National Audit of Care at the End of Life

Mental Health Spotlight Audit
Summary Report
England and Wales
(2021/22)

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This report was prepared by the NHS Benchmarking Network (NHSBN), with the advice of the NACEL Mental Health Clinical Lead, Dr Anushta Sivananthan and the Mental Health Reference Group. To ensure patient involvement in the audit, the NHSBN work closely with The Patients Association.

NHS BENCHMARKING NETWORK (NHSBN)
The NHS Benchmarking Network is a member led organisation promoting service improvement in the NHS through benchmarking and sharing good practice. Members are providers and commissioners of NHS services, spanning the acute, community and mental health sectors. The NHSBN Team support members in sharing data to compare service provision and performance with the aim of identifying improvement opportunities. In addition, the NHSBN run national clinical audits.

PATIENTS ASSOCIATION
The Patients Association is an independent patient charity campaigning for improvements in health and social care for patients. Uniquely for a charity with a remit covering all health and care issues, it works with patients directly: they are its members and supporters, and also the people who benefit from the charity's help and advice services. Through the Patients Association's helpline they support thousands of people each year with their concerns and queries about the health and social care system. The Patients Association speak to government, the NHS and other stakeholders about patients' priorities and concerns, to ensure the patient voice is heard and acted upon

National Audit of Care at the End of Life

Table of contents

Appendices

This report also has a number of appendices, contained in a separate report, which should be read in conjunction with these findings. See appendices for full details.

Appendix 1: National policy context

Appendix 2: Audit background and governance

Appendix 3: Audit objectives

Appendix 4: Audit standards

Appendix 5: Audit structure and scope

Appendix 6: Eligibility, recruitment and registration

Appendix 7: Data collection

Appendix 8: Data validation and cleansing

Appendix 9: NACEL Cause for Concern policy

Appendix 10: NACEL Management of Outliers policy

Appendix 11: NACEL Quality Improvement Plan

Appendix 12: Fourth round of NACEL

Appendix 13: Glossary

Appendix 14: References

Appendix 15: Method for scoring

Appendix 16: Patient demographics

Appendix 17: Characteristics of deaths in hospitals

Appendix 18: Staff Reported Measure demographics

Appendix 19: Audit summary

Appendix 20: Steering Group, Advisory Group, Mental Health Reference Group and Audit Team

Appendix 21: Audit participation

1. Foreword

This report presents the findings from the NACEL Mental Health Spotlight Audit carried out in 2021

I am pleased to present the first National Audit of Care at the End of Life (NACEL) Mental Health Spotlight Audit Summary Report. We commenced the planning for this audit in 2019, with the aim of running the Mental Health Spotlight Audit in 2020. However, it soon became apparent that we would not be able to run the audit as planned. We were faced with what was then the relative unknown of the Coronavirus pandemic, with the UK in lockdown, caring for patients dying with Covid-19, with families, friends and other loved ones not being able to say goodbye in person, due to visiting restrictions. Mental health inpatient facilities safely discharged patients to provide overflow capacity for the acute sector. Thankfully this was not required to any large degree. The Mental Health sector also delivered enhanced physical healthcare for Mental Health inpatients.

2021 was also not without its challenges, with subsequent waves of the pandemic testing the resilience and fortitude of the NHS and the social care sector. As we know, the impact of the pandemic on the care home sector has left its mark, with many people dying sooner than expected. However, I was pleased to see the Mental Health Spotlight Audit happening during 2021,to provide a baseline understanding of the care delivered to dying patients and those important to them in a mental health inpatient setting.

We have aligned the Mental Health Spotlight Audit to the main acute and community hospital audit wherever possible, and mental health providers were invited to participate in all four data elements (Organisational Level Audit, Case Note Review, the NACEL Quality Survey and the new Staff Reported Measure). I am delighted to report that mental health inpatient providers took up the challenge and the overall participation rate for the mental health sector was 83%. This is excellent coverage, given that we know the numbers of people dying in mental health facilities are very low. The low number of deaths in mental health inpatient settings resulted in very low numbers of Quality Surveys returned, and although this provides some understanding of the feedback from bereaved carers, we have been unable to use this data in this report.

I particularly wanted to thank the members of the NACEL Mental Health Reference Group who have helped enormously with the scope, design and interpretation of findings from the Mental Health Spotlight Audit. Thanks also go to the mental health providers who assisted the NHS Benchmarking Network with piloting the mental health audit.

This Spotlight Audit gives a much-needed baseline, against which to track progress against the *Five Priorities for Care* and the *NICE Quality Standards* and *Guidelines*. Given that end of life care is not usually a core function of mental health inpatient providers, I am extremely pleased to see that we now have evidence against key end of life care themes, in particular, personalised care planning and communication with families and others, where mental health providers perform very well. The results illustrate how good practice in care delivery is playing through into end of life care delivery. It is wonderful to see how well mental health providers are doing on these NACEL themes. This is due in part to long-established personalised care delivery in the mental health sector, where parity between mental health and physical needs assessments is given, and the fact that the families and friends of those in mental health inpatient settings become well known to staff. Documentation of conversations with patients, and those important to them, and involvement in decision-making therefore exhibits good compliance in this spotlight audit.

There are some areas where mental health services are not performing as well as acute and community hospital providers. Whilst thorough scrutiny of all deaths occurring in mental health services is demonstrated to be well embedded, through the audit, policies and guidelines around end of life care delivery are not as well developed.

1. Foreword

Similarly, the audit demonstrates that mental health services are not as likely to have the same access to and levels of the specialist palliative care team availability, as acute and community hospitals. The summary scores for these themes demonstrate this difference.

The new Staff Reported Measure gave us some key messages from mental health staff. There was a reasonable volume of responses to the staff survey. Whilst the summary scores derived from this audit element on staff confidence to deliver end of life care, staff support and care and culture are lower than for acute and community hospital providers, this finding was not entirely unexpected given that end of life care is not a primary focus of mental health services. However, there are areas identified here where all mental health providers can make improvements. For example, providers should be supporting staff and giving the appropriate training needed to deliver end of life care if necessary, such as to recognise when a person might be dying and to communicate this effectively to the dying person and those important to them. Furthermore, all staff should feel able to raise a concern about end of life care within the hospital if needed.

We have kept the recommendations short for the Mental Health Spotlight Audit and have focused on key aspects of care that can lead to an improved end of life care experience for both the dying person, and those close to them, as evidenced by the audit. I anticipate that the mental health sector will accept the challenge of improving end of life care in our mental health hospitals, in line with these recommendations.

I also commend you to read the findings in the National Summary Report from round three of NACEL for acute and community hospitals providers, carried out in 2021.

We commend the findings from the Mental Health Spotlight Audit to you.

Dr Anushta Sivananthan
NACEL Mental Health Clinical Lead
Medical Director
Cheshire & Wirral Partnership NHS Foundation Trust

2. Executive summary

This report sets out the findings of the Mental Health Spotlight Audit which took place in 2021. Results are compared to the acute and community findings, where appropriate.

The audit comprised:
- an **Organisational Level Audit (OLA)** covering Trust/Health Board (T/HB) and Hospital/Submission (H/S) level questions for 2020/21;
- a **Case Note Review (CNR)** which reviewed consecutive inpatient deaths from April 2021 to August 2021
- a **Quality Survey (QS)** completed online, or by telephone, by the bereaved person; and
- a **Staff Reported Measure (SRM)** completed online.

Data for all elements of the audit was collected between June and October 2021. Details of participation can be found at Appendix 21.
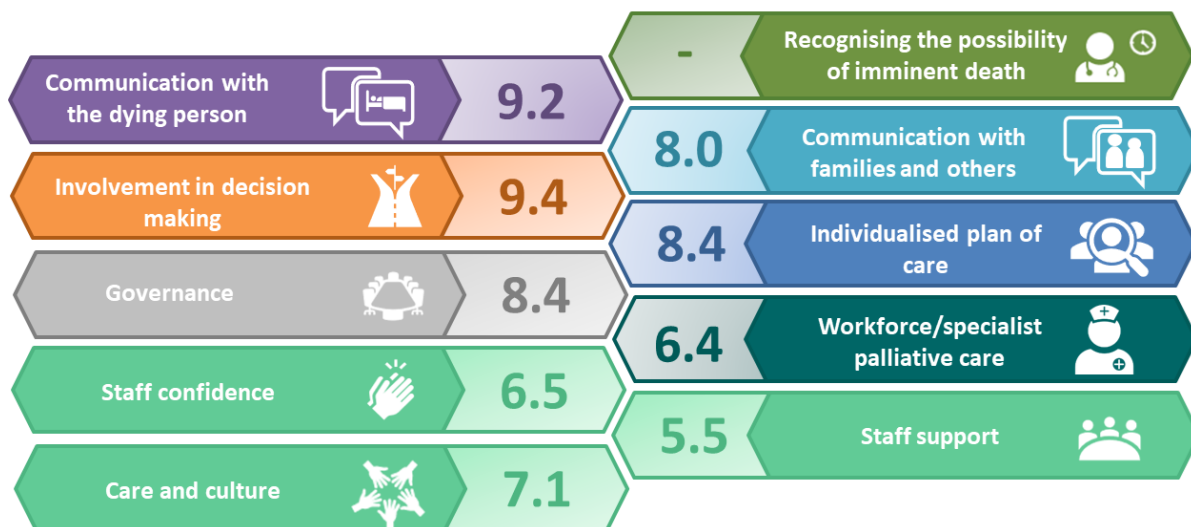
Key findings
A relatively low volume of deaths happen in mental health settings.

There are three key audit themes where the summary scores for mental health providers are lower than those reported for acute and community hospitals; **governance, workforce/specialist palliative care and staff reported feedback**. These areas require review, however, the results are not unexpected given the lower volume of patients dying in mental health settings.

For the remaining themes on **communication** and **individualised care planning** the mean summary scores for mental health providers were higher than for acute and community trusts. **Involvement in decisions regarding end of life care** were reported to be in line with acute and community trusts. High compliance with key end of life care quality standards, evidenced by these themes, may be due to the differing nature of mental health care. Care delivered in a mental health inpatient setting tends to be longer-term, with longer lengths of stay, than that offered in acute and community hospitals, allowing staff to develop a closer relationship with the patient and those important to them. In addition, the spotlight audit has demonstrated good documentation of decisions and conversations regarding end of life care, with both the dying patient and those close to them, reflecting the emphasis on care planning documentation in the mental health sector.

Mean summary scores for mental health providers[1]

Theme	Score	Theme	Score
Communication with the dying person	9.2	Recognising the possibility of imminent death	-
Involvement in decision making	9.4	Communication with families and others	8.0
Governance	8.4	Individualised plan of care	8.4
Staff confidence	6.5	Workforce/specialist palliative care	6.4
Care and culture	7.1	Staff support	5.5

1. A summary score has been calculated for each theme with the exception of 'recognising the possibility of imminent death'.

National Audit of Care at the End of Life

7

National Audit of Care at the End of Life 2021
Mental Health Spotlight Audit
Key findings at a glance

46 Trust/Health Board overviews (T/HB)
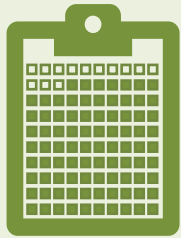
54 Hospital/site overview (H/S)

75 Case Note Reviews (CNR)

481 Staff Reported Measures (SRM)

(CNR – Cat 1₂)

75%
Case notes recorded that the patient might die within hours or days

(CNR – Cat 1)

98%
Case notes, with an individualised plan of care, recorded a discussion (or reason why not) with the patient regarding the plan of care

(CNR – Cat 1)

98%
Case notes recorded a discussion (or reason why not) with families/carers regarding the possibility the patient may die

82%
Case notes recorded an individualised plan of care

38%
Case notes recorded a preferred place of death as indicated by the patient
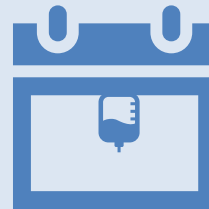
(CNR – Cat 1)

85%
Patient's hydration status was assessed daily once the dying phase was recognised

(CNR – Cat 1)

95%
Case notes recorded extent patient wished to be involved in care decisions, or a reason why not recorded

(T/HB)

100%
Trusts/HBs have guidelines for how to respond to/learn from, deaths of patients
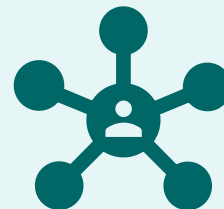
(H/S)

44%
Hospitals have face-to-face specialist palliative care service available 8 hours a day, 7 days a week

61%
Staff feel confident they can recognise when a patient might be dying imminently

48%
Staff felt supported by their specialist palliative care team

(SRM)

74%
Staff feel they work in a culture that prioritises care, compassion, respect and dignity

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2. Category 1. It was recognised that the patient may die

3. Recommendations

The findings from this first Mental Health Spotlight Audit (2021/22) have been reviewed by the NACEL Mental Health Reference Group who have formulated the following recommendations.

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

1. **Review local arrangements for integrated care for mental health patients with complex physical co-morbidities to ensure access to the right care in the right environment at the right time when they reach the end of life.** Mental health providers should work with their ICS and Health Boards to jointly develop pathways of care for those who are in mental health inpatient beds to ensure equity of access to specialist palliative care services.

Trust/Health Boards should:

2. **Ensure policies and guidelines are in place to support care planning for the *Five Priorities for Care of the Dying Person*. Processes should be put in place to link policies and guidelines to frontline practice.** In particular, staff should feel able to raise a concern about end of life care within their Trust/Health Board.

