National Audit of Care at the End of Life

Auditing last days of life in hospitals

HQIP
Healthcare Quality Improvement Partnership

Data Protection Impact Assessment
National Audit of Care at the End of Life (NACEL)
V.6

Document sign off and version control

Date completed	**Version**	**Summary of changes**	**Name / position of person who made the changes**	**Signed off by Project DPO** (Name, position, date)	**Signed off by HQIP's DPO** (Name, position, date) or Associate Director	**HQIP's DPO advice and recommendations**
24th November 2023	V.1	Revised HQIP template	Joylin Brockett, Project Manager	Tania Palmariellodiviney, RCI group DPO, 20.11.2023	Desislava Staykovska, Information Governance Lead, 01.12.2023	
22nd March 2024	v.2	Updated information about the NACEL Data and Improvement Tool access	Joylin Brockett, Project Manager			
6th February 2025	v.3	• Added reference to Jersey. • Changed the NACEL scope to no longer exclude deaths of people with a formal diagnosis of learning disability. • Updated information for NACEL 2025, including the mental health spotlight audit	Joylin Brockett, Senior Project Manager			
7th March 2025	v.4	• Updated ICB access to Data and Improvement Tool	Jessica Walsh, Senior Project Manager			
7th April 2025	v.5	• Included NHS Wales as having third party access. Included NHSE lawful basis to process data	Joylin Brockett, Senior Project Manager			
22nd October 2025	v.6	Included NCAPOP transparency information & updated data flow diagrams	Joylin Brockett, Senior Project Manager			

Screening checklist

No.	Screening questions	Yes / No	Comments
1.	Does your project involve any automated decision making, evaluation or scoring including profiling and predicting using information about a person? Does the outcome from your project decide who gets access to services?	No	
2.	Does your project involve any sensitive information or information of a highly personal nature?	Yes	Bereaved Persons' Focus Group – personal experiences shared with NHS Benchmarking Network (NHSBN/Network) /Patients Association. Case Note Review collects information about ethnicity and whether the patient was elderly. The Case Note Reviews are pseudonymised by the Trust/Health Board before being submitted to NHSBN. No identifiable information is held by NHSBN.
3.	Does the proposal involve any data concerning vulnerable individuals who may be unable to easily consent or oppose the processing, or exercise their rights? *This group may include children, employees, mentally ill persons, asylum seekers, or the elderly, patients, and cases where there is an imbalance in the relationship between the position of the individual and the controller.*	Yes	NACEL focuses on the care delivered to dying people. These people are vulnerable as they may be too ill to consent. NACEL further involves data from ethnic minorities, where English may not be their primary language, and older people, who may not have the capacity to act or advocate for themselves.
4.	Does your project involve any innovative use or applying new technological or organisational solutions? This could include biometric or genetic data, the tracking of individuals' location or behaviour?	No	
5.	Does your project match data or combine datasets from different sources?	Yes	Only within the audit. Data is pseudonymised from the Case Note Review, anonymous from

			the Quality Survey and anonymous from the Staff Reported Measure.
6.	Does your project collect personal data from a source other than the individual without providing them with a privacy notice ('invisible processing')?	No	
7.	Does your project process data that might endanger the individual's physical health or safety in the event of a security breach?	No	
8.	Is this a new project? Or have the requirements for your project changed since its initiation? Are you sharing new information or linking to new datasets that were not part of the original project specification. Have you added any new audit streams to your project?	Yes	New project commissioned in 2022. Structure of the project is set out in the HQIP tender and response. This is separate to the 2017 – 2022 contract. The NACEL is delivered by the team at NHSBN, under the contract held between ELFT and HQIP. NHSBN ran NACEL from 2017-2022, however the requirements for the project have since changed.

Stage 1. Identify the need for a DPIA

The National Audit of Care at the End of Life (NACEL) is a project to be delivered by NHS Benchmarking Network (NHSBN), under a new contract from Healthcare Quality Improvement Partnership (HQIP). The NHSBN team (Benchmark Management Consulting Ltd) is a subcontractor to East London NHS Foundation Trust (ELFT) (host of the Network).

