

Understanding Practice in Clinical Audit and Registries tool: UPCARE-tool

A protocol to describe the key features of clinical audits and registries

NATIONAL AUDIT OF CARE AT THE END OF LIFE (NACEL)



Benchmarking Network



National Audit of
Care at the End of Life

FAQ
Who should complete the tool?
This tool is designed to be completed by individuals and organisations planning and implementing clinical audits and registries. It has been specifically designed for national clinical audits and registries commissioned by the Healthcare Quality Improvement Programme (HQIP; Part of the National Health Service in England) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP), but can be adapted and used by audits and registries in other settings.
What is the tool for?
The tool is a protocol for audits and registries. It has been designed to provide a “one-stop” summary of the key information about how clinical audits and registries have been designed and carried out. It is expected that this will be published openly for anyone to view, and help users of audit/registry data and audit/registry participants understand the methods, evaluate the quality and robustness of the data, and find information and data that is most relevant to them. For national clinical audits and registries commissioned by HQIP, the intention is that publishing this information openly will reduce the requirement for reporting ad hoc and contract monitoring data and information to HQIP and other national agencies.
What type of information is contained within UPCARE?
It is intended that the responses to the tool are factual and written concisely. Where possible, documents can be embedded and hyperlinks provided if information is published elsewhere. This document is intended to be a complete account of the information for the audit or registry. Please be vigilant about keeping any links included in the document up to date so readers can access full information about the audit or registry. This tool is not intended to be used to formally “score” the quality of the responses. The design of this tool has been inspired by reporting checklists used for clinical guidelines (e.g. AGREE ¹) and in reporting research studies (e.g. STROBE ² , SQUIRE ³).
Who is the intended audience for the tool?
The information contained within the UPCARE tool will enable audit and registry stakeholders to access in one place and in a standard format key information about the audit/registry and evaluate the integrity and robustness of the audit. Examples of audit/registry stakeholders include: <ul style="list-style-type: none"> • Patients/Carers/Public/Patient representative organisations • Clinicians/Allied health professionals/Healthcare providers/Multi-disciplinary teams/Primary, secondary and tertiary care providers • National agencies • Commissioners • Healthcare regulators

¹ AGREE stands for the Appraisal of Guidelines for Research & Evaluation. See <https://www.agreetrust.org/about-the-agree-enterprise/introduction-to-agree-ii/>, last accessed 24 April 2018.

² STROBE stands for Strengthening the Reporting of Observational Studies in Epidemiology. See <https://www.strobe-statement.org/index.php?id=strobe-home>, last accessed 24 April 2018.

³ SQUIRE stands for Standards for Quality Improvement Reporting Excellence. See <http://www.squire-statement.org/>, last accessed 24 April 2018.

FAQ (cont'd)

How should the responses be written?

Please try and write responses clearly as this will help to make the tool accessible and useful. Some tips and suggestions for writing clearly include:

- avoiding technical jargon where possible
- using short paragraphs and bullet points
- using the “active” voice rather than passive
- keeping sentences short

Where information is published openly elsewhere please provide links and references rather than duplicating information that is already available

When and how often should I complete the tool?

The tool is intended to provide accurate and up to date information about the audit/registry, and so can be updated whenever and however frequently it is relevant to do so. For national clinical audits and registries commissioned by HQIP it is intended that the tool is updated annually, although audits can update the tool more frequently if they wish to.

Each version of the tool should include a date of publication and version number.

Where should the completed UPCARE report be published?

The completed tool should be published online e.g. on the website for the audit or registry.

How was UPCARE designed?

HQIP commission, manage and develop the NCAPOP (National Clinical Audit and Patient Outcomes Programme) under contract from NHS England and devolved nations. The work was led by HQIP who set up a Methodological Advisory Group (MAG) consisting of methodological, statistical and quality improvement experts. Meetings were held on a six monthly basis and the structure and content of the eight quality domains and their key items were agreed by the MAG. The tool was piloted by 5 programmes within the NCAPOP and re-edited in light of comments received. Other comments received by MAG members was also considered as part of the re-editing process. The final version of the UPCARE tool was signed off by the HQIP MAG and will be reviewed annually.

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Contents

Understanding Practice in Clinical Audit and Registries (UPCARE).....	1
FAQ.....	2
Domain 1: Organisational information	6
1.1. The name of the programme	6
1.2. The name of the organisation carrying out the programme	6
1.3. Main website for the programme.....	6
1.4. Date of publication and version number of the tool on your website	6
Domain 2: Aims and objectives.....	7
2.1. Overall aim	7
2.2. Quality improvement objectives.....	7
Domain 3: Governance and programme delivery.....	8
3.1. Organogram	8
3.2. Organisations involved in delivering the programme	8
3.3. Governance arrangements	10
3.4. Declarations and Conflicts of interest.....	10
Domain 4: Information security, governance and ethics.....	10
4.1. The legal basis of the data collection.....	10
4.2. Information governance and information security.....	11
Domain 5: Stakeholder engagement	12
5.1. Approaches to involving stakeholders.....	12
Domain 6: Methods	13
6.1. Data flow diagrams	13
6.2. The population sampled for data collection	13
6.3. Geographical coverage of data collection.....	15
6.4. Dataset for data collection.....	16
6.5. Methods of data collection and sources of data	16
6.6. Time period of data collection	17
6.7. Time lag between data collection and feedback	17
6.8. Quality measures included in feedback.....	18
6.9. Evidence base for quality measures	19
6.10. Case ascertainment.....	19
6.11. Data analysis	20
6.12. Data linkage.....	21
6.13. Validation and data quality.....	21

