

National Audit of Care at the End of Life (NACEL) 2025 Mental Health Spotlight Audit Case Note Review - data specification

Online data collection will open on **Monday 20th January 2025** and will close on **Friday 16th January 2026.**

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

Participation is open to all mental health inpatient providers in England, Wales and Jersey. A submission should have been created within the NACEL 2025 Mental Health Spotlight Audit registration pages.

Definitions of deaths to be included in NACEL Case Note Review

- Mental Health Hospitals should audit every death within the inclusion criteria from 1st January 2025 - 31st December 2025.
- 2. Include only ADULT deaths i.e. if the patient was aged 18+ at the time of death. The deaths must have occurred in an inpatient bed.
- 3. Trusts who deliver services in the three high-security psychiatric hospitals should include deaths of patients in line with the categories and exclusions below.
- 4. The Case Note Review will audit deaths which fall into the following two categories:
 - a. Category 1. It was expected that the patient would die during their final admission in hospital 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. Example: a patient on a mental health ward had been recognised by the MDT as being likely to die within hours to days, and a referral may have been made to the local palliative care service. Relatives may have been contacted, and anticipatory medicines may have been prescribed as required for terminal symptoms.
 - b. 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. Example: a patient was known to have heart disease, COPD or cancer which needed ongoing medical review. The physical health care plan may be up to date. Discussions about end of life care will not have occurred with the patient or relatives and palliative care services were not involved in their care. In accordance with Trust/UHB policy, the police and coroner were required to be informed of the death.
- 5. 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, the following:

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

IMPORTANT: This document is provided to support data collation only and CANNOT be used to submit data. All data must be submitted via online data collection at: www.nhsbenchmarking.nhs.uk



- Suicides
- Maternal deaths occurring in a Mother and baby unit
- 6. 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.

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.
- Definitions, if necessary, can be found next to each question in a green box. More comprehensive definitions can be found in the table of definitions on pages 15 to 21.
- An Excel version of the Case Note Review data specification available to download from the NACEL portal: https://www.nacel.nhs.uk/mental-health-spotlight
- 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.

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.



PATIENT DEMOGRAPHICS 1. There are two categories of deaths for patients included in the audit. Indicate whether for this patient: 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 would die during their final admission in hospital Category 2. It was not expected that the patient would die during their final admission in hospital Was it recognised that the patient was sick enough to die during the final admission? Assert for Cat 2 deaths only	РА	TIENT	CASE NOTE REVIEW CODE		
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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 See page 15 for 'sick enough to die' definition 3. Age (in years, at the time of death)				information on pa	ge 1. If this death is classed as
[Answer for Cat 2 deaths only]					
No Renough to die' definition	2.		·	ng the final admis	sion?
4. Ethnicity A White: British B White: Irish C White: Any other White background Mixed: White and Black Caribbean F Mixed: White and Black African Mixed: White and Asian Mixed: Any other mixed background H Asian or Asian British: Indian J Asian or Asian British: Pakistani K Asian or Asian British: Any other Asian background M Black or Black British: Caribbean N Black or Black British: Any other Black background R Other Ethnic Groups: Chinese S Other Ethnic Groups: Any other ethnic group Z Not stated		_			See page 15 for 'sick enough to die' definition.
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□ S Other Ethnic Groups: Any other ethnic group□ Z Not stated		_	•		
☐ Z Not stated			·		



5.	What was the person's religion or faith?		
	☐ A Baha'l		
	☐ 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 dis	sahility?	
0.	☐ Yes	sability.	If the patient was formally known to the
	□ No		community and/or hospital Learning Disabilit
			team, please answer "Yes".
7.	Did the person have a formal diagnosis of autism?		
	□ Yes		
	□ No		
	_ ···•		
8.	Did the person have a recorded diagnosis of a severe n	nental illne	ess, excluding dementia? Please
	consult the definition provided for severe mental illnes		_
	□ Yes		
	□ No		
9.	What was the person's primary language spoken?		
	☐ English		
	□ Welsh	Α	primary language is the language with which a
	□ Polish	pe	erson uses most frequently to communicate with.
	☐ Romanian	Th	nis is often the person's first language or native
	□ Panjabi		nguage. The person is likely to have a lot of
	□ Urdu	ex	sposure to this language and use at home.
	□ Portuguese		
	□ Spanish		
	□ Arabic		
	□ Bengali		
	☐ Gujarati		
	□ Italian		
	□ Other		
	☐ Unknown		
	U UTIKITUWII		