NHSBN previously ran NACEL from 2017-2022, however the requirements for the project have since changed. The screening assessment outcome of the NACEL 2024 & 2025 project outlines that a Data Protection Impact Assessment (DPIA) is required. A DPIA is required as data will be collected from multiple data sources, with an intention of combining datasets from different sources. Furthermore, data will be collected from vulnerable individuals. Data submitted to the Case Note Review is pseudonymised and collected via an online portal. It constitutes as personal data, however NHSBN cannot re-identify this information. The key is held by the Trust/Health Board, and only they can re-identify the data.

This DPIA will help NHSBN, for the purpose of NACEL, identify the most effective way to comply with data protection obligations and meet individuals' expectations of privacy. Data will be collected from multiple sources, where privacy risks are required to be considered and addressed. The DPIA will outline this process and act as a guide to NHSBN.

Conducting a DPIA is now a legal requirement under the GDPR (General Data Protection Regulation) which started on the 25th May 2018 and the new UK Data Protection Act. The DPIA ensures that NACEL is compliant with GDPR and UK data protection legislation. This document will be updated if further ICO guidance is published or there is change in legislation.

A DPIA is the basis of a "privacy by design" approach, to help meet privacy and data protection expectations of customers, employees and other stakeholders. A DPIA is intended to be prospective and proactive and should act as an early warning system by considering privacy and compliance risks in the initial design and throughout the project.

Purpose and benefits of completing a DPIA

- A DPIA is a process which assists organisations in identifying and minimising the privacy risks of new projects or policies.
- Conducting a DPIA involves working with people within the organisation, with partner organisations and with the people affected to identify and reduce privacy risks.
- The DPIA will help determine the appropriate controls needed to protect personal data i.e. technical, procedural and physical.
- The DPIA will help to ensure that potential problems are identified at an early stage, when addressing them will often be simpler and less costly.
- Conducting a DPIA should benefit organisations by producing better policies and systems and improving the relationship between organisations and individuals.
- The ICO may often ask an organisation whether they have carried out a DPIA. It is often the most effective way to demonstrate to the ICO how personal data processing complies with Data Protection legislation.

Supplementary guidance

- Data Protection Impact Assessment under GDPR guidance
- ICO's conducting privacy impact assessments code of practice
- The ICO's Anonymisation: managing data protection risk code of practice may help organisations to identify privacy risks associated with the use of anonymised personal data.
- The ICO's Data sharing code of practice may help organisations to identify privacy risks associated with sharing personal data with other organisations.
- The ICO's codes of practice on privacy notices, as well as other more specific guidance, will also help an organisation to focus DPIAs on those issues.
- The Government Data Programme has developed a Data Science Ethical Framework to help organisations understand the benefits and risks of using personal data when developing policy. The Framework can be used as part of the process to help you describe information flows and identify privacy risks and solutions.

Stage 2. Consultation

NHSBN are the data processor for NACEL. The NHSBN database is hosted by Midlands & Lancashire CSU, making them a sub-processor.

The NHSBN Project Team and Development Team are those mainly involved in the processing of data. This includes supporting organisations to submit their data to the audit, developing the technical solutions to collect, store and report the data, as well as analysing the data submitted to the audit. The data is analysis is supported by in-house analysts and a subcontracted statistician. NACEL statistical support is subcontracted with a consultant from Statsconsultancy Limited. The subcontracting arrangement is held under a data processing agreement with ELFT.

Subcontracts are further in place with the following roles:

- NACEL Clinical Lead – whom is a substantive employee of Oxford University Hospitals NHS Foundation Trust. A subcontract is in place under a data processing agreement with ELFT.
- NACEL Quality Improvement Clinical Advisor – whom is a substantive employee of University Hospitals of Leicester NHS Trust. A subcontract is in place under a data processing agreement with ELFT.

The above roles form the NACEL Clinical Team, along with the NACEL Quality Improvement Lead, who is directly employed by NHSBN. They are responsible for the design of the audit, including what data is reported.

- The Patients Association – the charity supports the delivery of the Bereaved Person's Focus Group. The charity is further represented on the NACEL Steering Group. A subcontract is in place under a data processing agreement with ELFT.
- NACEL Bereaved Persons' Focus Group Chair – A consultant in End of Life Care from Nikki Archer Consultancy supports NHSBN and the Patients Association in engaging with a small group of bereaved people. The subcontract is in place under a data processing agreement with ELFT.

