

National Audit of Care at the End of Life (NACEL) 2026 - acute and community inpatient sites

Case Note Review - data specification

Online data collection for Q4 will open on **Tuesday 20th January 2026**. Please see the table below for further data submission timelines.

Deaths to be audited	Data collection period
Q4: 1st January 2026 - 31st March 2026	20th January 2026 - 11th July 2026
Q1: 1st April 2026 - 30th June 2026	20th January 2020 - 11th July 2020
Q2: 1st July 2026 - 30th September 2026	1st July 2026 - 15th January 2027
Q3: 1st October 2026 - 31st December 2026	15t July 2020 - 15th January 2027

Data should be entered into the online data collection pages: www.nhsbenchmarking.nhs.uk

Participation is open to all Trusts/Health Boards in England, Wales and Jersey. A submission should have been created within the NACEL registration pages.

Acute and community hospitals should audit 20-70 consecutive deaths from the start of each quarter.

Please note:

- If you do not have the data to answer the question, please leave blank.
- Guidance notes to assist with the Case Note Review are available to download from the Network website.
- Clinical audit is a way to find out if healthcare is being provided in line with standards and lets care
 providers and patients know where their service is doing well and where there could be improvements.
 The aim is to allow quality improvement to take place where it will be most helpful and will improve
 outcomes for patients.
- We encourage you to liaise with the Audit Department and Business Intelligence Department in coordinating this submission with clinicians. Ask your organisation's Business Intelligence Department for support in identify.

Support:

 Definitions are provided, however, questions on interpretation of data items and any other queries can be submitted to: nhsbn.nacelsupport@nhs.net or telephone 0161 521 0866



Definitions of deaths to be included in NACEL Case Note Review

- **1.** Acute and community hospitals should audit 20-70 consecutive deaths from the start of each quarter.
- **2.** Data for Q4 and Q1 deaths should be submitted during 20th January 2026 11th July 2026. Data for Q2 and Q3 deaths should be submitted during 1st July 2026 15th January 2027.
- **3.** Separate submissions should be made for acute and community hospital sites. You will have defined these during the registration process.
- 4. Include only ADULT deaths i.e. if the patient was aged 18+ at the time of death.
- **5.** Include deaths in specialist palliative care beds that are fully managed and funded by the NHS. Hospices (NHS and non-NHS) are excluded.

Guidance for deaths to include - This is not an exclusive list (your organisation may code differently)		
Term		
Died in hospital		
Died in a community hospital		
Age 18+		

- 6. The Case Note Review will audit deaths which fall into the following two categories:
 - Category 1. It was expected that the patient would die during their final admission in hospital. Life sustaining treatments may still be being offered in parallel to end of life care.
 - Category 2. It was not expected that the patient would die during their final admission in hospital - 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.
- 7. The following exclusions apply for adult (18+) deaths occurring in a ward setting:
 - Deaths which are classed as "sudden deaths" are excluded from the Case Note Review. For the NACEL, this includes, but is not limited to, deaths which are sudden and unexpected and/or occur within 4 hours of admission.

Guidance for deaths to exclude, including paediatric deaths and sudden deaths - This is not an exclusive or exhaustive list (your organisation may code differently)	
Term	
Paediatric death (under 18's)	
Deaths within 4 hours of admission to hospital	
Sudden death/unexpected death:	



Sudden death (event)	
On examination - dead - sudden death (finding)	
Dead - sudden death (finding)	
Sudden cardiac death (disorder)	
Unexplained sudden death (event)	
Sudden death, cause unknown (event	
Unexpected sudden death of adult (event)	
Sudden cardiac death due to cardiac arrhythmia (disorder)	
Sudden unexpected death in epilepsy (finding)	
Died in accident and emergency department (finding)	
Suicide	
Maternal death:	
Maternal death	
Direct maternal death (event)	
Late maternal death (event)	
Sudden death of unknown cause during the puerperium (event)	
Deaths due to an acute condition caused by a sudden catastrophic event, with a full escalation of treatment plan in place. This would include, but not limited to:	
Died during operation (finding)	
Perioperative death	

It is recommended that you work with your organisation's Business Intelligence Unit for this submission, requesting support to identify the eligible patients to audit.