Domain 7: Outputs.....	22
7.1. The intended users or audience for the outputs.....	22
7.2. Editorial independence.....	23
7.3 The modalities of feedback and outputs	23
7.4 Recommendations	25
7.5 Comparators and benchmarking	25
7.6 Motivating and planning quality improvement.....	26

Domain 1: Organisational information

1.1. The name of the programme

National Audit of Care at the End of Life (NACEL)

1.2. The name of the organisation carrying out the programme

The NHS Benchmarking Network

1.3. Main website for the programme

<https://www.nhsbenchmarking.nhs.uk/nacel>

Note that these are the webpages available publicly; the results pages (online benchmarking toolkit) are available to participants only

1.4. Date of publication and version number of the tool on your website

Version 1 – September 2019

Uploaded to NACEL webpages 13th September 2019

Domain 2: Aims and objectives

2.1. Overall aim

Note:

A short description of the overall aim(s) of the programme

To improve the quality of care of adults (18+) at the end of life in acute, mental health inpatient facilities and community hospitals.

2.2. Quality improvement objectives

Note:

A list or description of the key quality improvement (QI) objectives of the programme.

A brief rationale for how the QI objectives were chosen. Please take into consideration evidence to support the QI objectives, including the COMET (Core Outcome Measures in Effectiveness Trials) initiative⁴.

Audit objectives for round 1 of NACEL:

- To establish whether appropriate structures, policies and training are in place to support high quality care at the end of life.
- To assess compliance with national guidance on care at the end of life.
- To determine what is important to dying people and those important to them.
- To provide audit outputs which enable stakeholders to identify areas for service

Audit objectives for the second round of NACEL:

⁴ The COMET initiative, established through funding from the Medical Research Council (MRC) North West Hub for Trials Methodology brings together people who are interested in developing and applying agreed standardised sets of outcomes known as core outcome sets (COS). The COMET website states that *'These [COS] sets should represent the minimum that should be measured and reported in all clinical trials, audits of practice or other forms of research for a specific condition.'* (<http://www.comet-initiative.org/about/overview>, accessed 24 April 2018). COMET has an online database of projects, trials, research etc., which can be searched to identify COS in a particular health area or population. The use of COMET and COS is endorsed by organisations such as the Health Research Authority (HRA), the National Institute for Health Research (NIHR), Cochrane Collaboration and other national and international organisations. See <http://www.comet-initiative.org/> for full information (last accessed 24 April 2018)

- 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.
- To measure the experience of care at the end of life for dying people and those important to them.
- To provide audit outputs which enable stakeholders to identify areas for service improvement.
- 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.

Domain 3: Governance and programme delivery

3.1. Organogram

Note:

Please attach a diagram (e.g. organogram) describing how the programme is organised

The diagram should demonstrate lines of accountability and responsibility, and include all governance groups, e.g. project team, Board, patient and public involvement, clinical reference groups, steering groups.



NACEL Organogram
2018.pdf

3.2. Organisations involved in delivering the programme

Note:

A list of organisations with a formal role in delivering the programme. This includes organisations which:

- Are contracted to carry out elements of the programme
- Have a formal role in governing or steering the programme

For each organisation list:

- Name
- Website URL if available
- A description of its role in the programme

A key partner in delivering NACEL is the Patients Association. Their webpages can be found at the following link:-

<https://www.patients-association.org.uk/>

The Patients Association has taken a lead role in developing, piloting/testing and providing advice to the NACEL Steering Group on the Carer Reported measured (now renamed the NACEL Quality Survey). The Patients Association has a representative on the NACEL Steering Group to ensure that a PPI perspective is considered for every element of NACEL.

End of Life Stakeholders are represented on either the NACEL [Steering Group](#) or the NACEL [Advisory Group](#).

3.3. Governance arrangements

Note:

Governance of the project should include representatives from all key stakeholders. Please describe the governance arrangements including:

- A list of individuals within each governance group described in the organogram (or the URL of where this information is available on the programme website)
- The process used for sign-off indicating that the audit or registry data/feedback/reports have been quality assured and are ready for release
- If available, the URL to publicly published meeting/Board minutes (e.g. by a board or steering group)

Information on how NACEL is governed can be found on the [NACEL Steering Group](#) section of the NACEL website. The Steering Group met monthly, via teleconference, for the first 6 months of the project, and every other month until September 2018. The NACEL Steering Group have 9 scheduled meetings for 2019 up until November 2019. The NACEL Steering Group has agreed their [Terms of Reference](#). It is chaired by Joint Clinical Leads, Dr Suzanne Kite, Consultant in Palliative Medicine and Elizabeth Rees, Lead Nurse for End of Life Care, both from Leeds Teaching Hospitals NHS Foundation Trust. Further meetings are to be organised for 2020 on a monthly basis.

