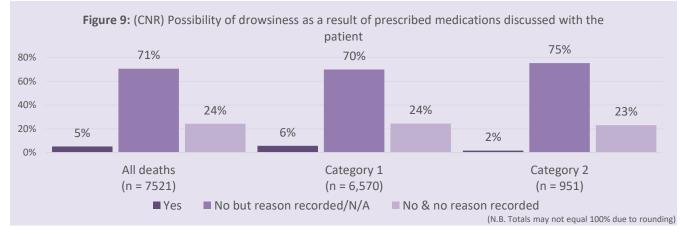


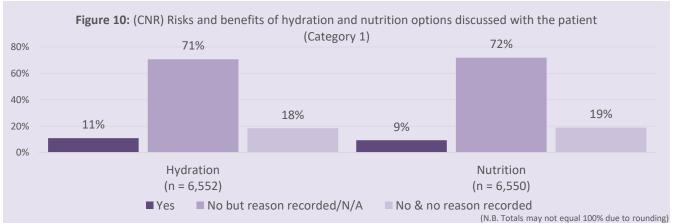
# 6.1 Communication with the dying person













### 6.2 Communication with families and others



**Priority 2:** Sensitive communication takes place between staff and the dying person, and those identified as important to them (*One Chance To Get It Right, 2014*).

**NICE QS144:** Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan (*Statement 2, NICE Quality Standard 144*).

Open and honest communication with families and others close to the dying person is crucially important to high quality end of life care. Guidance references the need for staff to actively seek to communicate with the dying person and those important to them, check the person's understanding of the information and to document this. The round four summary score taken from the Case Note Review for 'Communication with families and others' remains the same as round three (7.1). A high degree of variation is reported across hospital scores for this theme (Figure 11).

- Findings from the Case Note Review suggest little change over the rounds, with continued high
  compliance on recording conversations about the possibility that the person might die and involvement in
  discussions about an individualised plan of care.
- NACEL continues to evidence a gap in the documentation of discussions on hydration and nutrition with families and others. In round four, this was reported as only just over half of cases having documented evidence of discussions about hydration and nutrition, or if not, a reason recorded.
- Discussions regarding the possibility of drowsiness, as a result of prescribed medications, is documented in less than half of cases.
- Of respondents to the Quality Survey, 76% strongly agreed or agreed that they had been communicated with by staff in a sensitive way (79% in round three).
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"My biggest issue the whole time my Mum was in hospital was the lack of communication to her and to myself from staff. I found it very hard to get updates whilst I was there, or over the phone. When I did speak to someone, I would be told she was doing 'well', even when I knew she wasn't."

"I cannot fault the care and attention my son received in the two days in which he was in hospital. I was informed of changes in his condition, both good and bad, at all times, day and night by the doctor."

Table 2: (CNR) Communication with families and others	Yes or reason why not recorded		
Documented evidence (Category 1 only):	2022	2021	2019
Possibility that the patient may die had been discussed with families and others	98%	98%	97%
Families and others were notified that the patient was about to die	89%	90%	89%
Families and others were involved in discussing the individualised plan of care	94%	94%	93%
Possibility of drowsiness as a result of prescribed medications discussed with families and others	39%	36%	37%
Risks and benefits of hydration options discussed with the families and others	55%	52%	51%
Risks and benefits of nutrition options discussed with the families and others	51%	49%	47%

Figure 11: Range of hospital mean summary scores: Communication with families and others (n submissions = 156) (n CNR = 6,392)

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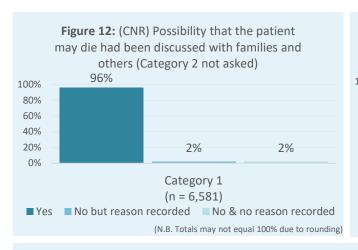
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## 6.2 Communication with families and others





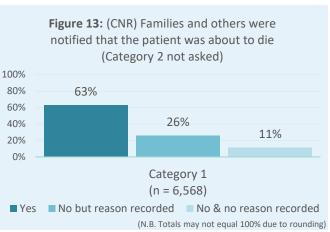
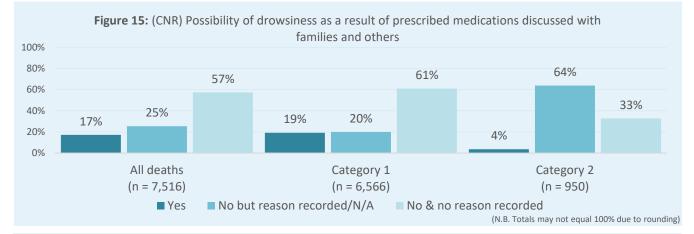
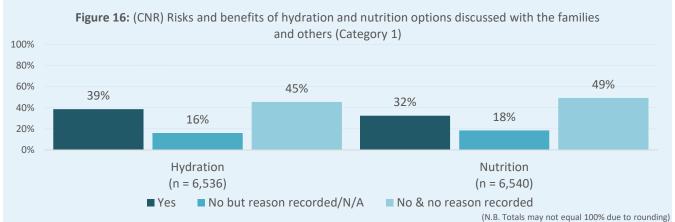


Figure 14: (CNR) Families and others were involved in discussing the individualised plan of care 91% 91% 100% 78% 80% 60% 40% 14% 8% 20% 6% 6% 3% 3% 0% All deaths Category 1 Category 2 (n = 5,038)(n = 4,939)(n = 99)■ No but reason recorded No & no reason recorded Yes (N.B. Totals may not equal 100% due to rounding)







# 6.3 Involvement in decision making



**Priority 3:** The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants (*One Chance To Get It Right, 2014*).

**Notes to Priority 1:** The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person (<u>One Chance To Get It Right</u>, 2014).