Chief Executives should:

3. **Ensure health and care staff, on wards more likely to care for patients at the end of life, have the appropriate training, managerial and emotional support to develop the competence and confidence to; recognise imminent death, communicate with the dying person and people important to them as early and sensitively as possible, and deliver end of life care.**

4. Background to the NACEL Mental Health Spotlight Audit

The Mental Health Spotlight Audit was run as part of the third round of NACEL during 2021, at the request of the audit commissioners. The audit was originally planned for 2020, but was delayed due to the Covid-19 pandemic.

The purpose of the spotlight audit was to provide a baseline position for mental health inpatient providers with regard to end of life care delivery, patient and families experience, and compliance with the *Five priorities for care* and the relevant *NICE Standards and Guidelines*.

Mental health providers of inpatient care participated in round one of NACEL, completing the Organisational Level Audit (OLA) data element only. Comparisons with round one are made where possible in this report. Comparisons have also been made with the acute and community hospital audit in round three, which have highlighted the differences in primary focus of the service and in service delivery. The findings from round three of the acute and community hospital audit can be found in the Summary Report.

Data was collected from the 1st June to the 8th October 2021. For the Case Note Review (CNR) data element, deaths were audited between 1st April and 31st August 2021 and Quality Surveys (QS) were sent out during this period to the bereaved. Staff were also asked to respond to the Staff Reported Measure (SRM) during this time.

A NACEL Mental Health Reference Group (MHRG) was established with the remit of advising the NACEL Co-Clinical Leads on the specialist circumstance and context within which mental health services are delivered, and the particular context of deaths occurring within mental health inpatient settings. The group was led by Dr Anushta Sivananthan, Medical Director at Cheshire and Wirral Partnership NHS Foundation Trust. All four data elements of NACEL were reviewed by the MHRG for their applicability to the mental health setting. All metrics were closely aligned to the mental health setting and additional guidance pertaining to mental health providers was made available. Mental health providers were invited to participate in all four data collection elements (Organisational Level Audit, Case Note Review, Quality Survey and Staff Reported Measure). Wales as a country opted out of participation in the Quality Survey. Due to the low numbers of Quality Surveys returned, this data element has not been utilised as evidence in the Mental Health Spotlight Audit.

Deaths in scope of the Mental Health Spotlight audit were adults over the age of 18, but with the specific exclusions of sudden deaths and deaths within 4 hours of admission as in the acute and community hospital audit. Additional exemptions were deaths by suicide, deaths of patients in a learning disability designated bed, deaths in a designated "addictions" bed and maternal deaths in a mother and baby unit, due to other national workstreams covering these categories of deaths.

Figure 1 highlights participation in the NACEL Mental Health Spotlight Audit which represents 83% of eligible organisations.

Figure 1 Mental Health provider participation in NACEL Mental Health Spotlight Audit			
	All	**England**	**Wales**
Organisations registered	49	44	5
Submissions (Hospital/Site) registered	58	53	5
Case Note Reviews (CNR)	75	50	25
Quality Surveys (QS)	8	8	0
Staff Reported Measures (SRM)	481	423	58

5. How the findings are presented

5.1 National results

Sections 6 to 8 of this report contains results from mental health inpatient providers in England and Wales taking part in the Mental Health Spotlight Audit. Audit participants have access to an online toolkit where their organisation's results can be explored and all metrics derived for the audit data collected can be reviewed. There is a key findings report for patients and carers.

There is a separate report for acute and community hospital providers who also participated in NACEL round three available on the NACEL outputs page.

5.2 Overview of key themes and summary scores

The information in this report is presented thematically in ten sections. The themes utilised in NACEL are derived from *NICE Quality Standards QS13 (2011)* and *QS144* (2017), *NICE Guideline NG31* (2015) and the *Five priorities for care of the dying person* from the Leadership Alliance for the Care of Dying People – *One Chance to Get It Right* (2014). The quality standard or guideline reference relevant to each theme is highlighted at the top of sections 8.1 to 8.10. 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. **Involvement in decision making (CNR)**
5. **Individualised plan of care (CNR)**
6. **Governance (T/HB)**
7. **Workforce/specialist palliative care (H/S)**
8. **Staff confidence (SRM)**
9. **Staff support (SRM)**
10. **Care and culture (SRM)**

A scoring system was devised in round one of NACEL to summarise the audit results under key themes. For the Mental Health Spotlight Audit, the summary scores are calculated for the mental health sample as a whole and not by individual hospitals (submissions), due to the small sample size. The maximum value of the summary score is 10.

Appendix 15 explains the process undertaken to select the key themes and their component indictors, together with an explanation of how the scores are calculated. Note that no summary score is calculated for 'recognising the possibility of imminent death'. The NACEL Steering Group reflected, following round one of NACEL, that to report a summary score for the 'recognising the possibility of imminent death' theme may be misleading, since it is not possible to incorporate key information on timescales in the calculation of a score.

As in previous rounds, each summary score only uses indicators for one element of the audit, and uses evidence from Category 1 deaths only. The following key is used to show the source of each theme:

- T/HB – Trust/Health Board Organisational Level Audit
- H/S – Hospital/Site Organisational Level Audit
- CNR – Case Note Review
- SRM – Staff Reported Measure

5. How the findings are presented

The Case Note Review audited inpatient deaths for the following two categories:-

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.

The charts in this report displaying Case Note Review data may show the split of findings for 'All deaths', 'Category 1 deaths' and 'Category 2 deaths'. It should be noted that the summary scores are derived from Category 1 deaths only.

Examples of these categories in relation to the mental health setting were made available to assist auditors.

6. Patient demographics of the audit sample

The charts below show the patient demographics for the audit sample.

From the Case Note Review sample, two-thirds of deaths occurred in a mental health older acute bed (figure 2). Around half of dying patients were being detained under a section of the Mental Health Act 1983 (figure 5). Two thirds of people in the audit sample were aged 75 or over (figure 4). 71% of deaths were of males and 29% females (figure 3).

The most common primary cause of death recorded for deaths in a mental health inpatient setting was dementia (36%); however in 19% of cases, auditors had no access to the death certificate to record this in the case notes (figure 6).

Figure 2: (CNR) Type of bed the patient was in when they died (n = 74)
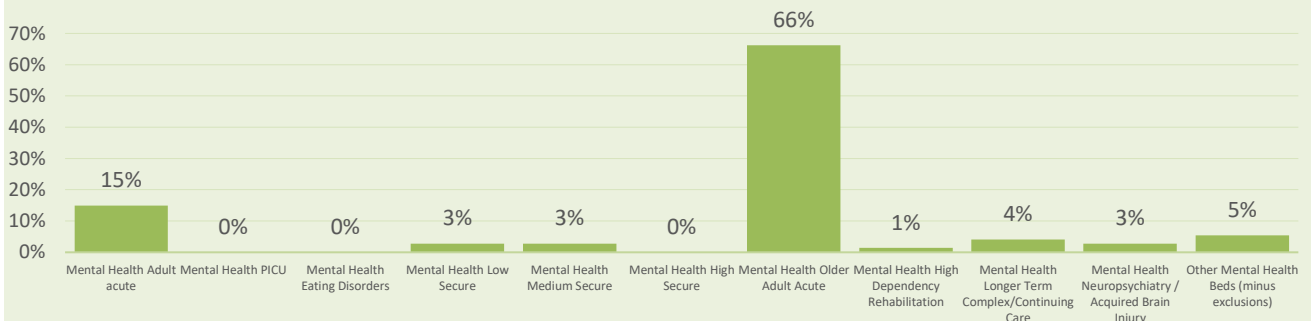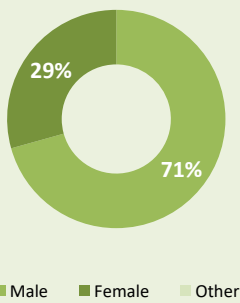
Bed type	%
Mental Health Adult acute	15%
Mental Health PICU	0%
Mental Health Eating Disorders	0%
Mental Health Low Secure	3%
Mental Health Medium Secure	3%
Mental Health High Secure	0%
Mental Health Older Adult Acute	66%
Mental Health High Dependency Rehabilitation	1%
Mental Health Longer Term Complex/Continuing Care	4%
Mental Health Neuropsychiatry / Acquired Brain Injury	3%
Other Mental Health Beds (minus exclusions)	5%

Figure 3: (CNR) Gender profile (n = 75)

Male 71%
Female 29%
Other

Figure 4: (CNR) Age profile at time of death (n = 75)

Age	%
18-64	15%
65-74	21%
75-84	32%
85-94	31%
95+	1%
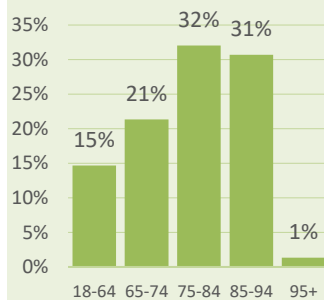
Figure 5: (CNR) Route of the patient's final admission (n = 74)

Route	%
Ambulance	11%
Self-presented	11%
GP referral	0%
Hospital transfer	24%
Via local gatekeeping process	4%
Detained under the Mental Healh Act	47%
Other	3%
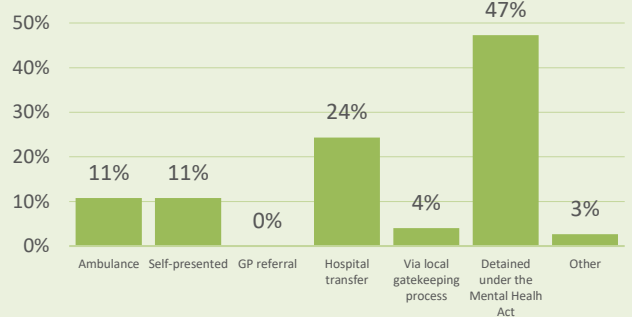
Figure 6: (CNR) Primary cause of death (n = 74)

Cause	%
Cancer	5%
Chronic respiratory disease	0%
COVID-19	4%
Dementia	36%
Heart failure	7%
Neurological conditions (such as motor neurone disease)	0%
Pneumonia	12%
Renal failure	0%
Stroke	0%
Other	16%
No access to death certificate	19%
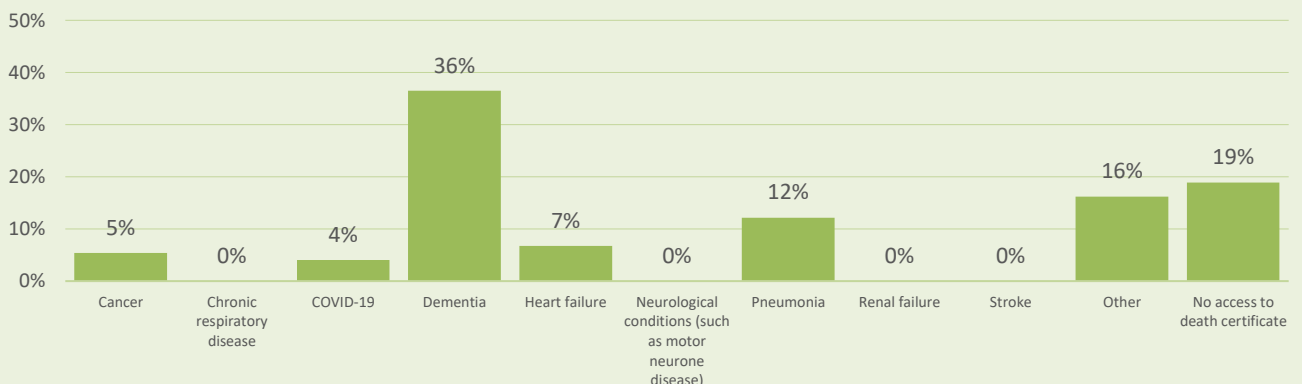
7. Commentary on the results

Recognising the possibility of imminent death (page 17)

- Timeliness in recognising imminent death is important in ensuring that appropriate discussions and planning can take place, in line with the wishes of the dying person and of those close to them. This underpins all priorities for improving the experience of end of life care in the last few days and hours of the dying person's life.
- Evidence from the CNR (figure 7) shows that of the deaths audited, 75% of deaths were Category 1 (see page 12 for definition) (87% for acute and community providers).
- The median time from admission to death was 64 days for Category 1 deaths illustrating that mental health providers will have been caring for such patients for a longer time period than in acute and community hospitals, where this was 8 days.
- The median time from imminent death being recognised to the patient dying was 117 hours, a period of nearly 5 days. This is considerably higher than the median time of 44 hours in the acute and community hospital audit.
- 52% of deaths audited had a formal mortality review after death.

There are three key themes where the summary scores for mental health providers are lower than those reported for acute and community hospitals; governance, workforce/specialist palliative care and staff reported feedback.

- The mean summary score for the **governance** theme (page 24) for mental health providers was 8.4 (n = 46) (9.7 for acute and community hospitals).
- However, progress with governance arrangements for care at the end of life was demonstrated between round one and round three of the audit for mental health providers. For example, 89% of mental health providers reported that they had an identified member of the Trust/Health Board with responsibility for end of life care (figure 37), compared to 72% in round one.
- Moreover, all mental health providers reported they had implemented a process whereby mortality is managed and reviewed in a systematic way according to national guidance. The evidence suggests that the systematic scrutiny of deaths in mental health settings is well embedded with a learning from deaths culture noted.

- As might be expected, given that end of life care is not a primary function of mental health providers, the summary score for the **workforce/specialist palliative care** theme was 6.4 (n= 42) compared to a summary score of 8.1 for the acute and community hospital providers.
- 89% of mental health providers reported that they had access to a palliative care service (figure 41), compared to 99% of acute and community hospital providers.
- 73% of mental health providers reported they had access to telephone advice (doctor/nurse) 24 hours a day, 7 days a week (figure 42) (compared to 92% for acute and community hospitals), whilst face-to-face specialist palliative care services (doctor/nurse) availability 8 hours a day, 7 days per week (figure 43) was reported at 44% (compared to 60% for acute and community hospitals).

