National Audit of Care at the End of Life

Third round of the audit (2021/22) 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](http://www.hqip.org.uk/national-programmes).

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1. Foreword

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

The last two years have been immensely tough for everyone, with uncertainty and loss affecting us all in different ways, and to differing degrees. As the Covid-19 pandemic, and lockdown, took hold in early 2020, many experienced dying, death and bereavement without the support needed at such very sad and difficult times. Families, and those close to the dying person, were often not able to be with them and to say goodbye, due to the severest of visiting restrictions. The NHS and social care faced the greatest, fastest redesign of services in 70 years, and there has been an ongoing need for continuous adaptation to meet changing priorities and needs. The demands on carers and health and social care professionals have been immense. It was in this context that the decision to defer the intended third round of NACEL was made, in agreement with the audit funders. One year on, the vaccination programme was underway, and impacting on serious illness and death from Covid. On this basis, the funders decided that the third round of the audit should go ahead in 2021, to provide evidence on end of life care delivery in a pandemic at national level.

There was a need to minimise data burden for healthcare providers who were both caring for large numbers of people with Covid-19, and trying to catch up with non-emergency care and treatment that had been delayed by the diversion of NHS resources to managing the pandemic. It was agreed that the NACEL Quality Survey (the survey of bereaved carers) and the new Staff Reported Measure, should be made optional. We are pleased to report that, even though these elements were optional, we had feedback from over 3,000 bereaved carers on their experiences of end of life care, and over 11,000 responses to the Staff Reported Measure. We would like to thank everybody who took the time to respond, giving us valuable feedback on the experience of care, and the impact on staff, during the pandemic. The narrative messages in particular from bereaved carers, families and friends resonated deeply, with a huge number of responses detailing the pain of not being present at the bedside of their loved one, and of only being able to say goodbye remotely. All feedback from the Quality Survey pertinent to individual healthcare providers has been provided to them, so that they can take the time to read through these accounts, and learn from this most difficult of times.

We were mindful that the intensity of the pandemic varied over time and across geographical areas. We are also conscious that the resources available in hospital to provide end of life care may have been different to pre-pandemic times. It is encouraging that the findings from NACEL in round three show that access to specialist palliative care support was perceived as good by staff, and that the proportion of providers providing 24/7 access to specialist palliative care and support has increased. However, there remains a significant shortfall in universal seven day a week access to face-face specialist palliative care services, and we seek reassurance in round four of NACEL that increased specialist palliative care provision will be maintained and further extended. We are particularly pleased to report that the documentation regarding many aspects of care remains stable despite the extremely challenging circumstances, notably patient’s preferred place of care; individualised end of life care planning; symptom management, and anticipatory prescribing. However, as in previous rounds of the audit, there is less documentation of wider needs such as spiritual, religious, cultural and emotional support given to both the dying person and those close to them. Some of this may have been in part due to the restrictions on visiting, however there remains a need for sustained improvement in these areas. The documentation of conversations about the hydration and nutrition needs of the dying person with those important to the dying person remains documented in only around a half of cases.

Supporting the needs of families and others close to the dying person is key to providing good end of life care. This was an area for improvement in rounds one and two of NACEL, and it is a concern that the 2021 findings suggest a deterioration in the support provided. The barriers faced by visitors being present in hospitals during the pandemic may have a part to play. In particular, the discrepancy between the documentation by staff of conversations, often necessarily by telephone, with families and those close to the person, and the lived experience of the bereaved, may reflect the inherent shortcomings of telephone communication at this time.
1. Foreword

However, improvements must be made to ensure that the needs of those close to the dying person are addressed in a timely and compassionate manner, and this is reflected in recommendation six from this round. Specific plans must be in place to achieve this.

The discrepancy between the documentation of conversations with families and those close to the person, and the reported experience of the bereaved, may reflect the reliance on telephone communication during the pandemic and the inherent shortcomings of this means of communication.

The new Staff Reported Measure provided broad insights on where staff responders perceived improvements could be made. Individual organisations will be able to analyse their own staff feedback, and highlight more specific areas for quality improvement in light of response rate and spread across staff groups. Around half of the staff surveyed said that they had received specific end of life care training in the last three years. A similar proportion of staff surveyed felt confident to respond to requests to die out of hospital, even though high numbers of hospitals report having specific arrangements in place for people to be discharged quickly home to die if that is their wish. Generally, survey responders felt confident to recognise imminent death, to communicate sensitively with the dying person and those important to them, and to manage pain and other physical health symptoms close to death. It must be noted, however, that confidence is not, per se, a marker of competence. It is concerning that 5% of staff felt that, if needed, they would not feel able to raise a concern about end of life care within their hospital. All the elements of the audit need to be viewed and interpreted together to provide organisations with a snapshot of their provision of end of life care, and the opportunity to identify where good practice can be consolidated, and where improvements must be made. We thank the staff across the NHS who responded to this survey and gave us valuable insight on caring for dying people during such a challenging time.

It is especially pleasing to report how the findings from previous rounds of NACEL have been utilised locally. Examples range from regular reporting at Board level on quality and service improvement opportunities, informing priority areas for staff training and development, promoting benchmarking at STP/ICS level, and improvements in key documentation pertaining to end of life care. Many participants report having used their NACEL findings to inform business cases for the specialist palliative care workforce, and for specific workstreams around gathering carer views.

We would also like to take this opportunity to recommend the findings from the 2021 Inpatient Mental Health Spotlight Audit to you. These results have ensured a baseline against which to measure progress with the Five Priorities for Care in mental health settings, with some excellent care highlighted.

NACEL round four (2022) is now in progress, with details available on the webpages. Round four will encompass the same four data elements as Round three (Organisational Level Audit, Case Note Review, Quality Survey and Staff Reported Measure).

Finally, we would like to thank Professor Bee Wee CBE, and Sherree Fagge, and the NACEL Steering Group, Advisory Group and Patients Association for their unwavering support, insights, commitment, hard work, enthusiasm and teamwork, particularly over these last two years. We are extremely grateful.

We commend the findings of the third round of NACEL to you.

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### National Audit of Care at the End of Life 2021

#### Key findings at a glance

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>(CNR – Cat 1)</td>
<td>171</td>
<td>Trust/Health Board overviews (T/HB)</td>
</tr>
<tr>
<td>(CNR – Cat 1)</td>
<td>239</td>
<td>Hospital/site overviews (H/S)</td>
</tr>
<tr>
<td>(CNR)</td>
<td>6,823</td>
<td>Case Note Reviews (CNR)</td>
</tr>
<tr>
<td>(QS)</td>
<td>3,118</td>
<td>Quality Surveys (QS)</td>
</tr>
<tr>
<td>(SRM)</td>
<td>11,045</td>
<td>Staff Reported Measures (SRM)</td>
</tr>
</tbody>
</table>

#### Case Notes Findings

- **87%** Case notes recorded that the patient might die within hours or days.
- **95%** Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care.
- **98%** Case notes recorded a discussion (or reason why not) with families/carerers regarding the possibility the patient may die.
- **86%** Case notes recorded extent patient wished to be involved in care decisions, or a reason why not.
- **73%** Case notes recorded an individualised plan of care.
- **57%** Families/carerers were asked about their needs.