A Bereaved Persons' Focus Group has been developed to obtain feedback, from a small group of bereaved people with lived experience of care at the end of life in hospitals. This feedback will be used to input into the design of NACEL.

The audit is supported by a Steering Group and Advisory Group.

Stakeholder engagement has been undertaken, by the NACEL Clinical Team (Clinical Lead, Quality Improvement Lead, Quality Improvement Clinical Advisor) and the Network Team (Head of National Clinical Audits, Project Manager, Graduate Project Co-ordinator, Product Designer, Development Manager, Software Developers, Analysts). The purpose of the stakeholder engagement is to design the scope and content of the audit and consult on the impact on privacy risks. The engagement process includes consulting with the following groups:

NACEL Steering Group: The role of the NACEL Steering Group is to advise the NACEL Project Team around specific aspects of the audit project and to provide assurance of their decisions and outputs. The steering group will consider clinical issues in detail and provide valuable insight into related regional and national activity in order that the project team can consider and align (where possible) with other health initiatives.

NACEL Steering Group meetings to date – 9th January 2023, 23rd January 2023, 21st February 2023, 20th March 2023, 5th June 2023, 17th July 2023, 25th September 2023, 1st November 2023, 8th February 2024, 24th April 2024, 12th September 2024, 17th October 2024, 5th December 2024, 26th February 2025.

NACEL Advisory Group: The role of the NACEL Advisory Group is to assist the NACEL Steering Group with specific areas of the NACEL design, development and delivery.

NACEL Advisory Group meetings to date – 9th January 2023, 23rd January 2023, 20th July 2023, 23rd October 2023, 4th March 2024, 26th September 2024, 23rd January 2025.

NACEL Bereaved Persons' Focus Group: The role of the Bereaved Persons' Focus Group is to input into three aspects of the NACEL:

1. The design of the audit and how it can be improved.
2. How we can improve the Quality Survey which is conducted as part of the audit
3. The outputs from the audit, including the reports provided to the public

NACEL Bereaved Persons' Focus Group meetings to date – 18th July 2023, 12th September 2023, 12th December 2023.

NACEL Mental Health Task and Finish Group: The role of the Mental Health Task and Finish Group is to advise on the scope and style of the NACEL Mental Health Spotlight Audit.

NACEL Equitable Care Group: The role of this group is to provide NHS Benchmarking Network with guidance to ensure that NACEL is auditing and reporting equitable care to the best of its ability.

Other consultation: -

- BMC Data Protection Officer
- HQIP Data Protection Officer
- HQIP Associate Director for Quality and Development
- HQIP Project Manager
- NACEL Statistical Support - An expert in statistics has been subcontracted to help support on statistical techniques, sampling and an analysis plan for NACEL.

- The Patients Association – supporting the delivery of the Bereaved Person's Focus Group.
- NACEL Bereaved Persons' Focus Group Chair – An experienced consultant in End of Life Care supporting NHSBN and the Patients Association in engaging with the small group of bereaved people.

Stage 3: Data processing

The data will be used to support the overall aim of NACEL, which is to improve the quality of care when somebody dies in a hospital inpatient setting in England, Wales and Jersey.

Overarching NACEL objectives:

- ❖ Improving quality of care by identifying areas for action in relation to delivery and outcomes, and adapting QI priorities in line with evidence and guidance
- ❖ Reducing unwarranted variation through benchmarking of outcome measures as well as identifying and managing outliers using the appropriate guidance
- ❖ Understanding and reducing health inequalities in relation to impact on the specified measures
- ❖ Sharing and adopting best practice including QI examples, and signposting to resources available in the wider End of Life landscape

Data collected from NACEL will provide high quality information about the quality, delivery and outcomes of care delivered to dying patients and those important to them during the final admission in hospital.

The information collected will be delivered to local providers of healthcare that have participated in the audit, to enable these organisations to assess their performance and identify how well they meet standards in end of life care. The information collected will also be reported nationally.