The following results for **staff confidence, support, care and culture** are taken from the Staff Reported Measure, which was a new element of NACEL introduced in this round of the audit for acute, community and mental health providers (see appendix 18 for analysis of staff groups completing the survey). Whilst these summary scores are lower for mental health providers, this is not entirely unexpected given that end of life care is not a primary focus for staff working in mental health settings. However, it is recognised that there is scope for improvement across a number of areas.

- The mean summary score for **staff confidence** (page 26) was 6.5 (n= 430) for mental health providers (7.5 for acute and community providers). As might be expected given that working with dying patients is less common on mental health inpatient wards, staff responding felt less confident in areas such as recognising when a patient might be imminently dying and their skills to communicate clearly and sensitively to the dying person/those important to them. Notably, only a third of those responding felt confident to respond to a request to die outside the hospital setting (figure 49).

7. Commentary on the results

- In relation to the **staff support** theme (page 27), the summary score was 5.5 (n= 459) for mental health providers (6.4 for acute and community providers). Of staff responding, 48% of respondents agreed that they had felt supported by the specialist palliative care team that the hospital had access to (figure 56), compared to 77% in acute and community providers.

- The **staff care and culture** theme (page 28) summary score was 7.1 (n= 447) for mental health providers and 7.3 for acute and community providers. Only three quarters of respondents agreed they felt able to raise a concern about end of life care within their hospital (figure 59).

Mental health providers report in line with acute and community hospitals on involvement in decision making regarding end of life care. For the remaining themes, where the summary scores are derived from the Case Note Review, communication with the dying person, communication with families and others and individualised plan of care, the mean summary scores for mental health providers were higher than for acute and community trusts. High compliance with key end of life care quality standards on these themes, may be due to the differing nature of mental health care, which tends to be longer-term and have longer lengths of stay than that offered in acute and community hospitals, allowing staff to develop a closer relationship with the patient and those important to them.

Mental health services are attuned to working with the friends, family and those important to the patient, given the nature of care, and support at the time of death is likely to be a continuation of the build up of these relationships over time. Mental health inpatients are very likely to have been cared for in the community by the mental health team prior to inpatient admission, and patients are more likely to have continuation of care planning into their inpatient admission.

In addition, the Spotlight Audit has demonstrated good documentation of decisions and conversations regarding end of life care, with both the dying patient and those close to them, reflecting the emphasis on person-centred care planning and documentation in the mental health sector. Parity between mental health and physical health needs assessment is evidenced in the findings from the Spotlight Audit. Again, this may be due to a longer time period to assess patients in a mental health inpatient setting, with admission protocols covering holistic assessment of mental and physical health care, with food and fluid protocols routinely carried out on admission to an inpatient setting, whilst considering an assessment of physical and clinical risk factors. High compliance with quality standards concerning anticipatory medication would suggest that mental health providers have robust policies in this area of end of life care.

- For the **communication with the dying person** theme (page 18), the mean summary score for mental health providers was 9.2 (n= 56) (7.9 reported in acute and community hospitals). The possibility that the patient may die had been discussed with the patient in 95% cases, for Category 1 deaths, or a reason recorded why not (figure 11) (90% for acute and community).

- For the **communication with families and others** theme (page 19), the mean summary score reported for mental health providers was 8.0 (n= 56) (7.0 for the acute and community hospitals audit). For Category 1 deaths, the possibility that the patient may die had been discussed with families and others, or a reason why not recorded, in 98% of cases (figure 15) (98% for acute and community).

- The **involvement in decision making** (page 20) mean summary score for the mental health audit was 9.4 (n= 56), with acute and community hospitals' summary score reported as 9.5. For Category 1 deaths, 95% of cases had documented evidence about the extent to which the patient wished to be involved in decisions about their care, or a reason why not documented (figure 20). As might be expected in the mental health setting, for Category 1 deaths, 93% of cases had documented evidence that the dying person had their capacity assessed to be involved in their end of life care planning, or a reason why not documented (figure 21).

7. Commentary on the results

- For the **individualised plan of care** theme (page 21), the mean summary score reported for mental health providers was 8.4 (n= 53) (7.7 for the acute and community hospital audit). For mental health providers, for Category 1 deaths, 82% of cases had an individualised plan of care (figure 26), with 87% of these cases with a documented plan being reviewed regularly (figure 27). For acute and community providers, these results were 73% and 78% respectively. Figure 28 indicates that 38% of patients had documented evidence of their preferred place of death. Figures 30 and 31 show whether the patient's hydration status and nutrition status had been documented daily once the dying phase was recognised for Category 1 deaths. Hydration status was documented in 85% of cases, similar to nutrition, where it was documented in 86% of cases. For acute and community providers, these results were 78% and 72% respectively. Additional findings on **anticipatory medication** show that mental health providers perform well in this area, in particularly on the administration, documenting a use and documenting discussions with the patient and those important to them. For Category 1 deaths, 93% of cases had anticipatory medication prescribed for symptoms likely to occur (figure 34) (89% for acute and community). An indication for the use of anticipatory medication was available for all medication in 96% of cases (figure 35), in comparison to 74% in acute and community.
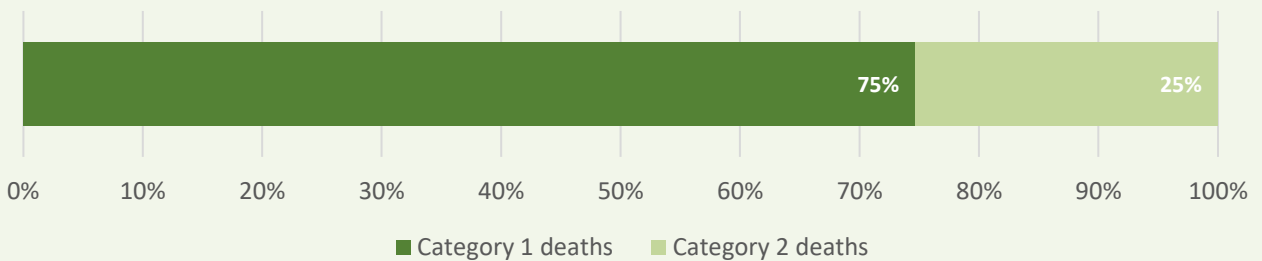
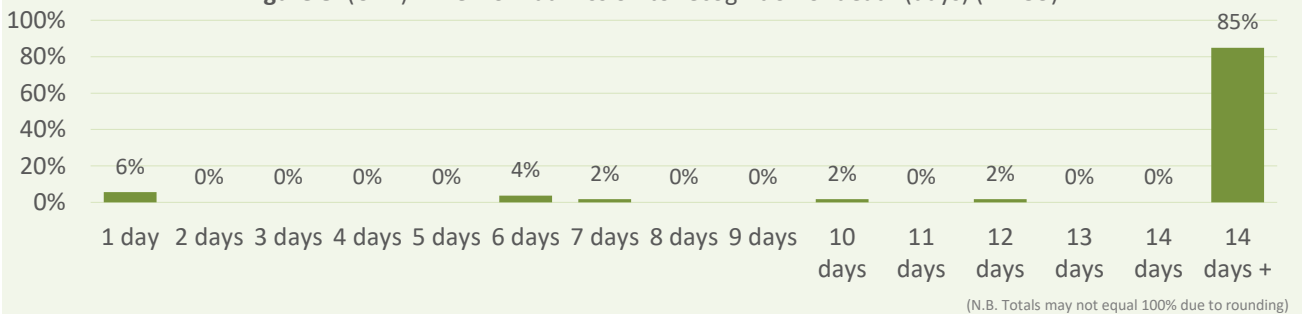# 8.1 Recognising the possibility of imminent death

Priority 1: This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly (*One Chance To Get It Right, 2014*).

NICE QS144: Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering (*NICE Quality Standard 144*).
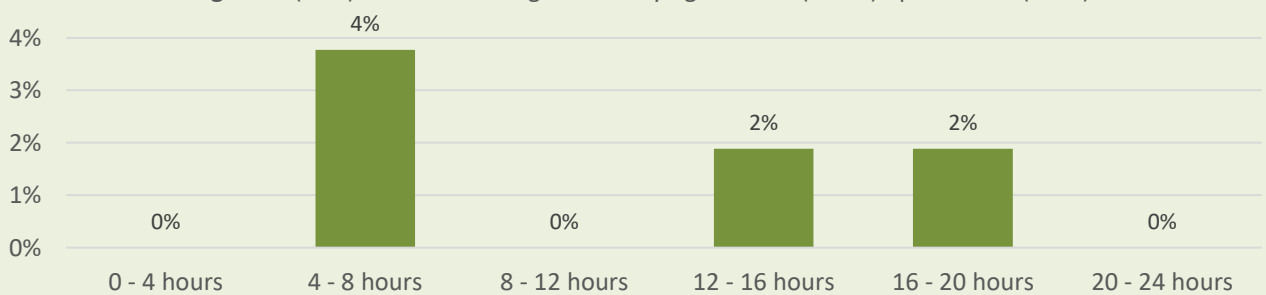
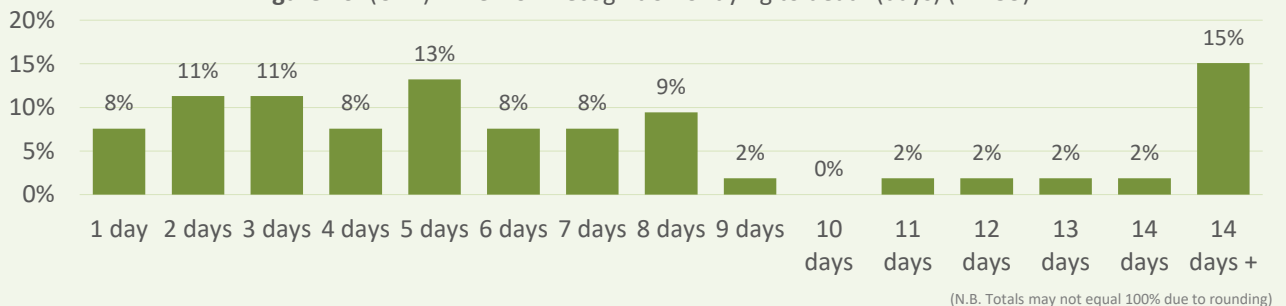**Figure 7:** (CNR) Category of deaths audited (n = 75)

75% 25%

■ Category 1 deaths ■ Category 2 deaths

Figure 8: (CNR) Time from admission to recognition of death (days) (n = 53)

1 day	2 days	3 days	4 days	5 days	6 days	7 days	8 days	9 days	10 days	11 days	12 days	13 days	14 days	14 days +
6%	0%	0%	0%	0%	4%	2%	0%	0%	2%	0%	2%	0%	0%	85%

(N.B. Totals may not equal 100% due to rounding)

Figure 9: (CNR) Time from recognition of dying to death (hours) up to 24 hrs (n = 6)

0 - 4 hours	4 - 8 hours	8 - 12 hours	12 - 16 hours	16 - 20 hours	20 - 24 hours
0%	4%	0%	2%	2%	0%

Figure 10: (CNR) Time from recognition of dying to death (days) (n = 53)

1 day	2 days	3 days	4 days	5 days	6 days	7 days	8 days	9 days	10 days	11 days	12 days	13 days	14 days	14 days +
8%	11%	11%	8%	13%	8%	8%	9%	2%	0%	2%	2%	2%	2%	15%

(N.B. Totals may not equal 100% due to rounding)

8.2 Communication with the dying person

Priority 2: Sensitive communication takes place between staff and the dying person, and those identified as important to them *(One Chance To Get It Right).*

NICE QS144: Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan *(Statement 2, NICE Quality Standard 144).*

Figure 11: (CNR) Possibility that the patient may die had been discussed with the patient (Category 2 not asked) (n = 56)

Figure 12: (CNR) Patient was involved in discussing the individualised plan of care

Figure 13: (CNR) Possibility of drowsiness as a result of prescribed medications discussed with the patient

(N.B. Totals may not equal 100% due to rounding)

Figure 14: (CNR) Risks and benefits of hydration and nutrition options discussed with the patient (Category 1)

