

National Audit of Care at the End of Life

**Second round of the audit (2019/20)
report
England and Wales**



Acknowledgements

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- Cardiff and Vale University Health Board
- Cwm Taf Morgannwg University Health Board
- King's College Hospital NHS Foundation Trust
- Norfolk Community Health and Care NHS Trust
- Western Health and Social Care Trust



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- Midlands Partnership NHS Foundation Trust
- North West Anglia NHS Foundation Trust
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- Oxford University Hospitals NHS Foundation Trust
- University Hospitals of North Midlands
- Wirral University Teaching Hospital NHS Foundation Trust

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- Betsi Cadwaladr University Health Board
- Cwm Taf Morgannwg University Health Board
- Essex Partnership University NHS Foundation Trust
- Hertfordshire Partnership University NHS Foundation Trust
- Mersey Care NHS Foundation Trust
- Swansea Bay University Health Board

This report presents data from the 2019/20 financial year, it is important to note that the audit and analysis took place before the COVID-19 pandemic and therefore does not reflect any data recorded during this time. It is acknowledged that future rounds of the audit will need to review ways in which end of life services were delivered during the pandemic and capture additional data in line with guidance published at this time.



Table of contents

Foreword.....	6
Executive summary.....	8
Recommendations.....	14
1. Audit background and development	
1.1 National policy context.....	17
1.2 Audit background and governance.....	18
1.3 Audit objectives.....	18
1.4 Audit standards.....	19
1.5 Audit structure and scope.....	20
2. Methodology	
2.1 Eligibility, recruitment and registration.....	22
2.2 Data collection.....	22
2.3 Data validation and cleansing.....	23
2.4 Reliability analysis.....	23
2.5 Management of Outliers Policy.....	23
2.6 Cause for Concern Policy.....	24
2.7 Quality Improvement Plan.....	24
3. Participation	25
4. How the findings are presented	
4.1 National results	27
4.2 Key themes and summary scores	27
4.3 Indicators in this report	29
4.4 Second round of NACEL outputs	29
5. Results	
5.1 Recognising the possibility of imminent death.....	30
5.2 Communication with the dying person.....	34
5.3 Communication with families and others.....	40
5.4 Needs of families and others.....	46
5.5 Individualised plan of care.....	50
5.6 Families’ and others’ experience of care.....	65
5.7 Workforce/specialist palliative care.....	68



Appendices

This report also has a number of appendices, contained in a separate report, which should be read in conjunction with these findings. See [NACEL appendices](#) for full details.

Appendix 1: Staff Reported Measure (SRM) development

Appendix 2: Third round of NACEL

Appendix 3: Glossary

Appendix 4: References

Appendix 5: Hospital score table

Appendix 6: Method for scoring

Appendix 7: Patient demographics

Appendix 8: Characteristics of deaths in hospitals

Appendix 9: Supplementary Quality Survey information

Appendix 10: Audit Summary

Appendix 11: Indicators included in the report

Appendix 12: Steering Group, Advisory Group and Audit Team

Appendix 13: Audit participation



Foreword

This report presents the findings from the second round of the National Audit of Care at the End of Life (NACEL).

The one certainty in life is that we will die. Wherever that might be, we should expect to receive the best possible care, according to our needs and wishes. National policy guidance in both England and Wales reflects the high priority that we as a society give to good end of life care. Given that over half of those who die in England and Wales currently will be in hospital, the focus of the National Audit of Care at the End of Life (NACEL) is on end of life care in an inpatient setting. NACEL focuses on the last admission to hospital prior to death and highlights how hospital care in England and Wales measures up to nationally agreed quality standards. The *NICE Quality Standards and Guidance*, and the *Five priorities for care* as outlined in *One Chance To Get It Right* set expectation and guide practice. NACEL provides reassurance that progress is being made to firmly embed these priorities for care across the NHS, and to improve these standards for end of life care year on year.

NACEL has taken care to align with, and not duplicate, other national workstreams which are already in place. For example, NACEL augments the work on *Learning from Deaths* (England), and *Delivering Safe Care, Compassionate Care* (Wales) which mandate all hospitals to have a consistent, standardised process for reviewing all inpatient deaths to detect potential harm via a structured mortality review process. High quality care at the end of life, and support for those close to the dying person, are high priorities for both governments.

The NACEL Steering Group and Advisory Group have reviewed and built upon the learning from round one of NACEL. In response to feedback from audit participants we have made changes to NACEL for round two. We have been particularly mindful of concerns from auditors, who are largely NHS clinical staff, regarding data burden, capacity and resources when undertaking the audit. Consequently, for round two, the number of Case Note Reviews to be completed was reduced and the scale of the review focused down to 25% of its original size, whilst ensuring the integrity and robustness of the audit. We are pleased to report that the high engagement of 97% of eligible participants undertaking the audit in round two has been sustained. The focus in round two has been on those areas highlighted as requiring the greatest attention in round one; the themes of 'recognising the possibility of imminent death' and 'individualised plan of care'. Themes reporting higher compliance in round one were not repeated in round two, however these will be revisited in the future. The sections in the main report give an indication of where comparisons can be made between the two rounds.

The first theme in this report is 'recognising the possibility of imminent death'. This underpins all other aspects of end of life care and is emphasised in *One Chance To Get It Right*. The earlier that it can be recognised that death may be imminent, or that the recovery of a person is uncertain, the greater the chance that a person can be involved in appropriate conversations, and in developing an individual plan of care, with consideration of the needs of those close to them. In round two, 88% of patients whose care was audited were recognised to be likely to die imminently (see page 30), with the median time from the recognition of the possibility of imminent death to death occurring being 41 hours (compared to 36 hours in round one). It is not possible to say whether the recognition of imminent death might have occurred earlier, however the results show that for many people there is a very short period of time in which to make and implement an individualised care plan.



Foreword

The main messages from NACEL round two are as follows:-

1. Whilst 71% of patients had an individualised end of life care plan, we should be striving for higher compliance in this key area.
2. Although most people felt that the patient and families had received good care overall, there remains a gap in identifying the needs of families and others.
3. 80% of participants perceived that hospital was the 'right' place to die; however, 20% remarked there was a lack of peace and privacy.
4. Two thirds of hospitals lack face-to-face specialist palliative care provision seven days a week.

During round two, additional elements of NACEL were progressed to be delivered in round three. A Staff Reported Measure (SRM) has been developed, piloted and validated and will be introduced in round three. This will give us valuable feedback from staff involved in delivering end of life care and will be triangulated with the other audit data sources. A new Mental Health Reference Group has been working hard to deliver all elements of NACEL in mental health inpatient settings and we look forward to the full involvement of mental health providers in round three.

We would like to once again acknowledge and thank the teams within trusts/Health Boards (HBs) who participated in the second round. The continued commitment and dedication of the Steering and Advisory Groups, and of The Patients Association, is highly valued, ensuring consideration and involvement of patients, and those close to them, in all aspects of NACEL. Huge thanks also go to the families and others who took the time to give us feedback on their experiences of end of life care and providing invaluable information for us to work with. Their involvement has been instrumental in framing the NACEL recommendations.



Dr Suzanne Kite
NACEL Co-Clinical Lead
Consultant in Palliative Medicine,
Leeds Teaching Hospitals NHS Trust



Elizabeth Rees
NACEL Co-Clinical Lead
Lead Nurse for End of Life Care,
Leeds Teaching Hospitals NHS Trust



Executive summary

Background

This report represents the findings of the second round of the National Audit of Care at the End of Life (NACEL) which took place in 2019. NACEL was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government in October 2017, and the first round of the audit took place in 2018. NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute, community hospitals and mental health inpatient facilities in England, Wales and Northern Ireland.

NACEL is an annual audit managed by the NHS Benchmarking Network, supported by the Clinical Leads, the NACEL Steering Group, and wider Advisory Group (Appendix 12).

Every year, over half a million people die in England and Wales, almost half of these in a hospital setting. Following the Neuberger review, *More Care, Less Pathway, 2013*, and the phasing out of the Liverpool Care Pathway (LCP), the Leadership Alliance published *One Chance To Get It Right, 2014*, setting out *the Five priorities for care of the dying person*. NACEL measures the performance of hospitals against criteria relating to the five priorities, and relevant *NICE Guideline (NG31)* and *Quality Standards (QS13 and QS144)*.

Who should read this report

In line with *HQIP Reporting for Impact guidance, 2016*, this report is designed to provide information for:

- people approaching end of life
- people important to those receiving care at the end of life (a patient friendly report is also available)
- people involved in providing care – Chief Executive Officers (CEOs), Non-Executive Directors, Medical Directors, Nursing Directors and other staff in provider organisations
- people involved in commissioning care – Accountable Officers of Clinical Commissioning Groups (CCGs) /Integrated Care Systems (ICSs) leads and other staff in commissioner organisations
- people who regulate care

Second round of NACEL

The audit, undertaken during 2019/20, comprised:

- an **Organisational Level Audit** covering hospital/submission level questions;
- a **Case Note Review** which reviewed consecutive deaths in the first two weeks of April 2019 and the first two weeks of May 2019 (acute providers) or deaths in April and May 2019 (community providers); and
- a **Quality Survey** completed online, or by telephone, by the bereaved person.

Data for all elements of the audit was collected between June and October 2019. In total, 175 trusts in England and 8 Welsh organisations took part in at least one element of the audit (97% of eligible organisations). Mental health trusts did not take part in round two but will participate in round three.



Executive summary

As in round one, the audit 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 section 1.5 for full definitions).

In response to round one findings and feedback, a number of changes to the scope and content of the audit were made in round two (see section 1.5). The key changes were as follows:

- There was no trust/HB level to the Organisational Level Audit since organisations scored well on governance in round one.
- To reduce data burden on participants, the number of Case Note Reviews completed by each hospital was reduced from 80 to 40.
- The audit period for the Case Note Review (see page 20) was amended.
- The content of the Case Note Review was reduced by 75%.
- The content of the Quality Survey was reviewed and amended.
- The Quality Survey was unlinked from the Case Note Review in order to increase the number of surveys returned.
- The 'involvement in decision making theme' was not utilised in round two, as part of the reduction in the size of the audit due to this theme scoring well in round one.
- Changes in the metrics utilised for the summary scores between audit rounds one and two are outlined in the 'Results' section (sections 5.1 to 5.7). Due to these changes, the summary scores can not be compared between years.

This report was published on 9th July 2020.

Overview of the results

Section 5 of this report contains results for acute and community hospitals in England and Wales taking part in the second round of NACEL. Results from the three elements of the audit are presented together under seven themes covering the *Five priorities for care* and other key issues. Two themes reported on in round one of NACEL, 'involvement in decision making' and 'governance', have not been covered in round two (see section 1.5).

For six of the seven themes, a summary score has been developed and calculated for each hospital. Unlike in round one, there is no summary score for 'recognising the possibility of imminent death' this year (see section 4.2). Further, the component metrics of the scores have changed since round one. Results are presented together and grouped into themes (see sections 5.1 – 5.7).

Appendix 6 sets out the process undertaken to select the key themes and their component indicators, and an explanation of how scores are calculated. Summary scores now include Category 1 deaths (see section 4.2). A table of scores per hospital can be found at Appendix 5. The range of hospital scores is shown in the figure at the beginning of each section. Scores are derived from different audit elements and should be viewed independently, for example, "Individualised plan of care" should be compared to other hospital scores on this theme, rather than other theme scores for that hospital. This is because a hospital's highest score may not be indicative of its highest achievement, if it is a theme which has scored highly overall.

The number of Case Note Reviews completed was 6,730. The total number of Quality Surveys returned was 1,581, double the number returned in round one. The Quality Survey results bring additional evidence to build the overall picture of the quality of care at the end of life in hospitals.



Executive summary

Key findings

Key findings and summary scores (see section 4.2) for each of the audit themes were as follows:



- a) The possibility that the patient may die within the next few hours/days was recognised in 88% of cases audited, compared with 89% in the first round of the audit (pg 30).
- b) The median time from recognition of dying to death was recorded as 41 hours, compared to 36 hours in the first round of the audit (pg 30).



- c) There was documented evidence that the possibility of death had been discussed with the patient, or a reason why not recorded, in 89% of cases where death was recognised, compared with 86% in round one (pg 35).
- d) There was an improvement in the documentation of discussions with the patient about their plan of care, medication, hydration and nutrition, since round one of the audit (pg 36-37).



- e) There was documented evidence that the possibility of death had been discussed with the families and others, or a reason why not recorded, in 97% of cases where death was recognised, compared with 96% in round one (pg 41).
- f) The findings of the second round of NACEL suggest there has been an improvement in the documentation of discussions with families and others, since round one of the audit (pg 41-43).



- g) In round two, the identification, and addressing of, needs of families and others have been assessed using the Quality Survey rather than the Case Note Review. It is not, therefore, possible to compare round two with round one results (pg 46).
- h) 58% of families and others responding to the Quality Survey felt that their needs had been asked about. Almost two-thirds of respondents to the Quality Survey felt that they had enough emotional and practical support (pg 47).



Executive summary

Individualised plan of care



7.2

- i) For 29% of Category 1 deaths, there was no documented care plan for the dying person, compared with 33% in round one (pg 52). In 45% of these cases, the time from recognition of dying to death was more than 24 hours (pg 62).
- j) The benefit of starting, stopping or continuing interventions is a key element of individualised end of life care planning. The documentation of the review of interventions has improved in round two (pg 53).
- k) As in round one, there was higher compliance with documentation of assessment of the patient's physical care needs, than other areas such as emotional/psychological and spiritual/religious/cultural needs (pg 54).
- l) Anticipatory medications were prescribed in the majority (88%) of cases, although there were no indications for usage documented in 20% of cases (pg 57).
- m) Three quarters of Quality Survey respondents agreed the patient had support to eat and drink, if he/she wished to do so, or stated this was not applicable. Documentation about supporting eating and drinking in the case notes could be improved (pg 56).
- n) The proportion of people who felt hospital was the right place for the person to die was 80% in round two compared to 75% in round one of NACEL (pg 61).
- o) As regards the location within the hospital, 20% of Quality Survey respondents disagreed with the statement that the person had a suitable environment with adequate peace and privacy (pg 61). As in round one, many narrative comments received from the Quality Survey related to a perceived lack of privacy, and peace and quiet (pg 62).

Families' and others' experience of care



7.0

- p) The majority of respondents to the Quality Survey, 79% and 84% respectively, felt communication with the patient and with families/others was sensitive (pg 66).
- q) The results for round two, as for round one, suggest the majority of people responding to the Quality Survey felt the patient and families had received good care and support overall. However, in around a quarter of cases, respondents rated the quality of care and support provided to families and others as 'poor' or 'fair' (pg 66).

Workforce/specialist palliative care



7.4

- r) Almost all hospitals (99%) have access to a specialist palliative care service, compared to 97% in round one (pg 69).
- s) However, around a third of hospitals (36%) report having a face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week (pg 70).



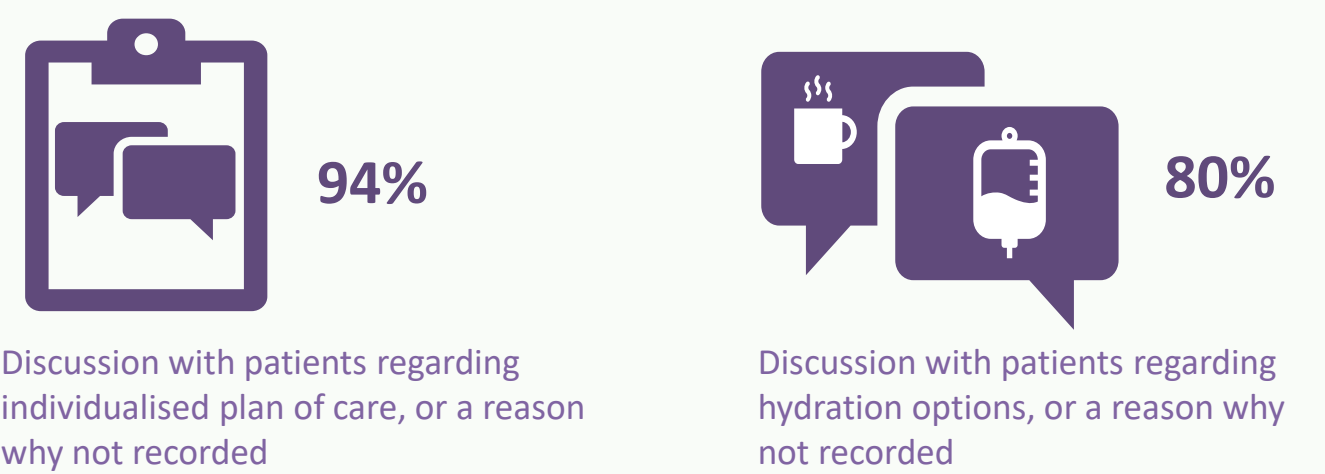
National Audit of Care at the End of Life 2019

Key findings at a glance

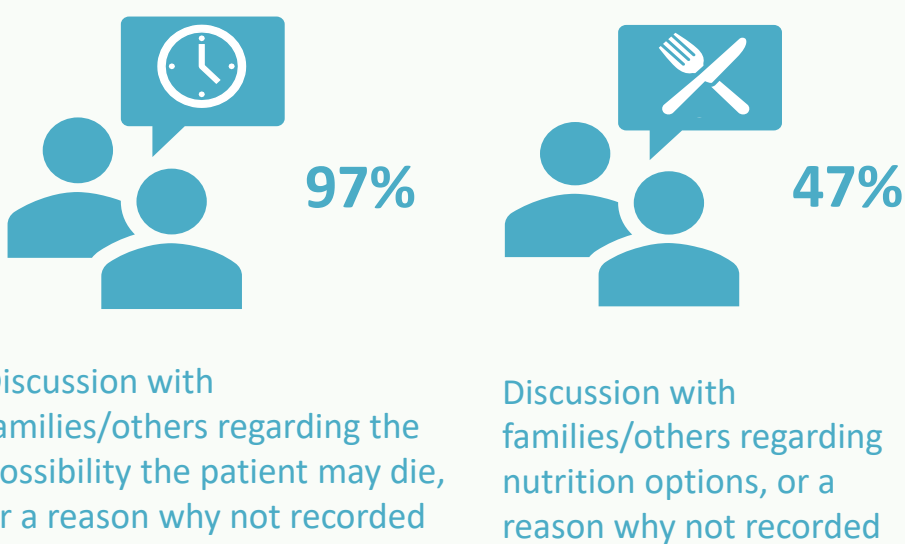
Recognising the possibility of imminent death



Communication with the dying person 7.8



Communication with families and others 6.9



Workforce 7.4



Individual plan of care 7.2



Needs of families and other 6.0



Families/carers were asked about their needs



Families/carers felt they were given enough emotional help and support by staff

Families' and others' experience of care 7.0

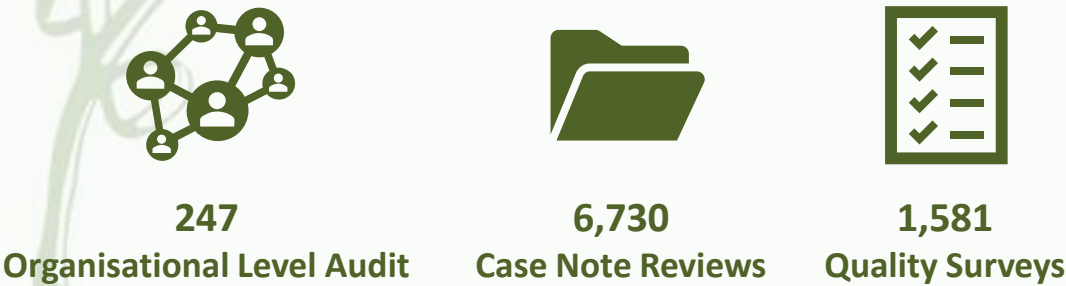


Families/carers felt the quality of care provided to the patient was good, excellent or outstanding



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

Participation



Recommendations

Attention is drawn to the national guidance set out in *One Chance To Get It Right* and the *NICE Quality Standards (QS13 and QS144)* which defines good care at the end of life and provides the basis of the NACEL audit standards (see section 1.4).

The recommendations include those brought forward from the first round of NACEL where no new evidence has been collected in round two (recommendations 1,2 and 8), however, these are still ongoing recommendations. The audit year when the recommendation was first introduced is indicated below each recommendation in brackets.

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

- 1. Put in place systems and processes to support people approaching the end of life to receive care that is personalised to their needs and preferences.** Health and care systems should work together to agree guidelines across primary, community, secondary care, social care and care homes for timely identification of, documentation of, and information sharing regarding people's wishes and needs.
[NACEL 2018 Recommendation 1 – updated for clarity]
- 2. Review capability and capacity across all care settings, to provide appropriate care at the end of life, and to support people important to the dying person through to bereavement, with the aim of better meeting people's needs and preferences.** Review should lead to service re-design where potential improvements are identified.
[NACEL 2018 Recommendation 2 – updated for clarity]
- 3. 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*). This would most often be provided by nurse specialists face-to-face supported by 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]
- 4. Create and implement an action plan to ensure the local findings and national recommendations of NACEL are reviewed, and providers of NHS funded care at the end of life in acute and community hospitals and other care settings are supported by commissioners in developing, implementing and monitoring their plans.**
[New for NACEL 2019]
- 5. Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system.** 'The system' refers to locality, Integrated Care System (ICS) or other networks of provision.
[New for NACEL 2019]



Recommendations

Chief Executives should:

6. **Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with the dying person and people important to them in the last days and hours of life.** Providers should review national resources to support communication skills training that are available, including serious illness communication skills training days, guidance from professional bodies, learning outcomes, e-learning programmes such as e-ELCA and modules accessed via Electronic Staff Record (ESR), such as the All Wales ESR Care Decisions Guidance module.
[NACEL 2018 Recommendation 6 - updated for clarity]
7. **Put systems in place to ensure the needs of people important to the dying person are assessed and addressed in a timely manner, both before and after death.** Specific senior, strategic and operational responsibility is required. Assessment and delivery of needs should cover emotional/psychological, spiritual/religious/cultural, social and practical needs.
[NACEL 2018 Recommendation 7 - updated for clarity]

End of Life Care Lead (Board member with accountability for end of life care) should:

8. **As part of a strong governance framework for end of life care, report annually to the Board with a performance report and action plan.** The report and plan should build on the learning from NACEL, other audits, *Learning from Deaths*, medical examiners' reports, complaints and feedback from surveys, including those from bereaved people.
[NACEL 2018 Recommendation 8 – updated for clarity]

Medical Directors and Nursing Directors should:

9. **Ensure that staff have an awareness of the possibility or likelihood of imminent death, and acknowledge and communicate to the dying person and people important to them, as early and sensitively as possible. Staff should have an awareness of the importance of recognising uncertainty and communicating uncertain prognosis early in hospital admission and continuing conversations with patients and those important to them at all stages.** Ensure that patients who have signs and symptoms that suggest they may be in the last days of life are monitored for changes.
[NACEL 2018 Recommendation 9 - updated for clarity]
10. **Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for the dying person and people important to them.** Consideration should be given to the provision of a side room, if that is the person's wish.
[NACEL 2018 Recommendation 10 - updated for clarity]



Recommendations

11. **Ensure that patients who are recognised to be dying have a clearly documented and accessible individual plan of care developed and discussed with the patient 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)* 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 Recommendation 11 - updated for clarity]
12. **Ensure that the intended benefit of starting, stopping or continuing treatment for the individual is clear, with documentation of the associated communication with the dying person and/or people important to them.** This may include, but is not limited to, discussions regarding assessment and management of food and fluid, the common side effects of medication, the review of routine monitoring of vital signs and blood sugar and the review of ongoing administration of medications e.g. oxygen and antibiotics.
[NACEL 2018 Recommendation 11 - updated for clarity]
13. **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*, 2010, and the NMC's *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*, 2018, should be implemented.
[NACEL 2018 Recommendation 13 - updated for clarity]
14. **Ensure patients who are recognised to be dying, and are likely to need symptom management, are prescribed anticipatory medicines and individualised indications for use, dosage and route of administration are documented.** The drugs prescribed must be appropriate to the individualised anticipated needs of the dying person and must be regularly reviewed. Anticipatory medication should be discussed with the dying person where appropriate, and with people important to them, and those discussions should be documented.
[New for NACEL 2019]
15. **Where relevant, ensure that clear explanations are given to the dying person, and people important to them, about the rationale for the use of, and medications delivered by, syringe pumps.** The dying person and people important to them should have the opportunity to discuss the use of, and medications delivered by, syringe pumps and such conversations should be documented.
[New for NACEL 2019]



1. Audit background and development

1.1 National policy context

Every year, over half a million people die in England and Wales, almost half of these in a hospital setting. For three quarters of these deaths, death could be anticipated. There is only one chance to get good care right at the end of life, for both the dying person, and for those people important to them. It is essential that the end of life care delivered is of a high quality and delivered compassionately by caring and competent staff. The [National Survey of Bereaved People \(VOICES\)](#) was last carried out in England in 2015 and survey findings showed that approximately one third of respondents whose relative had died in hospital rated their overall quality of care in the last three months of life as fair or poor.

In 2014, the [Leadership Alliance](#) undertook a system wide review to improve the care of people who are dying, and those that are important to them, and published the key document [One Chance to Get It Right](#), setting out an approach that all organisations can adopt in the planning and delivery of care. *One Chance To Get It Right* focuses on *Five priorities for care of the dying person* which, along with the *NICE Quality Standards and guidelines*, provide the audit standards for NACEL (see section 1.4). The Leadership Alliance was established following the Neuberger review into the Liverpool Care Pathway (LCP) which was phased out of care across acute and community hospital settings in 2013. In round two of NACEL, 100% of respondents confirmed that the LCP was not used in any circumstance of care delivery.

NHS England have established an End of Life care programme (2018/19), which aims to:

- increase the percentage of people identified as being in their last year of life so that their end of life care can be improved by personalising it according to their needs and preferences; and
- secure strong clinical engagement and support in improved end of life care by working with NHS England regional networks.

NHS England's programme is aligned to the [Ambitions Framework](#). Programme ambitions are: -

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is co-ordinated
5. All staff are prepared to care
6. Each community is prepared to help

NHS England's Palliative and End of Life Care Network is working with regional colleagues to promote end of life care through strong clinical engagement as well as delivering on [key measures of success](#).

Further strategies pertaining to the English system for care at the end of life have been introduced and reference is made to these on page 14 of the [National Audit of Care at the End of Life – First round of the audit \(2018/19\) report, England and Wales](#).



1. Audit background and development

[A Healthier Wales](#) sets out the Welsh Government's long-term plan for health and social care in Wales. The plan commits to having a greater emphasis on preventing illness, on supporting people to manage their own health and wellbeing, and to enable people to live independently for as long as they can, supported by new technologies and by integrated health and social care services which are delivered closer to home. End of life care remains a priority for the Welsh Government and the end of life care pathway is identified as an area of initial focus within the plan.

1.2 Audit background and governance

NACEL was commissioned by HQIP on behalf of NHS England and the Welsh Government, with the programme beginning in October 2017.

The NHS Benchmarking Network (NHSBN) was commissioned run the audit initially for three years. This report covers the findings from round two of the audit undertaken in 2019. As in the previous year, governance of NACEL has been through a multi-disciplinary Steering Group, with input from a wider Advisory Group. The membership of the Steering and Advisory Groups can be found at Appendix 12. Dr Suzanne Kite, Consultant in Palliative Medicine, and Elizabeth Rees, Lead Nurse for End of Life Care, from Leeds Teaching Hospitals NHS Trust, continue to provide joint clinical leadership of the audit.

A diagrammatic representation of the governance arrangements can be found on the NACEL Project Management and Governance Structure [organogram](#).