10.		there documented evidence that the team accessed an interpreter or suitable alternative as				
		eded for communication purposes with the patient?	Answer N/A if the patient did not require an interpreter or suitable alternative e.g.			
		Yes	the spoken language was the national			
		No N/A	primary language, or they were proficient			
	Ш	N/A	in speaking English/Welsh.			
11.		here documented evidence that the team accessed an interprete				
	nee	eded for communication purposes with those important to the dy	ving person?			
		Yes	Answer N/A if those important to the			
		No	patient did not require an interpreter or			
		N/A	suitable alternative e.g. the spoken language was the national primary			
			language, or they were proficient in			
			speaking English/Welsh.			
12 \	Mhai	t was the primary cause of death?				
12. \		Cancer	This is to be tall on form the death			
		Chronic respiratory disease	This is to be taken from the death certificate. Further definition on page 16.			
		Dementia	certificate. Further definition on page 10.			
		Heart failure				
		Neurological conditions (such as motor neurone disease)				
		Pneumonia				
		Renal failure				
		Stroke				
		Other				
		No access to death certificate				
13. \	Nha	t type of ward was the patient in when they died?				
		Mental Health Adult acute				
		Mental Health PICU				
		Mental Health Eating Disorders				
		Mental Health Low Secure				
		Mental Health Medium Secure				
		Mental Health High Secure				
		Mental Health Older Adult Functional				
		Mental Health Older Adult Organic/Dementia				
		Mental Health Other Older Adult				
		Mental Health High Dependency Rehabilitation				
		Mental Health Longer Term Complex/Continuing Care				
		Mental Health Neuropsychiatry / Acquired Brain Injury				
		Other Mental Health Beds				



Did the patient have contact with any of the following services during their last admission: 14. District Nurses Yes No 15. Community Physical Health Clinical Services Include AHPs. AHPs might include Occupational Yes Therapists, Physiotherapists, Speech & Language No Therapists and Dieticians. 16. General Practitioner П Yes П No 17. Chaplain staff Yes No 18. Accident and Emergency Department (A&E) Yes No 19. At some point during the final admission, was the patient on a section of the Mental Health Act (1983)? ☐ Yes - in place prior to death ☐ Yes - in place during death No 20. Did the person experience seclusion during the final admission? ☐ Yes - prior to death Seclusion refers to the supervised confinement ☐ Yes - during death and isolation of a patient way from other □ No patients in an area from which the patient is prevented from leaving.



Dates and times of final admission

21	What was the date of the final admission? (DD/MM/YYYY)		
		produce a	n to sites: Information services can I list that includes admission date from patient information system.
22.	What was the time of the final admission? (HH:MM)		
23.	What was the date of the first documented evidence of the reco	ognition	
	that the patient might die within the next few days and hours? (DD/MM/YYYY) [Answer for Cat 1 deaths only]		See page 16 for 'recognition that the patient might die' definition.
24.	What was the time of the first documented evidence of the recodie within the next few days and hours? (HH:MM) [Answer for Commonwealth of the first documented evidence of the recoding within the next few days and hours?	-	
25.	What was the date of death? (DD/MM/YYYY)		
26.	What was the time of death? (HH:MM)		
	N AND DO ely review of the dying patient		
	s there documented evidence that the patient was reviewed by a palliative care team during their final admission?	ı member o	of the specialist
	☐ Yes ☐ No		For further guidance see page 16.
28.	What was the date of referral to the specialist palliative care tea	am? <i>(DD/M</i>	M/YYYY)
			For further guidance see page 16.
29.	What was the time of referral to the specialist palliative care tea	am? <i>(HH:M</i>	M)
			For further guidance see page 17.



30	. What was the date of review by the specialist palliative care team? ((DD/MM/YYYY)
Only answer f 'Yes' to Q27		For further guidance see page 17.
31	What was the time of review by the specialist palliative care team? ((нн:мм)
Only answer f 'Yes' to Q27		For further guidance see page 17.
<u>IN</u>	DIVIDUALISED MANAGEMENT OF SYMPTOMS	
Pa	in	
	 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 	
Only answer f 'Yes' to Q32	 Is there documented evidence that actions to address pain were imple Yes - all actions implemented Yes - partially implemented No - reason recorded why not No - no reason recorded No - actions not required 	Partial - Not all recommendations actioned. 'Reason recorded why not' may include the patient declining the symptom control medication offered or another reason recorded.
_	 is there documented evidence of a review of the patient's agitation/d Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No 	elirium?
35	 Is there documented evidence that actions to address agitation/deliring Yes - all actions implemented 	um were implemented?
Only answer f 'Yes' to Q34	Yes - all actions implemented Yes - partially implemented No - reason recorded why not No - no reason recorded No - actions not required	Partial - Not all recommendations actioned. 'Reason recorded why not' may include the patient declining the symptom control medication offered or another reason recorded.