- **8.** Please note, deaths of people with a formal diagnosis of learning disability are to be <u>included</u> in NACEL 2026.
- **9.** The Case Note Review looks to audit the care delivered and documented during the final episode of care in the hospital, also referred as the "final admission".
- **10.** Throughout this Case Note Review, the term "nominated person(s)" has been used. This relates to the terminology "those identified as important to the dying person" as used in "One chance to get it right". This may not necessarily be the next of kin.



PATIENT CASE NOTE REVIEW CODE			
PATIENT DEMOGRAPHICS			
1. There a patient	are two categories of deaths for patients included in the are:	udit. Indica	te whether for this
during th	Category 1. It was expected that the patient would die during their final admission in hospital Category 2. It was not expected that the patient	on page 2. I	to the "Definition of deaths" information f this death is classed as "sudden", please t the case notes.
	would die during their final admission in hospital		
2. Was it recognised that the patient was sick enough to die during the final admission?[Answer for Cat 2 deaths only]Yes		Being 'sick enough to die' is when a patient is deteriorating, clinically unstable with limited reversibility and at the risk of dying during the episod of care despite treatment.	
	No		
3. Age (in	years, at the time of death)		
4. Ethnici	ty		
	A White: British		'National code Z - not stated' should
	B White: Irish		be used where the person had been
	C White: Any other White background		given the opportunity to state their ethnic category but chose not to.
	D Mixed: White and Black Caribbean		etimic category sur chose not to.
	E Mixed: White and Black African		
	F Mixed: White and Asian		
	G Mixed: Any other mixed background		
	H Asian or Asian British: Indian		
	J Asian or Asian British: Pakistani K Asian or Asian British: Bangladeshi		
	L Asian or Asian British: Any other Asian background		
П	M Black or Black British: Caribbean		
П	N Black or Black British: African		
П	P Black or Black British: Any other Black background		
П	R Other Ethnic Groups: Chinese		
	S Other Ethnic Groups: Any other ethnic group		
	Z Not stated		
П	Unknown		



5. What was the person's religion or faith? A Baha'i B Buddhist C Christian D Hindu E Jain F Jewish G Muslim H Pagan I Sikh J Zoroastrian K Other L None M Declines to Disclose N Patient Religion Unknown	
6. Did the person have a formal diagnosis of learning disability? ☐ Yes ☐ No	If the patient was formally known to the community and/or hospital Learning Disability
7. Did the person have a formal diagnosis of autism?	team, please answer "Yes".
☐ Yes ☐ No	
 8. Did the person have a recorded diagnosis of a severe mental illness, excluding dementia? Please consult the definition provided for severe mental illness Ves No No 9. What was the person's primary language spoken? English 	Definition: Severe mental illness is defined as debilitating illnesses that severely impair ability to engage in functional (e.g. managing everyday activities) and occupational activities for a prolonged or recurrent period. This includes: Schizophrenia Schizoaffective disorder Bipolar affective disorder Delusional disorder Severe depression
□ Welsh□ Polish	
RomanianPanjabiUrduPortugueseSpanish	A primary language (first/native language) is the language with which a person most frequently to communicates. These are languages we are usually born with, have a lot of exposure to, and use at home.
 Arabic Bengali Gujarati Italian Other Unknown 	



10. Is there documented evidence that the team accessed an interpreter or suitable alternative as needed for communication purposes with the patient?Yes	Answer N/A if the patient did not require an interpreter or suitable alternative e.g. the spoken language was the national primary language, or they were proficient in speaking English/Welsh.		
 □ N/A – The person did not need an interpreter or suitable alterna 	tive		
11. Is there documented evidence that the team accessed an interpret needed for communication purposes with those important to the dyi ☐ Yes			
 No N/A – Those important to the person did not need an interpreter or suitable alternative 	Answer N/A if those important to the patient did not require an interpreter or suitable alternative e.g. the spoken language was the national primary language, or they were proficient in speaking English/Welsh.		
Dates and times of final admission			
12. What was the date of the final presentation to the hospital? (DD/MM/YYYY)	The date of the patient's final presentation to the hospital in date, month and year DD/MM/YYYY. This may be through the Emergency Department, outpatient clinic/ward/ambulatory care or other		
13. What was the time of the final presentation to the hospital?? Time (HH:MM)	The time of the patient's final presentation to the hospital in date, month and year DD/MM/YYYY. This may be through the Emergency Department,		
	outpatient clinic/ward/ambulatory care or other		
14. What was the date of the final admission? (DD/MM/YYYY)	The date of the patient's final admission to this hospital prior to death expressed in date, month and year DD/MM/YYYY. Admission = arrival on ward. If the patient was admitted directly to the ward, please enter the same date/time as final presentation to the hospital (Q12 - Q13).		
15. What was the time of the final admission? Time (HH:MM)	The time of the patient's final admission to this hospital prior to death expressed in hours and minutes HH:MM. Admission = arrival on ward. If the patient was admitted directly to the ward, please enter the same date/time as final presentation to the hospital (Q12 - Q13).		



