National Audit of Care at the End of Life

Mental Health spotlight audit (2021/22) appendices

England and Wales

Healthcare Quality Improvement Partnership

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Appendix 1: National policy context

Death and dying are the one certainty in life, and being able to live as well as possible until death happens is something we all value in our society. Not only is having a 'good' death important, but the needs of those dying, those close to them, the bereaved families, friends and carers must be addressed, with personalised preferences, choices and wishes being taken into account. End of life care affects us all in one way or another, and NACEL undertakes close scrutiny of deaths in an inpatient setting taking into account the experiences of the dying person, those close to them, and for the first time in 2021, a baseline survey on staff experience of delivering end of life care. This has been particularly challenging given that NACEL was collecting data whilst in the grip of the pandemic. This Spotlight Audit reviews deaths occurring in a mental health inpatient setting, but specifically excludes deaths as a result of suicide or homicide, deaths in learning disability beds/patients with a primary learning disability diagnosis, deaths in addictions beds and maternal deaths occurring in a Mother and Baby Unit (MBU). This is because there are other national workstreams in place pertaining to such deaths.

In order to keep pace with the evolving pandemic, with different waves occurring in different parts of the country at different times, national governments were issuing guidance for clinicians and managers at speed to keep providers of end of life care up-to-date on managing the pandemic. The full suite of guidance issued can be accessed (for England) via NICE. A suite of resources was made available to help deliver services during the pandemic, with a considerable impact on the delivery of both emergency and elective care. The effects of the pandemic will continue to be felt with a backlog of elective care for the NHS to deliver. Mental health providers were requested to discharge as many patients as possible at the start of the pandemic in March 2020, so that beds in inpatient facilities might be used if excess capacity was required.

A range of analyses have also shown that people with severe mental illness have been more likely to die from Covid-19 than the general population.

The Leadership Alliance report, undertaken in 2014, still remains relevant for end of life care delivery. It undertook a system-wide approach to improve the care of people who are dying, and those that are important to them, and published the key document *One Chance to Get It Right*, setting out an approach that all organisations can adopt in the planning and delivery of care. *One Chance To Get It Right, 2014* focuses on the *Five priorities for care of the dying person* which, along with the *NICE Quality Standards* and *guidelines*, provide the audit standards for NACEL. The Leadership Alliance was established following the Neuberger review into the Liverpool Care Pathway (LCP) which was phased out of care across acute and community hospital settings in 2013. In round two of NACEL, 100% of respondents confirmed that the LCP was not used in any circumstance of end of life care delivery.

NHS England and NHS Improvement have an ambitious and transformative approach to palliative and end of life care, during 2021 – 2026, to ensure "sustainable, responsive, personalised palliative and end of life care for all, irrespective of age, area, condition or setting".

The programme is aligned to the recently refreshed *Ambitions for Palliative and End of Life Care: A national framework for local action 2021 – 2026.* Programme ambitions are:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is co-ordinated
5. All staff are prepared to care
6. Each community is prepared to help

Appendix 1: National policy context

Further strategies pertaining to the English system for care at the end of life have been introduced and reference is made to these on page 14 of the *National Audit of Care at the End of Life – First round of the audit (2018/19) report, England and Wales*.

A Healthier Wales sets out the Welsh Government's long-term plan for health and social care in Wales. The plan commits to having a greater emphasis on preventing illness, on supporting people to manage their own health and wellbeing, and to enable people to live independently for as long as they can, supported by new technologies and by integrated health and social care services which are delivered closer to home. End of life care remains a priority for the Welsh Government and the end of life care pathway is identified as an area of initial focus within the plan.

In relation to end of life care, the current End of Life Care Delivery Plan, will reach its term in 2022, alongside the establishment of an NHS Wales Executive and a National Clinical Framework . Progress has been made with the establishment of the End of Life Care Board (EOLB) and the Palliative Care Clinical Groups (paediatric and adult) in 2009 which strengthened the 'One Wales' approach. Every Health Board in Wales has developed an End of Life Delivery Plan as part of the Welsh Government's End of Life Strategy. Annual reporting on progress using the outcome indicators identified in the strategy has been undertaken. Collaboration and engagement between statutory and voluntary services providing specialist palliative care and strategic engagement within Health Boards has also taken place, and all services have an identified executive lead and an Advance/Future Care Planning (A/FCP) lead.

The Care Decisions for the Last days of Life policy and documentation is well utilised within Wales, and is aimed at providing consistent care appropriate to patients, and those important to them, in the last days of life. Health Boards in Wales are actively working with delivery partners to embed the policy and it is being used in mental health inpatients settings.

In 2021, NHS Wales undertook a Review of Specialist Palliative Care Services in Wales from 2010 to 2021. This report reviews the developments, improvements, and challenges of the past decade of specialist palliative care services in Wales, but importantly, it highlights the areas for improvement, change, and the challenges ahead into the next decade. It details where improvement has been made through a collaboration and partnership approach, and recognises the impact of audit to positively impact on patient care. The report also contains a number of recommendations recognising the new opportunities and ambitions from the last decade, including the impact of the pandemic in Wales.

Mental health provision at the end of life sits within the broad policy objectives outlined above for both England and Wales. However, although a death in an inpatient mental health setting is not a common occurrence, it is equally important that the *Five priorities for care of the dying person* are applied in these settings. Staff should have the knowledge, skills and support to deliver effective care and treatment to patients who are approaching the end of their life, in line with the preferences, wants and needs of the patient and those important to them. The additional needs of those with complex physical, learning or mental disabilities are important to identify in end of life care planning.

There are specific requirements in mental health inpatient settings where dying patients may be subject to detention under the Mental Health Act 2005, and in such cases, Responsible Clinicians must consider whether it is appropriate to continue with detention. Where the death of a detained patient occurs, the provider Mental Health Act Administration Manager must always be informed, to ensure the CQC (in England) is notified in accordance with statutory requirements.

Appendix 1: National policy context

The Mental Capacity Act 2005 is designed to provide a legal framework for acting and making decisions on behalf of adults who lack the capacity to make decisions for themselves. The provisions of the act apply across all sectors. In addition, the Mental Capacity Act Deprivation of Liberty Safeguards was introduced as an amendment under the Mental Health Act 2007 (but forms part of the Mental Capacity Act). This provides a legal framework to ensure people are only deprived of their liberty when there is no other way to care for them or safely provide treatment. Again, this applies across all sectors but more likely to be applied in a mental health setting.

Appendix 2: Audit background and governance

NACEL was commissioned by HQIP on behalf of NHS England and the Welsh Government, with the programme beginning in October 2017, initially commissioned to run for three years with an annual audit cycle. This was extended by a further two years, running until October 2022. 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*.

The governance of NACEL has been through a multi-disciplinary Steering Group, with input from a wider Advisory Group. The membership of the Steering and Advisory Groups can be found at Appendix 20. Dr Suzanne Kite, Consultant in Palliative Medicine, and Elizabeth Rees, Lead Nurse for End of Life Care, from Leeds Teaching Hospitals NHS Trust, continue to provide joint clinical leadership of the audit. 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.