Decisions are only taken at meetings where meetings are quorate. There is a process for reviewing membership to ensure an active Steering Group, quorate meetings and which leads the direction of the programme. An Advisory Group is also in place to enable wider consultation with End of Life key stakeholders.

3.4. Declarations and Conflicts of interest

Note:

Evidence that declarations and conflicts of interest have been considered, declared and where appropriate, mitigated appropriately :

- DOI/COI process and policy outlining how DOI and potential conflicts of interest are identified and managed
- A web URL to the publicly published DOI/COI register for all individuals involved in the programme and where appropriate, information about how these have been mitigated

Not applicable

Domain 4: Information security, governance and ethics

4.1. The legal basis of the data collection

Note:

A description of the legal basis for the data collection, specific to each country where the data are collected. Examples include:

- Informed consent
- Section 251 (NHS Health and Social Care Act 2006) approval
- Other types of patient controlled data permission

This could include links to:

- Consent forms
- Information provided to patients about participation and usage of data
- Further information about how patients can control the use of their data
- Information about ethical committee review

The legal basis for NACEL can be found in this document on "[NACEL Information Governance Guidance for Trusts/UHBS](#)", which has been published on the NACEL webpages. The [NACEL DPIA](#) can also be found on the NACEL webpages.

Future consent statements

All activities that we undertake are commissioned by organisations that have the appropriate legal basis. There will be circumstances that they allow access to the information that we have provided to them to other agreed third parties for research purposes. Access to the data for research, service evaluation or clinical audit purposes is managed via HQIP under the "[Accessing NCAPOP data](#)" guidance.

Your data matters

The NHS allows patients the chance to control how their data is used for service improvement and research purposes.

If you want to find out more go to <https://your-data-matters.service.nhs.uk/>.

You will need your NHS Number to find your information and you will be given choices about what you would like to happen.

4.2. Information governance and information security

Note:

Include:

- The Information Governance Toolkit score and URL to the organisation's Information Governance Toolkit Assessment Report
- If the IG toolkit score is less than satisfactory, indicate how the organisation is improving its security processes to achieve a satisfactory score and when the programme will be re-assessed
- Details of any other information governance and security accreditations achieved by the registry (e.g. ISO 27001)

The NHS Benchmarking Network have completed the new Data Security and Protection Toolkit (DSPT) as agreed with HQIP, which has replaced the previous Information Governance Toolkit from April 2018. The document has been submitted to HQIP.

The Network team's ICO number is Z1624069.

Section 251 is not applicable as the NHS Benchmarking Network do not collect any patient identifiable information across any element of NACEL.

Domain 5: Stakeholder engagement

5.1. Approaches to involving stakeholders

Note:

A description of how stakeholders are involved in designing and carrying out the programme

Examples of types of involvement that might be listed here include:

- Designing the programme
- Selecting quality metrics
- Defining aims and objectives
- Setting priorities
- Collecting data
- Contributing to data analysis and interpretation
- Governance
- Disseminating feedback and communications

The "[Ambitions Partnership](#)" is a complete list of stakeholders identified as being important to NACEL. Stakeholders have been identified across the 3 participating countries of England, Wales and Northern Ireland. They have been involved via representation at both the NACEL Steering Group and the NACEL Advisory Group. HQIP have been updating NHSE Programme Board on End of Life Care. There is a lay representative on the NACEL Steering Group. The NACEL Steering Group and Advisory Group have been instrumental in designing the content of all NACEL elements (Organisational Level Audit, Case Note Review, NACEL Quality Survey and Staff Reported Measure).

The National Clinical Director for End of Life Care, NHS England, and the Acting Clinical Lead for End of Life Care for NHS Wales are active members of the NACEL Steering Group. All public facing documents have been translated into Welsh.

The Patients Association, key partners in the audit, have developed the NACEL Quality Survey with the aid of patients and bereaved carers/families. Focus groups and individual interviews have assisted with what is important to patients and their carers in their experience of the delivery of end of life care.

Clinicians are involved by representation on the NACEL Steering Group and Advisory Groups. The audit findings will be presented at various professional conferences across England and Wales. There will be a separate national findings conference for Northern Ireland.