In round two of NACEL, as in round one, the Northern Ireland Public Health Agency separately commissioned the NHS Benchmarking Network to cover Northern Ireland's participation. The findings for [Northern Ireland](#) are reported in a separate document.

1.3 Audit objectives

NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission before death in acute, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

The audit objectives for the second round of NACEL encompass the following:

1. To refine the tools for assessing compliance with national guidance on care at the end of life – *One Chance To Get It Right*, *NICE guidelines* and the *NICE Quality Standards* for end of life care.
2. To measure the experience of care at the end of life for dying people and those important to them.
3. To provide audit outputs which enable stakeholders to identify areas for service improvement.
4. To provide a strategic overview of progress with the provision of high-quality care at the end of life in England, Wales and Northern Ireland.



1. Audit background and development

1.4 Audit standards

NACEL measures the performance of hospitals against criteria relating to the delivery of care at the end of life which are considered best practice. These criteria are derived from national guidance, including *One Chance To Get It Right* and *NICE Quality Standards and guidance*. Specifically, the audit was designed to capture information on the *Five priorities for care* of the dying person as set out in *One Chance To Get It Right*. The priorities make the dying person themselves the focus of care in the last few days and hours of life, and specifically cite outcomes which must be delivered for every dying person. The *Five priorities for care* of the dying person are as follows:

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.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
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.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
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.

The audit is also closely aligned with *NICE Quality Standards and guidelines*. *NICE Quality Standard 13 [End of life care for adults](#)* covers care for adults (aged 18 and over) who are approaching their end of life. It includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers and includes care provided by health and social care staff in all settings. It describes high-quality care in priority areas for improvement. In March 2017, this quality standard was updated and statement 11 on care in the last days of life was removed and replaced by *NICE's Quality Standard 144*.

More specifically, there are two publications from NICE which outline standards which should be expected for the dying person and people important to them in the last few days of life. *NICE Clinical Guidelines NG31 [Care of dying adults in the last days of life](#)* covers the clinical care of dying adults (18 years and over) in the last few days of life. It aims to improve care for people by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covered how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life. *NICE Quality Standard 144, [Care of dying adults in the last days of life](#)*, identifies priority areas for quality improvement for the same group of people as in NG31.



1. Audit background and development

1.5 Audit structure and scope

As in round one of the audit, NACEL covered the last admission to hospital prior to death and included NHS funded end of life care for adults (18+) in acute and community hospitals in England and Wales. Again, hospices were excluded. Mental health providers of inpatient care did not take part in round two of the audit although will be fully participating in round three as explained at Appendix 2.

As in round one, NACEL had several elements, however some changes in the way these elements were delivered are noted below:

An Organisational Level Audit covering hospital/submission level questions. As in round one of NACEL, organisations could create multiple 'submissions' for their different hospital sites if they wished to audit the hospitals separately. Following feedback from participants in round one of the audit, the data requested for this audit element was substantially reduced and focused on activity, the specialist palliative care workforce, staff training and new questions on anticipatory prescribing. The element of the Organisational Level Audit completed at the trust/HB level (rather than submission level) in round one, covering policies and governance, was not undertaken in round two of NACEL but will be resumed for the third round (see Appendix 2). The rationale for not including the trust/HB level data collection in round two was that audit participants demonstrated high compliance with the 'governance' summary score (9.5) and policies would not be expected to change significantly in one year.

A Case Note Review completed for each submission. The content of the Case Note Review was reduced by 75% in line with feedback from audit participants and focused on the themes of 'recognition of imminent death', 'communication' and 'individualised plan of care', highlighted in round one as key areas for improvement. Questions asked in round one on the 'involvement in decision making' theme were excluded in round two due to the high scores received in round one for this theme.

On the advice of the NACEL Steering Group, to reduce data burden, acute providers were asked to undertake up to 40 Case Note Reviews, rather than 80 as in round one. Acute providers were requested to audit 20 consecutive deaths from the first two weeks of April and 20 consecutive deaths from the first two weeks of May (rather than all deaths in April as in round one). Community hospital providers were requested to audit all deaths during April and May up to a maximum of 40 (rather than deaths in April to June as in round one). The definition of deaths to be reviewed remained unchanged, as feedback from audit participants demonstrated that clinical reviewers were able to categorise the deaths appropriately. The following categories of deaths were audited: -

Category 1: It was recognised that the patient may die - it had been recognised by the hospital staff that the patient may die imminently (i.e. within hours or days). Life sustaining treatments may still be being offered in parallel to end of life care.

Category 2: The patient was not expected to die - imminent death was not recognised or expected by the hospital staff. However, the patient may have had a life limiting condition or, for example, be frail, so that whilst death wasn't recognised as being imminent, hospital staff were "not surprised" that the patient died.



1. Audit background and development

As in year one, deaths which were classed as "sudden deaths" were excluded from the Case Note Review. These were deaths which were sudden and unexpected; this included, but was not limited to, the following:

- all deaths in Accident and Emergency departments
- deaths within 4 hours of admission to hospital
- deaths due to a life-threatening acute condition caused by a sudden catastrophic event, with a full escalation of treatment plan in place. These deaths would not fall into either Category 1 or 2 above.

A Quality Survey designed to gain feedback from relatives, carers and those close to the person who died, on their experiences of the care and support received at the end of life. This was separate to any bereavement survey conducted internally by participating trusts/HBs. In round one of NACEL, each Quality Survey was linked to a Case Note Review. In round two of NACEL, this was not linked, in order to increase uptake in the Quality Survey, and hence gain a greater volume of surveys/feedback from bereaved carers (see section 3 which outlines the participation of all NACEL elements in round two). Audit participants were requested to send Quality Survey invitations to the bereaved families and others from all deaths occurring in April and May 2019. Feedback was therefore potentially included within the Quality Survey on the care of patients who died suddenly, and a question was asked to identify these patients.

Additional elements of NACEL undertaken in 2019

In line with contractual requirements, the NHSBN was tasked with developing a Staff Reported Measure for rollout in the third round of NACEL. This additional audit element is covered at Appendix 1.



2. Methodology

2.1 Eligibility, recruitment and registration

All NHS acute sites and community hospital providers of adult inpatient care in England and Wales were eligible to take part in the audit. A letter inviting each organisation to take part in the audit was sent to the Chief Executive, Director of Nursing, the Lead Nurse for End of Life Care, where available, and project leads. Overall, 97% of eligible organisations participated in round two of NACEL (section 3).

Registration was completed online as in round one. During registration, all organisations had the option of setting up multiple submissions to cover different hospital sites. Community hospital providers were offered the option of combining all sites into one submission where appropriate, however, some organisations chose to register separate hospitals/sites.

2.2 Data collection

Data collection opened on the 3rd June 2019 and closed on the 11th October 2019 for all three elements of NACEL. No extensions were given due to timescales required to complete analysis and reporting.

For the Organisational Level Audit, participants were asked to complete one hospital/site level questionnaire for each submission created on registration. Questions related to the period 2018/19.

For the Case Note Review, participants were asked to audit up to 40 eligible patients for each submission created on registration.

In addition, audit participants were also requested to complete an Audit Summary data specification with the following information:

- the number of people dying in the audit period excluding deaths within A&E and within 4 hours of admission to hospital;
- the total number of people dying in A&E within the audit period;
- the total number of people dying within 4 hours of admission to hospital within the audit period; and
- the number of Quality Survey letters sent.

Data collection for NACEL was via a bespoke online data entry tool for the Organisational Level Audit and the Case Note Review. The audit tool included definitional guidance for each metric requested, including additional guidance for Wales where appropriate. Excel versions of all data specifications could be downloaded to assist audit participants with internal data collation prior to the input of data onto the data collection tool.

Further validation controls were built into the system to ensure, for example, that if a death was categorised as a Category 2 death, then limited, applicable questions were available to respond to. The online data collection pages were simplified, and clearer steps were defined to enable easier responses to each audit element.



2. Methodology

The Quality Survey was undertaken online via unique technology which enabled the response of the bereaved person to be linked to the participating organisation and submission. People identified by the trust/HB as the carer/next of kin were sent a letter with a URL to access the survey online. Each carer/next of kin had a unique code which linked their response to the relevant trust/HB submission, for the sole purpose of dealing with a safeguarding issue should one arise under the [Cause for Concern Policy](#) (see section 2.6). No patient or carer identifiable information was made available to the NHSBN. Details of how to contact the Patients Association telephone helpline were included in the letter should the carer/next of kin have difficulty completing the survey online or prefer to complete the survey on the telephone.

As well as the guidance on the online data collection pages, audit guidance was provided for all audit participants containing a step-by-step guide on how to complete each element of NACEL. Data collection was also supported by the NHSBN team with a telephone helpline and dedicated e-mail support address to deal with specific queries.

2.3 Data validation and cleansing

Data validation controls were implemented on several levels within the online data collection tool. Information buttons next to each metric contained definitional guidance of the data required to ensure consistency of the data collected. In addition, system validation was implemented to protect the integrity of the data collected, including allowable ranges, expected magnitude of data fields, numerical versus text completion, appropriate decimal point placing and text formatting.

An extensive data validation exercise was undertaken from mid-October to the end of November 2019. Outlying positions and unusual data were queried with NACEL participants. A draft online toolkit was made available to NACEL participants at the beginning of November 2019 to assist with checking data submissions.

2.4 Reliability analysis

The NACEL Steering Group agreed that a reliability analysis was not required in round two of NACEL due to the sample size of case notes being reduced and the results from the reliability analysis from round one of NACEL indicating 'agreement' on the summary score component metrics.

2.5 Management of Outliers Policy

The [Management of Outliers Policy](#) is available on the NACEL webpages. The policy has been informed by [Detection and management of outliers for national clinical audits: Implementation guide for NCAPOP providers](#) and approved by the NACEL Steering Group. For round two of NACEL, the NACEL Steering Group agreed that a second indicator be used in addition to the indicator utilised in round one.



2. Methodology

The two indicators tested were as follows:

1. the proportion of deaths where it was recognised that the patient may die imminently (Category 1) out of Category 1 and Category 2 deaths; and
2. the proportion of Category 1 deaths where there was documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs, out of all Category 1 deaths.

Four submissions were identified as outliers on one of the indicators above (see Appendix 14 for further detail). The relevant organisations were contacted and managed in accordance with the policy. Confirmation that a local review will be undertaken with independent assurance of the validity has been provided by the relevant organisations.

2.6 Cause for Concern Policy

The [Cause for Concern Policy](#) is available on the NACEL webpages. The Cause for Concern policy was updated for round two of NACEL to include an additional step, whereby responses not qualifying under the policy as a cause for concern, however still indicating poor care at end of life, were highlighted to trusts/HBs.

Comments to the narrative question in the Case Note Review and the narrative question from the Quality Survey were reviewed by the NACEL Director and the Clinical Leads. Whilst none of the issues identified met the formal 'cause for concern' definition as outlined in the policy, 12 comments were fed back to trusts/HBs with the case note code so that a review of the care could be undertaken. The disclosure of the identifying code was in accordance with an expectation set in explaining the use of the NACEL Quality Survey responses to the respondent.

All other comments received from respondents either to the Case Note Review or the Quality Survey were fed back anonymously to participating hospitals for consideration by them in the context of their internal governance procedures.

2.7 Quality Improvement Plan

The NACEL [Quality Improvement Plan](#) outlines how the findings from NACEL rounds one and two have established where trusts/HBs have better compliance against the *NICE Guidelines and Quality Standards* and the *Five priorities for care* as outlined in *One Chance To Get It Right*. The focus for quality improvement following round one of NACEL was for each trust/HB to review their NACEL audit outputs and develop internal quality improvement plans based upon their results. Baselines for the first year have been established in both the summary score reporting, and in the full set of metrics reported in the online benchmarking toolkit (available to audit participants only). Trusts/HBs should monitor progress against baselines established in round one, following the publication of NACEL round two results.

Because of the changes in data collection between round one and round two of the audit, it is not possible to compare summary scores between the years. Where comparison is possible, on individual metrics, this is included in sections 5.1 to 5.7.



3. Participation

As outlined in section 1.5, all NHS acute providers and community hospitals providers in England and Wales were eligible to register for NACEL. The final number of trusts/HBs participating in NACEL and providing data for at least one element of the audit was 175 trusts in England and in Wales, 7 HBs and Velindre NHS Trust took part, giving a total of 183 organisations. Participation represented 97% of all eligible organisations, reflecting the same level of participation as round one. As explained in section 1.5, organisations were able to set up ‘submissions’ for each of their hospital sites.

The Audit Summary data specification (as explained in section 2.2) had 100% completion.

The Organisational Level Audit (section 1.5) was completed for the following submissions:

Table 1: Number of submissions supplying data for the hospital/site overview

Submission type	England	Wales	Total
Acute	170	6	176
Community	67	4	71
Total	237	10	247

In total, 216 submissions for England and 10 for Wales supplied data for the Case Note Review element of NACEL. These organisations created a total of 226 submissions categorised as either acute or community hospitals as shown in table 2.

Table 2: Number of submissions supplying data for the Case Note Review

Submission type	England	Wales	Total
Acute	166	6	172
Community	50	4	54
Total	216	10	226

There were a total of 6,730 Case Note Reviews returned in round two of NACEL from England and Wales (table 3).

Table 3: Number of Case Note Reviews returned by type of submission

Submission type	England	Wales	Total
Acute	5,849	221	6,070
Community	555	105	660
Total	6,404	326	6,730



3. Participation

The number of submissions for whom at least one Quality Survey was returned, was 134 (table 4). A total of 1,581 Quality Surveys were returned across England and Wales (table 5).

Table 4: Submissions with at least one Quality Survey returned

Submission type	England	Wales	Total
Acute	116	4	120
Community	14	0	14
Total	130	4	134

Table 5: Total number of Quality Surveys returned by submission type

Submission type	England	Wales	Total
Acute	1,489	65	1,554
Community	27	0	27
Total	1,516	65	1,581

The response rate for the Quality Survey, for those that were sent a letter by the trust/HB (see section 1.5 for an explanation of the data collection methodology), was 18%, which was the same as for round one, although almost twice as many Quality Surveys were returned. The increase was due to changes in the way the Quality Survey was administered (section 1.5). From the Audit Summary data, 143 submissions participated in the Quality Survey element representing 58% of those eligible. Of those that participated, 9 submissions did not receive any Quality Survey responses. Reasons for not participating in the Quality Survey included:

- already undertaking a local bereaved persons survey;
- contact details of the relevant person were not collected or not easily accessible; and
- concerns regarding information governance processes at the trust/HB meaning policies were not in place regarding the contacting of carers.

Details of which audit element each trust/HB participated in, together with the number of Case Note Reviews completed and Quality Survey responses for each submission, are included at Appendix 13.

The Audit Summary data shows that 7% of all deaths occurring in acute and community hospitals during the audit period were excluded as they occurred within Accident and Emergency Departments, and 4% were excluded as death occurred within four hours of admission.



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 two of NACEL.

4.2 Key themes and summary scores

The information in this report is presented thematically in seven sections, derived from the *Five priorities for care* and other key issues. The themes are:

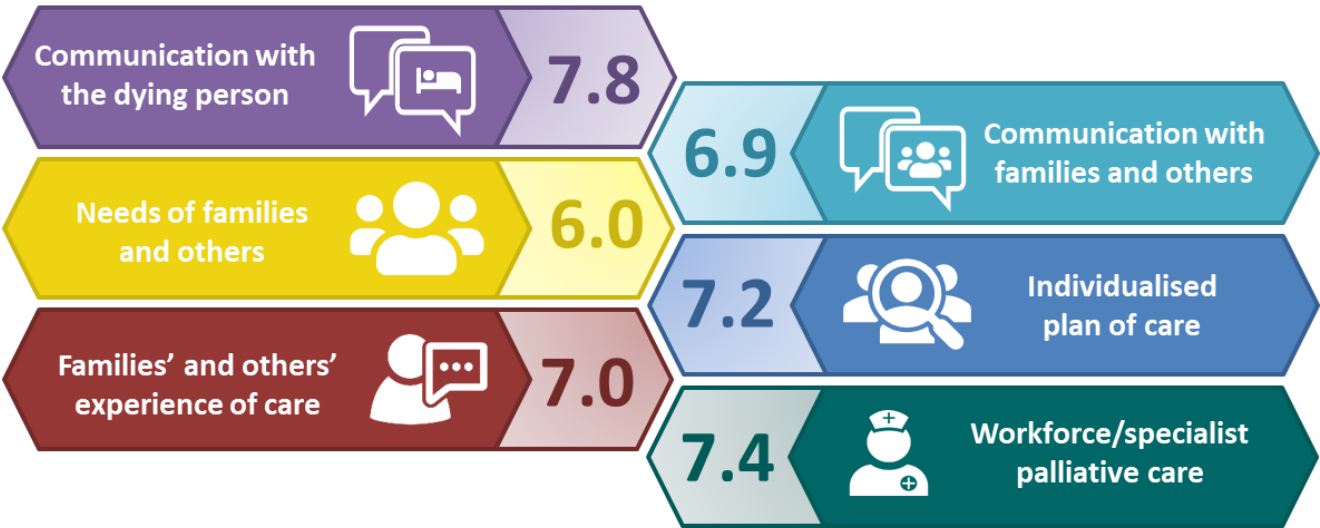
- 1. Recognising the possibility of imminent death (CNR)
- 2. Communication with the dying person (CNR)
- 3. Communication with families and others (CNR)
- 4. Needs of families and others (QS)
- 5. Individualised plan of care (CNR)
- 6. Families’ and others’ experience of care (QS)
- 7. Workforce/specialist palliative care (H/S)

As in round one of NACEL, each summary score can only use 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

Except for ‘recognising the possibility of imminent death’, a summary score has been developed and calculated for each theme for each hospital, with the mean values for the summary scores shown in the infographic below. The summary scores allow large amounts of data to be more easily digested and enable easy comparison between hospitals on the different themes within the audit.

The summary scores for round two are illustrated below:



4. How the findings are presented

The summary scores from round two of NACEL should not be compared directly with scores from round one, due the changes in the calculation of the scores as follows:

- No summary score has been calculated for the 'recognising the possibility of imminent death' theme, as the metrics used in round one to calculate this summary score have been utilised in the two communication themes (section 5.2 and 5.3) for round two. Further, the NACEL Steering Group reflected, following round one, that to report a summary score for the 'recognising the possibility of imminent death' theme may be misleading, since it is not possible to incorporate key information on timescales in the calculation of a score.
- Two themes reported on in round one of NACEL have not been covered in round two. As part of the work to reduce the size of the audit, it was decided by the Steering Group that 'involvement in decision making' and 'governance' would not be areas of focus in round two since they scored well in round one.
- All the summary scores now include Category 1 deaths only due to improved validation on the NACEL data collection pages. For Category 2 deaths, only a sub-set of relevant questions was accessible to be completed by auditors. Consequently, the required component metrics to create summary scores were not available for Category 2 deaths. However, results for key component metrics for Category 2 deaths are included in the report, since the Steering Group felt that opportunities to plan for the care at the end of life for this cohort of patients should be considered in the audit.
- The metrics which have been used in each summary score have changed between round one and round two of NACEL, with some removed or added, and the wording of some questions changed. The component metrics for each summary score, and a note of the changes since round one, can be found in sections 5.1 to 5.7.

A table of the summary scores for each hospital can be found at Appendix 5. Not every hospital has received a full set of summary scores. To receive a full set, hospitals were required to provide completed responses for 'workforce/specialist palliative care' summary score component indicators from the Organisational Level Audit, more than five Case Note Reviews and more than five Quality Survey responses.

It should be noted that the mean summary scores for the different themes should not be compared with each other, as they have been calculated from different elements of the audit and are derived by different methods.

Under each theme in this report, the component indicators of the summary score for the theme are reported on, together with other relevant indicators from all elements of the audit. Where findings on individual metrics can be compared between round one and round two of NACEL, these are noted within the report. In addition, narrative responses from the following open question within the NACEL Quality Survey have been analysed and the results are reported on:

'If you have any further comments regarding the care and support given to the person who died or to you and other close relatives or friends during the final admission in hospital, please detail below.'



4. How the findings are presented

A selection of quotes from the narrative received is also included. In addition, narrative comments about identified areas of excellent practice and learning points, received from auditors completing the Case Note Review, are referred to.

Additional Case Note Review metrics on patient demographics and characteristics of deaths in hospitals, alongside supplementary Quality Survey and Audit Summary metrics are provided in Appendices 7 to 10.

4.3 Indicators in this report

As in the round one report, the indicators used in this report are generally illustrated in column charts. To give an indication of the number of hospitals/sites responding, all charts include the number of responses (in the format n=number). For ease of reference, chart titles have been abbreviated from the actual questions asked in the data collection pages. The results for each indicator are also quoted within the text as percentages. Appendix 11 includes the full wording of the question requested which has been illustrated within the report, together with the number of responses (n) used to calculate the percentage results. Appendix 11 references the figure number of each chart and where values are referenced in the narrative, but not included within the figure, a note is provided in the text as a subscript.

4.4 Second round of NACEL outputs

There are three main outputs for audit participants:-

- 1. The online benchmarking toolkit.** A draft toolkit was made available at the beginning of November 2019 to assist participants with validation queries and give early sight of trust/HB positions against the full range of metrics. The final toolkit was published to participants in late November 2019 which incorporated all changes following validation of the data.
- 2. A national summary report for the second round of NACEL.** A summary report has been made available for England and Wales combined (this report). This contains the high level findings and recommendations from NACEL.
- 3. Bespoke dashboards.** These have been made available at submission level for every trust/HB. The bespoke dashboards contain a selection of key metrics where individual submission positions are compared against nationally reported positions.

All data is anonymised in the online benchmarking toolkit and participating organisations know their own position only. Participant codes to permit identification of participating organisations have not been shared amongst participants. However, this report contains identified positions for the summary scores for each submission in a table (see Appendix 5).



5.1 Recognising the possibility of imminent death



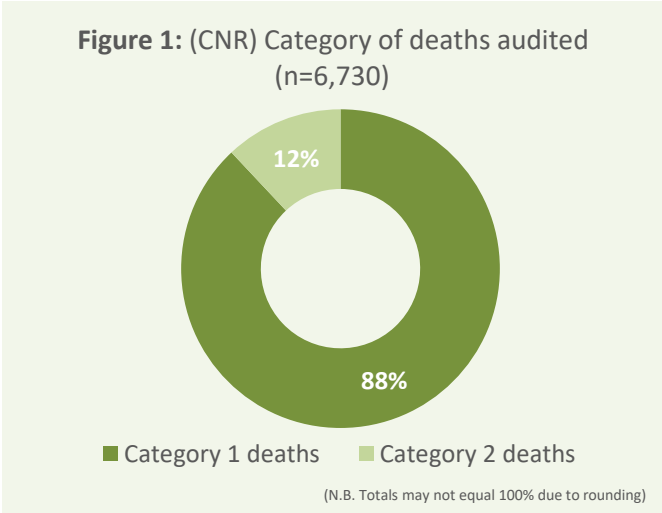
The importance of early recognition that a person may be dying imminently is emphasised in *One Chance To Get It Right, 2014* and the *NICE Quality Standard 144*.

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*).

Early recognition that a person may be dying enables an individual care plan to be developed, appropriate discussions with the dying person and those important to them to take place, treatment decisions to be made and the needs of the family to be considered. It underpins all the priorities for improving people’s experience of care in the last few days and hours of life.

As explained in section 4.2, there is no summary score for ‘recognising the possibility of imminent death’ in this round of the audit. The questions on whether the possibility that the patient may die had been discussed with the dying person and those important to them have been moved to the relevant sections on communication (sections 5.2 and section 5.3 respectively). This section will focus on the time when recognition of dying took place.



As in round one, auditors were asked to classify deaths between Category 1, where it had been recognised by the hospital staff that the patient may die imminently (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 show that 88% of patients audited were classified as Category 1, compared to 89% in round one.

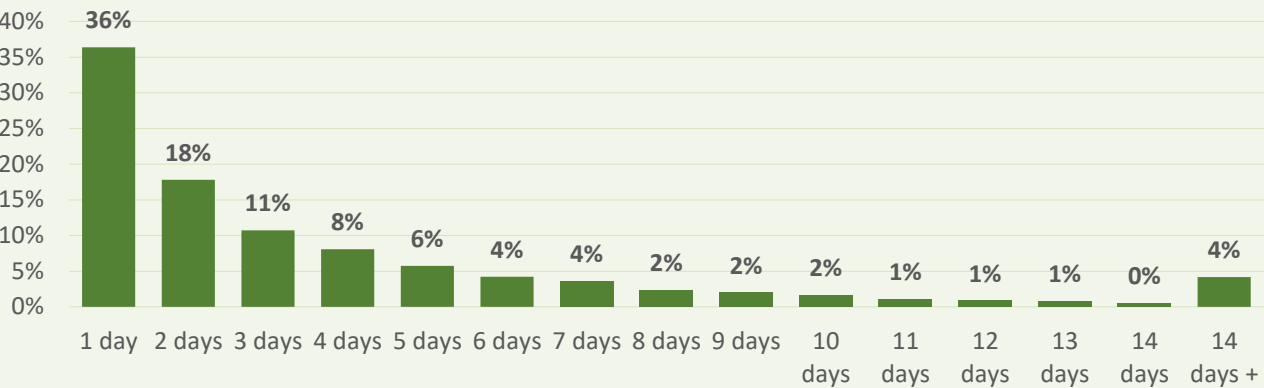
As noted above, timeliness of recognition of death is important to ensure appropriate discussions and planning can take place. The median time for the whole sample of case notes audited from first recognition of death to time of death was 41 hours₁ compared to 36 hours in round one.



5.1 Recognising the possibility of imminent death

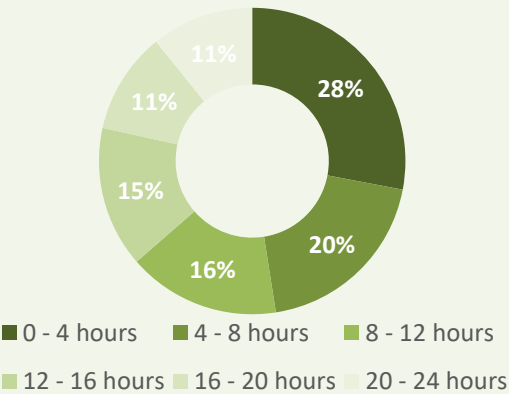


Figure 2: (CNR) Time from recognition of dying to death (days) (n = 5,781)



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

Figure 3: (CNR) Time from recognition of dying to death (hours) up to 24 hrs (n = 2,104)



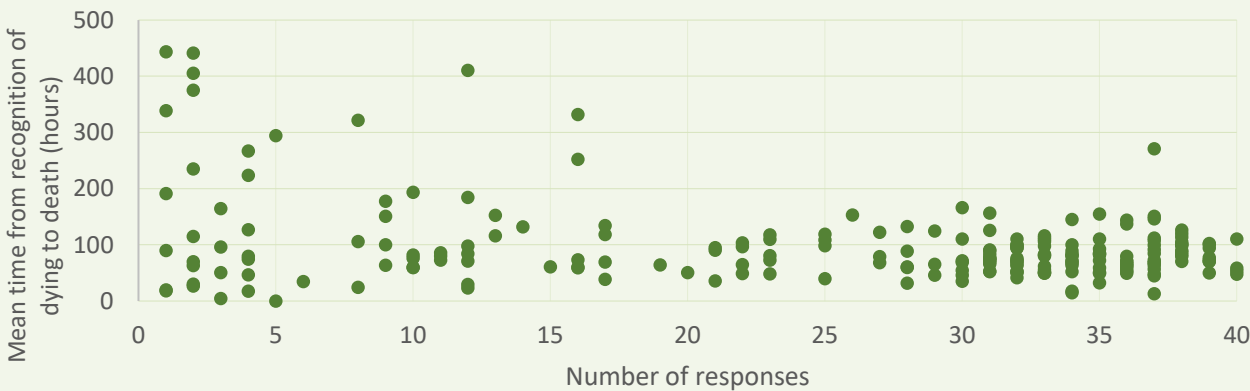
(N.B. Totals may not equal 100% due to rounding)

Figures 2 and 3 provide an analysis of the time from recognition of dying to death. Figure 2 considers the time in days for the whole Case Note Review sample, showing that 36% of people die within one day of recognition of the possibility that they may die.