A diagrammatic representation of the governance arrangements can be found on the NACEL Project Management and Governance Structure *organogram.*

Similar to round one and two of NACEL, an audit for acute and community inpatient providers was run in 2021. The findings from the audit can be found in the Third round of NACEL Summary Report available from the NACEL outputs page.

In round three of NACEL, as in previous rounds, the Northern Ireland Public Health Agency separately commissioned the NHS Benchmarking Network to cover Northern Ireland’s participation for acute and community inpatient care. The findings for Northern Ireland are reported in a separate document.

Appendix 3: Audit objectives

NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission before death in acute, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

The audit objectives for the third round of NACEL encompass the following:

1. To refine the tools for assessing compliance with national guidance on care at the end of life – *One Chance To Get It Right*, *NICE guidelines* and the *NICE Quality Standards* for end of life care.

2. To measure the experience of care at the end of life for dying people and those important to them.

3. To provide audit outputs which enable stakeholders to identify areas for service improvement.

4. To provide a strategic overview of progress with the provision of high-quality care at the end of life in England, Wales and Northern Ireland.

Appendix 4: Audit standards

NACEL measures the performance of hospitals against criteria relating to the delivery of care at the end of life which are considered best practice. These criteria are derived from national guidance, including *One Chance To Get It Right* and *NICE Quality Standards* and *guidance*. Specifically, the audit was designed to capture information on the *Five priorities for care* of the dying person as set out in *One Chance To Get It Right.* The priorities make the dying person themselves the focus of care in the last few days and hours of life, and specifically cite outcomes which must be delivered for every dying person. The *Five priorities for care* of the dying person are as follows:

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.

2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

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.

4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

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.

The audit is also closely aligned with *NICE Quality Standards* and *guidelines*. *NICE Quality Standard 13* *End of life care for adults* covers care for adults (aged 18 and over) who are approaching their end of life. It includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers and includes care provided by health and social care staff in all settings. It describes high-quality care in priority areas for improvement. In March 2017, this quality standard was updated and statement 11 on care in the last days of life was removed and replaced by *NICE's Quality Standard 144.*

More specifically, there are two publications from NICE which outline standards which should be expected for the dying person and people important to them in the last few days of life. *NICE Clinical Guidelines NG31* *Care of dying adults in the last days of life* covers the clinical care of dying adults (18 years and over) in the last few days of life. It aims to improve care for people by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covered how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

NICE Quality Standard 144, *Care of dying adults in the last days of life*, identifies priority areas for quality improvement for the same group of people as in NG31.

Appendix 5: Audit structure and scope

The NACEL Mental Health Spotlight Audit covered the last admission to hospital prior to death and included NHS funded end of life care for adults (18+) in mental health inpatient facilitates in England and Wales.

The audit had several elements, as outlined below:-

An **Organisational Level Audit** covering:-

- **Trust/Health Board** questions - metrics completed at the trust/Health Board (HB) level covering policies and governance
- **Hospital/site questions** – metrics covering hospital/submission level questions. Organisations could create multiple 'submissions' for their different hospital sites if they wished to audit the hospitals separately. This focused on the specialist palliative care workforce, staff training, anticipatory prescribing and quality and outcomes. Additional questions were asked across on the impact of COVID-19.

A **Case Note Review** completed for each submission focused on the themes of 'recognition of imminent death', and 'individualised end of life care planning' and 'involvement in decision making'.

Mental health inpatient providers were asked to undertake a Case Note Review, for consecutive deaths from the 1st April 2021 to the 31st August 2021. The definition of deaths to be audited were closely aligned to the acute and community audit, with additional examples given for mental health deaths: -

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.
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.

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.
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.

Deaths which were classed as "**sudden deaths**" were excluded from the Case Note Review. These were deaths which were sudden and unexpected; this included, but was 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.
- deaths by suicides
- deaths in learning disability beds
- deaths in addiction beds
- maternal deaths occurring in a mother and baby unit

Appendix 5: Audit structure and scope

A **NACEL Quality Survey** designed to gain feedback from relatives, carers and those close to the person who died, on their experiences of the care and support received at the end of life.

The survey was completed online, or by telephone, by those close to the person who died within the inpatient facility between 1st April 2021 and 31st August 2021.

A **Staff Reported Measure** (Additional element of NACEL undertaken in 2021)
In line with contractual requirements, the NHSBN was tasked with including the new Staff Reported Measure (SRM), developed and piloted during 2019/20.

The SRM is a survey aimed at members of staff who are most likely to come into contact with dying patients and those important to them. The survey asked questions pertaining to staff confidence and experience in delivering care at the end of life and was completed for each submission. Staff completed the online SRM questionnaire using a unique link generated for each hospital/site or through a unique QR code. Resources were made available to trusts/HBs to encourage responses from staff. The responses were linked to each submission and were anonymous. Trusts/HBs were encouraged to have 20 SRMs completed per hospital site. Guidance was made available to trusts/HBs on which staff groups and which locations ought to be covered. Exclusions were learning disabilities, substance misuse and paediatric inpatient staff, and any wards unlikely to have dying people on them.

Appendix 6: Eligibility, recruitment and registration

All NHS providers of adult mental health inpatient care in England and Wales were eligible to take part in the Mental Health Spotlight Audit. A letter inviting each organisation to take part in the audit was sent to the Chief Executive and End of Life Care Lead, where available, and Project Leads who had registered their organisations for NACEL in previous rounds. Overall, 83% of eligible organisations participated in the Mental Health Spotlight Audit.

Registration was completed online as in previous rounds. During registration, all organisations had the option of setting up multiple submissions to cover different hospital sites, or combine the sites into one overall submission.

Appendix 7: Data collection

Data collection opened on the 1st June 2021 and closed on the 8th October 2021 for all four elements of NACEL. No extensions were given due to timescales required to complete analysis and reporting.

For the Organisational Level Audit, participants were asked to complete one trust/health board overview, and one hospital/site level questionnaire for each submission created on registration. Questions related to the period 2020/21.

For the Case Note Review, mental health hospital providers were asked to audit eligible patients for each submission created on registration; consecutive deaths between 1st April 2021 – 31st August 2021.
In addition, audit participants were also requested to complete an Audit Summary data specification with the following information:

- the number of deaths in the audit period that fit the inclusion criteria
- The number of deaths in the audit period that fit the exclusion criteria
- the number of Quality Survey letters sent.

Data collection for NACEL was via a bespoke online data entry tool for the Organisational Level Audit and the Case Note Review. The audit tool included definitional guidance for each metric requested, including additional guidance for Wales where appropriate. Excel versions of all data specifications could be downloaded to assist audit participants with internal data collation prior to the input of data onto the data collection tool.

Further validation controls were built into the system to ensure, for example, that if a death was categorised as a Category 2 death, then limited, applicable questions were available to respond to. The online data collection pages were simplified, and clearer steps were defined to enable easier responses to each audit element.