Domain 6: Methods

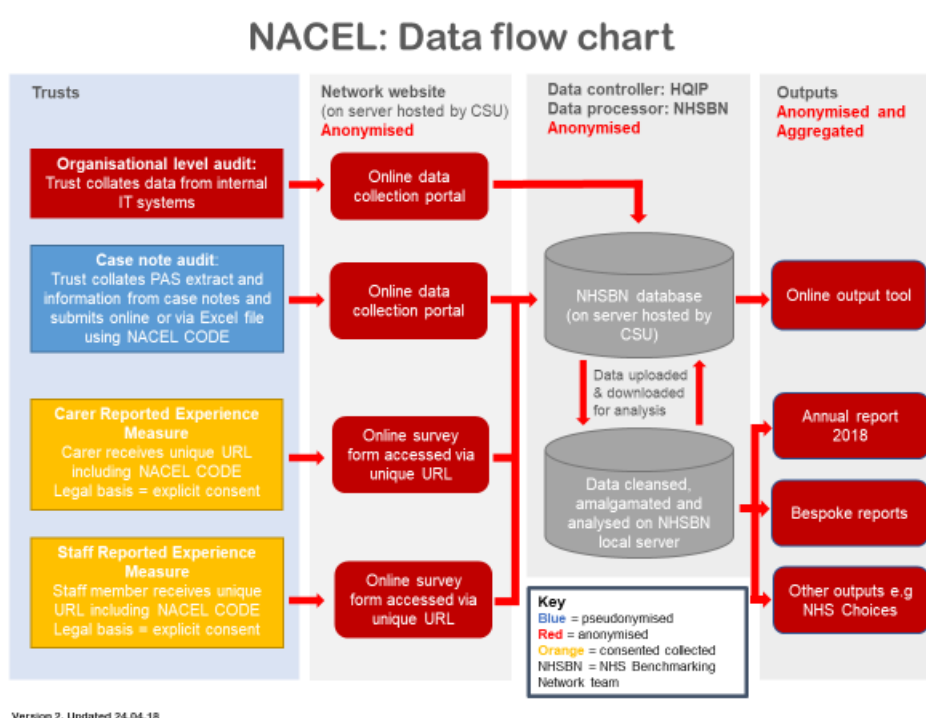
6.1. Data flow diagrams

Note:

A data flow diagram showing each data flow into and out of the audit/registry. The diagram should indicate:

- What organisations are flowing data in/out of the programme
- What data items are within each data flow in/out of the programme
- The legal basis for each data flow, e.g. section 251, consent

NACEL – Data flow diagram below



Ref: Accessing National Clinical Audit and Patient Outcomes Programme (NCAPOP) data: Guidance for applicants and data providers (v2). Healthcare Quality Improvement Partnership (HQIP), March 2017, <https://www.hqip.org.uk/wp-content/uploads/2018/03/hqip-accessing-ncapop-data-guidance-for-applicants-and-data-providers-v2.pdf>, last accessed 4 May 2018.

6.2. The population sampled for data collection

Note:

A description of the patient population or sampling frame for data collection. This might include:

- Details of inclusion and exclusion criteria
- Standard nomenclature to define patient populations (e.g. ICD codes, SNOMED terms)

There were 3 different elements to the first round of NACEL; an organisational level audit, a case note review and the NACEL Quality Survey (survey of bereaved carers). The audit was open to acute providers, mental health inpatient providers and community hospital providers. The patient population and timeframes for the data collection are as follows for each element: -

- **Organisational level audit** – Trust/UHB outturn positions for the financial year 2017/18. This was open to acute, mental health inpatient and community hospital providers.
- **Case note review** - The period for the audit was deaths between 1st April and 30th April 2018 for acute hospitals and between 1st April to 30th June 2018 for community hospitals. A minimum sample of 5% of deaths in one year and up to a maximum of 80 cases were required to be submitted in the Case Note Review collection for acute and community hospital providers. Mental health inpatient providers were excluded from the case note review. Only adult deaths (i.e. aged 18+ at the time of death) should be included. Deaths in specialist palliative care beds that are fully managed and funded by the NHS should be included. Hospices are excluded. The Case Note Review will audit deaths which fall into the following two categories: -

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.

2. **The patient was not expected to die** - imminent death was not recognised or expected by the hospital staff. However, the patient may have had a life limiting condition or, for example, be frail, so that whilst death wasn't recognised as being imminent, hospital staff were "not surprised" that the patient died.

Deaths which are classed as "sudden deaths" are excluded from the Case Note Review. These are deaths which are sudden and unexpected; this includes, but is not limited to, the following: -

- all deaths in Accident and Emergency departments
- 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.

NACEL Quality Survey – Trusts/UHBs should generate a NACEL Quality survey as per the criteria for the case note review. The cohort of patients included in the Case Note Review collection were the same for the NACEL Quality Survey.

The [NACEL Audit Guidance](#) provides a complete guide to the audit for the 2018 cycle.

For the second round of NACEL, there are again 3 different elements to NACEL; an organisational level audit, a case note review and the NACEL Quality Survey (survey of bereaved carers). Sampling adjustments have been made for the second round of NACEL. Mental health inpatient facilities are excluded from the second round of NACEL, with the aim to re-include them during the third round of NACEL.