#### Hospital Findings

- **68%** Care provided to families/carerers.
- **74%** Care provided to the patient.
- **60%** Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week.

#### Trust/Health Board Findings

- **99%** Trusts/Health Boards have guidelines on how to respond to/learn from deaths of patients.

#### Staff Findings

- **85%** Staff feel confident they can recognise when a patient might be dying imminently.
- **77%** Staff feel supported by their specialist palliative care team.
- **80%** Staff feel they work in a culture that prioritises care, compassion, respect and dignity.
2. Executive summary

This report sets out the findings of the third round of NACEL which took place in 2021. Results are compared to round two, which took place in 2019. The audit was not undertaken in 2020, due to the Covid-19 pandemic.

The audit comprised:

- an Organisational Level Audit covering Trust/Health Board (T/HB) and hospital/submission (H/S) level questions for 2020/21;
- a Case Note Review (CNR) which reviewed 20 consecutive deaths between 12th April 2021 and 25th April 2021 and 20 consecutive deaths between 1st May 2021 and 14th May 2021 for acute providers and up to 40 consecutive deaths in April and May 2021 for community providers;
- a Quality Survey (QS) completed online, or by telephone, by the bereaved person; and
- new for 2021, a Staff Reported Measure (SRM), completed online.

Key themes are taken from one audit element only, each element uses a different sample and therefore cannot be compared. Data for all elements of the audit was collected between June and October 2021. Details of participation can be found at Appendix 23.

Key findings

- The possibility that the patient may die within the next few hours/days was recognised in 87% of cases audited, compared to 88% in 2019 (pg 13).
- The median time from recognition of dying to death was recorded as 44 hours (41 hours in 2019) (pg 13).
- Results on all key metrics regarding the recording of conversations with the dying person remain similar to 2019, pre-pandemic levels (pg 15).
- However, from the Quality Survey, the proportion strongly disagreeing or disagreeing with the statement ‘staff communicated sensitively with the dying person’ increased from 7% (2019) to 11% (2021) (pg 15).
- There was little change in 2021 when compared to 2019, with continued high compliance on recording of conversations about the possibility that the person might die and on the individualised plan of care (pg 17).
- As in 2019, discussions on hydration and nutrition with families and others were documented, or a reason why not recorded, in only around half of cases (pg 18).
- Findings from the Case Note Review in 2021 suggest continued strong compliance on involvement in decision making, with similar results to those reported when this theme was last tested in 2018 (pg 19). However, from the Quality Survey, in 2021, 23% of people felt they would like to be more involved in the person’s care compared to 19% in 2019 (pg 19).
- Third round findings from the Case Note Review showed similar results for the existence of an individualised plan of care, 73% of cases compared to 71% in 2019, suggesting this is an ongoing area for improvement (pg 22).

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

Recognising the possibility of imminent death

- The possibility that the patient may die within the next few hours/days was recognised in 87% of cases audited, compared to 88% in 2019 (pg 13).
- The median time from recognition of dying to death was recorded as 44 hours (41 hours in 2019) (pg 13).

Communication with the dying person

- Results on all key metrics regarding the recording of conversations with the dying person remain similar to 2019, pre-pandemic levels (pg 15).
- However, from the Quality Survey, the proportion strongly disagreeing or disagreeing with the statement ‘staff communicated sensitively with the dying person’ increased from 7% (2019) to 11% (2021) (pg 15).

Communication with families and others

- There was little change in 2021 when compared to 2019, with continued high compliance on recording of conversations about the possibility that the person might die and on the individualised plan of care (pg 17).
- As in 2019, discussions on hydration and nutrition with families and others were documented, or a reason why not recorded, in only around half of cases (pg 18).

Involvement in decision making

- Findings from the Case Note Review in 2021 suggest continued strong compliance on involvement in decision making, with similar results to those reported when this theme was last tested in 2018 (pg 19). However, from the Quality Survey, in 2021, 23% of people felt they would like to be more involved in the person’s care compared to 19% in 2019 (pg 19).

Individualised plan of care

- Third round findings from the Case Note Review showed similar results for the existence of an individualised plan of care, 73% of cases compared to 71% in 2019, suggesting this is an ongoing area for improvement (pg 22).
2. Executive summary

Key findings continued

- Documented evidence of an assessment of wider needs such as emotional/psychological, spiritual/religious/cultural and social/practical shows a reduction since 2019, which may be a result of continuing pressures of the Covid-19 pandemic on services during 2021 (pg 23).

- Needs of families and others
  
  The needs of the family were identified as an improvement area in both round one and round two of the audit. Comparison with 2019 findings suggests performance has deteriorated, which may reflect the 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
  
  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 2019 (pg 27).

- Governance
  
  Governance was last measured in 2018 and Trusts/Health Boards (HB) continue to show high compliance with the existence of key policies related to care at the end of life in 2021 (pg 29).

- Workforce / specialist palliative care
  
  The results show an improvement in access to specialist palliative care, in particular, face-to-face access 8 hours a day, 7 days a week was available in 60% of hospitals/sites compared to 36% in 2019 (pg 30). The increased provision may reflect a response to the pandemic and it is not yet clear whether the change will be permanent.

- Staff confidence
  
  Staff completing the survey expressed 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, with less than 6% stating they strongly disagreed or disagreed with positive statements of confidence in these areas (pg 33).

- Staff support
  
  Training was identified as a potential area for improvement with only 49% of respondents stating they had completed training specific to end of life care within the last three years (pg 34). Although staff felt support was available from the specialist palliative care team, only 66% felt managerial support was available to help provide care at the end of life (pg 34).

- Care and culture
  
  Although 83% felt able to raise a concern about end of life care, this should be closer to 100%. Only 80% answered positively that they felt they work in a culture the prioritises care, compassion, respect and dignity, which is also a concern (pg 35).
3. Recommendations

The recommendations include those brought forward from the first and second rounds of NACEL where evidence has been collected in round three which indicate improvement is still required (recommendations 2, 3, 4 and 6). 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 Systems/Health Boards, working with providers:

1. **Quality Improvement:** Ensure the local findings and national recommendations of NACEL are used to set priorities for their Quality Improvement (QI) programme to improve palliative and end of life care across their ICS/Welsh Health Board. As part of the QI programme, the ICS/Welsh Health Board should support providers of NHS funded care at the end of life in acute and community hospitals and other care settings in developing, implementing and monitoring their local action plans. Action plans should focus on areas for improvement from the NACEL 2021 results, and learn from good practice at high performing sites, with the aim of improving results in the next round of the audit.