The NACEL Quality Survey and Staff Reported Measure were completed via an online questionnaire with unique links and QR codes. Additional help was made available by The Patients Association to help bereaved carers having difficulty with the online questionnaire response.

Appendix 8: Data validation and cleansing

Data validation controls were implemented on several levels within the online data collection tool. Information buttons next to each metric contained definitional guidance of the data required to ensure consistency of the data collected. In addition, system validation was implemented to protect the integrity of the data collected, including allowable ranges, expected magnitude of data fields, numerical versus text completion, appropriate decimal point placing and text formatting.

An extensive data validation exercise was undertaken from mid-October to the end of November 2021. Outlying positions and unusual data were queried with NACEL participants. A draft online toolkit was made available to NACEL participants at the beginning of November 2021 to assist with checking data submissions. The final NACEL toolkit was made available in February 2022.

The NACEL Quality Survey narrative was cleansed to remove identifiable information.

Appendix 9: NACEL Cause for concern policy

The *Cause for Concern Policy* is available on the NACEL webpages. The Cause for Concern policy was updated for round three of NACEL to include an additional process for Wales reporting.

Comments to the narrative question in the Case Note Review and the Quality Survey narrative section were reviewed by the NACEL Director and the Co-Clinical Leads. No mental health providers had any issues identified which met the formal 'Cause for concern' definition as outlined in the policy.

All comments received from respondents to the Case Note Review were fed back anonymously to participating hospitals for consideration by them in the context of their internal governance procedures. The Quality Survey narrative was not released to mental health providers, due to the risk of identification.

Appendix 10: NACEL Management of Outliers policy

The *Management of Outliers Policy* is available on the NACEL webpages. The policy has been informed by *Detection and management of outliers for national clinical audits: Implementation guide for NCAPOP providers* and approved by the NACEL Steering Group. Two indicators from the NACEL data collection are used to undertake the Management of Outliers analysis.

The Management of Outliers Policy was not instated for the NACEL Mental Health Spotlight Audit due to the small number of Case Note Reviews submitted to the audit to identify outliers.

Appendix 11: NACEL Quality Improvement Plan

The NACEL Quality Improvement Plan outlines how the findings from previous rounds of NACEL have established where trusts/HBs have better compliance against the *NICE Guidelines and Quality Standards* and the *Five priorities for care* as outlined in *One Chance To Get It Right.*

Appendix 12: Fourth round of NACEL

NACEL has been commissioned by HQIP to run as an annual audit, initially for three years from 2017 to 2020. A further two years of the audit have been commissioned via HQIP, resulting in one further round prior to the NACEL re-tender occurring in 2022.

NACEL round four will be delivered during the 2022/23 financial year. The scope and content of NACEL round four will be the same as NACEL round three with all four data elements remaining. The sample size for the number of Case Note Reviews to be completed is under discussion with the NACEL Steering Group.

There is evidence that the findings from the three rounds of NACEL completed to date are actively being used, with many audit participants providing information on the impact of their NACEL findings locally. These include having evidence for business cases for additional specialist palliative care staff, raising awareness at system level with system partners, internal dashboard developments, mechanisms to ensure capturing spiritual, religious and cultural needs and improvements in developing individualised end of life care plans. The NHSBN team, together with the Co-Clinical Leads continue to present the NACEL findings at relevant conferences and workshops.

The Mental Health Spotlight Audit will not be repeated in round four. Mental Health providers of inpatient care will not be required to participate in round four.

A NACEL 'round four warm-up' event, for acute and community hospital providers, will be held prior to data collection opening to ensure audit participants are well prepared for the requirements of round four. Feedback from round three has been reviewed and a number of improvements to NACEL processes will be implemented prior to the commencement of round four.

Appendix 13: Glossary

Acronyms and abbreviations	
CNR	**Case Note Review**
DNACPR	**Do Not Attempt Cardiopulmonary Resuscitation**
DPIA	**Data Protection Impact Assessment**
e-ELCA	**End of Life Care for All** - e-Learning
ESR	**Electronic Staff Record**
GDPR	**General Data Protection Regulation**
GMC	**General Medical Council**
H/S	**Hospital/Site** Organisational Level Audit
HB	**Health Board** (in Wales)
HDU	**High Dependency Unit**
HQIP	The **Healthcare Quality Improvement Partnership** is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices
ICS	**Integrated Care System**
ICU	**Intensive Care Unit**
IV	**Intravenous**
NACEL	The **National Audit of Care at the End of Life** commissioned by HQIP from NHSBN in October 2017
NCAPOP	**National Clinical Audit Programme and the Clinical Outcome Review Programmes**
NHSBN	The **NHS Benchmarking Network** is the in-house benchmarking service of the NHS promoting service and quality improvement through benchmarking and sharing good practice
NICE	**National Institute for Clinical Health and Excellence**
NMC	**Nursing and Midwifery Council**
OLA	**Organisational Level Audit**
QS	**Quality Survey**
SPC	**Specialist Palliative Care**
SRM	**Staff Reported Measure**

Appendix 13: Glossary

Terms used in this report	
'anticipatory medication'	Medication prescribed in anticipation of symptoms, designed to enable rapid relief at whatever time the patient develops distressing symptoms.
Audit Summary	The Audit Summary component of NACEL was requested from each hospital or site and covered four key metrics; three on the overall number of deaths within the audit period, and a final one on how many Quality Survey letters were sent to bereaved carers by the hospital or site.
Case Note Review	The patient level, Case Note Review component. A set of questions completed for each death occurring from April 2021 to August 2021 within a mental health inpatient facility (exclusions applied).
Category 1 death	Definition of deaths to be included in NACEL. 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 death	Definition of deaths to be included in NACEL. 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.
'Families and others', 'nominated person', 'next of kin', 'carer'	These terms are used interchangeably in this report to refer to 'those important to the dying person' as used in *One Chance To Get It Right*. It is recognised that some dying people do not have such a person.
'Five priorities for care'	The *Five priorities for care of the dying person* as set out in *One Chance To Get It Right.*
'Individualised plan of care'	An 'individualised plan of care' as envisaged in *One Chance To Get It Right*. This could include any form of care plan that documents an individualised plan for care at the end of life.
'Learning from deaths'	This is a national framework for NHS trusts (England only) on identifying, reporting and learning from deaths in care.
Likert Scale	A Likert Scale is a type of rating scale used to measure attitudes or opinions. With this scale, respondents are asked to rate items on a level of agreement.
Medical Examiners	From April 2019, a national system of Medical Examiners was introduced (in England and Wales) to provide greater scrutiny of deaths. The system offers a point of contact for bereaved families to raise concerns about the care provided to a loved one prior to death.
Organisational Level Audit	The Organisational Level Audit element of NACEL is where a set of questions is completed once at the trust/health board level and at overall hospital or site level. The metrics requested related to the financial year 2020/21

