

National Paediatric Diabetes Audit (NPDA) - data access

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 care quality and diabetes 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), regional, CCG, 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 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.

The RCPCH has managed the audit since 2012, but can provide data collected from 2004 onwards.

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

Unpublished summary statistics at national or regional level can be requested via the [NCAPOP Information Request Form](#) (Word format only), which may not need to be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.

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 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 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. 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.

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.

¹ HSCIC charging structure is available at http://www.hscic.gov.uk/media/20431/DARS-pricing-guide-201617/pdf/DARS_Service_Charges_-_April_2016_FINAL.pdf

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 participant.