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Dyspnoea/ breathing difficulty

30.	Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No	breatii	ng uniculty:
37.	ere documented evidence that actions to address dyspnoea/brea	nthing d	lifficulty were
nly answer 'Yes' to Q36	Yes - all actions implemented Yes - partially implemented No - reason recorded why not No - no reason recorded No - actions not required	actional 'Reaso the pa	n recorded why not' may include tient declining the symptom control ation offered or another reason
	nere documented evidence of review of hydration options in the laing if able?	ast days	s of life, including
39.	Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No ere documented evidence of communication about hydration with Yes - comprehensive communication	th the p	For further guidance see page 17.
	Yes - partial communication No - reason recorded why not No - no reason recorded		For further guidance see page 17.
40.	ere documented evidence of communication about hydration with person? Yes - comprehensive communication Yes - partial communication No - reason recorded why not No - no reason recorded	th those	e important to the For further guidance see page 18.



DETERMINE APPROPRIATE INTERVENTIONS

41. Is there documented evidence that anticipatory medication was prescribed fo to occur in the last days of life?				for symptoms likely
		Yes, anticipatory medicines prescribed but not use Yes, anticipatory medicines prescribed and admini No N/A		For further guidance see page 18.
4		ere documented evidence that the prescribed antici the patient?	patory medication v	vas individualised
Only answer		Yes, for all medications prescribed		For further guidance see page 18.
if 'Yes' to Q41		Yes, for some medications prescribed No		
4	3. Is the	ere documented evidence of active decision making changing interventions as appropriate?	regarding: reviewin	g, starting, stopping
		Yes - active decision making demonstrated for mo	st interventions	For further guidance see page 18.
		Yes - active decision making demonstrated for son	ne interventions	, , ,
		No		
<u>A</u>	CTIONS	TO MEET THE HOLISTIC NEEDS OF THE DYING PER	SON	
_		TO MEET THE HOLISTIC NEEDS OF THE DYING PER	<u>SON</u>	
E	motion 4. Is the	al/ psychological ere documented evidence of an assessment of the e		gical needs of the
E	motion	al/ psychological ere documented evidence of an assessment of the e	motional/psycholog Emotional/psycholog	gical needs may not be present
E	motion 4. Is the	al/ psychological ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days	motional/psycholog Emotional/psycholog during the initial ass	gical needs may not be present sessment but may emerge over time.
E	4. Is the patie	al/ psychological ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent	motional/psycholog Emotional/psycholog during the initial ass	gical needs may not be present ressment but may emerge over time. hy not' may include patient was
E	4. Is the patie	ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded wl semi-conscious or un	gical needs may not be present sessment but may emerge over time.
E	4. Is the patie	al/ psychological ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded while the semi-conscious or understand, patie	gical needs may not be present sessment but may emerge over time. hy not' may include patient was nconscious, patient lacked capacity
E 4	4. Is the patie	ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded will semi-conscious or un to understand, patie this discussion, or an	gical needs may not be present ressment but may emerge over time. Thy not' may include patient was neconscious, patient lacked capacity ent had asked not to be involved in nother reason recorded.
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E 4 Only answer	4. Is the patie	ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded ere documented evidence that staff addressed the eart? Yes - all fulfilled Yes - partially fulfilled	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded whisemi-conscious or unto understand, patie this discussion, or an emotional/psycholog 'N/A' refers to theme	gical needs may not be present ressment but may emerge over time. Thy not' may include patient was inconscious, patient lacked capacity and had asked not to be involved in nother reason recorded.
E 4	4. Is the patie	ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded ere documented evidence that staff addressed the eart? Yes - all fulfilled Yes - partially fulfilled No - reason recorded why not	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded whisemi-conscious or unto understand, patie this discussion, or an emotional/psycholog 'N/A' refers to theme	gical needs may not be present ressment but may emerge over time. Thy not' may include patient was inconscious, patient lacked capacity ent had asked not to be involved in nother reason recorded. Gical needs of the
E 4 Only answer	4. Is the patie	ere documented evidence of an assessment of the eart? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded ere documented evidence that staff addressed the eart? Yes - all fulfilled Yes - partially fulfilled	motional/psycholog Emotional/psycholog during the initial ass 'Reason recorded whisemi-conscious or un to understand, patie this discussion, or an emotional/psycholog 'N/A' refers to there needs to address, for	gical needs may not be present ressment but may emerge over time. Thy not' may include patient was inconscious, patient lacked capacity ent had asked not to be involved in nother reason recorded. Gical needs of the