(N.B. Totals may not equal 100% due to rounding)
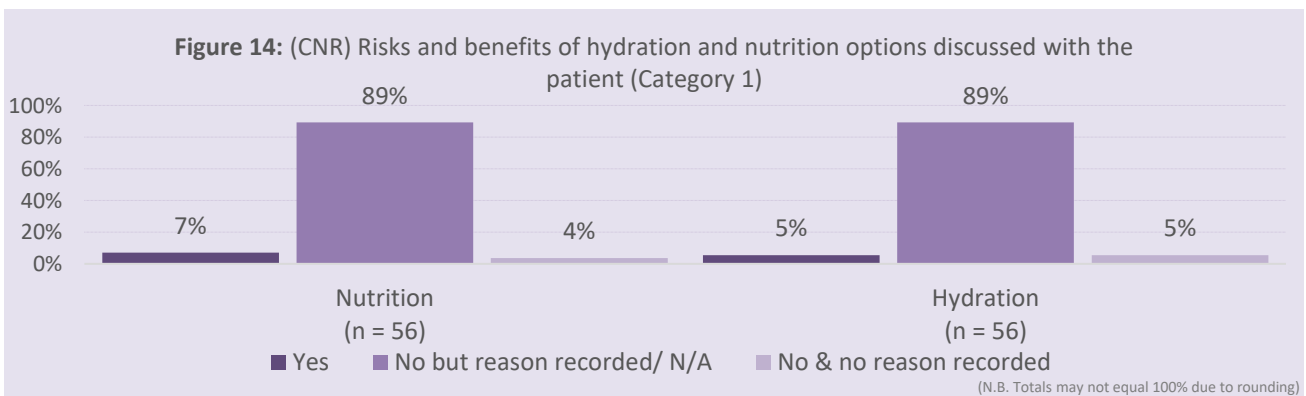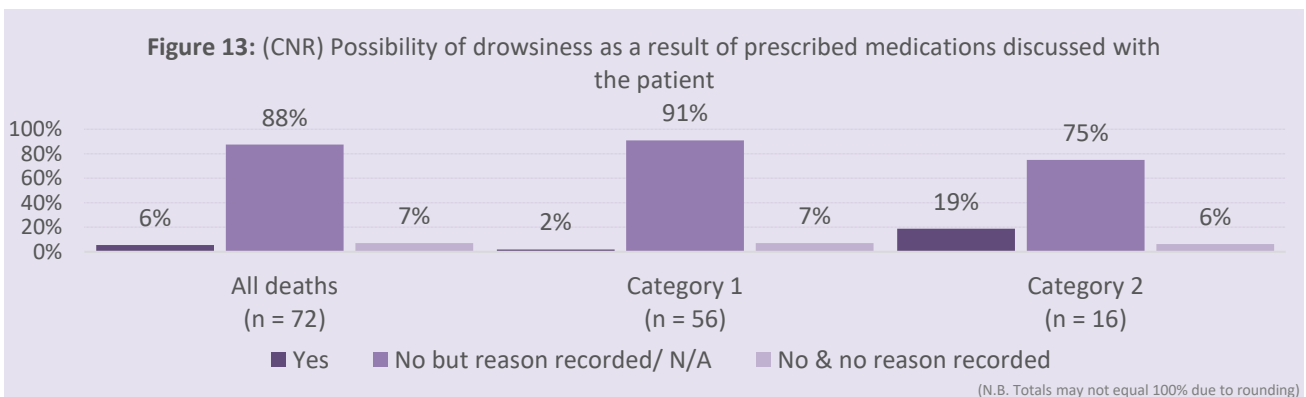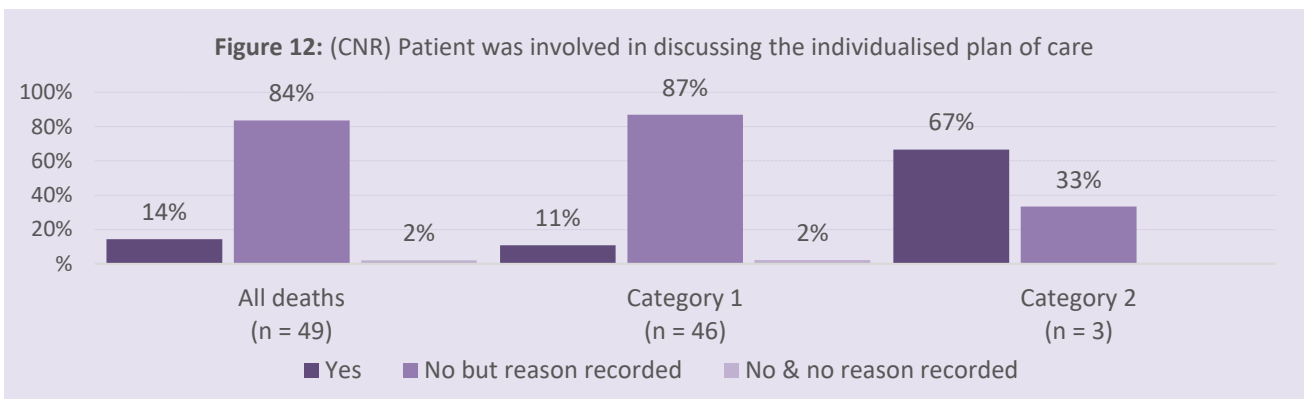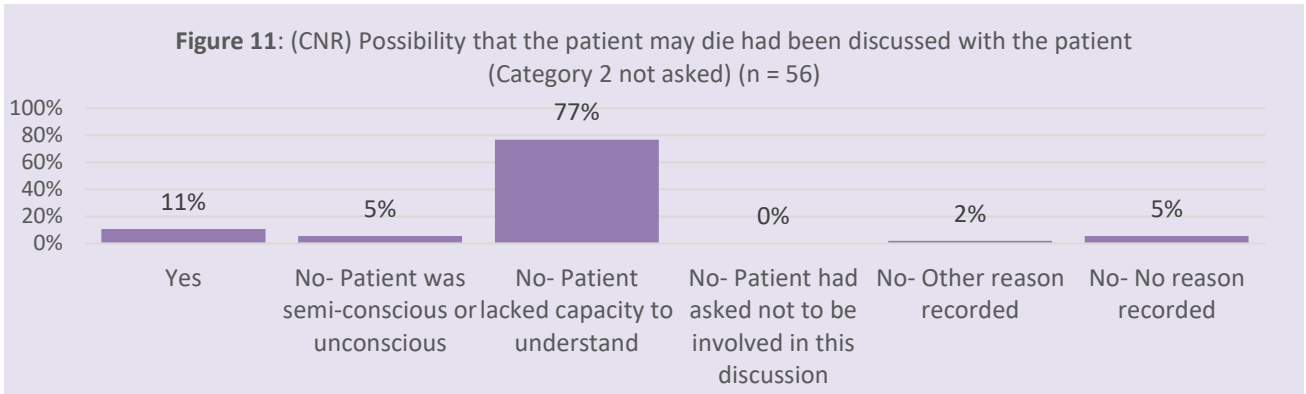
8.3 Communication with families and others

8.0

Priority 2: Sensitive communication takes place between staff and the dying person, and those identified as important to them *(One Chance To Get It Right)*.

NICE QS144: Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan *(Statement 2 , NICE Quality Standard 144)*.
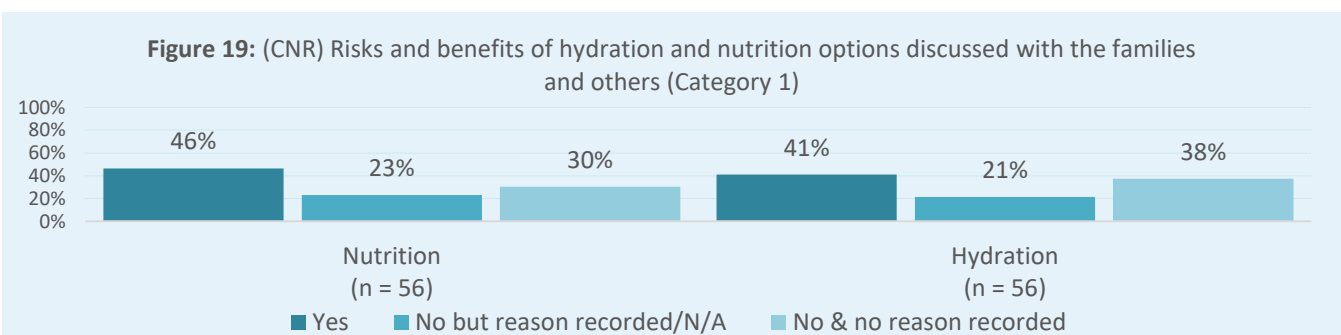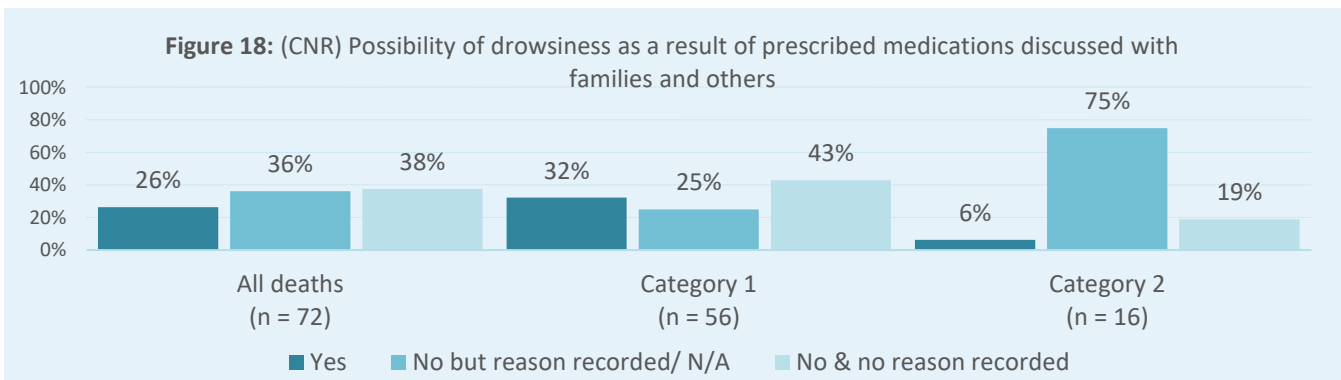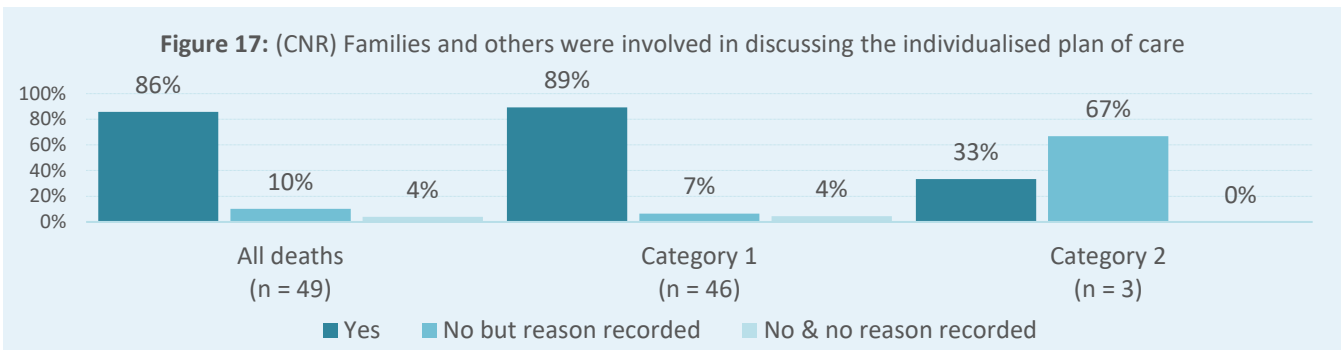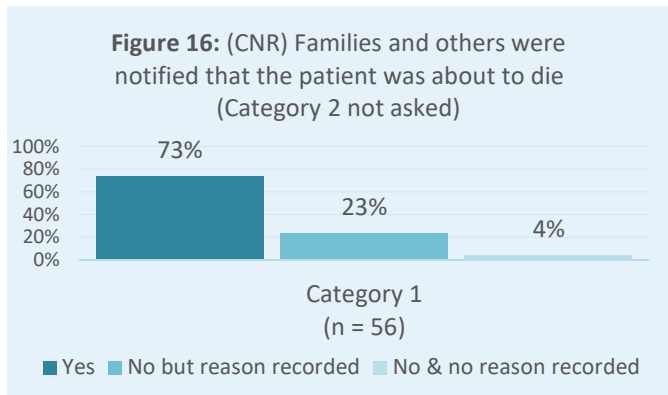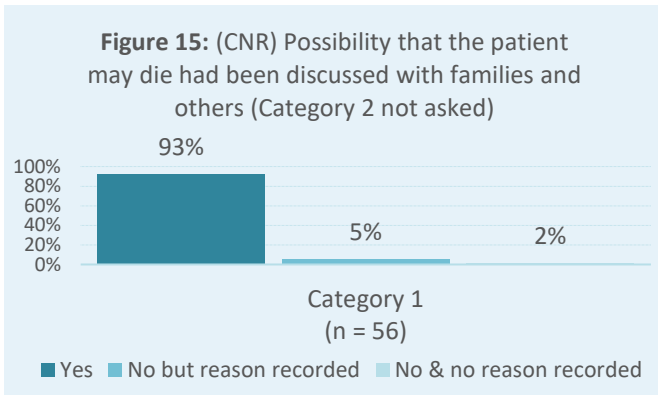
Notes to Priority 3: The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care *(One Chance To Get It Right)*.
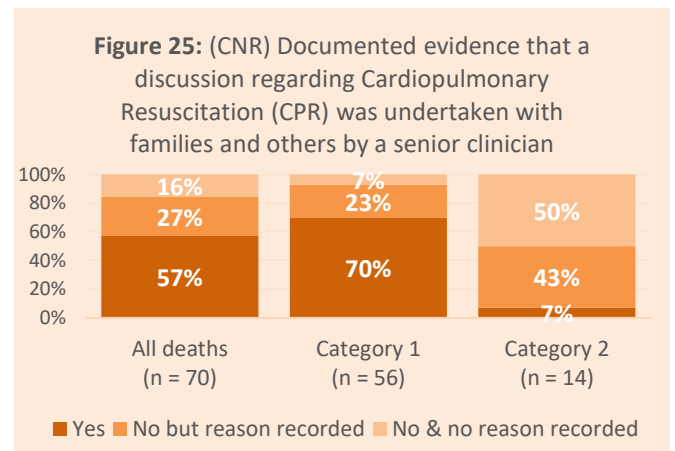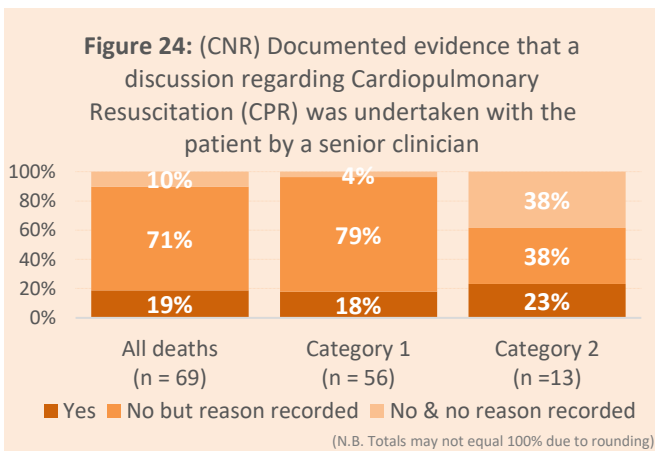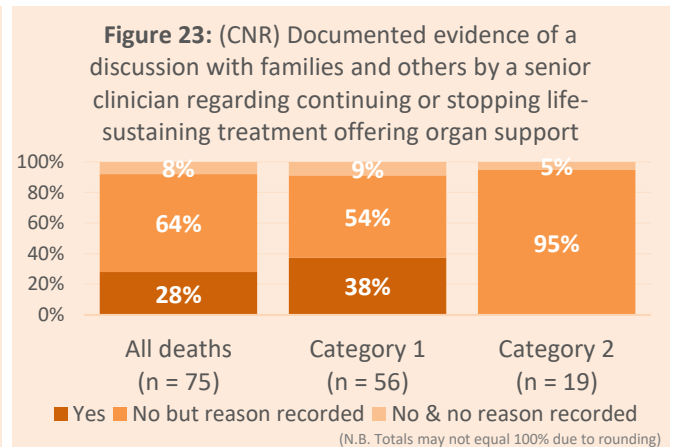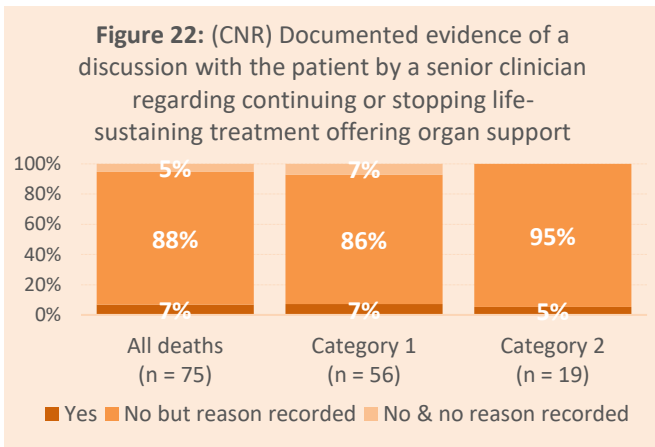
Figure 15: (CNR) Possibility that the patient may die had been discussed with families and others (Category 2 not asked)