- **Organisational level audit** – No longer includes the Trust /UHB overview, rather is specific to the Hospital Site for the 2018/19 outturn. This is open to acute and community hospital providers.

- **Case note review** - The period for the audit was deaths between 1st April and 14th April 2019 for acute hospitals and between 1st April to 30th May 2019 for community hospitals. Acute and community hospital providers were asked to submit up to a maximum of 20 cases per month, therefore up to a maximum of 40 cases in total. No minimum number of deaths was set. Only adult deaths (i.e. aged 18+ at the time of death) should be included. Deaths in specialist palliative care beds that are fully managed and funded by the NHS should be included. Hospices are excluded. The Case Note Review will audit deaths which fall into the following two categories: -

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.

2. **The patient was not expected to die** - imminent death was not recognised or expected by the hospital staff. However, the patient may have had a life limiting condition or, for example, be frail, so that whilst death wasn't recognised as being imminent, hospital staff were "not surprised" that the patient died.

Deaths which are classed as "sudden deaths" are excluded from the Case Note Review. These are deaths which are sudden and unexpected; this includes, but is not limited to, the following: -

- all deaths in Accident and Emergency departments
- 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.

NACEL Quality Survey – Trusts/UHBs should generate a NACEL Quality Survey Letter for nominated person(s) of patients who died within the hospital/site between 1st April and 31st May 2019. The Case Note Review and Quality Survey are no longer linked for the second round of NACEL.

Deaths excluded from the Quality Survey include: Deaths occurring within 4 hours of admission, deaths within A&E and for under 18's.

The [NACEL Guidance Notes – Second round of the audit](#) provides a complete guide to data collection for the second round of NACEL.

A Staff Reported Measure is being piloted in year 2 for full rollout in year 3 of NACEL.

6.3. Geographical coverage of data collection

Note:

A description of the geographical coverage of the data collection. Include details of both:

- geographical areas eligible for inclusion
- geographical areas that actually participated in data collection

This could include:

- A text description of coverage
- An illustration or map to visualise the coverage
- Summary data

- Links to data files containing geographical identifiers

All acute, mental health inpatient providers and community hospital providers in England, Wales and Northern Ireland were eligible to participate in the first round of NACEL. For the first round of NACEL audit, full coverage was achieved bar the exception of one mental health provider for the 2018 audit cycle. During the first round of NACEL, Northern Ireland participated in the organisational level audit only due to joining the audit cycle later in the year.

For the second round of NACEL, all acute and community hospital providers in England, Wales and Northern Ireland are eligible to take part in the audit. Mental Health inpatient providers are excluded from the second round of data collection. Northern Ireland Trusts will not be participating in the NACEL Quality Survey element.

6.4. Dataset for data collection

Note:

A list (or web URL to online documentation such as a data dictionary) of the items included in the data collection

State how the dataset chosen aligns with the QI objectives and COMET Core Outcome Sets (COS) as described in section 2.2.

Data collection for NACEL is online. Eligible organisations were requested to register their organisation and define their submissions for data entry. Data collection is behind the members' area of the NHS Benchmarking Network's website and is controlled via password. Eligible organisations were requested to define their list of key personnel who could collect and input data on behalf of their organisation.

Data specifications for each element of the audit can be found -

<https://www.nhsbenchmarking.nhs.uk/nacel-audit-guidance-and-data-specifications>

6.5. Methods of data collection and sources of data

Note:

A description (or web URL to online documentation) of how the data were collected and the sources of data.

Examples include:

- Online, e.g. webtool or portal
- Retrospective case record review
- Linkage to existing data sources
- Extracts of administrative data
- Surveys
- Extractions from electronic health records

For the organisational level audit and the case note review, data is collected by trusts /UHB teams and entered into a secure online webtool designed specifically for NACEL. Data is extracted from trust/UHB information systems.

For the first round of NACEL, the NACEL Quality Survey was notified to potential qualifying participants via letter containing a unique URL. Responses were collected online via a secure online webtool designed specifically for NACEL. As noted above, there was the option for bereaved carers to give their responses to the survey via the helpline run by the Patients Association.

Slight method adjustments were made to the NACEL Quality Survey for the second round of NACEL.

Qualifying participants receive a NACEL Quality Survey letter with a link to the online survey and unique 3-part code to enter their data under. The Quality Survey URL link was generic for all participants, accessed from www.nacel.nhs.net. Participants were instructed to enter their 3-part code into the online survey before accessing the questions. The unique code enables NHS Benchmarking Network to identify which submission the feedback relates to.

The Staff Reported Measure, for rollout in year 3 of NACEL will also be collected via the online portal.

6.6. Time period of data collection

Note:

The time period for data collection, using a start date (DD/MM/YYYY) and end date as applicable. For a continuous prospective data collection then this may only be a start date.

The time period for data collection, for the first round of NACEL, for all three elements was from 06/06/2018 to 12/10/2018 inclusive.

