National Audit of Care at the End of Life

First round of the audit (2018/19) report

England and Wales

Acknowledgements

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Foreword

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

Care at the end of life in hospitals touches everyone. Best possible care in this setting has rightly been the focus of national policy and media attention over the last decade. The National Audit of Care at the End of Life (NACEL) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) from the NHS Benchmarking Network (NHSBN), in October 2017. 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 providers. The audit comprises an Organisational Level Audit, Case Note Review and Quality Survey measuring the performance of hospitals against criteria relating to national guidance on care at the end of life, including *One Chance To Get It Right*, and the relevant *NICE Guideline* and *Quality Standards*. The audit has succeeded in establishing where we are doing well and where we need to focus our improvement efforts.

The patient-centred development of an individualised care plan is central to the guidance in *One Chance to Get it Right*. The *NHS Long Term Plan, 2019* places a continuing emphasis on personalisation of end of life care to enable people's choices on type of care and location to be supported. Around a quarter of a million people die in hospital each year and, the audit results suggest 75% of bereaved people feel that this was the right place for the person important to them to die. This audit reviews how people's preferences regarding care at the end of life are identified, discussed and implemented during their last admission in acute and community hospitals.

Care at the end of life in hospitals was last audited in 2015, with a report published by the Royal College of Physicians, End of Life Care – Dying in Hospital, National Report for England, 2016. Since then, trusts/UHBs have continued to interpret, and develop processes to embed, the five priorities for care as set out in One Chance To Get It Right. This work has been undertaken in the context of increasing demand pressures in the NHS, with emergency admissions growing by 12% since 2015, the A&E 4 hour wait target being regularly exceeded and delayed transfers of care peaking in February 2017.

NACEL has three components; an Organisational Level Audit, a Case Note Review and a Quality Survey. The Organisational Level Audit was designed to capture information on governance, training and specialist palliative care teams. The Case Note Review was developed to cover the *five priorities for care*: recognition of imminent death; communication; involvement in decision making; support for families/others, and the individual plan of care. The nature of the guidance presented some methodological challenges to auditing. Firstly, good practice statements needed to be converted into auditable standards and, secondly, with the individualised approach to care, case note documentation is not standardised. The Case Note Review will be further refined in the second round of the audit to reflect the learning from year one. Meanwhile, it is important to note in reviewing the results of the audit that a lack of documentation of an aspect of the guidance does not necessarily equate to poor care. The third component of the audit, the Quality Survey, was also designed to cover the *five priorities for care* and captured very valuable evidence on bereaved people's views on the care received by the dying person and the support they received.

The results of NACEL show high compliance with documenting recognition that a person may be dying during the last admission, with timeliness of recognition similar to that reported in 2016. Families' and others' experience of care given to the patient was good, excellent or outstanding in most cases (80%), as reported by those responding to the Quality Survey. All elements of the audit suggest that, in most cases, patients and those important to them are being appropriately involved in decision making. Governance of care at the end of life is also strong. Areas for improvement include communication with the dying person, communication with families and others, and the identification, and addressing of, the needs of families and others.

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NACEL highlighted the importance of advance care planning. 20% of the people whose care was audited by NACEL died within 8 hours of the recognition that death might be imminent, with a median of 36 hours across the whole group. Around half lacked the capacity to be directly involved in decision-making at this point. However, there was evidence of greater involvement of people in decisions regarding the review of the role of life-sustaining treatments earlier in their care. An increasing focus on the discussion of emergency care and treatment plans, particularly in the acute setting with those whose recovery is uncertain, is welcome.

In the second round of the audit, we aim to build on the success of the first round in identifying the key improvement areas for care at the end of life in hospitals. To reduce data burden for busy clinical staff, we intend to substantially reduce the number of questions in the Case Note Review and concentrate on the individual plan of care. We intend to extend the use of the Quality Survey in evaluating communication with, and support for those important to the dying person, which can best be explored through service user experience.

We would like to acknowledge and thank the audit teams who have done a huge amount of work to submit data to the first round of NACEL, largely in addition to maintaining day-to-day clinical care. We very much appreciate the input of the Patients Association in the development and support of the Quality Survey, and would like to our express our thanks to families and others who completed it during a difficult personal time.

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Executive summary

Background

The National Audit of Care at the End of Life (NACEL) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government in October 2017. 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 managed by the NHS Benchmarking Network, supported by the Clinical Leads, the NACEL Steering Group, and wider Advisory Group (Appendix 10).

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
- people involved in providing care
- people involved in commissioning care
- people who regulate care

First round of NACEL

The audit, undertaken during 2018/19, comprised:
- an **Organisational Level Audit** covering trust/University Health Board (UHB) and hospital/submission level questions
- a **Case Note Review** completed by acute and community providers only, which reviewed all deaths in April 2018 (acute providers) or deaths in April – June 2018 (community providers)
- 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 2018. In total, 206 trusts in England and 8 Welsh organisations took part in at least one element of the audit (97% of eligible organisations). Full details of participation in the Organisational Level Audit, Case Note Review and Quality Survey can be found on pages 22-23. No personal or patient identifiable data was collected.

This report was published on 11th July 2019.

Overview of the results

Section 5 of this report contains results from acute and community hospitals in England and Wales taking part in the first round of NACEL. Results from the three elements of the audit are presented together under nine themes covering the *five priorities for care* and other key issues. Section 6 contains results for mental health trusts who completed the Organisational Level Audit only. Northern Ireland participated in the Organisational Level Audit only and their findings can be found on the NACEL website.

For each of the nine themes (detailed on page 9), a summary score has been developed and calculated for each hospital. The summary scores allow easy comparison between hospitals on the different themes within the audit. Appendix 2 sets out the process undertaken to select the nine key themes and their component indicators, and an explanation of how the scores are calculated.

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A table of the scores per hospital can be found at Appendix 1. The range of hospital scores is shown in the figures at the beginning of each key theme section.

The number of Organisational Level Audits completed was 302. The number of Case Note Reviews completed was 11,034. The total number of Quality Surveys returned was 790, representing 7% of the Case Note Reviews completed (see pages 22-23 for further details). The Quality Survey results may not, therefore, be representative of the whole Case Note Review sample, however, the results do bring additional evidence to build the overall picture of the quality of care at the end of life in hospitals.

Key findings

Key findings for each of the audit themes were as follows:

Recognising the possibility that death may be imminent

Compliance with documenting that a person may die within the next few hours or days is high. However, for around half of patients, they are recognised to be dying less than one and a half days before they die, leaving a limited amount of time to discuss and implement an individual plan of care.

Communication with the dying person

Recording of discussions with the dying person could be improved. In around one third of cases, a discussion with the patient about the plan of care, and discussions about medication, hydration and nutrition had not been recorded.

Around three quarters of respondents to the Quality Survey reported a positive experience of communication, but concerns were raised about communication with the dying person not being sensitive or being 'mixed' in 22% of cases.

Communication with families and others

As would be expected given the timing of recognition of death, discussions about the plan of care were more likely to be held, and documented, with families and others than with the dying patient. Discussions about medication, hydration and nutrition could be better recorded.

In around a quarter of cases, the Quality Survey results suggest there was scope for improvement in communication with families and others.

Involvement in decision making

In the majority of cases, discussions with the patient and with the family/others about life-sustaining treatments and cardiopulmonary resuscitation (CPR) were held and documented or reasons recorded as to why the discussion did not take place.

Although the use of advance care planning has increased (in place in 7% of cases) compared to the *2016 Audit* result (4%, England, acute trusts only), there remains scope for improvement.

Responses to the Quality Survey suggest most people felt that they, and the dying person, were as involved in decision making as they wanted to be, however, 22% of those responding would like to have been more involved.

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The Quality Survey results indicate that around one third of dying patients were admitted to hospital three or more times within the last 12 months of life, suggesting there may be more opportunities to plan for end of life care from a much earlier stage.

Needs of families and others

There is documented evidence that the needs of the family were asked about in just over half of cases, a result which is in line with low compliance highlighted in this area in the previous audit (*End of Life Care Audit – Dying in Hospital, 2016*).

Although a high proportion of respondents to the Quality Survey felt they were supported after the patient's death, when asked more specifically about emotional and practical support during the last two or three days, almost one third of those responding felt they did not have enough support.

Individual plan of care

The evidence overall from the audit suggests there remains a gap in the development and documentation of an individual plan of care for every dying person. There was documented evidence of the existence of an end of life care plan in 62% of cases.

Review of routine monitoring of vital signs, blood sugar monitoring, administration of oxygen and antibiotics was not recorded, and no reason given for this, in between a third and a quarter of cases.

Three quarters of respondents felt that hospital was the right place for the person to die. From the Case Note Review, attempts were made to transfer 11% of patients out of hospital which were, for some reason, unsuccessful. Respondents to the Quality Survey reported that 16% felt no effort had been made to transfer the person from hospital if that was their wish. The audit will not have captured instances where a successful transfer out of hospital was made.

Many of the comments received in the Quality Survey related to a lack of privacy and appropriately quiet environment where the person was on a ward rather than in a side room. The results showed that around one third of people died in a shared bay.

Families' and others' experience of care

The results suggest the majority of people responding to the Quality Survey felt the patient had received good care and had been treated with compassion. However, around one in five Quality Survey respondents felt there was scope to improve the quality of care and sensitive communication with both the patient and the family and others.

Governance

Compliance with appropriate policies is generally high and the majority of organisations have action plans to promote improvements in end of life care. However, the results from other themes of the audit suggest further work needs to be done on the implementation of policies and action plans.

Workforce/specialist palliative care

Just over half of hospitals have specialist palliative care nurses available 7 days a week for face-to-face contacts (as recommended in *One Chance To Get It Right*).

Recommendations

Below are the recommendations from the first round of NACEL. These recommendations refer specifically to the findings of NACEL and are highlighted in the summary sections of the relevant themes in section 5 of this report. Attention is also 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 provide the basis of the NACEL audit standards (section 1.4).

Local action plans are expected to consider the NACEL recommendations, together with trust/UHB local audit results as shown in the NACEL online toolkit and bespoke dashboards, in the context of the national guidance.

Integrated Care Systems/Commissioners, 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, and effectively implement, guidelines across primary, community, secondary care, social care and care homes for timely identification of, documentation of, and information sharing regarding people's wishes.

2. **Review capability and capacity within primary care, community services and social care, to provide appropriate care at the end of life, and to support families 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.

3. **Implement processes to enable rapid discharge to home, care home or hospice, from hospital to die if that is the person's wish.**

4. **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.

Trust/UHB Boards should:

5. **Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and the people who are important to them.** Support all staff to have awareness, communicate sensitively and behave appropriately, when it is recognised that a person may be dying. See also Annex E of *One Chance To Get It Right*.

Chief Executives should:

6. **Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with patients and families in the last days and hours of life.** Training for clinicians and other staff who have contact with dying people should focus on supporting the delivery of the *NICE Quality Standards* within the broader context of *One Chance To Get It Right.* National resources to support training are available such as guidance from professional bodies, learning outcomes and e-ELCA.

Recommendations

7. **Ensure systems are in place to assess and address the needs of the families of dying patients in a timely manner.** Specific senior, strategic and operational responsibility is required. Assessment of needs should cover emotional/psychological, spiritual/religious/cultural, social and practical needs.

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*, complaints and feedback from surveys, including those from bereaved people.

Medical Directors and Nursing Directors should:

9. **Ensure that staff have an awareness of, acknowledge and communicate, as early and sensitively as possible, the possibility or likelihood of imminent death.** Ensure that patients who have signs and symptoms that suggest they may be in the last days of life are monitored for changes. 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.

10. **Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and their families.** Take into account the wishes of dying people and those important to them, to be cared for in a side room.

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 coordination of this plan must be in place especially at points of handover of care.

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 patient and/or person 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 rationale for the use of syringe pumps, the review of routine monitoring of vital signs and blood sugar and the review of ongoing administration of medications e.g. oxygen and antibiotics.

13. **Ensure the dying person is supported to eat and drink if they are able and wish to do so.**

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 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. The survey asks about the quality of care delivered in all settings in the last three months of life for adults who died in England from the perspective of their families or carers. 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. The overall experiences of people who died in their own home, in hospices or in care homes rated significantly higher.

The Liverpool Care Pathway (LCP) was an approach to care developed during the 1990s, based on the care of the dying within the hospice setting, with the aim of transferring best practice to other settings. The LCP had been widely adopted across the NHS and the charitable sector as best practice, however, concerns with the application of the LCP resulted in a review of the pathway in 2013 led by Baroness Julia Neuberger. The review identified significant variations in the care of dying people, including problems wider than the LCP itself: inadequacies in care and compassion, lack of suitably trained staff, and inconsistent access to palliative care advice outside 9am-5pm Monday to Friday. The report made over 40 recommendations, including abandonment of the term 'Liverpool Care Pathway' and 'pathway', and withdrawal of use of the LCP. The Minister of Care and Support took the decision to phase out the LCP in England following the Neuberger review _More Care, Less Pathway: A Review of the Liverpool Care Pathway,_ 2013.

The _Leadership Alliance_ was established following the Neuberger review to generate a system wide response to improve the care of people who are dying and those that are important to them. The Alliance published _One Chance To Get It Right,_ 2014 which clearly sets out an approach to caring for dying people that all organisations caring for dying people and those important to them 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 QS13_ and _QS144_ and _NICE Guideline (NG31)_, provide the audit standards for NACEL (see section 1.4).

The _Ambitions Framework, 2015_ is a national framework for local action, which incorporates NHS England's aims and objectives for end of life care. This was developed by a partnership of national organisations across both statutory and voluntary sectors. The ambitions are: -

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

The Government's response to the review of choice in end of life care amplifies Ambitions 1 and 4. Their commitment states that, as people approach the end of their life, they should be given the opportunity and support, to have honest conversations about their needs and preferences to make informed choices about their care. Furthermore, to develop and document a personalised care plan, share this plan with their professionals, involve their family, carers and those close to them to the extent that they wish, and know who to contact if they need help and advice. 'End of life' in this context refers to the last year of life.

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NHS England has established a cross-system Programme Board for End of Life Care to ensure and support progress against these commitments and the *Ambitions Framework*, working with its partners across the health and social care statutory and voluntary sector.

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

- Increasing the number of people identified and offered personalised care and support planning through the GP supportive/palliative care registers and offer for these plans to be included in local EPaCCS
- Reducing the number of people who have three or more emergency admissions in their last 90 days of life
- Improving outcomes and experience in end of life care for people with cancer, dementia, learning disabilities, requiring urgent or emergency care, and people who are homeless or living in detained settings
- Increasing access and usage of shared digital records (EPaCCS)
- Embed PEoLC priorities within Sustainability and Transformation Partnerships

Further strategies pertaining to the English system for care at the end of life have been introduced:
Medical Examiners (of the cause of death) were established by the *Coroners and Justice Act, 2009*, to provide better scrutiny of death certification, more accurate data on causes of death, provide advice to Coroners and can facilitate input of relevant information to the clinical governance systems of the NHS. The Royal College of Pathologists is leading on developments in this area. This applies to England only.

Further influential documents had also been published on end of life care in England:
In 2016, the CQC published *Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England*. It found that learning from deaths was not being given sufficient priority in some organisations and consequently valuable opportunities for improvements were being missed. The report also pointed out that there was more that could be done to engage families and carers and to recognise their insights as a vital source of learning.

National Guidance on Learning from Deaths was published by the National Quality Board in March 2017. This outlined a framework for NHS trusts in England on identifying, reporting, investigating and learning from deaths in care. It followed events in Mid Staffordshire which prompted a review of 14 hospitals with the highest mortality rates.

The *National Mortality Care Record Review Programme* (NMCRR), established in 2016, aims to develop and implement a standardised way of reviewing the case records of adults who have died in acute hospitals across England and Scotland by improving understanding and learning about problems and processes in healthcare associated with mortality, and also to share best practice.

In England, the recently published *NHS Long Term Plan, 2019* envisages the NHS becoming more differentiated in its support to individuals in their end of life care choices, including type and location of care. By rolling out training to help staff identify and support relevant patients, proactive and personalised care planning will be introduced for everyone identified as being in their last year of life. A consequence of better quality care will be a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen. The personalisation of healthcare will also be reflected in the increased use of personal health budgets for specialist end of life care.

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.

The *Palliative and End of Life Care Delivery Plan* was updated and published in March 2017 and covers all aspects of palliative and end of life care, delivered by both primary and secondary care, and also involves specialist palliative care services delivered by the NHS or third sector providers. The delivery plan is overseen by the End of Life Care Board, who are resolved to ensure that the updated delivery plan capitalises on the success achieved to date and maintains a collegiate approach to improving end of life care in Wales. Specifically their role is to drive forward the national plan and support health boards to deliver their local plans.

In the 2017-18 financial year, the Welsh Government announced an additional one-off funding of £1m to support the work of the End of Life Care Board. To ensure patients' experiences are consistently improving, the funding has been used for activities such as providing additional training for health professionals to initiate difficult conversations about end of life care with patients and their families as well as supporting the development of an all Wales streamlined, advance care planning electronic record system and to take forward research priorities. This additional funding has since been extended for a further two years in 2018-19 and 2019-20.

1.2 Audit background and governance

The National Audit of Care at the End of Life (NACEL) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government in October 2017. End of life care was prioritised as a National Clinical Audit and Patient Outcome Programme (NCAPOP) topic by NHS England in October 2015. The audit was commissioned from the NHS Benchmarking Network (NHSBN), who have been supported by the Patients Association in delivering the audit.

The Northern Ireland Public Health Agency separately commissioned NHSBN to cover Northern Ireland's participation. The findings are reported in a separate document.

Governance of NACEL is 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 10. Dr Suzanne Kite, Clinical Lead/Consultant in Palliative Medicine, and Elizabeth Rees, Clinical Lead/Lead Nurse for End of Life Care, Leeds Teaching Hospitals NHS Trust, provided 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.

The last national audit, *End of Life Care Audit – Dying in Hospital*, was delivered by the Royal College of Physicians and reported in 2016 on data collated in 2015 (hereafter referred to as "*the 2016 Audit*"). The audit scope covered care for people who died in acute NHS hospitals in England. NACEL builds on the experience and achievements of the previous end of life care audits.

National Audit of Care at the End of Life

1. Audit background and development

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 leading to death in acute, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

The objectives of the first round of NACEL are:

1. To establish whether appropriate structures, policies and training are in place to support high quality care at the end of life.
2. To assess compliance with national guidance on care at the end of life – *One Chance To Get It Right, NICE Guideline* and the *NICE Quality Standards* for end of life care.
3. To determine what is important to dying people and those important to them.
4. To provide audit outputs which enable stakeholders to identify areas for service improvement.
5. 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.

1.4 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 the *NICE Guideline* and *Quality Standards*. 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 Guideline* and *Quality Standards*. *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 Quality Standard 144*.

1. Audit background and development

There are two further publications from NICE which outline standards which should be expected for the dying person and those close to them in the last few days of life. *NICE Guideline NG31 Care of dying adults in the last days of life* covered the clinical care of dying adults (aged 18 years and over) in the last few days of life. It aimed 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*.

1.5 Audit structure and scope

NACEL covers the last admission to hospital prior to death. It is important to note that the scope of NACEL has widened since the *2016 Audit* (which covered acute provision in England) to include acute providers, community hospitals and mental health inpatient facilities. Hospices were excluded. NACEL covered NHS funded care at the end of life in hospital in both England and Wales. Northern Ireland joined NACEL at a later stage and is the subject of a separate report.

NACEL had several elements:-

An Organisational Level Audit covering trust/UHB and hospital/submission level questions. Organisations could create multiple 'submissions' for their different hospital sites if they wished to audit the hospitals separately. The Organisational Level Audit was completed by acute, community and mental health providers.

A Case Note Review completed by acute and community providers only, which reviewed all deaths in April 2018 (acute providers) or deaths in April – June 2018 (community providers). The following categories of deaths were defined: -

> **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 care at the end of life.

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

Deaths which are 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

1. Audit background and development

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/UHBs.

Mental health providers did not complete the Case Note Review or the Quality Survey.

1.6 Development of audit tools

Data specifications for all elements of the audit were developed in consultation with the NACEL Steering Group and wider Advisory Group. All final specifications were approved by the NACEL Steering Group.

The Organisational Level Audit concentrated on policies and pathways, activity, the specialist palliative care workforce, training and quality and outcomes.

The Case Note Review covered patient demographics, final admission details, advance care planning (ACP), treatment decisions, recognition of dying, individualised end of life care planning, physical care, communication with the nominated person, and finally, care prior to and immediately after death. The content of the Case Note Review was piloted with five sites.

The content of the Quality Survey was developed with the assistance of the Patients Association and was piloted with bereaved people. The Quality Survey included 24 questions and the opportunity to give narrative responses to the following questions:

1. Please add any comments or explain further about how the hospital cared for him/her during the last few days
2. Please add any comments or explain further about how the hospital met your needs during the last few days when he/she was dying
3. If you could improve or change one thing about care given by the hospital at the end of life to you or the person who died, what would it be?

2. Methodology

2.1 Eligibility, recruitment and registration

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

Registration was completed online. On registration, acute sector organisations had the option of setting up multiple submissions to cover different hospital sites. Due to the lower number of deaths occurring within community hospitals, it was recommended that organisations with community hospitals set-up one submission covering all of their community hospitals provision and not individual submissions for each.

2.2 Data collection

Data collection opened on the 4th June 2018 and closed on the 12th October 2018 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 trust/UHB level questionnaire for their organisation, and one hospital/site level questionnaire for each submission created on registration. Questions related to 2017/18 data.

Participants were asked to pull case notes for deaths in April and undertake a brief review to categorise them as Category 1, Category 2 or sudden deaths (see section 1.5 for definitions). Category 1 and 2 deaths were eligible to be included in the audit. Acute hospitals were requested to complete up to 80 Case Note Reviews for eligible deaths, with participating organisations being asked to ensure the minimum number of case notes reviewed was no less than 5% of the total annual deaths. Community hospitals were given an extended period of April to June deaths to review, due to the relatively small number of deaths occurring in these facilities.

Data collection for NACEL was via a bespoke online data entry tool for both the Organisational Level Audit and the Case Note Review. The audit tool included full definitional guidance for each data item requested. Excel versions of all data specifications could be downloaded to assist audit participants with internal data collation prior to the upload of datasets onto the data collection tool.

The Quality Survey was undertaken online via unique technology which enabled the Case Note Review and Quality Survey to be linked anonymously at a later stage. People identified by the trust/UHB as the carer/next of kin were sent a letter with a unique link to access the survey online. 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.

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 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 question 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.

2. Methodology

An extensive data validation exercise was undertaken from mid-October to the end of December 2018. As part of the validation process outlying positions were queried with NACEL participants. For the Case Note Review, when it was possible to identify data errors and inconsistencies in the responses returned, responses were changed, and these changes recorded. Where it was not possible to identify an error with complete confidence, no change was made. A draft online toolkit was made available to NACEL participants at the beginning of December to assist with checking data submissions.

2.4 Data confidentiality and security

As required by the Data Protection Act (DPA), 2018 and the General Data Protection Regulation (GDPR), 2018 the NHSBN has registered with the Information Commissioners Office (ICO) as an organisation which processes data.

The NHSBN is *Cyber Essentials* certified, a government sponsored programme which ensures network and data security.

Participating trusts/UHBs were requested to provide the NHSBN with the details of key personnel they wished to have access to the online data collection tool. Entry to the online data collection tool was restricted via unique identifiers and passwords assigned to individuals during the registration process.

The NHSBN provided assurance to HQIP that the legal basis to process data under contract to HQIP was met and reviewed regularly in line with contractual requirements.

A Data Protection Impact Assessment (DPIA) was completed for NACEL and updated on a regular basis. The DPIA was made available on the NACEL webpages. Completion of the NACEL DPIA was a requirement under GDPR. The DPIA outlines how data is be held and used and lays out expectations of privacy and privacy risks. The DPIA outlines the appropriate controls required to protect personal data in terms of technical, procedural and physical needs. The DPIA states that the data collected for NACEL may be used for clinical audit, service evaluation and research purposes, and that requests for the use of NACEL data will be managed via HQIP using their agreed process.

