National Audit of Care at the End of Life

Key findings for patients and carers
Second round of the audit (2019/20)
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. This report represents the findings of the second round of the National Audit of Care at the End of Life (NACEL) which took place in 2019.

NACEL round two included three main data collection elements;

1. Organisation Level Audit

Following feedback from participants in round one of the audit, the data requested for this audit element was substantially reduced and focused on activity, the specialist palliative care workforce, staff training and new questions on anticipatory prescribing.

2. Case Note Review

Patient level data collection, where organisations completed an in-depth review of case notes of patients (18+). Acute providers were requested to audit 20 consecutive deaths from the first two weeks of April and 20 consecutive deaths from the first two weeks of May. Community hospital providers were requested to audit all deaths during April and May up to a maximum of 40 (rather than deaths in April to June as in round one).

The 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 was completed by 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 second round of the National Audit of Care at the End of Life (NACEL) which took place in 2019. The results are based on data collected from 183 organisations, comprising 175 English trusts, 7 Welsh Health Boards (HB) 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 and community 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.

A total of 183 NHS organisations completed the following....

- 247 Hospital/Site organisational returns
- 6,730 Patient level Case Note Reviews
- 1,581 Quality Surveys were returned

The response rate for the Quality Survey, for those that were sent a letter by the trust/HB was 18%, which was the same as for round one, although almost twice as many Quality Surveys were returned in round two. The increase was due to changes in the way the Quality Survey was administered. 143 hospitals participated in the Quality Survey element representing 58% of those eligible.
Key findings

The information in this section is presented thematically in seven 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 (CNR)
2. Communication with the dying person (CNR)
3. Communication with families and others (CNR)
4. Needs of families and others (QS)
5. Individualised plan of care (CNR)
6. Families’ and others’ experience of care (QS)
7. Workforce/specialist palliative care (H/S)

Except for ‘recognising the possibility of imminent death’, a summary score has been developed and calculated for each theme 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 six themes. A full explanation of how the scores are calculated can be found at https://www.nhsbenchmarking.nhs.uk/nacel-audit-outputs. As in round one of NACEL, each summary score can only use indicators from one element of the audit.

The following key is used to show the source of each finding reported in the themes:

• H/S = Hospital/site Organisational Level Audit
• CNR = Case Note Review
• QS = Quality Survey

All figures reported from the Case Note Review are Category 1 deaths only. Totals may not equal 100% due to rounding.
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 dying person and those important to them to take place, treatment decisions to be made and the needs of the family to be considered. It underpins all the priorities for improving people’s experience of care in the last few days and hours of life.

*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.

Timeliness of recognition of death is important to ensure appropriate discussions and planning can take place. In this section, the results from the Case Note Review relating to recognising the possibility of imminent death are presented. The results suggest that, for around a third of patients, death occurs within one day of recognition of the possibility that they may die, leaving a limited amount of time to discuss and implement a plan of care.

88% Of case notes recorded that the patient might die imminently (CNR)

41 hours is the median time between recognition of dying and death (CNR)

**Time between recognition of dying and death (CNR):**

- **1 – 4 days**: 73%
- **5 – 9 days**: 18%
- **10+ days**: 9%

**Families’ and others’ comments from the Quality Survey:**

- “We were notified early of this decline (6 hours prior to death) so were able to be with him and at that time the staff were excellent in explaining the situation and looking after our needs.”
- “Felt that family should have been better informed about her imminent passing. The consultants didn’t emphasise how soon it would be.”
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. In this section, the results from the Case Note Review relating to communication with the dying person are presented.

In 89% of Category 1 cases, there was evidence in the case note that a discussion about dying had taken place with the patient, or a reason why not recorded, compared with 86% in round one. Reasons why a discussion may not be recorded include if the patient was semi-conscious or unconscious or had requested not to be included in discussions regarding their care.

For conversations about drowsiness as a result of medications, hydration and nutrition options, the Case Note Review showed an improvement in the proportion of cases where a documented discussion had taken place, or a reason why not had been recorded.

For Category 1 deaths in round two, where an individualised plan of care existed, there was documented evidence that the patient had the opportunity to be involved in discussing the plan of care, or a reason why not recorded in 93% of cases. This compares with 69% in round one.

| Score | 7.8 |

- **89%**
  Of case notes had documented evidence that a discussion took place with the patient regarding the possibility of death, or a reason why not recorded (CNR)

- **74% - 80%**
  Of case notes recorded discussions with patients about medication, nutrition and hydration, or a reason why not recorded (CNR)

- **93%**
  Of case notes recorded that the patient was involved in discussing the individualised plan of care, or a reason why not recorded (CNR)
Communication with families and others

In this section, the results from the Case Note Review relating to communication with families and others are presented. As in the ‘communication with the dying person’ theme, the findings of the second round of NACEL suggest there has been an improvement in the documentation of discussions with the families and others, since round one of the audit. There was documented evidence in the case note that the possibility that the patient may die had been discussed with those important to the dying person in nearly all cases.

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

Three quarters of respondents to the Quality Survey felt it was explained to them clearly that the person was likely to die in the next few days or the person died suddenly. 84% of respondents agreed with the statement ‘I was communicated to by staff in a sensitive way’.