The time period for data collection, for the second round of NACEL is 05/06/2019 to 11/10/2019.

6.7. Time lag between data collection and feedback

Note:

A description of the time lag between data collection and feedback to participants in the programme – try and be as specific as possible

If 'real time' please describe exactly what this means, e.g. monthly, daily, minute-by-minute

This could also include details about time intervals for the various steps between data collection and feedback/publication such as waiting for linked data to be supplied or for sign off

Feedback on NACEL is via three different methodologies: -

- A **high-level national summary** report for England and Wales (the same for Northern Ireland). The first round of NACEL report for England and Wales was published on the 11th July 2019.
- **Bespoke/dashboard reports** for each individual participating organisation. This contains key metrics/quality indicators and reports trust/UHB positions against nationally reported positions. Acute and community data was combined within the bespoke dashboards. Mental health inpatient facilities received a separate bespoke dashboard with only mental health data within the report. The bespoke dashboards for the first round of NACEL were sent to participants on the 6th February 2019.
- **Access to an online benchmarking toolkit** containing the full set of metrics, with individual trust /UHB positions highlighted. A draft toolkit was released to participants in December 2019, so that trusts/UHBs had early sight of this toolkit to assist with data validation. The final toolkit was published in January 2019.

The time from report submission by the NHS Benchmarking Network to commissioners and funders on 28/03/2019, to publication of the report, on 11/07/2019 was 90 working days.

6.8. Quality measures included in feedback

Note:

A list (or web URL to online documentation) of the quality measures reported by the programme

Provide a mapping to classify these as:

- Process metrics
- Outcome metrics
- Organisational/structure metrics

Please state what metrics are provided at trust level and how often this trust level information is made available, e.g. quarterly, 6-monthly. If 'real time' please describe exactly what this means, e.g. monthly, daily.

Summary score methodology has been developed by the NACEL Steering Group and presented in both the national Report and the bespoke dashboards.

The following nine key themes were identified for the first round of NACEL:

- Recognising the possibility of imminent death
- Communication with the dying person
- Communication with families and others
- Involvement in decision making
- Needs of families and others
- Individual plan of care
- Families' and others' experience of care
- Governance
- Workforce/specialist palliative care

A national summary score and submission score for participants was devised for each theme. The summary scores allow for easy comparison between hospitals on the different themes within the audit. Each score was calculated using data from a NACEL data collection element (Organisational level, Case Note Review or NACEL Quality Survey).

The summary score methodology and outcome metrics can be found within the [National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales](#). From page 24 onwards.

Furthermore, within the [National Audit of Care at the End of Life: First round of the audit \(2018/19\) appendices for England and Wales](#).

The NHS Benchmarking Network Team is currently working with CQC to define key indicators for inclusion within their data packs for their inspection visits with acute and community providers.

6.9. Evidence base for quality measures

Note:

A list or description of the sources of evidence used to define the quality metrics. Examples include:

- Clinical guidance (e.g. NICE guidance)
- Clinical standards
- Systematic reviews
- Professional society recommendations
- Policy documents
- Clinical trials

The quality indicators are being developed by the NACEL Steering Group to measure compliance/ progress against: -

- NICE quality standard QS13 'End of Life Care for Adults'
- NICE guideline NG31 'Care of dying adults in the last days of life'
- NICE quality standard QS144 'Care of dying adults in the last days of life'
- The '*Five Priorities for Care*' as outlined in '*One Chance to Get It Right*' published by the Leadership Alliance for the care of Dying People.

6.10. Case ascertainment

Note:

Describe the level of case ascertainment achieved. Include links or detail for additional information about methodology

97% of eligible organisations participated in the first round of NACEL.

Organisational level audit:

A total of 202 Trust/UHB submissions collected.

A total of 302 Hospital/Site overview submissions collected.

Case Note Review collection:

A total of 11,034 Case Note Reviews were collected

NACEL Quality Survey:

A total of 790 Quality Surveys were returned.

For further information about the methodology taken during the first round of NACEL, please see the report and appendices:

[National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales.](#)

[National Audit of Care at the End of Life: First round of the audit \(2018/19\) appendices for England and Wales.](#)

6.11. Data analysis

Note:

A description (or web URL to online documentation) of the methods of data analysis. Important considerations in the analysis of audit and registry data include:

- Missing data, and how these were handled
- Sources of measurement error and bias, and how these were addressed
- Methods and algorithms used for:
 - case mix adjustment
 - benchmarking
 - outlier detection
 - visualising and interpreting time series data
- Algorithms and statistical models used to process data

This might include:

- References for peer reviewed publications of methods used in the data analysis
- Links to:
 - analytical code
 - more detailed descriptions of the methods already published elsewhere

Missing data is excluded from the audit findings. Denominators only include data where a response has been provided.

Measurement error and bias – not applicable to this project

Summary scores are used to benchmark participants within the bespoke dashboards and national report. The high-level national report and appendices include methodology detail for this aspect of NACEL.