   [New for NACEL 2021]

Recommendations for Executive Boards:

2. **Specialist Palliative Care:** Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management. ‘Adequate’ means specialist palliative medical and nursing cover 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 Recommendation 4 & NACEL 2019 Recommendation 3 - updated for 2021]

3. **Training:** Ensure health and care staff have the appropriate training and ongoing support to develop the competence and confidence to; recognise when someone is likely to die in the next few days or hours, communicate with the dying person and people important to them as early, clearly and sensitively as possible, and continue 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 Recommendations 9 & 6 - updated 2021]

4. **Individual plan of care:** Ensure that people who are recognised to be dying have a clearly documented and accessible individual 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 individual plan of care may vary locally and may be part of standard care plans. Mechanisms to ensure the communication and coordination of this plan must be in place, especially at points of handover of care.

   [NACEL 2018 & 2019 Recommendation 11 - updated 2019]
3. Recommendations

Recommendations for Executive Boards (continued):

5. **Individual 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.

   [New for NACEL 2021]

6. **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. Assessment of needs should cover emotional, practical, spiritual, religious, and cultural needs to understand and deliver effective support.

   [NACEL 2018 & NACEL 2019 Recommendation 7 - updated 2021]
4. How the findings are presented

4.1 National results
Section 5 of this report contains results from acute and community hospitals in England and Wales taking part in round three of NACEL (2021). There is a separate report for mental health providers who also participated in NACEL round three.

4.2 Key themes and summary scores
The information in this report is presented thematically in twelve 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. Needs of families and others (QS)
7. Families’ and others’ experience of care (QS)
8. Governance (T/HB) – reintroduced in the third round of NACEL
9. Workforce/specialist palliative care (H/S)
10. Staff confidence (SRM) – new for the third round of NACEL
11. Staff support (SRM) – new for the third round of NACEL
12. Care and culture (SRM) – new for the third round of NACEL

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:

- T/HB – Trust/Health Board Organisational Level Audit
- 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 summary score has been developed and calculated for each theme for each hospital. The mean summary scores across all participants for round three can be found in the Executive Summary on pages 8 - 9. Summary scores using metrics from the case note review, only include Category 1 deaths. Appendix 16 explains the process undertaken to select the twelve key themes and their component indicators, together with an explanation of how the scores are calculated.
5.1 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 (NICE Quality Standard 144).

Recognising the possibility of imminent death: Summary

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. As in all previous rounds of NACEL, auditors were requested 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) but where life-sustaining treatments may still be being offered in parallel to care at the end of life, and Category 2, where the patient was not expected to die, but the hospital staff were “not surprised”.

- Figure 1 shows that 87% of patients audited were classified as Category 1, compared to 88% in round two.
- The median time for the whole audit sample from first recognition of imminent death to the time of death was 44 hours (n= 5,719) (41 hours in round two).
- Similar to previous rounds, 35% of people died within one day of recognition of imminent death (figure 4). This compares to 36% in round two.
- Of the Quality Survey narrative comments that related to communication (761 comments, out of a total of 2,526), the proportion referencing the likelihood of death increased by 10 percentage points between round two (27%) and round three of NACEL (37%). Of these references, 30% were positive, 25% negative and 45% of comments were neutral.
- Out of the 2,526 comments analysed, 115 (5%) related specifically to late recognition of dying, compared to 6% in round two.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

“We were allowed to be with him when the senior consultant recognised his needs as palliative and involved us with this decision.”

“I wish the consultant, looking after my husband, would have been able to tell my husband that he was going to die soon.”

“The hospital did not advise that Dad was deteriorating.”

![Figure 1: (CNR) Category of deaths audited (n = 6,823)](chart.png)

- Category 1 deaths
- Category 2 deaths
5.1 Recognising the possibility of imminent death

Figure 2: (CNR) Time from admission to recognition of dying (days) (n = 5,985)

Figure 3: (CNR) Time from recognition of dying to death (hours) up to 24 hrs (n = 2,020)

Figure 4: (CNR) Time from recognition of dying to death (days) (n = 5,983)

Figure 5: (CNR) Hours from recognition of dying to death (n = 5,720)
5.2 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).*

Communication with the dying person: Summary

Guidance emphasises the need for sensitive communication with the dying person. Findings from the Case Note Review suggest recording of conversations with the dying person has held up well in 2021, with results on all key metrics in this theme similar to 2019, pre-pandemic levels.

- New evidence from the Staff Reported Measure suggests the majority of staff who responded feel confident in their skills to communicate clearly and sensitively to dying patients and those important to them (86% agreeing, figure 59, Section 6.1).
- However, from the Quality Survey, the proportion strongly disagreeing or disagreeing with the statement ‘staff communicated sensitively with the dying person’ increased from 7% (2019) to 11% (2021).
- Of the Quality Survey narrative comments that related to communication, there was a reduction in comments made regarding ‘communication with the dying person’, between rounds two (32%) and three (4%), which may point to the restrictions that were in place due to the pandemic, making it harder for those close to the dying person to understand what communication had been undertaken with the dying person. 82% of respondents to the Quality Survey reported that there had been some form of visiting restrictions in place at the time of the patient dying.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

  - “Under very difficult circumstances I felt all staff were professional and communicated in a caring way.”
  - “I loved the way the nurses spoke to my mum even though she couldn’t hear them.”
  - “He had a lot of questions about his health while he was there and felt he wasn’t listened to and his questions not answered.”

### Table 1

<table>
<thead>
<tr>
<th>Documented evidence (Category 1 only):</th>
<th>Yes or a reason why not recorded</th>
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</thead>
<tbody>
<tr>
<td>2021</td>
<td>2019</td>
</tr>
<tr>
<td>Possibility that the patient may die had been discussed with the patient</td>
<td>90%</td>
</tr>
<tr>
<td>Patient was involved in discussing the individualised plan of care</td>
<td>95%</td>
</tr>
<tr>
<td>Possibility of drowsiness as a result of prescribed medications discussed with the patient</td>
<td>73%</td>
</tr>
<tr>
<td>Risks and benefits of hydration options discussed with the patient</td>
<td>81%</td>
</tr>
<tr>
<td>Risks and benefits of nutrition options discussed with the patient</td>
<td>81%</td>
</tr>
</tbody>
</table>

### Figure 6: Range of hospital mean summary scores: Communication with the dying person (n submissions = 158) (n CNR = 5,005)

![Figure 6: Range of hospital mean summary scores: Communication with the dying person](image-url)
5.2 Communication with the dying person

**Figure 7:** (CNR) Possibility that the patient may die had been discussed with the patient (Category 2 not asked)

- All deaths (n = 4,351)
  - Yes: 25%
  - No but reason recorded: 70%
  - No & no reason recorded: 5%

- Category 1 (n = 4,269)
  - Yes: 69%
  - No but reason recorded: 26%
  - No & no reason recorded: 5%

- Category 2 (n = 82)
  - Yes: 69%
  - No but reason recorded: 27%
  - No & no reason recorded: 1%

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

**Figure 8:** (CNR) Patient was involved in discussing the individualised plan of care

- All deaths (n = 4,351)
  - Yes: 25%
  - No but reason recorded: 70%
  - No & no reason recorded: 5%

- Category 1 (n = 4,269)
  - Yes: 70%
  - No but reason recorded: 5%
  - No & no reason recorded: 25%

- Category 2 (n = 82)
  - Yes: 59%
  - No but reason recorded: 35%
  - No & no reason recorded: 6%