Families’ and others’ comments from the Quality Survey:

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

“I didn’t feel I was kept in the picture enough - the communication was not direct enough - I like things in black and white.”
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 Quality Survey relating to the needs of families and others are presented.

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

58%
Of families and others responding to the Quality Survey felt that their needs were asked about (QS)

69%
Of families and others were kept well informed and had enough opportunity to discuss the person’s condition and treatment with staff (QS)

Families’ and others’ comments from the Quality Survey:

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

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

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

**Score 7.2**

<table>
<thead>
<tr>
<th>Case notes with documented review of (CNR)</th>
<th>Routine recording of vital signs</th>
<th>Blood sugar monitoring</th>
<th>Administration of oxygen</th>
<th>Administration of antibiotics</th>
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<tr>
<td><strong>71%</strong></td>
<td><strong>80%</strong></td>
<td><strong>84%</strong></td>
<td><strong>81%</strong></td>
<td><strong>85%</strong></td>
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</table>

Of case notes had documented evidence that the patient had an individualised plan of care (CNR)

Of case notes had documented evidence that the individualised plan of care was reviewed regularly (CNR)

There were 29% of Category 1 cases with no documented individualised plan of care for the dying person. Of these, in 45% of cases, the time from recognition of dying to death was over 24 hours.

The results of the Quality Survey also suggest a gap remains in the development and documentation of an individualised plan of care for every dying person, with two thirds of respondents agreeing that a plan was made for the person’s care which took account of their wishes.

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

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

New questions were included in round two in the Case Note Review on anticipatory medication for Category 1 deaths only. There was documented evidence that anticipatory medication was prescribed, and administered, for symptoms likely to occur in the last days of life, in 68% of cases, prescribed but not used in 20%, and no evidence regarding anticipatory prescribing in 11%, of cases.

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

68%
Of case notes had anticipatory medication prescribed and administered (CNR)

66%
Of case notes had an indication for the use of medication prescribed (CNR)

Documented evidence that a discussion regarding the use of anticipatory medication was undertaken, or a reason why not took place with (CNR)....

85%
The patient in of cases

65%
Families/others in of cases

Individual plan of care: Families’ and others’ comments from the Quality Survey:

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

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

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

“No one assisted her with eating or drinking or checked she was getting a meal she was able to eat.”
Individualised plan of care – Place of death

In round two, there was one question on place of death included in the Case Note Review. Views on place of death and location within the hospital were sought from bereaved families and others in the Quality Survey.

29% of cases for Category 1 deaths recorded the preferred place of death, as indicated by the patient. The results from the Quality Survey suggest most people (80%) were content that the hospital was the right place for the person to die, compared to 75% in round one of the audit. However, 10% disagreed or strongly disagreed that hospital was the right place.

**Place of death: Families’ and others’ comments from the Quality Survey:**

- “I feel people who are nearing the end of life deserve to have peace and quiet and dignity not in a bed with curtains drawn around it and people shouting.”
- “I feel a private room would have made a huge difference not only to my mum but emotionally to her family.”
- “The end of life care for us as a family was enhanced by us having access to the Suite which was very helpful.”
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, the results from the Quality Survey relating to families’ and others’ experience of care are presented.

The majority of respondents to the Quality Survey felt communication with the dying person (79%) and those important to them (84%) was sensitive. The results for round two, as for round one, suggest the majority of people responding to the Quality Survey felt the patient had received good care and support overall. However, in around a quarter of cases, respondents rated the quality of care and support provided to families and others as ‘poor’ or ‘fair’, suggesting room for improvement in this area.

### Overall rating of the care and support provided to the (QS)........

**Patient**
- Outstanding: 11%
- Good: 28%
- Fair: 18%
- Poor: 9%
- Not sure: 23%

**Families/others**
- Outstanding: 28%
- Good: 31%
- Fair: 21%
- Poor: 13%
- Not sure: 11%

### Families’ and others’ comments from the Quality Survey:

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

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

- “Considering she was on a ward for care of elderly the staff did not universally exhibit appropriate care or an understanding of this age group nor the needs of relatives.”
Workforce/specialist palliative care

National guidance recognises the need for organisations who provide healthcare 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, the results from the Hospital/Site relating to the specialist palliative care workforce are presented.

99%
Of hospitals provide or have access to a specialist palliative care service (H/S)

Hospitals with specialist palliative care doctor and/or nursing availability (H/S)

36%
Face-to-face availability
8 hours a day,
7 days a week

86%
Telephone availability
24 hours a day,
7 days a week

Most hospitals (99%) have access to a specialist palliative care service. However, around a third of hospitals (36%) report having a face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week.

The results suggest seven day palliative care services are not yet available in a large proportion of the NHS in England and Wales.