A Fair Processing Notice was also developed and displayed on the NACEL webpages, together with a data flow diagram which illustrated the various elements of data collection and how the data were to be used.

The NHSBN team also provided information governance guidance for participating trusts/UHBs for the various elements of NACEL. Guidance was developed with the NHSBN's Data Protection Officer. The new GDPR requirements came onstream during the operation of the NACEL data collection which heightened awareness of the issue by participating trusts/UHBs.

No patient identifiable information was collected in any element of NACEL by the NHSBN.

2.5 Reliability analyses

NACEL asked participating hospitals to re-audit five case notes from the submitted Case Note Review sample using a second auditor so that matching case notes could be compared for reliability. The NHSBN team advised that the first five applicable case notes should be used for this where possible. The reliability analysis can be found at Appendix 9. Each metric included within the NACEL summary scores received a score indicating either 'moderate agreement' or 'substantial agreement'. Summary scores have not been adjusted according to the reliability study results.

2. Methodology

2.6 Management of Outliers Policy

The Management of Outliers Policy is available on the NACEL webpages. The policy has been informed by HQIP guidance and approved by the NACEL Steering Group.

The outlier indicator included in the policy was the proportion of deaths where it was recognised that the patient may die imminently (Category 1 deaths) out of all deaths audited (Category 1 and Category 2 deaths).

Three hospitals who have been identified as potential outliers on the specified outlier indicator have been contacted and managed in accordance with the policy prior to the publication of this report.

2.7 Cause for Concern Policy

The Cause for Concern Policy is available on the NACEL webpages. The policy has been informed by HQIP guidance and approved by the NACEL Steering Group. Narrative responses from the Quality Survey, to the three questions listed in section 1.6, were reviewed by the NACEL Director and the Clinical Leads, following the removal of any identifying information. Twenty issues raised by respondents suggesting a possible cause for concern were discussed in detail with HQIP. Following discussion, it was agreed that none of the issues met the criteria for triggering the formal *Cause for Concern Policy*. However, in eleven cases the trust/UHB was contacted with the respondent's code so that they could be contacted about a perception of neglect or abuse that could potentially constitute a safeguarding issue. This disclosure of the identifying code was in accordance with an expectation set in explaining the use of the data to respondents.

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

3. Participation

As outlined in section 2.1, all NHS acute, community hospital and mental health inpatient providers in England and Wales were eligible to register for NACEL.

The final number of trusts/UHBs participating in NACEL, and providing data for at least one element of the audit, was 206 trusts in England, and in Wales, all 7 University Health Boards (UHBs) and Velindre NHS Trust took part, giving a total of 215 organisations (97% of eligible organisations). As explained in section 2.1, organisations were able to set up 'submissions' for each of their hospital sites.

For the Organisational Level Audit, two elements of data collection were requested:-

Trust/UHB overview. This data collection covered the organisation as a whole and was completed once per organisation, regardless of the number of submissions. The trust/UHB overview collected data on trust/UHB organisational policies and protocols. In total, 207 completed questionnaires for the trust/UHB overview were received (202 for England and 5 for Wales).

Hospital/site overview. This data collection covered hospital/site data and was completed for each submission registered. The hospital/site overview collected data on activity, workforce, quality and outcomes and good practice. The number of hospital/site overview data collection submissions, analysed by sector, is shown in table 1.

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

Submission type	England	Wales	Total
Acute	162	5	167
Community	62	3	65
Mental Health	68	2	70
Total	**292**	**10**	**302**

In total, 176 organisations (170 for England and 6 for Wales) supplied data for the Case Note Review. These organisations created a total of 221 submissions categorised as acute or community hospital as shown in table 2.

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

Submission type	England	Wales	Total
Acute	165	5	170
Community	47	4	51
Total	**212**	**9**	**221**

The total number of Case Note Reviews returned is shown in table 3. There were a total number of 11,034 Case Note Reviews included in the first round of NACEL.

3. Participation

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

Submission type	England	Wales	Total
Acute	9,647	377	10,024
Community	875	135	1,010
Total	**10,522**	**512**	**11,034**

The number of submissions for whom at least one Quality Survey was returned, was 118 (table 4). A total of 790 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	103	3	106
Community	11	1	12
Total	**114**	**4**	**118**

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

Submission type	England	Wales	Total
Acute	725	16	741
Community	34	15	49
Total	**759**	**31**	**790**

The response rate for the Quality Survey, for those that were sent a letter by the trust/UHB (see section 2.2 for an explanation of the data collection methodology), was 18%. This response rate from people contacted was encouraging. However, the absolute numbers of completed surveys received was low because some trusts/UHBs chose not to participate in this element of the audit for the following reasons:

- already undertaking a local bereaved persons survey
- contact details for relevant person not recorded or not easily accessible
- concerns regarding GDPR and use of contact details

Details of which audit element each trust/UHB submission participated in, together with the number of Case Note Reviews completed and Quality Survey responses received for each submission, is included at Appendix 11.

Northern Ireland participation can be found in the Northern Ireland NACEL first round report.

National Audit of
Care at the End of Life

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 the first round of NACEL. Results from the three elements of the audit are presented together. Section 6 contains the findings from the mental health provider participation in the Organisational Level Audit.

4.2 Key themes and summary scores

The information in this report is presented thematically in nine sections, covering the *five priorities for care* and other key issues. The themes are:

1. **Recognising the possibility of imminent death**
2. **Communication with the dying person**
3. **Communication with families and others**
4. **Involvement in decision making**
5. **Needs of families and others**
6. **Individual plan of care**
7. **Families' and others' experience of care**
8. **Governance**
9. **Workforce/specialist palliative care**

For each theme, a summary score has been developed and calculated for each hospital, the mean values for the summary scores are shown in the infographic below. The summary scores allow easy comparison between hospitals on the different themes within the audit. Appendix 2 sets out the process undertaken to select the nine key themes and their component indicators, and an explanation of how the scores are calculated. Each summary score can only use indicators from one element of the audit.

Theme	Score
Recognising the possibility of imminent death	9.1
Communication with the dying person	6.9
Communication with families and others	6.6
Involvement in decision making	8.4
Needs of families and others	6.1
Individual plan of care	7.4
Families' and others' experience of care	7.1
Governance	9.5
Workforce/specialist palliative care	7.6

National Audit of Care at the End of Life

4. How the findings are presented

4.2 Key themes and summary scores

A table of the scores per hospital can be found at Appendix 1. Not every hospital has received a full set of summary scores. To receive a full set, hospitals were required to provide completed responses for the Governance and Workforce/specialist palliative care summary score component indicators from the Organisational Level Audit, five or more Case Note Review responses for each component indicator and five or more 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 sections of the audit. In addition, narrative responses from three of the open questions within the Quality Survey (section 1.6) have been analysed and the results are reported on. A selection of quotes from the narrative received is also included. In addition, narrative comments received from auditors completing the Case Note Review are referred to.

Additional information on patient demographics, characteristics of deaths in hospitals, use of interventions, nominated person relationship to the patient and number of hospital admissions within the last 12 months is provided in appendices 3 to 7.

In reviewing the results in this report, it should be noted that the total number of Quality Surveys returned was 790, representing 7% of the Case Note Reviews completed (11,034). The Quality Survey results may not, therefore, be representative of the whole Case Note Review sample.

4.3 Comparison with previous audits

The previous audit was undertaken by the Royal College of Physicians and audited deaths in May 2015 in acute hospitals in England (the "*2016 Audit*"). The scope of NACEL which, as noted in section 1.5, covers care at the end of life in acute, community hospitals and mental health inpatient providers in England and Wales, is broader than the scope of the *2016 Audit*. Further, the *2016 Audit* included sudden deaths and 'sudden deaths/unexpected deaths' had a different definition to that used in NACEL. However, both the *2016 Audit* and NACEL excluded deaths where the person had been in hospital for less than 4 hours.

Due to the differences in scope and content, robust and meaningful comparisons between NACEL and the *2016 Audit* are difficult to make. However, reference to the *2016 Audit* is made in a small number of key areas to provide context for the first round of NACEL results.

4.4 Indicators in this report

The indicators presented in this report are generally illustrated in column charts. The charts include a note of the number of responses used to produce the result (n=number). For ease of reference, the audit questions to which the charts refer have been abbreviated in the chart titles. The results for each indicator are also quoted in the text as percentages. Appendix 8 includes the full wording of the relevant audit question for each indicator referenced in the report, together with the number of responses (n) used to calculate the percentage results. Appendix 8 references the figure number of each chart and where values are referenced in the narrative but not included within a figure, a note is provided next to the text in subscript.

4. How the findings are presented

4.5 First 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 December 2018 to assist participants with validation queries and to give early sight of trust/UHB positions against the range of metrics. The final toolkit was published in January 2019 incorporating all changes.
2. **A national summary report.** Summary reports are being made available for England and Wales (this report) and, separately, for Northern Ireland. These contain the high-level findings and recommendations from NACEL for the respective countries.
3. **Bespoke dashboards.** These have been made available at submission level for every participating trust/UHB in all three UK countries. The bespoke dashboards contain a selection of key metrics where individual submission positions are compared against nationally reported positions. The bespoke dashboards are made available as follows:

    *   England and Wales bespoke dashboard - acute and community providers
    *   Northern Ireland bespoke dashboard - five Health and Social Care Trusts in Northern Ireland
    *   Mental Health bespoke dashboard - all organisations who provided data for mental health inpatient facilities

All data is anonymised in the online benchmarking toolkit and participating organisations know their own position only. Participant codes for the toolkit have not been shared amongst participants. However, this report contains identified positions for the summary scores for each hospital/submission in a table (see Appendix 1).

5. Results

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*, 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)*.

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

Early recognition that a person may be dying enables an individual care plan to be developed, appropriate discussions with the patient and families 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.
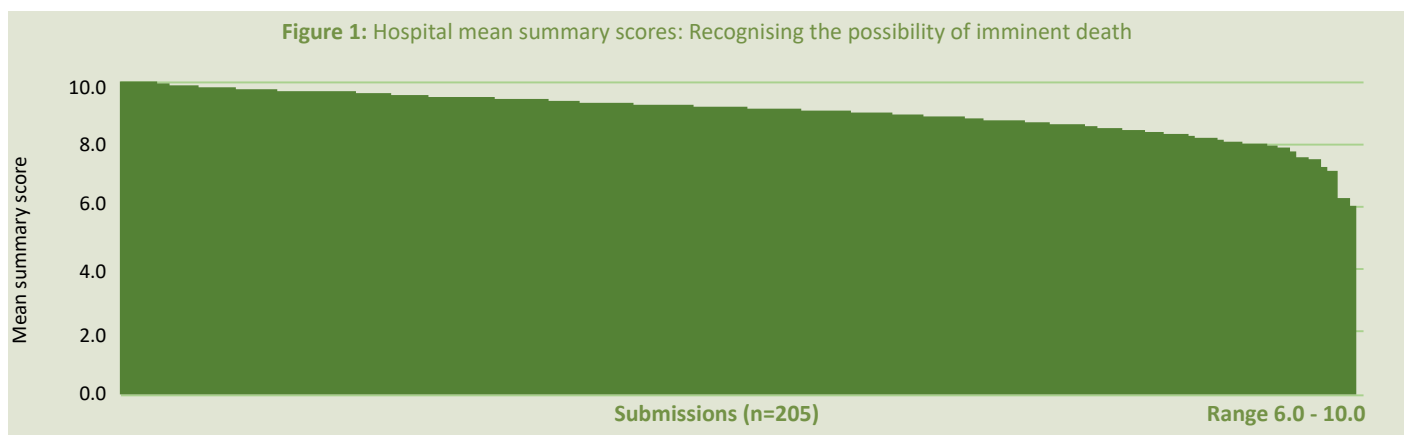
Recognising the possibility of imminent death: summary score

> Recognising the possibility of imminent death — **9.1**

The summary score for recognising the possibility of imminent death is calculated using the following information collected in the Case Note Review:

Documented evidence:
- of recognition that the patient may die imminently
- the possibility the patient may die discussed with the patient
- the possibility the patient may die discussed with families/others

Figure 1: Hospital mean summary scores: Recognising the possibility of imminent death

Submissions (n=205)   Range 6.0 - 10.0

The range of hospital mean summary scores for recognising the possibility of imminent death is shown in figure 1.

The mean value of the summary score across the whole sample of case notes is 9.1 (n=10,002).

It should be noted that the summary score, for technical reasons, does not capture the timeliness of recognition of the possibility that the person may die imminently and may therefore give an overly positive indication of progress on this key priority. Timeliness of recognition is considered in this section.

5. Results

Figure 2: (CNR) Documented evidence of recognition that the patient may die imminently

n=10,744

89%

■ Yes □ No
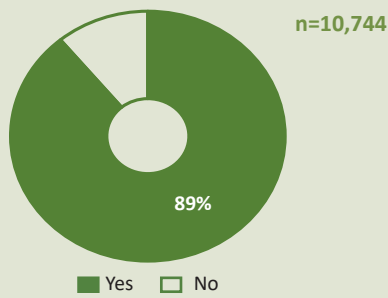
89% of patients audited had documented evidence that the patient might die imminently i.e. within the next few hours or days (figure 2). It should be noted that 'sudden deaths' were excluded from the audit (section 1.5). Sudden deaths represented 8% of all case notes assessed for audit inclusion.

Where imminent death was recognised, in $99\%_1$ of cases, medical staff were involved in the discussion about recognition of death, the specialist palliative care team in $41\%_2$ of cases, and nurses in $67\%_3$.

The importance of clearly and sensitively explaining to the patient that they are likely to be dying is emphasised in the guidance. From the Case Note Review, documented evidence that the possibility that the patient may die within the next few hours/days had been discussed with the patient existed in 23% of all cases audited. There was no documented discussion and no reason why not, in 15% of cases (figure 3). The discussion was more likely to take place with the people important to the dying person (90% of cases) (figure 4).

Figure 3: (CNR) Documented evidence the possibility that the patient may die discussed with the patient
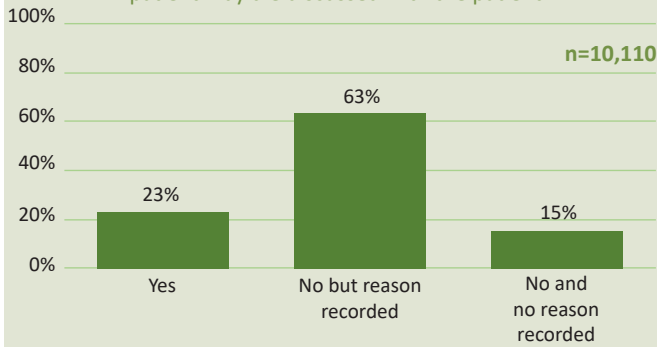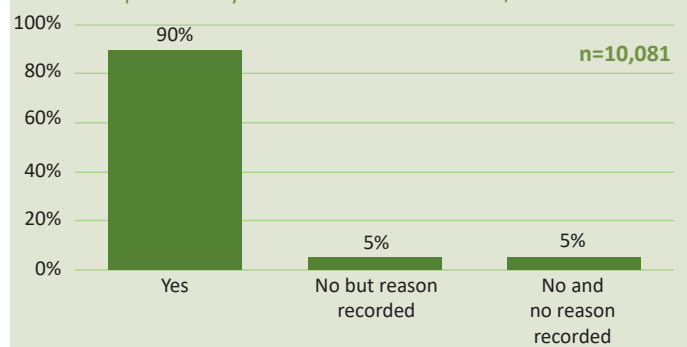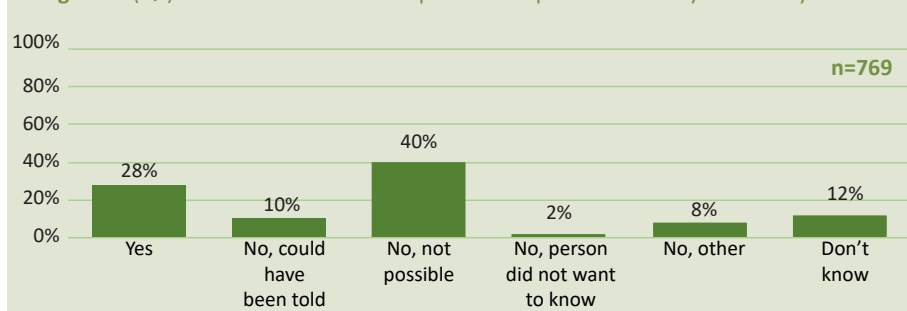
n=10,110

	Yes	No but reason recorded	No and no reason recorded
	23%	63%	15%

Figure 4: (CNR) Documented evidence the possibility that the patient may die discussed with families/others

n=10,081

	Yes	No but reason recorded	No and no reason recorded
	90%	5%	5%

In addition to the indicators used in the summary score and discussed above, the following results from the Quality Survey are relevant to recognition that a person may die in the next few days or hours. **As discussed in section 4.2, it should be noted that the total number of Quality Surveys returned was 790, representing 7% of the Case Note Reviews completed (11,034). The Quality Survey results may not, therefore, be representative of the whole Case Note Review sample.**
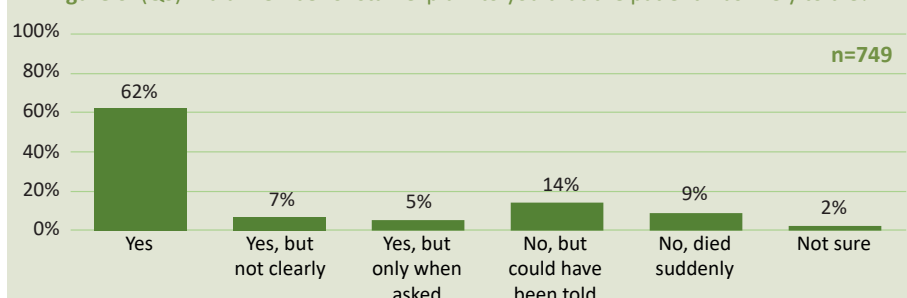
Respondents to the Quality Survey stated that a member of staff explained to the patient that they were likely to die in 28% of cases. In 10% of cases, the respondent stated the patient wasn't told but could have been (figure 5).

Figure 5: (QS) Did a member of staff explain to the patient that they were likely to die?

n=769

Yes	No, could have been told	No, not possible	No, person did not want to know	No, other	Don't know
28%	10%	40%	2%	8%	12%

A member of staff clearly explained to the bereaved person that the patient was likely to die in 62% of cases. This was explained but not clearly in 7% of cases and only when asked, in 5%. People felt they weren't told but could have been in 14% of cases (figure 6).

**Figure 6:** (QS) Did a member of staff explain to you that the patient was likely to die?

n=749

Yes	Yes, but not clearly	Yes, but only when asked	No, but could have been told	No, died suddenly	Not sure
62%	7%	5%	14%	9%	2%

5. Results

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 from first recognition of dying to time of death was 36 hours[4]. For deaths in acute hospitals in England the median time was 34 hours[5], which can be compared to the median time reported in the *2016 Audit* of 34 hours. Of those included in the audit, 20%[6] died within 8 hours of recognition that death might be imminent.

The scatter plot (figure 7) shows the mean average time (in hours) from first recognition of dying to time of death for each submission plotted against the number of responses received for that submission. The mean time for each submission is generally higher than the national median time, due to high outliers.
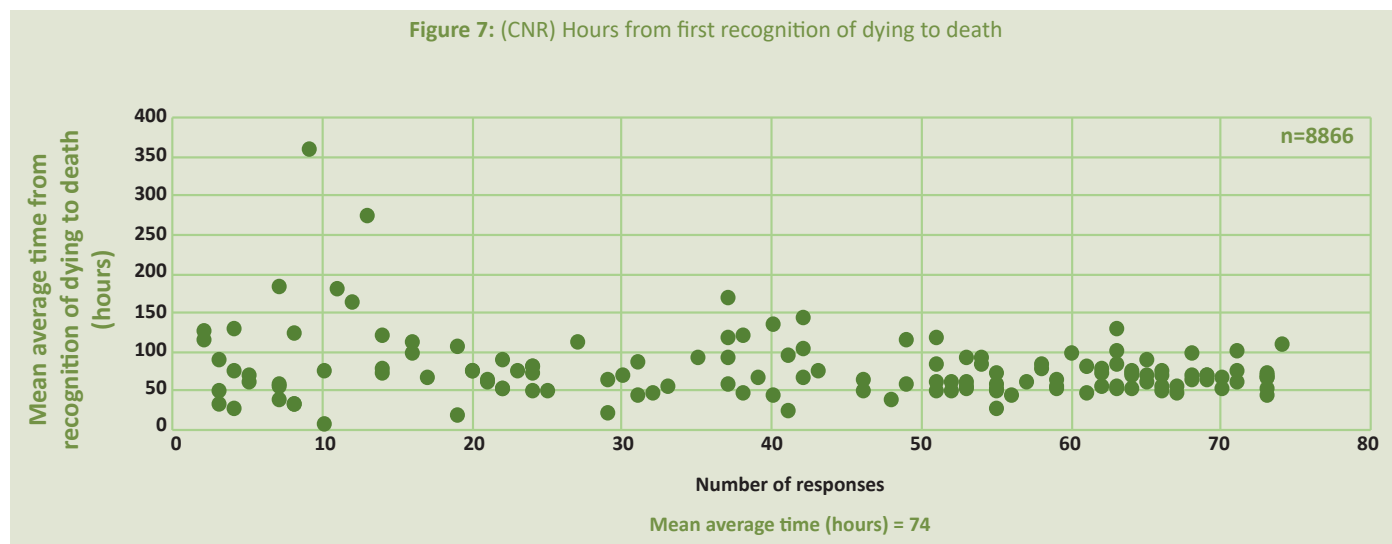
Figure 7: (CNR) Hours from first recognition of dying to death

n=8866

Mean average time (hours) = 74

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 issues identified when undertaking the Case Note Review, 8% (436/5,713) mentioned late, or lack of, recognition of deterioration or dying.

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

The Quality Survey captured narrative comments from people important to the dying person. 28% (89/321) of comments analysed referenced communication. Of these comments, 19% (17/89) were about recognition of imminent death.

"We were kept informed of decisions and made aware of what might begin to happen to our father as he approached the end, so we were not shocked when it happened. We were well prepared."

"He was not told that he was dying. Nor was I."

"We were not told my dad was as poorly as he was, otherwise, we would have been by his side at the end or, if possible, would have gotten him home. We felt we were not given sufficient time to get to hospital and my father died alone in a place he did not want to be."

5. Results

Recognising the possibility of imminent death: summary

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 high compliance with documentation of the possibility that the patient might die within the next few hours/days (89%).

There is scope to improve the recording of reasons why a discussion about imminent death did not take place with the patient (15%, no reason recorded). Compliance was high with discussing the possibility of death within the next hours/days with people important to the dying person (90%).

Although the results of the Quality Survey are caveated due to the low number of responses received (section 4.2), it is notable that 21% of respondents felt communication with them about the patient's imminent death either didn't happen or was unclear, with a further 5% saying they were told only when they asked. The narrative to the Case Note Review also raised some concerns regarding timely recognition of death.

The results suggest that, for around half of patients, death occurs within less than one and a half days of recognition of the possibility that they may die, leaving a limited amount of time to discuss and implement a plan of care. The median time from recognition of dying to death (acute and community hospitals, 36 hours, and England acute (excluding community), 34 hours) is similar to that recorded in the *2016 Audit* (34 hours). However, it is difficult to reach a conclusion on progress with timeliness of recognition because, 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.

Recommendation 9: Ensure that staff have an awareness of, acknowledge and communicate, as early and sensitively as possible, the possibility or likelihood of imminent death. Ensure that patients who have signs and symptoms that suggest they may be in the last days of life are monitored for changes. 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.

5. Results

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 Organisational Level Audit on communication with the dying person. The perspective of those important to the patient on whether communication with the dying person was sensitive was collected in the Quality Survey and is considered in section 5.7, Families' and others' experience of care.

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)*.