16. What was the date of the first documented evidence that the patient would die during their final admission in hospital? [Answer for Cat 1 deaths only] (DD/MM/YYYY)	This should be the date/time during the final spell of care in the hospital that it was first recorded the patient had been recognised as dying. If the patient was recognised as dying prior to presentation at the hospital, include the same time and date as the final presentation to the hospital (Q12 - Q13). This should only be answered for Category 1 deaths.
17. What was the time of the first documented evidence that the patient would die during their final admission in hospital? [Answer for Cat 1 deaths only]	This refers to recognition of dying anywhere in the hospital, including recognition within the Emergency Department.
(HH:MM)	
18. What was the date of death? (DD/MM/YYYY)	
19. What was the time of death? (HH:MM)	
<u>Plan and do</u>	
Timely review of the dying patient	
 20. Is there documented evidence that the patient was reviewed by a magnetic palliative care team/end of life care team during their final admission team advised on the care of/reviewed the patient. Yes - face to face review Yes - telephone review No 	•
21. What was the date of referral to the specialist palliative care/end of life care team? (DD/MM/YYYY)	This refers to the date/time a request was made to the specialist palliative care/end of life care team regarding patient care. If multiple referrals were made to the team, please submit the first date/time.
22. What was the time of referral to the specialist palliative care/end of life care team?	Please leave this question blank if a referral to the Specialist Palliative Care Team was not made during the final admission.
(HH:MM)	



23. What was the date of review by the specialist palliative care/end of care team? (DD/MM/YYYY)	care/end of life care team first advised on the care of the patient or reviewed the patient via telephone or face to face. This can include
24. What was the time of review by the specialist palliative care/end of care team?	a review of the notes & providing advice to ward staff. If there were multiple reviews, please submit the first date/time.
(HH:MM)	
Individualised management of symptoms	<u>s</u>
Pain	
 25. Is there documented evidence of a review of the patient's pain? Yes – daily Yes – every 2-3 days Yes – weekly or less frequent No 	
 26. Is there documented evidence that actions to address pain were implemented? Yes – all actions implemented Yes – partially implemented No – reason recorded why not 	'Partial' - Not all recommendations actioned. 'Reason recorded why not' may include the patient declining the symptom control medication offered or another reason recorded.
 No − reason recorded why not No − no reason recorded No − actions not required 	
Agitation/delirium	
 27. Is there documented evidence of a review of the patient's agitation Yes – daily Yes – every 2-3 days Yes - weekly or less frequent No 	n/delirium?
 28. Is there documented evidence that actions to address agitation/delle Yes – all actions implemented Yes – partially implemented No – reason recorded why not No – no reason recorded No – actions not required 	lirium were implemented?



Dyspnoea/breathing difficulty

29. Is	s there documented evidence of a review of the patient's dyspnoea/b	reathing difficulty?
	Yes – daily	
	Yes – every 2-3 days	
	Yes - weekly or less frequent	
	No	
	s there documented evidence that actions to address dyspnoea/breatolemented?	thing difficulty were
	Yes – all actions implemented	
	Yes – partially implemented	
	No – reason recorded why not	
П	No – no reason recorded	
	No – actions not required	
Hydr	ation	
	there documented evidence of review of hydration options in the days of life, including drinking if able?	See pages 15/16 for full details of reviews of hydration options
	Yes – daily	
	Yes – every 2-3 days	
	Yes – weekly or less frequent	
	No	
	there documented evidence of communication about hydration h those important to the dying person?	Partial communication: Aspects of comprehensive communication missing e.g. Explanation or interventions or management
	Yes - comprehensive communication	plan
	Yes - partial communication	'Reason recorded why not' may include
	No - reason recorded why not	attempts to contact the nominated person(s) were unsuccessful/no nominated person(s),
	No - no reason recorded	patient had not consented for these

discussions to take place with the nominated person(s), Independent Mental Capacity Adviser (IMCA) unavailable or another reason

recorded.



