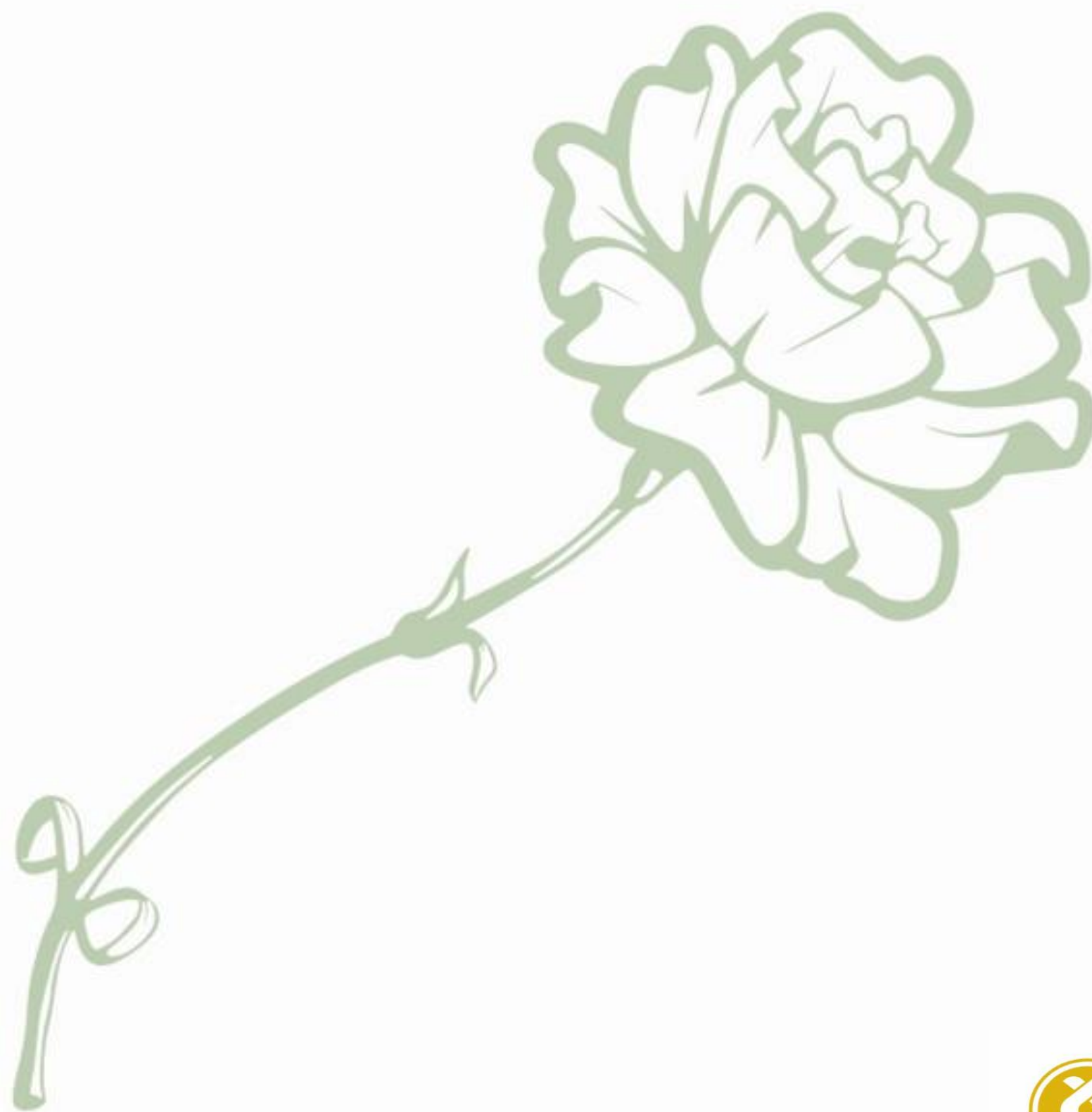


National Audit of Care at the End of Life

Key findings for patients and carers
First round of the audit (2018/19)
England and Wales



What is NACEL?

The National Audit of Care at the End of Life (NACEL) is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient facilities in England and Wales.