For the group of people that died within one day, figure 3 shows further detail, with analysis of the number of hours between recognition of dying and death. 28% of this cohort died within four hours of recognition of dying.

The scatter plot (figure 4) shows the mean average time (in hours) from first recognition of dying to time of death for each hospital plotted against the number of Case Note Reviews submitted for that hospital. The mean time for each hospital is generally higher than the national median time (41 hours), due to each trust having a number of high outliers. The hospital results tend towards the national mean time, as the number of responses increases.

Figure 4: (CNR) Hours from recognition of dying to death (n = 5,781)



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

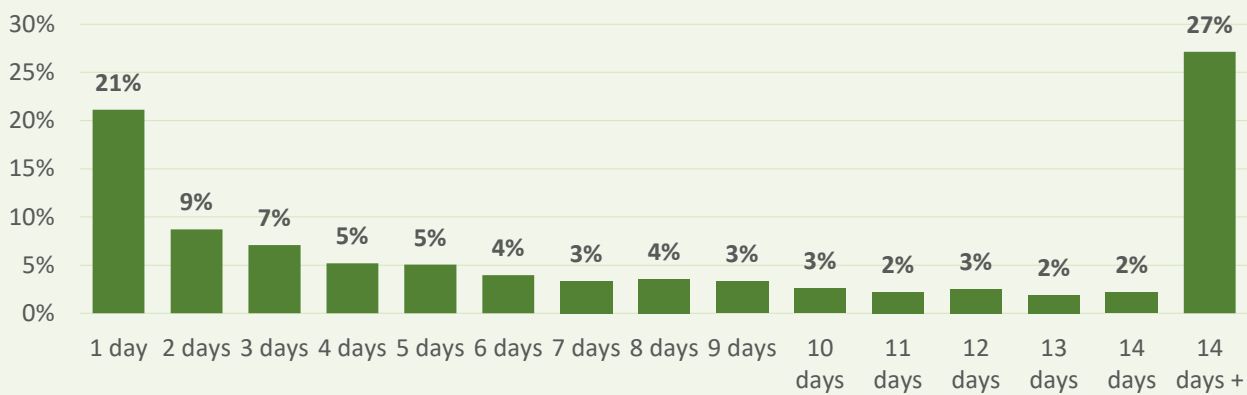


5.1 Recognising the possibility of imminent death



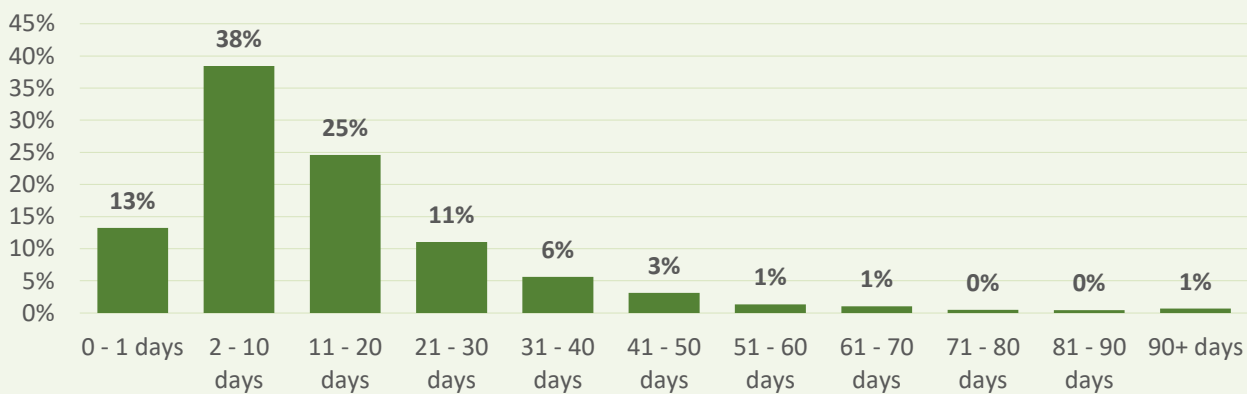
The time from admission to recognition of dying and the total length of stay were also considered in the audit. For over half of the Case Note Review sample (54%), the time between admission and recognition of dying was one week or less (figure 5). The distribution of total length of stay in days is shown in figures 6 and 7, illustrating that 12% of patients are in hospital for more than a month in total for Category 1 deaths and 10% for Category 2 deaths, in their last episode of care leading to death.

Figure 5: Time from admission to recognition time profile (days) (n = 5,769)



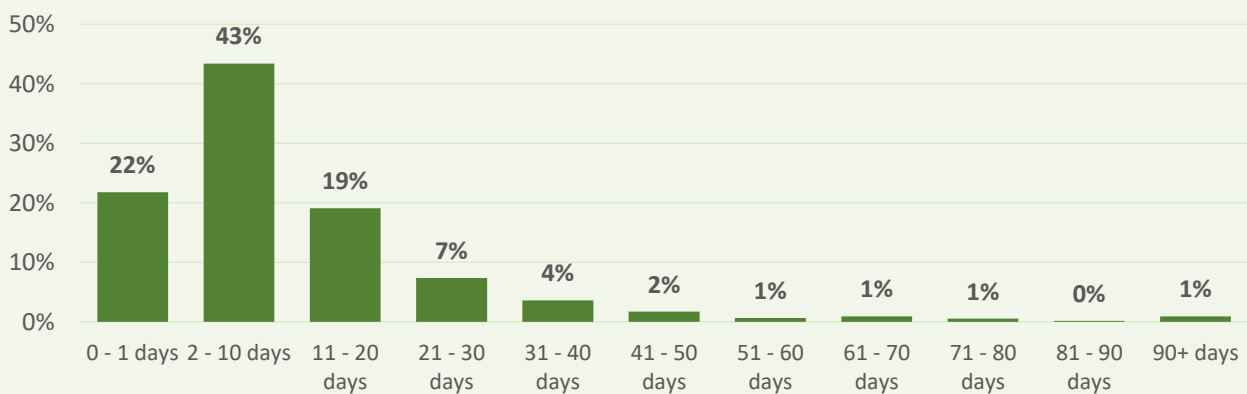
(N.B. Totals may not equal 100% due to rounding)

Figure 6: Time from admission to death (days) Category 1 deaths only (n = 5,904)



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

Figure 7: Time from admission to death (days) Category 2 deaths only (n = 776)



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



5.1 Recognising the possibility of imminent death



Recognising the possibility of imminent death: Families' and others' comments

The NACEL Quality Survey captured narrative comments from people important to the dying person. As noted in section 5.2 and 5.3, 41% (463/1,118) of comments referenced communication. Of these comments, 27% (123/463) were concerned about the recognition of death.

"We were notified early of this decline (6 hours prior to death) so were able to be with him and at that time the staff were excellent in explaining the situation and looking after our needs."

"We knew my father would not want to be told he was dying but she was insistent that he should know."

Furthermore, 6% (62/1,118) of all comments analysed referenced late recognition of dying.

"Felt that family should have been better informed about her imminent passing. The consultants didn't emphasise how soon it would be."

Narrative comments provided by auditors as part of the Case Note Review also suggested some concerns about timeliness of recognition that death may be imminent. Of the narrative comments made about learning points identified when undertaking the Case Note Review, 9% (243/2,727) were about late recognition of dying.

Summary: Recognising the possibility of imminent death

One Chance To Get It Right acknowledges that recognition of imminent death is not an exact science and staff should have an awareness of recognising and communicating uncertainty early in the hospital admission. The Case Note Review showed a high level of recognition of the possibility that the patient might die within the next few hours/days (88%).

In round two, the median time from recognition of dying to death was recorded as 41 hours, compared to 36 hours recorded in the first round of the audit. Whilst early recognition enables planning and discussions to take place, it is not possible or desirable to suggest an 'optimal' median time. Further, in hospitals where earlier recognition is achieved, it is possible that a greater number of people are transferred elsewhere and are therefore not included in this audit of hospital deaths.

However, narrative comments from the Case Note Review suggest opportunities to recognise dying, and plan accordingly, may be being missed in some instances indicating there is still room for improvement in this area.

Recommendation 9

Ensure that staff have an awareness of the possibility or likelihood of imminent death, and acknowledge and communicate to the dying person and people important to them, as early and sensitively as possible. Staff should have an awareness of the importance of recognising uncertainty and communicating uncertain prognosis early in hospital admission and continuing conversations with patients and those important to them at all stages. Ensure that patients who have signs and symptoms that suggest they may be in the last days of life are monitored for changes.

[NACEL 2018 Recommendation 9 - updated for clarity]



5.2 Communication with the dying person



Open and honest communication between staff and the person dying, and those identified as important to them, is critically important to good care. This section presents findings from the Case Note Review and Quality Survey on 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*).

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*).

Notes to Priority 3: The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care (*One Chance To Get It Right*).

Communication with the dying person: Round two (2019/20) summary score



Component metrics:

The round two summary score for 'communication with the dying person' is calculated using the following information collected in the Case Note Review (a weighting of 1.0 is allocated unless indicated otherwise):

Documented evidence:

- the possibility that the patient may die was discussed with the patient
- the patient had the opportunity to be involved in discussing the individualised plan of care
- the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with patient
- risks and benefits of hydration options was discussed with patient
- risks and benefits of nutrition options was discussed with patient

Changes between round one and round two:

The round two summary score has been changed from the round one summary score as follows:

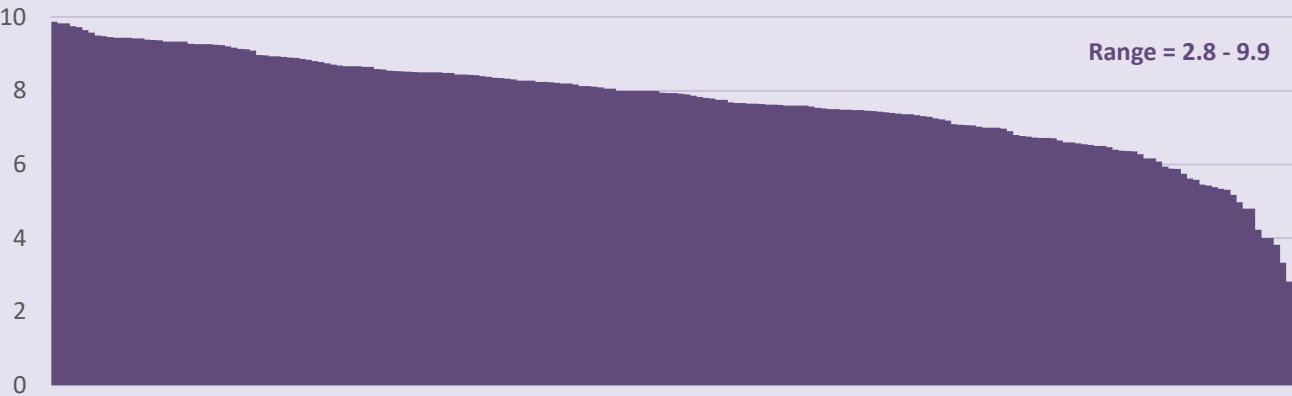
- The metric covering the discussion about the possibility that the patient may die has been moved to this 'communication with the dying person' theme from the section on 'recognising the possibility of imminent death'.
- The question on informing the patient of the professional responsible for their care was not included in round two, and hence is not included in the round two summary score.
- The wording of the remaining questions was updated to provide additional clarity.
- As explained in section 4.2, in round two, the summary scores are calculated from Category 1 deaths only.



5.2 Communication with the dying person



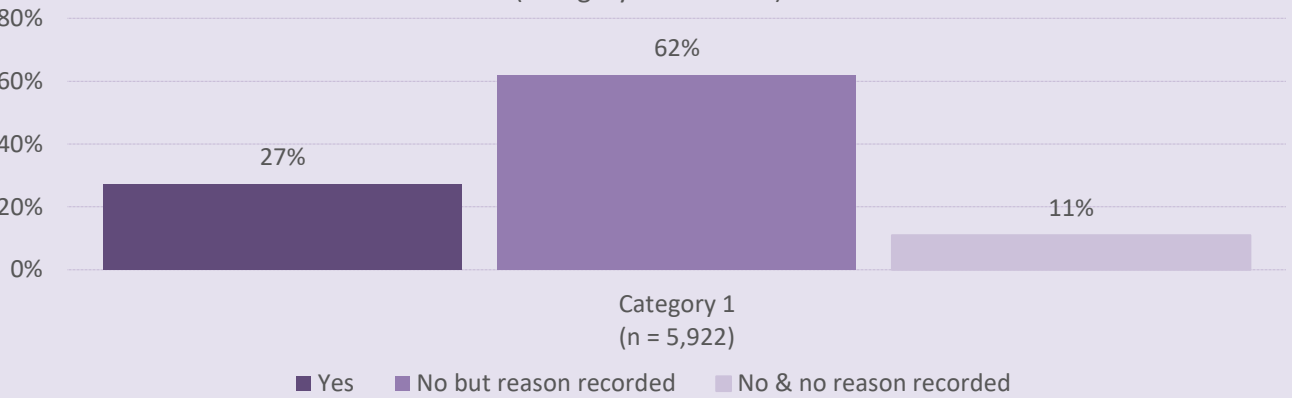
Figure 8: Hospital mean summary scores: Communication with the dying person (submissions n = 200)



The range of hospital mean summary scores for ‘communication with the dying person’ is shown in figure 8. The mean value of the summary score across the whole sample of case notes is 7.8 (n=5,721).

The importance of clearly and sensitively explaining to the patient that they are likely to die is emphasised in the guidance. For Category 1 deaths in round two, there was documented evidence that the possibility that the patient may die had been discussed with the patient, or a reason why not recorded, in 89% of cases (figure 9), compared with 86% in round one.

Figure 9: (CNR) Possibility that the patient may die had been discussed with the patient (Category 2 not asked)



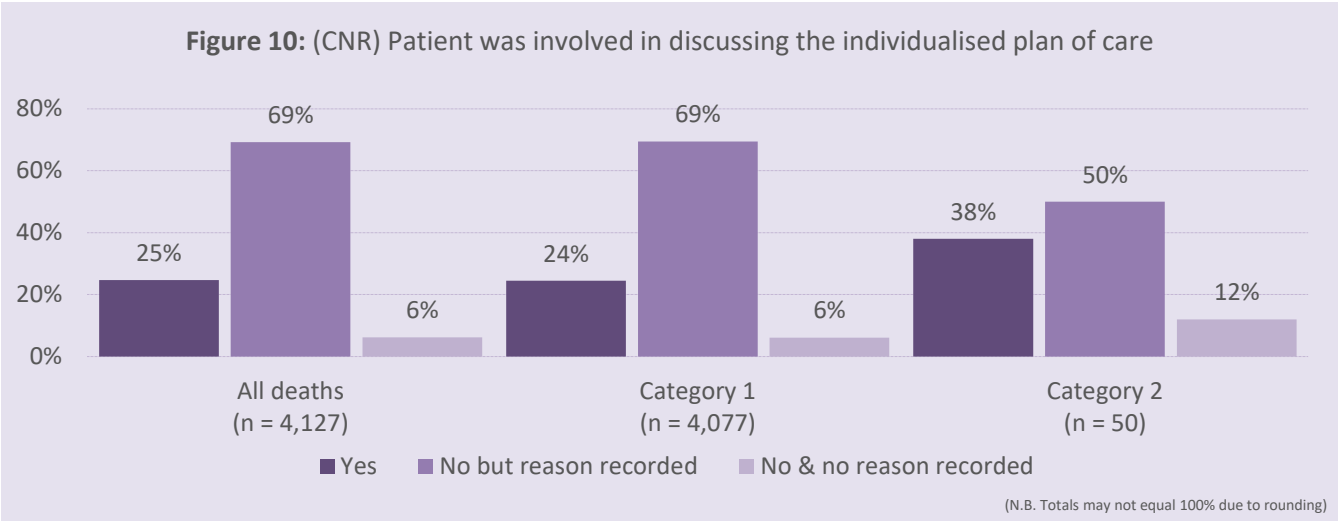
(N.B. Totals may not equal 100% due to rounding)



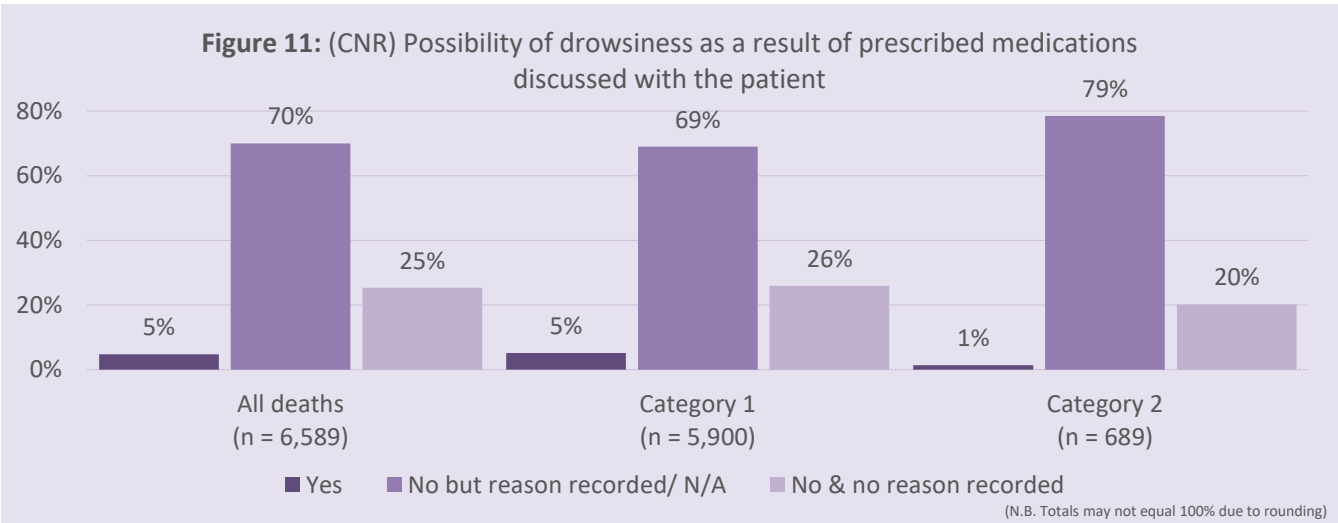
5.2 Communication with the dying person



Care at the end of life should be responsive to the needs and wishes of the person who is dying and those wishes should be captured in an individualised plan of care (see section 5.5). For Category 1 deaths in round two, where an individualised plan of care existed (see section 5.5), there was documented evidence that the patient had the opportunity to be involved in discussing the plan of care, or a reason why not recorded in 93% of cases (figure 10). This compares with 69% in round one. This change may be due to clarification of the question in round two of NACEL. In round one, the term ‘individualised end of life care plan’ was used, which some respondents may have interpreted as referring to a specific end of life template. In round two, it was clarified that the plan could be part of other care plans, as long as end of life care needs were covered (see also section 5.5).



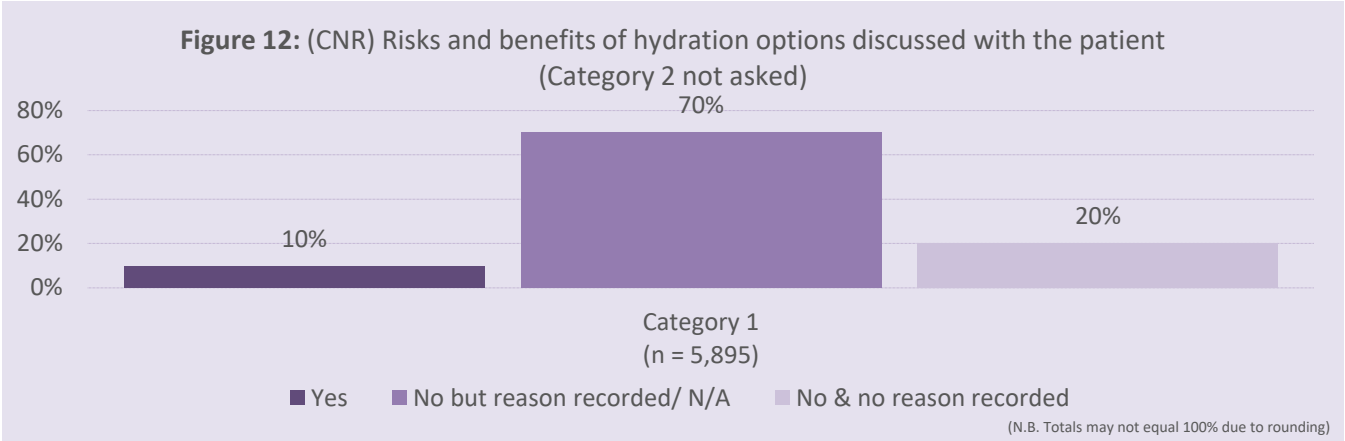
For Category 1 deaths in round two, there was evidence that the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with the patient, or a reason why not recorded, in 74% of cases (figure 11), compared to 70% in round one.



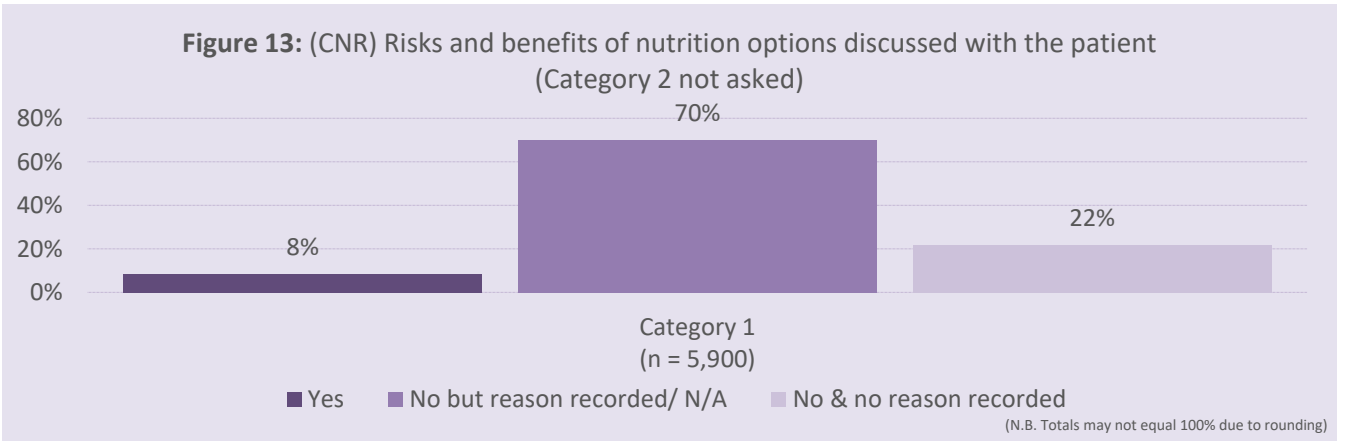
5.2 Communication with the dying person



Discussion about the risks and benefits of hydration options with the patient were recorded, or a reason why not documented, in 80% of cases in round two (figure 12), compared to 69% in round one.



The risks and benefits of nutrition options were documented as being discussed with the patient, or a reason why not documented, in 78% of cases in round two (figure 13), compared to 69% in round one. In both cases, instances where there was no documented discussion, and no reason why not recorded, have fallen from about a third to about one fifth of cases.



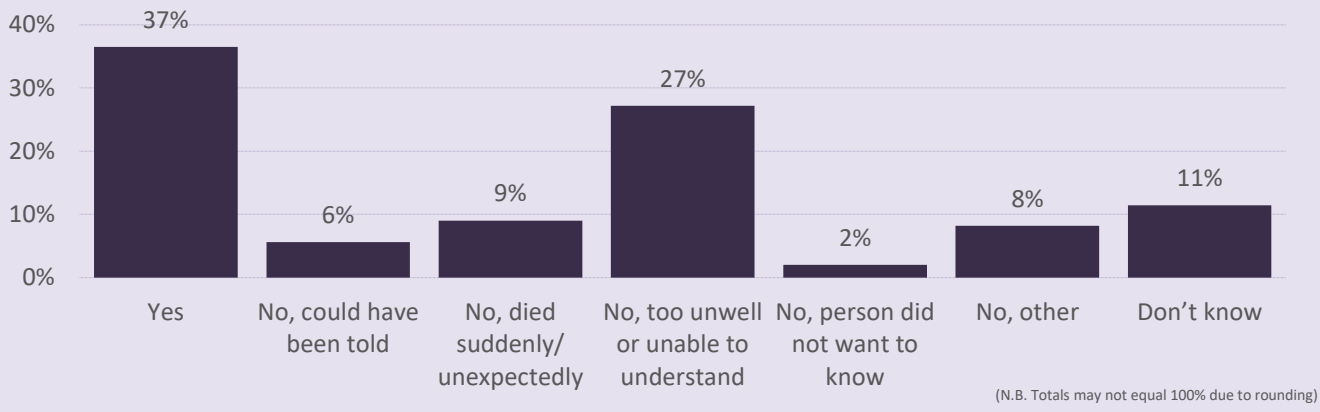
In addition to the indicators used in the summary score and discussed above, the following results from the Quality Survey are relevant to communication with the dying person.

Respondents to the Quality Survey in round two stated that a member of staff explained to the person that he/she was likely to die in the next few days, the person was too unwell to be told or died suddenly, in 73% of cases (figure 14), compared to 68% (yes or discussion not possible) in round one. In 6% of cases, the respondent stated the patient wasn't told but could have been (figure 14), compared to 10% in round one. In comparing Quality Survey results between years, the changes to the way the survey was administered, explained in section 1.5, should be noted.





Figure 14: (QS) A member of staff explained to the person that they were likely to die in the next few days (n = 1,574)



A further question from the Quality Survey on whether the respondent felt staff looking after the person communicated sensitively with him/her is considered in section 5.6, ‘families’ and others’ experience of care’.

Communication with the dying person: Families’ and others’ comments

As noted previously, from the NACEL Quality Survey, 41% (463/1,118) of all comments referenced communication, of these, 44% (204/463) were analysed as positive and 56% (259/463) negative. Out of all comments about communication, 32% (150/463) were about communication with the patient.

“I was very impressed how the staff spoke to him and cared for him with such empathy and dignity.”

“Dr XXX was excellent, very straight talking and told the what the options were and left the decisions to the patient. Thank you to her for excellent care. The other members of staff were also good.”

“The people who came around during meal times, asked my father what he wanted to order. At this point, my father was unconscious and it was clearly written at the front of the door stating that he is 'nil by mouth'. This was very upsetting for everyone in our family.”

“XX was not told of death till arrived in the hospital, that could have been handled differently. Very upsetting for XX. XX wanted to die at home. Staff knew XX was poorly could have communicated this better.”

Narrative comments provided by auditors as part of the Case Note Review also suggested some concerns about communication. Of the narrative comments made about learning points identified when undertaking the Case Note Review, 13% (356/2,727) related to a need for improvement in communication. Comments were also raised by auditors on the identification of areas of excellent practice. Of these comments, 24% (717/2,997) related to excellent communication with both the dying person and those important to them.