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

**Figure 9:** (CNR) Possibility of drowsiness as a result of prescribed medications discussed with the patient

- All deaths (n = 6,739)
  - Yes: 4%
  - No but reason recorded/N/A: 5%
  - No & no reason recorded: 26%

- Category 1 (n = 5,897)
  - Yes: 59%
  - No but reason recorded/N/A: 27%
  - No & no reason recorded: 1%

- Category 2 (n = 842)
  - Yes: 75%
  - No but reason recorded/N/A: 24%
  - No & no reason recorded: 1%

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

**Figure 10:** (CNR) Risks and benefits of hydration and nutrition options discussed with the patient (Category 2 not asked)

- Hydration - Category 1 (n = 5,871)
  - Yes: 71%
  - No but reason recorded/N/A: 19%
  - No & no reason recorded: 10%

- Nutrition - Category 1 (n = 5,873)
  - Yes: 72%
  - No but reason recorded/N/A: 9%
  - No & no reason recorded: 19%

- (N.B. Totals may not equal 100% due to rounding)
5.3 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).

Communication with families and others: Summary

Open and honest communication with families and others close to the dying person is crucially important to high quality end of life care. Findings from the Case Note Review suggest little change in 2021 when compared to 2019, with continued high compliance on recording of conversations about the possibility that the person might die and on the individualised plan of care.

- As in 2019, discussions on hydration and nutrition were documented, or a reason why not recorded, in only around half of cases.
- 79% of respondents to the Quality Survey strongly agreed or agreed that they had been communicated with by staff in a sensitive way in round three compared to 84% in round two.
- Of the Quality Survey narrative comments that related to communication, ‘communication with families and others’ accounted for 56% (427/761), similar to round two. Of these references, 42% were positive, with 24% negative and 34% deemed as neutral.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

“We received excellent treatment and everybody spoke to us with sensitivity and kept us informed every step of the way.”

“The communications we received just before she died were confusing and did not suggest she was likely to die imminently.”

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Documented evidence (Category 1 only):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes or reason why not recorded</td>
</tr>
<tr>
<td></td>
<td>2021</td>
</tr>
<tr>
<td>Possibility that the patient may die had been discussed with families and others</td>
<td>98%</td>
</tr>
<tr>
<td>Families and others were notified that the patient was about to die</td>
<td>90%</td>
</tr>
<tr>
<td>Families and others were involved in discussing the individualised plan of care</td>
<td>94%</td>
</tr>
<tr>
<td>Possibility of drowsiness as a result of prescribed medications discussed with families and others</td>
<td>36%</td>
</tr>
<tr>
<td>Risks and benefits of hydration options discussed with the families and others</td>
<td>52%</td>
</tr>
<tr>
<td>Risks and benefits of nutrition options discussed with the families and others</td>
<td>49%</td>
</tr>
</tbody>
</table>

Figure 11: Range of hospital mean summary scores: Communication with families and others (n submissions = 157) (n CNR = 5,012)
5.3 Communication with families and others

**Figure 12:** (CNR) Possibility that the patient may die had been discussed with families and others (Category 2 not asked)

- Yes: 96%
- No but reason recorded: 2%
- No & no reason recorded: 2%

Category 1 (n = 5,882)

**Figure 13:** (CNR) Families and others were notified that the patient was about to die (Category 2 not asked)

- Yes: 69%
- No but reason recorded: 21%
- No & no reason recorded: 10%

Category 1 (n = 5,871)

**Figure 14:** (CNR) Families and others were involved in discussing the individualised plan of care

- Yes: 91%
- No but reason recorded: 3%
- No & no reason recorded: 6%

All deaths (n = 4,351) - Category 1 (n = 4,269) - Category 2 (n = 82)

**Figure 15:** (CNR) Possibility of drowsiness as a result of prescribed medications discussed with families and others

- Yes: 14%
- No but reason recorded/N/A: 25%
- No & no reason recorded: 61%

All deaths (n = 6,751) - Category 1 (n = 5,904) - Category 2 (n = 847)

**Figure 16:** (CNR) Risks and benefits of hydration and nutrition options discussed with the families and others (Category 2 not asked)

- Hydration - Category 1 (n = 5,865)
  - Yes: 35%
  - No but reason recorded/N/A: 17%
  - No & no reason recorded: 48%

- Nutrition - Category 1 (n = 5,875)
  - Yes: 30%
  - No but reason recorded/N/A: 20%
  - No & no reason recorded: 51%

(N.B. Totals may not equal 100% due to rounding)
### 5.4 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 (*One Chance To Get It Right, 2014*).

#### Involvement in decision making: Summary

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*. This theme was last measured in the first round of NACEL where the results showed good compliance, and hence a decision to remove it from round two was made, but the theme was reintroduced into the third round to provide continued assurance.

- Findings from the Case Note Review (figures 18 to 23) suggest continued strong compliance.
- However, from the Quality Survey, in 2021, 23% of people felt they would like to be more involved in the person’s care compared to 19% in 2019.
- Further, 32% of respondents to the Quality Survey 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, with 6% stating that the person who died would like to have been more involved. 45% of respondents felt the person who was dying was not able to be involved in such decisions.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

  - “He talked to me about all treatment and withdrawal of it so that I was involved in all decisions about her final days.”
  - “It was very difficult to get a clear overview of her condition and treatment plan.”

#### Table 3: Documented evidence (Category 1 only):

<table>
<thead>
<tr>
<th>Documented evidence (Category 1 only):</th>
<th>Yes or reason why not recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extent to which the patient wished to be involved in decisions about their care</td>
<td>2021 86% 2018 -</td>
</tr>
<tr>
<td>Dying person had their capacity assessed to be involved in their end of life care planning</td>
<td>2021 91% 2018 -</td>
</tr>
<tr>
<td>Discussion with the patient by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support</td>
<td>2021 94% 2018 93%</td>
</tr>
<tr>
<td>Discussion with families and others by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support</td>
<td>2021 100% 2018 94%</td>
</tr>
<tr>
<td>Discussion regarding CPR was undertaken with the patient by a senior clinician</td>
<td>2021 99% 2018 93%</td>
</tr>
<tr>
<td>Discussion regarding CPR was undertaken with families and others by a senior clinician</td>
<td>2021 100% 2018 89%</td>
</tr>
</tbody>
</table>

#### Figure 17: Range of hospital mean summary scores: Involvement in decision making (n submissions = 164) (n CNR = 5,297)
5.4 Involvement in decision making

**Figure 18:** (CNR) Documented evidence about the extent to which the patient wished to be involved in decisions about their care.

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,787)</th>
<th>Category 1 (n = 5,918)</th>
<th>Category 2 (n = 869)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25%</td>
<td>59%</td>
<td>61%</td>
</tr>
<tr>
<td>No but reason recorded</td>
<td>16%</td>
<td>14%</td>
<td>25%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>26%</td>
<td>43%</td>
<td>32%</td>
</tr>
</tbody>
</table>

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

**Figure 19:** (CNR) Documented evidence the dying person had their capacity assessed to be involved in their end of life care planning.