- 93% Yes
- 5% No but reason recorded
- 2% No & no reason recorded

Category 1 (n = 56)

■ Yes ■ No but reason recorded ■ No & no reason recorded

Figure 16: (CNR) Families and others were notified that the patient was about to die (Category 2 not asked)

- 73% Yes
- 23% No but reason recorded
- 4% No & no reason recorded

Category 1 (n = 56)

■ Yes ■ No but reason recorded ■ No & no reason recorded

Figure 17: (CNR) Families and others were involved in discussing the individualised plan of care

	Yes	No but reason recorded	No & no reason recorded
All deaths (n = 49)	86%	10%	4%
Category 1 (n = 46)	89%	7%	4%
Category 2 (n = 3)	33%	67%	0%

■ Yes ■ No but reason recorded ■ No & no reason recorded

Figure 18: (CNR) Possibility of drowsiness as a result of prescribed medications discussed with families and others

	Yes	No but reason recorded/ N/A	No & no reason recorded
All deaths (n = 72)	26%	36%	38%
Category 1 (n = 56)	32%	25%	43%
Category 2 (n = 16)	6%	75%	19%

■ Yes ■ No but reason recorded/ N/A ■ No & no reason recorded

Figure 19: (CNR) Risks and benefits of hydration and nutrition options discussed with the families and others (Category 1)

	Yes	No but reason recorded/N/A	No & no reason recorded
Nutrition (n = 56)	46%	23%	30%
Hydration (n = 56)	41%	21%	38%

■ Yes ■ No but reason recorded/N/A ■ No & no reason recorded

(N.B. Totals may not equal 100% due to rounding)

National Audit of Care at the End of Life

8.4 Involvement in decision making

9.4

Priority 3: The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants *(One Chance To Get It Right, 2014)*.

Notes to Priority 1: The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person *(One Chance To Get It Right, 2014)*.

Figure 20: (CNR) Documented evidence about the extent to which the patient wished to be involved in decisions about their care

	All deaths (n = 75)	Category 1 (n = 56)	Category 2 (n = 19)
Yes	21%	11%	53%
No but reason recorded	71%	84%	32%
No & no reason recorded	8%	5%	16%

(N.B. Totals may not equal 100% due to rounding)

Figure 21: (CNR) Documented evidence the dying person had their capacity assessed to be involved in their end of life care planning

	All deaths (n = 70)	Category 1 (n = 56)	Category 2 (n = 14)
Yes	43%	48%	21%
No but reason recorded	44%	45%	43%
No & no reason recorded	13%	7%	36%

Figure 22: (CNR) Documented evidence of a discussion with the patient by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support

	All deaths (n = 75)	Category 1 (n = 56)	Category 2 (n = 19)
No & no reason recorded	5%	7%	
No but reason recorded	88%	86%	95%
Yes	7%	7%	5%

Figure 23: (CNR) Documented evidence of a discussion with families and others by a senior clinician regarding continuing or stopping life-sustaining treatment offering organ support

	All deaths (n = 75)	Category 1 (n = 56)	Category 2 (n = 19)
No & no reason recorded	8%	9%	5%
No but reason recorded	64%	54%	95%
Yes	28%	38%	

(N.B. Totals may not equal 100% due to rounding)

Figure 24: (CNR) Documented evidence that a discussion regarding Cardiopulmonary Resuscitation (CPR) was undertaken with the patient by a senior clinician

	All deaths (n = 69)	Category 1 (n = 56)	Category 2 (n =13)
No & no reason recorded	10%	4%	38%
No but reason recorded	71%	79%	38%
Yes	19%	18%	23%

(N.B. Totals may not equal 100% due to rounding)

Figure 25: (CNR) Documented evidence that a discussion regarding Cardiopulmonary Resuscitation (CPR) was undertaken with families and others by a senior clinician

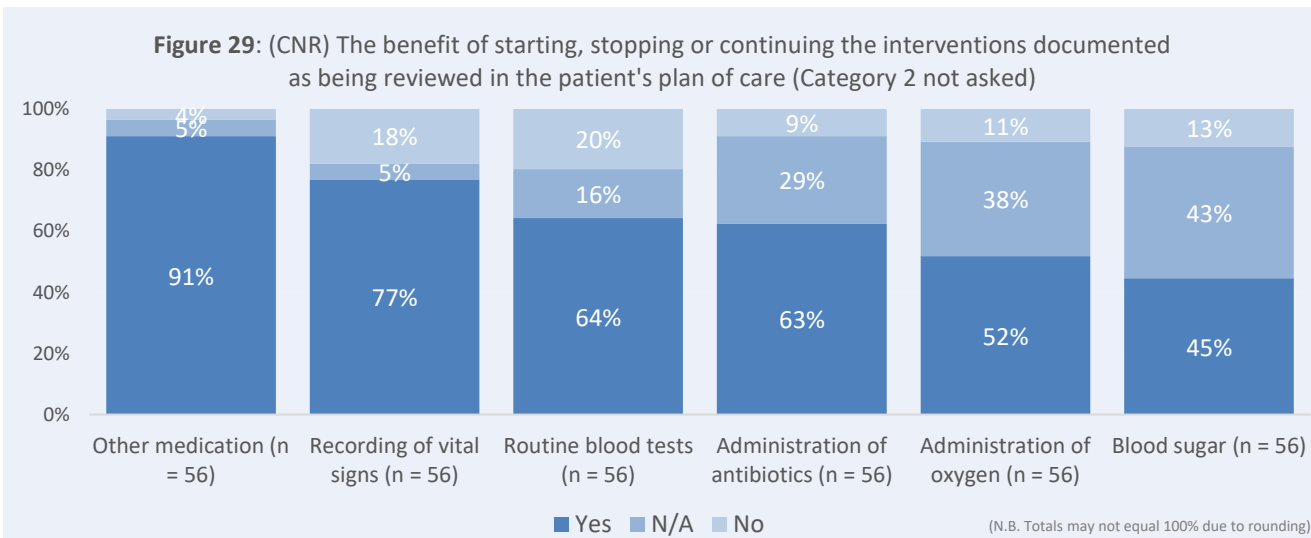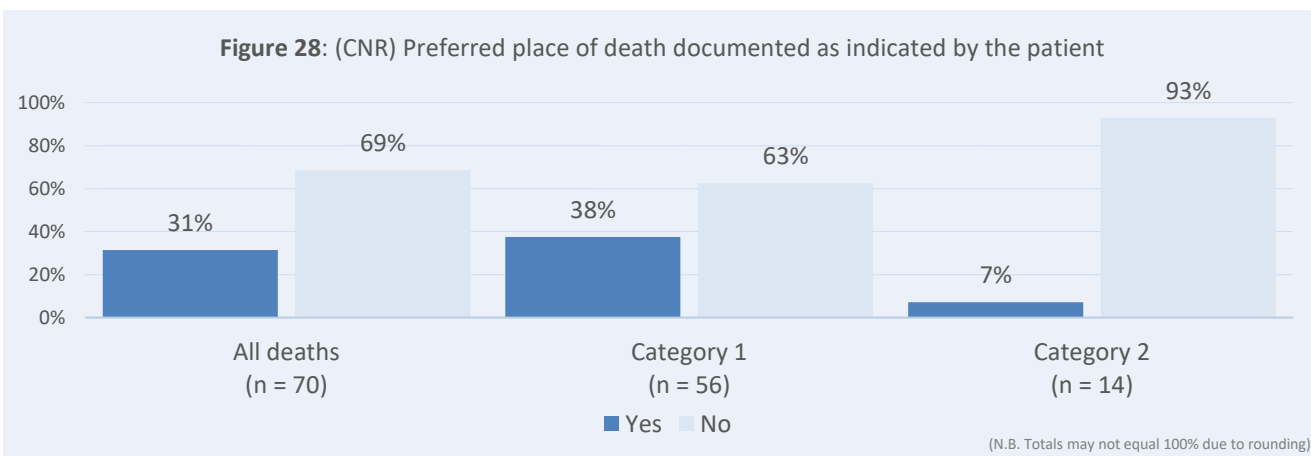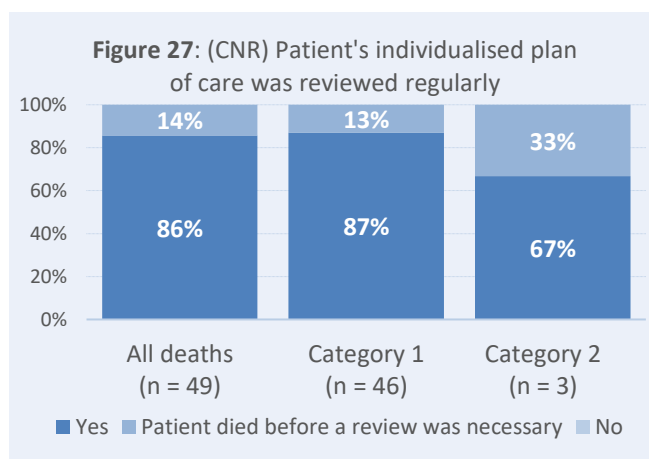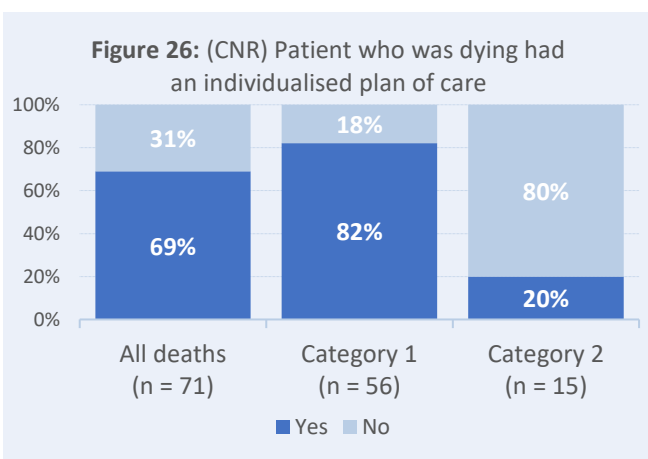|	All deaths (n = 70)	Category 1 (n = 56)	Category 2 (n = 14)
No & no reason recorded	16%	7%	50%
No but reason recorded	27%	23%	43%
Yes	57%	70%	7%

8.5 Individualised plan of care

Priority 5: An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion (*One Chance To Get It Right*).

NICE QS144: Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use, dosage and route of administration *(Statement 3, NICE Quality Standard 144).*

NICE QS144: Adults in the last days of life have their hydration status assessed daily, and have a discussion about the risks and benefits of hydration options (*Statement 4, NICE Quality Standard 144*).