5.2 Communication with the dying person



Summary: Communication with the dying person

In 89% of Category 1 cases there was evidence in the case note that a discussion about dying had taken place with the patient, or a reason why not recorded, compared with 87% in round one.

The improvement to 93% of cases, from 69% in round one, where there was a documented discussion about the individualised plan of care, where such a plan existed, may be due to the clarification of the question for round two. For conversations about drowsiness as a result of medications, hydration and nutrition options, the Case Note Review showed an improvement in the proportion of cases where a documented discussion had taken place, or a reason why not had been recorded.

From section 5.6 'Families' and others' experience of care', 7% of respondents disagreed with the statement 'I felt that staff looking after the person communicated sensitively with him/her' (see figure 56).

Recommendation 6

Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with the dying person and people important to them in the last days and hours of life. Providers should review national resources to support communication skills training that are available, including serious illness communication skills training days, guidance from professional bodies, learning outcomes, e-learning programmes such as e-ELCA and modules accessed via Electronic Staff Record (ESR), such as the All Wales ESR Care Decisions Guidance module.

[NACEL 2018 Recommendation 6 - updated for clarity]



5.3 Communication with families and others



As noted in section 5.2, open and honest communication between staff and the person dying, and those identified as important to them, is critically important to good care. In this section, findings from the Case Note Review and Quality Survey, on communication with those important to the dying person, are presented.

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*).

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*).

Notes to Priority 3: The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care (*One Chance To Get It Right*).

Communication with families and others: Round two (2019/20) summary score

Communication with
families and others



6.9

Component metrics:

The round two summary score for 'communication with families and others' is calculated using the following information collected in the Case Note Review (a weighting of 1.0 is allocated unless indicated otherwise):

Documented evidence:

- the possibility that the patient may die was discussed with the families and others
- families and others had the opportunity to be involved in discussing the patient's individualised plan of care
- families and others were notified that the patient was about to die
- the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with families and others (weighting 0.5)
- risks and benefits of hydration options was discussed with families and others
- risks and benefits of nutrition options was discussed with families and others (weighting 0.5)

Changes between round one and round two:

The round two summary score has been changed from the round one summary score as follows:

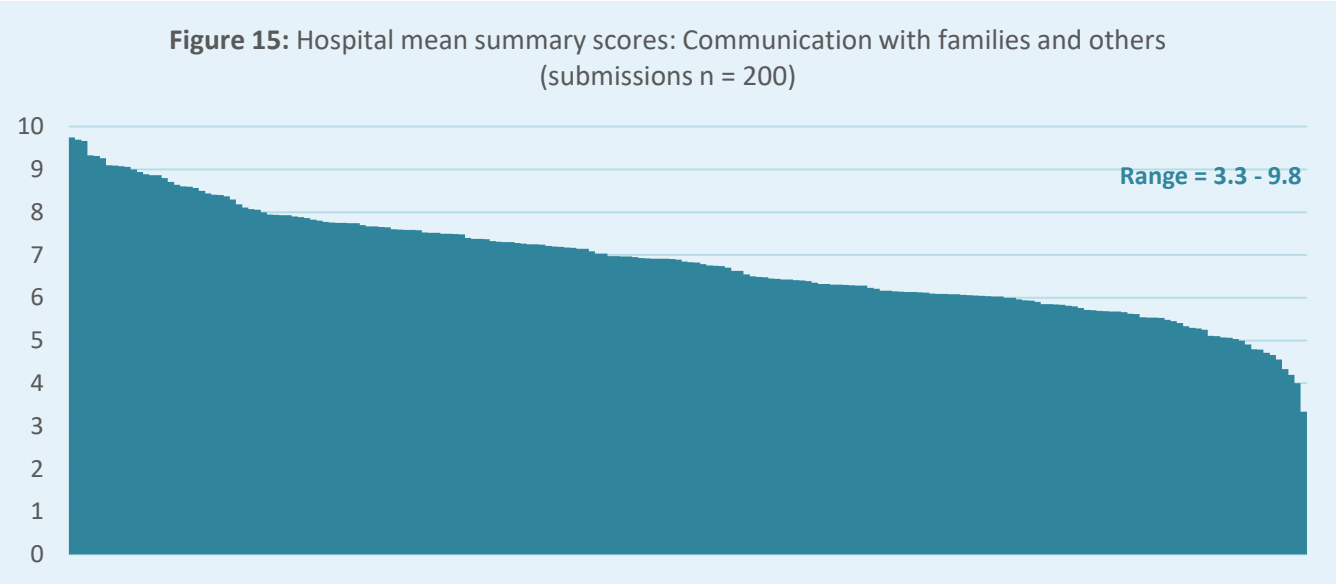
- The metric covering the discussion about the possibility that the patient may die has been moved to this 'communication with the families and others' theme from the section on 'recognising the possibility of imminent death'.
- The question on informing the families and others of the professional responsible for their care was not included in the Case Note Review in round two, and hence is not included in the round two summary score. This question was, however, included in the Quality Survey and is reported in this section.



5.3 Communication with families and others

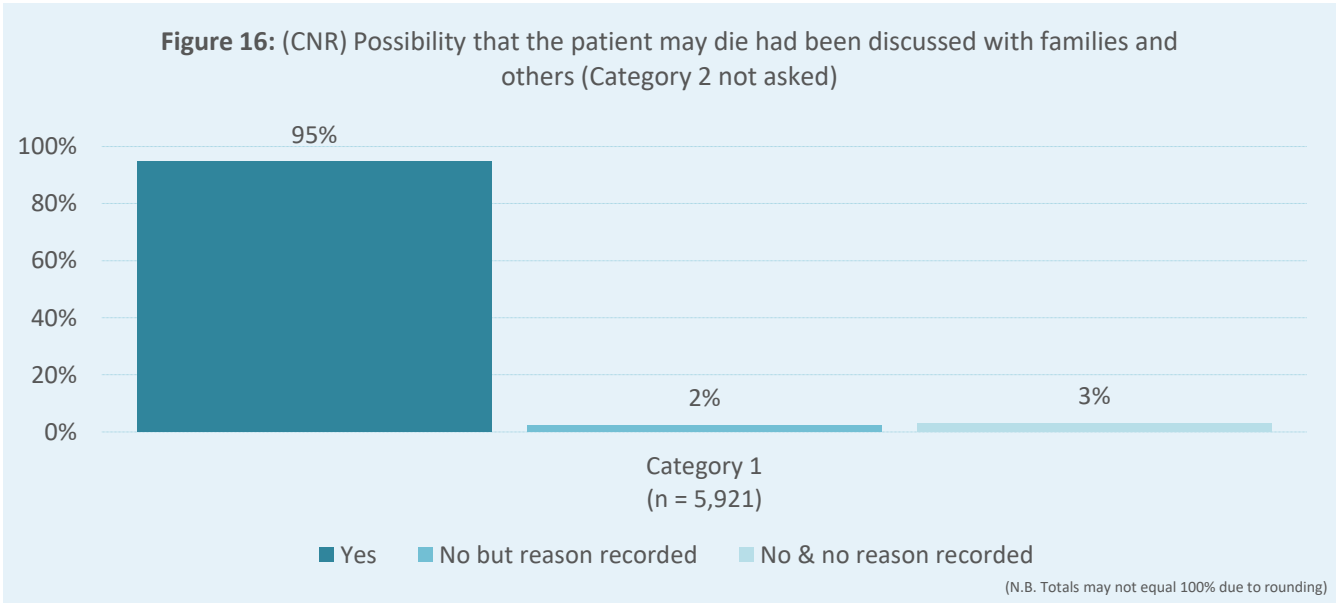


- The wording of the remaining questions was updated to provide additional clarity.
- As explained in section 4.2, in round two, the summary scores are calculated from Category 1 deaths only.



The range of hospital mean summary scores for ‘communication with families and others’ is shown in figure 15. The mean value of the summary score across the whole sample of case notes is 6.9 (n=5,704).

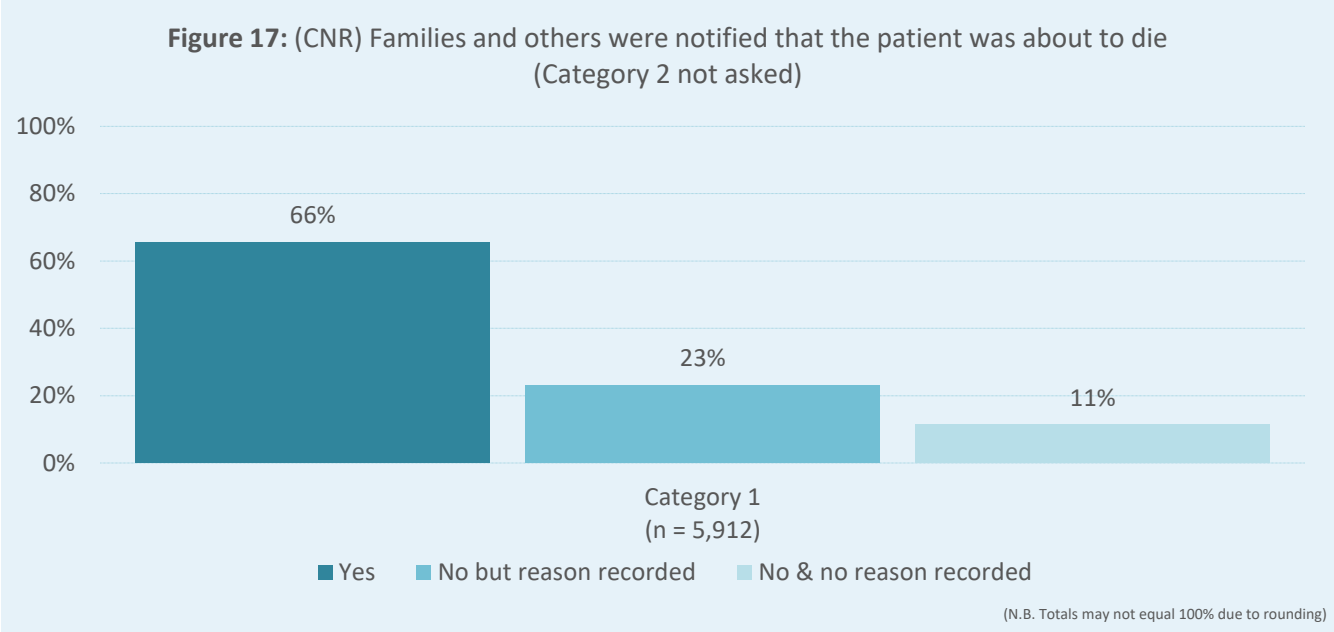
Given that the possibility that a person may be dying may only be recognised a day or two before death (section 5.1), it is more likely that key conversations will take place with those important to them, than with the dying patient themselves, and this is borne out by the audit results. For Category 1 deaths in round two, there was documented evidence that the possibility that the patient may die had been discussed with those important to them, or a reason why not recorded, in 97% of cases (figure 16), compared with 96% in round one.



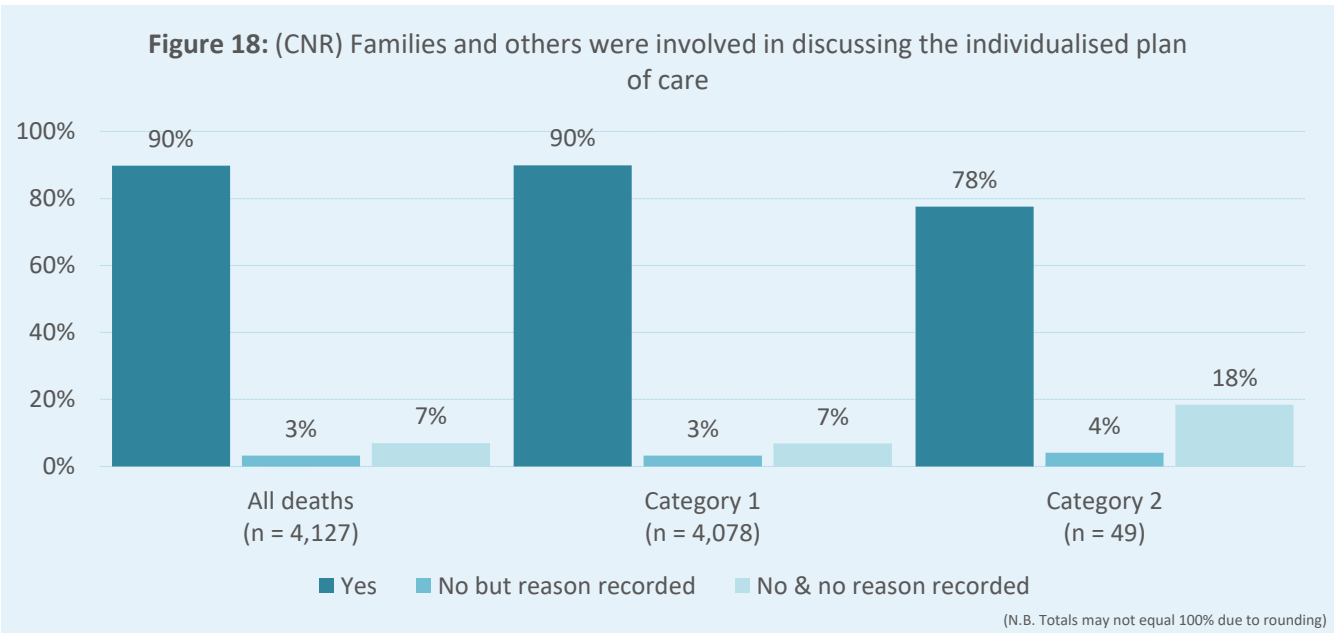
5.3 Communication with families and others



In round two, for Category 1 deaths, evidence that those important to the dying person were notified of the patient was about to die was recorded, or a reason why not documented, in 89% of cases (figure 17), compared 87% in round one.



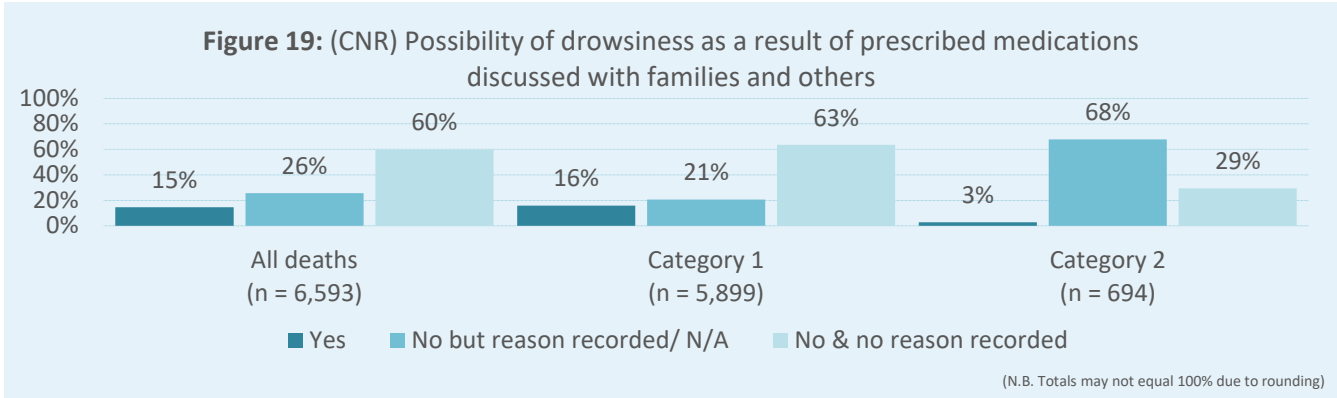
Where an individualised plan of care existed (see section 5.5), there was documented evidence, for Category 1 deaths in round two, that families and others had the opportunity to be involved in discussing the plan of care, or a reason why not recorded, in 93% of cases, (figure 18), compared with 76% in round one. As for the previous theme, ‘communication with the dying person’, this change may be due to clarification of the question in round two of NACEL.



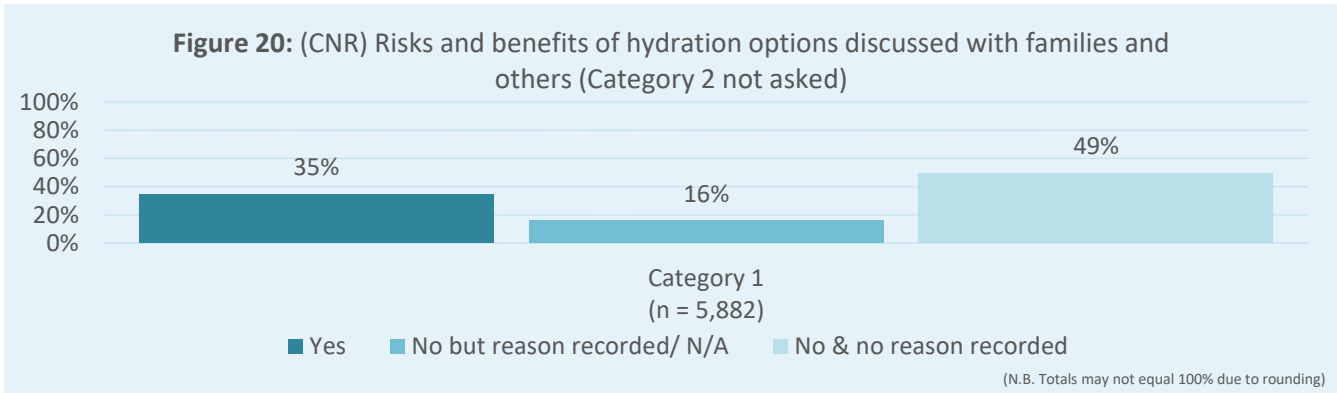
5.3 Communication with families and others



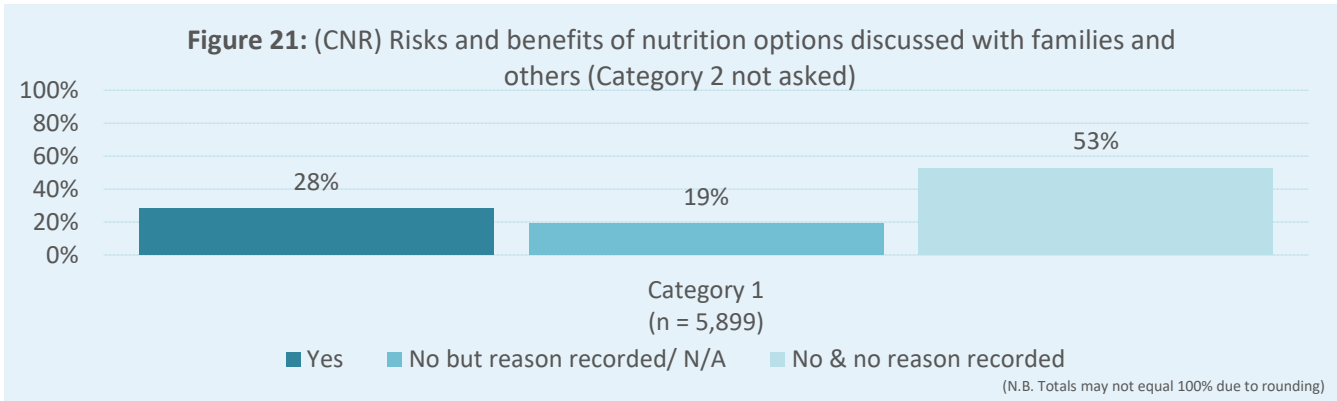
For Category 1 deaths in round two, there was evidence that the possibility of drowsiness, if likely as a result of prescribed medications, was discussed with families and others, or a reason why not recorded, in 37% of cases (figure 19), compared to 26% in round one.



Discussion about the risks and benefits of hydration options with those important to the dying person were recorded, or a reason why not documented, in 51% of cases in round two (figure 20), compared to 39% in round one.



The risks and benefits of nutrition options were documented as being discussed with those important to the dying person, or a reason why not documented, in 47% of cases in round two (figure 21), compared to 33% in round one. For these two areas, instances where there was no documented discussion, and no reason why not recorded, has fallen from about two-thirds (round one) to about half of cases (round two).

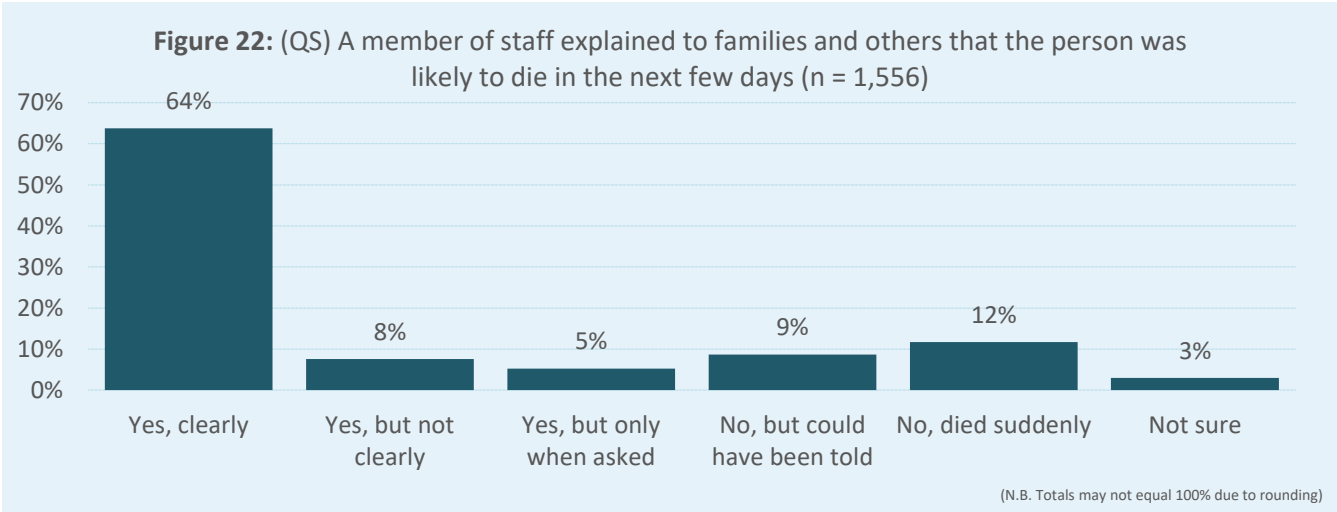


5.3 Communication with families and others



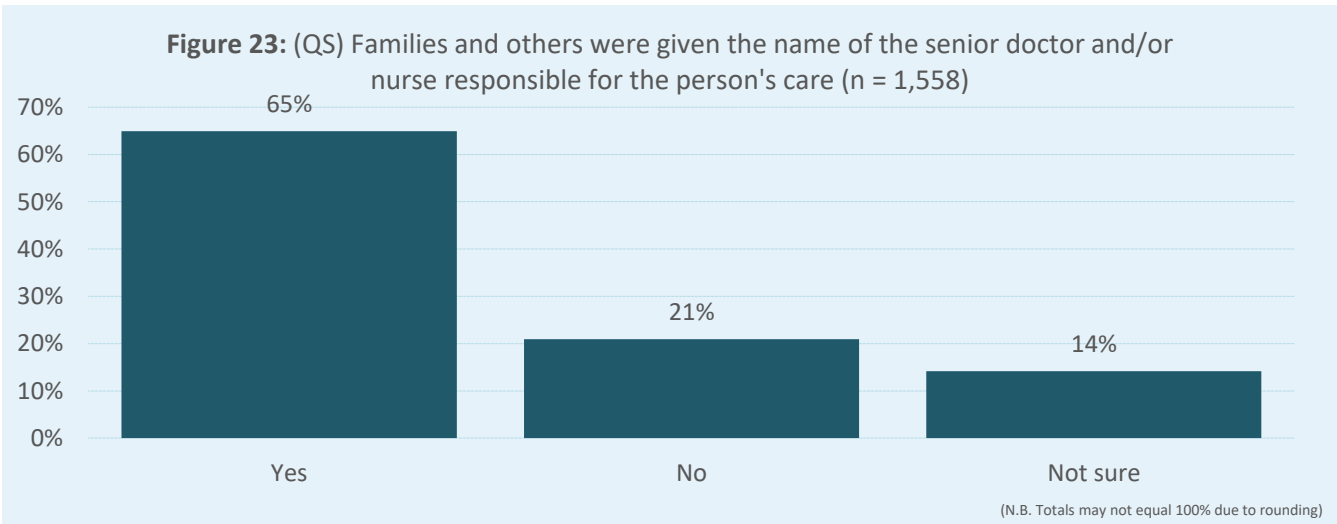
In addition to the indicators used in the summary score and discussed above, the following results from the Quality Survey are relevant to communication with families and others.

Respondents to the Quality Survey in round two stated that a member of staff explained to them clearly that he/she was likely to die in the next few days, or the person died suddenly, in 76% of cases (figure 22). In 9% of cases, the respondent stated that they weren't told but could have been (figure 22), compared to 14% in round one.



A further question from the Quality Survey on whether those important to the dying person were communicated to by staff in a sensitive way, is considered in section 5.6, 'Families' and others' experience of care'.

From the Quality Survey in round two, people important to the dying person reported being given the name of the senior doctor and/or nurse responsible for his/her care in 65% of cases (figure 23).



As mentioned in section 5.2, 13% (356/2,727) of narrative comments provided by auditors as part of the Case Note Review identified communication as a learning point, whilst 24% (717/2,997) of auditors comments about areas of excellent practice related to communication.



5.3 Communication with families and others



Communication with the dying person: Families' and others' comments

As noted in section 5.2, from the NACEL Quality Survey, 41% (463/1,118) of all comments referenced communication, of these, 44% (204/463) were analysed as positive and 56% (259/463) negative. Out of all the comments about communication, 57% (262/463) were about communication with families and others.

"My brother had a learning disability and staff were very supportive of his communication needs and the need to communicate with me on his behalf at times."

".... the staff explained everything that was going on, arranged for us not to have to pay for parking as we were there for long periods of time, gave us money off vouchers for meals in the canteen, and took time out to explain my mothers care and symptoms and what we could expect as time went by."

"I didn't feel I was kept in the picture enough - the communication was not direct enough - I like things in black and white."

"Communication with the doctors was almost non-existent."

Summary: Communication with families and others

As in the 'communication with the dying person' theme, the findings of the second round of NACEL suggest there has been an improvement in the documentation of discussions with the families and others, since round one of the audit. There was documented evidence in the case note that the possibility that the patient may die had been discussed with those important to the dying person in nearly all cases. There was also high compliance with documenting discussions with families and others about the individualised plan of care, where such a plan existed, although the large change on this metric may be due to the clarification of the question for round two.

For conversations about drowsiness as a result of medications, the Case Note Review showed a reduction in the proportion of cases where no discussion was documented, and no reason why not recorded, from around three quarters to two thirds of cases. For discussions around hydration and nutrition, there was a reduction in the cases of no documentation from around two thirds to a half of cases.

Three quarters of respondents to the Quality Survey felt it was explained to them clearly that the person was likely to die in the next few days or the person died suddenly (section 5.6). 8% of respondents disagreed with the statement 'I was communicated to by staff in a sensitive way' (see figure 57).

Recommendation 6

Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with the dying person and people important to them in the last days and hours of life. Providers should review national resources to support communication skills training that are available, including serious illness communication skills training days, guidance from professional bodies, learning outcomes, e-learning programmes such as e-ELCA and modules accessed via Electronic Staff Record (ESR), such as the All Wales ESR Care Decisions Guidance module.

[NACEL 2018 Recommendation 6 - updated for clarity]



5.4 Needs of families and others



People important to the dying person have their own needs, which they, and others, can overlook in times of distress. In this section, the results from the Quality Survey pertaining to the needs of the family and others are presented.