This information will be displayed in several NACEL outputs including:

- **An online Data and Improvement Tool** – The tool will identify improvement opportunities by benchmarking at differing system levels, from local to national, accessible to those with varying literacy in interpreting data. The tool will only display the findings from the acute & community hospital audit. The results from the mental health spotlight audit will be reported separately. he tool will act as a mechanism to monitor and report achievement against improvement goals. The tool is only accessible to organisations participating in NACEL and to those with third party access. All findings within the tool are identifiable at an organisational level, increasing the transparency of quality of care. The findings are reported at varying frequencies. The Case Note Review and Bereavement Survey data will be reported in real time from April 2025, whilst the results shown in the PowerBI dashboards are refreshed each quarter. The timescales for reporting can be found on the NACEL website: https://www.nacel.nhs.uk.
- **Public Facing Tool**: A subset of the annual NACEL findings for acute and community hospitals will be published in line with the State of the Nations Report. This tool will display the aggregated positions at a the following levels: organisational/regional/national. Small numbers will be suppressed.
- **State of the Nations Report –** A condensed report with a summary of the key national findings and recommendations.
- **A Good Practice Compendium Report** – The report will encourage shared learning and networking by including local examples of quality improvement initiatives in end of life care and to learn from those performing well.
- **A range of Quality Improvement activities, including webinars.** The aim of these will be to share quality improvement ideas and questions and celebrate success.

- **Dataset to be shared with Care Quality Commission (CQC).** A subset of the data will be shared with CQC to support both CQC inspections and hospitals' QI and their quality assurance.
- **Locally produced bespoke**

By processing the data to create a range of outputs, NACEL hope to stimulate improvement at local, regional and national (and international) levels.

The benefit of NHS Benchmarking Network processing the data is to provide the audit with the information needed. The data collected will act as a central dataset on care at the end of life, which is currently not available elsewhere. The process of the NACEL data gives a library of information on the variation on service availability, care delivered to patients and those important to them, feedback from bereaved persons on their experience and lived experiences from staff. This information will be benchmarked and displayed in the outputs, so it can be accessed by local healthcare providers for service improvement activities.

Data flow diagram

Data Flow diagram available at the following link:

Acute/community hospital audit 2024: https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2024/NACEL%202024%20Data%20Flow%20Chart.pdf

Acute/community hospital audit 2025: https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2025/NACEL%202025%20Acute%20&%20Community%20Hospitals.%20Data%20Flow%20Chart%20v2.0.pdf

Mental Health spotlight audit 2025: https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2025/NACEL%202025%20Mental%20Health%20Spotlight%20Audit.%20Data%20Flow%20Chart%20v2.0.pdf

Data will be submitted to NACEL via the NHS Benchmarking Network members' area, or via a survey website. The data submitted to both platforms is held securely in the Network's SQL database hosted by the CSU.

Only the Network Technical Team and a CSU administrator have direct access to the database. The Network Project Team have indirect access to individual data items in the database via a password protected Administration Utility.

Processing that will take place

Organisational data, patient data, feedback from bereaved persons' and members of staff are all collected as part of NACEL. There are five elements of NACEL data collection in England, Wales and Jersey, outlined below:

1. **Hospital/Site Overview (organisational data)**

The Hospital/Site Overview does not contain any personal information. Data is aggregated to a high degree e.g., whether the hospital/site has access to a specialist palliative care team. The data is submitted directly to the NACEL data collection pages, via the NHBSN members' area, by the participating organisation. This data is stored in the NHSBN database. Data is collected and input by the hospital/site

staff undertaking the audit who may be clinicians or clinical audit managers. Access to the data collection portal is password protected. All users of the portal have unique log in.

Data from the Hospital/Site Overview will be collected once a year, from the 1st July 2025 – 30th September 2025.

2. Case Note Review

Limited personal data is collected in the Case Note Review. Data is pseudonymised and collected via the NHS Benchmarking Network members' area (NACEL data collection pages) and stored in the NHSBN database. Data is collected and input by the hospital/site staff undertaking the audit who may be clinicians or clinical audit managers. Access to the data collection portal is password protected. All users of the portal have unique log in detail.

The only organisations that have access to directly identifiable data linked to deceased individuals are the data controllers (Trusts and Welsh Health Boards) that are participating in the audit. The data transferred to NHSBN is pseudonymised, and data included in outputs will be anonymous at a patient level and further aggregated.