Spiritual/religious/cultural

40.		ere documented evidence of an assessment of the sp	iritual/religious/cultural fleeds of the
	patie		Spiritual/religious/cultural needs may not be present
		Yes - every 2-3 days	during the initial assessment but may emerge over
		Yes - weekly or less frequent	time.
		No - reason recorded why not	
		No - no reason recorded	'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 further guidance see page 19.
47.	Is the	ere documented evidence that staff addressed the spont?	oiritual/religious/cultural needs of the
		Yes - all fulfilled	'N/A' refers to there being no spiritual/religious/
nly answer		Yes - partially fulfilled	'N/A' refers to there being no spiritual/ religious/ cultural needs to address, following assessment. For
'Yes' to Q46		No - reason recorded why not	further guidance see page 19.
		No - no reason recorded	, , , ,
		N/A - No spiritual/religious/cultural needs to address	
		d practical ere documented evidence of an assessment of the so Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not	cial and practical needs of the patient? Social and practical needs may not be present during the initial assessment but may emerge over time. 'Reason recorded why not' may include patient was
		No - no reason recorded	semi-conscious or unconscious, patient lacked capacity to understand, patient had asked not to be involved in this discussion, or another reason recorded. For further guidance see page 19.
49.	. Is the	ere documented evidence that staff addressed the so Yes - all fulfilled	cial and practical needs of the patient?
nly answer		Yes - partially fulfilled	'N/A' refers to there being no social or practical needs
Yes' to Q48		No - reason recorded why not	to address, following assessment. For further guidance
		No - no reason recorded	see page 19.
		N/A - No social and practical needs to address	



ACTIONS TO MEET THE NEEDS OF THOSE IMPORTANT TO THE DYING PERSON

Emotional/ psychological

50.	. Is there documented evidence of an assessment of	the emotional/psychological needs of those
	important to the dying person? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded	Emotional/psychological 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), "declined", Independent Mental Capacity Adviser (IMCA) unavailable or another reason recorded.
51.	. Is there documented evidence that staff addressed important to the dying person?	I the emotional/psychological needs of those
only answer 'Yes' to Q50	 Yes - all fulfilled Yes - partially fulfilled No - reason recorded why not 	'N/A' refers to there being no emotional/psychological needs to address, following assessment.
Spi	 □ No - no reason recorded □ N/A - No emotional/psychological needs to a 	address
52.	. Is there documented evidence of an assessment of	the spiritual/religious/cultural needs of those
	important to the dying person? 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 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), "declined", Independent Mental Capacity Adviser (IMCA) unavailable or another reason recorded. For further guidance see page 20.
53.	. Is there documented evidence that staff addressed important to the dying person?	I the spiritual/religious/cultural needs of those
	Yes - all fulfilledYes - partially fulfilled	'N/A' refers to there being no spiritual/ religious/ cultural needs to address, following assessment. For further
ly answer Yes' to Q52	No - reason recorded why notNo - no reason recorded	guidance see page 20.



Social and practical

	s there documented evidence of an assessment o	of the social and practical needs of those			
i	mportant to the dying person? Yes - daily Yes - every 2-3 days Yes - weekly or less frequent No - reason recorded why not No - no reason recorded	Social and practical 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), "declined", Independent Mental Capacity Adviser (IMCA) unavailable or another reason recorded. For further guidance see page 20.			
	s there documented evidence that staff addresse the dying person?	ed the social/practical needs of those important			
yes - all fulfilled ☐ Yes - partially fulfilled ☐ Yes - partially fulfilled		'N/A' refers to there being no social or practical needs to address, following assessment. For further guidance see page 20.			
 No - reason recorded why not No - no reason recorded N/A - No social and practical needs to address 					
56.	Following the patient's death, was there a request — Yes and completed	st for urgent release of the body?			
Yes but unable to complete No - not requested The timeframe for 'urgent' may mean same day, within 24 hours or as soon as possible.					
	□ Unknown				