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*. The round four summary score taken from the Case Note Review for 'Involvement in decision making' (9.2) has dropped slightly since round three (9.5).

- The results show a shortfall in the documentation of discussions by senior clinicians regarding life sustaining treatment and CPR with families and others.
- The extent to which the patient wished to be involved in decisions about care was documented in 25% of Category 1 cases. Reasons for no documentation include semi-consciousness or unconsciousness (38%), lack of capacity (22%), patient had asked not to be involved (<1%), other reasons (2%) and there was no reason recorded in 13% of cases.</p>
- Earlier conversations are required with patients regarding their involvement in decisions about treatment and care to ensure opportunities are not missed.
- From the Quality Survey, 35% of respondents felt that the person who died was involved in decisions about treatment and care as much as they would have wanted in the last two to three days of life; 8% stated the person who died would have liked to be more involved.
- Around a quarter of Quality Survey respondents (26%) felt they would have liked to be more involved in the person's care and treatment, compared to 23% in 2021.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"The doctor made so much time for me discussing the options and then we presented them to mum together. I really felt this was a partnership between family and hospital and I cannot speak too highly of them."

"We felt rushed in trying to make care decisions, and were upset that someone had spoken to mum about this before we had arrived that morning."

Table 3: (CNR) Involvement in decision making	Yes o	reason wh	y not
Documented evidence (Category 1 only):	2022	2021	2018
Extent to which the patient wished to be involved in decisions about their care	87%	86%	-
Dying person had their capacity assessed to be involved in their end of life care planning	92%	91%	-
Discussion with the patient by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support	94%	94%	93%
Discussion with families and others by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support	93%	100%	94%
Discussion regarding CPR was undertaken with the patient by a senior clinician	96%	99%	93%
Discussion regarding CPR was undertaken with families and others by a senior clinician	91%	100%	89%

Figure 17: Range of hospital mean summary scores:
Involvement in decision making (n submissions = 154) (n CNR = 6,551)

10

9.5

9

8.5

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6.5



# 6.3 Involvement in decision making



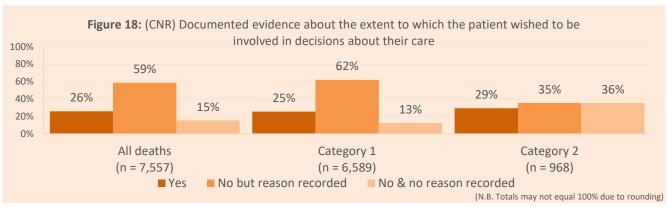


Figure 19: (CNR) Documented evidence the dying person had their capacity assessed to be involved in their end of life care planning 100% 80% 59% 59% 55% 60% 32% 31% 25% 40% 20% 10% 8% 20% 0% All deaths Category 1 Category 2 (n = 7,562)(n = 6,599)(n = 963)■ No but reason recorded No & no reason recorded (N.B. Totals may not equal 100% due to rounding)

**Figure 20:** (CNR) Documented evidence of a discussion with the patient by a senior clinician regarding whether to continue or stop lifesustaining treatment offering organ support

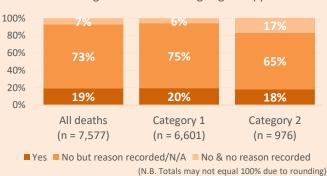


Figure 21: (CNR) Documented evidence of a discussion with families and others by a senior clinician regarding whether to continue or stop life-sustaining treatment offering organ

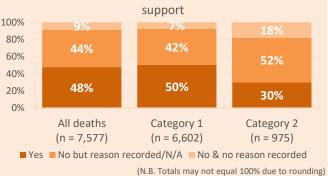
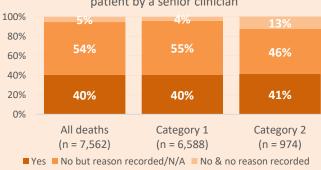
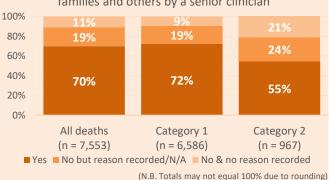


Figure 22: (CNR) Documented evidence that a discussion regarding Cardiopulmonary Resuscitation (CPR) was undertaken with the patient by a senior clinician



(N.B. Totals may not equal 100% due to rounding)

Figure 23: (CNR) Documented evidence that a discussion regarding Cardiopulmonary Resuscitation (CPR) was undertaken with families and others by a senior clinician







**Priority 5:** An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion (*One Chance To Get It Right, 2014*).

**NICE QS144:** Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use, dosage and route of administration (<u>Statement 3, NICE</u> Quality Standard 144).

**NICE QS144:** Adults in the last days of life have their hydration status assessed daily, and have a discussion about the risks and benefits of hydration options (*Statement 4, NICE Quality Standard 144*).