In this report, communication with the dying person and communication with families and others, are reviewed separately, in this and the next section.
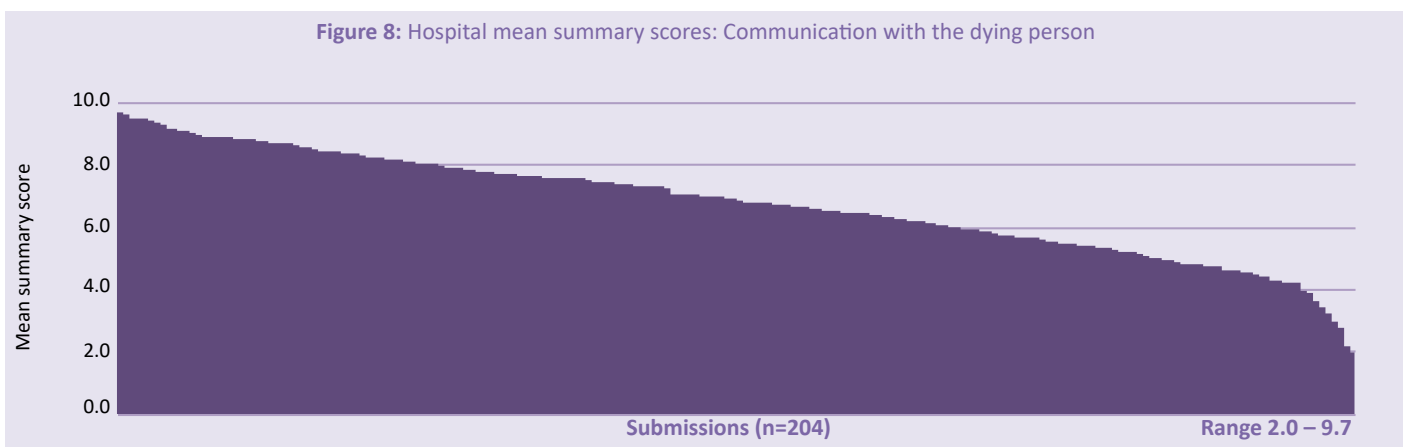
Communication with the dying person: summary score

Communication with the dying person **6.9**

The summary score for communication with the dying person is calculated using the following information collected in the Case Note Review:

Documented evidence:
- the patient had the opportunity to be involved in discussing their plan of care
- the patient was informed of professional responsible for their care
- the possibility of side effects of medication was discussed with the patient
- risks and benefits of hydration was discussed with the patient
- risks and benefits of nutrition was discussed with the patient

Figure 8: Hospital mean summary scores: Communication with the dying person

Submissions (n=204)   Range 2.0 – 9.7

The range of hospital mean summary scores for communication with the dying person is shown in figure 8.
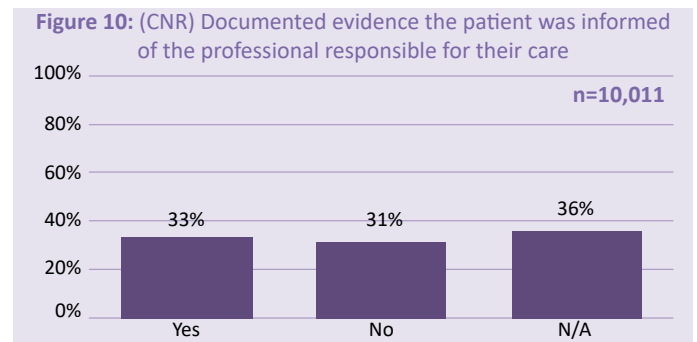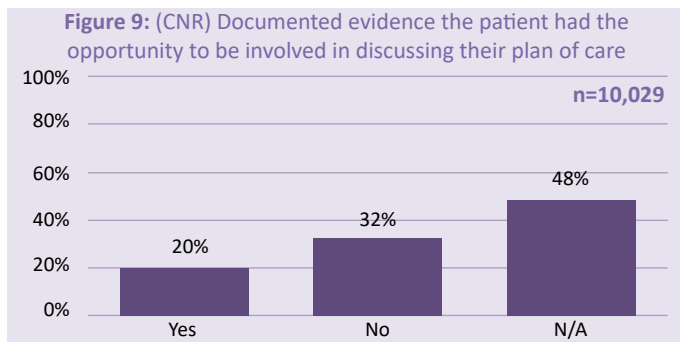
The mean value of the summary score across the whole sample of case notes is 6.9 (n=8,831).

5. Results

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 individual plan of care (see section 5.6).

There was documented evidence that the patient had the opportunity to be involved in discussing the plan of care in 20% of cases, and no evidence in 32% of cases (figure 9). Helpline discussion with those completing the audit suggests some potential misunderstanding about the use of the terms 'individualised end of life care plan' and 'plan of care' in the audit (see section 5.6), which may have affected this result. This point will be clarified in the second round of NACEL.

Patients, and those important to them, should know the name of the senior responsible doctor for their care. There was documented evidence that the patient had been informed about their senior responsible clinician in 33% of cases, and no evidence in 31% of cases (figure 10). This result may reflect instances where communication regarding the senior clinician was established earlier in the episode of care.

Figure 9: (CNR) Documented evidence the patient had the opportunity to be involved in discussing their plan of care

n=10,029

Figure 10: (CNR) Documented evidence the patient was informed of the professional responsible for their care

n=10,011

Evidence was recorded that the side effects of medications been discussed with the patient in 8% of cases and, the risks and benefits of hydration and nutrition, in 9% and 7% of cases, respectively. For each of these discussion areas, no evidence and no reason was recorded in around one third of cases (figures 11, 12 and 13).

Figure 11: (CNR) Documented evidence the possibility of side effects of medication was discussed with the patient

n=9,984

Figure 12: (CNR) Documented evidence risks and benefits of hydration was discussed with the patient

n=9,803

Figure 13: (CNR) Documented evidence risks and benefits of nutrition was discussed with the patient

n=9,664
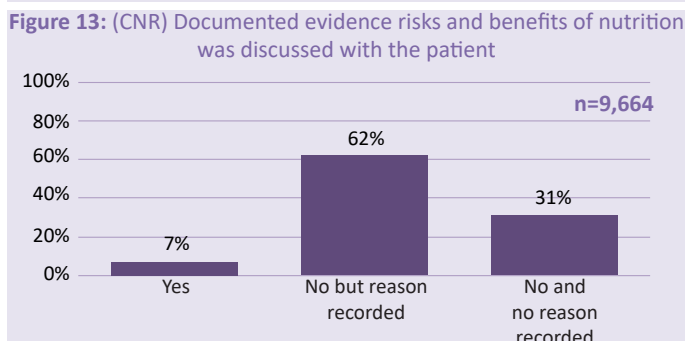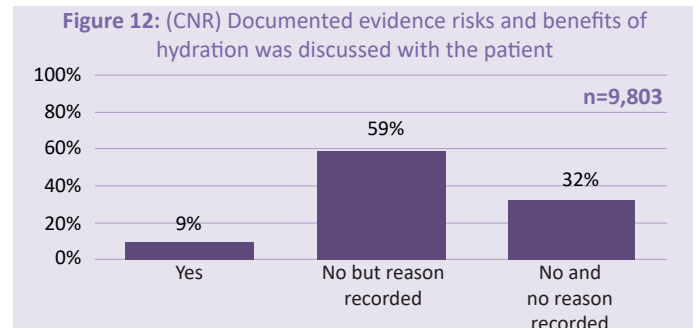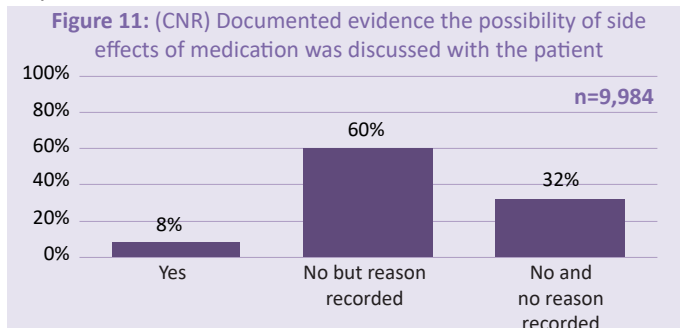
Communication with patients and families/others was the most frequently cited topic for narrative comments provided by auditors as part of the Case Note Review (20% (1,147/5,713) of all comments analysed). Of the comments about communication, 61% (705/1,147), were analysed as positive and 39% (442/1,147), as negative. Poor documentation was cited in 16% (938/5,713) of comments.

In addition to the indicators used in the summary score and discussed above, the following result from the Organisational Level Audit is relevant to communication with the dying person:

• 90%[7] of trusts/UHBs have guidelines to promote dignity.

See also section 5.9 Workforce/specialist palliative care for information on staff training to improve culture, attitudes, behaviours around communication skills.

5. Results

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

As noted above, from the Quality Survey, 28% (89/321) of all comments referenced communication, of these, 39% (35/89) were analysed as positive and 61% (54/89), negative. Out of all comments about communication, 20% (18/89) were about communication with the patient.

"Felt communication was lacking between the team caring for her. HCA didn't seem aware of her dying and even brought a tray of food to her when she was heavily sedated and a few hours from death. This was extremely distressing for all members of the family around her."

"Even in the final couple of days, where there was very little response, the staff spoke to our father personally (not just 'about' him, to us) and in hushed tones, positioning their faces near to his so that he could hear their voices and respond in the small way that he was able."

Communication with the dying person: summary

As there are no directly comparable questions from the *2016 Audit*, the findings from NACEL 2018 provide a baseline against which progress on communication with the dying person can be measured in future rounds of the audit.

The findings of the first round of NACEL suggest most organisations have put in place policies to promote dignity, and training to improve the organisational culture and communication skills (see section 5.9), suggesting trust/UHB Boards are aware of the importance of appropriate behaviours and good communication during care at the end of life. However, in around one third of cases a discussion with the patient about the plan of care had not been recorded and, in one third of cases, no discussions, and no reason why not, about medication, hydration and nutrition had been recorded. The lack of documentation does not necessarily mean the discussion did not take place, but does suggest recording of conversations could be improved.

Responses received from the Quality Survey also indicate room for improvement with 22% of respondents reporting that communication with the dying person was not sensitive or was 'mixed' (see figure 73, section 5.7).

Recommendation 5: Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and the people who are important to them. Support all staff to have awareness, communicate sensitively and behave appropriately, when it is recognised that a person may be dying. See also Annex E of *One Chance To Get It Right*.

Recommendation 6: Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with patients and families in the last days and hours of life. Training for clinicians and other staff who have contact with dying people should focus on supporting the delivery of the *NICE Quality Standards* within the broader context of *One Chance To Get It Right*. National resources to support training are available such as guidance from professional bodies, learning outcomes and e-ELCA.

5. Results

5.3 Communication with families and others

As noted in section 5.2, open and honest communication between staff and the dying person, and those identified as important to them, is critically important to good care. In this section, findings from the Case Note Review, Organisational Level Audit and Quality Survey, on communication with families and others, 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 Standards, 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*).
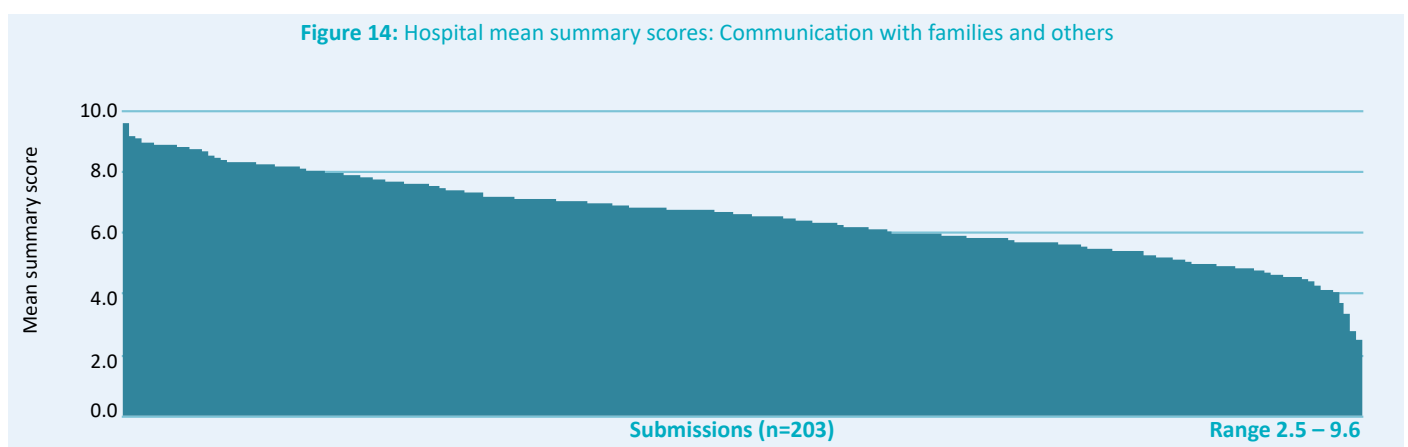
Communication with families and others: summary score

> Communication with families and others ▷ **6.6**

The summary score for communication with families and others is calculated using the following information collected in the Case Note Review:

Documented evidence:
- families/others had the opportunity to discuss the patient's plan of care
- families/others were notified of the professional responsible for the patient's care
- families/others were notified of the patient's imminent death
- the possibility of side effects of medication was discussed with families/others (weighting 0.33)
- risks and benefits of hydration was discussed with families/others (weighting 0.33)
- risks and benefits of nutrition was discussed with the families/others (weighting 0.33)

Figure 14: Hospital mean summary scores: Communication with families and others

Submissions (n=203)   Range 2.5 – 9.6

The range of hospital mean summary scores for communication with families and others is shown in figure 14.

The mean value of the summary score across the whole sample of case notes is 6.6 (n=8,622).

5. Results

Figure 15: (CNR) Documented evidence families/others had the opportunity to discuss the patient's plan of care
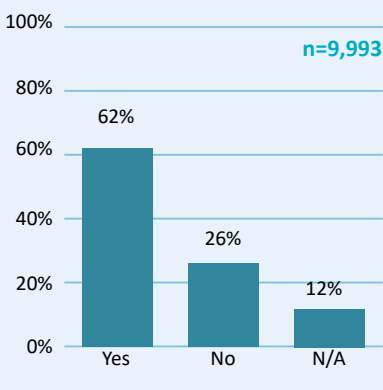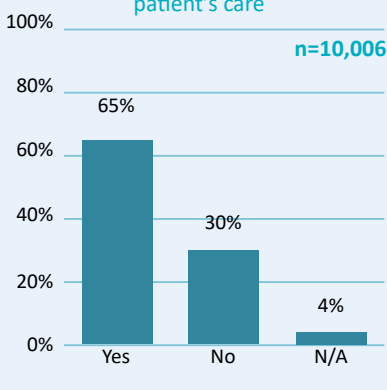

n=9,993

Figure 16: (CNR) Documented evidence families/others were notified of professional responsible for the patient's care

n=10,006

Figure 17: (CNR) Documented evidence families/others were notified of the patient's imminent death

n=10,650

Figure 18: (CNR) Documented evidence the possibility of side effects of medication was discussed with families/others

n=9,792

Figure 19: (CNR) Documented evidence risks and benefits of hydration was discussed with families/others

n=9,791
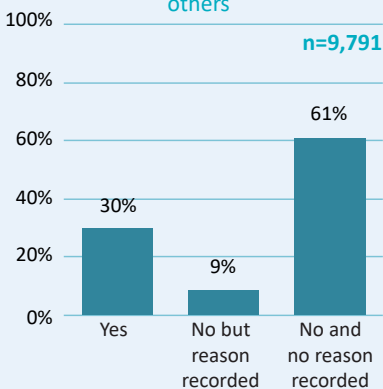
Figure 20: (CNR) Documented evidence risks and benefits of nutrition was discussed with the families/others

n=9,655

Given that the possibility a person may be dying may only be recognised a day or two before death (section 5.1), it is more likely that conversations will take place with those important to the person, than with the dying patient themselves and this is borne out by the audit results. There was documented evidence that the families/others had the opportunity to be involved in discussing the plan of care in 62% of cases, and no evidence in 26% of cases (figure 15).

There was documented evidence that the family/others had been informed about the senior responsible clinician in 65% of cases, and no evidence in 30% of cases (figure 16).

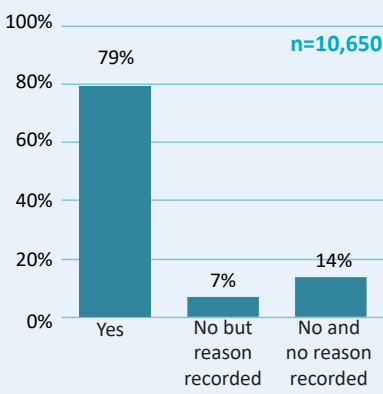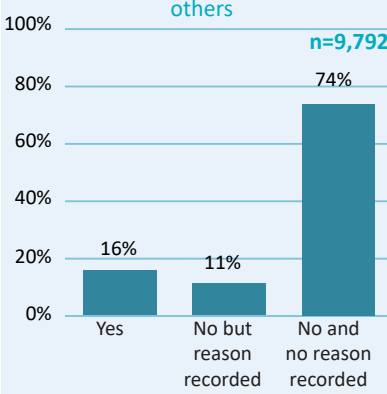Evidence that families/others were notified of the patient's imminent death was recorded in 84%[8] of cases, for Category 1 deaths, and 79% of all deaths audited (Categories 1 and 2) (figure 17). In the *2016 Audit*, when sudden and unexpected deaths were excluded (see section 4.3), the result was 84% (England, acute trusts only). The findings on this measure therefore appear consistent with the *2016 Audit*. For all deaths audited in NACEL, the family were not notified and no reason was recorded in 14% of cases (figure 17).

From the Case Note Review, in 49%[9] of cases the families/others were recorded as being present at the time of death, 6%[9] requested not to be present, 22%[9] were recorded as not present, no evidence was recorded in 21%[9] of cases and there was no nominated person(s) in 2%[9] of cases.

Evidence was recorded that the side effects of medications had been discussed with the family/others in 16% of cases (figure 18) and the risks and benefits of hydration and nutrition in 30% and 23% of cases respectively (figure 19 and 20). For each of these discussion areas, no evidence and no reason for not discussing was recorded in 74%, 61% and 66% of cases respectively (figures 18, 19 and 20).

In addition to the indicators discussed above, the following metrics from the organisational audit are relevant to communication with families and others:

- 70%[10] of trusts/UHBs have guidelines for meaningful and compassionate engagement with bereaved families and carers
- 76%[11] of sites sought bereaved relatives' or friends' views during the last two financial years

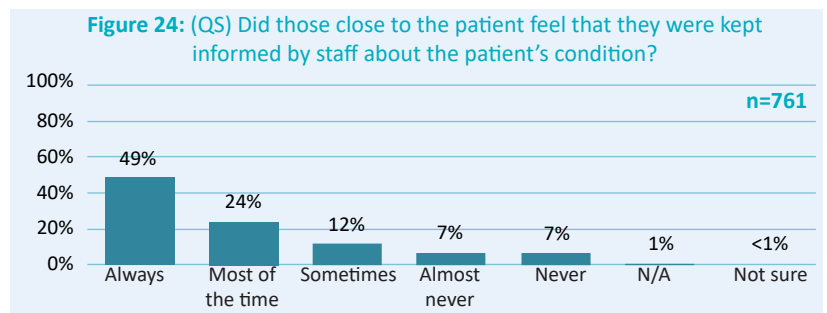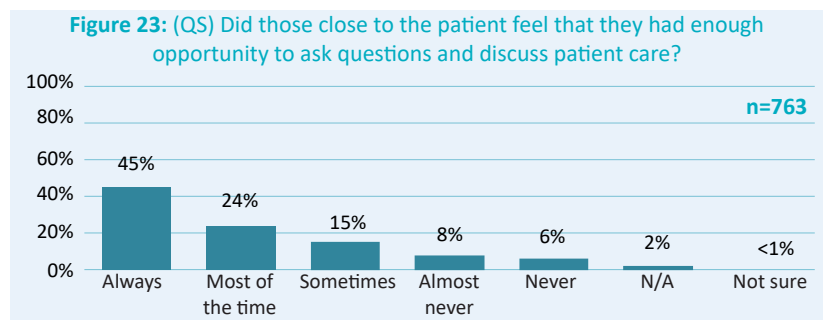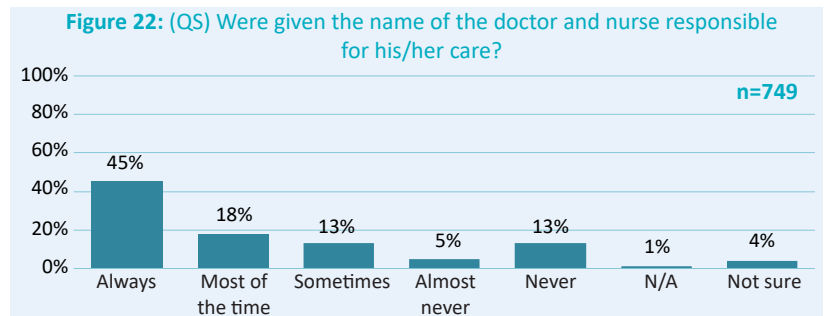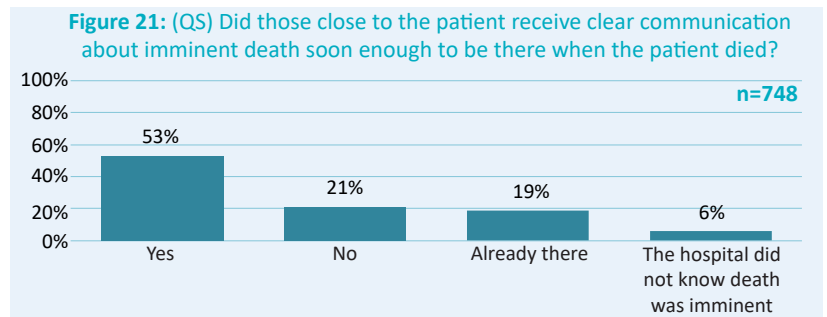National Audit of Care at the End of Life

5. Results

The Quality Survey included a number of questions relating to communication with those important to the patient. Of respondents, 53% said they received clear communication about the patient's imminent death soon enough to be there when the patient died, 19% were already there and 21% responded 'no' (figure 21).

Respondents were given the name of the doctor and nurse responsible for the patient's care always or most of the time in 63% of cases and sometimes, almost never or never in 31% of cases (figure 22).

Enough opportunity to ask questions was available always or most of the time in 69% of cases, sometimes, almost never or never in 29%, of cases (figure 23).

During the last two or three days of the patient's life, 73% of respondents felt they were kept informed about the patient's condition and treatment always or most of the time. Around one quarter (26%), responded sometimes, almost never or never (figure 24).

A question on whether those close to the patient felt they had been communicated with in a sensitive and compassionate way was included in the Quality Survey and is considered in section 5.7, Families' and others' experience of care (figure 75).

Figure 21: (QS) Did those close to the patient receive clear communication about imminent death soon enough to be there when the patient died?

n=748

Figure 22: (QS) Were given the name of the doctor and nurse responsible for his/her care?

n=749

Figure 23: (QS) Did those close to the patient feel that they had enough opportunity to ask questions and discuss patient care?

n=763

Figure 24: (QS) Did those close to the patient feel that they were kept informed by staff about the patient's condition?

n=761

Communication with families and others: Families' and others' comments

As noted in section 5.2, from the Quality Survey, 28% (89/321) of comments referenced communication. Of these comments, 78% (69/89) were about communication with families and others.

 "Wouldn't want to change anything. Staff dealt with death, communication and support for me and my family in a very professional manner."

"Need better communication, the standard of nursing care was poor. The family and patient were given information only when asked."

5. Results

Communication with families and others: summary

Discussions about the plan of care and notification of the responsible clinician were more likely to be held, and documented, with families and others than with the dying patient. However, in a quarter of cases, there was no documentation and no reason recorded regarding a discussion about the plan of care, and, in around a third of cases, no discussion and no reason recorded regarding informing those important to the patient about the senior responsible clinician.