NACEL was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government in October 2017. The audit was commissioned from the NHS Benchmarking Network (NHSBN), who have been supported by [The Patients Association](#) in delivering the audit.

What did we do ?

NACEL included three main data collection elements;

1. Organisational Level Audit

Reviewing policy and protocols, service models, activity, workforce and quality data for the organisation during 2017/18.

2. Case Note Review

Patient level data collection, where organisations completed an in-depth review of case notes of patients (18+) who died during 1st April – 30th April 2018 for acute hospital providers and 1st April – 30th June 2018 for community hospital providers.

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

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

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

Deaths classed as "sudden deaths" were excluded from the Case Note Review. These were deaths which were sudden and unexpected, including deaths within A&E and deaths which occurred within 4 hours of admission.

3. Quality Survey

An online survey for the relatives, carers and those close to the person who died, to report their experiences of the care and support received at the end of life.

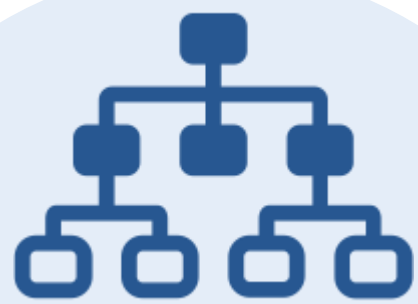
What does this report include?

This report provides a summary of the key findings from the first round of the National Audit of Care at the End of Life (NACEL) which took place in 2018. The results are based on data collected from 214 organisations, comprising 206 English trusts, 7 Welsh Health Boards and 1 Welsh trust. Full details of the findings can be found at <https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs>.

Who took part?

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

A total of **214 NHS** organisations completed the following....



302

Hospital/ Site organisational returns



11,034

Patient level Case Note Reviews



790

Quality Surveys were returned

The total number of Quality Surveys returned was 790. As these were linked to the Case Note Reviews, these represented 7% of the Case Note Reviews completed. 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

The information in this section is presented thematically in nine sections, covering the *NICE Quality Standards*, *NICE Guideline* and the *five priorities for care of the dying person*, as set out in *One Chance To Get It Right*. The themes are:

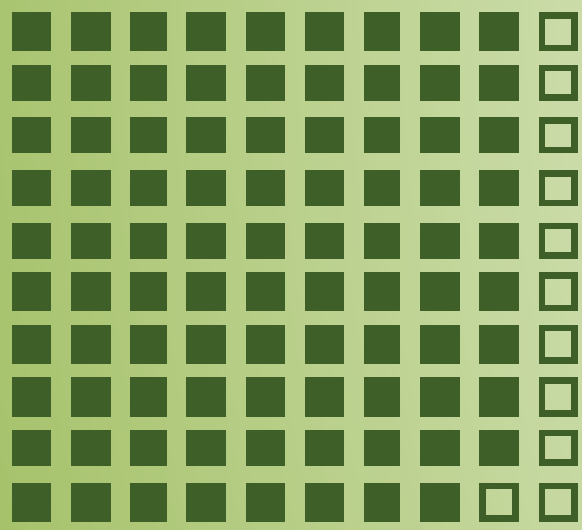
1. **Recognising the possibility of imminent death**
2. **Communication with the dying person**
3. **Communication with families and others**
4. **Involvement in decision making**
5. **Needs of families and others**
6. **Individual plan of care**
7. **Families' and others' experience of care**
8. **Governance**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

For each theme, a summary score has been developed and calculated for each hospital. The average values for the summary scores are shown in the image below. Each score has a maximum possible value of ten. The summary scores are developed using key metrics identified across each of the nine themes. A full explanation of how the scores are calculated can be found at <https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs>.



Recognising the possibility of imminent death

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.



89%

Of case notes recorded that the patient might die imminently



36 hours is

the median time between recognition of dying and death

Documented evidence that a discussion regarding the possibility of death, or a reason why not took place with....

the patient in **85%** of cases



families/others in **95%** of cases

Families' and others' comments from the Quality Survey:

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

"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."

[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 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.

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 at the end of life.

