

# **RCPCH Censsus Platform Documentation**

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## **User and Developer Manual**

The Royal College of Paediatrics and Child Health

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# 1. Home

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## 1.1 Introduction

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### Guidance for Clinicians

Go to the Clinician Guide above for guidance on entering patient data.

### 1.1.1 RCPCH Census Platform

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## 1.2 KPIs and Quality Improvement

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### 1.2.1 10 key performance indicators

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1. Paediatrician with expertise in epilepsies
2. Epilepsy specialist nurse
3. a. Tertiary input b. Epilepsy surgery referral
4. ECG
5. MRI brain
6. Assessment of mental health issues
7. Mental health support
8. Sodium valproate
9. a. Care planning agreement b. Care planning content
10. School individual health care plan

### 1.2.2 Quality Improvement

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Epilepsy12 engaged with relevant stakeholders to identify priority areas of care and agree five Health Improvement Goals to align with these.

1. Increase the proportion of children receiving input from an epilepsy specialist nurse by 5% per year; from 76% in Cohort 3 to 91% in Cohort 6.
2. For children with complex epilepsy, increase the proportion receiving input from a tertiary specialist by 5% per year; from 69% in Cohort 3 to 84% in Cohort 6.
3. Increase the proportion of children receiving all core elements of care planning by 5% per year; from 75% in Cohort 3 to 90% in Cohort 6.
4. Increase the proportion of Health Boards and Trusts using structured transition resources by 5% per year; from 62% in Cohort 3 to 77% in Cohort 6.
5. Increase the number of Health Boards and Trusts screening children with epilepsy for mental health disorders by 5% per year; from 19% in Cohort 3 to 34% in Cohort 6.

Epilepsy12 collaborated with QI experts when designing the improvement goals and strategies. We will continue to receive their input when delivering these strategies and seek guidance on how we can embed Epilepsy12's evaluation and learning to improve the plan and explore avenues of collaboration with NHS, HQIP, and other improvement programmes.

You can find out more about our quality improvement plans for 2022-25 in our [Quality Improvement Strategy](#).

## 1.3 Citing the Epilepsy12 audit

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### 1.3.1 Citation of the Epilepsy12 audit in academic publications

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You can use our Zenodo DOI button to cite this audit

DOI [10.5281/zenodo.6549072](https://doi.org/10.5281/zenodo.6549072)

## 2. Contact

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### 2.1 Contact Page

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For enquiries please contact the project team:

Email: [rcpch.census.platform@rcpch.tech](mailto:rcpch.census.platform@rcpch.tech)

Tel: 020 7092 6157 / 6056

You can find more information about the audit at <https://www.rcpch.ac.uk/epilepsy12>.

## 3. Legal

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## 3.3 Clinical Safety

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### 3.3.1 Clinical Safety

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The Epilepsy12 audit engine does not have any role in the direct clinical management of patients, it is solely for recording the milestones in childrens' care for the purposes of national audit, which is a secondary use of data, not a direct care use. It does not therefore require a clinical safety case or a Clinical Safety Officer.

### 3.3.2 Medical Device Registration

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The Epilepsy12 audit engine does not have any role in the clinical management of patients, it is solely for recording the milestones in childrens' care for the purposes of national audit. It is not a medical device and as such requires no medical device registration.

## 3.4 Privacy Overview

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Within the Epilepsy12 project we take the privacy of patients and our duty of confidentiality very seriously. We have complied with all relevant legislation and moral and ethical codes to support the project.

### 3.4.1 National Data Opt Out Implementation (England only)

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The Secretary of State for Health and Social Care, having considered the advice from the Health Research Authority Confidentiality Advisory Group, have granted Epilepsy12 an exemption to the National Data Opt-Out (NDO). Epilepsy12 were granted this exemption because applying the National Opt-Out would introduce biases to the data and make it difficult to monitor care safety and quality at Trust level, risking quality of care and patient safety.

This means that healthcare providers in England no longer need to screen patients against the opt-out list prior to entering their data into Epilepsy12.

