National Neonatal Audit Programme (NNAP) - data access

Introduction

The 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 from every baby admitted to neonatal care in England and Wales from an agreed dataset.

The NNAP reports annually on key measures of the process and outcomes of neonatal care and supports professionals, families and commissioners to the improve care to babies requiring specialist treatment. To do this, the audit collects and processes patient data to assess the care given to babies admitted to neonatal units. It uses this information to highlight areas where services are performing well, and to identify areas where they need to improve.

Data available

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. 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.

Unpublished summary statistics at national or regional level can be requested via the NCAPOP Information Request Form (Word format only), which may need to be considered by the HQIP DARG. HQIP also provide a guide on how to access these data.

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 or LSOA in place of postcode).

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. They will include a standard £350 + VAT admin fee to cover consultation and processing of the application, plus a £350 + VAT per day of analyst time– chargeable in half day increments. Where an external contractor is required for preparation of data files, this will be charged at £500 + VAT per half day.

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.

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[1] Data Access Request Service (DARS) charges from 2020/2021 available at:
https://digital.nhs.uk/services/data-access-request-service-dars/data-access-request-service-dars-charges

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

- Reject the application
- 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.