Appendix 13: Glossary

Terms used in this report	
Project Lead	The person who will act as the lead contact for this project within participating organisations. This role will be the primary recipient of any correspondence and will be responsible for co-ordinating the data collection.
Quality Survey	An online survey to capture the views of those important to the dying person.
Staff Reported Measure	The Staff Reported Measure element of the audit, which was piloted in round two, and implemented in round three, captures the views of staff who work closely with people who are dying and those important to them.
'submission'	A hospital or site identified by the participating organisation to be audited separately.
'sudden death'	Deaths which were sudden and unexpected; this included, but was 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. • deaths by suicide • deaths of patients in a learning disability designated bed • deaths in a designated "addictions" bed • maternal deaths in a mother and baby unit

Appendix 14: References

- **Department of Health.** *Mental Health Act 2007 (Amendments to Mental Health Act 1983).* 2007
- **Department of Health.** *Mental Capacity Act 2005.* April 2005
- **National Palliative and End of Life Care Partnership.** *Ambitions for Palliative and End of Life Care: A national framework for local action 2021 – 2026.* May 2021
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- **NICE**. Quality Standard 13, *End of life care for adults*. November 2011
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- **Welsh Government.** *A Healthier Wales: Our Plan for Health and Social Care.* 2019
- **Welsh Government/NHS Wales**. *Safe Care, Compassionate Care. A National Governance Framework to enable high quality care in NHS Wales.* January 2013
- **Welsh Government**. *National Clinical Framework: A Learning Health and Care System.* 2021
- **Welsh Health Circular.** WHC/2016/004 Care Decisions for the Last Days of Life. April 2016

Appendix 15: Method for scoring

A scoring system was devised in round one of NACEL to summarise the audit under key themes. A similar summary score methodology has been adopted for the Mental Health Spotlight Audit in England and Wales, reporting on ten themes. The scoring system used in the Mental Health Spotlight Audit aligns to the NACEL round three, acute and community audit.

This appendix sets out the component indicators of the ten key themes and an explanation of how the summary scores are calculated.

The NACEL key themes for round three were developed by the NACEL Steering Group and were discussed with the wider NACEL Advisory Group and NACEL Mental Health Reference Group. The themes are based on the *Five priorities for care*:

Key theme	National summary score
Recognising the possibility of imminent death (RD)	-
Communication with the dying person (CDP)	9.2
Communication with families and others (CFO)	8.0
Involvement in decision making (IDM)	9.4
Individual plan of care (IPC)	8.4
Governance (G)	8.4
Workforce/specialist palliative care (W/SPC)	6.4
Staff Confidence (SC)	6.5
Staff Support (SS)	5.5
Care and Culture (CC)	7.1

Only indicators from one element of the audit (either The Trust/HB overview, the Hospital/Site overview, the Case Note Review or the Staff Reported Measure) are utilised for each theme. At least four indicators were used for each summary score, to provide granularity in the results.

Note that no summary score is calculated for 'recognising the possibility of imminent death'. Summary scores calculated from the Case Note Review data, use evidence from Category 1 deaths only (It was recognised that the patient may die).

Individual summary scores for hospital submissions are not provided in the NACEL Mental Health Spotlight Audit due to the smaller amount of deaths, thus the smaller amount of data submitted. The data is instead used to give national summary scores.

Appendix 15: Method for scoring

The component indicators and scoring for each theme are as follows:

Key theme	Source	Component indicators
Recognising the possibility of imminent death (RD)	Case Note review	No summary score.
Communication with the dying person (CDP)	Case Note review	5 questions on discussions with the dying person on plan of care, the possibility that the patient may die, side effects of medication (including drowsiness), hydration and nutrition.
Communication with families and others (CFO)	Case Note review	6 questions on discussions with the nominated person on plan of care, notification of possible and imminent death, side effects of medication, hydration and nutrition.
Involvement in decision making (IDM)	Case Note review	6 questions on discussions regarding how much the patient wished to be involved in decision making and how involved the patient was in decision making.
Individual plan of care (IPC)	Case Note review	25 questions on having a care plan that was reviewed regularly, assessment of 14 needs, the benefit of starting, stopping or continuing 6 interventions, review of hydration and nutrition status and preferred place of death.
Governance (G)	Trust/HB overview	4 questions on policy/guidance regarding how it responds to deaths of patients, requests for rapid discharge and advanced care planning.
Workforce/specialist palliative care (W/SPC)	Hospital/site overview	7 questions on specialist palliative care access, seven day availability and training.
Staff Confidence (SC)	Staff Reported Measure	11 questions regarding staff confidence in delivering end of life care.
Staff Support (SS)	Staff Reported Measure	5 questions regarding the support and training provided to staff from the hospital/site.
Care and Culture (CC)	Staff Reported Measure	6 questions on the environment in which staff deliver end of life care.

Appendix 15: Method for scoring

5.2 Communication with the dying person (Source: Case Note Review)				
Section	**Question**	**Scoring**		
		Yes	No but reason recorded and/or N/A	No and no reason recorded
Recognising the possibility of imminent death	Is there documented evidence that the possibility that the patient may die had been discussed with the patient?	1	1	0
Individualised end of life care planning - The patient	Is there documented evidence that the patient was involved in discussing the individualised plan of care?	1	1	0
Individualised end of life care planning - Symptom management	Is there documented evidence that the possibility of drowsiness, if likely, as a result of prescribed medications, was discussed with the patient?	1	1	0
Individualised end of life care planning - Drinking and assisted hydration	Is there documented evidence that a discussion about the risks and benefits of hydration options was undertaken with the patient once the dying phase was recognised?	1	1	0
Individualised end of life care planning - Eating and assisted nutrition	Is there documented evidence that a discussion about the risks and benefits of nutrition options was undertaken with the patient once the dying phase was recognised?	1	1	0
Maximum possible score:		**5**		

5.3 Communication with families and others (Source: Case Note Review)				
Section	**Question**	**Scoring**		
		Yes	No but reason recorded and/or N/A	No and no reason recorded
Recognising the possibility of imminent death	Is there documented evidence that the possibility that the patient may die had been discussed with the nominated person(s)?	1	1	0
Recognising the possibility of imminent death	Is there documented evidence that the nominated person(s) was involved in discussing an individualised plan of care for the patient?	1	1	0
Recognition of dying	Is there documented evidence that the nominated person(s) were notified that the patient was about to die?	1	1	0
Individualised end of life care planning - Symptom management	Is there documented evidence that the possibility of drowsiness, if likely, as a result of prescribed medications, was discussed with the nominated person(s)?	0.5	0.5	0
Individualised end of life care planning - Drinking and assisted hydration	Is there documented evidence that a discussion about the risks and benefits of hydration options was undertaken with the nominated person(s)?	1	1	0
Individualised end of life care planning - Eating and assisted nutrition	Is there documented evidence that a discussion about the risks and benefits of nutrition options was undertaken with the nominated person(s)?	0.5	0.5	0
Maximum possible score:		**5**		