Determine appropriate interventions

prescribed for symptoms likely to occur in the last days of life? Yes, anticipatory medicines prescribed but not used Yes, anticipatory medicines prescribed and administered No N/A	Clinical judgement required to answer this question. 'Clinical judgement is required to answer this question. This question does not place an expectation that a certain amount of anticipatory medication was prescribed (e.g. use of 4 main drugs), nor that patients not recognised as dying would have anticipatory medication prescribed for symptoms likely to occur in the last days of life. If a patient was a Category 2 death and anticipatory medication is not present, please answer "No". For full details see page 16
Actions to meet the holistic needs of the dying person	
Spiritual/religious/cultural	
34. Is there documented evidence of an assessment of the spiritual/religious/cultural needs of the patient? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded	Spiritual/religious/cultural needs may not be present during the initial assessment but may emerge over time. 'Reason recorded why not' may include patient was semi-conscious or unconscious, patient lacked capacity to understand, patient had asked not to be involved in this discussion or another reason recorded. For full details see pages 16/17
spiritual/religious/cultural needs of the patient? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded	
Communicate & involve	

Personalised care and support planning

No

36. Is there documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs? [Answer for Cat 1 deaths only]
Yes - documented in IPC template
Yes - documented in notes

'Please respond 'Yes' if a plan of care personalised to the individual was used which covered their specific end of life care needs such as food and drink, symptom control, psychological, social and spiritual support.

'Yes - documented in IPC template' refers to a document currently utilised locally to capture all individualised end of life care needs of the dying person.

'Yes - documented in notes' refers to a plan of care found in general clinical, nursing and therapy care plans.



37. Is there documented evidence that the patient participated in perplanning (advance care planning) conversations? ☐ Yes	ersonalised care and support	
□ No 38. When did the patient participate in these conversations? [Answer if 'Yes' to Q37]	Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and wellbeing within the context of their whole life and family situation.	
 Prior to admission and available to inpatient team Prior to admission but not available to inpatient team During admission Prior and during admission 		
Recognising the possibility of imminent death		
39. Is there documented evidence that the likelihood of dying was di	scussed with the patient?	
 Yes No - reason recorded why not No - no reason recorded 	Answer 'Yes' if there is any record within the case note by ANY health professional to indicate that a conversation took place with the patient regarding the likelihood of dying. Discussion includes receiving information, asking questions and receiving answers.	
40. Is there documented evidence that the likelihood that the patient may die had been discussed with the nominated person(s)?		
☐ Yes☐ No - reason recorded why not☐ No - no reason recorded	Answer 'Yes' if there is any record within the case note by ANY health professional to indicate that a conversation took place with the nominated person(s) regarding recognition of the patient dying. Discussion includes receiving information, asking questions and receiving answers	



DEFINITIONS

QUESTION NUMBER	DEFINITION
1	Please refer to the "Definition of deaths" information. If this death is classed as "sudden", please do not audit the case notes.
	This refers to explicit documentation that the patient was dying during this final admission in hospital. An expected death can be expected at any point during the final admission (including on admission or after admission). This question is looking to capture whether during the final admission it was expected and recognised that the patient would die during the final admission. In other terms, was it identified that the patient was dying at any time between their final admission to hospital and the verification of their death.
	An example, if it is documented in the notes that the patient was expected to die during the final admission in hospital and then died 10 minutes later, this death should be categorised as a Category 1 death. A review of the timeliness of recognition will be conducted using the findings from Q16 & 17.
	Documentation might look like: "Patient now dying", "Patient in the last hours to days of life".
	Please note, NACEL understand that it is not always possible to know when a patient is dying. Category 2 death doesn't necessarily equate to bad care.
2	Being 'sick enough to die' is when a patient is deteriorating, clinically unstable with limited reversibility and at the risk of dying during the episode of care despite treatment.
	This does not classify as the recognition of imminent death but is a significant point in the patient's journey.
	Not all patients will have this. For some, it may happen hours prior to the actual recognition of dying, to consider what the patient or family want i.e. full active treatment or more time for discussions about end of life care.
	This might look like the patient was recognised as being at risk of dying and unlikely to recover, with poor outcomes expected, even though imminent death was not made explicit.
3	In years
4	This should be recorded in the case notes or on the Patient Information System.
	The answer options are the National Ethnic Category Codes as per the NHS Data dictionary.
	National code Z - not stated should be used where the person had been given the opportunity to state their ethnic category but chose not to
5	Drop down options have been taken from the NHS codes: https://www.datadictionary.nhs.uk/attributes/religious or other belief system affiliatio
	n group code.html#attribute religious or other belief system affiliation group code. national codes