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*).

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*).

Needs of families and others: Round two (2019/20) summary score

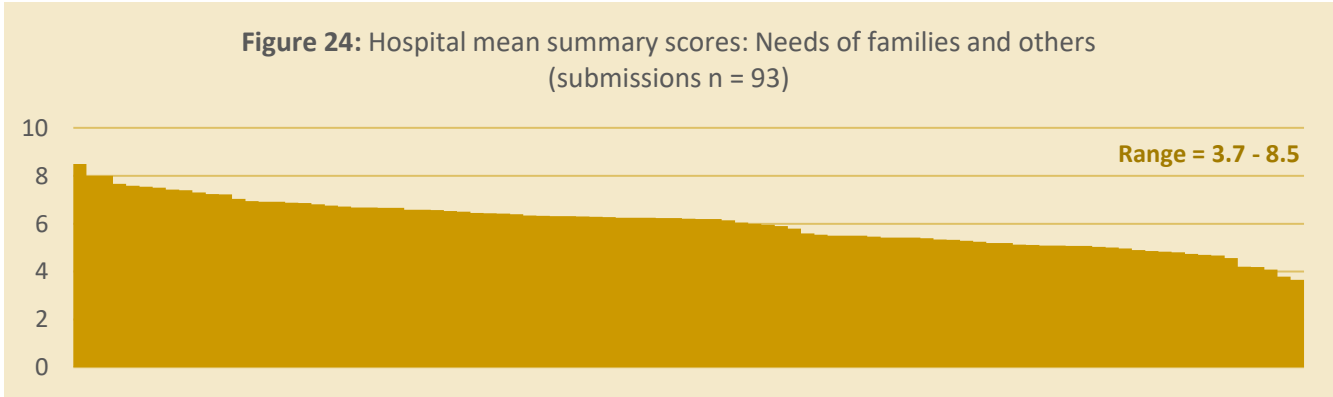


Component metrics:

For round two, the ‘needs of families and others’ summary score has been calculated from metrics from the Quality Survey, rather than from the Case Note Review, as in round one. Families and others were felt to be best placed to comment on whether their needs had been taken into account, since this would not necessarily be well documented in the patient’s notes.

The summary score for the ‘needs of families and others’ is calculated using responses to the following:

- I was asked about my needs
- I was given enough emotional help and support by staff
- I was given enough practical support (for example with finding refreshments and parking arrangements)
- I was given enough spiritual/religious/cultural support
- I was kept well informed and had enough opportunity to discuss his/her condition and treatment with staff



The range of hospital mean summary scores for ‘needs of families and others’ is shown in figure 24. The mean value of the summary score across the whole sample of case notes is 6.0 (n=1,525).

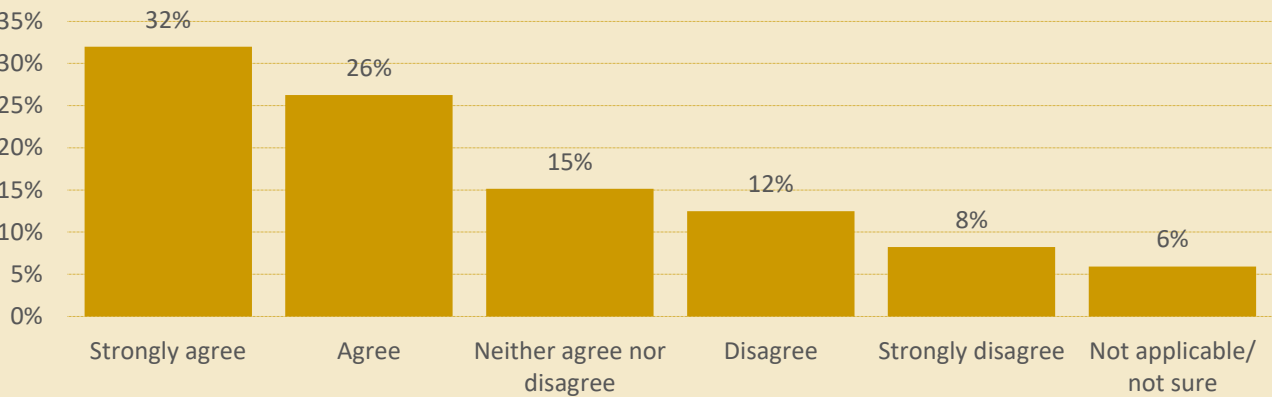


5.4 Needs of families and others



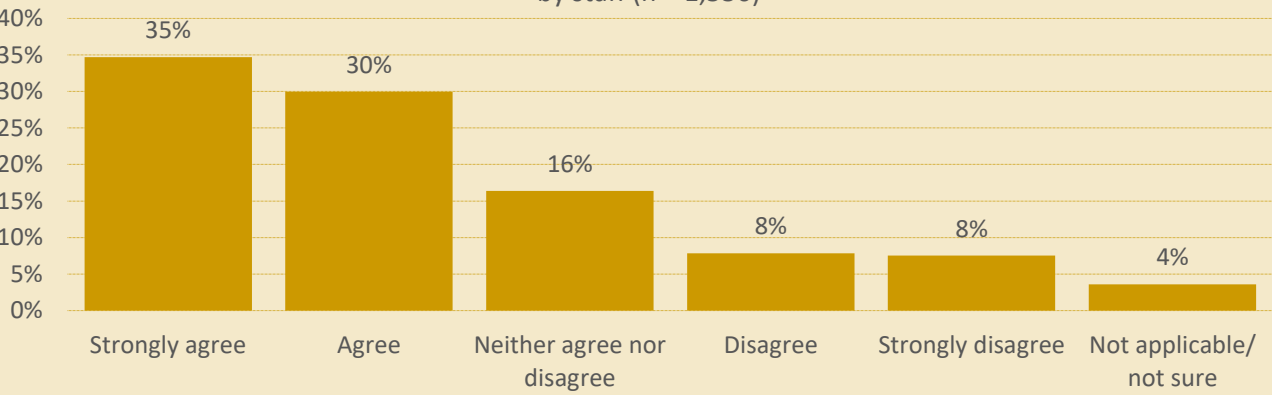
Respondents to the Quality Survey agreed they were asked about their needs in 58% of cases, and disagreed in 20% of cases (figure 25). This result is in line with the round one result from the Case Note Review where there was documented evidence that the needs of families and others were asked about in 60% of cases. In round two, 65% agreed they were given enough emotional help and support by staff, with 16% disagreeing (figure 26).

Figure 25: (QS) The families and others were asked about their needs (n = 1,554)



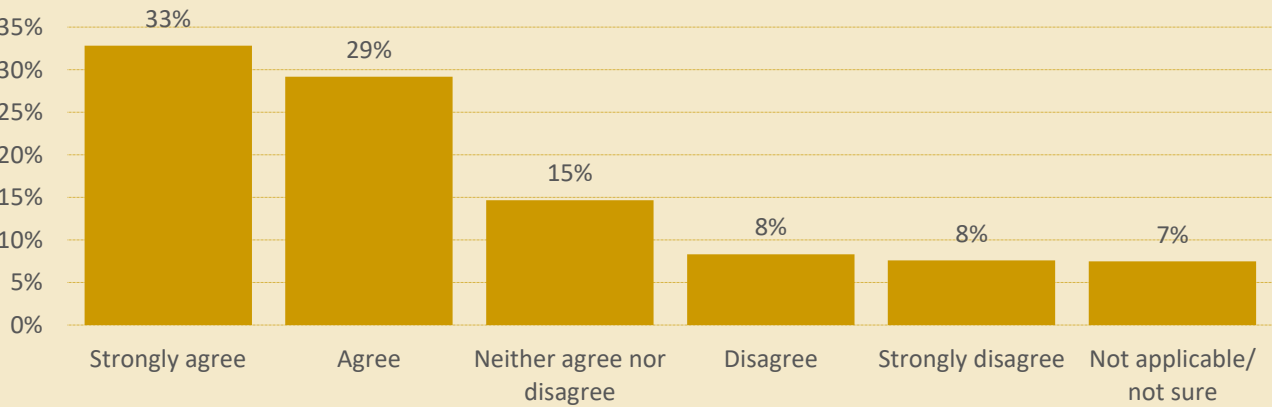
(N.B. Totals may not equal 100% due to rounding)

Figure 26: (QS) The families and others were given enough emotional help and support by staff (n = 1,556)



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

Figure 27: (QS) The families and others were given enough practical support (n = 1,556)



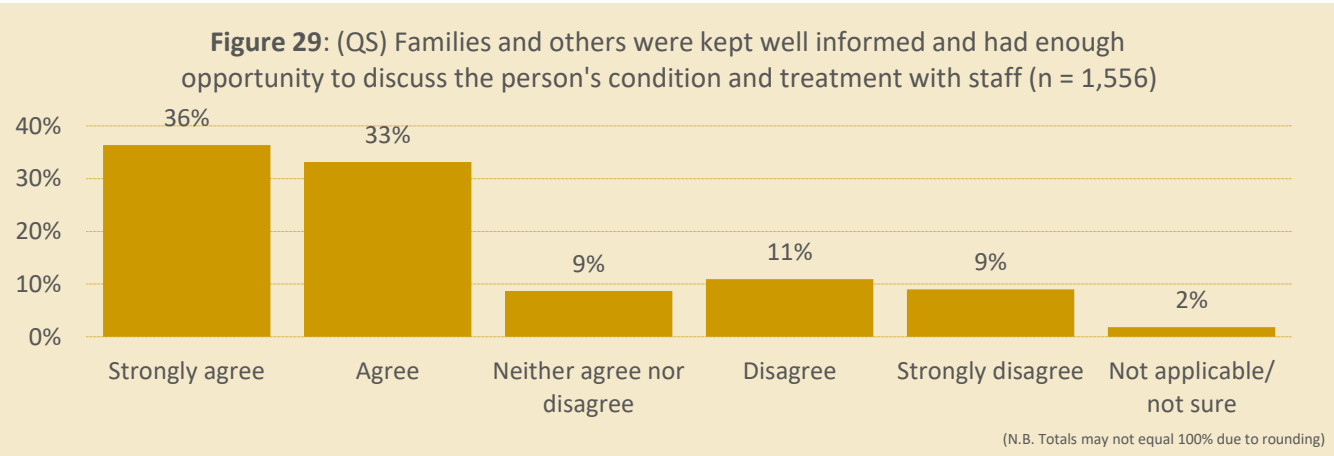
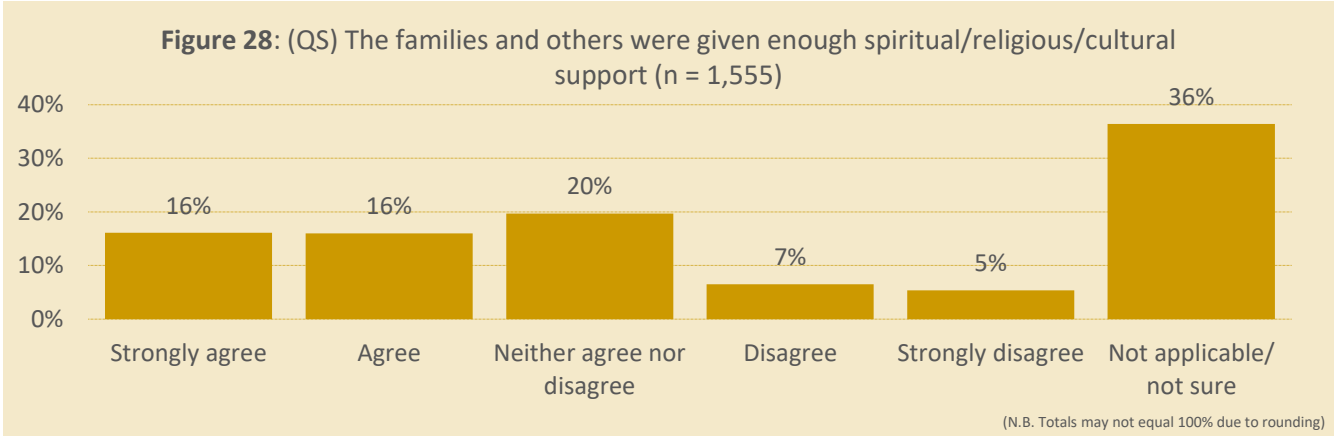
(N.B. Totals may not equal 100% due to rounding)



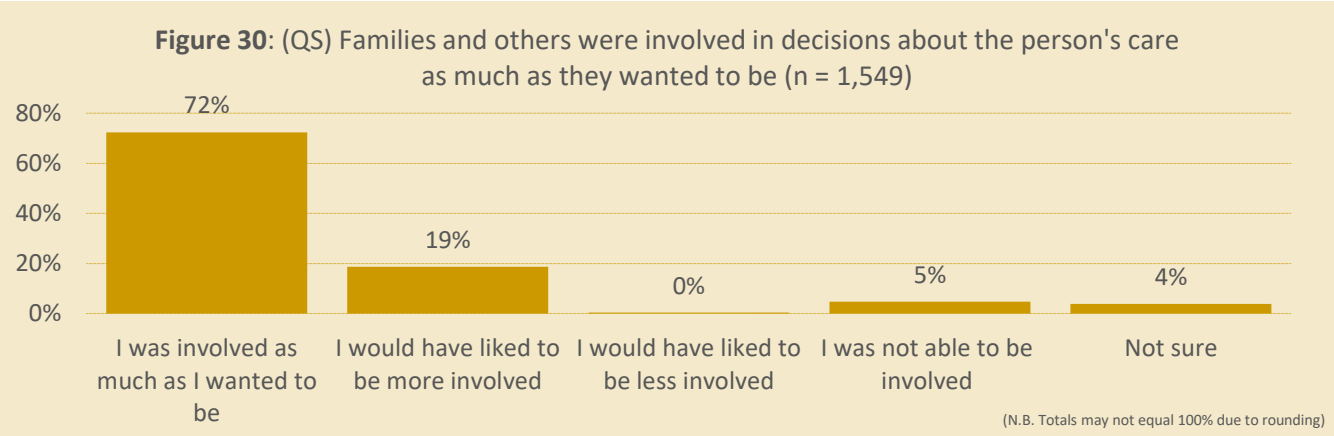
5.4 Needs of families and others



On practical issues, 62% agreed they were given enough support and 16% disagreed (figure 27) and on spiritual/religious/cultural matters 32% agreed they were given enough support, and 12% disagreed (figure 28). In the latter instance, 56% were neutral or felt the question was not applicable (figure 28). Respondents agreed they were kept well informed and had enough opportunity to discuss his/her condition and treatment with staff in 69% of cases, and disagreed in 20% of cases (figure 29).



In addition to the indicators used in the summary score, figure 30 reflects the families' and others' involvement in decision making with 19% of respondents reporting they would have liked to be more involved in decisions about the person's care and treatment.



5.4 Needs of families and others



Needs of families and others: Families' and others' comments

From the NACEL Quality Survey narrative responses, 28% (316/1,118) referenced the needs of the family. Of these comments, 62% (196/316) were analysed as positive and 38% (120/316) negative. Out of all comments related to needs of the family, 16% (51/316) related to support after death and 50% (157/316) referenced practical areas of care delivered to the family and others. Of these comments:

- 15% (24/157) were about refreshments/food for relatives
- 20% (31/157) mentioned parking.
- 25% (40/157) related to provision of the death certificate
- 42% (66/157) related to overnight stays/places for the relatives to stay

"After he died we were told exactly what would happen and given time to sort ourselves out, no-one rushed us and we weren't made to feel we had to go."

"As a family we felt well supported. The nurses were excellent and went out of their way to make sure we were as comfortable as we could be while staying overnight with Mum."

"After the person had died we (the relatives) were put in a room, best described as a cupboard, with no information whilst waiting for transport home. We found the care and support severely lacking in all respects."

Summary: Needs of families and others

In round two, the identification, and addressing of, needs of families and others have been assessed using the Quality Survey rather than the Case Note Review. It is not, therefore, possible to compare round two with round one results.

58% of families and others responding to the Quality Survey felt that their needs had been asked about. Almost two-thirds of respondents to the Quality Survey felt that they had enough emotional and practical support. There was less concern amongst respondents on spiritual/religious/cultural support, with over half neither agreeing nor disagreeing, or stating this question was not applicable.

Recommendation 7

Put systems in place to ensure the needs of people important to the dying person are assessed and addressed in a timely manner, both before and after death. Specific senior, strategic and operational responsibility is required. Assessment and delivery of needs should cover emotional/psychological, spiritual/religious/cultural, social and practical needs.

[NACEL 2018 Recommendation 7 - updated for clarity]



5.5 Individualised plan of care



The *Five priorities for care* of the dying person make clear that there must be an individualised plan of care. The plan for end of life care should be documented and should be part of other care planning processes. The dying person and those important to them should have the opportunity to discuss the plan, covered in section 5.2, 'Communication with the dying person' and section 5.3, 'Communication with families and others'.

In this section, the results from the Case Note Review and the Quality Survey relating to the individualised plan of care are presented.

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*).

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: Round two (2019/20) summary score



Component metrics:

For round two of NACEL, the summary score for 'individualised plan of care' is calculated using the following information collected in the Case Note Review (a weighting of 1.0 is allocated unless indicated otherwise):

- documented evidence that patient had an individualised care plan (weighting 0.5)
- regular review of patient and plan of care (weighting 0.5)
- documented evidence of preferred place of death as indicated by patient
- documented review of (weighting 0.25 each):
 - routine recording of vital signs
 - blood sugar monitoring
 - administration of oxygen
 - administration of antibiotics
 - routine blood tests
 - other medication
- documented assessment of hydration status once dying phase recognised
- documented assessment of nutrition status once dying phase recognised
- holistic assessment of needs covering 14 domains (weighting 0.25 each)

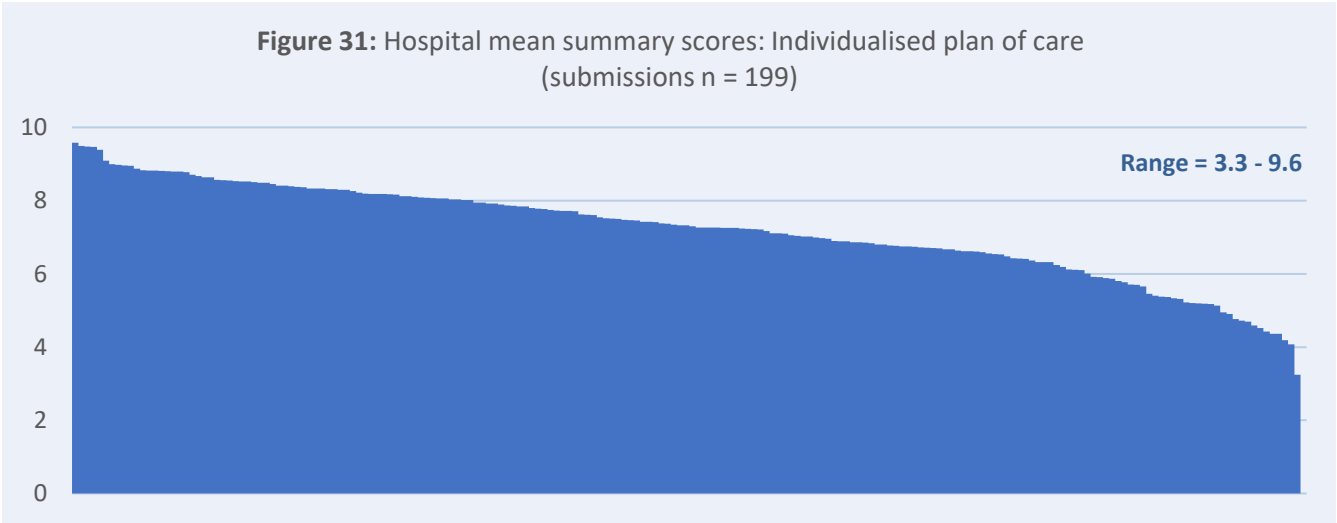


5.5 Individualised plan of care



The round two summary score has been changed from the round one summary score as follows:

- The wording of the existence, and review, of the individualised plan of care, the preferred place of death and hydration and nutrition questions, was updated to clarify the questions.
- Routine blood tests and other medication have been added to the list of tests and treatments reviewed for the benefit of starting, stopping or continuing the interventions.
- Under the assessment of needs domains, spiritual/religious and cultural needs have been combined, as have social and practical needs, reducing the total number of domains considered from 16 to 14.
- As explained in section 4.2, in round two, the summary scores are calculated from Category 1 deaths only.



The range of hospital mean summary scores for ‘individualised plan of care’ is shown in figure 31. The mean value of the summary score across the whole sample of case notes is 7.2 (n=5,294).

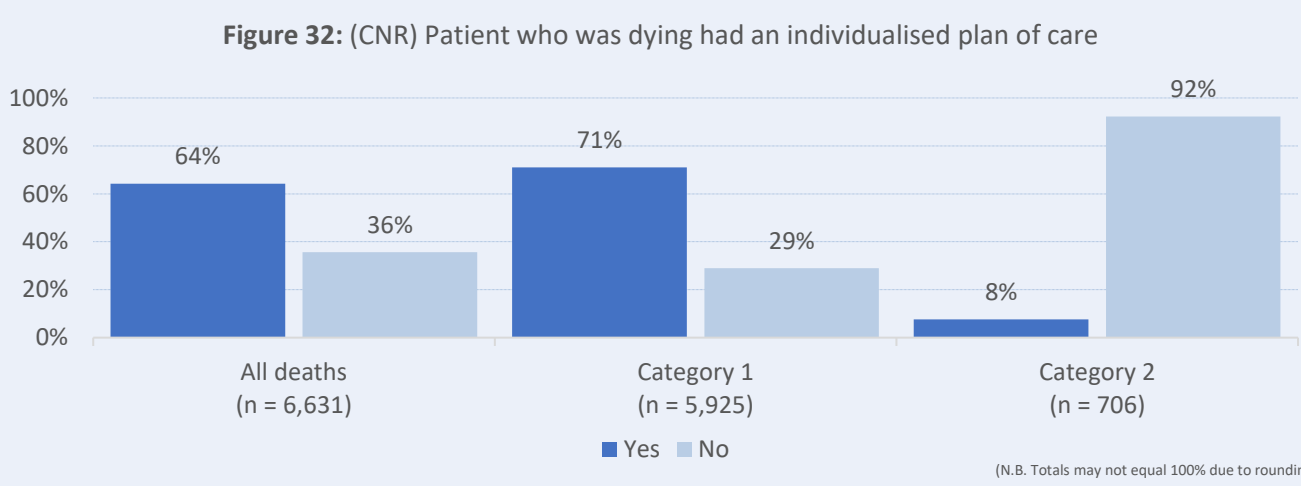




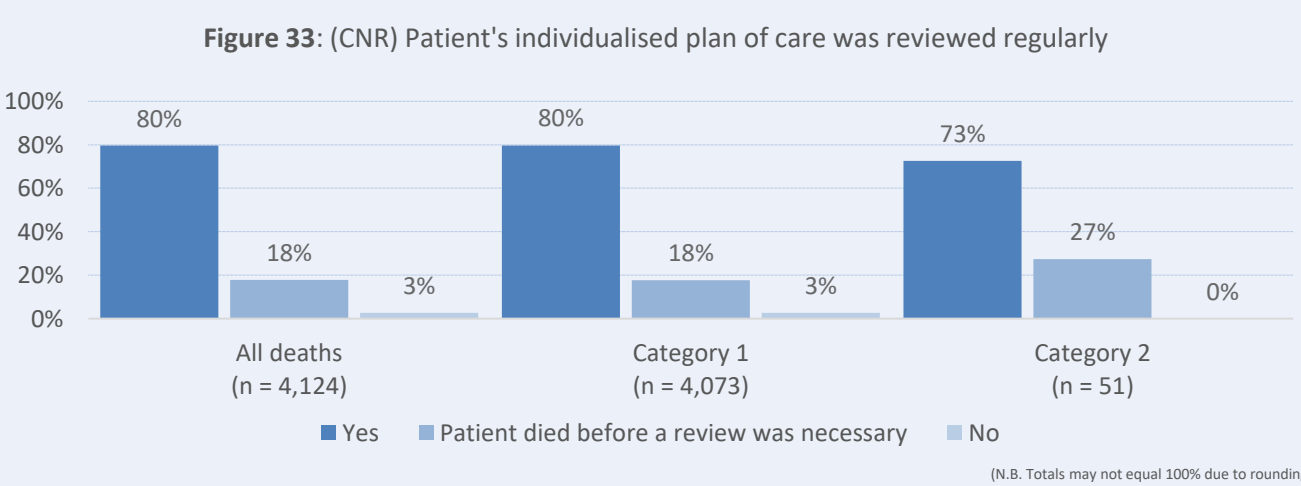
5.5 Individualised plan of care

For Category 1 deaths in round two, there was documented evidence that the patient who was dying had an individualised plan of care in 71% of cases (figure 32), compared with 67% in round one. Category 2 deaths are much less likely to have a plan in place (8%) (figure 32).

In round one, the phrase ‘end of life care plan’ was used in the key question about the existence of a plan of care, possibly leading auditors to respond ‘no’ where a specific ‘end of life’ template was not being used. For round two, the question was re-phrased to ask ‘Is there documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs?’. The following additional guidance was provided; ‘Please respond ‘Yes’ if a plan of care personalised to the individual was used which covered their specific end of life care needs such as food and drink, symptom control, psychological, social and spiritual support. This plan of care does not need to be a separate document to the general clinical and nursing care’.



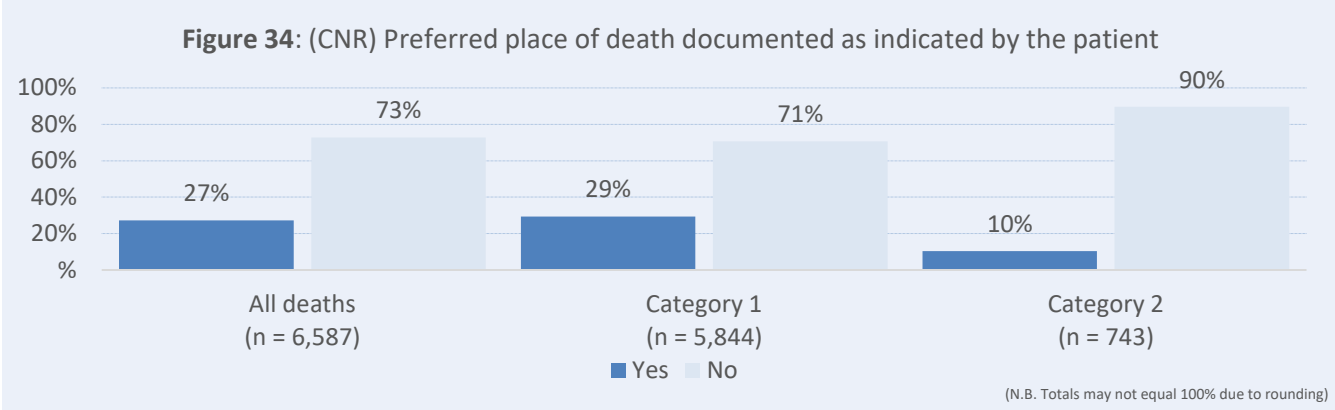
As in round one, narrative comments provided by auditors as part of the Case Note Review suggested some concerns about the existence and quality of care plans. Of comments made about learning points identified when undertaking the Case Note Review, 21% (563/2,727) were about care planning, including no, or lack of a clear care plan or poor documentation of care plan. In the second round of NACEL, for Category 1 deaths, where a plan existed, the patient and their plan of care was reviewed regularly, or the patient died before the review was necessary, in 98% of cases (figure 33), compared with 95% in round one. For Category 2 deaths, in the small number of instances where a plan existed, 100% were reviewed or the patient died before the review was necessary.