Every person nearing the end of their life should have an individualised end of life care plan that captures the needs and wishes of the dying person, further taking into account the views of those important to them. There should be an opportunity for open and sensitive communication to discuss the plan, which is covered in sections 6.1 and 6.2. The round four summary score taken from the Case Note Review for 'Individualised plan of care' is consistent to the round three results at 7.6.

- Findings from the Case Note Review show a slight improvement in the documentation of an individualised plan of care since 2021. However, with a quarter of cases with no plan in existence, there remains room for improvement (Figure 25).
- Regular reviews of the patient's hydration and nutrition status, once the dying phase was recognised, were evidenced in around three quarters of cases similar to the results in round three.
- Documented evidence of an assessment of wider needs such as emotional/psychological, spiritual/religious/cultural and social/practical is similar to the results from 2021, down from prepandemic levels.
- Documented evidence of physical needs continues to show higher compliance in general nursing care, such as a review of pressure areas and bladder function, with fewer assessments of needs prominent at the end of life such as nausea/vomiting and noisy breathing/death rattle.
- With reference to anticipatory medications, for Category 1 deaths only, there was documented evidence
  that anticipatory medications were prescribed and administered in 69% of cases and prescribed but not
  used in 20% of cases. This is in line with 2021 reporting.
- Of the Quality Survey respondents, 54% agreed that staff made a plan for the person's care which took account of their individual requirements and wishes (57% in 2021).
- For all Category 1 deaths, the preferred place to die was documented in just over a quarter of cases (30%).
- Findings from the Case Note Review and Quality Survey continue to show a gap in advance care planning. The results from the case notes show that 56% had no documented plan. This is further corroborated by 57% of Quality Survey respondents stating an absence of an advance care plan.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"There were about 3 weeks with lots of activity to try and keep her going with various treatments for different conditions, which she found exhausting and she asked me several times if I could just take her back home [...] It would have been good to have a more definite plan for end of life care, we didn't have one and I didn't know how to make it happen."

"My family have strong views on death. We were able to communicate these to the medics. My brother had the sort of death that we would have wished for him. Thank you."

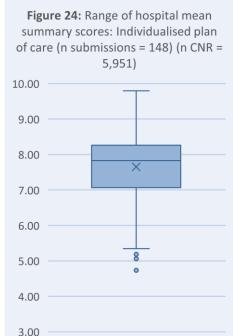
"There was not an advanced [sic] care plan that I was aware of. I was asked if my mother would want to be resuscitated [...] but that was the only question I was asked."

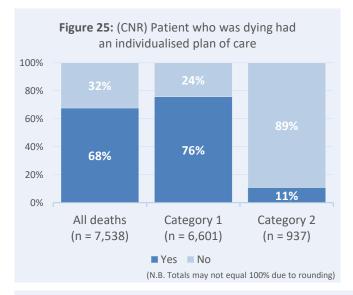
"They made Mum as comfortable as possible and tried their best to make sure she had the correct level of pain relief."





Table 4: (CNR) Individualised plan of care		Yes	
Documented evidence (Category 1 only):	2022	2021	2019
Patient had an individualised plan of care	<b>76</b> %	73%	71%
Patient's individualised plan of care was reviewed regularly (includes <i>N/A/Patient died before review was necessary</i> )	98%	98%	97%
Preferred place of death documented as indicated by the patient	30%	30%	29%
Patient's hydration status was assessed daily once the dying phase was recognised	<b>79</b> %	78%	77%
Patient's nutrition status was reviewed regularly once the dying phase was recognised	73%	72%	68%





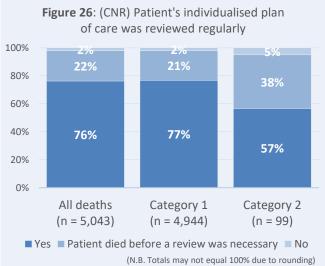


Figure 27: (CNR) The benefit of starting, stopping or continuing the interventions documented as being reviewed in the patient's plan of care (Category 2 not asked) 100% 80% 22% 60% 40% 79% 76% 70% 67% 60% 20% 36% 0% Other medication Routine blood tests Administration of Recording of vital Administration of Blood sugar signs (n = 6,522)(n = 6,548)antibiotics oxygen monitoring (n = 6,557)(n = 6,554)(n = 6,551)(n = 6,557)■ Yes ■ N/A ■ No





Figure 28: (CNR) The patient's hydration status was assessed daily once the dying phase was recognised (Category 2 not asked) (n = 6,436) Yes No (N.B. Totals may not equal 100% due to rounding)

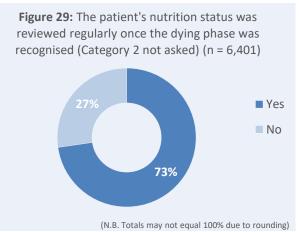


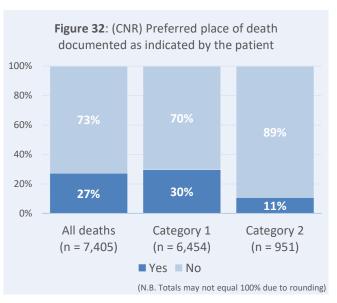
Figure 30: (CNR) Documented evidence of an assessment of the following needs (Category 1 only) Pressure areas (n = 6,593)93% Bladder function (n = 6,593) 91% Hygiene requirements (n = 6,581) 90% Pain (n = 6,590)88% Bowel function (n = 6,586) 86% 129 Dyspnoea/breathing difficulty (n = 6,590) 86% Agitation/delirium (n = 6,585) 82% Mouth care (n = 6,573)83% Noisy breathing/death rattle (n = 6,565) 72% Nausea/vomiting (n = 6,576) 21% 66% 0% 20% 40% 60% 80% 100% ■ Yes ■ No ■ N/A





