

A Guide to Utilising the National Neonatal Research Database (NNRD)

Background information

The National Neonatal Research Database (NNRD) has been created through the collaborative efforts of neonatal services across the country to be a national resource. The NNRD is maintained and managed at the Neonatal Data Analysis Unit (NDAU) at Imperial College London and Chelsea and Westminster NHS Foundation Trust.

The NNRD contains a defined set of data items (the Neonatal Dataset) that have been extracted from the Badger.net neonatal electronic health record of all admissions to NHS neonatal units. Badger.net is managed by Clevermed Ltd, an authorised NHS hosting company. The Neonatal Dataset is an approved NHS Information Standard (ISB1575). Contributing neonatal units are known as the UK Neonatal Collaborative.

The NNRD is a national Research Ethics Committee (REC) approved database. The Caldicott Guardians and Neonatal Lead Clinicians of all contributing Trusts have approved the use of data held in the NNRD for health services evaluations. No research utilising the NNRD is undertaken without additional specific REC approval for each study, and the explicit agreement of each contributing Trust.

Researchers, clinicians, managers, commissioners, and others are welcome and encouraged to utilise the NNRD. The NDAU receives no core funding to support the NNRD. For this reason a charge is necessary to cover the costs of maintaining and developing the NNRD, data transfer, extraction, cleaning, and storage, and any analyses requested.

Please note that if you need access to your own neonatal unit data this can be done through the Badger.net platform provider, Clevermed Ltd. Please contact Clevermed Ltd directly.

The NDAU Steering Board approves all requests for assistance. The NNRD is utilised for national audit; other outputs to-date include NHS outcomes indicators, patient safety indices, commissioning, evaluations of quality improvement programmes and service reconfigurations, and a range of research studies.

Research studies

Before approaching the NDAU we recommend that you define your research question/s and draft a study protocol. You may also find it helpful to consider the following issues:

- 1 Are the data you require available in the NNRD?
 - Please see the [National Data Set](#) for the fields in the NNRD.
- 2 What is your time period of interest and which geographical regions do you want included?
 - The NNRD is updated each quarter; approximately 80,000 new patient records are incorporated each year.
 - For historical work, please note that data are currently available from 2010 when 96% of neonatal units in England contributed; from 2012 there has been 100% contribution from English neonatal units.

- From October 2012 all Welsh neonatal units have contributed data to the NNRD.
 - As of October 2014 15 of 17 Scottish Neonatal units contribute data to the NNRD.
 - At present no Northern Irish neonatal units contribute data to the NNRD.
- 3 Will you only require a data extract or will you additionally require data analysis support?
- Data extraction to meet specific needs is undertaken on a purpose-by-purpose basis from the NNRD by the NDAU data analysts.
 - The NDAU may be able to provide statistical support; please feel free to discuss this with us.
- 4 Please consider how you intend to fund your requirements.
- We recommend you contact us in advance so that you are able to include any NNRD related costs in your grant applications.
 - The NDAU is required to submit all research related costs to Department of Medicine, Imperial College London for approval.
- 5 We require confirmation of agreement to participate in the specified project from all Neonatal Units before the release of any data.
- NHS approval (“R&D Approval”) is only required from Chelsea and Westminster NHS Foundation Trust as the host organisation of the NNRD, and is not required from each individual participating NHS Trust.
 - The NDAU will contact neonatal units on your behalf if you wish, in order to gain confirmation of agreement to participate.
- 6 Have you obtained Research Ethic Committee (REC) approval?
- All research projects involving the NNRD require national REC approval.
 - The NDAU will advise on NNRD related aspects of any REC application.
- 7 Do you require patient identifiable data?
- At present the NDAU hold approval from the Confidentiality Advisory Group of the Health Research Authority to receive and hold patient identifiers without explicit patient consent only for the purposes of data linkage. These approvals are currently being revised.
 - If you require patient identifiers without patient consent you will require specific Confidentiality Advisory Group approval, additional to REC approval.
 - You will also require explicit permission from individual NHS trusts for the NDAU to release patient identifiers.

If you would like to discuss your project or are unsure about any of the above points the NDAU team will be happy to help. Please send your protocol to the NDAU manager who will schedule it for the next Steering Board meeting.

Health Services Evaluations and Audits

If you have a health services evaluation or audit to undertake the NDAU team can also help.

The first step is to clarify your needs. Please refer to questions 1-3 posed to researchers above. We recommend you then contact the NDAU for an informal discussion.

Once your proposal is complete send this to the NDAU manager. This will be considered by the NDAU team and Steering Board. You will be provided with confirmation if your analysis is possible, the estimated length of time required, and the cost.

You will then be contacted by Imperial College Consultants (ICON) to draw up a contract setting out the services the NDAU will provide, the time frame for completion, and the cost. As this is a consultancy VAT will apply and a 10% fee levied by ICON.

Contact details

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