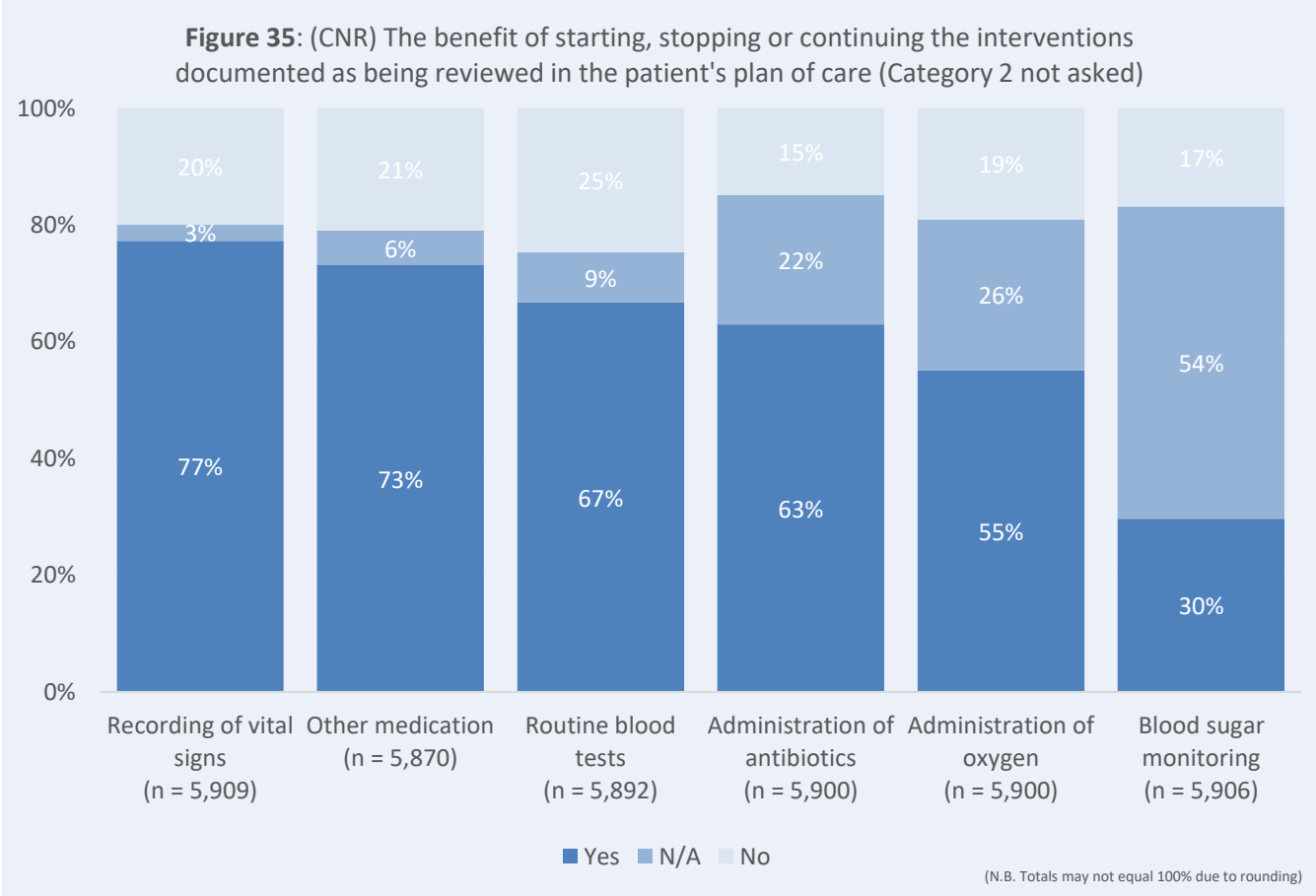
5.5 Individualised plan of care



The summary score for ‘individualised plan of care’ includes an indicator on documentation of the preferred place of death as indicated by the patient (figure 34). This indicator is considered, with other relevant indicators, under the sub-heading ‘Place of death’ later in this section.



Priority 1 of the *Five priorities for care* for the dying person (*One Chance To Get It Right*) (considered in section 1.4) emphasises the importance of regular review and revision of decisions accordingly. The remaining metrics in the ‘individualised plan of care’ summary score relate to documentation of review and assessment. As shown in figure 35, the benefit of starting, stopping or continuing routine recording of vital signs, the administration of oxygen and antibiotics, routine blood tests and other medication was reviewed and documented in between 55% and 77% of cases. A review was not recorded in between 15% and 25% of cases, a reduction from between 19% and 31%, in round one. Blood sugar monitoring was reviewed in 30% of cases, but was not applicable in 54% of cases (figure 35).

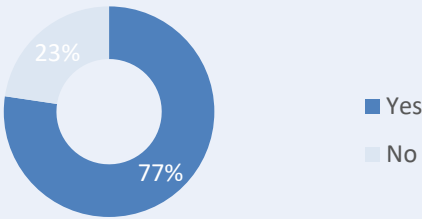


5.5 Individualised plan of care



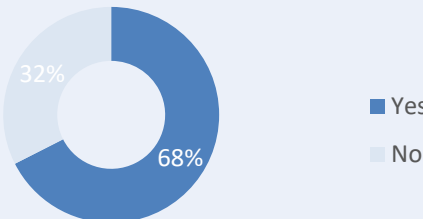
Hydration status was documented as being assessed daily once the dying phase was recognised in 77% of cases (77% in round one, for Category 1), and nutrition, 68% of cases (63% in round one, for Category 1), (figures 36 and 37).

Figure 36: (CNR) The patient's hydration status was assessed daily once the dying phase was recognised (Category 2 not asked) (n = 5,754)



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

Figure 37: The patient's nutrition status was reviewed regularly once the dying phase was recognised (Category 2 not asked) (n = 5,723)

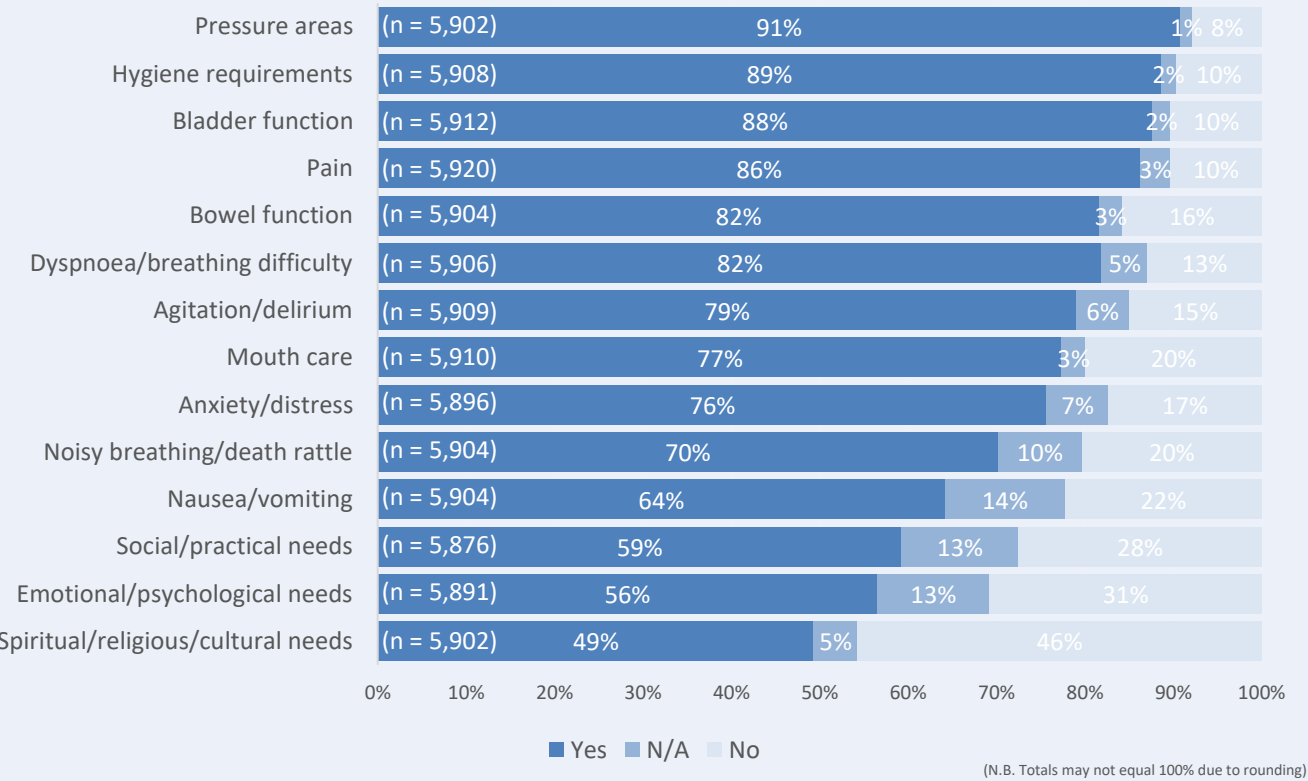


(N.B. Totals may not equal 100% due to rounding)

Assessment of needs across 14 domains was included in the 'individualised plan of care' summary score. Figure 38 shows which needs were assessed as part of holistic needs assessment. Compliance was generally high when assessing physical needs (from 64% for nausea/vomiting to 91% for pressure care), although the percentage stating 'no' for mouth care has increased to 20% from 14% in round one, with 'yes' reducing to 77% from 82% (Category 1 deaths).

Lower compliance was recorded for other needs, with the percentage stating 'no' at 46% for spiritual/religious/cultural needs and 28% for social/practical needs (as noted above these domains were changed for round two). For emotional/psychological needs, for Category 1 deaths, the percentage stating 'yes' has increased to 56% in round two (figure 38) from 54% in round one, with 'no' also increasing to 31% from 25%, and N/A reducing.

Figure 38: (CNR) Documented evidence of an assessment of the following needs (Category 1 only)



5.5 Individualised plan of care



Holistic care: results from the Quality Survey

Figure 39: (QS) A plan was made for the person's care which took account of their wishes (n = 1,561)

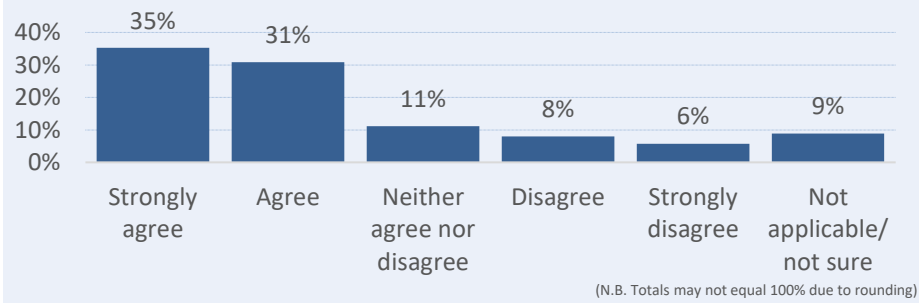
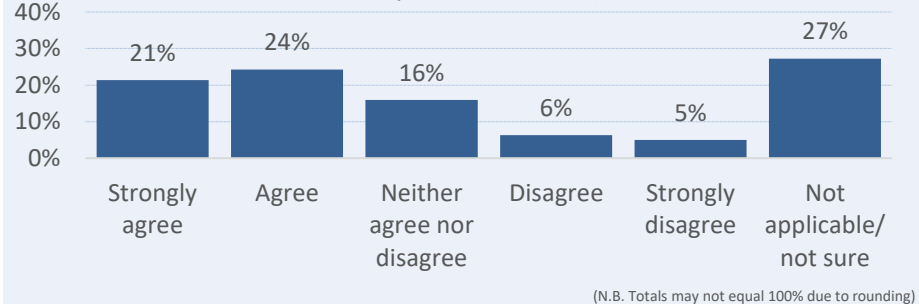


Figure 40: (QS) The person had care for emotional needs met by staff (n = 1,548)



Physical care: results from the Quality Survey

Figure 41: (QS) The person was given sufficient pain relief (n = 1,561)

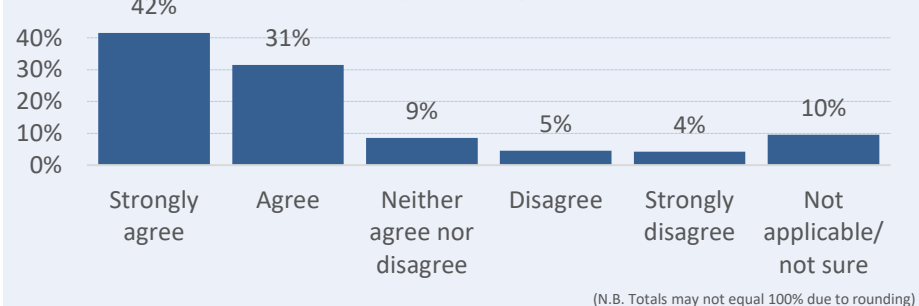
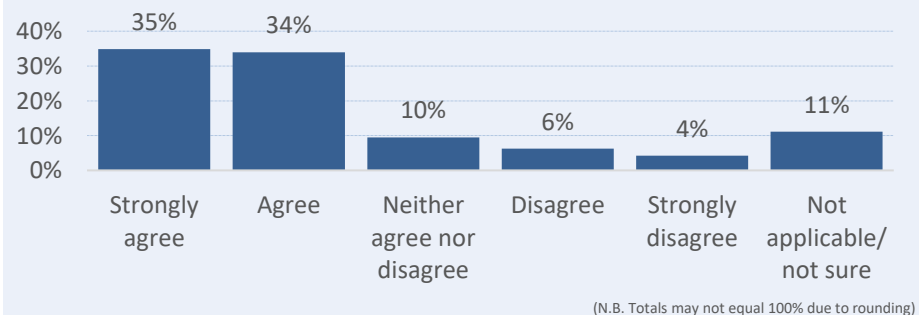


Figure 42: (QS) The person was given sufficient relief of symptoms other than pain (n = 1,555)



In addition to the indicators used in the summary score and discussed previously, the following results from the Quality Survey are relevant to individualised plan of care. Respondents to the Quality Survey agreed that staff at the hospital made a plan for the person's care which took account of his/her individual requirements in 66% of cases, and disagreed in 14% of cases (figure 39).

Respondents agreed that the person had care for emotional needs (e.g. feeling low, feeling worried, feeling anxious), met by staff in 45% of cases, with 11% disagreeing. A further 27% of respondents stated this question was not applicable (figure 40).

Respondents to the Quality Survey were also asked a number of questions about the physical care of the dying person.

73% of respondents agreed that the dying person was given sufficient pain relief, and 9% disagreed (figure 41).

69% agreed that the person had sufficient relief of symptoms other than pain (such as nausea or restlessness), with 10% disagreeing (figure 42).

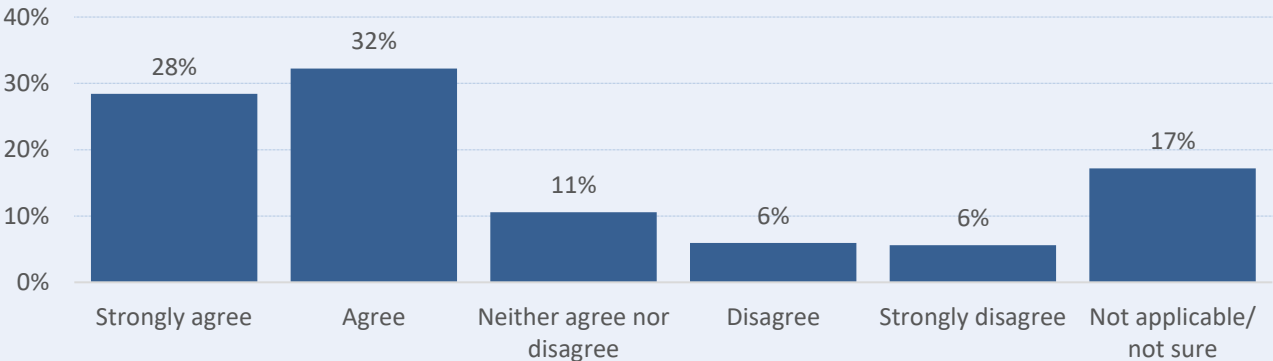


5.5 Individualised plan of care



60% agreed the person had support to drink or receive fluid if he/she wished, with 12% disagreeing and 17% stating this was not applicable (figure 43). Further evidence on this point from the Case Note Review shows that there was documented evidence that the patient was supported to drink as long as they were able and wished to do so in 63%₂ of cases, no evidence in 11%₂, and assessed as not able to drink or did not wish to do so in 26%₂ of cases.

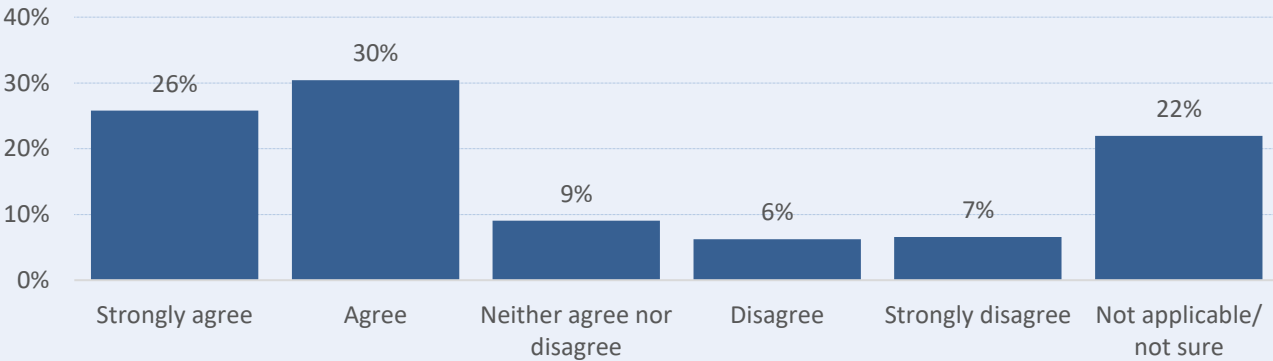
Figure 43: (QS) The person had support to drink or receive hydration if they wished
(n = 1,551)



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

Respondents agreed that the person had support to eat or receive nutrition if he/she wished in 56% of cases, with 13% disagreeing and 22% stating this was not applicable (figure 44). Evidence from the Case Note Review shows documented evidence that the patient was supported to eat as long as they were able and wished to do so in 57%₃ of cases, no evidence in 14%₃, and assessed as not able to eat or did not wish to do so in 29%₃ of cases.

Figure 44: (QS) The person had support to eat or receive nutrition if they wished
(n = 1,555)



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



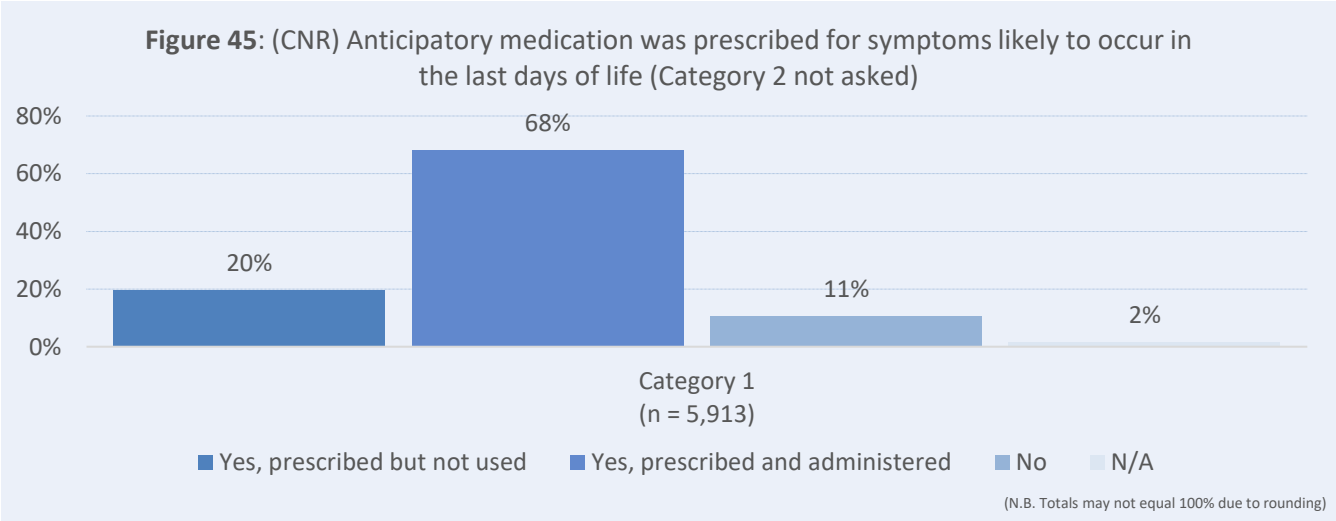
5.5 Individualised plan of care



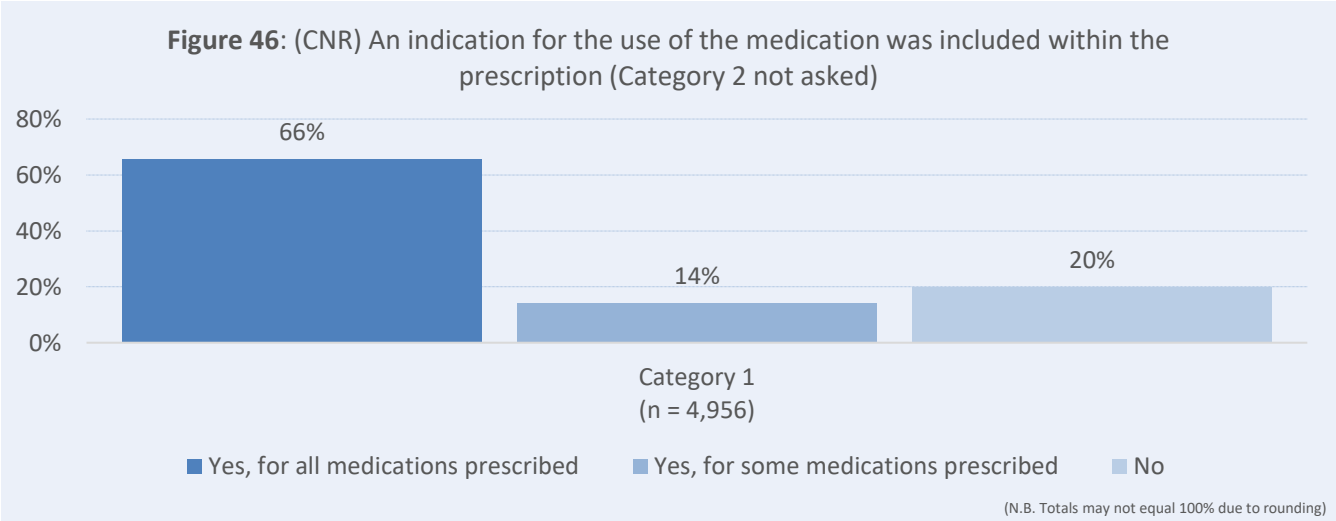
Anticipatory medicines: results from Case Note Review and Organisational Level Audit

In addition to the indicators used in the summary score, new questions were included in round two in the Case Note Review on anticipatory prescribing for Category 1 deaths only.

There was documented evidence that anticipatory medication was prescribed, and administered, for symptoms likely to occur in the last days of life, in 68% of cases, prescribed but not used in 20%, and no evidence regarding anticipatory prescribing in 11%, of cases (figure 45). For 2% of cases, patients were in the High Dependency Unit (HDU)/Intensive Care Unit (ICU) setting with symptoms managed by existing Intravenous (IV) infusions and the question was therefore not applicable (figure 45).



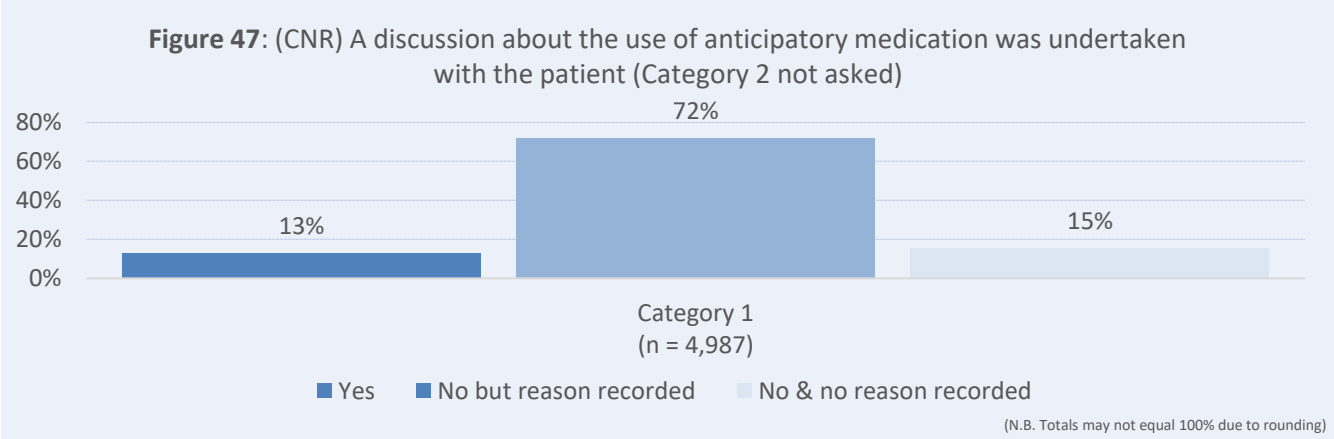
An indication for the use of the medication was included within the prescription for all medications prescribed in 66% of cases, for some medications prescribed, in 14%, and no indication documented in 20% of cases (figure 46).