(N.B. Totals may not equal 100% due to rounding)





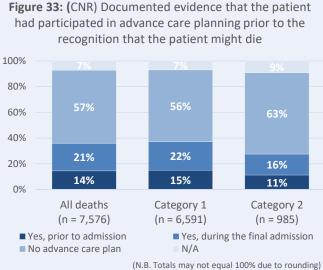


Figure 34: (CNR) Documented evidence that anticipatory medication was prescribed for symptoms likely to occur in the last days of life (Category 2 not asked) (n = 6,565)



Figure 35: (CNR) Where anticipatory medicines prescribed, documented evidence that an indication for use of the medication was included within the prescription (Category 2 not asked)



Figure 36: (CNR) Where anticipatory medicines prescribed, documented evidence that a discussion about the use of anticipatory medication was undertaken with patient and nominated person (Category 2 not asked):

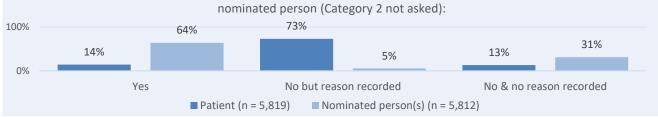
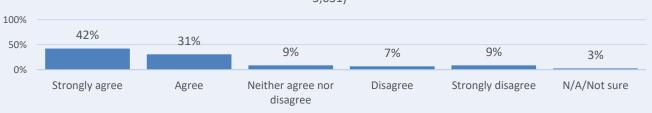


Figure 37: (QS) In the circumstances, the hospital was the right place for the person to die (n = 3,631)





### 6.5 Needs of families and others



**Priority 4:** The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible (*One Chance To Get It Right, 2014*).

**Notes to Priority 4:** Where they have particular needs for support or information, these should be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help (*One Chance To Get It Right*, 2014).

Family and others important to the dying person have their own care needs when somebody close to them is dying that should be listened to, acknowledged and met as far as possible. Results from the Quality Survey are used to measure performance on this theme. The round four summary score taken from the Quality Survey for 'Needs of families and others' (5.5) is lower than previous rounds (5.6 in round three and 6.0 in round two).

- Consideration of the needs of families and others remains an improvement area.
- A downward trend in the support given to families and others is noted from the Quality Survey (Table 5).
- The deterioration in performance may reflect the ongoing impact of the pandemic. This includes visitation restrictions remaining in some areas and lack of staff capacity, due to staff shortages and stretched resources, to assess and address the needs of families and others.
- The account of restrictions in place to visit the dying person in hospital due to COVID-19 nearly halved from 82% in round three to 44% in round four.
- Of Quality Survey respondents, 27% disagreed that the needs of families and others were asked about.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"The staff also cared for my needs too, I stayed with him for the last 2 days of his life, I was provided with meals, drinks and a fold down bed, but more importantly I was supported emotionally during this traumatic time."

"The doctors and nurses did their best to care for my emotional needs as well as my mum's."

"As a family at the end we didn't feel fully informed about the dramatic decline of my husband."

"In hindsight, I should have requested that a chaplain or vicar visit but no one offered or suggested."

Table 5: (QS) Needs of families and others	Strongly agree/Agree			
Families and others were:	2022	2021	2019	
Asked about their needs	54%	57%	58%	
Given enough emotional help and support by staff	57%	60%	65%	
Given enough practical support	51%	51%	62%	
Given enough spiritual/religious/ cultural support	31%	32%	32%	
Kept well informed	61%	64%	69%	
	As much as I wanted			
Involved in decisions about care	65%	66%	72%	

Figure 38: Range of hospital mean summary scores: Needs of families and others (n submissions = 52) (n QS = 3,574)

8.0

7.5

6.5

6.0

5.5

X

5.0

4.5

4.0

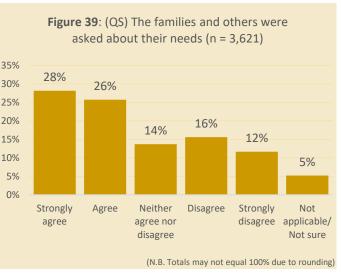
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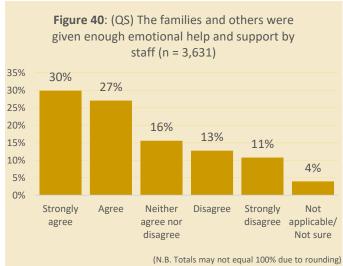
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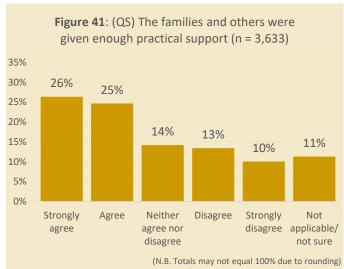