Appendix 15: Method for scoring

5.4 Involvement in decision making (Source: Case Note Review)				
Section	Question	Scoring		
		Yes	No but reason recorded and/or N/A	No and no reason recorded
Involvement in decision making	Is there documented evidence about the extent to which the patient wished to be involved in decisions about their care?	1	1	0
Involvement in decision making	Is there documented evidence in the notes that the dying person had their capacity assessed to be involved in their end of life care planning?	1	1	0
Involvement in decision making	Is there documented evidence within the final admission of a discussion with the patient by a senior clinician regarding whether to continue or stop life-sustaining treatment offering organ support such as assisted ventilation, implanted defibrillator, renal dialysis?	1	1	0
Involvement in decision making	Is there documented evidence within the final admission of a discussion with the nominated person by a senior clinician regarding whether to continue or stop life-sustaining treatment offering organ support such as assisted ventilation, implanted defibrillator, renal dialysis?	1	1	0
Involvement in decision making	Is there documented evidence that a discussion with the patient regarding Cardiopulmonary Resuscitation (CPR) was undertaken by a senior clinician?	1	1	0
Involvement in decision making	Is there documented evidence that the Cardiopulmonary Resuscitation (CPR) decision was discussed with the nominated person(s) by a senior clinician ?	1	1	0
Maximum possible score		6		

Appendix 15: Method for scoring

5.5 Individualised plan of care (Source: Case Note Review)				
Section	**Question**	**Scoring**		
		Yes	No but reason recorded and/or N/A	No and no reason recorded
Individualised end of life care planning - Advance care planning	Was there documented evidence of the preferred place of death as indicated by the patient?	1	-	0
Individualised end of life care planning - The patient	Is there documented evidence that the patient who was dying had an individualised plan of care addressing their end of life care needs?	0.5	-	0
Individualised end of life care planning - The patient	Is there documented evidence that the patient and their individualised plan of care were reviewed regularly?	0.5	0.5	0
Individualised end of life care planning - The patient	Is there documented evidence of an assessment of the following needs:			
	agitation/delirium	0.25	0.25	0
	dyspnoea/breathing difficulty	0.25	0.25	0
	nausea/vomiting	0.25	0.25	0
	pain	0.25	0.25	0
	noisy breathing/death rattle	0.25	0.25	0
	anxiety/distress	0.25	0.25	0
	bladder function	0.25	0.25	0
	bowel function	0.25	0.25	0
	pressure areas	0.25	0.25	0
	hygiene requirements	0.25	0.25	0
	mouth care	0.25	0.25	0
	emotional/psychological needs	0.25	0.25	0
	spiritual/religious/cultural needs	0.25	0.25	0
	social/practical needs	0.25	0.25	0
Individualised end of life care planning - The patient	Was the benefit of starting, stopping or continuing the following interventions documented as being reviewed in the patient's plan of care?			
	routine recording of vital signs	0.25	0.25	0
	blood sugar monitoring	0.25	0.25	0
	the administration of oxygen	0.25	0.25	0
	the administration of antibiotics	0.25	0.25	0
	routine blood tests	0.25	0.25	0
	other medication	0.25	0.25	0
Individualised end of life care planning - Drinking and assisted hydration	Is there documented evidence that the patient's hydration status was assessed daily once the dying phase was recognised?	1	-	0
Individualised end of life care planning - Eating and assisted nutrition	Is there documented evidence that the patient's nutrition status was reviewed regularly once the dying phase was recognised?	1	-	0
Maximum possible score:		**9**		

Appendix 15: Method for scoring

5.6 Governance (Source: Trust/HB Overview)			
Section	**Question**	**Scoring**	
		Yes	No
Trust/HB overview	Does your Trust/HB have an identified member of the Trust/HB board with accountability for end of life care?	1	0
Trust/HB overview	Does your Trust/ HB have policies/guidance in place which include guidelines for: How it responds to and learns from, deaths of patients who die under its management and care?	1	0
Trust/HB overview	Which of the following are used within your Trust/HB: Specific care arrangements to enable rapid discharge home to die, if this is the person's preference?	1	0
Trust/HB overview	Which of the following are used within your Trust/HB: A care plan to support the Five Priorities for Care of the Dying Person?	1	0
Maximum possible score:		**4**	

5.7 Workforce (Source: Hospital/Site Overview)				
Section	**Question**	**Scoring**		
		Yes	No but reason recorded and/or N/A	No and no reason recorded
Specialist palliative care workforce	Does your hospital have access to a Specialist Palliative Care service?	1	1	0
		Yes	**No**	
Specialist palliative care workforce	Is the face to face specialist palliative care service (doctor and/or nurse) available 8 hours a day, 7 days a week?	1	0	
Specialist palliative care workforce	Is the telephone specialist palliative care service (doctor and/or nurse) available 24 hours a day, 7 days a week?	1	0	
Staff training for all hospital/ site staff	In the period between 1st April 2020 and 31st March 2021 was the following available:			
	End of life care training included in Induction Programme	0.25	0	
	End of life care training included in Mandatory/ Priority Training	0.25	0	
	Communication skills training specifically addressing end of life care	0.25	0	
	Other training in relation to end of life care	0.25	0	
Maximum possible score		4		

Appendix 15: Method for scoring

5.8 Staff Confidence (Source: Staff Reported Measure)								
Section	**Question**	**Scoring**						
		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A/Not sure
Questions about you	I am confident I can recognise when a patient might be dying imminently (within hours to days)	4	3	2	1	0	2
Questions about you	I feel confident in my skills to communicate clearly and sensitively to dying patients and those important to them	4	3	2	1	0	2
Questions about you	I am confident I 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	4	3	2	1	0	2
Questions about you	I know how to access specialist palliative care advice, if required, when addressing specific end of life care needs for dying patients	4	3	2	1	0	2
Questions about you	I know how to respond to requests to die outside of the hospital setting from dying people and/or those important to them	4	3	2	1	0	2
Questions about you	I feel confident to respond to the practical and social needs of the dying person	4	3	2	1	0	2
Questions about you	I feel confident to respond to the spiritual, emotional and cultural needs of the dying person	4	3	2	1	0	2
Questions about you	I am confident in my ability to discuss hydration options with dying patients and those important to them	4	3	2	1	0	2
Questions about you	I am confident in assessing and managing patient pain and physical symptoms at the end of life	4	3	2	1	0	2
Questions about you	I feel confident to respond to the practical and social needs of those important to the dying person	4	3	2	1	0	2
Questions about you	I feel confident to respond to the spiritual, emotional and cultural needs of those important to the dying person	4	3	2	1	0	2
Maximum possible score		**44**					

Appendix 15: Method for scoring

5.9 Staff Support (Source: Staff Reported Measure)								
Section	Question	Scoring						
		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A/Not sure
Work during the COVID-19 pandemic	I received appropriate and responsive training to deliver end of life care during the COVID-19 pandemic	4	3	2	1	0	2
Work during the COVID-19 pandemic	I felt supported to deliver end of life care during the COVID-19 pandemic	4	3	2	1	0	2
Questions about you	I feel supported by the specialist palliative care team that the hospital has access to, when addressing specific end of life care needs for dying patients	4	3	2	1	0	2
Questions about you	I have completed training specific to end of life care within the last three years	4	3	2	1	0	2
Clinical area/area you work in	Managerial support is available to help provide care at the end of life	4	3	2	1	0	2
Maximum possible score		**20**					