Where death was recognised (Category 1 deaths), most people were notified of the patient's imminent death (84%), with the results for this measure showing a consistent picture when compared to the *2016 Audit*. For all deaths audited, there was no evidence the family were notified and no reason was recorded in 14% of cases. From the Quality Survey, 21% of respondents felt they were not told soon enough to be with the patient when they died, though some may have been notified but not in sufficient time.

Discussion about medication, hydration and nutrition were more likely to take place with the person important to the patient rather than the person themselves, but there was less likely to be a reason recorded, where the conversation did not take place. However, this may reflect clinicians being unlikely to record a reason for 'not having had' a conversation with families and others. These questions have been given a lower weighting in the summary score for this reason. The framing of these questions will be reviewed in the second round of NACEL.

Around three quarters of respondents to the Quality Survey report a positive experience of communication, but in around a quarter of cases there appears to be scope for improvement in communication (see also section 5.2).

It is recognised that not all dying people will have family or others with whom discussions can take place or who are able to share their experience of the care provided.

Recommendation 5: **Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and the people who are important to them.** Support all staff to have awareness, communicate sensitively and behave appropriately, when it is recognised that a person may be dying. See also Annex E of *One Chance To Get It Right*.

Recommendation 6: **Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with patients and families in the last days and hours of life.** Training for clinicians and other staff who have contact with dying people should focus on supporting the delivery of the *NICE Quality Standards* within the broader context of *One Chance To Get It Right.* National resources to support training are available such as guidance from professional bodies, learning outcomes and *e-ELCA.*

5. Results

5.4 Involvement in decision making

The right to be involved in decisions about one's health and care, including care at the end of life, is enshrined in *The NHS Constitution for England*. Where appropriate, this right includes the families and carers. In this section, the findings from the Case Note Review and Quality Survey on involvement in decision making are presented.

> **Priority 3:** The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants *(One Chance To Get It Right).*
>
> **Notes to Priority 1:** The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person *(One Chance To Get It Right).*

Involvement in decision making: summary score

Involvement in decision making — **8.4**

The summary score for involvement in decision making is calculated using the following information collected in the Case Note Review:

Documented evidence:
- of the extent the patient wished to be involved in decisions about care
- the patient had capacity assessed to be involved in care planning
- life-sustaining treatments were discussed with the patient
- life-sustaining treatments discussed with families/others
- a clinician discussed CPR with patient
- a senior clinician discussed CPR with families/other

Figure 25: Hospital mean summary scores: Involvement in decision making

Mean summary score — Submissions (n=201) — Range 3.3 – 10.0
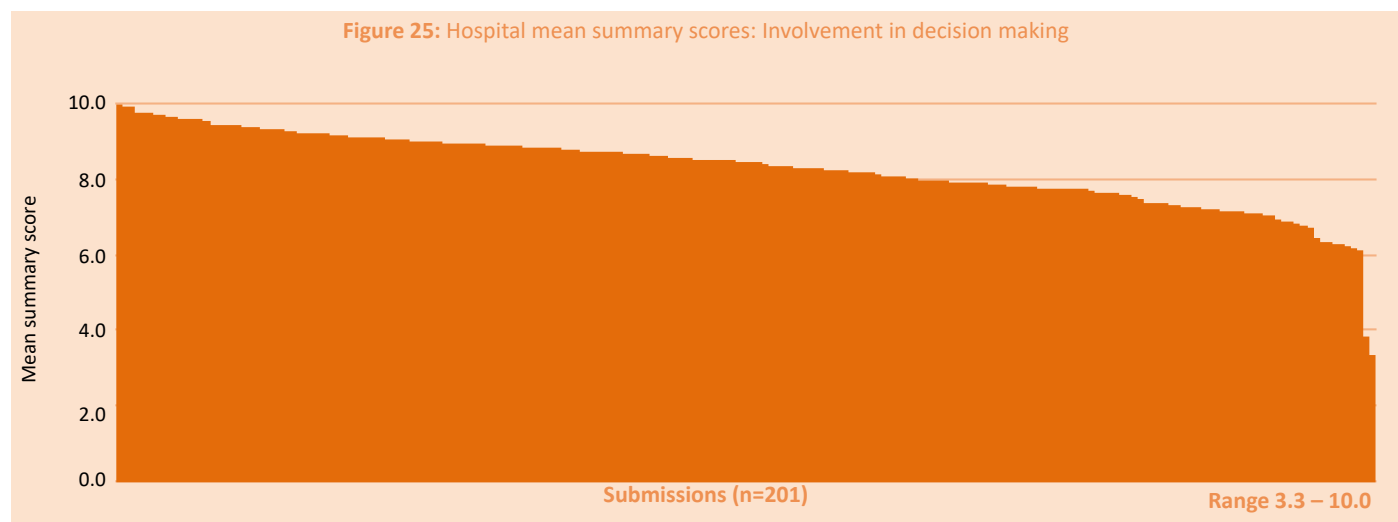
The range of hospital mean summary scores for involvement in decision making is shown in figure 25.

The mean value of the summary score across the whole sample of case notes is 8.4 (n=9,170).

5. Results

Figure 26: (CNR) Documented evidence of the extent the patient wished to be involved in decisions about care
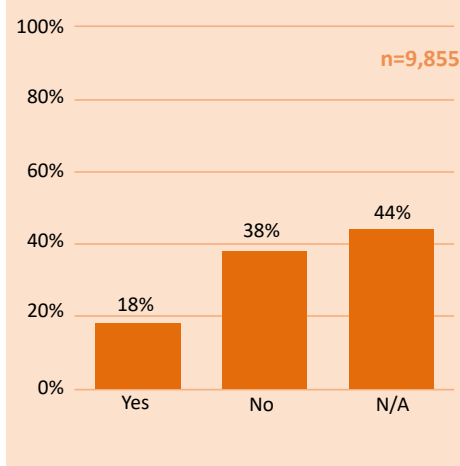
n=9,855

- Yes: 18%
- No: 38%
- N/A: 44%

Figure 27: (CNR) Documented evidence the patient had capacity assessed to be involved in care planning

n=10,673

- Yes: 43%
- No: 23%
- N/A: 34%
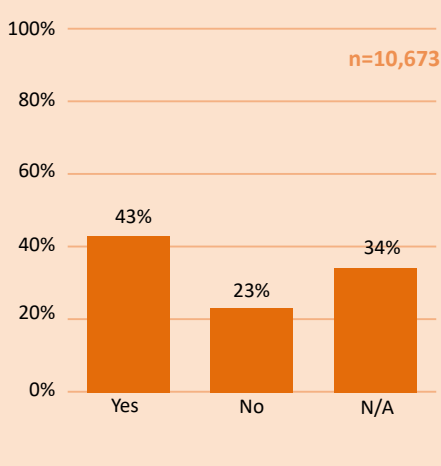
Figure 28: (CNR) Documented evidence life-sustaining treatments were discussed with the patient

n=10,616

- Yes: 15%
- No but reason recorded: 76%
- No and no reason recorded: 8%
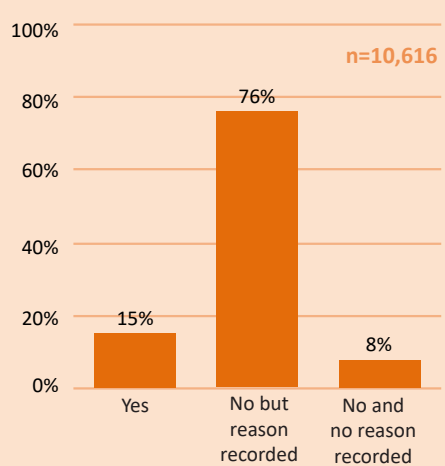
Figure 29: (CNR) Documented evidence life-sustaining treatments were discussed with families/others

n=10,487

- Yes: 35%
- No but reason recorded: 57%
- No and no reason recorded: 7%
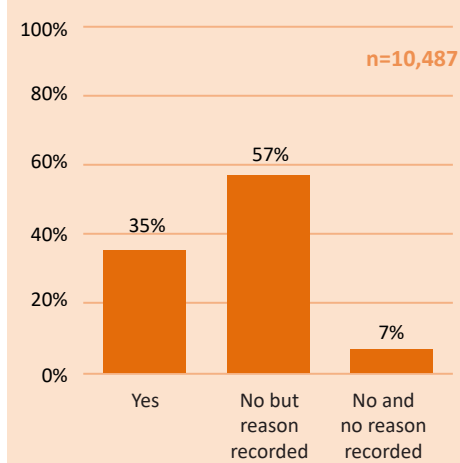
Figure 30: (CNR) Documented evidence a clinician discussed CPR with the patient

n=10,608

- Yes: 42%
- No but reason recorded: 50%
- No and no reason recorded: 8%
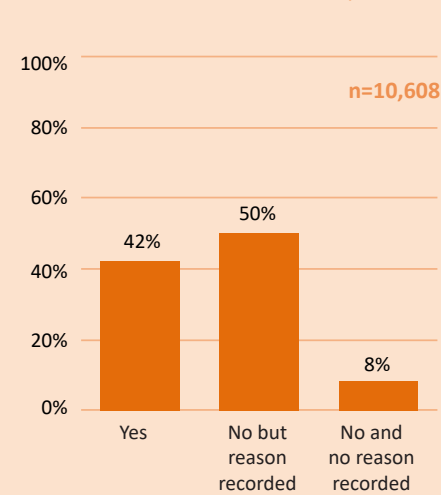
Figure 31: (CNR) Documented evidence a senior clinician discussed CPR with families/others

n=10,293

- Yes: 80%
- No but reason recorded: 8%
- No and no reason recorded: 12%
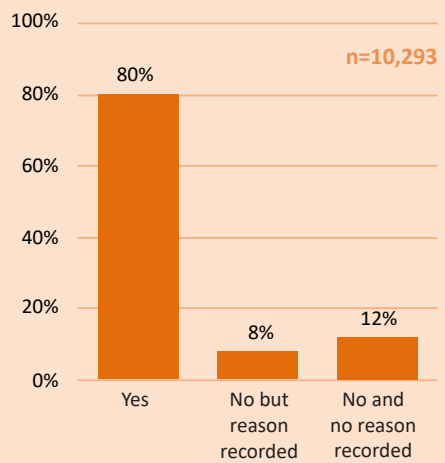
From the Case Note Review, there was documented evidence of the extent to which the patient wished to be involved in decisions about their care in 18% of cases, with no evidence and no reason recorded in 38% of cases (figure 26).

In 43% of cases, there was documented evidence that the dying person had their capacity assessed to be involved in their end of life care planning (figure 27).There was documented evidence that the dying person lacked capacity to be involved in their care planning in 49%[12] of cases.

Decisions regarding continuing or stopping life-sustaining treatments were documented as being discussed with the patient in 15% of cases and the families/others in 35% of cases (figures 28 and 29). Where no discussion took place, a reason was recorded in most cases, with 'no and no reason recorded' only in 8% of cases for the patient and 7% for the families/others.

A discussion between the patient and a clinician about CPR was held and documented in 42% of cases. No discussion was documented, with no reason given, for 8% of patients (figure 30). The discussion with the patient took place with a senior clinician in 73%[13] of cases. A discussion about CPR with the families/others took place with a senior clinician in 80% of cases (figure 31). No discussion with the families/others was documented, with no reason given, for 12% of cases (figure 31). DNACPR was in place at the time of death in 97%[14] of cases.

National Audit of Care at the End of Life

5. Results

In addition to the Case Note Review indicators discussed above, the Quality Survey obtained the perspective of families/others on involvement in decision making.

As regards involving the patient in decision making, in 43% of cases, respondents to the Quality Survey felt the patient was not able to be involved, and in 38%, the patient was involved as much as they wanted to be. 7% were judged by families/others to have wanted to be more involved (figure 32). Of families and others responding, 70% felt they had been involved as much as they had wanted to be, with 22% stating 'would have liked to be more involved' (figure 33).

Figure 32: (QS) Did staff involve the patient in decisions about care and treatment?
n=773

- He/she was involved as much as he/she wanted to be: 38%
- He/she would have liked to be more involved: 7%
- He/she would have liked to be less involved: <1%
- He/she was not able to be involved: 43%
- Not sure: 11%

Figure 33: (QS) Did staff involve those close to the patient about care and treatment?
n=748

- I was involved as much as he/she wanted to be: 70%
- I would have liked to be more involved: 22%
- I would have liked to be less involved: <1%
- I was not able to be involved: 4%
- Not sure: 3%

Involvement in decision making: Advance Care Planning

NACEL covers care in hospitals when death is expected within hours or days. However, for people living with life limiting conditions, the general principles of palliative and end of life care apply from a much earlier point. Advance Care Planning is an important element of helping an individual to live well before they die.

From the Case Note Review, there was documented evidence of an advance care plan prior to admission in 7%[15] of cases (6%[16] for England, acute trusts only). This appears to be an improvement on the *2016 Audit* result when such a plan was in place in 4% of cases (England, acute trusts only).

There was documented evidence that the advance care plan had been reviewed in 19%[17] of cases, and taken into account in decision making, in 59%[18] of cases.

The Quality Survey results indicate that 31% of patients were admitted to hospital three or more times within the last 12 months of life (see Appendix 7). This result suggests there may be more opportunities to plan for end of life care from a much earlier stage.

National Audit of Care at the End of Life

5. Results

Involvement in decision making: Families' and others' comments

From the Quality Survey narrative responses, 6% (19/321) specifically referenced involvement in decision making (not just communication regarding care). Of these comments, 58% (11/19) were analysed as positive and 42% (8/19), negative. Out of all comments about decision making, 89% (17/19) referenced involvement of the family and the remainder, involvement of the patient.

"My partner and his family were kept well informed of all procedures and next steps. The man from the outreach team was very supportive. He and the doctors were very compassionate but honest so my partner was able to have control right to the end which I know mattered a great deal to him and has since given us much comfort. With their support he was able to make his own decisions and kept his pride and dignity."

"I did not feel there was good communication between members of the clinical team, and we as a family were not kept up to date or involved in decision making even though we had power of attorney for health decisions. His care was inconsistent."

Involvement in decision making: summary

In the majority of cases, discussions with the patient and with the families/others about life-sustaining treatments and CPR were either held and documented, or reasons recorded as to why the discussion did not take place. The documentation of patient's wishes regarding how involved they want to be in decisions about their care could be improved (no documentation in 38% of cases).

Responses to the Quality Survey suggest most people felt that they, and the dying person, were as involved in decision making as they wanted to be, however, 22% of those responding would like to have been more involved. It is evident from the narrative responses that people very much value conversations with clinicians.

There has been a welcome increase in the use of advance care planning since the previous audit. The *NHS Long Term Plan* emphasises increased individualisation in its support to individuals in end of life care choices, including type and location of care. This can only be achieved if personal preferences are discussed, documented and shared across the system at an early stage. The audit finding that 31% of patients were admitted to hospital three or more times within the last 12 months of life, suggests a significant opportunity for earlier end of life care planning.

Involvement in decision making

Recommendation 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 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.

Recommendation 2: Review capability and capacity within primary care, community services and social care, to provide appropriate care at the end of life, and to support families through to bereavement, with the aim of better meeting people's needs and preferences.

5. Results

5.5 Needs of families and others

Families and those 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 Case Note Review, Organisational Level Audit and 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 must 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: summary score

Needs of families and others **6.1**
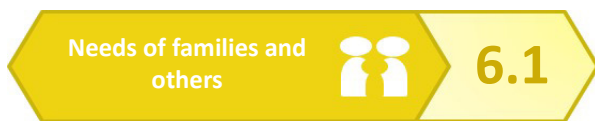
The summary score for the needs of families and others is calculated using the following information collected in the Case Note Review:

Documented evidence:
- the needs of families/others asked about
- of care and support provided to families/others at the time of and immediately after death
- needs of families/others assessed (weighting 0.2 each point):
  - emotional/psychological needs
  - spiritual/religious needs
  - cultural needs
  - social needs
  - practical needs

Figure 34: Hospital mean summary scores: Needs of families and others

Submissions (n=185)   Range 0.6 – 9.6
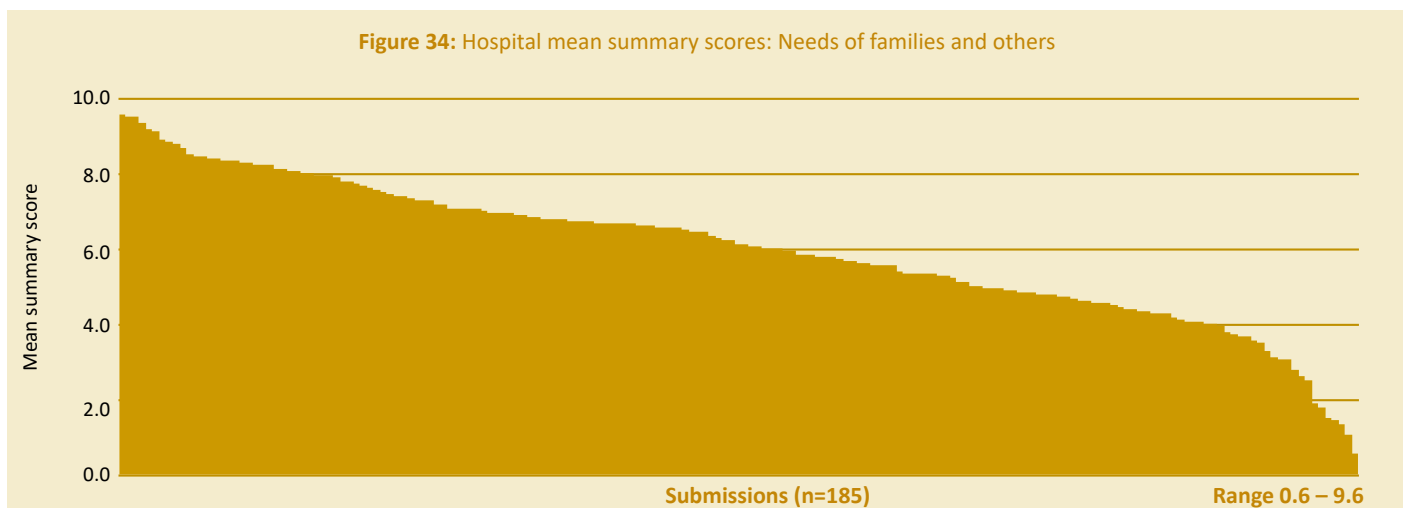
The range of hospital mean summary scores for needs of families and others is shown in figure 34.

The mean value of the summary score across the whole sample of case notes is 6.1 (n=6,108).

5. Results

Figure 35: (CNR) Documented evidence the needs of families/others asked about?

n=9,901

56%

Yes ☐ No

Figure 36: (CNR) Documented evidence of care and support provided to families/others at the time of and immediately after death

n=10,478

61%

36%

2%

Yes | No | No but there was no nominated person(s)

Figure 37: (CNR) Documented evidence needs of families/others were assessed? (% Yes)

67% — n=7,337 — Emotional/psychological needs
34% — n=6,759 — Spiritual/religious needs
25% — n=6,476 — Cultural needs
46% — n=6,823 — Social needs
61% — n=7,110 — Practical needs

There was documented evidence that the needs of families/others were asked about in 56% of cases (figure 35). In the *2016 Audit*, 54% of case notes showed that the needs of the person important to the patient were asked about (the denominator in this instance included sudden deaths). In the NACEL Case Note Review, the care and support provided to families and others at the time of, and immediately after, death was recorded in 61% of cases (figure 36).
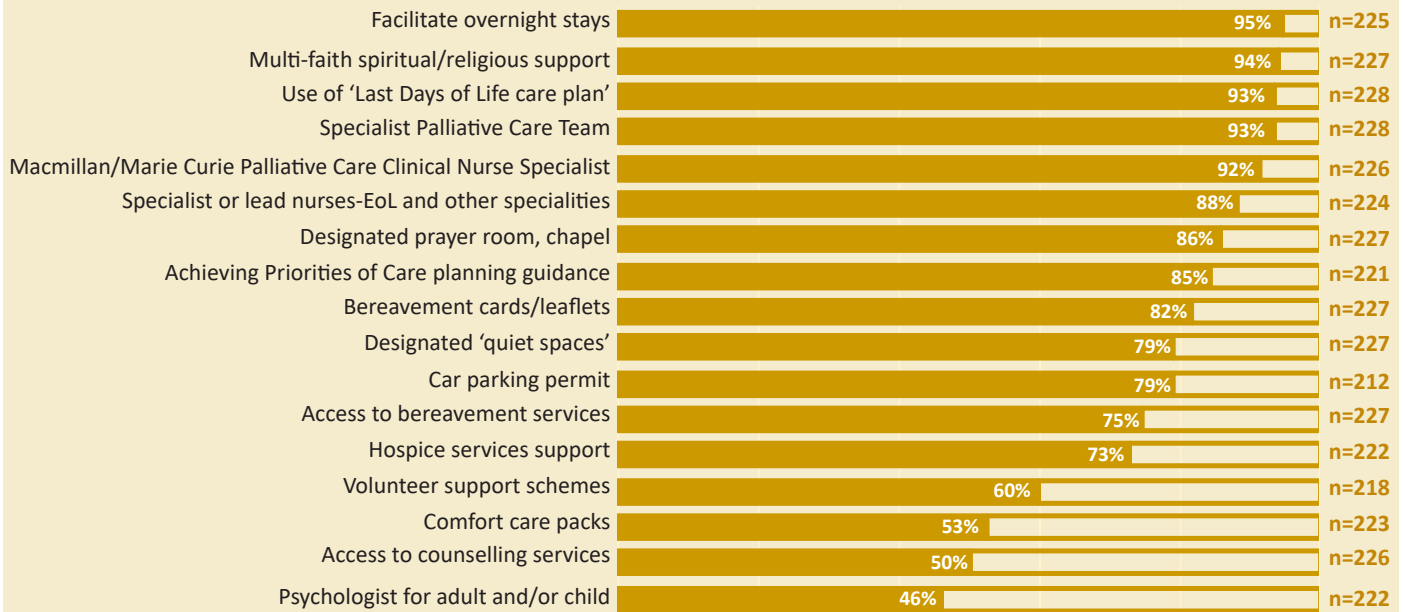
Emotional/psychological needs was the category of need most likely to be documented as having been assessed (67%) (figure 37). In the *2016 Audit*, psychological assessment was recorded in 71% of cases. In NACEL, spiritual/religious needs were recorded as being assessed in 34% of cases and cultural needs in 25% of cases (figure 37). As in other parts of the audit (see section 5.6), it has been noted by the NACEL Steering and Advisory Groups, that it may be difficult to distinguish between 'spiritual/religious' and 'cultural' needs, and these will be combined in future rounds of the audit. For social and practical needs, documented assessment existed in 46% and 61% of cases respectively (figure 37).

In addition to the indicators from the Case Note Review used in the summary score discussed above, the Organisational Level Audit included the following questions regarding information provided to families/others:

- 90%[19] of trusts/UHBs have a care after death and bereavement policy
- 97%[20] of trusts/UHBs have guidelines for providing relatives/carers with verification and certification of the death
- 85%[21] of trusts/UHBs have guidelines for referral to pastoral care/chaplaincy team
- 90%[22] of trusts/UHBs have guidelines for viewing the body in the immediate time after the death of a patient
- 87%[23] of trusts/UHBs make the *DWP 'What to do after death'* leaflet 1027 available
- 96%[24] of trusts/UHBs have a leaflet explaining procedures to be undertaken after death

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5. Results

Figure 38: (H/S) Support processes available in the hospital for people important to the dying person:

Support process	%	n
Facilitate overnight stays	95%	n=225
Multi-faith spiritual/religious support	94%	n=227
Use of 'Last Days of Life care plan'	93%	n=228
Specialist Palliative Care Team	93%	n=228
Macmillan/Marie Curie Palliative Care Clinical Nurse Specialist	92%	n=226
Specialist or lead nurses-EoL and other specialities	88%	n=224
Designated prayer room, chapel	86%	n=227
Achieving Priorities of Care planning guidance	85%	n=221
Bereavement cards/leaflets	82%	n=227
Designated 'quiet spaces'	79%	n=227
Car parking permit	79%	n=212
Access to bereavement services	75%	n=227
Hospice services support	73%	n=222
Volunteer support schemes	60%	n=218
Comfort care packs	53%	n=223
Access to counselling services	50%	n=226
Psychologist for adult and/or child	46%	n=222

The Quality Survey included questions relevant to the needs of the families and others.