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,781)</th>
<th>Category 1 (n = 5,917)</th>
<th>Category 2 (n = 864)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>30%</td>
<td>59%</td>
<td>60%</td>
</tr>
<tr>
<td>No but reason recorded</td>
<td>11%</td>
<td>9%</td>
<td>24%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>31%</td>
<td>55%</td>
<td>21%</td>
</tr>
</tbody>
</table>

(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 continuing or stopping life-sustaining treatment offering organ support.

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,795)</th>
<th>Category 1 (n = 5,919)</th>
<th>Category 2 (n = 876)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7%</td>
<td>6%</td>
<td>16%</td>
</tr>
<tr>
<td>No but reason recorded/N/A</td>
<td>74%</td>
<td>75%</td>
<td>69%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>19%</td>
<td>19%</td>
<td>15%</td>
</tr>
</tbody>
</table>

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

**Figure 21:** (CNR) Documented evidence of a discussion with families and others by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support.

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,797)</th>
<th>Category 1 (n = 5,920)</th>
<th>Category 2 (n = 877)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>51%</td>
<td>48%</td>
<td>69%</td>
</tr>
<tr>
<td>No but reason recorded/N/A</td>
<td>49%</td>
<td>52%</td>
<td>31%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>19%</td>
<td>19%</td>
<td>15%</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,791)</th>
<th>Category 1 (n = 5,920)</th>
<th>Category 2 (n = 871)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>58%</td>
<td>59%</td>
<td>56%</td>
</tr>
<tr>
<td>No but reason recorded/N/A</td>
<td>41%</td>
<td>41%</td>
<td>42%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>41%</td>
<td>41%</td>
<td>42%</td>
</tr>
</tbody>
</table>

(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.

<table>
<thead>
<tr>
<th></th>
<th>All deaths (n = 6,793)</th>
<th>Category 1 (n = 5,923)</th>
<th>Category 2 (n = 870)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>30%</td>
<td>28%</td>
<td>44%</td>
</tr>
<tr>
<td>No but reason recorded/N/A</td>
<td>70%</td>
<td>72%</td>
<td>56%</td>
</tr>
<tr>
<td>No &amp; no reason recorded</td>
<td>41%</td>
<td>41%</td>
<td>42%</td>
</tr>
</tbody>
</table>

(N.B. Totals may not equal 100% due to rounding)
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 (Statement 3, NICE 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).

Individualised plan of care: Summary

Every dying person should have an individualised end of life care plan. The dying person and those close to them should have the opportunity to discuss the plan, which is covered in sections 5.2 and 5.3.

- Third round findings from the Case Note Review showed similar results to 2019 for the existence of an individualised plan of care, 73% (figure 25), suggesting there is still room for improvement.
- The documentation of the benefit of starting, stopping or continuing the interventions, review of hydration and nutrition status, and evidence of clinical needs assessment, was similar or slightly improved in most areas.
- Documented evidence of an assessment of wider needs such as emotional/psychological, spiritual/religious/cultural and social/practical shows a reduction since 2019, which may be a result of continuing pressures of the Covid-19 pandemic on services during 2021.
- With reference to anticipatory medications, for Category 1 deaths only, there was documented evidence that anticipatory medications were prescribed and administered in 71% of cases, and prescribed but not used in 18% of cases. This is in line with the 2019 reporting.
- For all Category 1 deaths, the preferred place to die was documented in just over a quarter of cases (30%).
- In round three, 348 comments (out of a total of 2,526 comments) from Quality Survey narrative responses related to care of the dying person, of which 15% referenced care planning specifically. Of all references to care of the dying person, 68% were positive, 18% negative and 14% neutral. Pain relief for the dying person was mentioned in 32% of comments relating to care of the dying person, 19% of comments referenced spiritual care, 12% hydration and nutrition and 6% referenced CPR or DNACPR.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"The nursing staff provided all of the care, both medical and personal, that he needed, always ensuring that he was comfortable and not in pain."

"She was clearly unable to eat or drink by herself, I did not get the impression they were making arrangements for her to gain nutrition other than regular fluids."

"Even though my father was in the last days of his life, a junior nurse gave him a shave, as he hadn’t had one for a number of days. I bless her for that thoughtfulness."

"In the last few days, I kept having to ask for more pain relief for my husband."
5.5 Individualised plan of care

Table 4

<table>
<thead>
<tr>
<th>Documented evidence (Category 1 only):</th>
<th>2021</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient had an individualised plan of care</td>
<td>73%</td>
<td>71%</td>
</tr>
<tr>
<td>Patient’s individualised plan of care was reviewed regularly * includes N/A/Patient died before review was necessary</td>
<td>98%</td>
<td>97%</td>
</tr>
<tr>
<td>Preferred place of death documented as indicated by the patient</td>
<td>30%</td>
<td>29%</td>
</tr>
<tr>
<td>The patient’s hydration status was assessed daily once the dying phase was recognised</td>
<td>78%</td>
<td>77%</td>
</tr>
<tr>
<td>The patient’s nutrition status was reviewed regularly once the dying phase was recognised</td>
<td>72%</td>
<td>68%</td>
</tr>
</tbody>
</table>

Figure 25: (CNR) Patient who was dying had an individualised plan of care

Figure 26: (CNR) Patient’s individualised plan of care was reviewed regularly

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)

Table 4

<table>
<thead>
<tr>
<th>Documented evidence (Category 1 only):</th>
<th>2021</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient had an individualised plan of care</td>
<td>73%</td>
<td>71%</td>
</tr>
<tr>
<td>Patient’s individualised plan of care was reviewed regularly * includes N/A/Patient died before review was necessary</td>
<td>98%</td>
<td>97%</td>
</tr>
<tr>
<td>Preferred place of death documented as indicated by the patient</td>
<td>30%</td>
<td>29%</td>
</tr>
<tr>
<td>The patient’s hydration status was assessed daily once the dying phase was recognised</td>
<td>78%</td>
<td>77%</td>
</tr>
<tr>
<td>The patient’s nutrition status was reviewed regularly once the dying phase was recognised</td>
<td>72%</td>
<td>68%</td>
</tr>
</tbody>
</table>

Table 4

<table>
<thead>
<tr>
<th>Documented evidence (Category 1 only):</th>
<th>2021</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient had an individualised plan of care</td>
<td>73%</td>
<td>71%</td>
</tr>
<tr>
<td>Patient’s individualised plan of care was reviewed regularly * includes N/A/Patient died before review was necessary</td>
<td>98%</td>
<td>97%</td>
</tr>
<tr>
<td>Preferred place of death documented as indicated by the patient</td>
<td>30%</td>
<td>29%</td>
</tr>
<tr>
<td>The patient’s hydration status was assessed daily once the dying phase was recognised</td>
<td>78%</td>
<td>77%</td>
</tr>
<tr>
<td>The patient’s nutrition status was reviewed regularly once the dying phase was recognised</td>
<td>72%</td>
<td>68%</td>
</tr>
</tbody>
</table>
5.5 Individualised plan of care