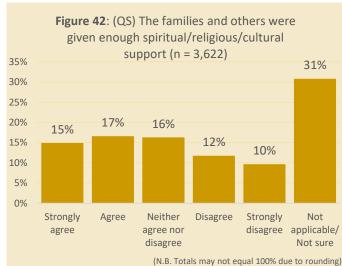
### 6.5 Needs of families and others

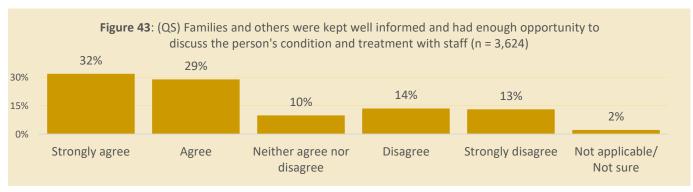


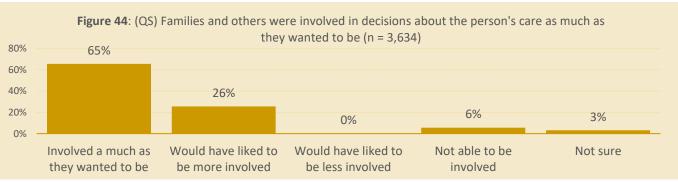














# 6.6 Families' and others' experience of care



Feedback from families and others provides valuable information about the perception of the quality of care at the end of life. The round four summary score taken from the Quality Survey for 'Families' and others' experience of care' (6.3) has reduced since previous rounds (6.5 in round three and 7.0 in round two).

- Results pertaining to sensitive communication with the dying person, and with families and others, scored lower than in 2021 (Table 6).
- The overall rating of care and support to the person who died, and the overall rating of care and support provided to families and others, are also lower than round three (Figures 48-49).
- Similar to previous findings, the care and support provided to the person who died was rated higher (71%) than that provided to families and others (66%).
- As noted earlier, visiting restrictions due to COVID-19 remained in place in certain geographical locations during the audit period, which is likely to have had a negative impact on the experience of families and others close to the dving person.
- A selection of comments from the Quality Survey reference hospital services being stretched due to staff shortages and unclear policies around COVID-19 visitation restrictions hindering the quality of care delivered. Comments referencing exemplary care often mentioned compassionate care and clear communication being key contributors to an overall positive end of life experience for those important to the dying patient.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"Mum was treated with the utmost kindness, compassion, and respect by everyone involved in her care during her final days [...]. No-one in the hospital could have done any more."

"COVID restrictions were overly rigidly applied, limiting visiting until the final few days."

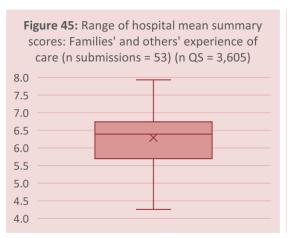
"I cannot praise the staff at X enough for their care and support given to the whole family during the final hours of my wife's life. They facilitated in my wife passing away how she wanted to. Peaceful and respectful with her family by her side." "I was not prepared for the manner of her death [...] I suggest that advice is made available to loved ones, about the sort of form it may take, before the critical period arrives. This will reduce heartache."

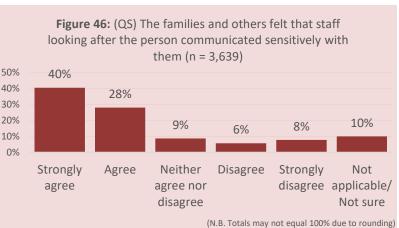
Table 6: (QS) Families' and others' experience of care	Strongly agree/Agree			Strongly disagree/Disagree		
Families and others:	2022	2021	2019	2022	2021	2019
Felt that staff caring for the person who died communicated sensitively with them	68%	68%	79%	13%	11%	7%
Felt they were communicated to by staff in a sensitive way	76%	79%	84%	14%	12%	8%
	Outstanding/Excellent/Good			/Good Fair/Poor		
Rating of care and support provided to the person who died	71%	74%	80%	27%	22%	20%
Rating of care and support provided to families and other	66%	68%	75%	33%	29%	24%

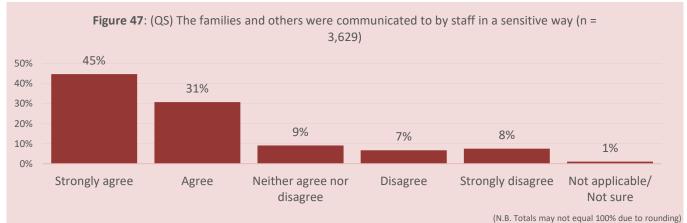


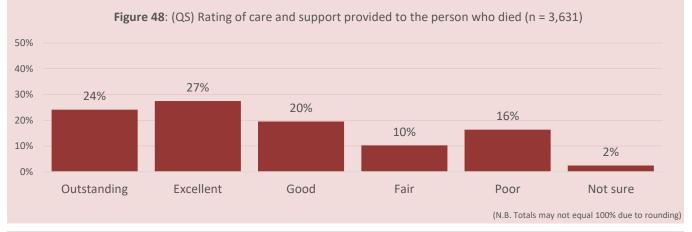
# 6.6 Families' and others' experience of care

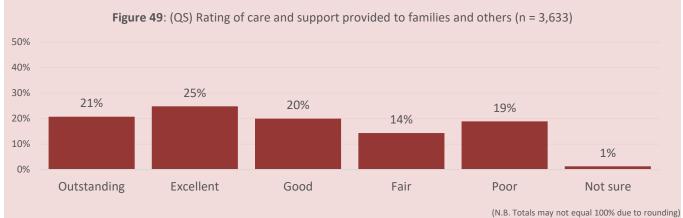














# 6.7 Workforce/specialist palliative care



**Notes to Priority 5:** There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this (<u>One Chance To Get It Right</u>, 2014).