Those close to the patient felt supported by the hospital staff after the patient's death in 82% of cases, definitely or to some extent (figure 39). However, when asked specifically about emotional help and support during the last two or three days, 61% responded always or most of the time and 31%, sometimes, almost never or never (figure 40).

Similarly, 58% felt those close to the patient were given enough practical support during the last two or three days, always or most of the time but 27% felt practical support was given sometimes, almost never or never (figure 41).

Of respondents to the Quality Survey, 15% said there were unexplained delays in the hospital providing a death certificate (figure 42).

Figure 39: (QS) Did those close to the patient feel supported by hospital staff after the patient's death?
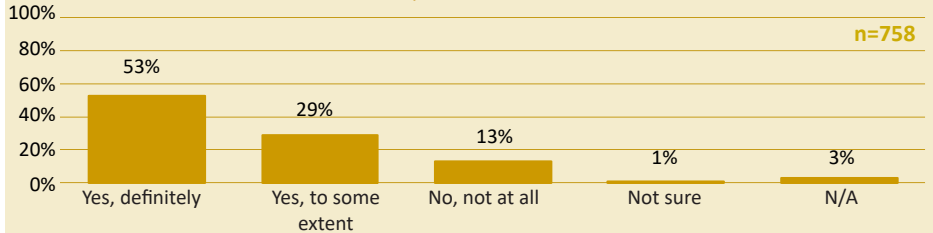
n=758

Response	%
Yes, definitely	53%
Yes, to some extent	29%
No, not at all	13%
Not sure	1%
N/A	3%

Figure 40: (QS) Did those close to the patient feel they were given enough emotional help and support?

n=762

Response	%
Always	44%
Most of the time	17%
Sometimes	13%
Almost never	6%
Never	12%
N/A	6%
Not sure	1%
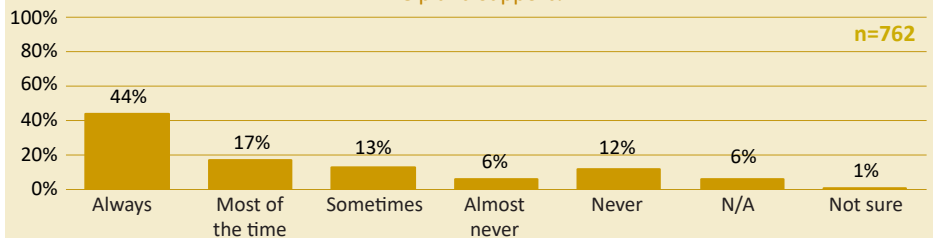
Figure 41: (QS) Did those close to the patient feel they were given enough practical support?

n=757

Response	%
Always	44%
Most of the time	14%
Sometimes	8%
Almost never	5%
Never	14%
N/A	14%
Not sure	1%
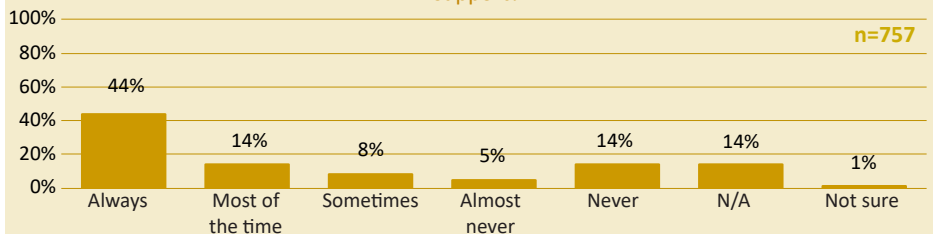
Figure 42: (QS) Were there any unexplained delays in the hospital providing you with certification of death?

n=760

Response	%
Yes	15%
No	82%
Don't know	2%

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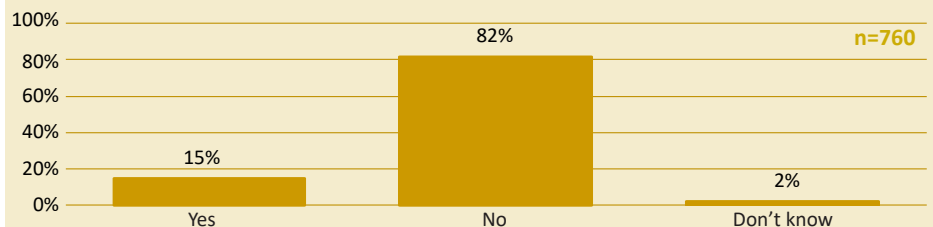
5. Results

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

From the Quality Survey narrative responses, 17% (53/321) referenced the needs of the family. Of these comments, 28% (15/53) were analysed as positive and 72% (38/53), negative. Out of all comments related to needs of the family, 47% (25/53) mentioned emotional support and 58% (31/53) mentioned privacy.

"Privacy and dignity. Not to be surrounded by half a dozen visitors to the bed opposite who were swearing and joking in a crude manner at all hours, even outside of visiting time. It was no way for my aunt to die."

"…Although it was a very sad time I remembered what the Macmillan nurse said to me earlier that day and it was a huge comfort to me."

Further, 12% (38/321) of all comments related to practical issues for the family and others. Of these comments:

- 24% (9/38) related to provision of the death certificate
- 29% (11/38) were about refreshments/food for relatives
- 42% (16/38) related to overnight stays/places for the relatives to stay
- 11% (4/38) mentioned parking

"The nurse who was allocated to support my father during the final 24 hours was excellent. She even made me and my two brothers tea and toast following our attendance throughout the night at his bedside."

"Delays in receiving the death certificate were upsetting and stressful at a difficult time."

Needs of families and others: summary

There is documented evidence that the needs of families and others were asked about in only just over half of cases, a result which is in-line with low compliance highlighted in this area in the *2016 Audit*. It was noted in section 5.1, that for around half of patients, death occurs within less than a day and a half of recognition of imminent death, which may limit the opportunity for discussion with families and others about their own needs. This highlights the importance of early recognition of uncertainty and possibility of death.

The results from the Case Note Review are corroborated by the results from the Quality Survey. Although a high proportion of people feel they were supported after the patient's death, when asked more specifically about emotional and practical support during the last two or three days, almost one third of those responding did not feel they had enough support.

Although the majority of trusts/UHBs have appropriate policies and guidelines in place, this does not appear to always be translating into action on the ground.

Recommendation 7: Ensure systems are in place to assess and address the needs of the families of dying patients in a timely manner. Specific senior, strategic and operational responsibility is required. Assessment of needs should cover emotional/psychological, spiritual/religious/cultural, social and practical needs.

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5. Results

5.6 Individual plan of care

The *five priorities for care* of the dying person make clear that there must be an individual 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 (this point is discussed under Communication with the dying person (section 5.2) and Communication with families/others (section 5.3)).

In this section, the results from the Case Note Review and the Quality Survey relating to the individual 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).*

Individual plan of care: summary score

Individual plan of care — **7.4**
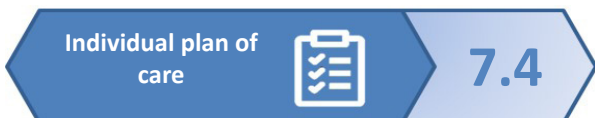
The summary score for the individual plan of care is calculated using the following information collected in the Case Note Review:

- documented evidence the patient had an individual end of life care plan (weighting 0.5)
- regular review of the patient and their plan of care (weighting 0.5)
- documented evidence of the 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
- documented assessment of hydration status between recognition and time of death
- documented assessment of nutrition status between recognition and time of death
- assessment of needs covering 16 domains (weighting 0.25 each)

Figure 43: Hospital mean summary scores: Individual plan of care
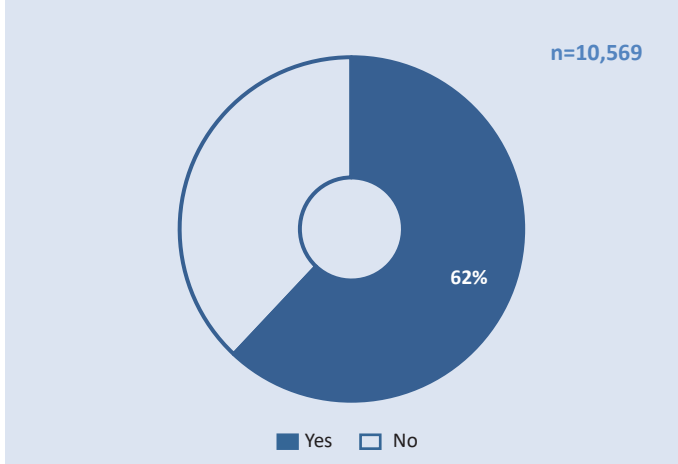
Submissions (n=195)　　　　Range 4.7 - 9.7
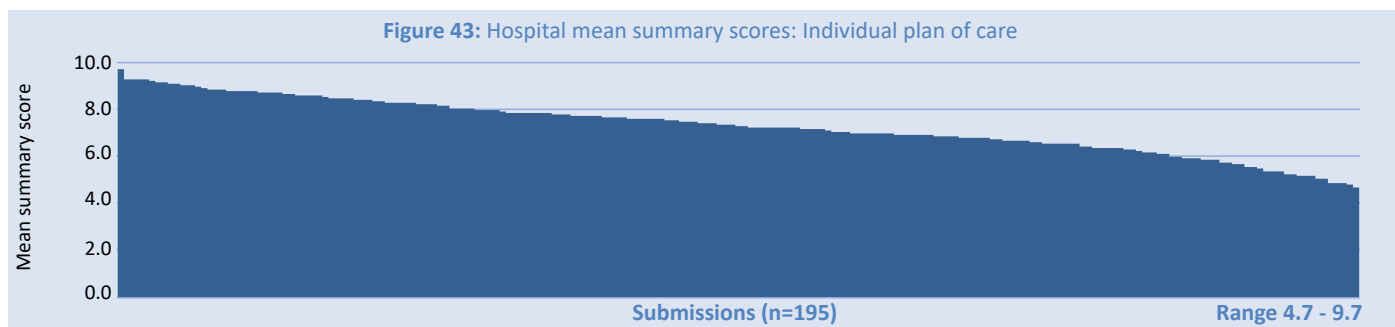
The range of hospital mean summary scores for the individual plan of care is shown in figure 43.

The mean value of the summary score across the whole sample of case notes is 7.4 (n=6,463).

Figure 44: (CNR) Documented evidence the patient had an individual end of life care plan

n=10,569

62%

■ Yes ☐ No

Figure 45: (CNR) Regular review of the patient and their plan of care

n=7,488

64%

5%

31%

Yes | No | Patient died soon after recognition

There was documented evidence that the patient who was dying had an individual end of life care plan in 62% of cases (figure 44). Discussion with audit participants on the helpline suggested there may have been some confusion about the use of the term 'end of life care plan' in the question, possibly leading auditors to respond 'no' where a specific 'end of life' template was not being used, even though audit guidance was provided indicating that 'any individualised care plan' was acceptable.

The guidance in *One Chance To Get It Right* notes that in many cases people will already be receiving care, and the care plan for their last few days will be part of planning process that started days, weeks or months before. The process of planning should be part of these and other care planning processes.

Consideration will be given to clarifying the question in future rounds of NACEL to better capture the context of end of life care planning.

Although the figure of 62% is caveated for the reasons above, it is instructive to note that the *2016 Audit* also found low compliance in this area. The report found that in 56% of cases (England, acute only) the 'team were aware of an individual plan of care for the dying person'. The *2016 Audit* report recommended that this be increased.

In the first round of NACEL, where a plan existed, the patient and their plan of care was reviewed regularly in 64% of cases. Where review was not documented, a reason was given in 31% of cases, and no reason recorded in 5% of cases (figure 45).

Narrative comments provided by auditors as part of the Case Note Review also suggested some concerns about care plans. Of comments made about issues identified when undertaking the Case Note Review, 17% (972/5,713) were about care planning, with 41% (403/972) of these comments analysed as positive and 59% (569/972), as negative. Negative comments included no, or lack of clear, end of life care plan or poor documentation of care plan.

Figure 46: (CNR) Documented evidence of the preferred place of death as indicated by patient

n=10,289

28%

■ Yes ☐ No

The summary score for individual plan of care includes an indicator on documentation of the preferred place of death as indicated by the patient (figure 46). This indicator is considered, with other relevant indicators, under the sub-heading 'Place of death'.

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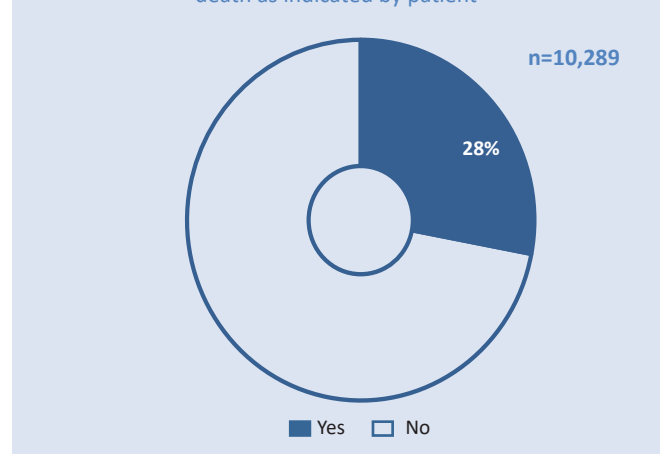
5. Results

Priority 1 of the *five priorities for care* of the dying person (*One Chance To Get It Right*) (considered in section 1.1) emphasises the importance of regular review and revision of decisions accordingly. The remaining metrics in the individual plan of care summary score relate to documentation of review and assessment.

As shown in figures 47-50, for vital signs, blood sugar monitoring, oxygen and antibiotics, a review was not recorded in between a third and a quarter of cases. Hydration status was documented as being assessed in the time between recognition of death and death in 75%, and nutrition, 61% of cases (figures 51 and 52).
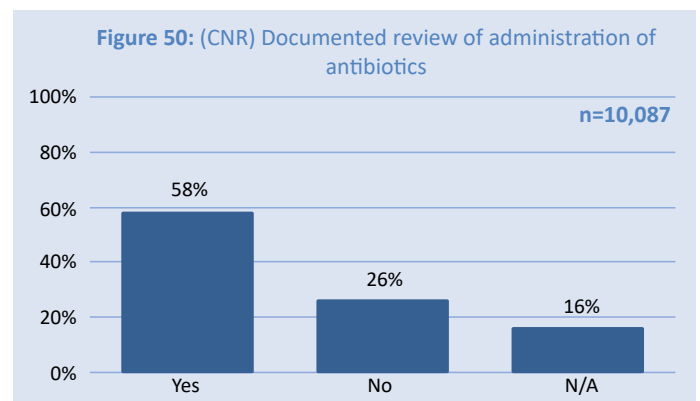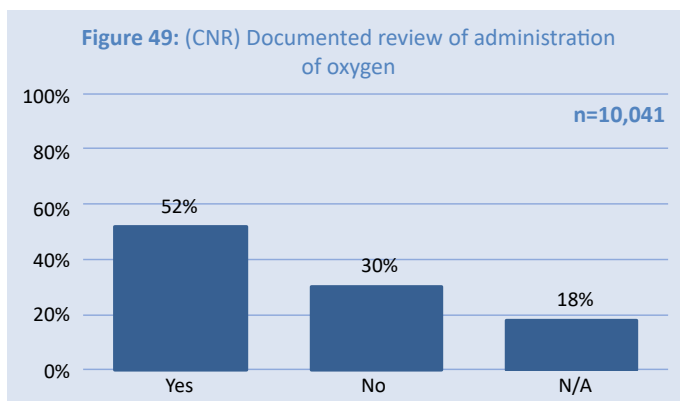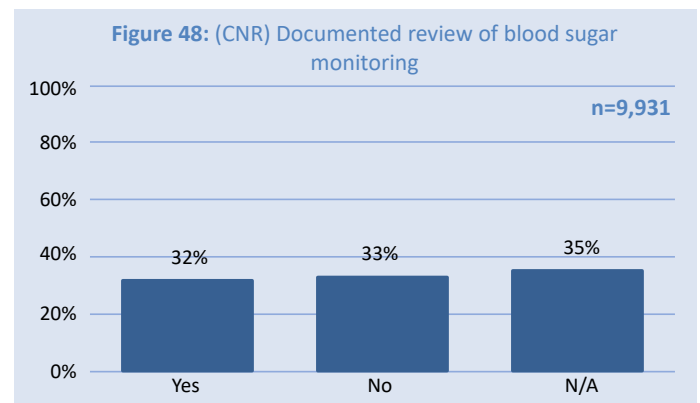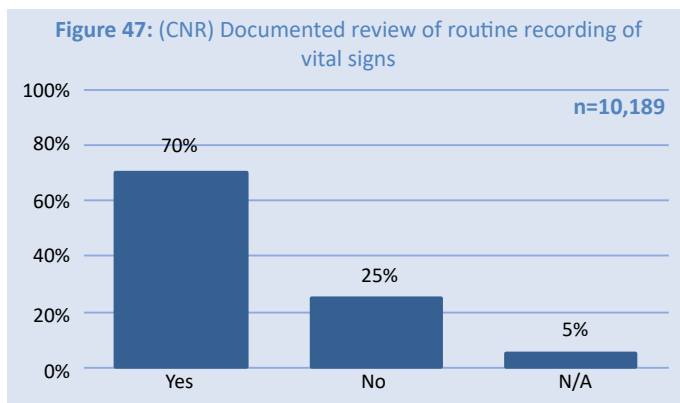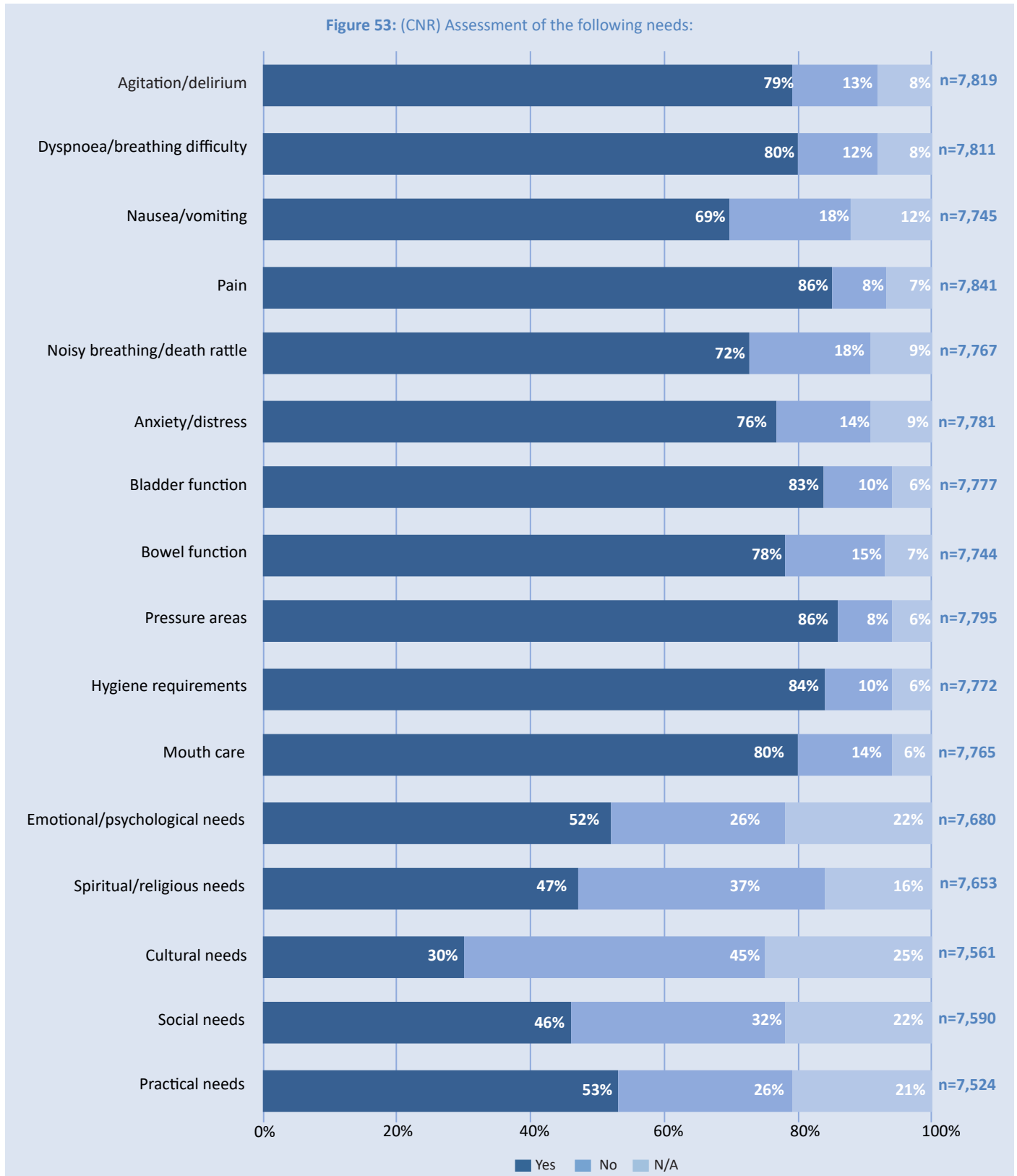
In addition to the component metrics for the individual plan of care summary score, the Case Note Review also asked if the patient had a syringe pump, and whether there was evidence that the reason for this had been discussed with the patient and the families/others. Where a syringe pump was in place, the discussion with the patient took place in 34%[25] of cases, with no and no reason recorded in 12%[25], and with the families/others in 72%[26] of cases, with no and no reason recorded in 24%[26] of cases.

Figure 47: (CNR) Documented review of routine recording of vital signs

n=10,189

Yes 70% No 25% N/A 5%

Figure 48: (CNR) Documented review of blood sugar monitoring

n=9,931

Yes 32% No 33% N/A 35%

Figure 49: (CNR) Documented review of administration of oxygen

n=10,041

Yes 52% No 30% N/A 18%

Figure 50: (CNR) Documented review of administration of antibiotics

n=10,087

Yes 58% No 26% N/A 16%

Figure 51: (CNR) Documented assessment of hydration status between recognition and time of death

n=10,011

75%

■ Yes □ No

Figure 52: (CNR) Documented assessment of nutrition status between recognition and time of death

n=9,820

61%

■ Yes □ No

5. Results

Assessment of needs was included in the individual plan of care summary score. Figure 53 shows which needs were assessed as part of an holistic needs assessment. Compliance was generally high with assessing physical needs, with the percentage stating 'no' ranging from 8% for pressure areas and pain, to 18% for nausea/vomiting and noisy breathing/death rattle. However, lower compliance was recorded for other needs, with the percentage stating 'no' rising to 45% for cultural needs and 32% for social needs. It has been noted by the NACEL Steering and Advisory Groups, that it may be difficult to distinguish between 'spiritual/religious' needs (where the 'no' percentage was 37%), and 'cultural' needs, and these will be combined in future rounds of the audit.

Figure 53: (CNR) Assessment of the following needs:

Need	Yes	No	N/A	n
Agitation/delirium	79%	13%	8%	n=7,819
Dyspnoea/breathing difficulty	80%	12%	8%	n=7,811
Nausea/vomiting	69%	18%	12%	n=7,745
Pain	86%	8%	7%	n=7,841
Noisy breathing/death rattle	72%	18%	9%	n=7,767
Anxiety/distress	76%	14%	9%	n=7,781
Bladder function	83%	10%	6%	n=7,777
Bowel function	78%	15%	7%	n=7,744
Pressure areas	86%	8%	6%	n=7,795
Hygiene requirements	84%	10%	6%	n=7,772
Mouth care	80%	14%	6%	n=7,765
Emotional/psychological needs	52%	26%	22%	n=7,680
Spiritual/religious needs	47%	37%	16%	n=7,653
Cultural needs	30%	45%	25%	n=7,561
Social needs	46%	32%	22%	n=7,590
Practical needs	53%	26%	21%	n=7,524

5. Results

Holistic care: results from Quality Survey

Respondents to the Quality Survey felt that staff at the hospital took time to explore what was important to the dying person in terms of individual requirements and care in the last few days of life, definitely or to some extent, in 61% of cases (figure 54).

