Epilepsy12 - data access requests

Introduction

The Epilepsy12 audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP), who, along with NHSE, act as joint data controllers. The Epilepsy12 audit is managed by the Royal College of Paediatrics and Child Health (RCPCH), who acts as the data processor. Epilepsy12 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 Epilepsy12 audit collects data from every child and young person with epilepsy and a first paediatric assessment for a suspected seizure in England and Wales.

Epilepsy12 reports annually on key measures of the process and outcomes of paediatric epilepsy care and supports professionals, families and commissioners to the improve care to children and young people with epilepsy 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

It may be possible to share unpublished summary statistics. Please contact the project team at epilepsy12@rcpch.ac.uk for more information. 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 Epilepsy12 team at the RCPCH.

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

Clinical audit data

The Epilepsy12 clinical audit dataset is available to view on the Epilepsy12 website. This dataset applies to Cohort 6 onwards (first paediatric assessment after 1 December 2022). The dataset used for Cohorts 1-5 (first paediatric assessment between 12 July 2018 and 30 November 2022) can be found here. For details of previous datasets and variables derived from those collected, please contact epilepsy12@rcpch.ac.uk.

In Cohorts 1-5, the audit collected data on all children and young people with a first paediatric assessment for suspected epileptic seizures. The audit has collected data from each patient with a first paediatric assessment for a paroxysmal episode since 2018.

From Cohort 6 onwards, the audit collects data on children and young with a first paediatric assessment for a paroxysmal episode who then receive a diagnosis of epilepsy. Children and young people who have a first paediatric assessment, but do not obtain a diagnosis of epilepsy, are not included in the audit.

The audit collects data about the epilepsy care provided to children and young people with a new diagnosis of epilepsy during the first 12 months following a first paediatric assessment. Results are published at a national, regional, and Trust/Health Board level. Some data may be masked in line with the RCPCH data disclosure policy.

Organisational audit data

The current Epilepsy12 organisational audit dataset is available on the Epilepsy12 website. For details on previous datasets, please contact epilepsy12@rcpch.ac.uk.

The organisational audit has collected data on the organisational structure and resources of Trusts and Health Boards providing paediatric epilepsy care since 2018. Results are published at a national, regional, and Trust/Health Board level.

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.

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 Epilepsy12 audit programme, 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 Epilepsy12 audit. 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 Epilepsy12 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

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

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[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

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 the Epilepsy12 audit data and wish to submit a Data Access Request to the HQIP DARG, please complete the '**Epilpesy12 Data Access Request Specification**' (Appendix 1 in this document), and email this to epilepsy12@rcpch.ac.uk.

The Epilepsy12 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. Epilpesy12 Data Access Request Specification

If you are seeking to access data from the Epilepsy12 audit, 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 epilepsy12@rcpch.ac.uk for the audit team to review.

Applicant Organisation	
Primary Contact name and email	
Method of data sharing	
Project Title	
Project Objective	
Patient identifiable data, de-personalised or fully anonymous?	
Geographical area (England and/or Wales)	
How is this defined (eg. by phone/GP postcode, Hospital etc)	
Time frame (cohort(s) if appropriate)	
Epilepsy status; epilepsy, uncertain, non-epilepsy	
Age-range	
Audit measures required	
Any data transformations	
Any additional exclusion criteria outside of typical processes (eg. CYP with missing postcodes)	
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