

National Paediatric Diabetes Audit (NPDA) Data Access Requests

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Introduction

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

The NPDA collects data from every single patient visit to every paediatric diabetes unit (PDU) in England and Wales from an agreed dataset that is updated every few years. The audit includes all children and young people under the care of paediatric services up to the age of 25, with all types of diabetes.

The NPDA reports annually on the numbers of children and young people with diabetes receiving key care processes, and their diabetes-related health outcomes. Results are published at national level (Type 1 and Type 2 diabetes), network, regional, ICB, and unit level (Type 1 only), and these aggregated results are available to view and download from the [RCPCH website](#). 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 NPDA team at RCPCH.

Data available

The [current NPDA dataset](#) is available to view on the NPDA website. For details of previous datasets and variables derived from those collected, please contract npda@rpch.ac.uk.

The RCPCH has managed the audit since 2012, but can provide data collected from 2004 onwards. The audit has collected data from each patient visit since 2012 and prior to this summary data was collected for each patient seen within the audit year.

Clean data is available from 2004, and unclean (raw) data from 2013. Please consider whether cleaned or uncleaned data is needed.

Requesting aggregated data

Unpublished summary statistics at national or regional level can be requested via the [NCAPOP Information Request Form](#) (Word format only), which may not need to be considered by the HQIP DARG if the request is not judged too granular or too wide in scope.

HQIP also provide a [video guide](#) on how to access these data.

Requesting patient-level data

To make a request for patient-level data, please complete the form in Appendix A and send to npda@rcpch.ac.uk. The request will be initially reviewed by the NPDA team and clinical lead. If accepted, requests for patient-level data may need to progress through the [HQIP DARG](#) review process.

De-personalised data

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).

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 Section 251 of the NHS Act 2006 (Reference 24/CAG/0108). For more information on data sharing for uses outside of the NPDA, please see the [NCAPOP privacy notice - HQIP](#).

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.

Requests with Substantial Public Interest

Requests for patient-level data (de-personalised or identifiable) may not need to go via the HQIP DARG if they have substantial public interest for access to NPDA data, such as those from national inquiries.

Upon receiving a request of this nature, the NPDA Project Manager will liaise with HQIP to determine the appropriate data sharing protocol.

Cost recovery

The costs of data sharing are not explicitly included in the funding received to deliver the NPDA. 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 NPDA is now 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 or not patient identifiers are requested, for example.

A standard application will normally include:

- Receipt, processing and review of application including discussion with audit 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 NPDA team consider the request viable after an initial assessment, regardless of whether 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.

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 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 NPDA 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 NPDA Manager 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.

Appendix A. NPDA Data Access Request Specification

If you are seeking to access data from the NPDA, for which formal application to HQIP's Data Access Request Group (DARG) is necessary, please complete the following table to and submit this specification to npda@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	
Applicant primary contact name and email address	
Project title	
Project objective	
Data requirements	
Geographical area of data coverage (check all that apply)	☐ England ☐ Wales ☐ Jersey ☐ Isle of Man ☐ Other, e.g. sub-national region. Please specify:
NPDA audits (check all that apply)	☐ Core Audit ☐ Spotlight Audits (e.g. Type 2 spotlight, Workforce) ☐ PREMs ☐ Other. 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 diagnosis or date of birth.	
NPDA measures or data fields of interest. Please refer to the latest NPDA dataset.	
Any specific inclusion or exclusion criteria (e.g. diabetes type, age range)	
If known, what type of data do you require. This can be discussed and determined by the NPDA team/HQIP if you are not sure.	☐ Aggregated data ☐ De-personalised patient-level ☐ Personal identifiable patient-level ☐ Not sure