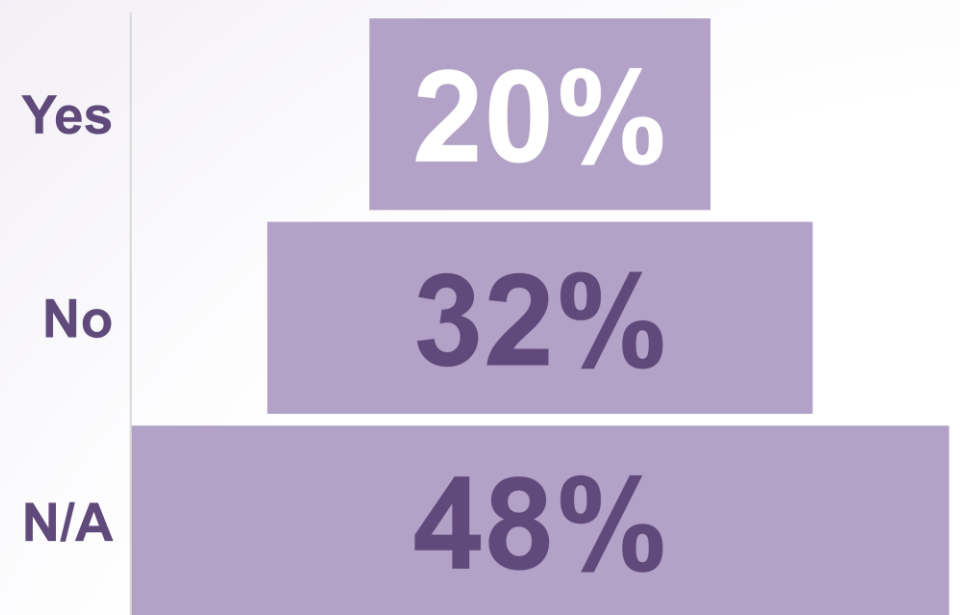


68-69%

Of case notes recorded discussions with patients about medication, nutrition and hydration, or a reason why these did not take place

68%

Of case notes had documented evidence that the patient had the opportunity to be involved in discussing their plan of care, or this was not applicable



67%

Of families/carers responding to the Quality Survey reported that communication was sensitive 'definitely', or 'to some extent'

Most organisations have put in place policies to promote dignity, and training to improve the organisational culture and communication skills, suggesting trust/UHB Boards are aware of the importance of appropriate behaviours and good communication during care at the end of life.

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 in communication with 22% of respondents reporting that communication with the dying person was not sensitive or was 'mixed'.

Communication with families and others

As previously noted, open and honest communication between staff and the dying person, and those identified as important to them, is critically important to good care.

62%

Of case notes documented evidence that the families/others had the opportunity to be involved in discussing the patient's plan of care



84%

Of case notes, for category 1 deaths, where it was recognised that the patient may die, it was recorded that families/ carers were notified of the patient's imminent death

Families' and others' comments from the Quality Survey:

"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."

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.

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 clinician responsible for the patient's care.

Around three quarters of respondents to the Quality Survey reported a positive experience of communication, but in around a quarter of cases there appeared to be scope for improvement in communication. 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.

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.



80%

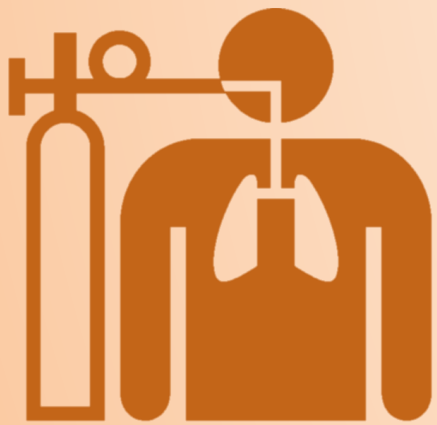
Case notes recorded discussions by a senior clinician regarding CPR with families/carers



81%

Families/carers reported that the patient was either involved in decision making as much as they wanted to be or were unable to be involved

Documented evidence of a discussion with the patient or a documented reason why the discussion could not take place regarding.....



Life-sustaining treatments in **92%** of case notes



CPR in **92%** of case notes

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.

Families and those important to the dying patient responding to the Quality Survey suggest that 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.

