

NNAP - data access requests

Introduction

The National Neonatal Audit Programme (NNAP) is commissioned by the Healthcare Quality Improvement Partnership (HQIP), who, along with NHSE, act as joint data controllers. The NNAP is managed by the Royal College of Paediatrics and Child Health (RCPCH), who acts as the data processor. The NNAP is responsible for ensuring that the data collected as part of the audit is used to its full potential to facilitate improvements to care quality and neonatal outcomes, and also for enabling access to third parties wishing to use it for research.

The NNAP collects data relating to mothers and babies when a baby is admitted to a neonatal unit in England, Scotland, Wales and the Isle of Man from an agreed dataset.

The NNAP reports monthly and annually on key measures of the process and outcomes of neonatal and supports professionals, families and commissioners to the improve care given to babies who need neonatal care. It uses this information to highlight areas where services are performing well, and to identify areas where they need to improve.

This document describes the audit data available and how access can be requested.

Data available

Annual data is available to view and download from [NNAP Online](#). This interactive reporting tool enables you to view and compare the audit's results for a specific neonatal unit or network for results since 2014. Frequently updated time series data are also available to view on the NNAP Dashboard, available at: <https://www.rcpch.ac.uk/resources/nnap-data-dashboard>.

Unpublished summary statistics can be requested via the [NCAPOP Information Request Form](#), which may not need to be considered by the HQIP Data Access Request Group (DARG). However, some researchers may wish to access patient level data, or request a novel analysis, for which formal application to HQIP's Data Access Request Group (DARG) is necessary, following consultation with the NNAP team at RCPCH.

Please see the section on '**HQIP DARG applications**' for more information on how to apply.

About NNAP data

A description of the NNAP measures is available in the NNAP measures guide. A full list of data fields collected and held by the NNAP is available in the NNAP data dictionary. These are available at: <https://www.rcpch.ac.uk/work-we-do/clinical-audits/nnap/measures>

Requesting patient identifiable data

Identifiable data can only be shared if the applying organisation has the appropriate legal basis for receiving it. In most cases, this will be Section 251 approval. Most patient level data is shared after it has been pseudonymised. This involves replacing NHS numbers with a pseudocode, which masks the patient's identity but enables tracking of the same patient's outcomes across successive audit years. Other identifiable fields are replaced with less specific data (e.g. age in full years in place of date of birth, intervention times in minutes from birth, or LSOA in place of postcode).

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*). **For more information on data sharing for uses outside of the NNAP, please see the [NCAPOP privacy notice - HQIP](#).**

Cost recovery

The costs of data sharing are not explicitly included in the funding received to deliver the NNAP. These costs are incurred in terms of the staff time involved in the various activities necessary before data can be shared. They are not insignificant, and in the context of a growing audit remit with static funding, the NNAP is obliged to levy a charge to cover them.

Costing structure

Costs associated with each application will vary according to the time necessary to prepare the data and ensure that the data can be shared. This may depend on a number of factors, including the number of years' data requested, or whether patient identifiers are requested.

A standard application will normally include:

- Receipt, processing and review of application including discussion with the audit's clinical lead
- Advising applicants on viability of project, utility of data items requested, any concerns about duplication

- Information governance review and advice
- Processing of data including de-identifying disclosive fields, provision of calculated fields, lookup against codesets (e.g. geographical or social deprivation codes)
- Secure transfer of data to applicant
- Responding to queries and clarifications
- Review of draft publications

Some applications may also require:

- Meetings to discuss scope and direction of proposed project
- Contribution to drafting of publications e.g. methods sections

An indicative cost will be provided to applicants upon application. Charges will be based on workload associated with the application and will be charged following sharing of the data or completion of the process where the application to HQIP is not successful.

They will include a standard £500 + VAT admin fee to cover consultation and processing of the application, plus a £500 + VAT per day of analyst time—chargeable in half day increments. Should the consultation and processing of the application require more than one day administration time, we reserve the right to apply additional charges at the rate of £500 + VAT per day. The admin fee will apply where the NNAP team consider the request viable after an initial assessment, regardless of whether it the application to HQIP is successful.