As regards the duty of confidentiality, all data that is collected is obtained directly from deceased individuals clinical record and is factual with elements of that data already accessible via other means – as an example death certificate, coroner court or disclosure as part of the death notification process. There is no disclosure of confidential data to NHSBN since all data received by NHSBN is pseudonymised.

The risk of re-identification of the individual from the pseudonymised data is extremely low since:

- Data is held securely in the Network's SQL database hosted by the CSU.
- Only the Network Technical Team and a CSU administrator have direct access to the database.
- The Network Project Team have indirect access to individual data items in the database via a password protected Administration Utility. To obtain a download of all the data items a request must be made to the Technical team by the NACEL Project Team (4 individuals).
- De-identification of the data by an individual in the Network team or sharing the data outside the team without the Director's approval, is a breach of the Network's Data Security Policy (very low risk event).
- De-identification of the data would, in any case, be difficult and would require a motive, knowledge of the data set and knowledge of other data sources such as ancestry.co.uk to obtain further data from death certificates (minimal risk).
- Small numbers will be supressed within the NACEL outputs, so that information will only be shown for an aggregated number of patients at one time.

The risk of losing data and it then being re-identified is therefore extremely low.

The data collection timescales & methodology slightly differ for the acute/community hospital audit & the mental health spotlight audit.

Acute/community hospital audit

A six-monthly data collection will be used for the Case Note Review (patient level information), collecting quarterly data on deaths during 1st January 2025 – 31st December 2025, with the following date collection timescales: 20th Jan - 12th July 2025 and from the 1st July – 16th January 2026.

Consecutive inpatient deaths for adults (18+) within acute and community inpatient sites per quarter are to be submitted to the NACEL Case Note Review. Categories of data will be collected for the Case Note Review:

- Category 1. It was expected that the patient would die in the final admission
- Category 2. It was not expected that the patient would die during the final admission

Exclusions: "sudden deaths", deaths which occurred within 4 hours of admission, deaths within an Emergency Department, deaths due to an acute condition caused by a sudden catastrophic event with a full escalation of treatment plan in place, suicides and maternal deaths.

Mental health inpatient facility spotlight audit

An annual data collection will be used for the Case Note Review (patient level information), collecting data on deaths during 1st January 2025 – 31st December 2025, with the following date collection timescales: 20th – 16th January 2026.

Data will be collected for vulnerable groups of people given they have died within the audit period. This includes ethnic minorities, people with a learning disability and autism and older people. The purpose of collecting this information is to provide a measurement of equity of care delivered to a dying person and those important to them.

National data opt-out

The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning. The opt-out continues to be upheld following the patient's death. As a provider of services commissioned by the NHS, NHSBN are required to comply with the National Data Opt-out (https://www.nhs.uk/your-nhs-data-matters/). Patients have the ability to help decide how their data is used by the NHS for research and planning purposes.

NHSBN comply with this requirement BUT:

- it is NHS organisations who must check how the data is to be used before it is submitted to NHSBN (NACEL Case Note Review).
- NHSBN will remind NHS organisations that they must check to see if the National Data Opt-out will have to be considered for any data collection activities that we are involved in. Patients can make a choice about how their data is used by following this link https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/. Preferences can be changed at any point.

3. Bereavement Survey (eligible for acute & community hospitals only)

No personal data is collected in the Quality Survey.

Only acute and community hospital providers are taking part in the Bereavement Survey during 2025. This data collection element is not applicable to the mental health spotlight audit.

Data is collected from bereaved carers/relatives via a web-based survey form under voluntary participation. The online form is accessed by a unique URL for the NACEL submission (hospital/site). NACEL Project Leads can access their organisations unique URL via the online data collection pages. A link to this form is provided to the carer by the hospital/site. The hospital/site are responsible for disseminating the

survey link. The process of dissemination is not determined by NHSBN. The link is unique for the hospital/site and can be used multiple times. The carer's contact details are not shared with the Network. No identifying data is collected during this process and there is no way for the audit to trace the bereaved persons' who completed the survey. There are no narrative fields therefore no risk of identifiable or personal information being recorded. The data input by the bereaved is saved in the Network's SQL database and data security applies as above.