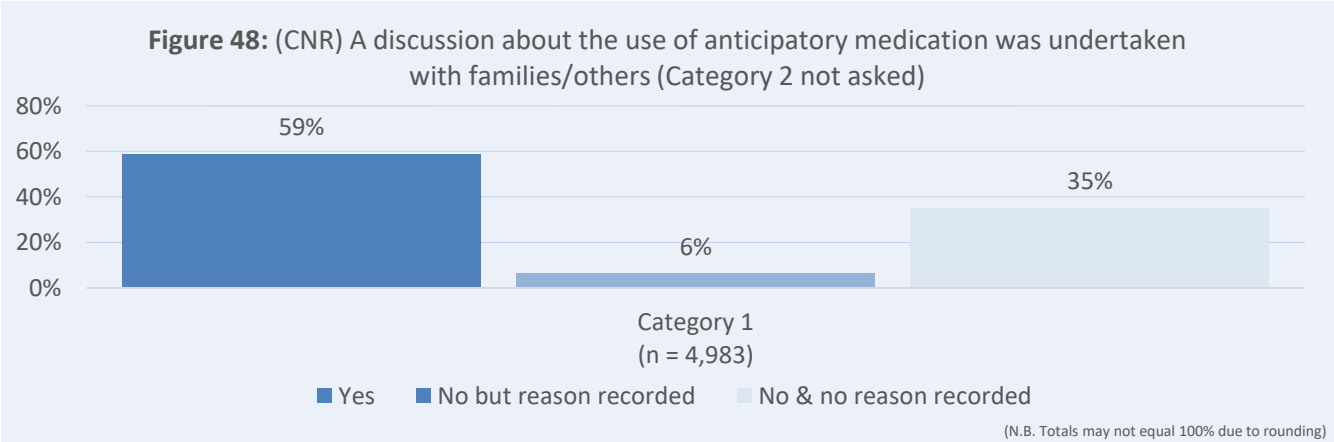


5.5 Individualised plan of care

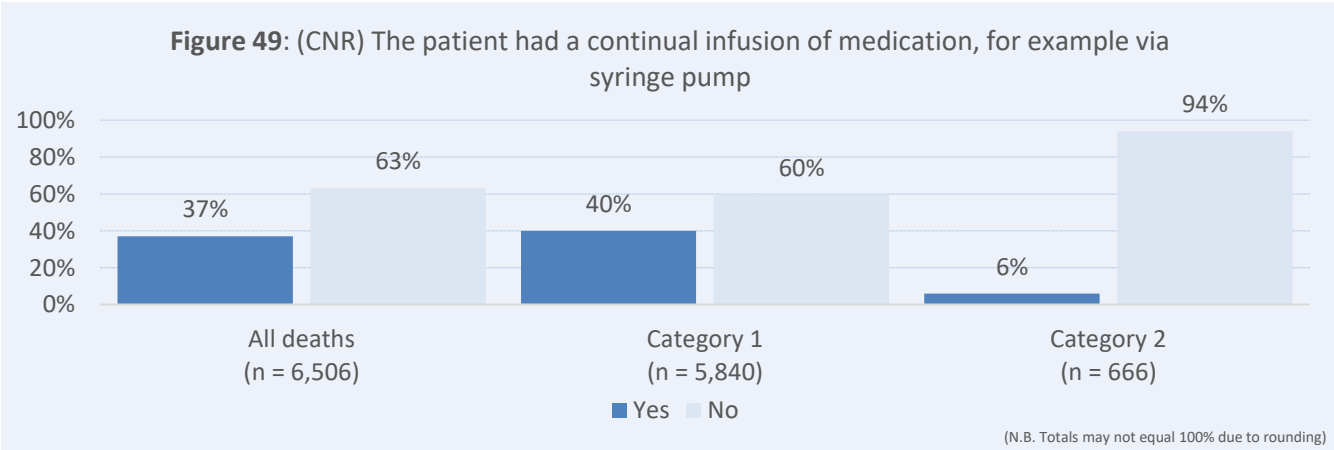
For those patients where anticipatory medication was prescribed, a discussion with the patient about their use was held in 13% of cases, with no documented discussion and no reason why not, in 15% of cases (figure 47).



This discussion was much more likely to be held with people important to the dying person (59% of cases), but in 35% of cases there was no discussion recorded and no reason why not (figure 48).



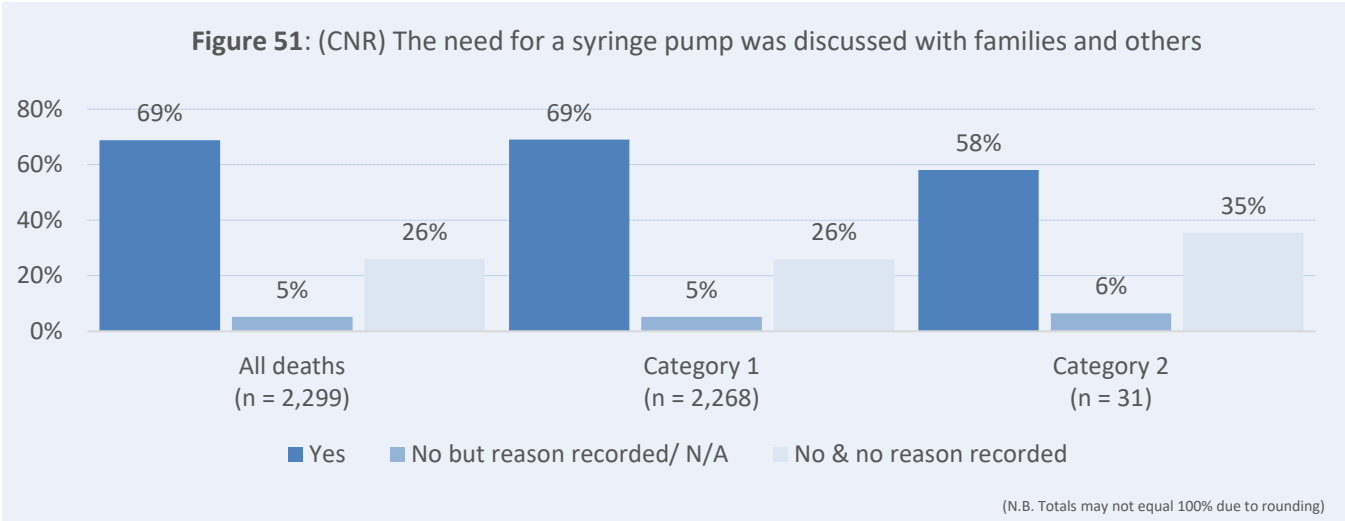
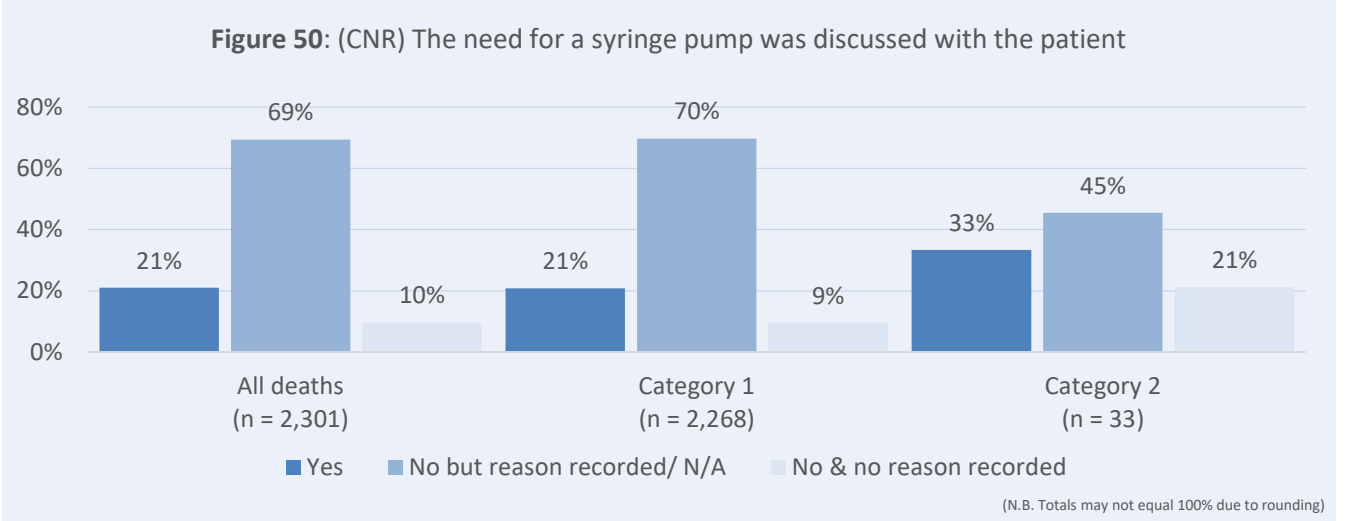
A question on the use of continual infusion of medication was asked for all people who died in round two of the audit. As shown in figure 49, for Category 1 deaths, 40% of patients had a continual infusion of medications, for example via syringe pump. For Category 2 deaths, this was 6% (figure 49).



5.5 Individualised plan of care



Where a syringe pump was in place, for Category 1 deaths, a discussion with the patient took place in 21% of cases, with no and no reason recorded in 9% of cases (figure 50), and with the family/others in 69% of cases, with no and no reason recorded in 26% of cases (figure 51).



From the Organisational Level Audit, 98%₄ of hospitals have guidelines for anticipatory prescribing which specifically requires medication to have individualised indications for use, dosage and route of administration. 89%₅ of hospital guidelines include guidance on anticipatory prescribing for patients transferring from hospital to home or care home to die.



5.5 Individualised plan of care



Individualised plan of care: Families' and others' comments

From the Quality Survey narrative responses, 58% (647/1,118) related to the care received by the patient. Of these comments, 62% (401/647) were analysed as positive and 38% (246/647), negative. Of all the comments about care:

- 56% (365/647) related to quality of care (see section 5.6, Families' and others' experience of care)
- 19% (124/647) related to pain relief
- 12% (75/647) related to anticipatory medication
- 10% (64/647) related to hydration/nutrition
- 3% (22/647) related to dementia/mental health
- 3% (22/647) related to care planning
- 2% (16/647) related to active treatment
- 2% (12/647) related to spiritual care
- 1% (9/647) related to DNACPR (Do Not Attempt Cardiopulmonary Resuscitation).

"The nursing staff did their best to make him comfortable but he was very difficult to deal with and was in great discomfort and pain. The palliative care nurse was extremely kind and compassionate and he finally had a peaceful death."

"They treated him with great dignity, swabbing his mouth with a wet sponge so he wouldn't be thirsty and putting lip salve on his lips so they wouldn't get sore. As family it was much appreciated at a very difficult and emotional time for us."

"My wife and I received the most caring, patient and expert attention we could have wished for over my uncle's last few days, and were involved closely with the decisions taken regarding his treatment."

"No one assisted her with eating or drinking or checked she was getting a meal she was able to eat."

"My wife went to hell and back with unbearable pain for a full night before she passed away, it was not until her last few hours was the pain relief 'ramped up enough to help her relax'."

Of the auditors narrative comments from the Case Note Review about the identified learning points:

- 21% (563/2,727) related to care planning
- 14% (369/2,727) related to anticipatory medication
- 8% (205/2,727) related to hydration and nutrition
- 6% (164/2,727) related to advanced care planning
- 3% (86/2,727) related to DNACPR
- 3% (77/2,727) related to syringe pumps
- 2% (42/2,727) related to mental capacity



5.5 Individualised plan of care



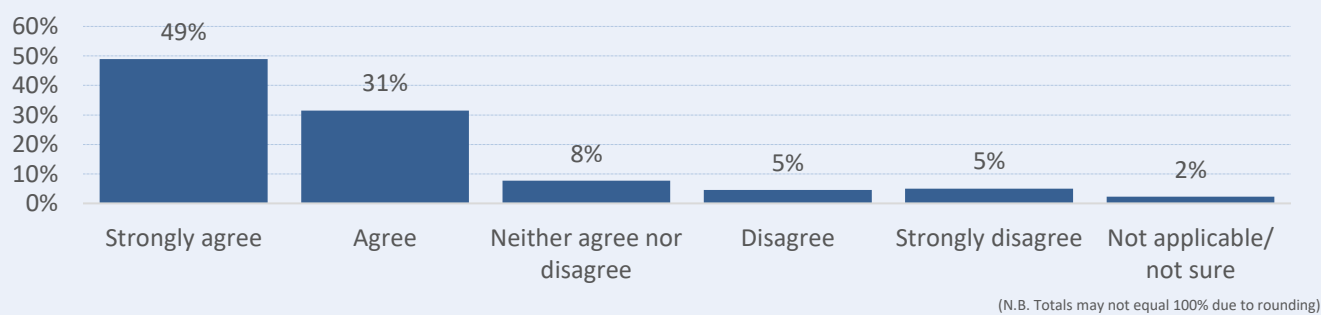
Place of death: results from Case Note Review and Quality Survey

As noted previously, a question from the Case Note Review was included in the summary score regarding documentation of the preferred place of death as indicated by the patient. Evidence of this preference was recorded in 29% of cases for Category 1 deaths and 10% for Category 2 deaths (figure 34, section 5.5).

In round two, there were no other questions on place of death included in the Case Note Review. Views on place of death and location within the hospital were sought from bereaved families and others in the Quality Survey.

The results from the Quality Survey suggest most people (80%) were content that the hospital was the right place for the person to die (figure 52), compared to 75% in round one of the audit. However, 10% disagreed or strongly disagreed that hospital was the right place (figure 52).

Figure 52: (QS) The hospital was the right place for the person to die (n = 1,560)



73% of respondents agreed that the location within the hospital where the person died was appropriate, with 18% disagreeing (figure 53). When specifically asked about whether the person had a suitable environment with adequate peace and privacy, 69% agreed and 20% disagreed (figure 54).

Figure 53: (QS) The location within the hospital where the person died was appropriate (n = 1,556)

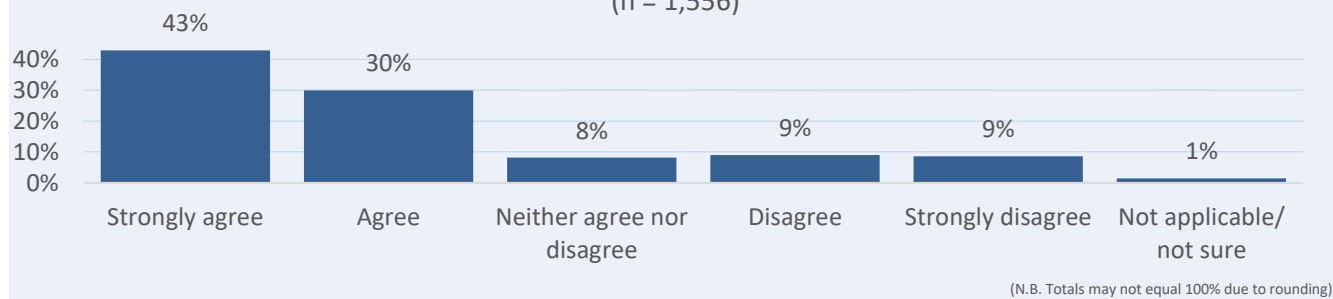
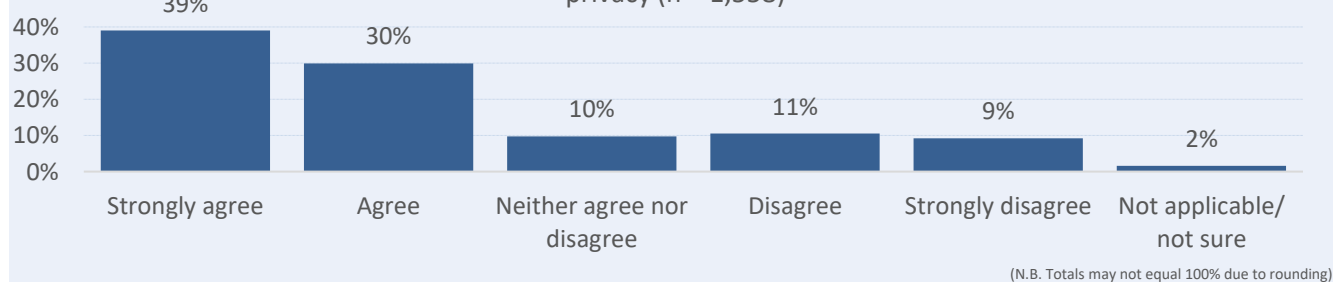


Figure 54: (QS) The person had a suitable environment with adequate peace and privacy (n = 1,558)



5.5 Individualised plan of care



Individualised plan of care/place of death: Families' and others' comments

In addition, from the NACEL Quality Survey narrative responses, 48% (540/1,118) related to the location of care. Of these comments,

- 40% (217/540) related to provision of a side room
- 23% (124/540) related to movement in location
- 20% (109/540) related to privacy
- 13% (72/540) referenced care at home or a desire for the patient to have been cared for at home
- 7% (40/540) related to A&E.

"I feel a private room would have made a huge difference not only to my mum but emotionally to her family."

"The end of life care for us as a family was enhanced by us having access to the XX Suite which was very helpful."

"I feel people who are nearing the end of life deserve to have peace and quiet and dignity not in a bed with curtains drawn around it and people shouting."

"She was moved from one ward to another without us knowing."

Summary: Individualised plan of care

There were 29% of Category 1 cases with no documented individualised plan of care for the dying person. Of these, in 45%₆ of cases, the time from recognition of dying to death was over 24 hours. Further, a high proportion of narrative comments from those completing the Case Note Review, highlighted concerns with end of life care planning and missed opportunities to do so. The results of the Quality Survey also suggest a gap remains in the development and documentation of an individualised plan of care for every dying person, with two thirds of respondents agreeing that a plan was made for the person's care which took account of their wishes.

The recording of the review of the benefit of starting, stopping or continuing interventions has improved in round two. Recording of the daily assessment of hydration status is the same as in round one (77%), but the recording of regular assessment of nutrition status has improved.

As in round one, there was higher compliance with documentation of assessment of the patient's physical care needs, than other areas such as emotional/psychological and spiritual/religious/cultural needs. With regards to meeting those needs, from the Quality Survey, a proportion of people responding, ranging from 9% to 11%, didn't agree that the person had their needs for emotional support, pain relief and relief for other symptoms met.

Whilst anticipatory medications were prescribed in the majority (88%) of cases, there were no indications for usage documented in 20% of cases. Discussions about anticipatory prescribing were more likely to take place with those important to the dying person, than with the patient. There is scope for better recording of such conversations. Whilst most hospitals have appropriate policies in place on anticipatory prescribing, the remaining 2% to 11% of hospitals should ensure they do so.



5.5 Individualised plan of care



Three-quarters of Quality Survey respondents agreed the patient had support to eat and drink, if he/she wished to do so, or stated this was not applicable. Documentation about supporting eating and drinking in the case notes could be improved.

The proportion of people who felt hospital was the right place for the person to die was 80% in round two compared to 75% in round one of NACEL. As regards the location within the hospital, 20% disagreed with the statement that the person had a suitable environment with adequate peace and privacy. As in round one, many narrative comments received from the Quality Survey related to a perceived lack of privacy, and peace and quiet.

Recommendation 11

Ensure that patients who are recognised to be dying have a clearly documented and accessible individual plan of care developed and discussed with the patient 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)* 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 Recommendation 11 - updated for clarity]

Recommendation 12

Ensure that the intended benefit of starting, stopping or continuing treatment for the individual is clear, with documentation of the associated communication with the dying person and/or people important to them. This may include, but is not limited to, discussions regarding assessment and management of food and fluid, the common side effects of medication, the review of routine monitoring of vital signs and blood sugar and the review of ongoing administration of medications e.g. oxygen and antibiotics.

[NACEL 2018 Recommendation 12 - updated for clarity]

Recommendation 13

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*, 2010, and the NMC's *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*, 2018, should be implemented.

[NACEL 2018 Recommendation 13 - updated for clarity]





5.5 Individualised plan of care

Place of death

Recommendation 10

Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for the dying person and people important to them. Consideration should be given to the provision of a side room, if that is the person's wish.

[NACEL 2018 Recommendation 10 - updated for clarity]

Anticipatory medicines

Recommendation 5

Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system. 'The system' refers to locality, Integrated Care System (ICS) or other networks of provision.

[New for NACEL 2019]

Recommendation 14

Ensure patients who are recognised to be dying, and are likely to need symptom management, are prescribed anticipatory medicines and individualised indications for use, dosage and route of administration are documented. The drugs prescribed must be appropriate to the individualised anticipated needs of the dying person and must be regularly reviewed. Anticipatory medication should be discussed with the dying person where appropriate, and with people important to them, and those discussions should be documented.

[New for NACEL 2019]

Recommendation 15

Where relevant, ensure that clear explanations are given to the dying person, and people important to them, about the rationale for the use of, and medications delivered by, syringe pumps. The dying person and people important to them should have the opportunity to discuss the use of, and medications delivered by, syringe pumps and such conversations should be documented.

[New for NACEL 2019]



5.6 Families’ and others’ experience of care



The [NHS Outcomes Framework](#) for England, which sets out high level national outcomes for the NHS, has five domains, including ensuring that people have a positive experience of care. The [NHS Delivery Framework and Guidance document for 2019-20](#) in Wales, is modelled on ‘[A Healthier Wales](#)’ quadruple aims and has a suite of outcomes, indicators and performance measures that will evaluate the impact that health and social care services are having upon the health and well-being of people in Wales.

When a person has died, those important to them, be it families, carers, friends or others, are best placed to comment on both the experience of care of the patient and the support they received themselves.

In this section, evidence on the experience of care from the Quality Survey is presented.

Families’ and others’ experience of care: Round two (2019/20) summary score

Families’ and others’ experience of care

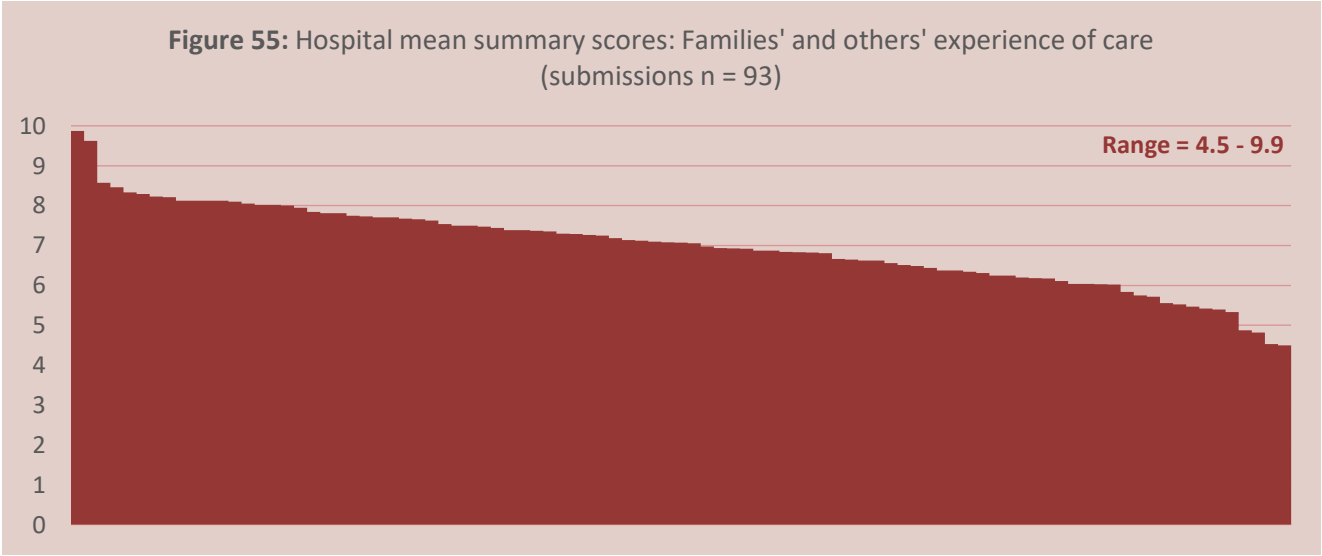


7.0

Component metrics:

The summary score for ‘families’ and others’ experience of care’ is calculated using responses to the following ‘I’ statements, and other questions, included in the Quality Survey:

- I felt that staff looking after the person communicated sensitively with him/her
- I was communicated to by staff in a sensitive way
- Overall, how would you rate the care and support given by the hospital to the person who died during the final admission?
- Overall, how would you rate the care and support given by the hospital to YOU and other close relatives or friends during the person’s final admission in hospital?



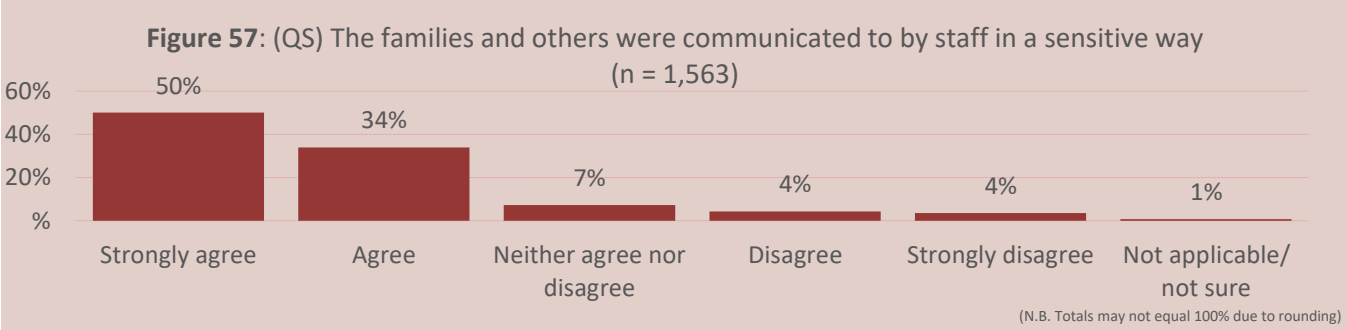
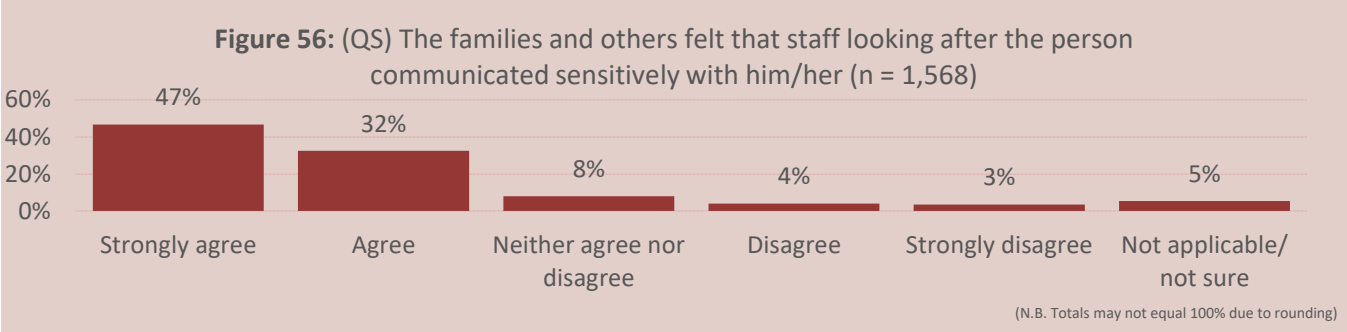
The range of hospital mean summary scores for ‘families’ and others’ experience of care’ is shown in figure 55. The mean value of the summary score across the whole sample of Quality Survey responses is 7.0 (n=1,545).



5.6 Families' and others' experience of care

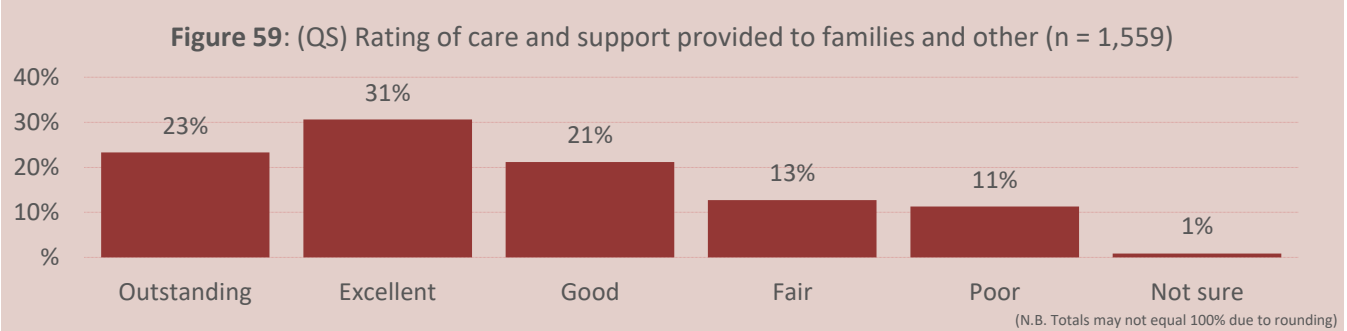
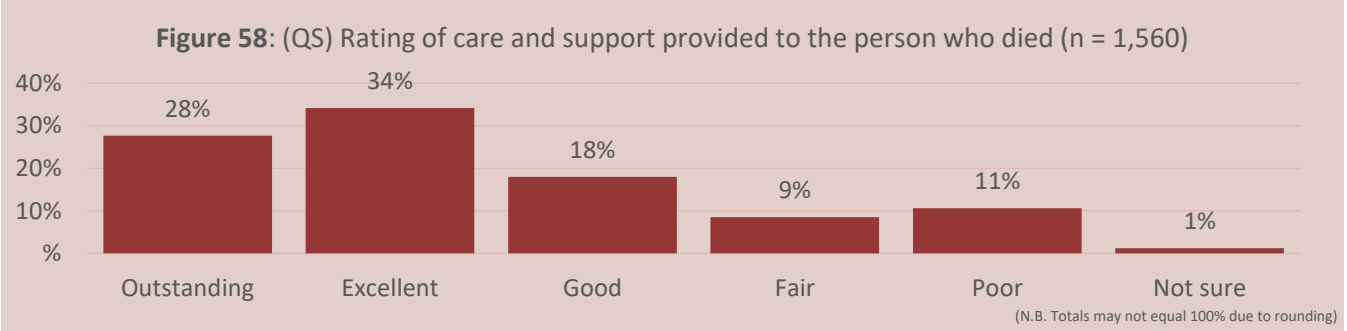


Respondents to the Quality Survey agreed that staff looking after the person communicated sensitively with him/her in 79% of cases, with 7% disagreeing (figure 56). As regards communication with those important to the dying person, 84% agreed this was sensitive, and 8% disagreed (figure 57).