**Notes to Priority 5:** [service providers must] work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. 'Adequate' means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am – 5pm seven days a week and a 24 hour telephone advice service (*One Chance To Get It Right, 2014*).

Ongoing education and training for all health and care staff: [....all] staff who have contact with dying people must have the skills to do this effectively and compassionately. This includes clinical and support staff (e.g. porters, reception staff and ward clerks.) Those organisations that deliver such care have the prime responsibility for ensuring that the people they employ are competent to carry out their roles effectively, including facilitating and funding ongoing professional development, where this is appropriate (One Chance To Get It Right, 2014).

National guidance reinforces the need for providers to work with commissioners to ensure access to an adequately resourced specialist palliative care workforce. Guidance also states the importance of providers to ensure that staff have the necessary training and skills to deliver care at the end of life. The round four summary score on 'Workforce/specialist palliative care' (8.1), taken from the Hospital/Site Overview, remains consistent with round three.

- The results show the increased provision of specialist palliative services have remained in place following the pandemic. Consistent with the round three results, access to specialist palliative care, face-to-face, 8 hours a day, 7 days a week, was available in 60% of participating hospitals/sites.
- Evidence from the Case Note Review shows that 52% of Category 1 patients were reviewed by a member of the specialist palliative care team during their final admission.
- Overall, the inclusion of end of life care training in hospital programmes is recorded above 2019 levels.
- A selection of Quality Survey comments referenced the hospital workforce including staff shortages, delays in accessing the specialist palliative care team and giving thanks to individual members of staff.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"The palliative care team were particularly responsive, caring, informative and very helpful in considering our mother's needs."

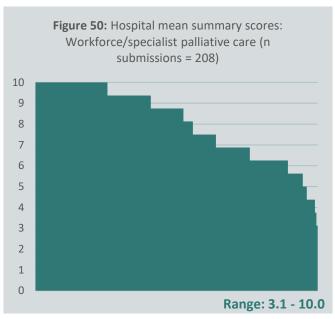
"They did the best they could for my mother in her final days, taking into account the constraints put upon them by shortages of staff, bed space and resources."

Table 7: (H/S) Workforce/specialist palliative care		Yes			No	
Does the hospital/site have:	2022	2021	2019	2022	2021	2019
Access to a Specialist Palliative Care service	98%	99%	99%	2%	1%	1%
Telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week	91%	92%	86%	9%	8%	14%
Face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week	60%	60%	36%	40%	40%	64%
End of life care training included in:						
Induction Programme	64%	66%	62%	36%	34%	38%
Mandatory/Priority Training	51%	50%	46%	49%	50%	54%
Communication skills	75%	77%	74%	25%	23%	26%
Other training	99%	96%	95%	1%	4%	5%



# 6.7 Workforce/specialist palliative care





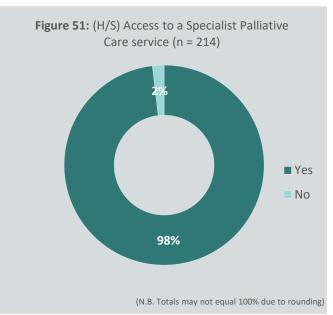
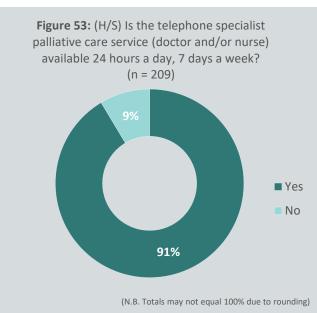


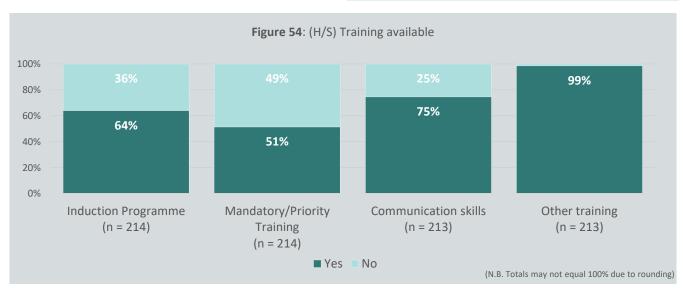
Figure 52: (H/S) Is the face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week?

(n = 210)

Yes

(N.B. Totals may not equal 100% due to rounding)







### 6.8 Staff confidence

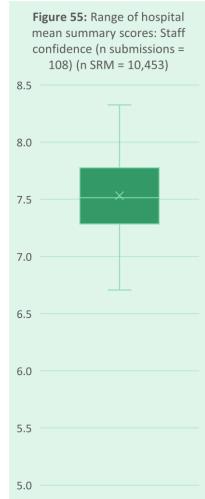


The Staff Reported Measure (SRM) collects data from both clinical and non-clinical staff working in hospitals where they may be expected to come into contact with the dying person and those important to them. It should be noted that the group completing the SRM were self-selected. Of respondents, 92% were clinical staff. Further detail on respondent demographics is included at Appendix 20.