Figure 28: (CNR) The patient’s hydration status was assessed daily once the dying phase was recognised (Category 2 not asked) (n = 5,761)

Figure 29: The patient’s nutrition status was reviewed regularly once the dying phase was recognised (Category 2 not asked) (n = 5,743)

Figure 30: (CNR) Documented evidence of an assessment of the following needs (Category 1 only):

- Pressure areas (n = 5,924) 92% Yes, 7% No, 2% N/A
- Bladder function (n = 5,915) 89% Yes, 9% No, 2% N/A
- Hygiene requirements (n = 5,917) 88% Yes, 9% No, 3% N/A
- Pain (n = 5,922) 87% Yes, 10% No, 3% N/A
- Bowel function (n = 5,913) 85% Yes, 13% No, 3% N/A
- Dyspnoea/breathing difficulty (n = 5,921) 83% Yes, 12% No, 5% N/A
- Agitation/delirium (n = 5,920) 82% Yes, 13% No, 5% N/A
- Mouth care (n = 5,908) 82% Yes, 15% No, 3% N/A
- Noisy breathing/death rattle (n = 5,907) 70% Yes, 20% No, 10% N/A
- Nausea/vomiting (n = 5,916) 66% Yes, 21% No, 13% N/A

Figure 31: (CNR) Documented evidence of an assessment of the following needs (Category 1 only):

- Anxiety/distress (n = 5,928) 58% Yes, 34% No but reason recorded, 8% N/A
- Social/practical needs (n = 5,915) 41% Yes, 46% No but reason recorded, 13% N/A
- Spiritual/religious/cultural needs (n = 5,920) 39% Yes, 39% No but reason recorded, 21% N/A
- Emotional/psychological needs (n = 5,924) 35% Yes, 52% No but reason recorded, 13% N/A

(N.B. Totals may not equal 100% due to rounding)
### 5.5 Individualised plan of care

#### Figure 32: (CNR) Documented evidence that anticipatory medication was prescribed for symptoms likely to occur in the last days of life (Category 2 not asked) (n = 5,880)

<table>
<thead>
<tr>
<th>Prescription Status</th>
<th>Yes, anticipatory medicines prescribed and administered</th>
<th>Yes, anticipatory medicines prescribed but not used</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory Medicines Used</td>
<td>71%</td>
<td>18%</td>
<td>9%</td>
<td>2%</td>
</tr>
</tbody>
</table>

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

#### Figure 33: (CNR) Where anticipatory medicines prescribed, documented evidence that an indication for use of the medication was included within the prescription (Category 2 not asked) (n = 5,235)

<table>
<thead>
<tr>
<th>Medication Coverage</th>
<th>Yes for all medications</th>
<th>Yes for some medications</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory Medicines Used</td>
<td>74%</td>
<td>12%</td>
<td>13%</td>
</tr>
</tbody>
</table>

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

#### Figure 34: (CNR) Where anticipatory medicines prescribed, documented evidence that a discussion about the use of anticipatory medication was undertaken with (Category 2 not asked):

<table>
<thead>
<tr>
<th>Discussion Undertaken</th>
<th>Yes</th>
<th>No but reason recorded</th>
<th>No &amp; no reason recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory Medicines Used</td>
<td>15%</td>
<td>62%</td>
<td>72%</td>
</tr>
<tr>
<td>Patient (n = 5,250)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nominated person(s) (n = 5,242)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

#### Figure 35: (CNR) Preferred place of death documented as indicated by the patient

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>All deaths (n = 6,665)</th>
<th>Category 1 (n = 5,814)</th>
<th>Category 2 (n = 851)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred</td>
<td>28%</td>
<td>30%</td>
<td>12%</td>
</tr>
<tr>
<td>Not preferred</td>
<td>72%</td>
<td>70%</td>
<td>88%</td>
</tr>
</tbody>
</table>

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

#### Figure 36: (QS) In the circumstances, the hospital was the right place for the person to die (n = 3,099)

<table>
<thead>
<tr>
<th>Agreement Level</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A/Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>46%</td>
<td>31%</td>
<td>8%</td>
<td>5%</td>
<td>8%</td>
<td>3%</td>
</tr>
</tbody>
</table>

(N.B. Totals may not equal 100% due to rounding)
5.6 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).

Needs of families and others: Summary

Families and others important to the dying person also have their own care needs when somebody close to them is dying. Results from the Quality Survey are used to measure performance on this theme.

- The needs of the family were identified as an improvement area in both round one and round two of the audit.
- Comparison with 2019 findings (table 5) suggests performance has further deteriorated, which may reflect the 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. 82% of respondents to the Quality Survey reported that there were restrictions on visiting during the period the patient died, which is likely to have impacted on families’ and others’ needs being met.
- ‘Care needs of the family’ accounted for 258 comments out of the 2,526 comments analysed from the Quality Survey narrative, of which 70% were positive, 17% negative and 13% neutral.
- Of the comments on ‘care needs of the family’, 38% related to support provided to families and others after the death compared to 16% in round two. The proportion referencing practicalities such as a place for relatives to stay overnight and parking reduced significantly, again reflecting restricted visiting.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

“The hospital Chaplain provided great support to all the family and myself at a very difficult time.”

“I personally felt very supported during my time in the hospital, but not at all after I came home.”

“Spiritual and cultural support was not offered.”

Table 5

<table>
<thead>
<tr>
<th>Families and others:</th>
<th>Strongly agree/Agree</th>
<th>Strongly disagree/Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asked about their needs</td>
<td>2021: 57% 2019: 58%</td>
<td>2021: 24% 2019: 20%</td>
</tr>
<tr>
<td>Given enough emotional help and support by staff</td>
<td>2021: 60% 2019: 65%</td>
<td>2021: 20% 2019: 16%</td>
</tr>
<tr>
<td>Given enough practical support</td>
<td>2021: 51% 2019: 62%</td>
<td>2021: 20% 2019: 16%</td>
</tr>
<tr>
<td>Given enough spiritual/religious/cultural support</td>
<td>2021: 32% 2019: 32%</td>
<td>2021: 20% 2019: 12%</td>
</tr>
<tr>
<td>Kept well informed</td>
<td>2021: 64% 2019: 69%</td>
<td>2021: 25% 2019: 20%</td>
</tr>
</tbody>
</table>

![Figure 37: Range of hospital mean summary scores: Needs of families and others (n submissions = 40) (n QS = 2,320)](image-url)
5.6 Needs of families and others

**Figure 38**: (QS) The families and others were asked about their needs (n = 3,093)

- Strongly agree: 30%
- Agree: 27%
- Neither agree nor disagree: 12%
- Disagree: 14%
- Strongly disagree: 10%
- Not applicable/Not sure: 8%

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

**Figure 39**: (QS) The families and others were given enough emotional help and support by staff (n = 3,090)

- Strongly agree: 32%
- Agree: 28%
- Neither agree nor disagree: 14%
- Disagree: 10%
- Strongly disagree: 10%
- Not applicable/Not sure: 5%