In round two, as in round one, 80% of respondents rated overall care and support to the person who died during the final admission as outstanding, excellent or good (figure 58). Further, in round two, 20% gave an overall rating of fair or poor (figure 58), compared to 19% in round one.

The overall rating of care and support provided to families and others during the person's final admission to hospital was outstanding, excellent or good in 75% of cases in round two (figure 59), compared to 76% in round one. The overall rating in round two was fair or poor in 24% of cases, compared to 23% in round one.



5.6 Families' and others' experience of care



Families' and others' experience of care: Families' and others' comments

As noted in section 5.5, 'Individualised plan of care', 58% (647/1,118) of the NACEL Quality Survey narrative responses, related to the care received by the patient. Of these comments, 56% (365/647) related to quality of care, 83% (304/365) were analysed as positive and 17% (61/365) were analysed negative.

"The XXX ward was an eye-opener in terms of how well they treated patients. I would hope that all hospital wards were as good as this."

"I can't fault the care given to my husband."

"All members of staff at the XX from the specialist down to the cleaners treated me and my family with respect kindness and were very helpful when I needed them, I can not thank them for all their help."

"Considering she was on a ward for care of elderly the staff did not universally exhibit appropriate care or an understanding of this age group nor the needs of relatives."

"We found the care and support severely lacking in all respects."

Please also refer to comments about communication in sections 5.2 and 5.3.

Summary: Families' and others' experience of care

The majority of respondents to the Quality Survey felt communication with the dying person and those important to them was sensitive. See also section 5.2 'Communication with the dying person' and section 5.3 'Communication with families and others'.

The results for round two, as for round one, suggest the majority of people responding to the Quality Survey felt the patient had received good care and support overall. However, in around a quarter of cases, respondents rated the quality of care and support provided to families and others as 'poor' or 'fair'. The result is consistent with views expressed by the bereaved in section 5.4 'Needs of families and others', suggesting room for improvement in this area.

Recommendation 4

Create and implement an action plan to ensure the local findings and national recommendations of NACEL are reviewed, and providers of NHS funded care at the end of life in acute and community hospitals and other care settings are supported by commissioners in developing, implementing and monitoring their plans.

[New for NACEL 2019]



5.7 Workforce/specialist palliative care



National guidance recognises the need for providers to work with commissioners to ensure access to an adequately resourced specialist palliative care (SPC) workforce to provide leadership, education and training, including for pre-qualifying education, and support to non-specialist front-line health and care workers. In this section, findings from the Organisational Level Audit and Quality Survey regarding the specialist and non-specialist workforce are presented.

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*).

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*).

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*).

Workforce/specialist palliative care: Round two (2019/20) summary score

Workforce/specialist
palliative care



7.4

Component metrics:

The summary score for 'workforce/specialist palliative care' is calculated using information collected in the Organisational Level Audit (a weighting of 1.0 is allocated unless indicated otherwise):

- does the hospital/site have access to a specialist palliative care service?
- availability of face-to-face specialist palliative care service (doctor and/or nurse) 8 hours a day, 7 days a week
- availability of telephone advice service (doctor and/or nurse) 24 hours a day, 7 days a week
- training (weighting 0.25 each)
 - end of life care training and education included in induction programme
 - end of life care education and training in mandatory/priority training
 - other training in relation to end of life care
 - communication skills training specifically addressing end of life care

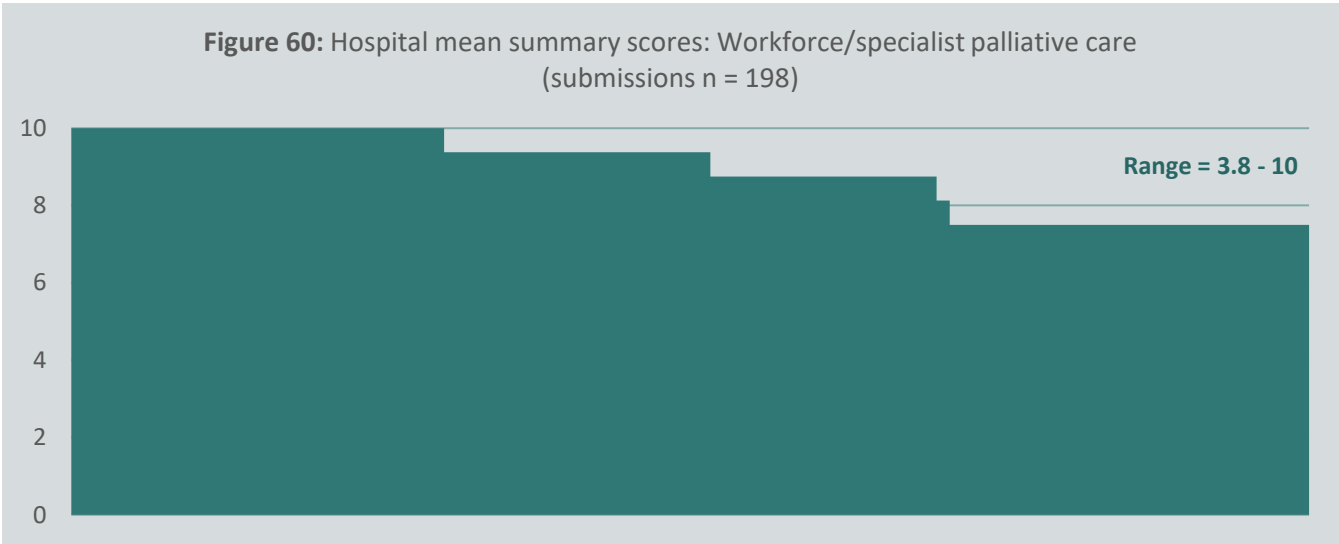




5.7 Workforce/specialist palliative care

The component indicators for the ‘workforce/specialist palliative care’ summary score have changed between round one and round two of the audit. The first indicator used in round two asks whether the hospital/site “have access” to a specialist palliative care service rather than “provide/have access” to a specialist palliative care service as in round one.

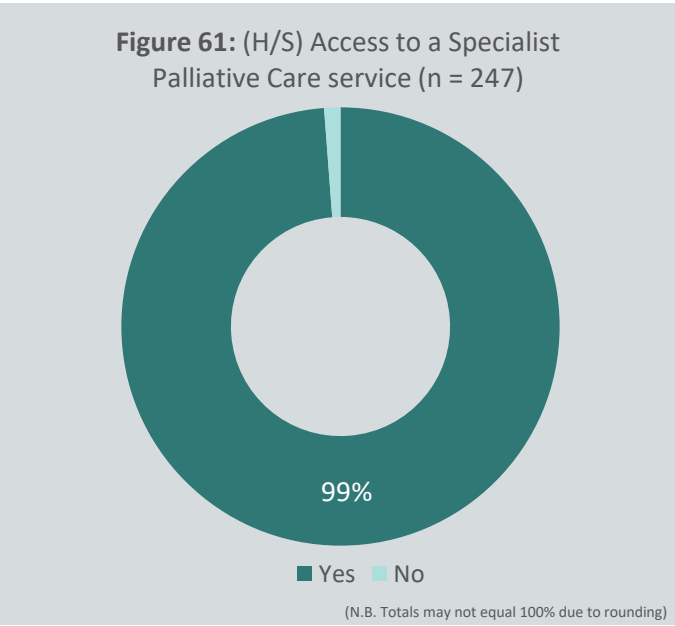
Components regarding the availability of the specialist palliative care workforce (either face-to-face or via telephone) are now calculated from a re-worked workforce section where the days and hours of availability (Monday to Friday, Saturday and Sunday) for doctors, nurses and other staff are requested. The question on communication skills training has been updated from round one specifically asking about communication skills training in relation to end of life care. The other training elements remain the same between the two years of reporting.



The range of hospital mean summary scores for ‘workforce/specialist palliative care’ is shown in figure 60. The mean value of the summary score across participating hospitals is 7.4 (n=198).

From the Organisational Level Audit, 99% of hospitals reported that they had access to a specialist palliative care service (figure 61), compared to 97% in round one.

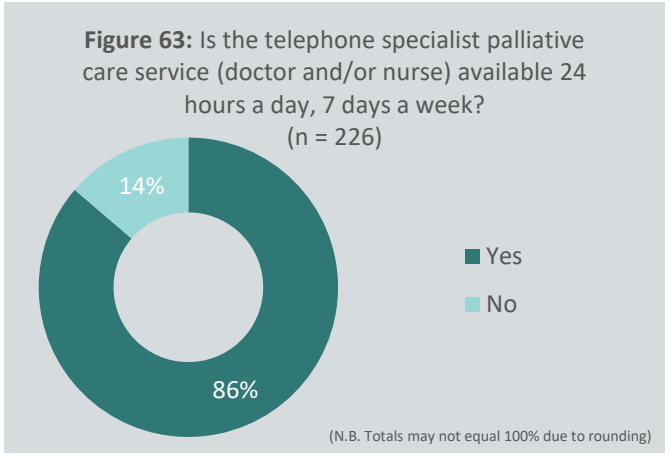
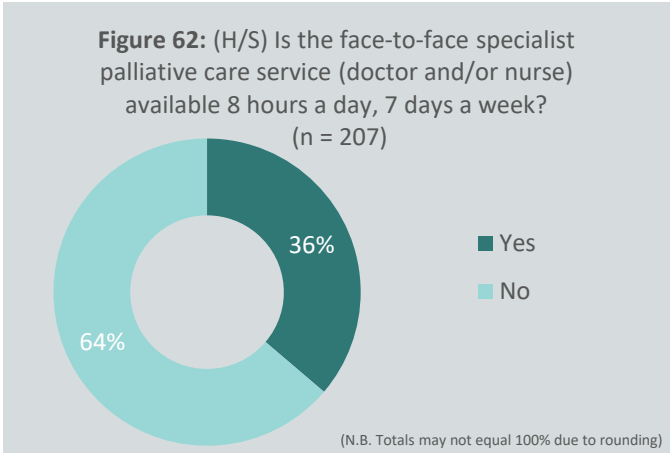
Figures 62 and 63 show the collated information, for face-to-face and telephone availability of the specialist palliative care team, used to create the component metrics for the summary score. As the questions have changed between years, comparisons are not made between the two rounds.



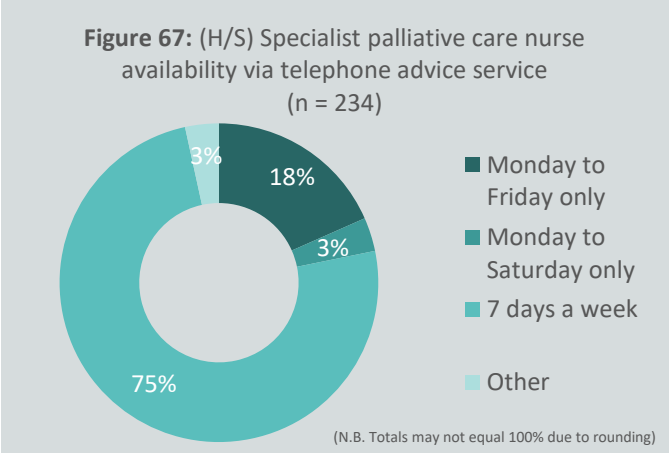
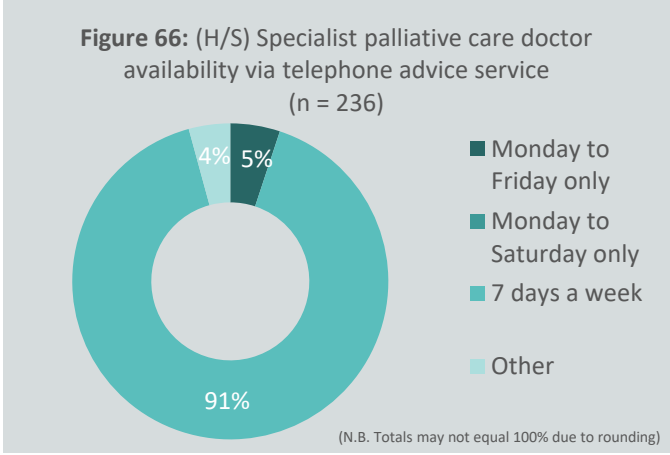
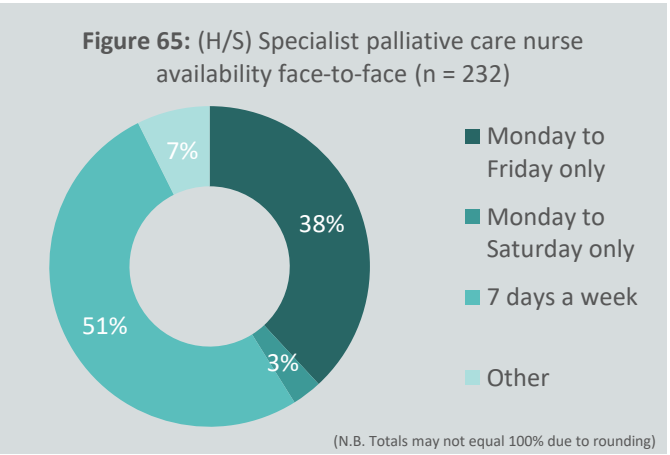
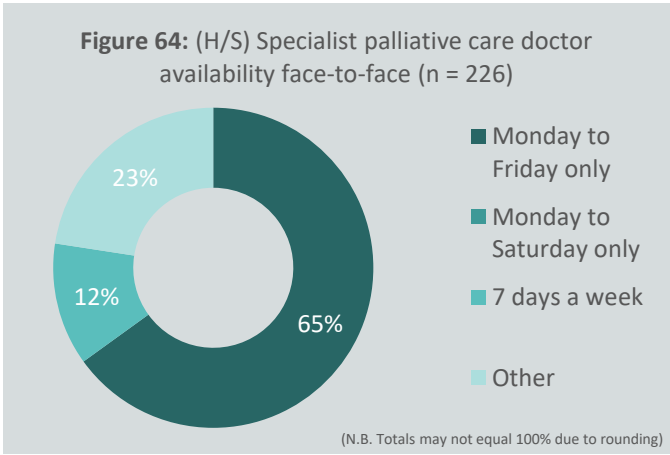
5.7 Workforce/specialist palliative care



36% of hospitals have a face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week (figure 62). 86% of hospitals report having a telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week (figure 63).



Figures 64 to 67 give a further breakdown of the availability of specialist palliative care services on different days of the week.



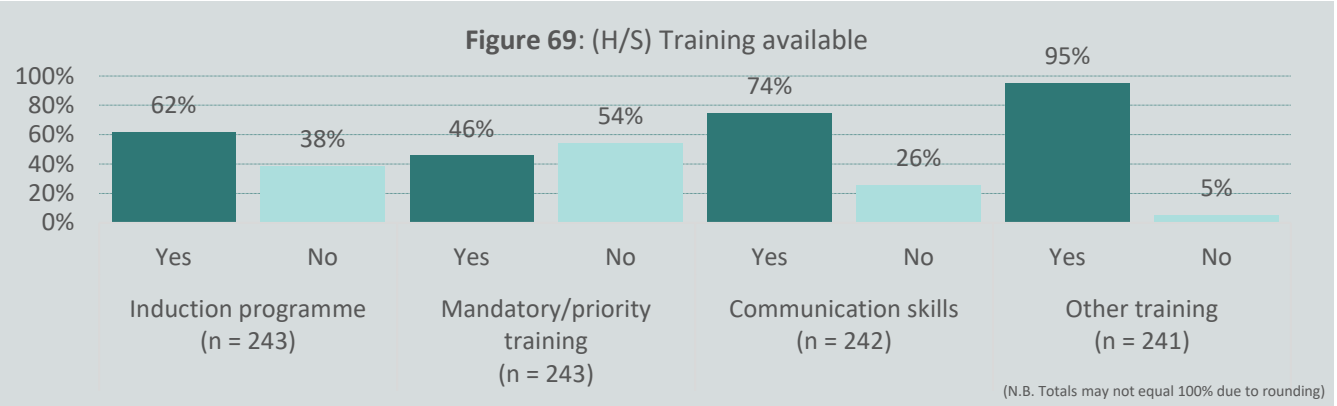
Reviewing medical days of face-to-face availability, 12% of hospitals reported having availability 7 days a week (figure 64) whereas for nursing staff, 51% reported having this level of availability (figure 65). Seven day a week availability of medical staff for telephone advice is reported for 91% of hospitals (figure 66), for nursing staff this model is used in 75% of hospitals (figure 67).

5.7 Workforce/specialist palliative care



The hours of availability for specialist palliative care doctors and nurses, face-to-face and telephone, weekdays and weekends are shown in figure 68.

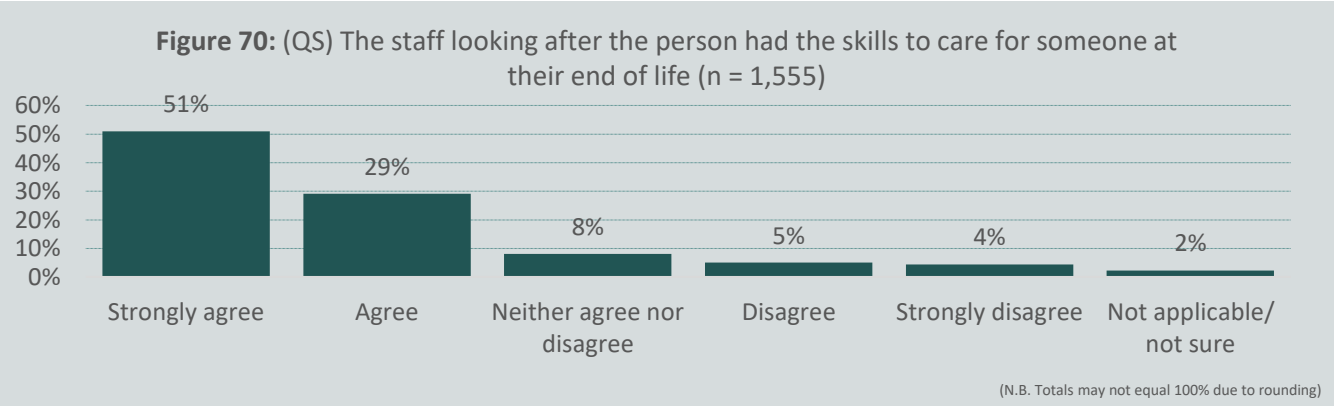
Figure 68: (H/S) Mean hours available	Face-to-face weekdays (hours out of 120)	Face-to-face weekends (hours out of 48)	Telephone weekdays (hours out of 120)	Telephone weekends (hours out of 48)
Doctors	39	5	109	44
Nurses	44	10	74	28



Availability of training is shown in figure 69:

- 62% of hospitals report that they have end of life care training within their induction programme (61% in round one)
- 46% of hospitals have end of life care training within mandatory/priority training programmes (47% in round one)
- 74% of hospitals provide communications skills training specifically addressing end of life care. As the question on communications skills training was amended for round two, this cannot be compared directly with the round one findings.
- 95% of hospitals provide other forms of training in relation to end of life care (other than those areas noted above). This was the same as in round one.

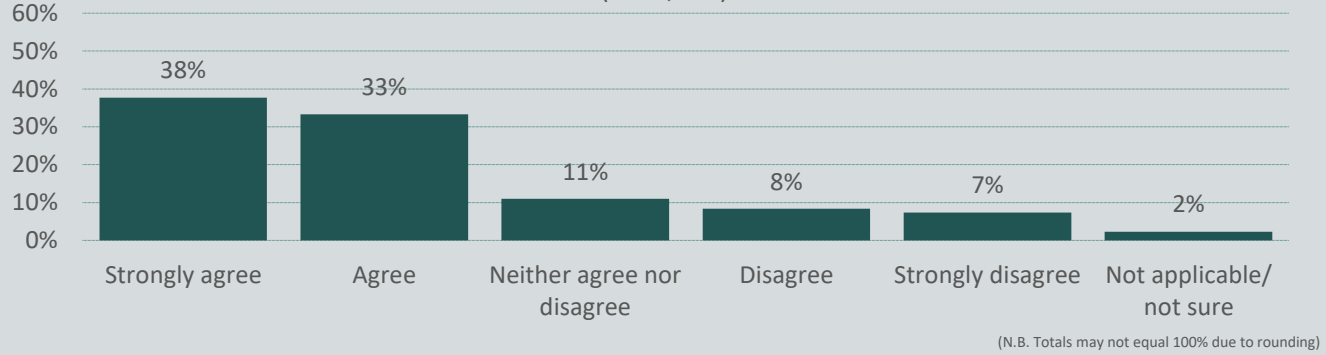
In addition to the summary score, in 80% of cases, Quality Survey respondents agreed that the staff looking after the dying person had the skills to care for someone at their end of life (figure 70) and, in 71% of cases, agreed that there was good co-ordination between staff (figure 71).



5.7 Workforce/specialist palliative care



Figure 71: (QS) There was good co-ordination between different members of staff
(n = 1,554)



Workforce indicators, and in particular vacancy rates, are a way of measuring the stability of the workforce delivering care. From the Organisational Level Audit, the following mean vacancy rates were reported across the specialist palliative care workforce:

- Medical staff – 6%₇
- Nursing – 6%₈, and
- AHPs – 8%₉.

Workforce/specialist palliative care: Families’ and others’ comments

From the Quality Survey narrative responses, 53% (587/1,118) comments related to staff. Of the comments relating to the staff, 67% (393/587) were analysed as positive and 33% (194/587) negative. Of all the comments about staff:

- 12% (70/587) relate to perceived staff shortages
- 5% (29/587) relate to delays in the specialist palliative care
- 3% (18/587) relate to weekend/bank holiday cover
- 2% (13/587) relate to training
- 1% (6/587) relate to care from night staff.

“The care and support from all members of staff throughout my wife’s care from beginning to end was outstanding. They were very respectful of my wife’s wishes and the wishes of mine and our children’s.”

“The Consultant and ward staff were very caring, helpful and knowledgeable. It made our brother's death so much better.”

“My husband was under the Palliative Care Team, and unfortunately his decline took place on a Saturday and there was no weekend number for that team.”

“It should be a 7 day service not just 9-5, 5 days a week.”

From the narrative question on learning points from the Case Note Review, 4% (103/2,727) of comments related to possible earlier referral or delays in referral to the specialist palliative care team. Of the auditors comments from the Case Note Review identifying areas of excellent practice, 11% (332/2997) related to the involvement of the specialist palliative care team.



5.7 Workforce/specialist palliative care



Summary: Workforce/specialist palliative care

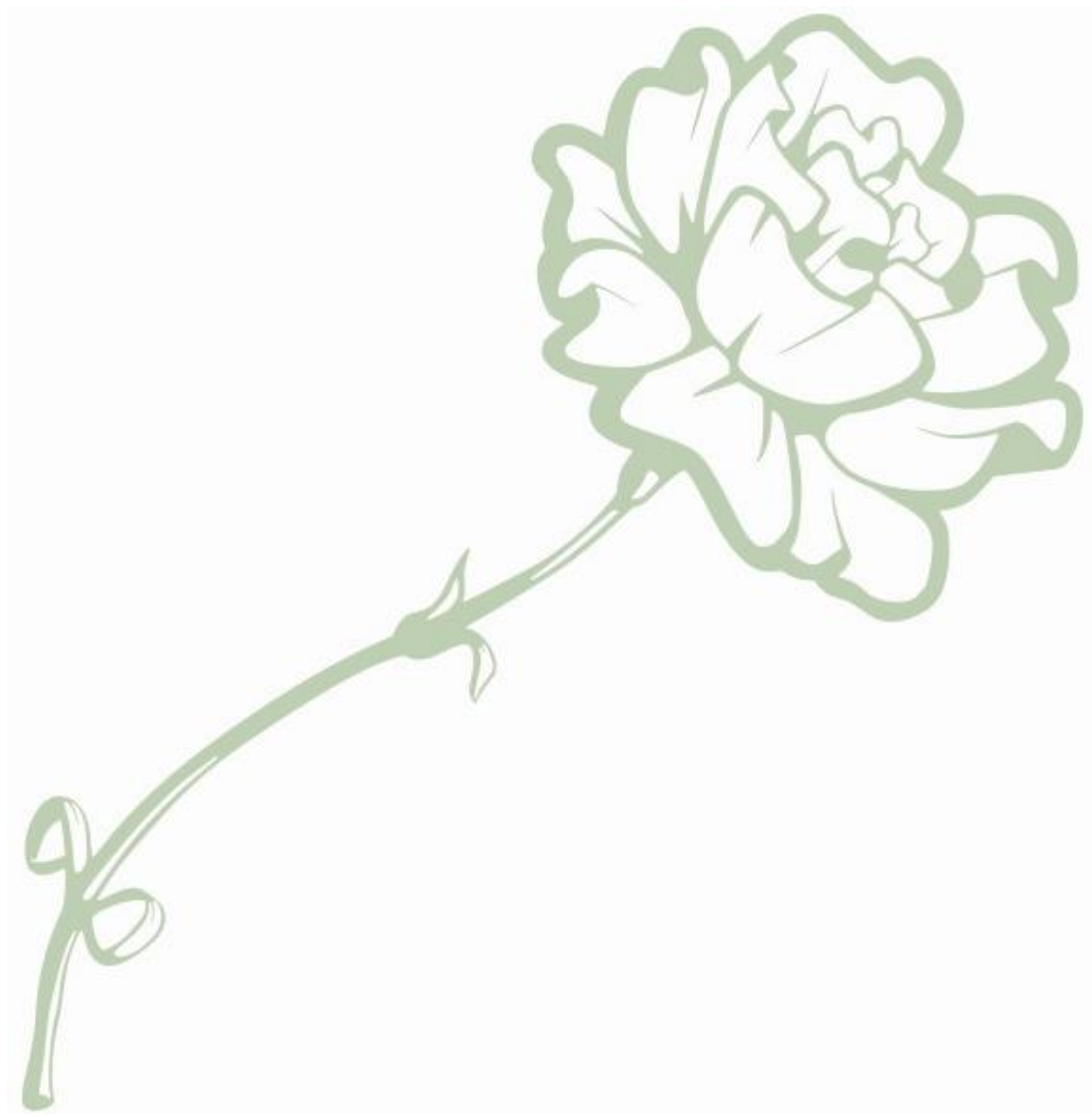
Most hospitals (99%) have access to a specialist palliative care service. However, around a third of hospitals (36%) report having a face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week. The results suggest seven day palliative care services are not yet available in a large proportion of the NHS in England and Wales.

Recommendation 3

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*). This would most often be provided by nurse specialists face-to-face supported by 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]





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