In 67% of cases, respondents felt staff at the hospital made a plan for the person's care which took account of his/her individual requirements and wishes, definitely or to some extent (figure 55).

Care for emotional needs (e.g. feeling low, feeling worried, feeling anxious), according to respondents, was met by staff always or most of the time in 35% of cases, 19% sometimes, almost never or never, with 45% stating this question was not applicable or they weren't sure (figure 56).

In 40% of cases, staff took into account the person's beliefs, hopes, traditions, religion and spirituality always or most of the time, 12% sometimes, almost never or never, with 47% stating this question was not applicable or they weren't sure (figure 57).

Figure 54: (QS) Do you feel that staff at the hospital took time to explore what was important to him/her in terms of individual requirements and care in the last few days of life?
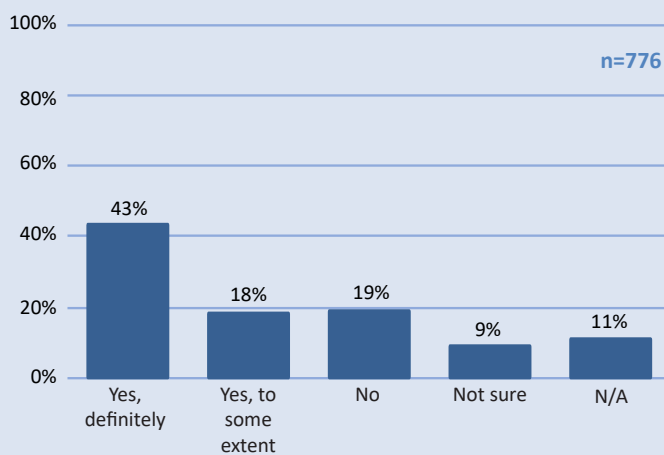
n=776

Figure 55: (QS) Do you feel that staff at the hospital made a plan for the person's care which took account of his/her individual requirements and wishes?
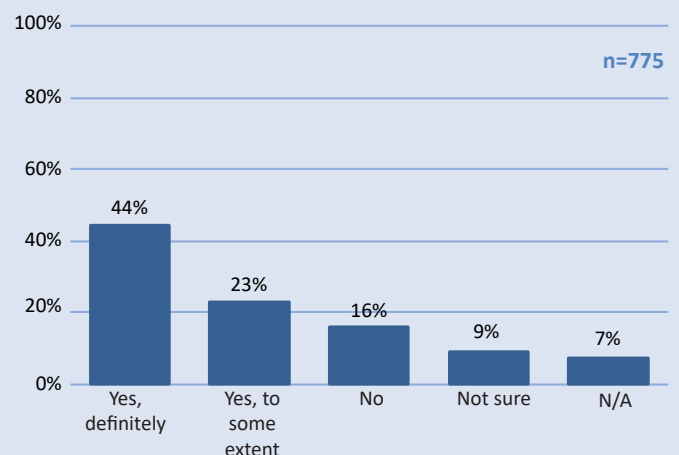
n=775

Figure 56: (QS) Had care for emotional needs (e.g. feeling low, feeling worried, feeling anxious) met by staff
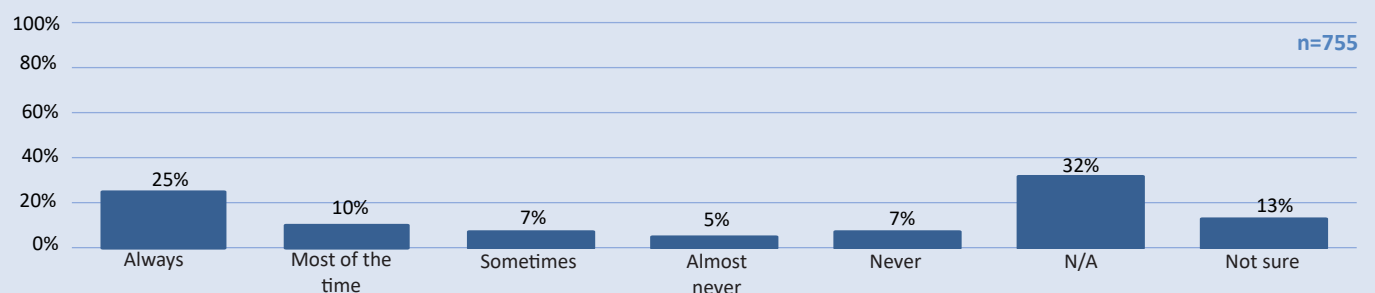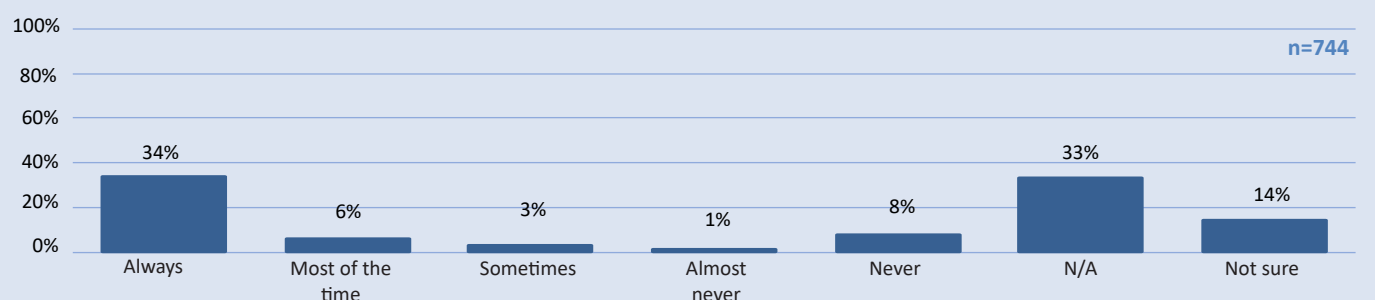
n=755

Figure 57: (QS) Staff took into account his/her beliefs, hopes, traditions, religion and spirituality

n=744

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5. Results

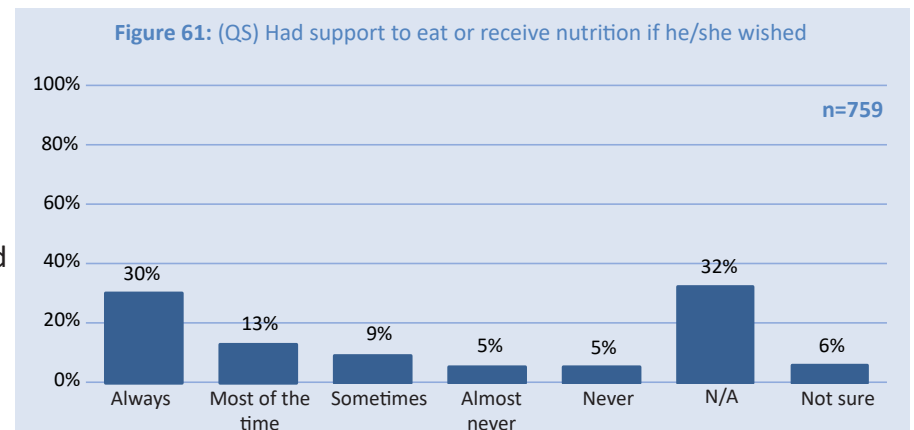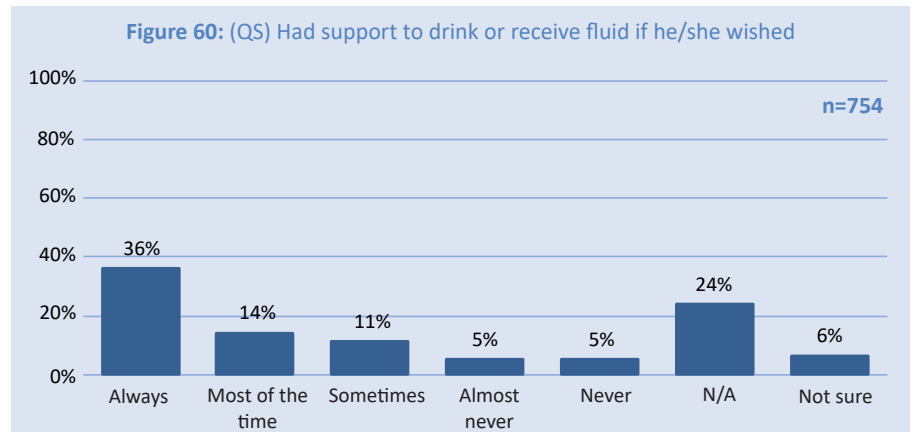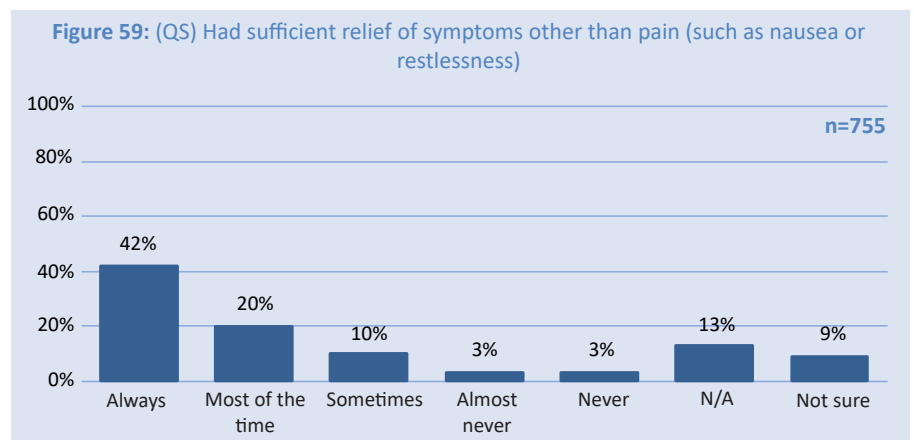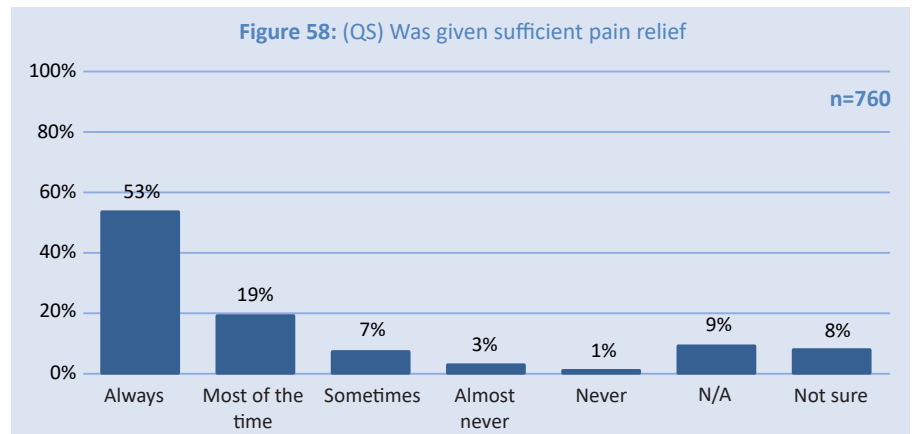### Physical care: results from Quality Survey

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

72% of respondents felt the person was given sufficient pain relief always or most of the time, 11% sometimes almost never or never, and 17% answered not applicable/not sure (figure 58).

62% felt the person had sufficient relief of symptoms other than pain (such as nausea or restlessness) always or most of the time, 16% sometimes, almost never or never, and 22% responded not applicable/not sure (figure 59).

50% felt the person had support to drink or receive fluid if he/she wished always or most of the time, 21% sometimes, almost never or never, and 30% not applicable/not sure (figure 60). Further evidence on this point from the Case Note Review shows that there was documented evidence that the patient was supported to drink once death was recognised in 39%[27] of cases, no evidence in 20%[27], and assessed as not able to drink in 40%[27] of cases.

43% felt the person had support to eat or receive nutrition if he/she wished always or most of the time, 19% sometimes, almost never or never, and 38% not applicable/not sure (figure 61). Evidence from the Case Note Review shows documented evidence that the patient was supported to eat once death was recognised in 27%[28] of cases, no evidence in 23%[28], and assessed as not able to eat in 49%[28] of cases.

Figure 58: (QS) Was given sufficient pain relief

n=760

Figure 59: (QS) Had sufficient relief of symptoms other than pain (such as nausea or restlessness)

n=755

Figure 60: (QS) Had support to drink or receive fluid if he/she wished

n=754

Figure 61: (QS) Had support to eat or receive nutrition if he/she wished

n=759

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Individual plan of care: Families' and others' comments

From the Quality Survey narrative responses, 28% (90/321) related to the care received by the patient. Of these comments, 47% (42/90) were analysed as positive and 53% (48/90), negative. Of all the comments about care:

- 88% (79/90) related to quality of care (see section 5.7, Families' and others' experience of care)
- 4% (4/90) related to dementia/mental health
- 18% (16/90) related to pain relief
- 17% (15/90) related to hydration/nutrition

"My brother received good care from some excellent staff. However, I do not feel that there was a 'plan' of any kind. People were just doing their best in the circumstances they found when they came in the room. He died from a complex illness and I got the impression that the staff did not know what to do for the best at the end of his life."

"The daytime care was excellent. At night time it fell apart."

"Not enough communication with us until we insisted to see a doctor the day before he died to discuss his issues and end of life plan."

"The withdrawal of fluids and nutrition was not discussed with dad and made the end of his life traumatic."
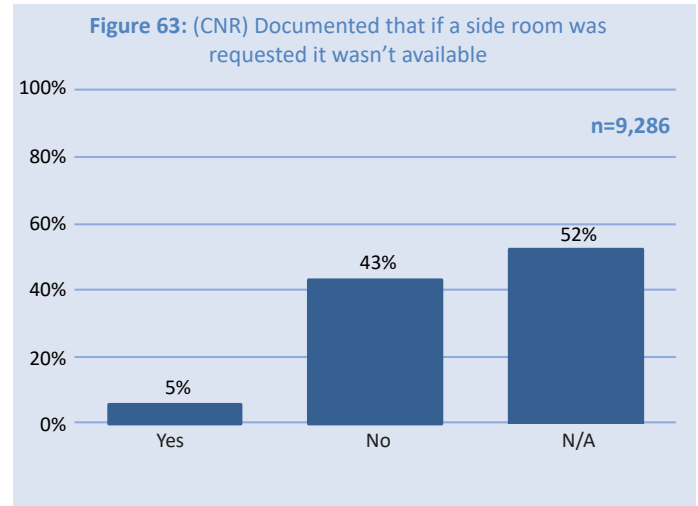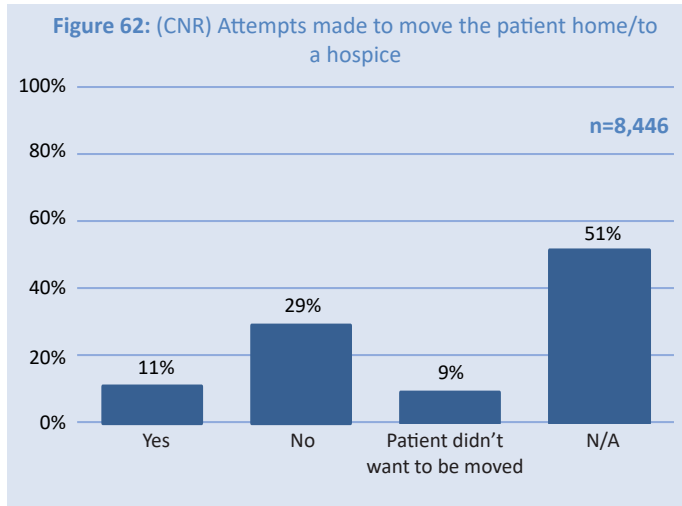
"More effective communication between doctors in charge and ward staff to ensure appropriate treatment."

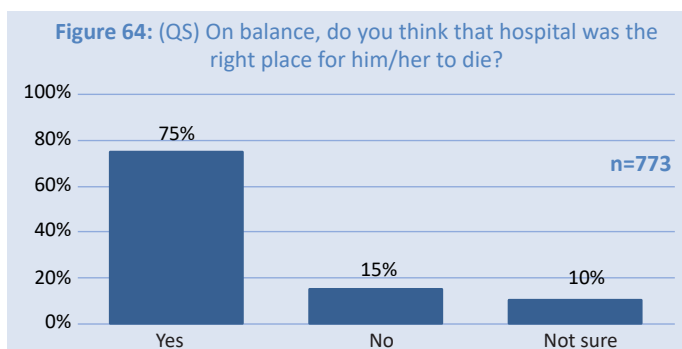Please also refer to comments about communication in sections 5.2 and 5.3.

5. Results

Place of death

Place of death is a complex and important topic which is addressed in this sub-section of the individual plan of care theme. The first round of NACEL covered issues relating to preferred place of death as between hospital and home/care home, attempts to transfer people home and issues concerning the location of care within the hospital. It should be noted that cases where transfer home succeeded would not be captured in the audit since the scope of this round of NACEL was limited to deaths occurring in hospitals (section 1.5).

Figure 62: (CNR) Attempts made to move the patient home/to a hospice

n=8,446

Figure 63: (CNR) Documented that if a side room was requested it wasn't available
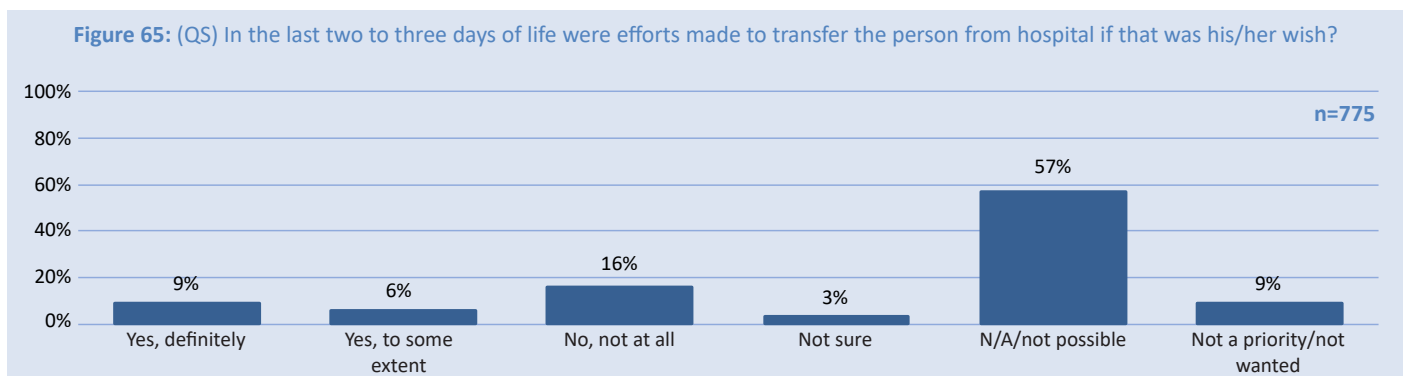
n=9,286

As noted above, 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 28% of cases (figure 46). The following additional indicators from the Case Note Review are relevant to the place of death. In 11% of cases an attempt was made to move the patient home/to a hospice if that was their preferred place of death, no attempt was made in 29% of cases, 9% of patients didn't want to be moved and, for 51% of cases, the question was not applicable (figure 62). In 5% of cases there was documented evidence that if a side room had been requested for the patient, it wasn't available, with 43% stating this was not the case and 52%, not applicable (figure 63).

The following indicators from the Quality Survey are also relevant to place of death.

Figure 64: (QS) On balance, do you think that hospital was the right place for him/her to die?

n=773

The results from the Quality Survey suggest most people (75%) were content that the hospital was the right place for the person to die. However, 15% disagreed that hospital was the right place (figure 64). In a separate question about transfer, 16% felt no effort had been made to transfer the person from hospital if that was their wish, and 15% suggested some efforts had been made (figure 65).

Figure 65: (QS) In the last two to three days of life were efforts made to transfer the person from hospital if that was his/her wish?

n=775

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Place of death

Figure 66: (QS) Within the hospital where did the person die?

n=767

- Bay shared with other patients: 32%
- Side room: 56%
- Intensive Care/HDU: 8%
- Other: 5%

Figure 67: (QS) Were you satisfied that this location within the hospital was appropriate?

n=774

- Yes: 75%
- No: 18%
- Not sure: 7%

Figure 68: (QS) Had adequate privacy

n=737

- Always: 51%
- Most of the time: 23%
- Sometimes: 10%
- Almost never: 5%
- Never: 6%
- N/A: 1%
- Not sure: 2%

Around a third of patients died in a shared bay and 56% in a side room (figure 66). 75% of respondents to the Quality Survey were satisfied with the location within the hospital, but 18% were not (figure 67). However, when this result is further analysed by location, 91%[29] of respondents where the patient had died in a side room felt the location was appropriate, compared to 44%[29] of those who died on a shared bay.
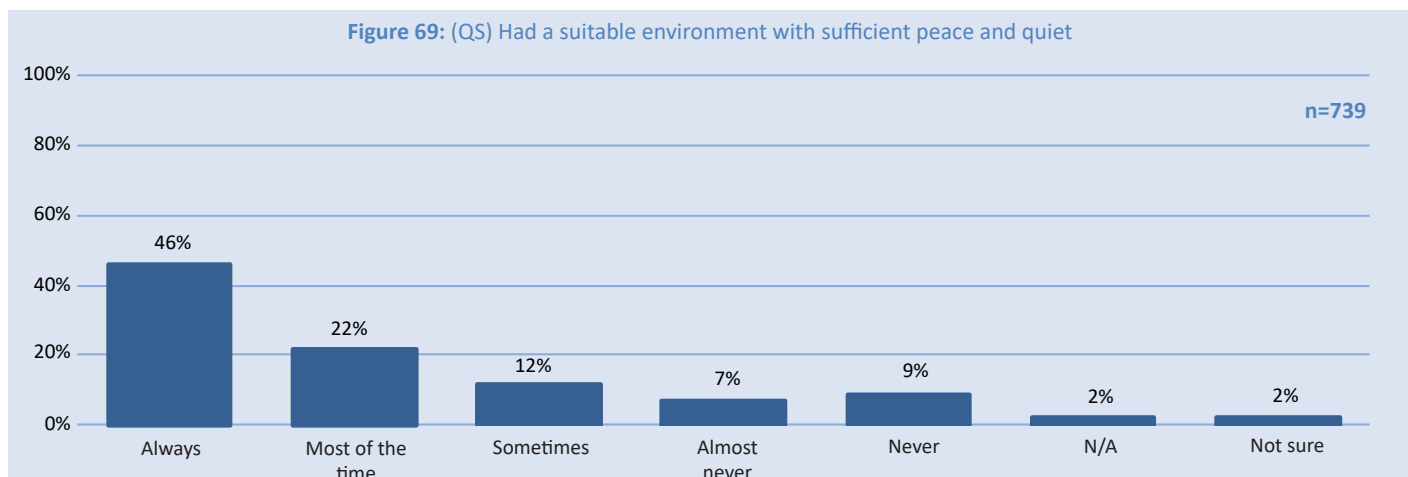
Location was an issue for 21% of people who felt they had adequate privacy sometimes, almost never or never (figure 68), and 28% who felt they had a suitable environment with sufficient peace and quiet sometimes, almost never or never (figure 69).