5.10 Staff Care and Culture (Source: Staff Reported Measure)								
Section	**Question**	**Scoring**						
		Strongly agree	Agree	Niether agree nor disagree	Disagree	Strongly disagree	N/A/Not sure
Questions about you	I would feel able to raise a concern about end of life care within my hospital if I needed to	4	3	2	1	0	2
Clinical area/area you work in	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	4	3	2	1	0	2
Clinical area/area you work in	Priority is given to the provision of an appropriate peaceful environment, that maximises privacy, for dying people and those important to them	4	3	2	1	0	2
Clinical area/area you work in	Staff actively share information with each other about the individuals' end of life care needs	4	3	2	1	0	2
Clinical area/area you work in	Deaths are actively reviewed, and action plans are implemented to improve end of life care	4	3	2	1	0	2
Clinical area/area you work in	We have a culture that priorities care, compassion, respect and dignity as fundamental in all interactions with dying patients and those important to them	4	3	2	1	0	2
Maximum possible score		**24**					

Appendix 16: Patient demographics

Age profile	All deaths	Category 1	Category 2
18-64	14.67%	7.14%	36.84%
65-74	21.33%	23.21%	15.79%
75-84	32.00%	32.14%	31.58%
85-94	30.67%	35.71%	15.79%
95+	1.33%	1.79%	0.00%
Number of responses	**75**	**56**	**19**

Age	All deaths	Category 1	Category 2
Range	37-97	56-97	37-93
Mean	77	80	68
Median	80	82	73
Number of responses	**75**	**56**	**19**

Usual place of residency	All deaths	Category 1	Category 2
Home	53.33%	50.00%	63.16%
Residential home	9.33%	10.71%	5.26%
Nursing home	20.00%	25.00%	5.26%
Prison	0.00%	0.00%	0.00%
No fixed abode	1.33%	0.00%	5.26%
NHS other hospital provider	9.33%	10.71%	5.26%
Other	6.67%	3.57%	15.79%
Number of responses	**75**	**56**	**19**

Gender profile	All deaths	Category 1	Category 2
Male	70.67%	71.43%	68.42%
Female	29.33%	28.57%	31.58%
Other	0.00%	0.00%	0.00%
Number of responses	**75**	**56**	**19**

Ethnicity profile	All deaths	Category 1	Category 2
White	85.33%	92.86%	63.16%
Mixed	0.00%	0.00%	0.00%
Asian or Asian British	1.33%	1.79%	0.00%
Black or Black British	8.00%	0.00%	31.58%
Other Ethnic Groups	0.00%	0.00%	0.00%
Not stated	5.33%	5.36%	5.26%
Number of responses	**75**	**56**	**19**

Appendix 17: Characteristics of deaths in hospitals

Primary cause of death	All deaths	Category 1	Category 2
Cancer	5.41%	7.14%	0.00%
Chronic respiratory disease	0.00%	0.00%	0.00%
COVID-19	4.05%	5.36%	0.00%
Dementia	36.49%	46.43%	5.56%
Heart failure	6.67%	5.36%	11.11%
Neurological conditions	0.00%	0.00%	0.00%
Pneumonia	12.16%	12.50%	11.11%
Renal failure	0.00%	0.00%	0.00%
Stroke	0.00%	0.00%	0.00%
Other	16.22%	8.93%	38.89%
No access to death certificate	18.92%	14.29%	33.33%
Number of responses	**74**	**56**	**18**

Day of death	All deaths	Category 1	Category 2
Monday	17.57%	17.86%	16.67%
Tuesday	16.22%	19.64%	5.56%
Wednesday	9.46%	8.93%	11.11%
Thursday	25.68%	26.79%	22.22%
Friday	6.76%	3.57%	16.67%
Saturday	8.11%	3.57%	22.22%
Sunday	16.22%	19.64%	5.56%
Number of responses	**74**	**56**	**18**

Time of death	All deaths	Category 1	Category 2
00:00 – 06:00	20.55%	19.64%	23.53%
06:01 – 12:00	21.92%	19.64%	29.41%
12:01 – 18:00	19.18%	19.64%	17.65%
18:01 – 23:59	38.36%	41.07%	29.41%
Number of responses	**73**	**56**	**17**

Length of stay profile	All deaths	Category 1	Category 2
0 – 1 days	4.17%	3.57%	6.25%
2 – 10 days	8.33%	1.79%	31.25%
11 – 20 days	8.33%	8.93%	6.25%
21 – 30 days	5.56%	5.36%	6.25%
31 – 40 days	13.89%	12.50%	18.75%
41 – 50 days	4.17%	5.36%	0.00%
51 – 60 days	5.56%	7.14%	0.00%
61 – 70 days	11.11%	10.71%	12.50%
71 – 80 days	2.78%	3.57%	0.00%
81 – 90 days	4.17%	5.36%	0.00%
90+	31.94%	35.71%	18.75%
Number of responses	**72**	**56**	**16**

Appendix 18: Staff Reported Measure demographics

Gender profile	
Male	21.76%
Female	78.24%
Other	0.00%
Number of responses	**478**

Ethnicity profile	
White	77.29%
Mixed	2.08%
Asian or Asian British	7.71%
Black or Black British	9.38%
Other Ethnic Groups	1.67%
Not stated	1.88%
Number of responses	**480**

Staff group			
Registered nurse (Band 5 or 6)	31.52%	Social worker	0.21%
Registered nurse (Band 7 or above)	19.62%	Therapy assistant	0.42%
Healthcare assistant (Band 2 - 4)	30.27%	Pharmacist	0.00%
Doctor (Consultant)	4.80%	Chaplain	0.00%
Doctor (Foundation)	1.04%	Ward based administration/support	1.46%
Doctor (Speciality training)	0.21%	Housekeepers	0.63%
Doctor (Other)	0.63%	Porters	0.00%
Allied health professional	7.31%	Other	1.88%
Number of responses		**479**	

Main clinical area that the staff member is based in	
Mental health adult acute	9.49%
Mental health PICU	0.63%
Mental health eating disorders	0.63%
Mental health low secure	2.95%
Mental health medium secure	4.22%
Mental health high secure	3.16%
Mental health older adult acute	55.70%
Mental health high dependency rehabilitation	2.53%
Mental health longer term complex/continuing care	4.22%
Mental health neuropsychiatry/acquired brain injury	3.16%
Other mental health unit location	13.29%
Number of responses	**474**

Length of time the staff member has worked in this hospital profile	
Less than a year	10.00%
1-5 years	41.04%
6-10 years	14.17%
More than 10 years	34.79%
Number of responses	**480**

Capacity in which the staff member typically comes into contact with patients at the end of life (usual role)	
Senior clinician (nurse/doctor) responsible for leading patient care	26.11%
Caring for patients as a member of the ward team	60.08%
Working in an advisory capacity across different areas	6.37%
Provide non-clinical care	7.43%
Number of responses	**471**