The Quality Survey results indicate that 31% of patients were admitted to hospital three or more times within the last 12 months of life, suggesting a significant opportunity for earlier end of life care planning.

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. The 2018 audit found that in just over half of cases there was documented evidence that the needs of families and others were asked about.



56%

Of case notes had documented evidence that the needs of families/others were asked about

82%

Families/carers felt supported by the hospital staff after the patient's death



Families' and others' comments from the Quality Survey:

"...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."

"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."

"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."

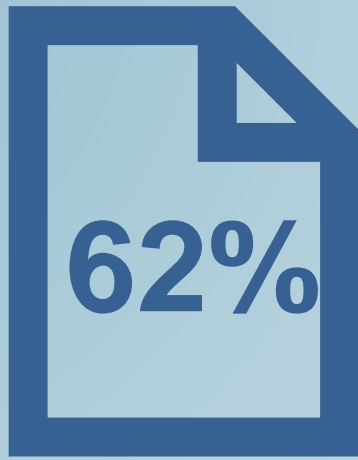
"Delays in receiving the death certificate were upsetting and stressful at a difficult time."

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.

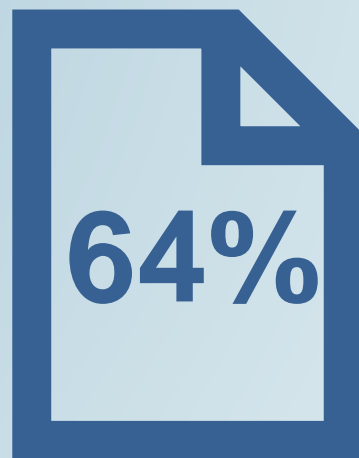
From the Quality Survey, though a high proportion of people felt they were supported after the patient's death (82%), when asked more specifically about emotional and practical support during the last two or three days, almost one third of those responding did not feel they had enough support.

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



Of case notes had documented evidence that the patient had an individual end of life care plan



Of case notes had documented evidence that the individual end of life care plans was reviewed regularly

Case notes with documented review of.....

Routine recording of vital signs



75% Yes or N/A

Blood sugar monitoring



67% Yes or N/A

Administration of oxygen



70% Yes or N/A

Administration of antibiotics



74% Yes or N/A

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.

62% of case notes had documented evidence that the patient had an individual end of life care plan. 67% of those responding to the Quality Survey felt that a plan had been made either definitely or to some extent.

From the Case Note Review, hydration status was documented as being assessed in the time between recognition of dying and death in 75% of cases, and nutrition status, in 61% of cases. 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.

There was higher compliance with documentation of assessment of the patient's physical care needs, than other areas such as psychological and social needs from the Case Note Review.

Individual plan of care - Place of death

Place of death is a complex and important topic which is addressed as a subsection of the individual plan of care theme. Three quarters of respondents to the Quality Survey 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. Further, adequate resources need to be available in the community to provide support to patients and those important to them.



11%

Of case notes showed attempts were made to move the patient home/to a hospice



75%

Respondents to the Quality Survey felt that the hospital was the right place for the patient to die

Families' and others' comments from the Quality Survey:

“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 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.”

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.