National guidance mentions the requirement of individual providers to ensure that staff have the experience and competence they need to do their jobs well. The round four summary score taken from the Staff Reported Measure for 'Staff confidence' measures the feeling of certainty and self assurance in staff's abilities to deliver elements of care at the end of life. The round four score has remained stable when compared to round three at 7.5

- Results show little change in staff confidence to deliver care at the end of life. Staff completing the survey expressed confidence in recognition of dying; communication; responding to the needs of, and involving in decision making, both the dying person and those important to them; accessing specialist palliative care; and managing pain and physical symptoms. Weaker areas were knowing how to respond to requests to die out of the hospital setting (13% strongly disagreed/disagreed) (Figure 60) and having confidence in the ability to discuss hydration options with dying patients and those important to them (8% strongly disagreed/disagreed) (figure 63).
- The survey answer option of 'N/A/not sure' was updated in round four to 'N/A'. Direct comparisons of the 'N/A' results are therefore caveated, although this has not impacted the summary score calculation.
- It is interesting to note that staff confidence to deliver end of life care is not reflected in the families' and carers' rating of care and support from the Quality Survey. This emphasises the fact that the SRM results reflect confidence rather than capability as experienced by families and carers.

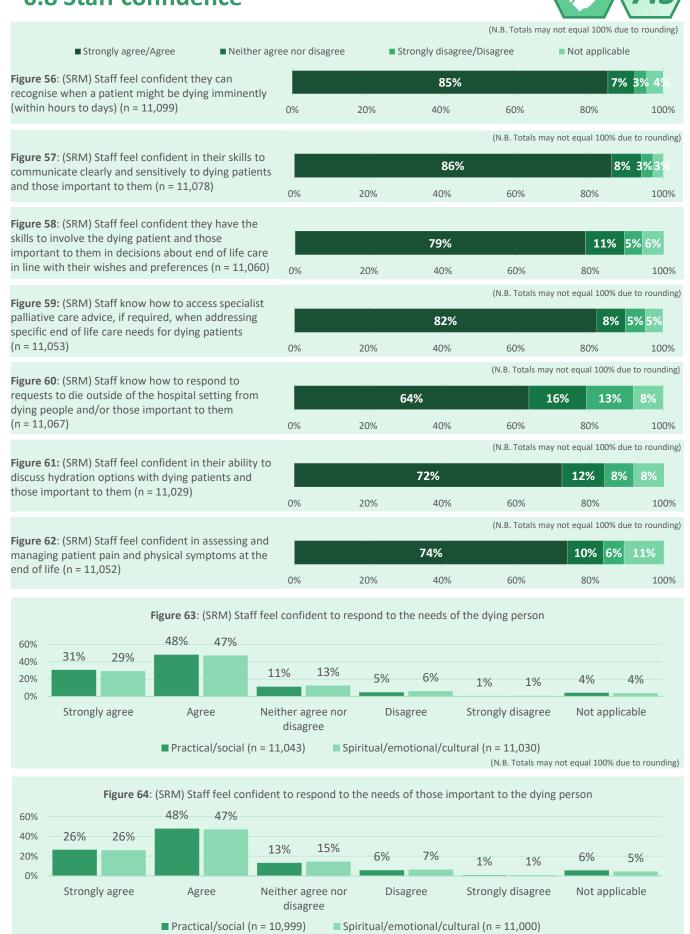
Table 8: (SRM) Staff confidence		ngly 'Agree
Staff survey respondents:	2022	2021
Feel confident to recognise when a patient might be dying imminently	85%	84%
Feel confident in skills to communicate clearly and sensitively	86%	86%
Feel confident to respond to practical and social needs of the dying person	79%	78%
Feel confident to respond to spiritual, emotional and cultural needs of the dying person	77%	76%
Feel confident to respond to practical and social needs of those important to the dying person	74%	74%
Feel confident to respond to spiritual, emotional and cultural needs of those important to the dying person	73%	<b>72</b> %
Feel confident in skills to involve the dying patient and those important to them in decisions about end of life care	79%	79%
Know how to access specialist palliative care advice	82%	82%
Know how to respond to requests to die outside of the hospital	64%	63%
Feel confident in abilities to discuss hydration options	72%	71%
Feel confident in assessing and managing patient pain and physical symptoms at the end of life	74%	74%





### 6.8 Staff confidence







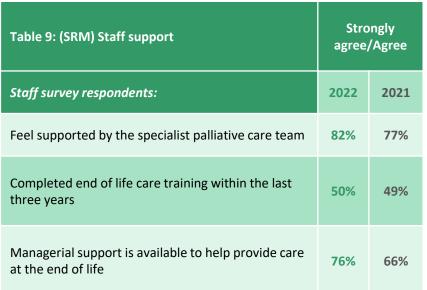
(N.B. Totals may not equal 100% due to rounding)

# 6.9 Staff support



Feedback from staff provides valuable information about the work environment and resources available to deliver high quality care at the end of life. Evidence of staff support to deliver care at the end of life from the Staff Reported Measure is utilised in this theme.