Figure 26: (CNR) Patient who was dying had an individualised plan of care

Figure 27: (CNR) Patient's individualised plan of care was reviewed regularly

Figure 28: (CNR) Preferred place of death documented as indicated by the patient

(N.B. Totals may not equal 100% due to rounding)

Figure 29: (CNR) The benefit of starting, stopping or continuing the interventions documented as being reviewed in the patient's plan of care (Category 2 not asked)

(N.B. Totals may not equal 100% due to rounding)

8.5 Individualised plan of care

Figure 30: (CNR) Patient's hydration status was assessed daily once the dying phase was recognised (Category 2 not asked) (n = 55)
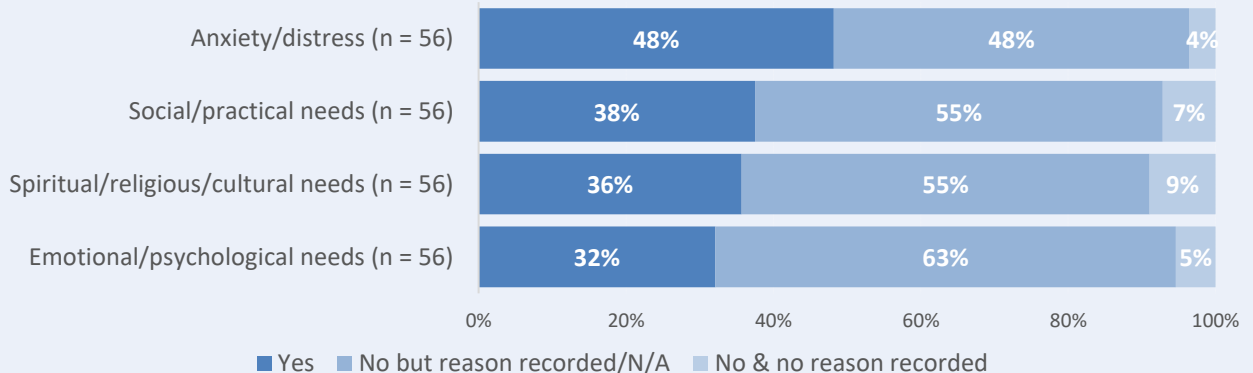
- 15% No
- 85% Yes
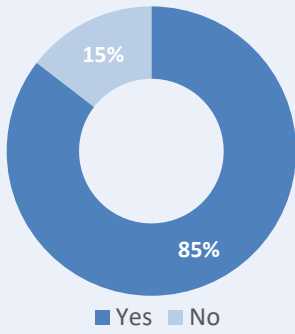
Figure 31: Patient's nutrition status was reviewed regularly once the dying phase was recognised (Category 2 not asked) (n = 56)

- 14% No
- 86% Yes
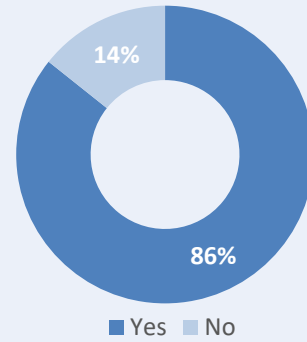
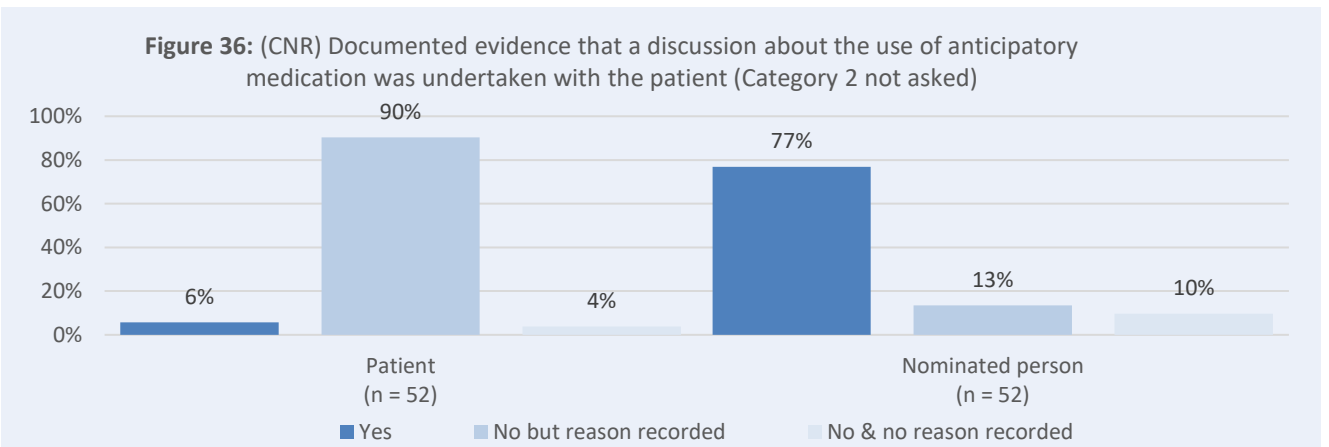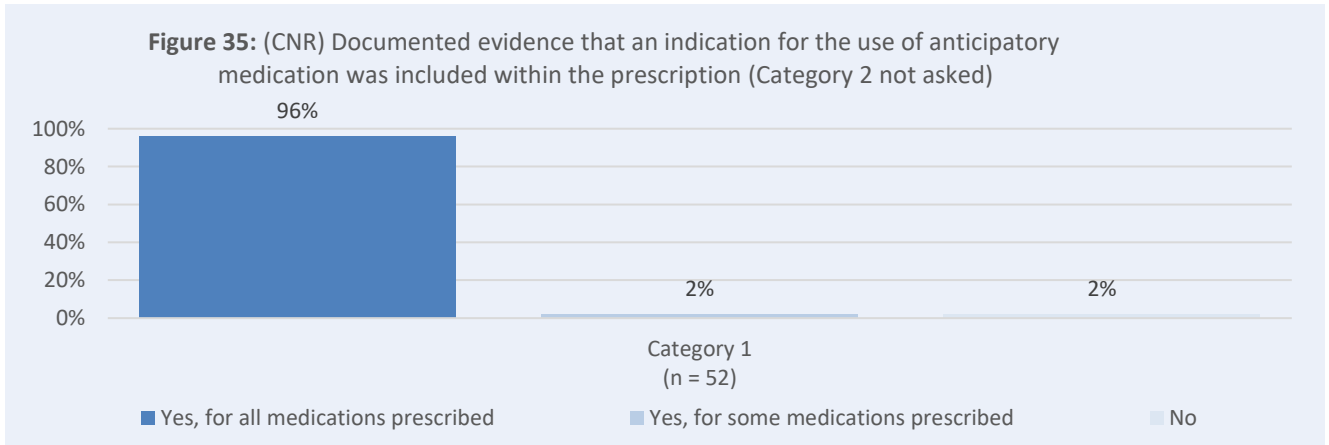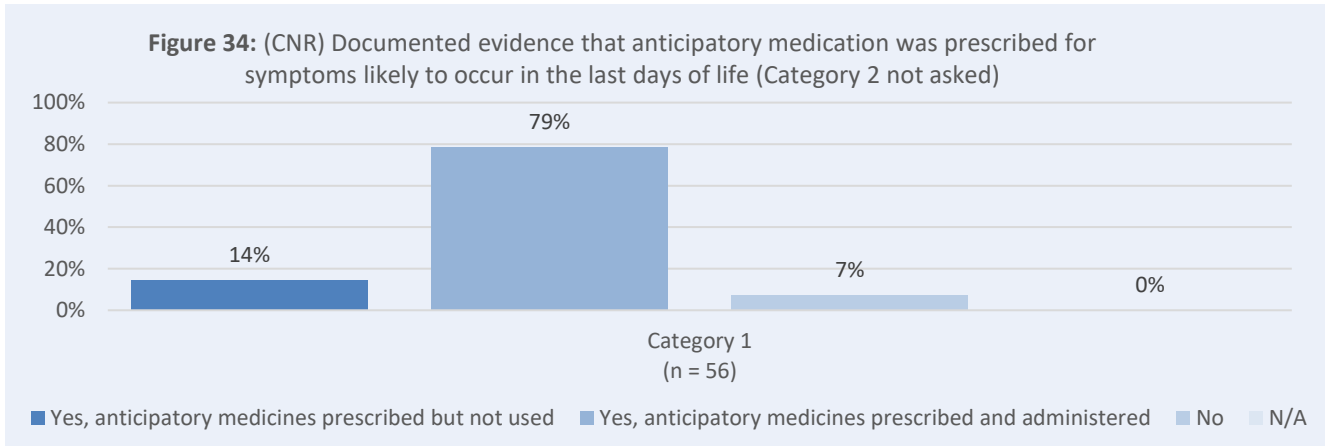**Figure 32**: (CNR) Documented evidence of an assessment of the following needs (Category 1 only)

Need	Yes	No	N/A
Pain (n = 56)	98%		2%
Mouth care (n = 56)	93%	2%	5%
Agitation/delirium (n = 56)	88%	7%	5%
Dyspnoea/breathing difficulty (n = 56)	88%	2%	11%
Pressure areas (n = 54)	87%	6%	7%
Hygiene requirements (n = 56)	82%	5%	13%
Noisy breathing/death rattle (n = 56)	77%	11%	13%
Bowel function (n = 56)	73%	11%	16%
Bladder function (n = 56)	71%	9%	20%
Nausea/vomiting (n = 56)	61%	9%	30%

(N.B. Totals may not equal 100% due to rounding)
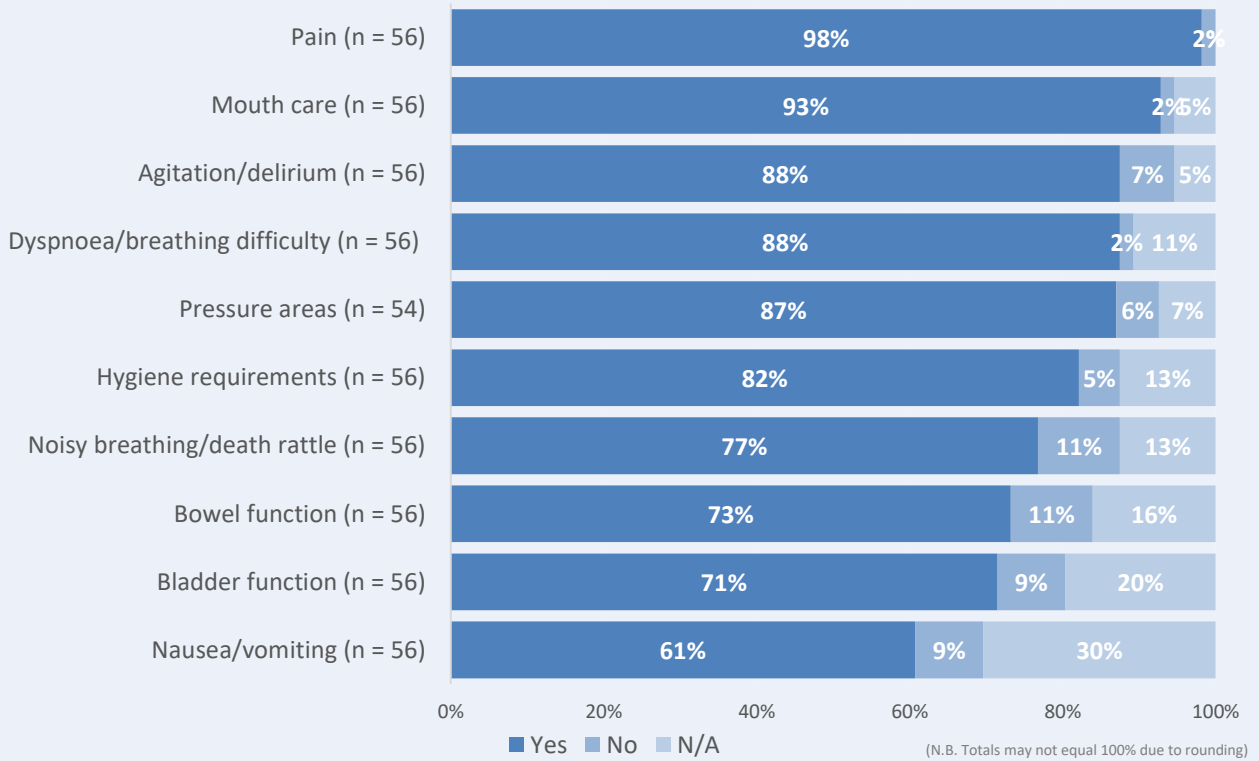
Figure 33: (CNR) Documented evidence of an assessment of the following needs (Category 1 only)

Need	Yes	No but reason recorded/N/A	No & no reason recorded
Anxiety/distress (n = 56)	48%	48%	4%
Social/practical needs (n = 56)	38%	55%	7%
Spiritual/religious/cultural needs (n = 56)	36%	55%	9%
Emotional/psychological needs (n = 56)	32%	63%	5%

National Audit of Care at the End of Life

8.5 Individualised plan of care

Additional reporting on anticipatory medication
The following metrics are not included in the 'Individualised plan of care' summary score but are included for additional context .