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

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

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

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

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

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

1. Put in place systems and processes to support people approaching the end of life to receive care that is personalised to their needs and preferences. Health and care systems should work together to agree guidelines across primary, community, secondary care, social care and care homes for timely identification of, documentation of, and information sharing regarding people’s wishes and needs.
   [NACEL 2018 Recommendation 1 – updated for clarity]

2. Review capability and capacity across all care settings, to provide appropriate care at the end of life, and to support people important to the dying person through to bereavement, with the aim of better meeting people’s needs and preferences. Review should lead to service re-design where potential improvements are identified.
   [NACEL 2018 Recommendation 2 – updated for clarity]

3. Ensure adequate access to specialist palliative care in hospitals for holistic assessment, advice and active management. ‘Adequate’ means specialist palliative medical and nursing cover 9am-5pm, 7 days a week and a 24 hour telephone advice service (One Chance To Get It Right). This would most often be provided by nurse specialists face-to-face supported by medical telephone advice. Where this service does not exist, an action plan committing to provision of such services within a specified timeline should be developed.
   [NACEL 2018 Recommendation 4]

4. Create and implement an action plan to ensure the local findings and national recommendations of NACEL are reviewed, and providers of NHS funded care at the end of life in acute and community hospitals and other care settings are supported by commissioners in developing, implementing and monitoring their plans.
   [New for NACEL 2019]

5. Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system. ‘The system’ refers to locality, Integrated Care System (ICS) or other networks of provision.
   [New for NACEL 2019]
Recommendations

Chief Executives should:

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

[NACEL 2018 Recommendation 6 - updated for clarity]

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

[NACEL 2018 Recommendation 7 - updated for clarity]

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

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

[NACEL 2018 Recommendation 8 – updated for clarity]

Medical Directors and Nursing Directors should:

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

[NACEL 2018 Recommendation 9 - updated for clarity]

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

[NACEL 2018 Recommendation 10 - updated for clarity]
11. Ensure that patients who are recognised to be dying have a clearly documented and accessible individual plan of care developed and discussed with the patient and those important to them to ensure the person’s needs and wishes are known and taken into account. The plan will be based on the holistic care standards set out in the Five priorities for care (One Chance To Get It Right) and NICE Quality Standards and take into account previously expressed wishes. Documentation for the individual plan of care may vary locally and may be part of standard care plans. Mechanisms to ensure the communication and coordination of this plan must be in place, especially at points of handover of care. 

[NACEL 2018 Recommendation 11 - updated for clarity]

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

[NACEL 2018 Recommendation 11 - updated for clarity]

13. Ensure the dying person is supported to eat and drink if they are able and wish to do so. Professional guidance from the General Medical Council, Treatment and care towards the end of life: good practice in decision making, 2010, and the Nursing and Midwifery Council’s The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates, 2018, should be implemented. 

[NACEL 2018 Recommendation 13 - updated for clarity]

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

[New for NACEL 2019]

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

[New for NACEL 2019]
What's next?

NACEL has been commissioned by HQIP to run as an annual audit, initially for three years from 2017 to 2020. The NHS Benchmarking Network (NHSBN) is in discussion with HQIP regarding a contract extension to deliver a further two years of the audit.

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 findings from round one and round two of NACEL have been successful in identifying key priorities for improvements in care at the end of life in acute and community hospitals, and there is evidence that the findings from the first two rounds are actively being used. In order to disseminate the findings locally, the NHSBN team, together with the Co-Clinical Leads have spoken at conferences and workshops on the NACEL findings over the time period of the first two rounds.

The scope and content of NACEL round three is under discussion with HQIP, the funders of the audit, the NACEL Steering Group and Advisory Group following feedback from audit participants. At the time of publication NACEL round three has been postponed due to COVID-19. For further information please go to the [NACEL webpages](#).

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<th>Glossary</th>
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<tr>
<td><strong>Anticipatory prescribing</strong></td>
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<td>Medication prescribed in anticipation of symptoms, designed to enable rapid relief at whatever time the patient develops distressing symptoms.</td>
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<td><strong>Commissioners</strong></td>
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<td>Organisations who buy health on behalf of local populations</td>
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<td><strong>e-ELCA</strong></td>
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<td>The e-learning programme End of Life Care for All, Health Education England</td>
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<td><strong>‘Families and others’, ‘nominated person’, ‘next of kin’, ‘carer’, ‘bereaved person’</strong></td>
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<td><strong>HB</strong></td>
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<tr>
<td>Health Board (Wales) is an organisation delivering health care to patients in a geographical area.</td>
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<td><strong>HQIP</strong></td>
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<td>Healthcare Quality Improvement Partnership</td>
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<td><strong>Integrated Care System (ICS)</strong></td>
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<td>An ICS occurs when NHS organisations work together to meet the needs of their local population. Integrated care involves local authorities and the third sector in working towards these objectives alongside NHS organisations.</td>
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<td><strong>NACEL</strong></td>
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<tr>
<td>The National Audit of Care at the End of Life commissioned by HQIP from NHSBN</td>
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<td><strong>Specialist Palliative Care workforce</strong></td>
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<td>The SPC workforce provide specialist support and advice to patients who have been diagnosed with a life-limiting illness. Care is provided by a multi disciplinary team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support.</td>
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<tr>
<td><strong>Trust</strong></td>
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<tr>
<td>An NHS trust is an organisation delivering healthcare to patients in a geographical area.</td>
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