COMMUNICATE & INVOLVE

Personalised care and support planning

57. 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	For further guidance see page 20.			
58. Is there documented evidence that the patient participated in personalised care and support planning (advance care planning) conversations? Yes - prior to admission and available to inpatient team				
Yes - prior to admission but not available to inpatient teamYes - during admission	For further guidance see page 21.			
Yes - during admission Yes - prior and during admission No - reason recorded why not No - no reason recorded Recognising the possibility of imminent death 59. Is there documented evidence that the likelihood of dying was discussed with the patient?				
□ No - reason recorded why not	For further guidance see page 21.			
 No- no reason recorded 60. Is there documented evidence that the likelihood that the patient may die h with the nominated person(s)? Yes No - reason recorded why not No- no reason recorded 	ad been discussed For further guidance see page 21.			



DEFINITIONS

DEFINITION
PATIENT DEMOGRAPHICS
Please refer to the 'Definition of deaths' information on page 1. If this death is classed as "sudden",
please do not audit the case notes.
An expected death can be expected at any point during the final admission. This question is looking to
capture whether during the final admission it was expected/recognised that the patient would die during
the final admission.
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 is documentation that the patient may not survive this admission.
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 should be recorded in the case notes or on the Patient Information System.
The answer options are a condensed version of 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
Dropdown options have been taken from the NHS codes:
https://www.datadictionary.nhs.uk/attributes/religious_or_other_belief_system_affiliation_group_code
.html#attribute_religious_or_other_belief_system_affiliation_group_code.national_codes
If the patient was formally known to the community and/or hospital Learning Disability team, please
answer "Yes".
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 Schizophrenia
Schizoaffective disorder Disclar offective disorder
Bipolar affective disorder Delucional disorder
Delusional disorder Source degreesing
Severe depression. A primary language is the language with which a person uses most frequently to communicate with This. The severe depression is the language with which a person uses most frequently to communicate with This. The severe depression is the language with which a person uses most frequently to communicate with This.
A primary language is the language with which a person uses most frequently to communicate with. This is often the person's first language or native language. The person is likely to have a lot of exposure to
this language and use at home.
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.
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 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.
12	This is to be taken from the death certificate. Generally this will be the primary causation in 1 (i.e. 1c, and
12	if that is blank then 1b, and if nothing in either, record what is in 1a) However where for instance the
	primary causation is recorded as smoking, alcohol or industrial exposure as a cause of a terminal illness
	then the terminal illness should be recorded.
15	Include AHPs. AHPs might include Occupational Therapists, Physiotherapists, Speech & Language
	Therapists and Dieticians.
20	Seclusion refers to the supervised confinement and isolation of a patient way from other patients in an
	area from which the patient is prevented from leaving.
	DATES AND TIMES OF FINAL ADMISSION
21	The date of the patient's final admission prior to death expressed in date, month and year DD/MM/YYYY
	This includes the entire hospital episode even if the patient has been moved between wards/locations
	during the final admission.
	Instruction to sites: Information services can produce a list that includes admission date and time from
	patient information system.
	patient information system.
22	The time of the patient's final admission to hospital prior to death expressed in hours and minutes
	HH:MM. This includes the entire hospital episode even if the patient has been moved between
	wards/locations during the final admission.
23	Indicate the date using the following format DD/MM/YYYY.
	This should be the date during the final admission that it was first recorded the patient had been
	recognised as dying. If the patient was recognised as dying prior to admission, include the same time and
	date as the final admission.
24	Indicate the time using the following format HH:MM.
27	This should be the time it was first recorded during the final admission that the patient had been
	recognised as dying.
	If the patient was recognised as dying prior to admission, include the same time and date as the final
25	admission.
25	The date of the patient's death expressed in date, month and year DD/MM/YYYY.
26	The time of the patient's death expressed in hours and minutes HH:MM
	PLAN AND DO
27	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 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.
28	This refers to the date a request was made to the specialist palliative care team regarding patient care. I
_•	multiple referrals were made to the team, please submit the first date/time.
	manaple reservation were made to the team, piease submit the mot date, time.
	The purpose of this question is to evidence timely escalation to the specialist palliative care team, if the
	ward team were unable to address a dying person's needs.