A standard application will not include:

- Costs associated with amendment of the application
- Costs associated with re-preparing data files where the applicant has incorrectly specified the requirements.
- Cost of linkage to third party datasets.¹
- Applicants should discuss their requirements with the audit before bidding for project funding

Unfunded applications

While many applications will be part of funded programmes of academic research, some applications will be from clinical teams without external funding to be able to deliver this work. In these circumstances, and where the applicant

¹ Data Access Request Service charges from 2020/2021 available at <https://digital.nhs.uk/services/data-access-request-service-dars/data-access-request-service-dars-charges>

has declared a genuine inability to pay the fees, the audit programme has the discretion to do one of the following:

- Reject the application on the basis of it being unfunded.
- Signpost the applicant to appropriate funding sources or collaborators
- Apply a discount to the fees charged
- Waive the application fees.

The decisions taken by the audit programme will need to weigh up the perceived benefit of the proposed work to the clinical community against the costs to be absorbed by the programme. Decisions should be documented and communicated to the applicants in writing. Decisions to discount or waive fees will be made by the audit clinical lead, the appropriate budget holder and a non-executive member of the audit Project Board.

Authorship of publications and acknowledgements

Applicants should discuss authorship of publications with the audit team. The level of contribution to the publication – in terms of advice, preparation of data or drafting of methods – may warrant inclusion of audit team staff and clinical leads as authors of the publication.

All publications resulting from audit data should acknowledge the audit, its commissioners (HQIP) and participants.

HQIP DARG applications

If you are interested in NNAP data and wish to submit a Data Access Request to the HQIP DARG, please complete the '**NNAP Data Access Request Specification**' (Appendix 1 in this document), and email this to nnap@rcpch.ac.uk.

The NNAP project team will then consider your request and get in contact to arrange a meeting to discuss further. If accepted, you can proceed with the HQIP DARG application with the project team's support. More information on the application can be found on the [HQIP website](#).

Appendix 1. NNAP Data Access Request Specification

If you are seeking to access data from the NNAP, for which formal application to HQIP's Data Access Request Group (DARG) is necessary, please complete the following table to describe the aims of your project and the data you require. Please then submit this specification to nnap@rcpch.ac.uk for the audit team to review. This is not a formal data access request process, but will allow the team to consider your request and whether we can support you with it.

Applicant information	
Applicant organisation	Click or tap here to enter text.
Applicant name	Click or tap here to enter text.
Applicant title	Click or tap here to enter text.
Email address	Click or tap here to enter text.
Project title	Click or tap here to enter text.
Project objective	Click or tap here to enter text.
Research question/s	Click or tap here to enter text.
Data requirements	
Geographical area of data coverage, by hospital of admission (check all that apply)	<input type="checkbox"/> England <input type="checkbox"/> Wales <input type="checkbox"/> Scotland <input type="checkbox"/> Isle of Man <input type="checkbox"/> Northern Ireland <input type="checkbox"/> Other, e.g. sub-national region. Please specify:
Time period of interest. Please specify start and end dates as MM/YYYY. Please also specify any criteria for the time period, e.g. based on date of first admission/date of birth, or date of discharge.	
NNAP measures or data fields of interest. Please refer to the latest NNAP measures guide and data dictionary.	Click or tap here to enter text.
Gestational age range of interest	Lower gestational age: Click or tap here to enter text. Upper gestational age: Click or tap here to enter text.

Any specific inclusion or exclusion criteria	Click or tap here to enter text.
If known, what type of data do you require. This can be discussed and determined by the NNAP team/HQIP if you are not sure.	<input type="checkbox"/> Anonymous <input type="checkbox"/> De-personalised <input type="checkbox"/> Personal identifiable <input type="checkbox"/> Not sure