Hospital/sites have the option to print the Bereavement Survey on paper and distribute this to the bereaved. This process is reliant on the hospital/site receiving the feedback and uploading this to the online survey. No identifiable data should be collected or linked for the purposes of the Bereavement Survey

Data will be collected from bereaved persons of deceased adults (18+), who died within the hospital/site covered by the organisations' NACEL submission, from the 1st January 2025 – 31st December 2025.
Exclusions: "sudden deaths", deaths which occurred within 4 hours of admission, deaths within an Emergency Department, deaths due to an acute condition caused by a sudden catastrophic event with a full escalation of treatment plan in place, suicides & maternal deaths.

Data is not collected for collected children or vulnerable groups of people.
Data collection for the Bereavement Survey will run from 1st January 2025 – 31st December 2025.

Information about the use of the respondent's feedback will be included in an information pack, to be shared with the invitation to participate in the NACEL Bereavement Survey. This information will also appear as preliminary text on the online survey.

4. Staff Reported Measure (eligible to mental health inpatient staff only)

No personal data is collected in the Staff Reported Measure.

This data collection element is for the 2025 NACEL Mental Health Spotlight Audit only. This data collection element is not applicable to inpatient staff working in acute or community hospitals.

Data is collected from members of staff via a web-based survey form under voluntary participation. The online form is accessed by a unique URL for the NACEL submission (hospital/site). NACEL Project Leads can access their organisations unique URL via the online data collection pages. The link is then emailed to the relevant staff members, no identifying data is collected during this process and there is no way for the audit to trace the Staff Reported Measure back to the person who completed it. There are no narrative fields therefore no risk of identifiable or personal information being recorded. The data input by staff is saved in the Network's SQL database.

Feedback is to be collected from members of staff that work within the mental health inpatient facility outlined in the NACEL submission, who are most likely to come into contact with dying patients and their loved ones. Data is not collected or identified for vulnerable groups of people. Data will be collected once per year, from 1st April – 30th June 2025.
Information about the use of the staff respondent's feedback will be included as preliminary text on the online survey.

5. Annual death data collection

The Annual death data collection does not contain any personal information. Data is aggregated to understand the total number of deaths that occurred within the hospital/site during the audit period. The data is submitted directly to the NACEL data collection pages, via the NHBSN members' area, by the participating organisation. This data is stored in the NHSBN database. Data is collected and input by the hospital/site by staff undertaking the audit who may be clinicians or clinical audit managers. Access to the data collection portal is password protected. All users of the portal have unique log in.

Data from the annual death data collection will be collected once a year, from the 1st January 2026 – 16th January 2026.

After patient identifiers have been removed from the data in this programme, data may be used for secondary research purposes. HQIP's Overarching Research Database Approval for the NCAPOP permits this re-use under S.251 of the NHS Act 2006 (Reference 24/CAG/0108)

Stage 4: Necessity and proportionality assessment

The lawful basis *for processing under the UK GDPR and the UK Data Protection Act 2018*

The legal basis for Trusts/Health Boards to undertake clinical audit is direct care, dealt with under:

Article 6(1)(e) '…processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.', using the Article 9 condition for direct care or administrative purpose 9(2)(i)@...to ensure high standards of quality and safety in health care.

Trusts will be reminded that the audit should be identified as data sharing activity in line with data protection requirements and Trust/HB fair processing notices should be reviewed to ensure compliance with legislation. The legal basis for NHSBN to process the data is under contract with HQIP/NHSE/Welsh Government/ Jersey Government, the Data Controller.

Transparency:

Latest FPN: https://s3.eu-west-2.amazonaws.com/nhsbn-static/Other/2024/NHSBN%20Fair%20Processing%20Notice%20-%20August%202024.pdf

Data minimisation:

Personal data to be collected by NHSBN, for the purpose of NACEL, has been carefully considered and minimised. The data to be collected is the minimum necessary to cover the ten primary drivers of NACEL for end of life care improvement, as outlined in the NACEL driver diagram.

No personal data, pseudonymised or else will be included within the NACEL outputs, including the online Data and Improvement Tool. All patient, staff and bereaved carer data will be anonymous.

Registration and data collection

Information submitted during registration and data collection is done via the NHSBN website. To access the NHSBN members' area, an individual login is required by staff from the NHS provider organisation. Only staff of the provider organisation can access their organisation's member account on the NHBSBN

members' area and therefore access the registration and data collection pages. Information about the outputs is shown further below.