Figure 34: (CNR) Documented evidence that anticipatory medication was prescribed for symptoms likely to occur in the last days of life (Category 2 not asked)

Category 1 (n = 56)
- 14% — Yes, anticipatory medicines prescribed but not used
- 79% — Yes, anticipatory medicines prescribed and administered
- 7% — No
- 0% — N/A

Figure 35: (CNR) Documented evidence that an indication for the use of anticipatory medication was included within the prescription (Category 2 not asked)

Category 1 (n = 52)
- 96% — Yes, for all medications prescribed
- 2% — Yes, for some medications prescribed
- 2% — No

Figure 36: (CNR) Documented evidence that a discussion about the use of anticipatory medication was undertaken with the patient (Category 2 not asked)

Patient (n = 52)
- 6% — Yes
- 90% — No but reason recorded
- 4% — No & no reason recorded

Nominated person (n = 52)
- 77% — Yes
- 13% — No but reason recorded
- 10% — No & no reason recorded

8.6 Governance

Organisational leadership and governance: Each [organisation] needs to have leadership that is committed to ensuring that those people to whom it provides services who are dying receive high-quality, compassionate care, focused on the needs of the dying person and their family (*One Chance To Get It Right, 2014)*.

Education, training and professional development: Individual providers of health and care are responsible for ensuring their staff have the experience and competence they need to do their jobs well. This includes making time and other resources available for staff to undergo professional development (*One Chance To Get It Right, 2014)*.

Figure 37: (T/HB) An identified member of the trust/UHB board with a responsibility for end of life care (n = 46)

11%
89%
■ Yes ■ No
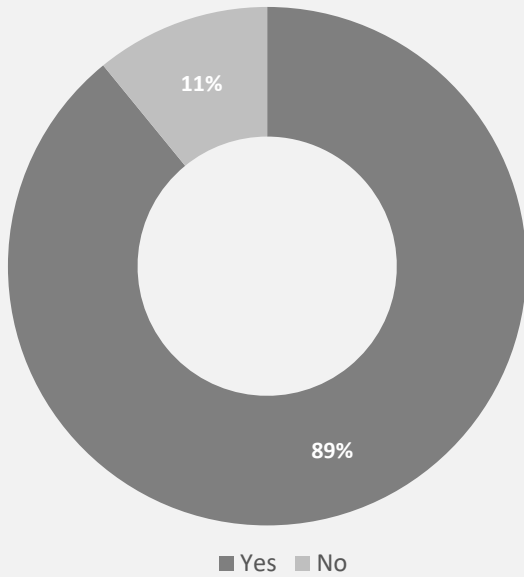
Figure 38: (T/HB) Guidelines for how it responses to/learns from, deaths of patients who die under its management (n = 46)

100%
■ Yes ■ No
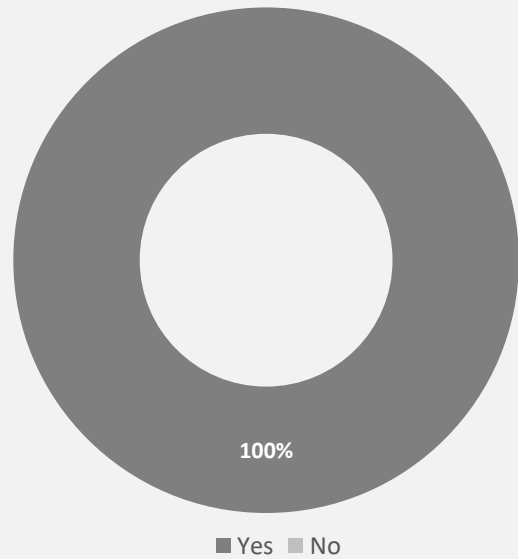
Figure 39: (T/HB) Specific care arrangements to enable rapid discharge home to die, if this is the person's preference (n = 46)

26%
74%
■ Yes ■ No
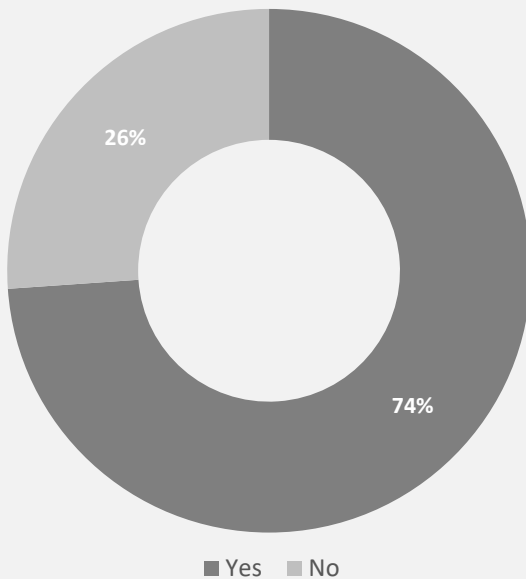
Figure 40: (T/HB) A care plan to support the Five Priorities for Care of the Dying Person (n = 46)

28%
72%
■ Yes ■ No
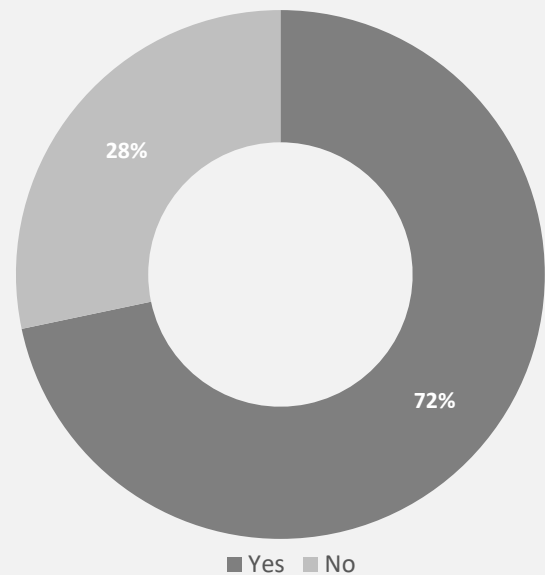
8.7 Workforce/specialist palliative care

Notes to Priority 5: There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this (*One Chance To Get It Right, 2014*).

Notes to Priority 5: [service providers must] work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. 'Adequate' means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am – 5pm seven days a week and a 24 hour telephone advice service (*One Chance To Get It Right, 2014*).

Ongoing education and training for all health and care staff: [….all] staff who have contact with dying people must have the skills to do this effectively and compassionately. This includes clinical and support staff (e.g. porters, reception staff and ward clerks.) Those organisations that deliver such care have the prime responsibility for ensuring that the people they employ are competent to carry out their roles effectively, including facilitating and funding ongoing professional development, where this is appropriate (*One Chance To Get It Right, 2014*).

Figure 41: Access to a Specialist Palliative Care service (n = 53)

89%   11%

■ Yes ■ No
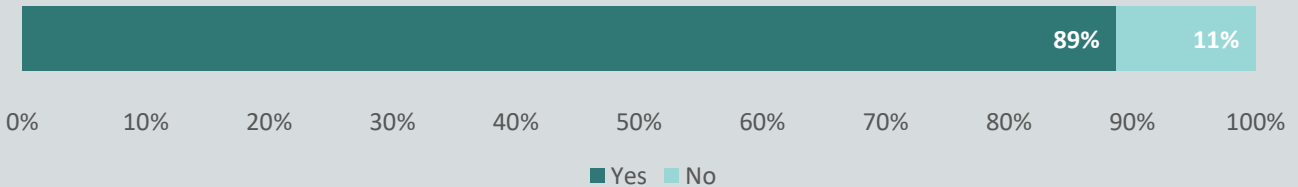
Figure 42: Is the telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week? (n = 44)
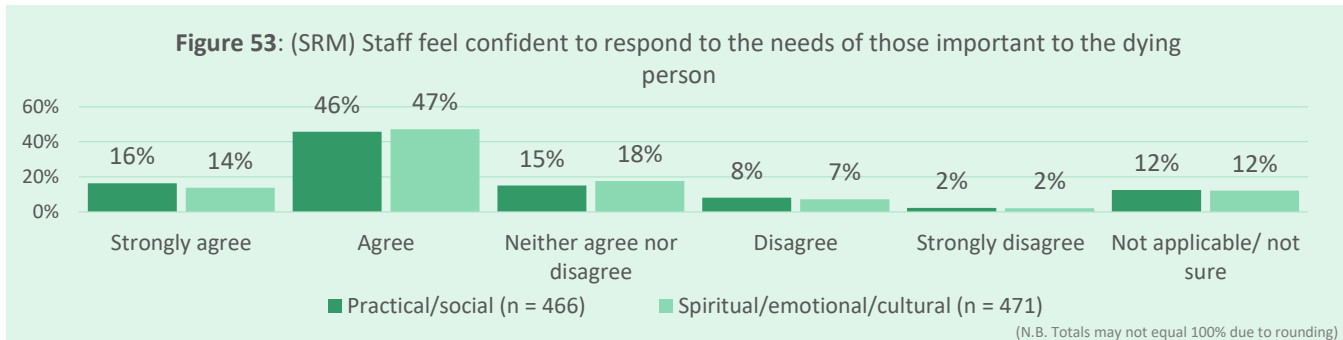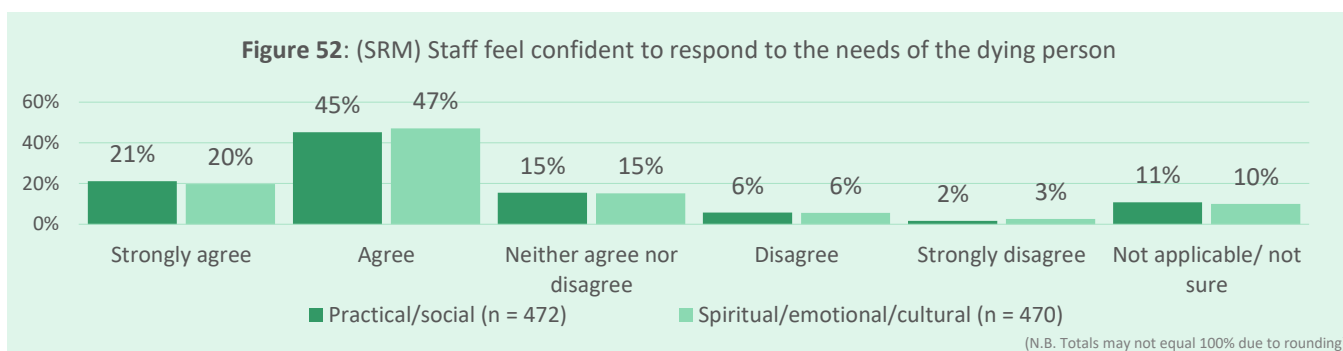
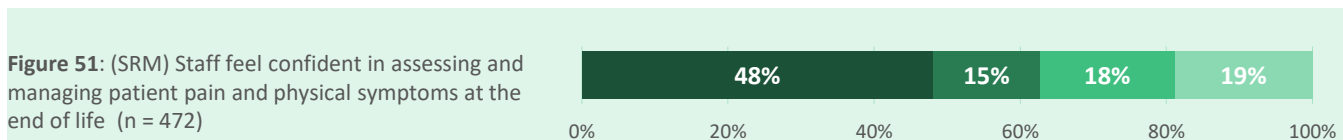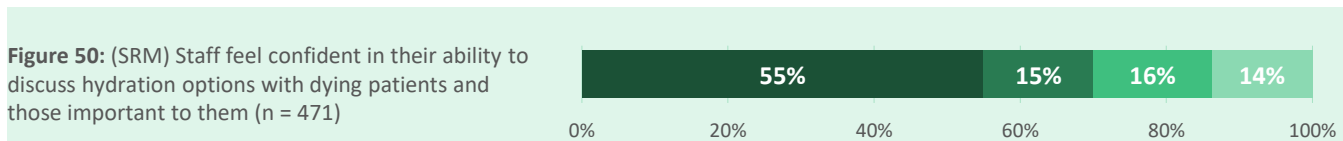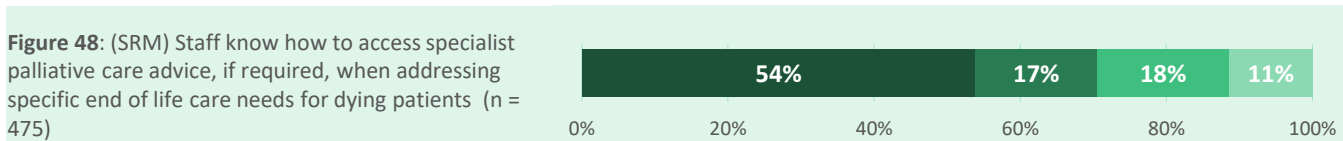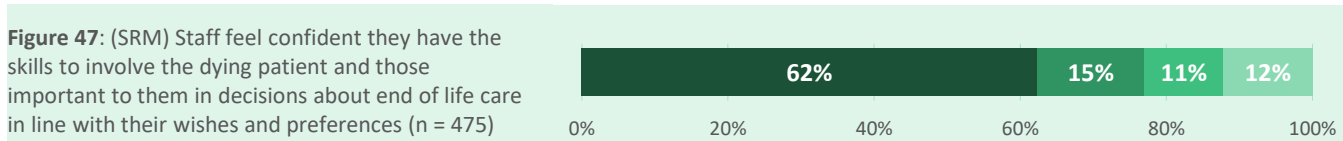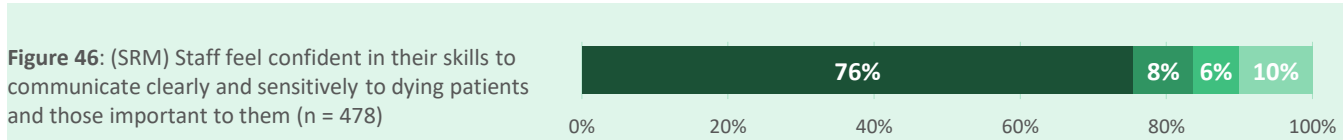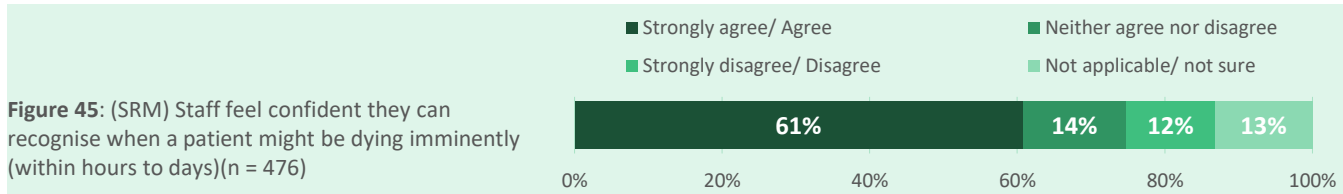27%   73%