6	If the patient was formally known to the community and/or hospital Learning Disability team, please answer "Yes".
8	Definition: Severe mental illness is defined as debilitating illnesses that severely impair ability to engage in functional (e.g. managing everyday activities) and occupational activities for a prolonged or recurrent period. This includes: Schizophrenia Schizoaffective disorder Bipolar affective disorder Delusional disorder Severe depression
9	Definition: Severe mental illness is defined as debilitating illnesses that severely impair ability to engage in functional (e.g. managing everyday activities) and occupational activities for a prolonged or recurrent period. This includes: Schizophrenia Schizoaffective disorder Bipolar affective disorder Delusional disorder Severe depression
10	National primary language: e.g. English in England, Welsh (official language) and English in Wales. This question includes whether a British Sign Language (BSL) interpreter was accessed to translate sign language into spoken English for hearing people, and translate spoken English into British Sign Language for deaf people. Answer N/A if the patient did not require an interpreter or suitable alternative e.g. the spoken language was the national primary language, or they were proficient in speaking English/Welsh.
11	National primary language: e.g. English in England, Welsh (official language) and English in Wales. This question includes whether a British Sign Language (BSL) interpreter was accessed to translate sign language into spoken English for hearing people, and translate spoken English into British Sign Language for deaf people. Answer N/A if the patient did not require an interpreter or suitable alternative e.g. the spoken language was the national primary language, or they were proficient in speaking English/Welsh.



12	The date of the patient's final presentation to the hospital in date, month and year DD/MM/YYYY.
	This may be through the Emergency Department, outpatient clinic/ward/ambulatory care or other route.
13	The time of the patient's final presentation to the hospital in hours and minutes HH:MM.
13	This may be through the Emergency Department, outpatient clinic/ward/ambulatory care
	or other route.
44	
14	The date of the patient's final admission to this hospital prior to death expressed in date,
	month and year DD/MM/YYYY. Admission = arrival on ward. If the patient was admitted
	directly to the ward, please enter the same date/time as final presentation to the hospital
	(Q12 - Q13).
	It is recommended that you liaise with your Business Intelligence Department to complete
	the date/time questions. They should be able to produce a list that includes admission date
	and time from the EPR.
15	The time of the patient's final admission to hospital prior to death expressed in hours and
	minutes HH:MM. Admission = arrival on ward. If the patient was admitted directly to the
	ward, please enter the same date/time as final presentation to the hospital (Q12 - Q13).
	It is recommended that you liaise with your Business Intelligence Department to complete
	the date/time questions. They should be able to produce a list that includes admission date
	and time from the EPR.
16	Indicate the date using the following format DD/MM/YYYY.
	This should be the date during the final spell of care in the hospital that it was first recorded
	the patient had been recognised as dying. If the patient was recognised as dying prior to
	presentation at the hospital, include the same time and date as the final presentation to
	the hospital (Q12 - Q13). This should only be answered for Category 1 deaths.
	This refers to recognition of dying anywhere in the hospital, including recognition within
	the Emergency Department.
17	Indicate the time using the following format HH:MM.
	This should be the time during the final spell of care in the hospital that it was first recorded
	the patient had been recognised as dying. If the patient was recognised as dying prior to
	presentation at the hospital, include the same time and date as the final presentation to
	the hospital (Q12 - Q13). This should only be answered for Category 1 deaths.
	the hospital (Q12 Q15). This should only be answered for category 1 deaths.
	This refers to recognition of dying anywhere in the hospital, including recognition within
	the Emergency Department.
18	The date of the patient's death expressed in date, month and year DD/MM/YYYY.
19	The time of the patient's death expressed in hours and minutes HH:MM