Figure 69: (QS) Had a suitable environment with sufficient peace and quiet

n=739

- Always: 46%
- Most of the time: 22%
- Sometimes: 12%
- Almost never: 7%
- Never: 9%
- N/A: 2%
- Not sure: 2%

National Audit of Care at the End of Life

5. Results

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

From the Quality Survey narrative responses, 18% (57/321) related to the location of care. Of these comments, 56% (32/57) related to provision of a side room, 5% (3/57) related to A&E, 16% (9/57) referenced care at home or a desire for the patient to have been cared for at home.

"When my brother was dying we had no privacy other than the curtain around us which didn't block out sound. He should have been moved to somewhere more private where he and the family would have had more dignity and the family could grieve without the rest of the ward listening, so this is what I would like to change."

"My mum was in hospital for a week following a fall. We had a bed for her at a nursing home from which she had just been discharged. This information was the one thing that wasn't consistently passed between staff and I think that if it had been, she could have been transferred to the home at the beginning of the week thus freeing up a bed and allowing her to die in a place that she knew and liked."

"When my mum was taken into XXX Hospital she was treated with dignity and outstanding care. By all staff on the ward. XXX Hospital could not have done anymore for her or myself and family."

Individual plan of care: summary

Although the result for the existence of an end of life care plan (62%) is caveated due to the potential misunderstanding of the question, the result is in line with that reported for a similar question in the *2016 Audit*. Further, around 10% (569/5713) of narrative comments from those completing the Case Note Review, highlighted concerns with end of life care planning. Information from the Quality Survey appears to further corroborate the result, with only 67% of those responding feeling that a plan had been made either definitely or to some extent. The evidence overall from the audit suggests there remains a gap in the development and documentation of an individual plan of care for every dying person.

Review of routine monitoring of vital signs, blood sugar monitoring, administration of oxygen and antibiotics was not recorded, and no reason given for this, in between a third and a quarter of cases. Hydration status was documented as being assessed in the time between recognition of death and death in 75% of cases, and nutrition status, in 61% of cases.

There was higher compliance with documentation of assessment of the patient's physical care needs, than other areas such as psychological and social needs. With regards to meeting those needs, from the Quality Survey, a proportion of people responding ranging from 11% to 19%, were not always content with emotional support, pain relief and relief for other symptoms.

The results of the Quality Survey are caveated due to low numbers (section 4.2). Of those responding to the Quality Survey, 21% had concerns about support for the patient to drink, and 19% had some concerns about support for the patient to eat. From the results of the Case Note Review, there was no documentation about supporting drinking in 20% of cases and no documentation about supporting eating in 23% of cases.

5. Results

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 coordination of this plan must be in place especially at points of handover of care.

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 patient and/ or person 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 rationale for the use of syringe pumps, the review of routine monitoring of vital signs and blood sugar and the review of ongoing administration of medications e.g. oxygen and antibiotics.

Recommendation 13: **Ensure the dying person is supported to eat and drink if they are able and wish to do so.**

Place of death

Three quarters of respondents felt that hospital was the right place for the person to die. From the Case Note Review, attempts were made to move 11% of patients which were, for some reason, unsuccessful. Respondents to the Quality Survey reported that 16% felt no effort had been made to transfer the person from hospital if that was their wish. The audit will not have captured instances where a successful transfer was made.

In order for successful transfers home to be made, early recognition of dying is critical as discussed in section 5.1. Further, adequate resources need to be available in the community to provide support to patients and those important to them.

Recommendation 2: **Review capability and capacity within primary care, community services and social care, to provide appropriate care at the end of life, and to support families through to bereavement, with the aim of better meeting people's needs and preferences.**

Recommendation 3: **Implement processes to enable rapid discharge to home, care home or hospice, from hospital to die if that is the person's wish.**

Many of the comments received in the Quality Survey related to a lack of privacy and appropriately quiet environment where the person was on a ward rather than in a side room. The results showed that around one third of people died on a shared bay.

Recommendation 10: **Ensure that priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and their families.** Take into account the wishes of dying people and those important to them, to be cared for in a side room.

5. Results

5.7 Families' and others' experience of care

The [NHS Outcomes Framework](#), which sets out high level national outcomes for the NHS, has five domains, including ensuring that people have a positive experience of care. When a person has died, those important to the person, 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.
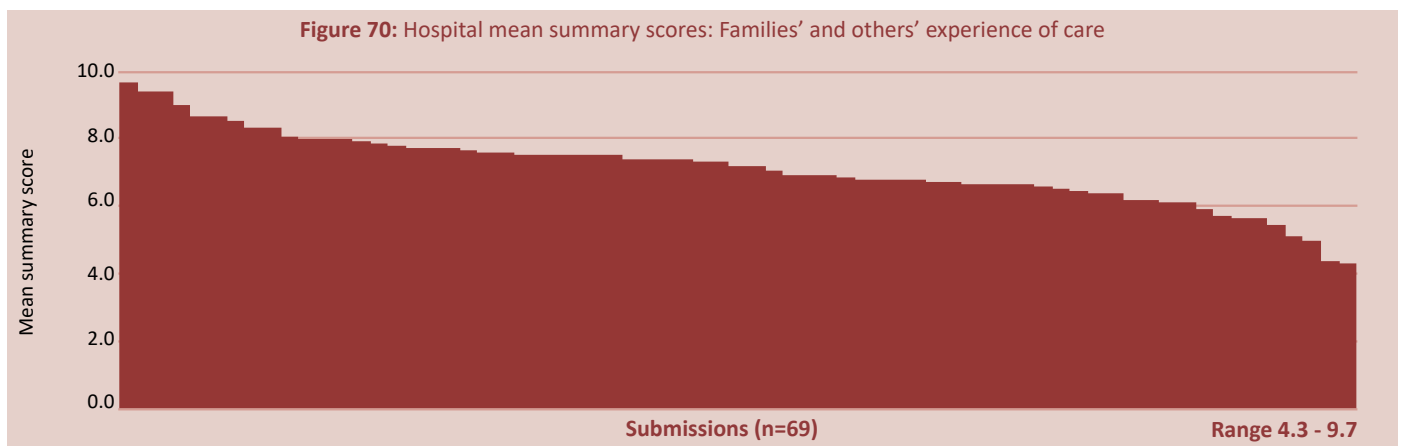
Families' and others' experience of care: summary score

Families' and others' experience of care	7.1

In reviewing the results for this theme, it should be noted that the total number of Quality Surveys returned was 790, representing 7% of the Case Note Reviews completed (11,034). The Quality Survey results may not, therefore be representative of the whole Case Note Review sample. The number of responses used to calculate each of the summary score component metrics is shown at Appendix 8.

The summary score for families' and others' experience of care is calculated using the following information collected in the Quality Survey:

- overall quality of care and support provided to the patient
- overall quality of care and support provided to friends and family of the patient
- staff looking after the patient communicated sensitively
- patient treated with compassion
- families/friends communicated with compassionately

Figure 70: Hospital mean summary scores: Families' and others' experience of care

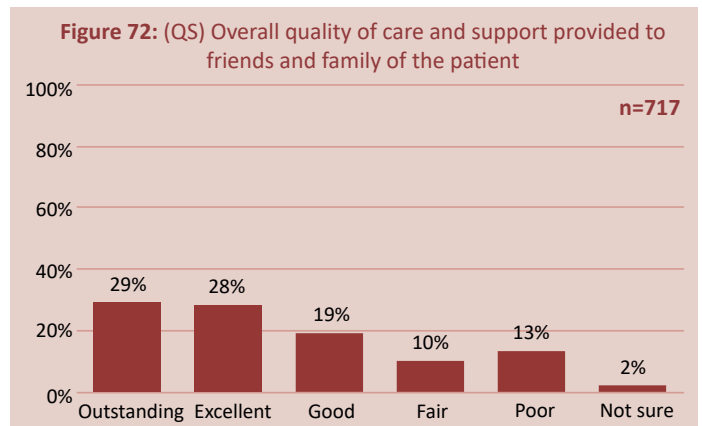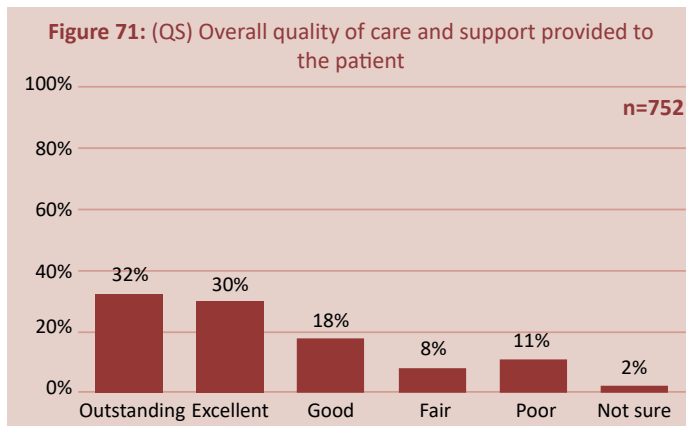*Submissions (n=69)* — *Range 4.3 - 9.7*

The range of hospital mean summary scores for families' and others' experience of care is shown in figure 70.

The mean value of the summary score across the whole sample of Quality Survey responses is 7.1 (n=682).
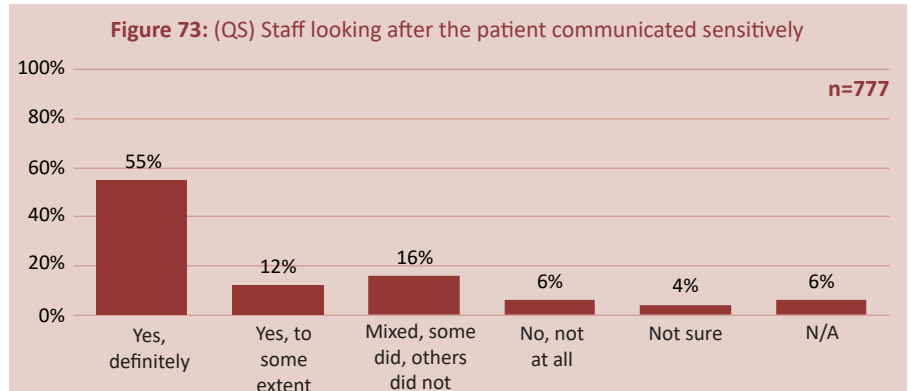
5. Results

Overall quality of care provided to patients was rated as outstanding, excellent or good by 80% of Quality Survey respondents and fair or poor by 19% (figure 71).
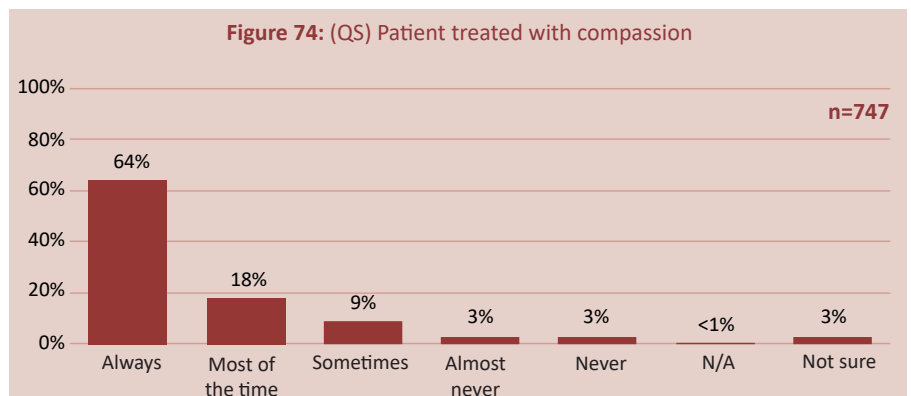
Quality of care provided to family/friends was rated as outstanding, excellent or good by 76% of survey respondents and fair or poor by 23% (figure 72).

Figure 71: (QS) Overall quality of care and support provided to the patient

n=752

Outstanding	Excellent	Good	Fair	Poor	Not sure
32%	30%	18%	8%	11%	2%

Figure 72: (QS) Overall quality of care and support provided to friends and family of the patient

n=717

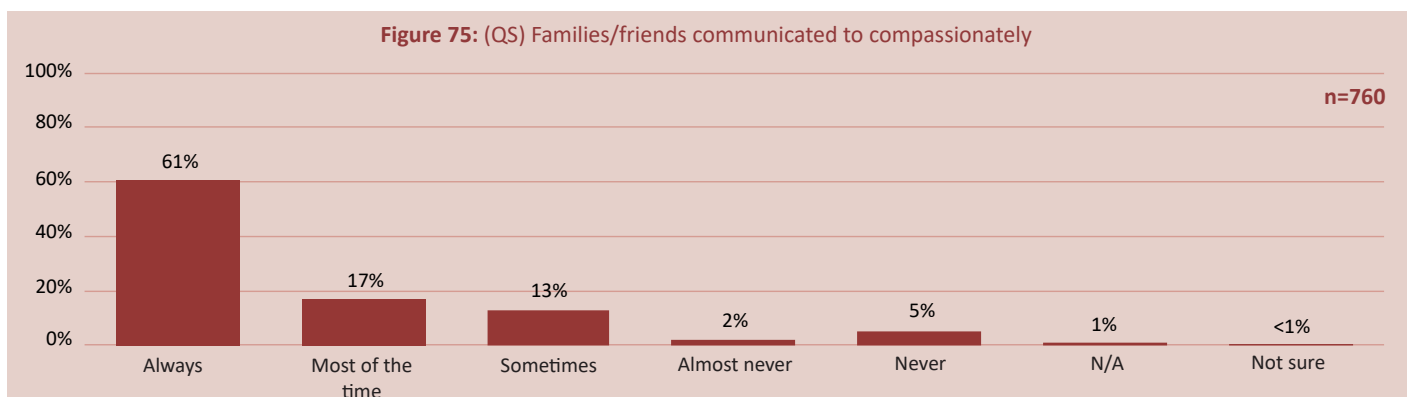| Outstanding	Excellent	Good	Fair	Poor	Not sure
29%	28%	19%	10%	13%	2%

Members of healthcare staff looking after the patient were felt to have communicated sensitively during the last few days of life by 67% of respondents, definitely or to some extent, with 16% responding that communication was mixed and 6%, 'no, not at all' (figure 73).

Figure 73: (QS) Staff looking after the patient communicated sensitively

n=777

Yes, definitely	Yes, to some extent	Mixed, some did, others did not	No, not at all	Not sure	N/A
55%	12%	16%	6%	4%	6%

The patient was considered to have been treated with compassion in 82% of cases, always or most of the time, and 15%, sometimes, almost never or never (figure 74).

Figure 74: (QS) Patient treated with compassion

n=747

Always	Most of the time	Sometimes	Almost never	Never	N/A	Not sure
64%	18%	9%	3%	3%	<1%	3%

78% felt they had been communicated to by staff in a sensitive and compassionate way, always or most of the time, with 20% stating sometimes, almost never or never (figure 75).

Figure 75: (QS) Families/friends communicated to compassionately

n=760

Always	Most of the time	Sometimes	Almost never	Never	N/A	Not sure
61%	17%	13%	2%	5%	1%	<1%

5. Results

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

As noted in section 5.6, Individual plan of care, 28% (90/321) of the Quality Survey narrative responses, related to the care received by the patient. Of these comments, 88% (79/90) related to quality of care, of which 67% (53/79) were analysed as positive and 33% (26/79) negative.

"I considered the care, comfort and dignity of my sister to be my priority and could not have asked for more. My own comfort was not a priority for me but was for all staff who showed great concern and compassion during the last few days and afterwards. I believe that the hospital staff from the most senior to the most junior were an outstanding example of the best nursing anyone could hope for."

"Through the whole process we were made so welcome, we never felt as if we were in the way. Even though they knew Mum would not survive they kept her clean and comfortable. Every time we felt she needed attention they were quick to attend which is hard as they are so busy. The nursing staff were incredible, I really cannot thank them enough from A&E through to the wards."

"On the day of her death I did feel like I was left to my own devices to care for her. I felt a bit of a nuisance."

"Nursing staff did their best but were very busy, myself and my sister administered the majority of the care. When we asked for help sometimes staff were too busy, more senior staff were not sympathetic or understanding of my mother's needs and although a care plan was discussed it was not put in place."

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

Families' and others' experience of care: summary

The results suggest the majority of people responding to the Quality Survey felt the patient had received good care and had been treated with compassion. However, in around one in five cases, respondents felt there was scope to improve the quality of care and sensitive communication with both the patient and the family and others.

Recommendation 5: **Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and the people who are important to them.** Support all staff to have awareness, communicate sensitively and behave appropriately, when it is recognised that a person may be dying. See also Annex E of *One Chance To Get It Right*.

5. Results

5.8 Governance

Local leadership is essential to securing improvements in the overall care of people in the last few days and hours of life. In this section, evidence on governance arrangements for end of life care from the Organisational Level Audit are presented.

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

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

Governance: summary score

The summary score for governance is calculated using information collected in the trust/UHB level audit:

- an identified member of the trust/UHB board with a responsibility for end of life care
- policy on how to respond to and learn from the death of patients under the organisation's management and care
- specific care arrangements to enable rapid discharge home to die, if this is the person's preference
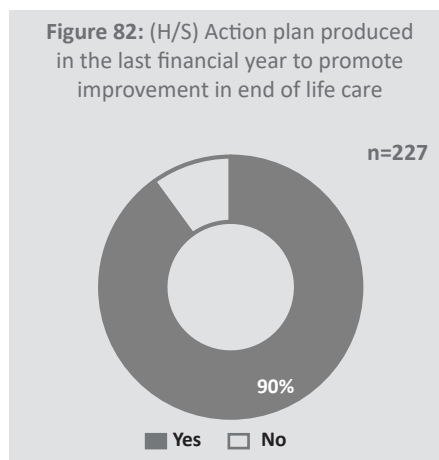- a care plan to support the *five priorities for care* for the dying person *(One Chance To Get It Right)*
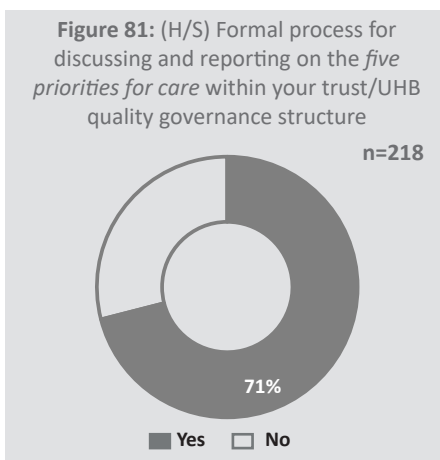

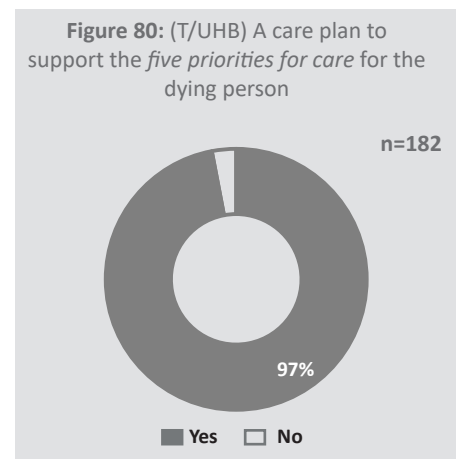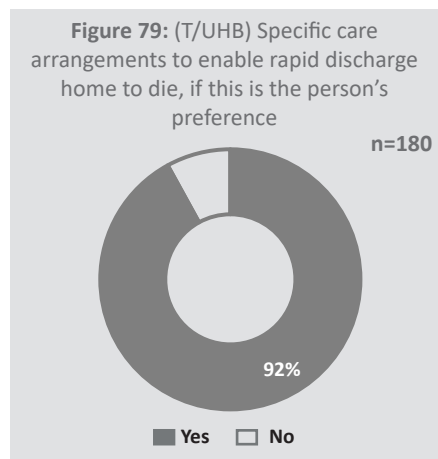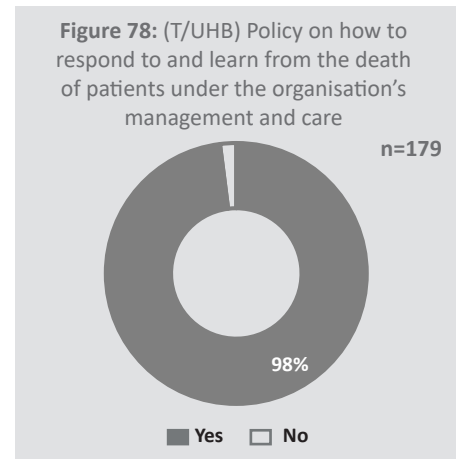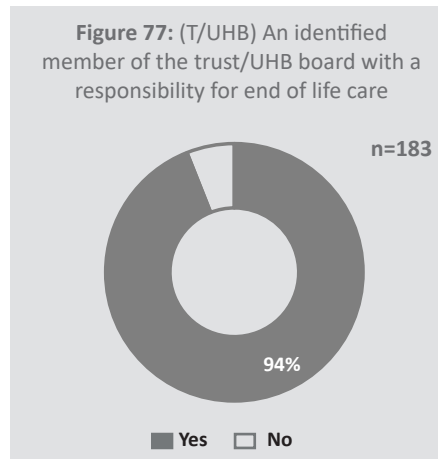**Figure 76:** Hospital mean summary scores: Governance
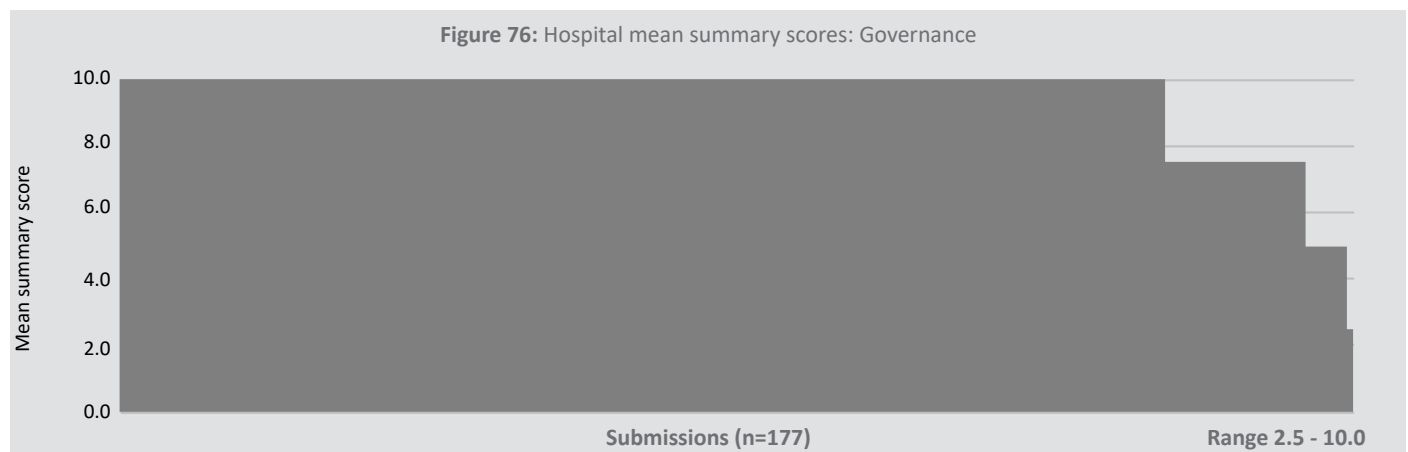
The range of hospital mean summary scores for governance is shown in figure 76.