■ Yes ■ No

Figure 43: (H/S) Is the face-to-face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week? (n = 43)
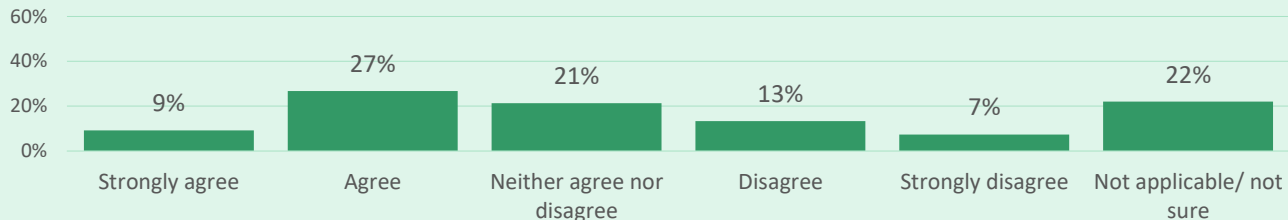
44%   56%

■ Yes ■ No

Figure 44: (H/S) Training available

	Induction Programme (n = 52)	Mandatory/ Priority Training (n = 52)	Communication skills (n = 52)	Other training (n = 52)
Yes	14%	12%	40%	71%
No	87%	89%	60%	29%

(N.B. Totals may not equal 100% due to rounding)

8.8 Staff confidence

Figure 45: (SRM) Staff feel confident they can recognise when a patient might be dying imminently (within hours to days)(n = 476)

Strongly agree/ Agree	Neither agree nor disagree	Strongly disagree/ Disagree	Not applicable/ not sure
61%	14%	12%	13%

Figure 46: (SRM) Staff feel confident in their skills to communicate clearly and sensitively to dying patients and those important to them (n = 478)

| 76% | 8% | 6% | 10% |

Figure 47: (SRM) Staff feel confident they have the skills to involve the dying patient and those important to them in decisions about end of life care in line with their wishes and preferences (n = 475)

| 62% | 15% | 11% | 12% |

Figure 48: (SRM) Staff know how to access specialist palliative care advice, if required, when addressing specific end of life care needs for dying patients (n = 475)

| 54% | 17% | 18% | 11% |

(N.B. Totals may not equal 100% due to rounding)

Figure 49: (SRM) Staff know how to respond to requests to die outside of the hospital setting from dying people and/or those important to them (n = 477)

| 33% | 22% | 27% | 19% |

Figure 50: (SRM) Staff feel confident in their ability to discuss hydration options with dying patients and those important to them (n = 471)

| 55% | 15% | 16% | 14% |

Figure 51: (SRM) Staff feel confident in assessing and managing patient pain and physical symptoms at the end of life (n = 472)

| 48% | 15% | 18% | 19% |

Figure 52: (SRM) Staff feel confident to respond to the needs of the dying person

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
Practical/social (n = 472)	21%	45%	15%	6%	2%	11%
Spiritual/emotional/cultural (n = 470)	20%	47%	15%	6%	3%	10%

(N.B. Totals may not equal 100% due to rounding)

Figure 53: (SRM) Staff feel confident to respond to the needs of those important to the dying person

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
Practical/social (n = 466)	16%	46%	15%	8%	2%	12%
Spiritual/emotional/cultural (n = 471)	14%	47%	18%	7%	2%	12%

(N.B. Totals may not equal 100% due to rounding)

Figure 54: (SRM) Staff felt supported to deliver end of life care during the COVID-19 pandemic (n = 478)

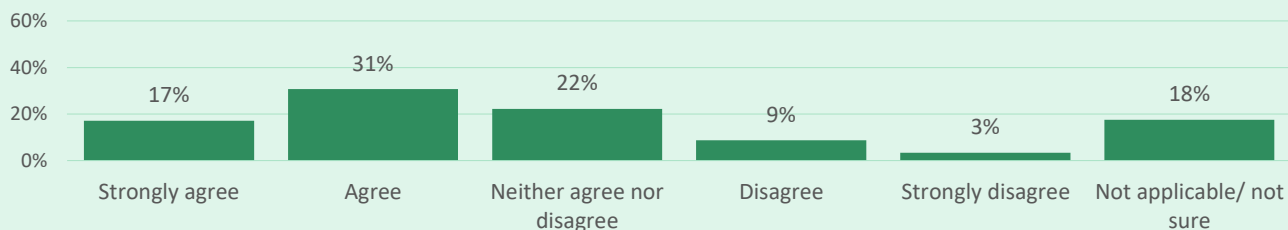| Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
9%	27%	21%	13%	7%	22%

(N.B. Totals may not equal 100% due to rounding)

Figure 55: (SRM) Staff received appropriate and responsive training to deliver end of life care during the COVID-19 pandemic (n = 478)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
7%	23%	21%	16%	12%	21%

Figure 56: (SRM) Staff felt supported by the specialist palliative care team that the hospital has access to, when addressing specific end of life care needs for dying patients (n = 471)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
17%	31%	22%	9%	3%	18%

Figure 57: (SRM) Staff have completed training specific to end of life care within the last three years (n = 474)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
11%	19%	6%	30%	20%	15%
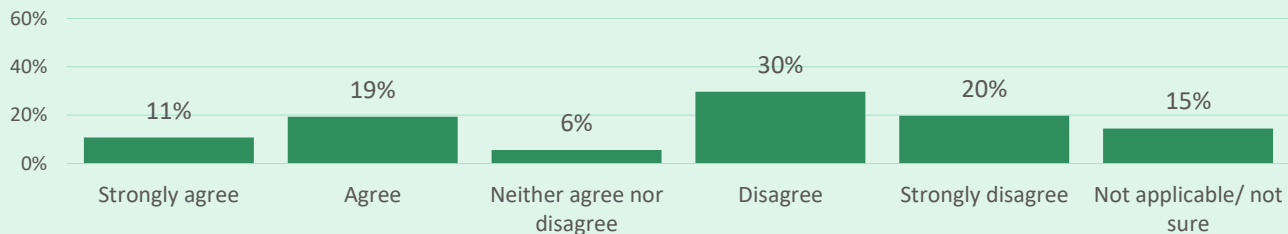
(N.B. Totals may not equal 100% due to rounding)

Figure 58: (SRM) Managerial support is available to help provide care at the end of life (n = 473)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
21%	43%	13%	8%	2%	14%

(N.B. Totals may not equal 100% due to rounding)

National Audit of Care at the End of Life
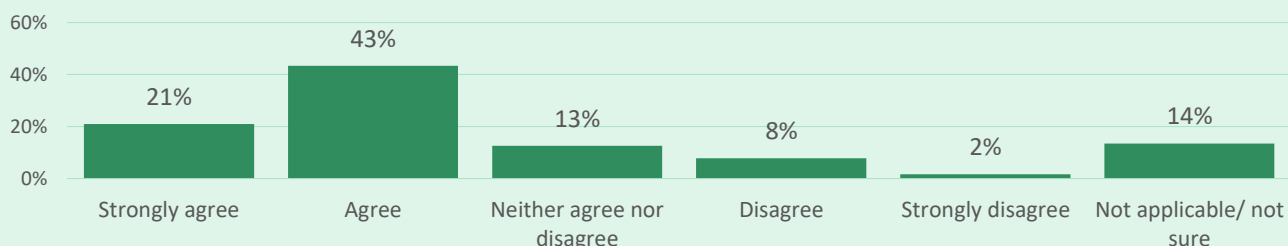
8.10 Care and culture

7.1

Figure 59: (SRM) Staff feel able to raise a concern about end of life care within the hospital if needed to (n = 474)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
25%	49%	9%	6%	2%	9%
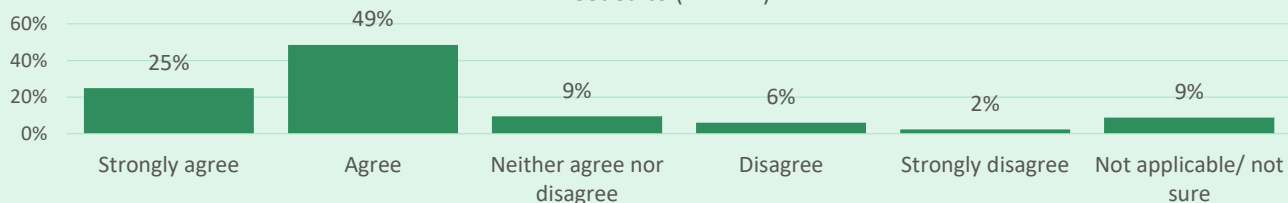
Figure 60: (SRM) Staff feel they work in a culture that prioritises care, compassion, respect and dignity as fundamental in all interactions with dying patients and those important to them (n = 469)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
33%	42%	10%	3%	1%	12%
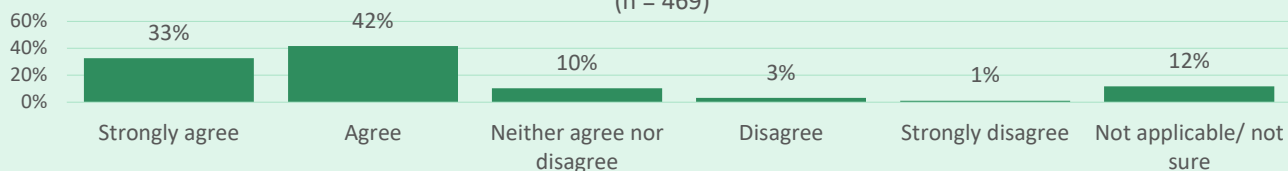
(N.B. Totals may not equal 100% due to rounding)

Figure 61: (SRM) Staff work in partnership with the dying person and those important to them in planning and making decisions about their health, treatment and end of life care (n = 471)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
21%	48%	12%	3%	1%	14%
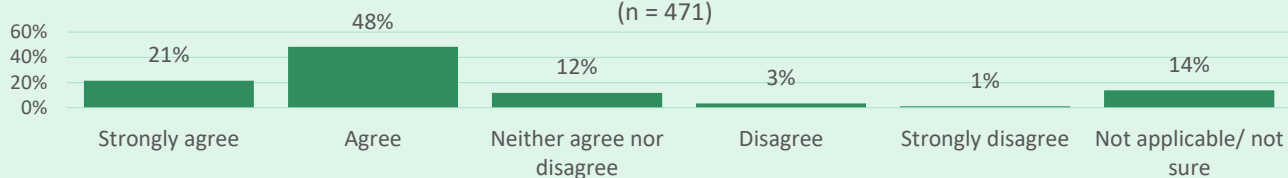
(N.B. Totals may not equal 100% due to rounding)

Figure 62: (SRM) Priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and those important to them (n = 472)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
25%	40%	13%	4%	2%	15%
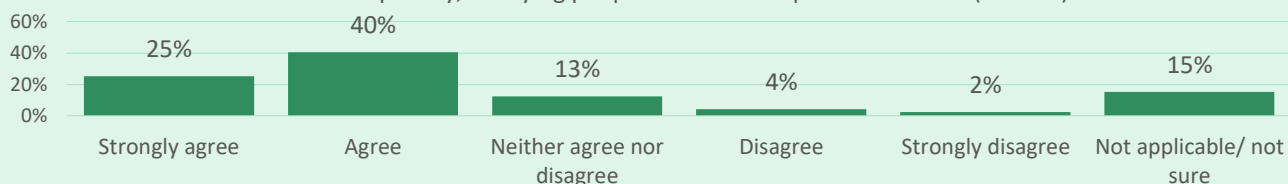
(N.B. Totals may not equal 100% due to rounding)

Figure 63: (SRM) Staff actively share information with each other about the individuals' end of life care needs (n = 468)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
24%	47%	11%	3%	1%	14%
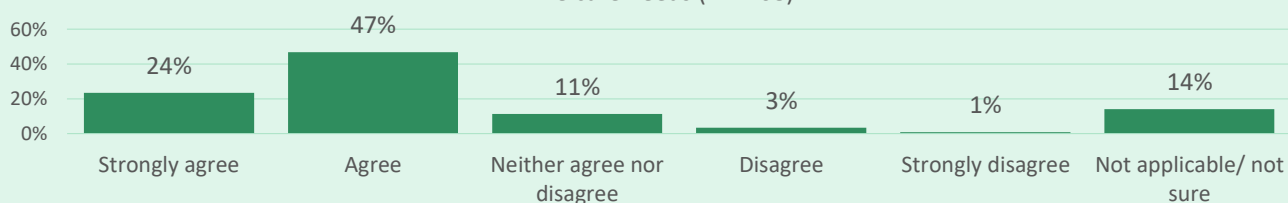
Figure 64: (SRM) Deaths are actively reviewed, and action plans are implemented to improve end of life care (n = 472)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable/ not sure
17%	33%	19%	6%	1%	24%

National Audit of Care at the End of Life

9. Acknowledgements