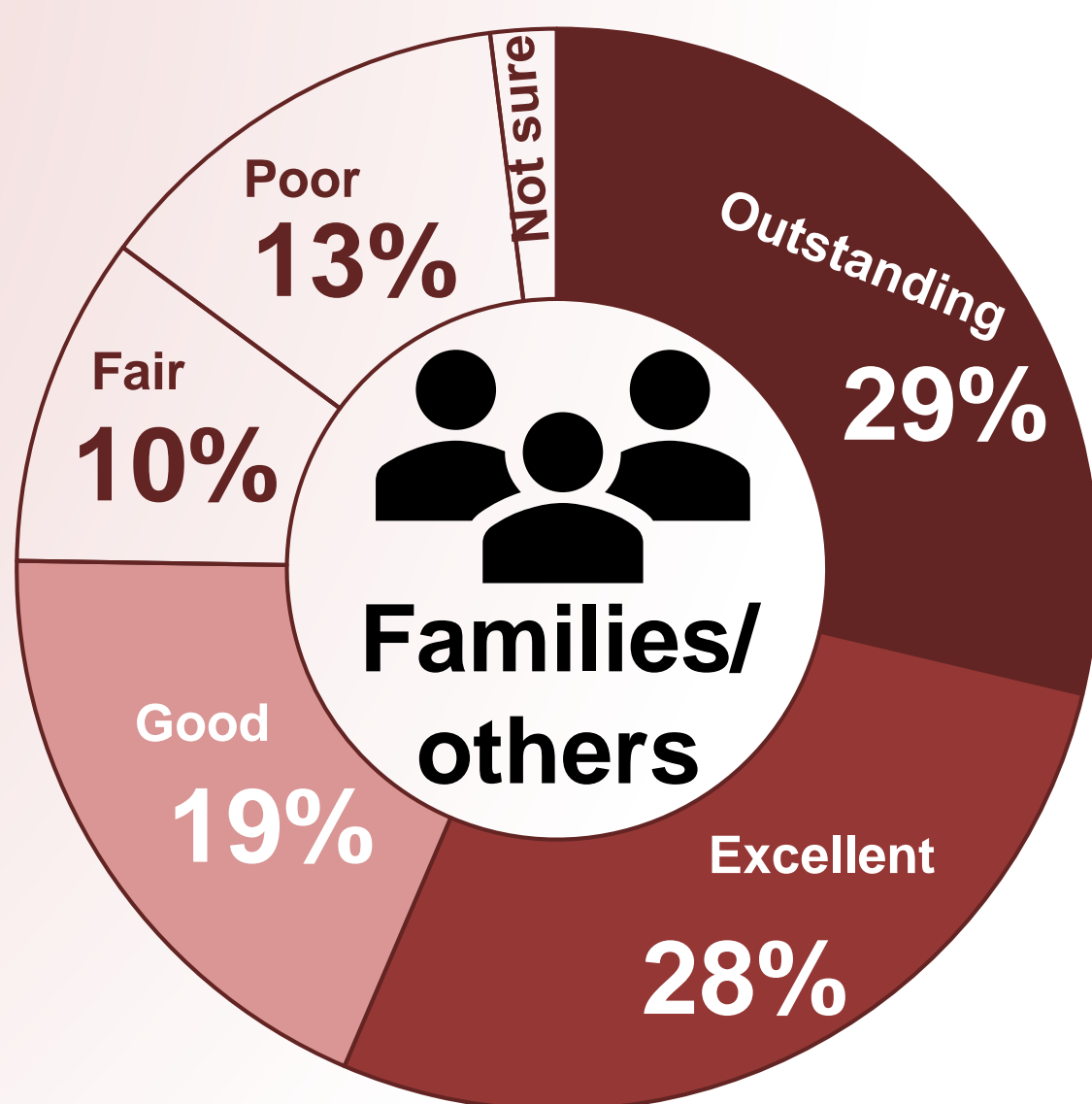
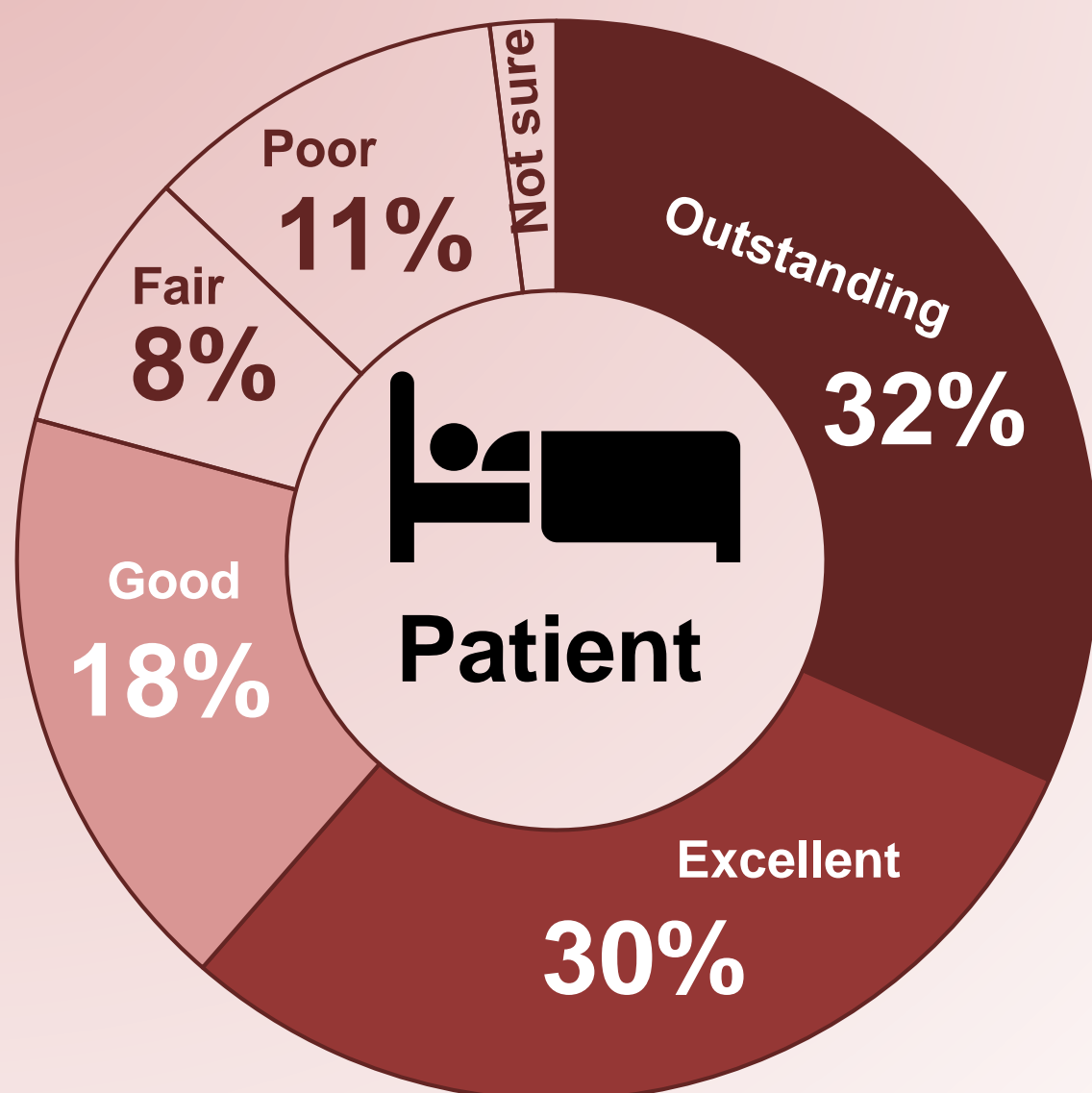
The results suggest the majority of people responding to the Quality Survey felt the patient had received good care and had been treated with compassion.