Existing Authorised Users of the NHSBN member's area can grant new Authorised User access via the NACEL registration pages hosted on the NHSBN members' area. This can be done for a certain number of employees who need access to the NHSBN member account for the NACEL 2024 project. Each Authorised User will be granted a login to the organisation's member account. Each user login is personal to each Authorised User and sharing of login credentials to any other person without the prior written permission from the Host or the NACEL/Network Support Team is strictly prohibited. Each NACEL Project Lead, shall procure that its Authorised Users use the Member Accounts only for the purpose of and in accordance with the terms of this Agreement and that they do not share their login credentials with any other person (including other employees, Members or third parties). In the event an Authorised User ceases to be an employee of the provider organisation, the Host or the NACEL/Network Support Team should be promptly notified to ensure that the User Login of that Authorised User is no longer accessible by that Authorised User.
The patient data transferred to NHSBN for the Case Note Review collection is pseudonymised, and data included in outputs will be anonymous at a patient level and further aggregated. Feedback from bereaved persons and members of inpatient staff is submitted to NHSBN as anonymous.

Data is held securely in the Network's SQL database hosted by the CSU. Only the Network Technical Team and a CSU administrator have direct access to the database. The Network Project Team have indirect access to individual data items in the database via a password protected Administration Utility. To obtain a download of all the data items a request must be made to the Technical team by the NACEL Project Team (4 individuals). De-identification of the data by an individual in the Network team or sharing the data outside the team without the Director's approval, is a breach of the Network's Data Security Policy (very low risk event).

Outputs
The benchmarked findings using the NACEL data will be released via several outputs. No personal data, pseudonymised or else will be included within the NACEL outputs, including the online Data and Improvement Tool. All patient, staff and bereaved carer data will be anonymous.

a) Data and Improvement Tool

Commercial data is shared within the NACEL Data and Improvement Tool to provide transparency in the quality of care to support quality improvement. Data will be aggregated and identifiable at an organisational and hospital/site level, depending on how the organisation registers at the start of the project. The online tool will name the participating organisation's findings, so that comparisons can be made between organisations.

Active staff members of participating organisations are given access to view the NACEL data.

Third party access is given to NHS England, NHS Wales, Welsh Government & HQIP, as funders of NACEL. Third party access is further given to Integrated Care Boards (ICBs are to use the NACEL data to support service improvement by identifying areas for enhancement and enabling informed decision-making), the NACEL Steering Group, as well as to colleagues from the Northern Ireland Public Health Agency and the

five Health and Social Care Trusts to support shared benchmarking across England, Wales, Jersey and Northern Ireland.

***NHS England lawful basis to process**: NHS England has the basis for operating under the Health and Social Care Act (2012) – Schedule 18, part 10 (1) "General Powers" – "may do anything which appears to be necessary or expedient for the purposes of, or in connection with, the exercise of its functions.", NHS act 2006 13(e) i.e. duty to improve quality of services.*

The Data and Improvement Tool is hosted on NHS Benchmarking Network server at the following domain - https://data.nacel.nhs.uk .

An individual user login is required to access the Data and Improvement Tool. Access to the Data and Improvement Tool is managed by a Site Administrator from the participating organisation. Each Authorised User will be granted a login to the organisations' member account. Each user login is personal to each Authorised User and sharing of login credentials to any other person without the prior written permission from the Host or the NACEL/Network Support Team is strictly prohibited. Members of staff will request a User login under their organisations account via the NACEL DIT registration form. The Site Administrator from the participating organisation will either verify the account, granting access to the User, or decline the request. It is the responsibility of the Site Administrator to monitor who has access to the NACEL findings from their organisation.

The Site Administrator is required to control the Authorised Users from their organisation. Each year, the Site Administrator will be asked to review who has access to the online Data and Improvement Tool, and de-activate accounts who haven't accessed the results.