29	This refers to the date a request was made to the specialist palliative 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 team, if the
_	ward team were unable to address a dying person's needs.
30	Definition of reviewed: This refers to when the specialist palliative 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 team if the
31	ward team were unable to address a dying person's needs.
31	Definition of reviewed: This refers to when the specialist palliative 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 team if the
	ward team were unable to address a dying person's needs.
33	Partial - Not all recommendations actioned.
	'Reason recorded why not' may include the patient declining the symptom control medication offered or
	another reason recorded.
35	Partial - Not all recommendations actioned.
	'Reason recorded why not' may include the patient declining the symptom control medication offered or
	another reason recorded.
37	Partial - Not all recommendations actioned.
	'Reason recorded why not' may include the patient declining the symptom control medication offered or
	another reason recorded.
38	Review can include: Examination of the patient's mouth, difficulty swallowing, need for additional help
	with drinking, observation of discomfort arising from dimished 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 day word Ora Characta Cat II Birth and 25 have full days in the day in the day in the
	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.
39	Comprehensive communication: Explanation of assessment and examination of hydration status
	(including oral hydration) to patient leading to a discussion of appropriate interventions and an agreed
	management plan. This is a 3 step process – explain the clinical information gathered and explain how
	that clinical information is used to weigh the clinical need (or not) to support any intervention to
	maintain hydration (e.g. dedicated staff time at mealtimes to support additional food and fluids,
	intravenous or subcutaneous fluids or nasogastric feeding). The third step is that the advantages and
	disadvantages of any intervention suggested are weighed with the patient to put a plan in place that is
	effective and acceptable to the patient.
	Partial communication: one or more of the steps in comprehensive assessment are missing e.g. decision
	is communicated but not the clinical reasoning.





	'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	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) unavailable or another reason recorded.
41	Clinical judgement required to answer this question. This question does not place an expectation that all 4 anticipatory medication was prescribed, nor that patients not recognised as dying would have anticipatory medication prescribed for symptoms likely to occur in the last days of life. If 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.
42	Clinical judgement required to answer this question. If there was no known reason to individualise anticipatory medication for the patient, please answer "Yes, for all medications prescribed".
	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.
	Individualised refers to the medication being tailored to the needs of this patient.
42	'Most' refers to more than or equal to 50% of interventions, 'some' refers to less than 50%
43	The question is seeking to understand your view of whether the MDT thought about interventions (e.g., intravenous antibiotics, oxygen therapy, medications, routine physiological observations) and came to a clinical decision regarding whether to change, continue or discontinue the interventions.
	'Most' refers to more than or equal to 50% of interventions, 'some' refers to less than 50%.





44	Emotional/psychological 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.
45	
45	'N/A' refers to there being no emotional/psychological needs to address, following assessment.
46	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.
47	'N/A' refers to there being no spiritual/religious/cultural needs to address, following assessment.
	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.
	reisonal of religious objects, symbols of rituals (including prayer of 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.
48	Social and practical needs may not be present during the initial assessment but may emerge over time.
	Social needs may be wide and varied but might include for example, the need for interaction and contact with friends, family, romantic attachments, and social and community groups. Practical needs may be wide and varied but may include help with communication, help with walking, help with daily tasks etc.
	"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.
49	'N/A' refers to there being no social or practical needs to address, following assessment.
	Social needs may be wide and varied but might include for example, the need for interaction and contact with friends, family, romantic attachments, and social and community groups. Practical needs may be wide and varied but may include help with communication, help with walking, help with daily tasks etc.
50	Emotional/psychological 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), "declined", Independent Mental Capacity Adviser (IMCA) unavailable or
	another reason recorded.
51	'N/A' refers to there being no emotional/psychological needs to address, following assessment.





52	Spiritual/religious/cultural needs may not be present during the initial assessment but may emerge over time.
	Descen recorded why not may include attempts to contact the neminated nercen(s) were
	'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), "declined", 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.
53	'N/A' refers to there being no spiritual/religious/cultural needs to address, following assessment.
	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.
54	Social and practical 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), "declined", Independent Mental Capacity Adviser (IMCA) unavailable or
	another reason recorded.
55	'N/A' refers to there being no social or practical needs to address, following assessment.
	Social needs may be wide and varied but might include for example, the need for interaction and contact
	with friends, family, romantic attachments, and social and community groups. Practical needs may be
	wide and varied but may include help with parking, walking, access to showers etc.
56	The timeframe for 'urgent' may mean same day, within 24 hours or as soon as possible.
	COMMUNICATE & INVOLVE
57	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, co-ordinated 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".
58	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/
	'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.
59	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.
60	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.