The Specialist Palliative Care team will deliver assessment, advice and care for people with progressive, life-limiting illness who have complex or complicated palliative care needs, and those people who are important to them. The care may be provided by physicians in palliative medicine or other suitably trained practitioners, such as clinical nurse specialists in palliative care. Social workers, occupational therapists, physiotherapists and other therapists may also have specialist training and skills in palliative care through a formal post-graduate qualification. Definition of reviewed: This refers to whether the SPCT/EoLC team have advised on the care of the patient or reviewed the patient via telephone or face to face. This can include
a review of the notes & providing advice to ward staff. If the SPC/EOL team interacted only with the family and not the patient, please select "No."
This refers to the date/time a request was made to the specialist palliative care/end of life care team regarding patient care. If multiple referrals were made to the team, please submit the first date/time. The purpose of this question is to evidence timely escalation to the specialist palliative care/end of life care team, if the ward team were unable to address a dying person's needs.
Please leave this question blank if a referral to the Specialist Palliative Care Team was not made during the final admission.
This refers to the date/time a request was made to the specialist palliative care/end of life care team regarding patient care. If multiple referrals were made to the team, please submit the first date/time.
The purpose of this question is to evidence timely escalation to the specialist palliative care/end of life care team, if the ward team were unable to address a dying person's needs. Please leave this question blank if a referral to the Specialist Palliative Care Team was not
made during the final admission.
Definition of reviewed: This refers to when the specialist palliative care/end of life care team first advised on the care of the patient or reviewed the patient via telephone or face to face. This can include a review of the notes & providing advice to ward staff. If there were multiple reviews, please submit the first date/time.
The purpose of this question is to evidence timely response from specialist palliative care/end of life care team if the ward team were unable to address a dying person's needs.
Definition of reviewed: This refers to when the specialist palliative care/end of life care team first advised on the care of the patient or reviewed the patient via telephone or face to face. This can include a review of the notes & providing advice to ward staff. If there were multiple reviews, please submit the first date/time.
The purpose of this question is to evidence timely response from specialist palliative care/end of life care team if the ward team were unable to address a dying person's needs.
Partial - Not all recommendations actioned.
'Reason recorded why not' may include the patient declining the symptom control medication offered or another reason recorded.



20	Partial Not all recommendations actioned
28	Partial - Not all recommendations actioned.
	'Reason recorded why not' may include the patient declining the symptom control
	medication offered or another reason recorded.
30	Partial - Not all recommendations actioned.
	'Reason recorded why not' may include the patient declining the symptom control
24	medication offered or another reason recorded.
31	Review can include: Examination of the patient's mouth, difficulty swallowing, need for additional help with drinking, observation of discomfort arising from diminished drinking/dehydration, plan to start clinically assisted hydration, observation of problems with fluid overload, responding to questions and concerns raised by patient or their family.
	The document One Chance to Get It Right page 25 has a full description of a hydration plan. Please use clinical judgment. For example, it may be that an active plan of care which includes fluids could be considered as evidence of a hydration review.
32	Comprehensive communication: Explanation of assessment and examination of hydration status (including oral hydration) to those important to the dying person leading to a discussion of appropriate interventions and an agreed management plan. Partial communication: Aspects of comprehensive communication missing e.g. Explanation or interventions or management plan
	'Reason recorded why not' may include attempts to contact the nominated person(s) were
	unsuccessful/no nominated person(s), patient had not consented for these discussions to
	take place with the nominated person(s), Independent Mental Capacity Adviser (IMCA)
33	unavailable or another reason recorded. Clinical judgement is required to answer this question. This question does not place an
33	expectation that a certain amount of anticipatory medication was prescribed (e.g. use of 4 main drugs), nor that patients not recognised as dying would have anticipatory medication prescribed for symptoms likely to occur in the last days of life. If a patient was a Category 2 death and anticipatory medication is not present, please answer "No".
	NICE QS144/3: "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."
	Anticipatory medication may also be referred to as 'just in case medication'.
	Medication prescribed in anticipation of symptoms are designed to enable rapid relief at whatever time the patient develops distressing symptoms. Drugs prescribed in anticipation may include previous or current prescriptions, sometimes with a change in the route of administration, and newly prescribed drugs for anticipated new symptoms.
	N/A should be selected for patients in the HDU/ICU setting where symptoms are managed at the end of life by existing IV infusions.
	Some Trusts/Health Boards will prescribe in a bundle, others will do it individually. Common anticipatory medicines include the following:



Medicine for pain – an appropriate opioid, for example, morphine, diamorphine, oxycodone or alfentanil.

Medicine for breathlessness - midazolam or an opioid.

Medicine for anxiety – midazolam.

Medicine for delirium or agitation – haloperidol, levomepromazine, midazolam or phenobarbital.

Medicine for nausea and vomiting – cyclizine, metoclopramide, haloperidol or levomepromazine.

Medicine for noisy chest secretions – hyoscine hydrobromide or glycopyrronium. Guidance taken from the Marie Curie Palliative Care Knowledge Zone: Anticipatory medications at the end of life, July 2022:

https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/anticipatory-medicines

Spiritual/religious/cultural needs may not be present during the initial assessment but may emerge over time.

'Reason recorded why not' may include patient was semi-conscious or unconscious, patient lacked capacity to understand, patient had asked not to be involved in this discussion or another reason recorded.

The person's spiritual needs will be individual to them, and may include questions about meaning, faith and belief. These needs should be addressed and respected as much as the medical aspects of care. Personal or religious objects, symbols or rituals (including prayer or readings) may be used.

The person's cultural needs should be acknowledged and respected. Cultural needs can be influenced by a range of factors, for example, where the person lives, their gender and their language.

Please note, this information may be located within nursing assessments or chaplain notes.

Spiritual/religious/cultural needs may not be present during the initial assessment but may emerge over time.

'Reason recorded why not' may include attempts to contact the nominated person(s) were unsuccessful/no nominated person(s), patient had not consented for these discussions to take place with the nominated person(s), Independent Mental Capacity Adviser (IMCA) unavailable or another reason recorded.

The person's spiritual needs will be individual to them, and may include questions about meaning, faith and belief. These needs should be addressed and respected as much as the medical aspects of care. Personal or religious objects, symbols or rituals (including prayer or readings) may be used.

The person's cultural needs should be acknowledged and respected. Cultural needs can be influenced by a range of factors, for example, where the person lives, their gender and their language.

Please note, this information may be located within nursing assessments or chaplain notes.

35



36	Please respond 'Yes' if a plan of care personalised to the individual was used which covered their specific end of life care needs such as food and drink, symptom control, psychological, social and spiritual support.
	'Yes - documented in IPC template' refers to a document currently utilised locally to capture all individualised end of life care needs of the dying person. 'Yes - documented in notes' refers to a plan of care found in general clinical, nursing and therapy care plans.
	For instances where an individualised plan of care was documented in both the notes and the IPC, select the location where it was most predominant.
	One Chance to Get it Right - Priority 5: "An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion."
	NG31 - 1.36: "Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multiprofessional care team".
37	Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. https://www.england.nhs.uk/personalisedcare/pcsp/
38	Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. https://www.england.nhs.uk/personalisedcare/pcsp/
39	Answer 'Yes' if there is any record within the case note by ANY health professional to indicate that a conversation took place with the patient regarding the likelihood of dying. Discussion includes receiving information, asking questions and receiving answers.
	'Reason recorded why not' may include patient was semi-conscious or unconscious, patient lacked capacity to understand, patient had asked not to be involved in this discussion or another reason recorded.
40	Answer 'Yes' if there is any record within the case note by ANY health professional to indicate that a conversation took place with the nominated person(s) regarding recognition of the patient dying. Discussion includes receiving information, asking questions and receiving answers.
	'Reason recorded why not' may include attempts to contact the nominated person(s) were unsuccessful/no nominated person(s), patient had not consented for these discussions to take place with the nominated person(s), Independent Mental Capacity Adviser (IMCA) unavailable or another reason recorded.