Each NACEL Site Administrator, shall procure that its Authorised Users use the Member Accounts only for the purpose of and in accordance with the terms of this Agreement and that they do not share their login credentials with any other person (including other employees, Members or third parties). In the event an Authorised User ceases to be an employee of the provider organisation, the Host or the NACEL/Network Support Team should be promptly notified to ensure that the User Login of that Authorised User is no longer accessible by that Authorised User.

b) Public facing data - Data and Improvement Tool

In 2025, a subset of the NACEL 2024 benchmarked findings will be accessible to the public via the Data and Improvement Tool. A log in will not be required to view this information. The public audience will include Bereaved Persons, Patients, Academics etc.

c) Outliers

As per the NACEL Management of Outliers Policy, organisations identified with alert and alarm level outlier status will be reported to Care Quality Commission (CQC), Healthcare Quality Improvement (HQIP), Jersey Government and the Welsh Government.

Furthermore, there will be public disclosure of comparative information that identifies providers with alarm level outlier status. This will be included in the NACEL annual state of the nation report and featured

in an online appendix. The alert- and alarm- level status will be noted in the Data and Improvement Tool at the end of each audit cycle.

Security

NHSBN has submitted a Data Security and Protection Toolkit (DSPT) self-assessment, with standards met for 2023-2024.

Storage

NACEL data will be collected, transmitted and stored securely.

Only registered staff members of the NACEL project, with Information Support, Submission Lead, Deputy Project Lead or Project Lead status, can access their organisation's NACEL data collection pages. The data input by staff is saved in the Network's SQL Database hosted by the CSU.

Only the NHSBN Technical Team and a CSU administrator have direct access to the database. The NHSBN Project Team have indirect access to individual data items in the database via a password protected Administration Utility. To obtain a download of all the data items a request must be made to the Technical team by the NACEL Project Team.

Deletion

Data will only be shared under the direction of HQIP. Data will have the audit code removed before being returned to HQIP at the end of the contract and deleted from the Network database as required by the contract.

Research

The data from NACEL may be used for clinical audit, service evaluation or research purposes. All requests for the use of this data will be logged and managed via HQIP, as the data controller, in accordance with the *Accessing NCAPOP Data – Guidance for applicants and data providers v2* .

Stage 5: Risk assessment and mitigation

1. Impact on Individuals

(Will the processing lead to individuals suffering)

Risks of processing	**Likelihood/ Impact of harm** Low Medium High	**Overall risk** Low Medium High	**Measure taken to reduce or eliminate risk**	**Risk** Reduced Eliminated Accepted
Inability to exercise their privacy rights (e.g., right to access their personal data, request correction, request erasure, restrict processing, object to personal data being processed for marketing purposes or object	Low	Low		

to automated decision making and profiling)				
Inability to access services	Low	Low		
Loss of control over personal data	Low	Low		
Discrimination	Low	Low		
Identity theft	Low	Low		
Fraud	Low	Low		
Financial loss	Low	Low		
Reputational damage	Low	Low		
Physical harm	Low	Low		
Emotional harm	Low	Low		
Loss of confidentiality	Low	Low		
Re-identification of pseudonymised data	Low	Low		
Any other significant economic disadvantage	Low	Low		
Any other significant social disadvantage	Low	Low		
2. Source of risk to individuals *(A breach of security leading to individuals suffering)*				
Risks of processing	**Likelihood/ Impact of harm** Low Medium High	**Overall risk** Low Medium High	**Measure taken to reduce or eliminate risk**	**Risk** Reduced Eliminated Accepted
Loss, destruction, or alteration of personal as a result of: • *Insecure electronic devices* • *Unencrypted memory sticks* • *Paper copies removed from secure work environment* • *IT system*	Low	Low		
Unauthorised disclosure of personal data as a result of: • *Insecure paper waste or hardware disposal* • *Use of insecure email accounts*	Low	Low		
Unauthorised access to personal data as a result of: • *Inadequate doors and locks*	Low	Low		

• *Inadequate supervision of visitors* • *Inadequate IT system security*				
Inability to access personal data due to unavailable systems for processing, or inability of the organisation or a third-party provider to restore access to systems in a timely manner	Low	Low		
3. Compliance / corporate risk *(Is the processing likely to result in)*				
Risks of processing	**Likelihood/ Impact of harm** Low Medium High	**Overall risk** Low Medium High	**Measure taken to reduce or eliminate risk**	**Risk** Reduced Eliminated Accepted
The organisation's non-compliance with Data Protection legislation and IG requirements	Low	Low		
Reputational risk to the organisation or a third-party provider	Low	Low		
Financial or reputational risks to HQIP as the data controller	Low	Low		