Appendix 19: Audit summary

Number of deaths (with exclusions)	Average per submission
Number of deaths within the audit period (excl. deaths in A&E and within 4 hours of admission) as a percentage of all deaths in the audit period	67.28%
Number of responses	**33**

Number of deaths excluded	Average per submission
Number of deaths excluded within the audit as a period as a percentage of all deaths in the audit period	32.72%
Number of responses	**33**

Number of Quality Surveys sent	Average per submission
Number of Quality Surveys sent	0.33
Surveys returned as a percentage of letter sent	87.5%

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

The National Audit of Care at the End of Life Steering Group		
Name	**Title**	**Representing**
Dr Suzanne Kite	Co-Clinical Lead, NACEL	NACEL
Elizabeth Rees	Co-Clinical Lead, NACEL	NACEL
Dr Anushta Sivananthan	Mental Health Clinical Lead, NACEL	NACEL
Claire Holditch	Project Director, NACEL	NHS Benchmarking Network
Debbie Hibbert	Project Manager, NACEL	NHS Benchmarking Network
Professor Bee Wee CBE	National Clinical Director for End of Life Care	NHS England/Improvement
Dr Helen Milbourn	Consultant Geriatrician	British Geriatrics Society
Caroline Nicholson	Senior Clinical Lecturer, Supportive and End of Life Care	British Geriatrics Society
Gloria Clark	Project Manager	The Patients Association
Dr Joe Cosgrove	Consultant in Anaesthesia and Intensive Care Medicine	Royal College of Anaesthetists/Faculty of Intensive Care Medicine
Dr Sarah Cox	Consultant in Palliative Care	Large acute hospitals
Andrew Dickman	Consultant Pharmacist – Palliative Care	Association of Supportive and Palliative Care Pharmacists
Dr Catriona Mayland	Consultant in Palliative Medicine and Senior Clinical Research Fellow	Research/Academic Interest
Professor John Ellershaw	Director of the Palliative Care Institute, University of Liverpool	Association for Palliative Medicine
Dr David Brooks	Chair, JSC in Palliative Care/Macmillan Consultant in Palliative Care	Royal College of Physicians
Sherree Fagge	End of Life Care Lead	NHS England/Improvement
Annette Furley	End of Life Doula/Member of NICE guideline committee	NACEL lay representative
Sarah Tilsed	Head of Patient Partnerships	The Patients Association
Rachel Power	Chief Executive	The Patients Association
Dr Melanie Jefferson	Welsh Lead for NACEL	NHS Wales
Dr Di Laverty	Chair	National Nurses Group (Palliative Care)
Giselle Martin-Dominguez	Professional Lead for End of Life Care	Royal College of Nursing
Dr Amelia Swift	Professional Lead for End of Life Care	Royal College of Nursing
Dr Catherine Millington-Sanders	General Practitioner	Royal College of General Practitioners
Ann Ford	End of Life Lead	Care Quality Commission
Tina Strack	Associate Director, Quality & Improvement	Healthcare Quality Improvement Partnership (HQIP)
Kevin Tromans	Chaplain	College of Healthcare Chaplains
Diane Walker	Palliative Care in Partnership Macmillan Programme Manager	Northern Ireland Public Health Agency

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

The National Audit of Care at the End of Life Advisory Group		
Name	Title	Representing
Dr Amit Arora	Consultant Geriatrician	University Hospital of North Midlands
Ashling Lillis	Consultant in Emergency Medicine	Macmillan Cancer Care
Jennifer Beveridge	Analyst, Uptake and Impact	The National Institute for Health and Care Excellence
Dr Sarah Holmes	Medical Director	Marie Curie - UK
Dr Sally Carding	Consultant in Palliative Medicine	Sue Ryder
Dawn Hart	Senior Clinical and Quality Improvement Lead	Hospice UK
Dr Thomas Cowling	Assistant Professor, Department of Health Services Research and Policy Faculty of Public Health and Policy London School of Hygiene and Tropical Medicine	Royal College of Surgeons
Susan Dewar	District Nurse	Sussex Community NHS Foundation Trust
Vivien Dunne	Project Manager	Healthcare Quality Improvement Partnership (HQIP)
Ray Elder	Strategic Lead Palliative Care	South Eastern Health and Social Care Trust
Peter Bower	Representative	Healthwatch UK
Dr Paul Hopper	Consultant Psychogeriatrician	Central and North West London NHS Foundation Trust
Johanna Kuila	Policy Manager – Education Policy	General Medical Council
Dr Paul Perkins	Chief Medical Director	Sue Ryder
John Powell	End of Life Lead	Association of Directors of Adult Social Services (ADASS)
Charlotte Rock	Regional co-clinical lead for EoLC/Palliative Care for Yorkshire & the Humber/Palliative Care Lead Nurse	Harrogate and District NHS Foundation Trust
Dr Joy Ross	Consultant in Palliative Medicine	St Christopher's Hospice
Lucie Rudd	End of Life Specialist Advisor	Macmillan Cancer Care
Dr Rebekah Schiff	Consultant Geriatrician and General Medicine/Service Lead Ageing and Health	Guys and St Thomas' NHS Foundation Trust
Veronica Snow	Palliative Care Implementation Board - Wales	Powys University Health Board
Lucy Sutton	End of Life Care Lead	Health Education England
Jessica Watkin	Policy Manager – Standards and Ethics	General Medical Council
Dr Victoria Wheatley	Consultant in Palliative Care	Cwm Taf University Health Board

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

The National Audit of Care at the End of Life Mental Health Reference Group		
Name	Title	Representing
Dr Anushta Sivananthan	NACEL Mental Health Clinical Lead / Medical Director	Cheshire & Wirral NHS Foundation Trust
Alison Rickard	Mental Health and Learning Disability Service Group	Swansea Bay University Health Board
Andy Wardle	Nurse (Physical Health)	North Straffordshire Combined Healthcare NHS Trust
Ann Thomas	Nurse Consultant	Tees, Esk & Wear Valley NHS Foundation Trust
Bina Jumnoodoo	Head of Nursing	Hertfordshire Partnership University NHS Foundation Trust
Brid Kelly	Practice Audit and Clinical Effectiveness (PACE) Manager	Hertfordshire Partnership University NHS Foundation Trust
Corrina Bentley	Clinical Audit Manager	North Straffordshire Combined Healthcare NHS Trust
Dorothy Matthews	Macmillan nurse for LD patients	Northumberland Tyne and Wear NHS Foundation Trust
Dr Paul Hopper	Old Age Psychiatrist	Central and North West London NHS Foundation Trust
Elizabeth Davies	Deputy Director, MH and Vulnerable Groups	Welsh Government
Emma Walsh	Clinical Audit & Effectiveness Facilitator	Berkshire Healthcare NHS Foundation Trust
Fiona McDowall	Consultant old age psychiatrist	Essex Partnership University NHS Foundation Trust
Guy Whalley	Clinical Audit Lead	Surrey and Borders Partnership NHS Foundation Trust
Helen Hanks	Occupational Therapist and Quality Improvement Manager	Devon Partnership NHS Trust
Jason Hibbitt	Quality Accounts and NICE Lead	Berkshire Healthcare NHS Foundation Trust
Joanne Reay	MH Commissioner	NHS West Essex CCG
Julie Young	Challenging Behaviour Lead Practitioner	Northumberland Tyne and Wear NHS Foundation Trust
Leah Penny	Acting ward sister on a Mental health for Older people ward	Cardiff and Vale UHB - Palliative Care
Lesley Chapman	Associate Nurse Consultant	Tees, Esk & Wear Valley NHS Foundation Trust
Lynn Dolan	Clinical Audit Facilitator (North Locality/ NICE Implementation/National Audits)	Northumberland Tyne and Wear NHS Foundation Trust
Marie Williams	Lead Nurse - Quality Improvement	Swansea Bay University Health Board
Suzi Lloyd-Ellington	Mortality and Incident Review Practitioner	Mersey Care NHS Foundation Trust
Tracy Reed	Clinical Lead on End of Life Care	Essex Partnership University NHS Foundation Trust
Wendy Harlow	Clinical Audit Team Leader	Sussex Partnership NHSFT