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

**Figure 40**: (QS) The families and others were given enough practical support (n = 3,094)

- Strongly agree: 27%
- Agree: 24%
- Neither agree nor disagree: 13%
- Disagree: 11%
- Strongly disagree: 9%
- Not applicable/Not sure: 15%

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

**Figure 41**: (QS) The families and others were given enough spiritual/religious/cultural support (n = 3,089)

- Strongly agree: 33%
- Agree: 17%
- Neither agree nor disagree: 16%
- Disagree: 11%
- Strongly disagree: 9%
- Not applicable/Not sure: 3%

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

**Figure 42**: (QS) Families and others were kept well informed and had enough opportunity to discuss the person’s condition and treatment with staff (n = 3,089)

- Strongly agree: 35%
- Agree: 29%
- Neither agree nor disagree: 8%
- Disagree: 12%
- Strongly disagree: 13%
- Not applicable/Not sure: 3%

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

**Figure 43**: (QS) Families and others were involved in decisions about the person’s care as much as they wanted to be (n = 3,092)

- Involved a much as they wanted to be: 66%
- Would have liked to be more involved: 23%
- Would have liked to be less involved: 0%
- Not able to be involved: 7%
- Not sure: 4%

(N.B. Totals may not equal 100% due to rounding)
Families’ and others’ experience of care: Summary

Evidence on the experience of care from the Quality Survey is utilised in this theme.

- Families and others report lower scores for sensitive communication with both themselves and with the dying person, than in 2019 (figures 45 - 46).
- 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 in 2019 (figures 47 - 48).
- The results may reflect the prioritisation of clinical needs over wider emotional, spiritual and social needs during the pandemic, as suggested in the results for the individualised plan of care (section 5.5). As noted earlier, visiting was still restricted during the audit period in most Trusts/HBs, which is likely to have had a negative impact on the experience of families and others close to the dying person.
- Overall analysis of comments from the Quality Survey responses illustrates that comments were mainly positive (62%) with many respondents mentioning the particular circumstances of the pandemic impacting upon care. 27% of all comments analysed were negative and 11% neutral.
- Examples of comments from those close to the dying person via the Quality Survey can be found below:

"I cannot speak highly enough of the care and compassion both he and I received from all the staff on his ward."

"The care was insufficient due to the fact that my dad was exposed to the Covid virus while being treated for a water infection and dehydration."

"ALL of the staff were so kind and considerate from the cleaners, ward clerk, healthcare assistants to the ward sisters and consultants and although they were clearly busy with other patients, would always try and help with my/the family's queries and were very empathetic."

"She did not receive the care she needed. She was not treated with dignity."

<table>
<thead>
<tr>
<th>Table 6</th>
<th>Strongly Agree/Agree</th>
<th>Strongly disagree/Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families and others:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt that staff looking after the person communicated sensitively with them</td>
<td>68%</td>
<td>79%</td>
</tr>
<tr>
<td>Felt they were communicated to by staff in a sensitive way</td>
<td>79%</td>
<td>84%</td>
</tr>
<tr>
<td>Rating of care and support provided to the person who died</td>
<td>Outstanding/Excellent/Good</td>
<td>Fair/Poor</td>
</tr>
<tr>
<td>Rating of care and support provided to families and other</td>
<td>74%</td>
<td>80%</td>
</tr>
</tbody>
</table>
5.7 Families’ and others’ experience of care

**Figure 44**: Range of hospital mean summary scores: Families’ and others’ experience of care (n submissions = 42) (n QS = 2,402)

**Figure 45**: (QS) The families and others felt that staff looking after the person communicated sensitively with them (n = 3,102)

**Figure 46**: (QS) The families and others were communicated to by staff in a sensitive way (n = 3,100)

**Figure 47**: (QS) Rating of care and support provided to the person who died (n = 3,098)

**Figure 48**: (QS) Rating of care and support provided to families and other (n = 3,098)

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

**Organisational leadership and governance**: Each [organisation] needs to have leadership that is committed to ensuring that those people to whom it provides services who are dying receive high-quality, compassionate care, focused on the needs of the dying person and their family (*One Chance To Get It Right*, 2014).

**Education, training and professional development**: Individual providers of health and care are responsible for ensuring their staff have the experience and competence they need to do their jobs well. This includes making time and other resources available for staff to undergo professional development (*One Chance To Get It Right*, 2014).

**Governance: Summary**

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. This theme has been reintroduced for round three of NACEL. The theme was not included in round two, as high compliance was reported in round one.

Evidence on governance arrangements submitted for the Organisational Level Audit (Trust/HB audit) is utilised.

- As in round one, Trusts/HBs show high compliance with the existing of key policies related to care at the end of life (table 7).

<table>
<thead>
<tr>
<th>Table 7</th>
<th>Yes</th>
<th>2021</th>
<th>2018</th>
</tr>
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<tbody>
<tr>
<td>Trust/HB:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>An identified member of the Trust/HB board with a responsibility for end of life care</td>
<td>97% (n = 167)</td>
<td>94%</td>
<td></td>
</tr>
<tr>
<td>Guidelines for how it respond to and learns from, deaths of patients who die under its management</td>
<td>99% (n = 169)</td>
<td>98%</td>
<td></td>
</tr>
<tr>
<td>Specific care arrangements to enable rapid discharge home to die, if this is the person’s preference</td>
<td>94% (n = 169)</td>
<td>92%</td>
<td></td>
</tr>
<tr>
<td>A care plan to support the Five Priorities for Care of the Dying Person</td>
<td>100% (n = 169)</td>
<td>97%</td>
<td></td>
</tr>
</tbody>
</table>
5.9 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 (*One Chance To Get It Right, 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*).

Workforce/specialist palliative care: Summary

National guidance reinforces the need for providers to work with commissioners to ensure access to an adequately resourced specialist palliative care (SPC) workforce. The summary score utilises evidence on Workforce/specialist palliative care submitted for the Organisational Level Audit (Hospital/Site audit).

- The results show an improvement in access to specialist palliative care, in particular, face-to-face access 8 hours a day, 7 days a week, was available in 60% of hospitals/sites compared to 36% in 2019 (figure 53). The increased provision may reflect a response to the pandemic and it is not yet clear whether the change will be permanent.
- On average, across all participating sites, the inclusion of end of life care training in wider training programmes is at or above 2019 levels.
- ‘Staffing’ accounted for 132 comments out of the 2,526 comments analysed from the Quality Survey narrative, of which 71% were positive, 16% negative and 13% neutral.
- Of the comments on staffing, perception of staff shortages accounted for 43% in round three, compared to 12% in round two. Delays in accessing the specialist palliative care team was a further theme from the Quality Survey narrative responses, with this being cited in 20% of the comments on staffing in round three, compared to 5% in round two.