[National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales.](#)

[National Audit of Care at the End of Life: First round of the audit \(2018/19\) appendices for England and Wales.](#)

Outlier detection is covered in the “Management of Outliers Policy”. 3 cases were identified within the Management of Outliers Policy. All cases were closed.

A reliability analysis was undertaken in the first round of NACEL. Appendix 9 of the [National Audit of Care at the End of Life: First round of the audit \(2018/19\) appendices for England and Wales](#). Contains the findings from the reliability analysis.

Time series analysis is not available to a large extent in the findings as there has been a significant time lag between NACEL and the last audit, and as described, NACEL represents a significant departure in the data items collected from the previous audit. Subsequent years of NACEL should be able to pick up on time series analysis.

The NACEL findings are largely supported by descriptive statistics i.e. there are summaries about the sample and the measures reported forming the quantitative analysis of data. National averages, median positions, quartile ranges, sample ranges have been reported where possible. Where narrative statements are provided (across all three elements of NACEL), qualitative statistical methods have been employed to add intelligence to the key findings and recommendations. Examples of this is used throughout [National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales](#).

6.12. Data linkage

Note:

A description of any data linkage carried out as part of the audit or registry. Include details of:

- Data sources
- Methods of linkage
- Evaluation of the quality of data linkage

If no data linkage carried out, state “No linkage performed”

This could include details about the impact of patient opt outs where these apply, e.g. the proportion of patients before and after opt outs are applied; changes in key characteristics of patient group following opt out such as gender, ethnicity

HQIP requested that the data be linked for the case note review and the NACEL Quality Survey during the first round of NACEL. Whilst NHS Benchmarking Network will not receive any patient/ carer identifiable information, trusts/UHBs were requested to link the data collection via the NACEL Audit Monitoring Sheet. This was the first time this has been attempted for a national audit. However, there was not enough data received from the NACEL Quality Survey to link the data at trust/UHB level; rather this was reported at national level.

The Case Note Review and NACEL Quality Survey are no longer linked during the second round of NACEL. This process was agreed by HQIP and the NACEL Steering Group in consensus of being able to increase the Quality Survey sample. By unlinking the data, a larger cohort of nominated person(s) can complete the NACEL Quality Survey as this element is no longer restricted by the Case Note Review sample.

6.13. Validation and data quality

Note:

A description of how data quality and analyses have been validated. Examples of validation include:

- Piloting and refining data collection methods and dataset changes
- Building in validation processes at the point of data entry
- Validation by clinical teams
- Data cleaning
- Statistical analyses of data quality (e.g. missing data)
- Validation of statistical models and algorithms
- Quality assurance and unit testing of analytical code

A reliability study on the first 5 sets of case notes audited was carried out for the case note review. The analysis was included in the high-level national summary report. The reliability analysis can be found within the First round of the audit (2018/19) appendices for England and Wales.

[National Audit of Care at the End of Life: First round of the audit \(2018/19\) appendices for England and Wales.](#)

Each metric included within the NACEL summary scores received a score indicating either 'moderate agreement' or 'substantial agreement'. Summary scores were not adjusted according to the reliability study results.

All data submitted in the organisational level audit and the case note review was subject to validation by the NHS Benchmarking Network analytical team. Outlying positions were checked and queried with NACEL participants. Any identified data errors were changed and logged.

A "Management of Outlier Policy" was created following guidance from the HQIP document "Detection and management of outliers for NATIONAL Clinical Audits: Implementation Guide for NCAPOP providers".

The outlier indicator included in the policy was the proportion of deaths where it was recognised that the patient may die imminently (Category 1 deaths) out of all deaths audited (Category 1 and Category 2 deaths).

Three hospitals were identified as potential outliers on the NACEL outlier indicator. The hospitals were contacted and managed in accordance with the policy.

Domain 7: Outputs

7.1. The intended users or audience for the outputs

Note:

A list or description of the intended users or audience of feedback data produced by the programme. Examples include:

- Clinical commissioning groups or Health Boards
- Specialist commissioners

- Trust/hospital boards
- Clinical teams
- Individual clinicians
- General public
- Patients
- Carers
- Policy makers
- Politicians
- Media
- National agencies

The audit designs and produces feedback for:

- Patients and carers – in the form of a patient friendly report. The patient friendly report is currently in development.
- Trusts/UHBs – via the bespoke dashboards, the online benchmarking toolkit and high-level [National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales.](#)
- The national funding organisations e.g. NHS England, NHS Wales and the Northern Ireland Health and Social Care Board.
- The high-level National Summary Report will be available for other stakeholders identified e.g. the Ambitions Partnership, the CQC, etc.

7.2. Editorial independence

Note.

A statement about the independence of the programme in regards to the content, e.g. findings, recommendations.

As an independently commissioned programme, the contents of the outputs have been written by the NHS Benchmarking Network, with the assistance of the NACEL Clinical Leads and the NACEL Steering Group and Advisory Group.