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.

Families' and others' comments from the Quality Survey:

“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.”

Overall rating of the care and support provided to the



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.



94%

Of trust/HBs have an identified member of the trust/UHB board with a responsibility for end of life care

98%

Of trust/HBs have a policy on how to respond to and learn from the death of patients under the organisation's management and care



92%

Of trust/HBs have specific care arrangements to enable rapid discharge home to die, if this is the person's preference

Compliance with having appropriate policies in place is generally high and the majority of organisations have action plans to promote improvement of end of life care. 98% of trusts/UHBs state that their organisation has policies in place which include how it responds to, and learns from, deaths of patients who die under its management and care.

Whilst the Organisational Level Audit suggests policies are in place, the results from other themes of the audit suggest further work needs to be done on the implementation of policies and action plans particularly with respect to communication, the needs of the families and others, consistent use of individual care plans and the workforce.

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 workforce to provide leadership, education and training and support to non-specialist front-line health and care workers. In this section, findings regarding the specialist and non-specialist workforce are presented.



97%

Of hospitals provide or have access to a specialist palliative care service

Hospitals with specialist palliative care nursing availability 9am-5pm, 7 days a week (or better/equivalent)



52%

Face-to-face



32%

Telephone

Most hospitals (97%) have access to a specialist palliative care service and more than a third of patients included in the Case Note Review audit 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.

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

“The staff were incredible - so sensitive and supportive.”

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

Recommendations

Below are the recommendations from the first round of NACEL. Local action plans are expected to consider the NACEL recommendations, together with local audit results, in the context of the national guidance.