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

The National Audit of Care at the End of Life Audit Team		
Name	Title	Representing
Claire Holditch	NACEL Director	NHS Benchmarking Network
Debbie Hibbert	NACEL Project Manager	NHS Benchmarking Network
Jessica Grantham	Head of Technology	NHS Benchmarking Network
Jessica Walsh	Project Manager	NHS Benchmarking Network
Joylin Brockett	Project Manager	NHS Benchmarking Network
Chloe Hocking	Project Coordinator	NHS Benchmarking Network
Paris Selby-Grace	Project Coordinator	NHS Benchmarking Network
Michael Wong	Project Coordinator	NHS Benchmarking Network

Appendix 21: Audit participation

Organisation and submission	T/HB	H/S	CNR	SRM	QS
Aneurin Bevan University Health Board - ABUHB MH	-	✓	0	0	0
Avon and Wiltshire Mental Health Partnership NHS Trust	✓	✓	5	0	0
Berkshire Healthcare NHS Foundation Trust - Mental Health Inpatients	✓	✓	0	0	0
Betsi Cadwaladr University Health Board - Mental Health	✓	✓	3	27	0
Birmingham and Solihull Mental Health NHS Foundation Trust	✓	✓	2	21	1
Black Country Healthcare NHS Foundation Trust	✓	✓	0	0	0
Bradford District NHS Foundation Trust	✓	✓	0	8	0
Cambridgeshire and Peterborough NHS Foundation Trust - CPFT: Adult and Specialist Mental Health Wards	✓	✓	0	0	0
Cambridgeshire and Peterborough NHS Foundation Trust - CPFT: OPAC Mental Health Wards	✓	✓	0	0	0
Camden and Islington NHS Foundation Trust	✓	✓	1	7	0
Central and North West London NHS Foundation Trust - CNWL Mental Health Units	✓	✓	0	14	0
Cheshire and Wirral Partnership NHS Foundation Trust	✓	✓	0	0	0
Cornwall Partnership NHS Foundation Trust - MH	-	-	2	0	0
Coventry and Warwickshire Partnership NHS Trust	✓	✓	1	1	0
Cumbria Northumberland Tyne and Wear NHS Foundation Trust	✓	✓	0	0	0
Cwm Taf Morgannwg University Local Health Board - Mental Health	✓	✓	10	21	0
Devon Partnership NHS Trust	✓	✓	1	21	1
Dorset HealthCare University NHS Foundation Trust	✓	-	0	0	0
East London NHS Foundation Trust - Mental Health	✓	✓	6	4	0
Essex Partnership University NHS Foundation Trust - MH	✓	✓	0	20	0
Gloucestershire Health and Care NHS Foundation Trust - MH	✓	✓	0	31	0
Greater Manchester Mental Health NHS Foundation Trust	✓	✓	1	3	0
Herefordshire and Worcestershire Health and Care NHS Trust - Mental Health	✓	✓	1	5	0
Hertfordshire Partnership University NHS Foundation Trust	✓	✓	2	20	0
Hywel Dda University Health Board - Mental Health	✓	✓	4	10	0
Lancashire & South Cumbria NHS Foundation Trust - Mental Health	✓	✓	0	4	0
Leeds and York Partnership NHS Foundation Trust	✓	✓	0	25	0
Lincolnshire Partnership NHS Foundation Trust	✓	✓	0	0	0

Appendix 21: Audit participation

Organisation and submission	T/HB	H/S	CNR	SRM	QS
Livewell Southwest - Mental Health	✓	✓	3	0	0
Mersey Care NHS Foundation Trust	✓	✓	0	3	0
Midlands Partnership NHS Foundation Trust - Mental Health	✓	✓	0	16	0
Norfolk and Suffolk NHS Foundation Trust	✓	✓	1	10	0
North Staffordshire Combined Healthcare NHS Trust	✓	✓	4	26	3
North West Boroughs Healthcare NHS Foundation Trust	✓	✓	0	0	0
Northamptonshire Healthcare NHS Foundation Trust - Mental Health Wards	✓	✓	0	13	0
Northumbria Healthcare NHS Foundation Trust – NT (IP Psych wards)	✓	✓	1	0	0
Nottinghamshire Healthcare NHS Foundation Trust - FS	✓	✓	0	14	0
Nottinghamshire Healthcare NHS Foundation Trust - MHS	✓	✓	0	23	0
Oxford Health NHS Foundation Trust - Mental Health	-	✓	0	21	0
Oxleas NHS Foundation Trust - Mental Health	✓	✓	1	0	0
Pennine Care NHS Foundation Trust - Bury Adult & Older Adult	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Oldham Adult & Older Adult	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Rochdale Adult & Older Adult	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Rochdale RHS	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Stockport Adult & Older Adult	✓	✓	2	39	0
Pennine Care NHS Foundation Trust - Stockport RHS	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Tameside Adult & Older Adult	✓	✓	0	0	0
Pennine Care NHS Foundation Trust - Tameside RHS	✓	✓	0	0	0
Sheffield Health and Social Care NHS Foundation Trust	✓	✓	0	0	0
Somerset NHS Foundation Trust - MH	✓	✓	1	4	0
South West London and St George's Mental Health NHS Trust	✓	-	0	20	0
South West Yorkshire Partnership NHS Foundation Trust - MH	✓	✓	0	0	0
Southern Health NHS Foundation Trust - MH	✓	✓	0	12	0
St Andrew's Healthcare	✓	✓	4	36	3
Surrey and Borders Partnership NHS Foundation Trust	✓	✓	0	0	0
Sussex Partnership NHS Foundation Trust	✓	✓	2	1	0
Swansea Bay University Health Board - Mental Health	✓	-	8	0	0
Tees, Esk and Wear Valleys NHS Foundation Trust	✓	✓	9	1	0

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