7.3 The modalities of feedback and outputs

Note:

A description of how data are fed back to participants of the programme

Please also describe how outputs are agreed, i.e. the quality assurance process within the programme such as Board sign off.

Examples of types of feedback commonly used in audits and registries include:

- Summary written reports
- Comprehensive written reports
- Online feedback

- Dashboards
- Slide sets
- Data visualisations
- Infographics
- Data tables
- Interactive tools
- Maps
- Meetings and workshops
- Professional conferences
- Verbal feedback by a national peer
- Verbal feedback by a local peer
- Information resources for patients (e.g. NHS Choices)
- Data that will be adapted and synthesised by other organisations (e.g. CQC) and programmes (e.g. GIRFT)
- Press releases
- Case studies
- Examples of best practice

The audit provides feedback as outlined in section 7.1 above. This feedback exists in the following forms:-

- Summary high level national report/s (England & Wales and Northern Ireland)
- Online benchmarking toolkit
- Bespoke dashboard report for each participating organisation
- Slide sets
- Infographic (see below)



NACEL
Infographic.pdf

- Data tables
- Anonymised narrative extracts from the Case Note Review and Quality Survey
- National feedback event for Northern Ireland
- Brief NACEL presentation at NHS Benchmarking Network regional events
- Information resources for patients (e.g. NHS Choices)
- Data that will be adapted and synthesised by other organisations (e.g. CQC) and programmes (e.g. GIRFT)
- Press releases
- Case studies
- Examples of best practice
- Selected national professional conferences where content, is of relevance

7.4 Recommendations

Note:

The programme, in making specific recommendations about how to improve the quality or safety of healthcare services should provide a web URL to any documents making recommendations to participants

As a general principal, recommendations should:

- be specific, action oriented, and tailored to the intended audience
- agreed and signed off through an agreed process
- reviewed (e.g. annually)
- be underpinned by evidence and be supported by data collected by the programme

be designed to have impact

The recommendations for the first round of NACEL are included within the [National Audit of Care at the End of Life: First round of the audit \(2018/19\) report for England and Wales.](#)

The recommendations were agreed and signed off by the NACEL Steering Group, NHS England, NHS Wales and HQIP. An annual review of the recommendations will follow each round of NACEL data collection. A total of 13 recommendations were developed from the findings from the first round of NACEL and supported by national guidance; One Chance To Get It Right and the NICE Quality Standards (QS13 and QS144).

The first round of NACEL recommendations were addressed at the below audiences for having key responsibility in the quality of end of life care within the Trust/Hospital;

- Integrated Care Systems/Commissioners, working with providers
- Trust/UHB Boards
- Chief Executives
- End of Life Care Lead (Board member with accountability for end of life care)
- Medical Directors and Nursing Directors

7.5 Comparators and benchmarking

Note:

A description or list of if/how performance is compared between healthcare providers or areas, and the benchmark against which performance is measured.

This should provide a high-level overview of how comparisons are made using the programme data, not a detailed list of all indicators and how they are individually used to benchmark or compare performance.

Examples of benchmarks include:

- National
- International
- Regional
- Organisational
- Clinical team
- Individual clinician

- Audit/registry standards
- Relative benchmarks (e.g. top 10%)
- Temporal (e.g. changes over time)
- Results from randomised controlled trials

The audit provides comparative performance data for trusts/UHBs. Each trust/UHB has performance measured against:

- Other trusts/UHBs
- All trusts/UHBs in England & Wales
- All HSCTs in Northern Ireland
- The online benchmarking toolkit further includes a “Peer group profile” against country (England, & Wales and Northern Ireland), and by type of organisation (e.g. acute, mental health and community hospital provider). The online benchmarking toolkit further has the facility for ‘all’ country results to be profiled. An additional peer group was included for the Case Note Review collection, enabling participants to filter by category of deaths: Category 1: It was recognised that the patient might die or Category 2 deaths: The patient was not expected to die.

The high-level national summary report for the first round of NACEL showcased the benchmarked findings for acute and community hospitals in England and Wales. A brief summary was included within the report for Mental health providers. The same provider combinations were to be used within the bespoke dashboard reports; acute and community hospital data was combined, mental health inpatient facility findings were separated.

7.6 Motivating and planning quality improvement

Note:

A short description of the approaches the programme uses to motivate and support quality improvement.

Programmes are not expected to provide a bespoke service to support trusts to interpret the findings or recommendations. The programme should, however, provide information in a format that is easy to digest and ready to use for the intended audience.

Examples of approaches include:

- Recommendations for action
- Action plans
- Education and training
- Supporting peer learning
- Providing positive feedback
- Workshops
- Including motivating statements as part of feedback

The draft NACEL QI plan has been developed and is awaiting review and feedback by HQIP.

All outputs from the first round of NACEL are available to individual trusts/UHBs to help them identify potential areas for improvement. This audit is a significant departure from previous

audits; therefore, time series analysis is limited, due to the development of different quality indicators.