<table>
<thead>
<tr>
<th>Table 8</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Does the hospital/site have:</strong></td>
<td>2021</td>
<td>2019</td>
</tr>
<tr>
<td>Access to a Specialist Palliative Care service</td>
<td>99%</td>
<td>99%</td>
</tr>
<tr>
<td>Telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week</td>
<td>92%</td>
<td>86%</td>
</tr>
<tr>
<td>Face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week</td>
<td>60%</td>
<td>36%</td>
</tr>
<tr>
<td><strong>End of life care training included in:</strong></td>
<td>66%</td>
<td>62%</td>
</tr>
<tr>
<td>Induction Programme</td>
<td>50%</td>
<td>46%</td>
</tr>
<tr>
<td>Communication skills</td>
<td>77%</td>
<td>74%</td>
</tr>
<tr>
<td>Other training</td>
<td>96%</td>
<td>95%</td>
</tr>
</tbody>
</table>
5.9 Workforce/specialist palliative care

**Figure 50:** Hospital mean summary scores: Workforce/specialist palliative care (n submissions = 235)

Range: 2.5 - 10.0

**Figure 51:** Access to a Specialist Palliative Care service (n = 239)

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

**Figure 52:** Is the telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week? (n = 236)

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

**Figure 53:** (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 = 236)

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

**Figure 54:** (H/S) Training available

(N.B. Totals may not equal 100% due to rounding)
6. Key themes from the Staff Reported Measure

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 summary scores against the three themes of **staff confidence**, **staff support** and **care and culture** are introduced in this section. See Appendix 5 for an explanation of how the SRM was developed and the methodology for the three summary scores. In reviewing the results, it should be noted that the group completing the survey were self-selected. 92% of those responded were clinical staff. Further detail on respondent demographics is included at Appendix 20. Figures 55, 56, and 57 show the range of summary scores for the hospitals where staff responded to the SRM.

**Staff confidence:**
- Staff completing the survey expressed confidence in recognition of dying, communication, responding to 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, with less than 7% stating they strongly disagreed or disagreed with positive statements of confidence in these areas. Note this reflects reported confidence rather than capability.
- Weaker areas were knowing how to respond to requests to die out of the hospital setting (12% strongly disagreed/disagreed, 11% not sure) (figure 62) and ability to discuss hydration options with dying patients and those important to them (9% strongly disagreed/disagreed, 10% not sure) (figure 63).

**Staff support:**
- As in section 5.9, training was identified as a potential area for improvement with only 49% of respondents stating they had completed training specific to end of life care within the last three years (figure 70) and 39% stating they had received appropriate and responsive training during the Covid-19 pandemic (figure 68). Although staff felt support was available from the specialist palliative care team, only 66% felt managerial support was available to help provide care at the end of life (figure 71).

**Staff care and culture:**
- Although 83% felt able to raise a concern about end of life care, this should be closer to 100% (figure 72). Only 80% answered positively that they felt they work in a culture that prioritises care, compassion, respect and dignity, which is also a concern (figure 73). There is also potential to improve engagement with review of deaths, with just 54% agreeing deaths are actively reviewed and action plans implemented to improve end of life care (figure 77).
6.1 Staff confidence

Figure 58: (SRM) Staff feel confident they can recognise when a patient might be dying imminently (within hours to days) (n = 10,875)

Figure 59: (SRM) Staff feel confident in their skills to communicate clearly and sensitively to dying patients and those important to them (n = 10,873)

Figure 60: (SRM) Staff 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 (n = 10,833)

Figure 61: (SRM) Staff know how to access specialist palliative care advice, if required, when addressing specific end of life care needs for dying patients (n = 10,837)

Figure 62: (SRM) Staff know how to respond to requests to die outside of the hospital setting from dying people and/or those important to them (n = 10,835)

Figure 63: (SRM) Staff feel confident in their ability to discuss hydration options with dying patients and those important to them (n = 10,814)

Figure 64: (SRM) Staff feel confident in assessing and managing patient pain and physical symptoms at the end of life (n = 10,809)

Figure 65: (SRM) Staff feel confident to respond to the needs of the dying person

Figure 66: (SRM) Staff feel confident to respond to the needs of those important to the dying person
6.2 Staff support

Figure 67: (SRM) Staff felt supported to deliver end of life care during the COVID-19 pandemic (n = 10,815)

Figure 68: (SRM) Staff received appropriate and responsive training to deliver end of life care during the COVID-19 pandemic (n = 10,831)

Figure 69: (SRM) Staff felt supported by the specialist palliative care team that the hospital has access to, when addressing specific end of life care needs for dying patients (n = 10,830)

Figure 70: (SRM) Staff have completed training specific to end of life care within the last three years (n = 10,844)

Figure 71: (SRM) Managerial support is available to help provide care at the end of life (n = 10,825)

(N.B. Totals may not equal 100% due to rounding)
6.3 Care and culture

**Figure 72:** (SRM) Staff feel able to raise a concern about end of life care within their hospital if they needed to (n = 10,811)

- **Strongly agree:** 33%
- **Agree:** 50%
- **Neither agree nor disagree:** 8%
- **Disagree:** 4%
- **Strongly disagree:** 1%
- **Not applicable/Not sure:** 3%

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

**Figure 73:** (SRM) Staff feel they work in a culture that prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and those important to them (n = 10,788)

- **Strongly agree:** 30%
- **Agree:** 50%
- **Neither agree nor disagree:** 11%
- **Disagree:** 4%
- **Strongly disagree:** 1%
- **Not applicable/Not sure:** 3%

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

**Figure 74:** (SRM) Staff work in partnership with the dying person and those important to them in planning and making decisions about their health, treatment and end of life care (n = 10,821)

- **Strongly agree:** 29%
- **Agree:** 54%
- **Neither agree nor disagree:** 9%
- **Disagree:** 3%
- **Strongly disagree:** 1%
- **Not applicable/Not sure:** 6%

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

**Figure 75:** (SRM) Priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and those important to them (n = 10,832)

- **Strongly agree:** 26%
- **Agree:** 44%
- **Neither agree nor disagree:** 13%
- **Disagree:** 9%
- **Strongly disagree:** 3%
- **Not applicable/Not sure:** 5%

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

**Figure 76:** (SRM) Staff actively share information with each other about the individuals’ end of life care needs (n = 10,802)

- **Strongly agree:** 27%
- **Agree:** 53%
- **Neither agree nor disagree:** 11%
- **Disagree:** 4%
- **Strongly disagree:** 1%
- **Not applicable/Not sure:** 5%

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

**Figure 77:** (SRM) Deaths are actively reviewed, and action plans are implemented to improve end of life care (n = 10,828)

- **Strongly agree:** 17%
- **Agree:** 37%
- **Neither agree nor disagree:** 19%
- **Disagree:** 8%
- **Strongly disagree:** 2%
- **Not applicable/Not sure:** 16%

(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 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 third round of the audit. Their feedback will be invaluable 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 newly instituted NACEL Staff Reported Measure (SRM), which has given the team real insight into staff confidence and support to deliver end of life care, during an unparalleled 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, particularly when still being faced with delivering acute care to those suffering from Covid-19, as well as all other patients in hospital. 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.

Particular thanks to Professor Bee Wee CBE, for her unrivalled support and assistance with all aspects of the audit, whilst delivering national leadership to the palliative care community.