Recognising the possibility of imminent death:

Medical Directors and Nursing Directors should:



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.

Communication:

Chief Executives should:



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 (an online education/training programme on end of life care).

Involvement in decision making:

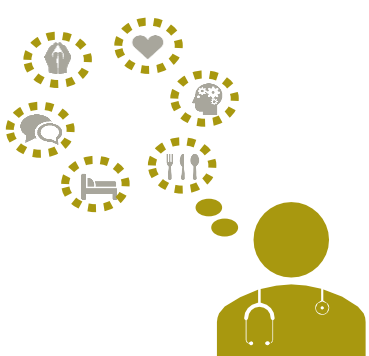
Integrated Care Systems/Commissioners, working with providers, should:



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.

Needs of families and others:

Chief Executives should:



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.

Recommendations

Individual plan of care:

Medical Directors and Nursing Directors should:



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.



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.



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



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.

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



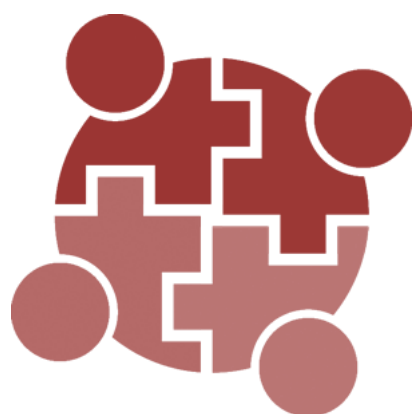
Review capability and capacity within primary care, community services and social care, to provide appropriate care at the end of life, and to support families through to bereavement, with the aim of better meeting people's needs and preferences. Review should lead to service re-design where potential improvements are identified.



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

Recommendations

Families' and others' experience of care:
Trust/UHB Boards should:



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](#).

Governance:

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



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.

Workforce/specialist palliative care:

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



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.

Mental Health key findings

There was a total of 70 mental health providers of inpatient care who participated in the audit, in England and Wales. Mental health organisations were only required to complete the Organisational Level Audit, due to the relatively small number of deaths occurring in mental health inpatient settings. The data collected included deaths in mental health facilities, policies and protocols, specialist palliative care workforce, training, communication and quality. A selection of mental health key findings are included below.

Deaths in mental health facilities



- **55%** of all deaths occurred in older persons acute beds
- **4** deaths occur per annum per 100 beds
- **91%** of beds are adult single beds

Training and development



- **6%** MH providers have end of life care training available as part of their induction programme
- **13%** include end of life care in mandatory/priority training
- **91%** reported that they had access to some form of end of life communication training to help improve communication skills.

Quality and outcomes – support offered to those important to the dying person

66%

Bereavement services



13%

Comfort care packs



90%

Designated quiet spaces



89%

Multi-faith/religious support



What's next?

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

All participants of round one of NACEL have received access to an online toolkit showing all data collected in the audit, as well as bespoke dashboards for each hospital/organisation. 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 second round of NACEL opened for data collection in June 2019 and closed during October 2019. The scope and content of NACEL has been reviewed by the Steering and Advisory Groups, HQIP and the funders, taking into account feedback from participants in the first round of the audit. The second round of NACEL aimed to reduce data burden across participants by reducing the number of questions included in the Case Note Review, and expanding the sample size of the Quality Survey to ensure greater reliance can be placed on the experience of care reported by those important to the dying person.

The first round has been successful in identifying key priorities for quality improvement in care at the end of life in hospitals which have been noted on pages 15-17 of this report. 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](#).

For further information please go to the [NACEL webpages](#).

Glossary	
e-ELCA	The e-learning programme End of Life Care for All, Health Education England
CPR	Cardiopulmonary Resuscitation
'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 <i>One Chance To Get It Right</i> . It is recognised that some dying people do not have such a person.
HQIP	Healthcare Quality Improvement Partnership
NACEL	The National Audit of Care at the End of Life commissioned by HQIP from NHSBN in October 2017.
Trust	An NHS trust is an organisation delivering healthcare to patients in a geographical area.
UHB	University Health Board (in Wales) is an organisation delivering health care to patients in a geographical area.