- Overall, there has been a positive improvement in the findings relating to staff support.
- The round four summary score for 'Staff support', 7.1, is considerably higher than the round three score of 6.4. However, the scores can not be directly compared given the changes to the scoring methodology.
- Changes include the removal of two metrics regarding support during the pandemic. Furthermore, as
  mentioned in Section 6.8, the survey answer option of 'N/A/not sure' was updated in round four to 'N/A'.
  Direct comparisons of the 'N/A' results are therefore caveated.
- Table 9 shows an increase in the staff survey respondents who feel supported by the specialist palliative care team from 77% in 2021 to 82% in 2022. The largest improvement was in staff's perception of managerial support being available to help provide care at the end of life, from 66% in 2021 to 76% 2022.
- Training continues to be highlighted as an area for improvement, with only half of respondents stating they had completed training specific to end of life care within the last three years (Figure 67).







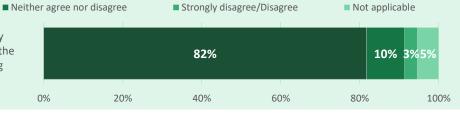
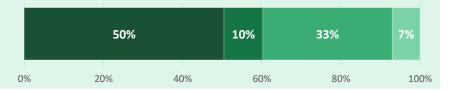


Figure 67: (SRM) Staff have completed training specific to end of life care within the last three years (n = 11,063)



**Figure 68:** (SRM) Managerial support is available to help provide care at the end of life (n = 11,035)



### 7.0 Care and culture



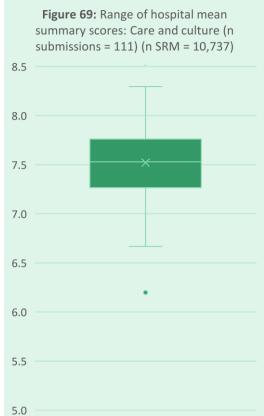
**Notes to Priority 5:** [service providers and employers must] promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental to caring for dying people. (<u>One</u> Chance To Get It Right, 2014).

**Notes to Priority 5:** [service providers and employers must] implement and support mechanisms for feedback which facilitate service improvement. (*One Chance To Get It Right*, 2014).

Evidence from the Staff Reported Measure on the care and culture specific to the last days of life is utilised in this theme. The round four summary score taken from the Staff Reported Measure for 'Care and culture' is reported at 7.6, showing an improvement since round three (7.3).

- Table 10 shows a slight improvement in the proportion of respondents agreeing that priority is given to the provision of an appropriate peaceful environment at the end of life. This may be a result of side rooms being more readily available since the height of the COVID-19 pandemic, reported in 2021.
- A considerable improvement is recorded in the perception of staff strongly agreeing/agreeing that deaths are actively reviewed and action plans implemented to improve end of life care (62%), since 2021 (54%). This may be linked to an increased awareness of the Medical Examiner system, newly rolled out across England and Wales.
- Most staff respondents (83%) answered positively that they felt they work in a culture that prioritises care, compassion, respect and dignity (Figure 71). Although 10% of staff respondents were neutral and 5% answered negatively, suggesting room for improvement.
- As mentioned in section 6.8, the survey answer option of 'N/A/not sure' was updated in round four to 'N/A'. Direct comparisons of the 'N/A' results are therefore caveated, although this has not impacted the summary score calculation.
- Improvement is required in increasing the proportion of staff that feel able to raise a concern about end of life care if needed. This was reported as 84%, yet should be closer to 100% (Figure 70).

Table 10: (SRM) Care and culture	Stro agree,		
Staff survey respondents:	2022	2021	
Feel able to raise a concern about end of life care if they needed to	84%	83%	
Feel they work in a culture that prioritises care, compassion, respect and dignity	83%	80%	
Staff work in partnership with the dying person and those important to them in planning and making decisions	85%	82%	
Priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and those important to them	74%	70%	
Staff actively share information with each other about the individual's end of life care needs	82%	80%	
Deaths are actively reviewed, and action plans are implemented to improve end of life care	62%	54%	





### 7.0 Care and culture





disagree



(N.B. Totals may not equal 100% due to rounding)

# **Acknowledgements**

This report was prepared by the NHS Benchmarking Network (NHSBN), with support from the NACEL Co-Clinical Leads; Dr Suzanne Kite, Clinical Lead for Palliative and End of Life Care and Elizabeth Rees, Lead Nurse for Palliative and End of Life Care at Leeds Teaching Hospitals NHS Trust. The content of this report is advised and approved by all members of the NACEL Steering Group.

We would like to thank the families and others close to the patients who died, who completed the Quality Survey during the fourth round of the audit. Their feedback will be instrumental in helping healthcare organisations deliver high quality end of life care.

We would also like to thank the staff of the NHS for responding in large volumes to the NACEL Staff Reported Measure (SRM), which has given the team real insight into staff confidence and support to deliver end of life care, post pandemic. Thanks must go to hospital staff across all acute and community hospitals who participated in NACEL, giving us data for the Organisational Level Audit and the Case Note Review. We hope that your perseverance in obtaining this data will help all hospitals to improve end of life care to the dying and those close to them.

The Patients Association once again provided valuable support in delivering the telephone helpline, which assisted the families and others close to the dying patients in completing the Quality Survey. Their assistance in signposting additional help for the bereaved has been invaluable, particularly during the pandemic.

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