The mean value of the summary score across the participating hospitals is 9.5 (n=177).
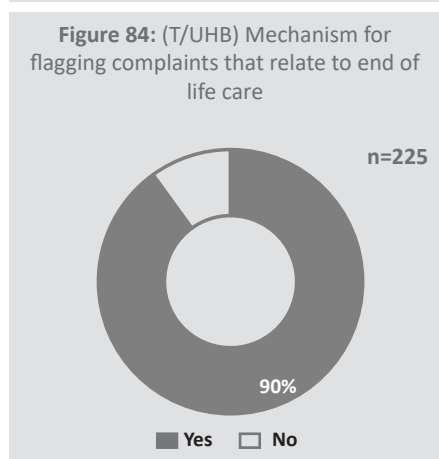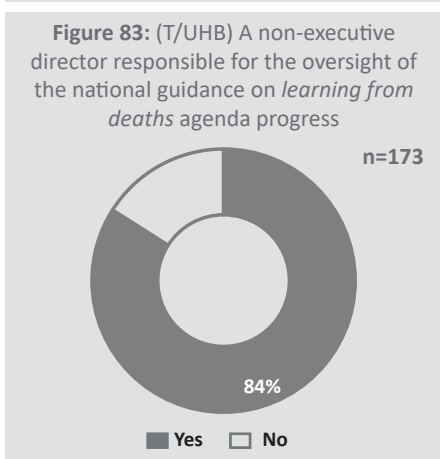
5. Results

Compliance with the four indicators included in the summary score is as follows:

- 94% of trusts/UHBs have an identified member of the trust/UHB board with a responsibility/role for End of Life Care (figure 77).
- 98% of trusts/UHBs have policies in place which include how it responds to, and learns from, deaths of patients who die under its management and care (figure 78).
- 92% of trusts/UHBs have specific care arrangements to enable rapid discharge home to die, if this is the person's preference (figure 79).
- 97% of trusts/UHBs have a care plan to support the *five priorities for care* for the dying person (figure 80).

Figure 77: (T/UHB) An identified member of the trust/UHB board with a responsibility for end of life care

n=183

94%

■ Yes □ No

Figure 78: (T/UHB) Policy on how to respond to and learn from the death of patients under the organisation's management and care

n=179

98%

■ Yes □ No

Figure 79: (T/UHB) Specific care arrangements to enable rapid discharge home to die, if this is the person's preference

n=180

92%

■ Yes □ No

Figure 80: (T/UHB) A care plan to support the *five priorities for care* for the dying person

n=182

97%

■ Yes □ No

Figure 81: (H/S) Formal process for discussing and reporting on the *five priorities for care* within your trust/UHB quality governance structure

n=218

71%

■ Yes □ No

Figure 82: (H/S) Action plan produced in the last financial year to promote improvement in end of life care

n=227

90%

■ Yes □ No

Figure 83: (T/UHB) A non-executive director responsible for the oversight of the national guidance on *learning from deaths* agenda progress

n=173

84%

■ Yes □ No

Figure 84: (T/UHB) Mechanism for flagging complaints that relate to end of life care

n=225

90%

■ Yes □ No

In addition, the following metrics are relevant to governance:

- 71% of hospitals have a formal process within their quality governance structure for discussing and reporting on the *five priorities for care*, between 1st April 2017 and 31st March 2018 (figure 81).
- 90% of hospitals had an action plan produced in the financial year (i.e. between 1st April 2017 and 31st March 2018) to promote improvement in end of life care in their trust/UHB (figure 82).
- 84% of hospitals have a non-executive director responsible for the oversight of the national guidance on *Learning from Deaths* agenda progress (figure 83).
- 90% of hospitals have a mechanism for flagging complaints that relate to end of life care (figure 84).

Governance: summary

Compliance with appropriate policies is generally high and the majority of organisations have action plans to promote improvement of end of life care. However, the results from other themes of the audit suggest further work needs to done on the implementation of policies and action plans particularly with respect to communication (sections 5.2 and 5.3), the needs of the families and others (section 5.5), consistent use of individual care plans (section 5.6) and the workforce (section 5.9).

Recommendation 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*, complaints and feedback from surveys, including those from bereaved people.

5. Results

5.9 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 for 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: summary score

Workforce/specialist palliative care — **7.6**

The summary score for workforce/specialist palliative care is calculated using information collected in the Organisational Level Audit:
- does the hospital provide/have access to a specialist palliative care service
- nurses in specialist palliative care teams available 9am-5pm, 7 days a week, face-to-face (or better/equivalent)
- training (weighting 0.25 each)
    - end of life care training included in induction programme
    - end of life care training included in mandatory/priority training
    - training to improve the culture, behaviours, attitudes around communication skills
    - other training in relation to end of life care

Figure 85: Hospital mean summary scores: Workforce/specialist palliative care

Submissions (n=196)   Range 1.7 - 10.0
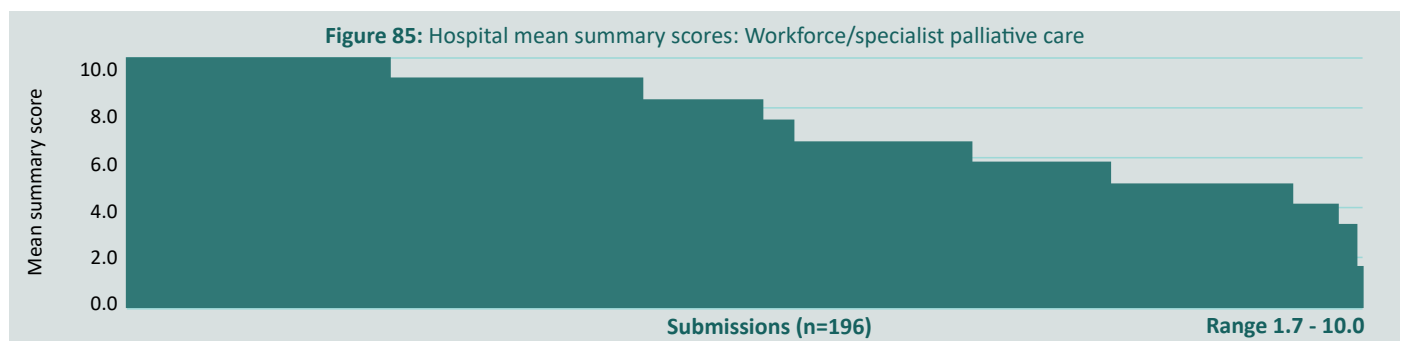
The range of hospital mean summary scores for workforce/specialist palliative care is shown in figure 85.

The mean value of the summary score across participating hospitals is 7.6 (n=196).

5. Results

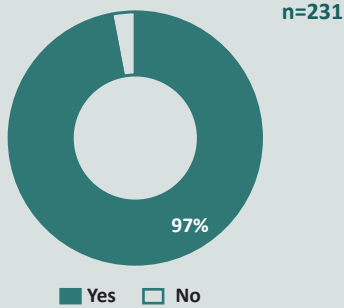**Figure 86:** (H/S) Does the hospital provide/have access to a specialist palliative care service?

n=231

97%

■ Yes □ No

Figure 87: (H/S) Nurses in SPC teams available 9am-5pm, 7 days a week, face-to-face (or better/equivalent)

n=208

52%

■ Yes □ No
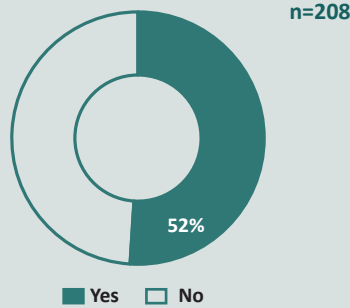
Figure 88: (H/S) End of life care training included in induction programme

n=224

61%

■ Yes □ No
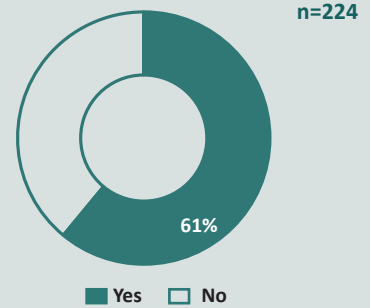
Figure 89: (H/S) End of life care training included in mandatory/priority training

n=219

47%

■ Yes □ No

Figure 90: (H/S) Training to improve the culture, behaviours, attitudes around communication skills

n=223

86%

■ Yes □ No
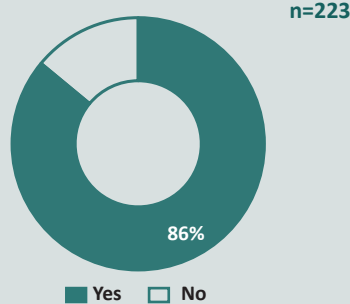
Figure 91: (H/S) Other training in relation to end of life care

n=218

95%

■ Yes □ No

The results for the component indicators of the workforce/specialist palliative care summary score are as follows:

- 97% of hospitals have access to a specialist palliative care service (figure 86), although this increases to 99%[30] if community hospitals are excluded
- 52% of hospitals have specialist palliative care nurses available 9am-5pm, 7 days a week for face-to-face contacts (or better/equivalent) (figure 87)
- 61% of hospitals have end of life care training included in their induction programme and 47% in their mandatory/priority training (figures 88 and 89)
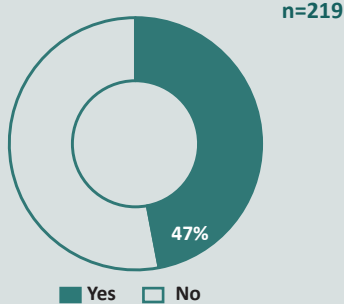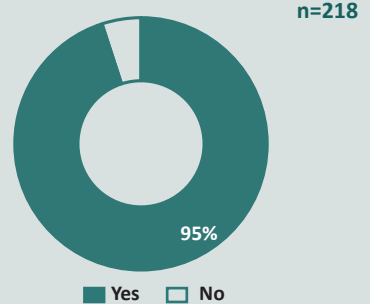- 86% of hospitals provide training to help improve the culture, behaviours, attitudes around communication skills (figure 90)
- 95% have other training in relation to end of life care (figure 91)

In addition to the summary score, the Case Note Review shows that 38% of patients were reviewed by a member of the specialist palliative care team during their final admission (figure 92). Trusts/UHBs results for this metric will vary depending on their model of specialist palliative care.

Figure 92: (CNR) Patient reviewed by the specialist palliative care team during final admission

n=10,662

38%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes □ No
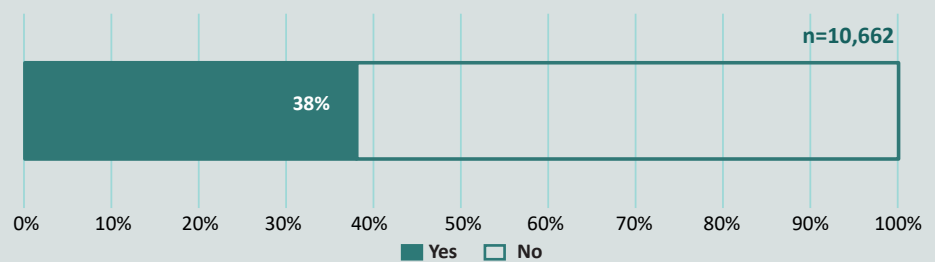
Data from the Organisational Level Audit on take up of training shows that the percentage of staff who have received mandatory or priority training on end of life care is 69% or less across all disciplines (figure 93).

Figure 93: (H/S) Percentage of staff who have received mandatory/priority end of life care training
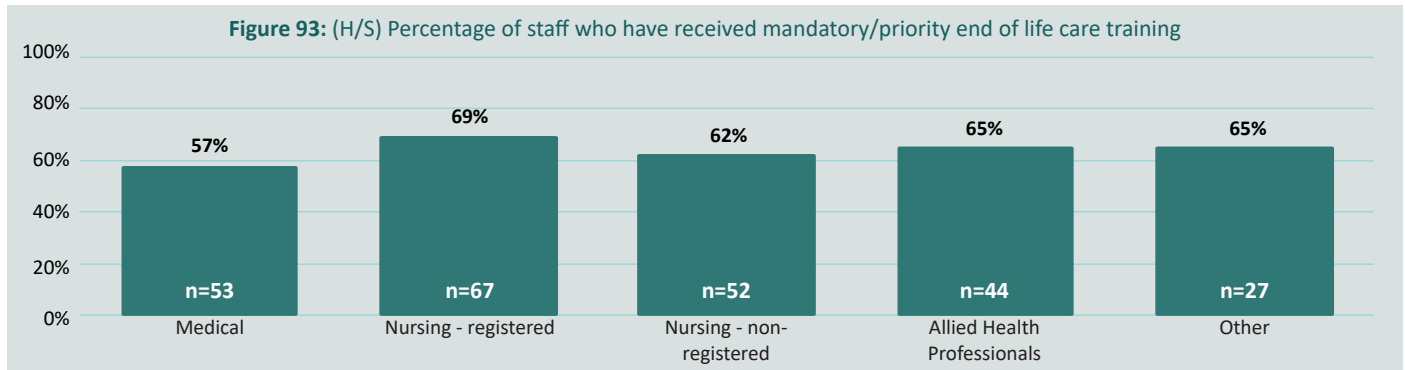
Workforce/specialist palliative care: Families' and others' comments

From the Quality Survey narrative responses, 37% (120/321) related to staff. Of all the comments about staff:

- 16% (19/120) related to perceived staff shortages
- 78% (94/120) at least partially praised staff
- 28% (34/120) at least partially criticised staff
- 3% (4/120) mentioned training

"The staff were incredible - so sensitive and supportive."

"The night staff on duty the evening before my dad died were very attentive. My dad was quite agitated, trying to get out of bed and they could see that it was upsetting me. They administered a mild sedative which settled him. This gave me peace of mind and I could go home with a peaceful image of my dad."

"Overall I thought staff training was inadequate and that there should be a palliative care specialist available over the weekend."

"Majority of the doctors were junior doctors, when asked to speak with a senior doctor, there was none available. The staff who were at present weren't fully qualified to care for palliative care."

Of the 28% (89/321) of comments referencing communication discussed in sections 5.2 and 5.3, 15% (13/89) related to communication between staff.

"No one seemed to have an overview of all the issues."

"Communication between staff in different departments seemed to be lacking."

5. Results

Workforce/specialist palliative care: summary

Most hospitals (97%) have access to a specialist palliative care service and more than a third of patients were reviewed by a palliative care specialist. However, just over half of hospitals have specialist palliative care nurses available 9am-5pm (or better/equivalent), 7 days a week for face-to-face contacts. The results suggest seven day palliative care services are not yet available in a large proportion of the NHS in England and Wales. Comments from people completing the Quality Survey suggest instances where poor care took place at weekends due to lack of access to specialist services.

Recommendation 4: **Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management.** 'Adequate' means specialist palliative medical and nursing cover 9 am-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.

The inclusion of end of life care training within other training programmes is variable across responding organisations.

Recommendation 6: **Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with patients and families in the last days and hours of life.** Training for clinicians and other staff who have contact with dying people should focus on supporting the delivery of the *NICE Quality Standards* within the broader context of *One Chance To Get It Right*. National resources to support training are available such as guidance from professional bodies, learning outcomes and e-ELCA.

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6. Mental health providers

The NACEL Steering Group considered that mental health inpatient sites be excluded from both the Case Note Review and the Quality Survey based on the following: -

- the relatively small number of deaths occurring in mental health inpatient sites making the sample too small to enable benchmarked comparisons and robust conclusions. It was advised by the NACEL Steering Group that even extending the case note review period from April through to June, would not result in substantially more data (in the way that it would for Community Hospital sites)
- the small numbers of deaths occurring in mental health inpatient facilities making the patients potentially identifiable when reporting back
- the resource required to undertake the case note review in mental health inpatient facilities for relatively little gain in the way of robust findings.

It was however, agreed that the mental health inpatient sites should still complete an Organisational Level Audit, to pick up and explore the specific complexities of mental health provision in relation to end of life care. The mental health sites completed a slightly different Organisational Level Audit which was developed with the assistance of a sub-group of the NACEL Advisory Group representing mental health providers.

As noted earlier in section 3, there were a total of 70 mental health submissions in England and Wales.

Policies and protocols

The questions on policies and protocols concerned with care at the end of life were asked at trust/UHB level. The findings indicate that whilst almost three-quarters of mental health providers have an identified member of the trust/UHB board with responsibility for end of life care, only 10%[31] have a lay member with similar responsibility. Likewise, less than half of mental health providers (43%[32]) have a non-executive director with responsibility for end of life care. However, almost three-quarters of mental health providers are represented in regional or local end of life care networks.

Mental health trusts/UHBs report high compliance with other policies and protocols (for example, how the organisation responds to and learns from patients who die whilst under their care (98%[33]) and guidelines to promote dignity (91%[34])). Just over three-quarters (76%[35]) of participants reported having guidelines for meaningful and compassionate engagement with bereaved families and carers. Many mental health providers will transfer patients who are identified as being near the end of life to acute or community providers and 68%[36] of trusts/UHBs report having a policy covering such transfers.

There is high compliance with the use of Advance Care Planning; 90%[37] of mental health providers report having ACP processes in place. Three quarters (75%[38]) of mental health providers specifically have a care plan which supports the *five priorities for care* (compared to 97%[39] in England and Wales acute and community providers).

Deaths in mental health facilities

Data was collected on the mental health bed types offered across all mental health providers. There was a high rate of adult single beds available as a proportion of total beds available (91%[40]). The highest number of deaths in mental health providers occurred in older persons acute beds (55%[41] of all deaths). 19%[41] of all deaths took place in adult acute mental health beds. The total numbers of deaths per annum per 100 beds is 4[42], within mental health providers. Deaths in mental health beds are low compared to deaths in acute and community beds.

6. Mental health providers

Specialist palliative care workforce in mental health providers

Only 10%[43] of mental health providers reported having a specialist palliative care service provided directly by their own organisation (compared to 95%[44] in acute providers in England and Wales). Most mental health providers reported having access to specialist palliative care outside of their hospital. 16%[45] of mental health providers reported having access to one or more end of life care facilitators, 40%[46] of which sat within the specialist palliative care team.

The predominant model of availability of specialist palliative care doctors face-to-face was 9am-5pm, 7 days a week (49%[47]). With respect to nursing staff availability face-to-face, 60%[48] of mental health providers reported having nurses available 9am-5pm, 7 days a week. In terms of medical staff availability by telephone, 57%[49] of mental health providers reported having availability 24 hours per day, 7 days per week. For nursing staff, 42%[50] of mental health providers reported that they were available over the telephone 24 hours per day, 7 days per week. Of those that provide a specialist palliative care team, the skill mix was reported as 5%[51] medical staff, 84%[51] nursing staff, 9%[51] AHP staff and 2%[51] other staff. More detail on skill and discipline mix is available in the online benchmarking toolkit.

Training and development

During the financial year (1st April 2017 to 31st March 2018), only 6%[52] of mental health providers reported having end of life care training available as part of their induction programme. When the question was asked regarding inclusion of end of life care in mandatory/priority training, this rose to 13%[53] of mental health providers (in comparison England and Wales acute and community providers reported this as 47%[54]). However, 91%[55] of mental health providers reported that they had access to some form of end of life communication training to help improve the culture, behaviours and attitudes around communication skills.

Communication with the Trust/UHB Board on end of life care

62%[56] of mental health providers reported producing an action plan to promote improvement in end of life care. Where this was in place, 92%[57] of mental health providers reported feeding this back to clinical teams, and three quarters (75%[58]) reported feeding this back to the trust/UHB board. In terms of mental health providers having a formal process for discussing and reporting on the *five priorities for care*, 29%[59] reported they had this in place.

Quality and outcomes

Mortality reviews completed per 100 deaths in mental health providers was reported as 80%[60] compliance (median position reported was 100%[60]). Just over half (54%[61]) of mental health providers reported having a mechanism for flagging complaints relating to care at the end of life.

In terms of support offered to those important to the dying person, two thirds of mental health providers (66%[62]) reported that people had access to bereavement services. Comfort care packs were only available in 13%[63] of facilities, however high compliance on multi-faith/religious support and designated quiet spaces was recorded (89%[64] and 90%[65] respectively). Just over half of providers (51%[66]) reported having the use of a "last days of life care plan", whilst 77%[67] of mental health providers reported that guidance on achieving the priorities of care was available locally. Volunteer support schemes are in place in 21%[68] of mental health providers relating to care at the end of life.

7. Second round of NACEL

NACEL has been commissioned by HQIP to run as an annual audit, initially for three years from 2017 to 2020. There is the possibility that NACEL may be extended for a further 2 years.

The second round of NACEL will take place during the 2019/20 financial year. The scope and content of NACEL is being reviewed by the Steering and Advisory Groups, HQIP and funders, taking into account feedback from participants in the first round of the audit.

The first round has been successful in identifying key priorities for quality improvement in care at the end of life in hospitals. The three elements of the audit provide rich and complementary data sets which together build a detailed picture of progress against the *five priorities for care.* Participants have expressed appreciation for the timely receipt of the online toolkit and bespoke dashboards, which have enabled them to identify local improvement areas and commence action planning within four months of completing data collection.

The audit process did highlight some challenges in:
- converting good practice statements into auditable standards
- balancing the individualised approach to care with ensuring good case note documentation without moving to an overly standardised or check list approach
- data burden, given the requirement to complete an extensive questionnaire for up to 80 case notes

To address these challenges, the Steering Group is considering:
- clarifying the wording of questions, as where the wording was taken directly from guidance it may have been ambiguous when applied in practice
- reinforcing the acceptability of local solutions to care planning documentation, but encouraging the recording of key discussions with dying patients and those important to them
- reducing the size of the Organisational Level Audit
- reducing the Case Note Review questionnaire substantially, and focusing on the themes recognition of imminent death and individual plan of care
- reducing the number of Case Note Reviews to be completed
- unlinking the Quality Survey from the Case Note Review to enable a greater number of Quality Surveys to be distributed and returned. Greater reliance can then be placed on the Quality Survey to measure, in particular, communication and needs of families and others

Mental health providers will not be participating in the second round of the audit, with a view to taking part in all elements in the third round of NACEL.

8. Glossary

Acronyms and abbreviations	
ACP	**Advance Care Planning**
CNR	NACEL **Case Note Review** data collection
CPR	**Cardiopulmonary Resuscitation**
DNACPR	**Do Not Attempt Cardiopulmonary Resuscitation**
DPA	**Data Protection Act**
DPIA	**Data Protection Impact Assessment**
e-ELCA	The e-learning programme **End of Life Care for All,** Health Education England
EPaCCS	**Electronic Palliative Care Co-ordination Systems**
GDPR	The **General Data Protection Regulation**, 2018
H/S	NACEL **Hospital/site** data collection
HQIP	**Healthcare Quality Improvement Partnership**
IV	**Intravenous** (in relation to nutrition and hydration)
NACEL	The **National Audit of Care at the End of Life** commissioned by HQIP from NHSBN in October 2017.
NCAPOP	The **National Clinical Audit and Patient Outcomes Programme**
NG	**Nasogastric** (in relation to nutrition and hydration)
NHSBN	The **NHS Benchmarking Network**
NMCRR	**National Mortality Case Record Review** programme
PEG	**Percutaneous endoscopic gastrostomy** (in relation to nutrition and hydration)
PEoLC	NHS England's **Palliative End of life Care Network**
SC	**Subcutaneous**
QS	NACEL **Quality Survey** data collection
SPC	**Specialist Palliative Care**
T/UHB	NACEL **Trust/UHB** data collection
UHB	**University Health Board** (in Wales)

8. Glossary

Terms used in this report	
Case Note Review	The case note review component of the first round of NACEL. A set of questions completed for each death in April 2018 (acute hospitals) and each death in April 2018 to June 2018 (community hospitals).
Category 1 death	Definition of deaths to be included in NACEL. 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 care at the end of life.
Category 2 death	Definition of deaths to be included in NACEL. 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.
'Families and others', 'nominated person', 'next of kin', 'carer', 'bereaved person'	These terms are used interchangeably in this report to refer to 'those important to the dying person' as used in *One Chance To Get It Right*. It is recognised that some dying people do not have such a person.
'five priorities for care'	The *five priorities for care* of the dying person as set out in *One Chance To Get It Right*.
'individual plan of care'	An 'individual plan of care' as envisaged in *One Chance To Get It Right*. This could include any form of care plan that documents an individualised plan for care at the end of life.
Quality Survey	The survey designed for the first round of NACEL to capture the views of those important to the dying person.
'submission'	A hospital or site identified by the participating organisation to be audited separately.
Sustainability and Transformation Partnerships	STPs were created to bring local health and care leaders together to plan around the long-term needs of local populations.
'the 2016 Audit'	The previous audit on care at the end of life. Royal College of Physicians. *End of Life Care Audit – Dying in Hospital. National Report for England. March 2016*

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