#### Patients can still opt out of Epilepsy12 by contacting their Epilepsy clinical team

Withdrawal of consent can be indicated in the audit detail submission for that patient, and the record will be deleted. Please take a look at the [clinician user guide](#) for more information on this.

Withdrawal of consent can be indicated in the audit detail submission for that patient, and the record will be deleted. Please take a look at the [clinician user guide](#) for more information on this.

### 3.4.2 Privacy Notice

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The Privacy Notice for the Epilepsy12 Project is viewable or downloadable from the [Privacy Notice page](#)

### 3.4.3 Data Protection Impact Assessment

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Our Data Protection Impact Assessment is viewable or downloadable from the [DPIA page](#)

## 3.5 Privacy Notice

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### 3.5.1 Privacy Notice

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The RCPCH has published a Privacy Notice for the Epilepsy 12 Project, these are embedded below in English and Welsh. You can also download them from the below links:

[Privacy Notice \(English\)](#) | [Privacy Notice \(Welsh\)](#)

#### Privacy Notice (English)

If the PDF cannot be embedded here, it is available to download from [this link](#)

#### Privacy Notice (Welsh)

If the PDF cannot be embedded here, it is available to download from [this link](#)



## 3.6 Data Protection Impact Assessment

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The RCPCH's Data Protection Impact Assessment for the Epilepsy12 Audit is below. You can also download it from [this link](#).

### Data Protection Impact Assessment

If the PDF cannot be embedded here, it is available to download from [this link](#)

## 3.7 Section 251 Exemption

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The Epilepsy12 audit engine has been granted an exemption from Section 251 of the NHS Act 2006 by the Confidentiality Advisory Group (CAG) of the Health Research Authority (HRA). This means that healthcare providers in England no longer need to screen patients against the opt-out list prior to entering their data into Epilepsy12.

We are reviewed annual for compliance with conditions of the exemption, and a selection of the most recent and relevant documents are embedded below. You can see more information on the [Epilepsy12 section of the RCPCH website](#)

### Section 251 Support - Annual Review 2023

If the PDF cannot be embedded here, it is available to download from [this link](#)

### Section 251 - Change in Data Processor to use RCPCH and sub-processors

If the PDF cannot be embedded here, it is available to download from [this link](#)

### NDO Deferral Request - Conditionally Supported

If the PDF cannot be embedded here, it is available to download from [this link](#)

### Section 251 Support - Annual Review 2022

If the PDF cannot be embedded here, it is available to download from [this link](#)

## 3.8 Terms of Service

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### Important

**The Terms of Service must be accepted as a condition of use of the Epilepsy12 Platform**

### 3.8.1 Key points

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- You will maintain a secure, confidential password and assume responsibility for all activities that occur under your user account.
- The Royal College of Paediatrics and Child Health (RCPCH) makes no express or implied warranties with regard to the content or reports from the site.
- The Epilepsy12 platform is not an electronic medical record for direct care purposes and should not be used as such. You will refer to the official patient medical record when making medical decisions.

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### 3.8.3 Your Account Obligations

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You are responsible for maintaining a secure, confidential password, and for all activities that occur under your user account. You agree to notify us immediately of any unauthorised use of your username or password or any other breach of security.

### 3.8.4 Disclaimers

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Contents do not substitute for review of an individual's medical record and consultation with a physical or other qualified health provider. Clinics in England should apply the NHS National Data Opt Out process and not submit data from patients who have opted out.

### 3.8.5 No warranties

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### 3.8.6 Fair Processing Statement

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The RCPCH has HSCA Section 251 approval for Epilepsy12 to collect patient identifiable data without explicit patient consent (see references below). This data is processed and reported by the Epilepsy12 project team within the RCPCH with the Healthcare Quality Improvement Partnership (HQIP) as the Data Controller.

Full details of fair processing documentation for the collection of patient identifiable information without consent in Health Boards and Trusts in England and Wales will be added to this page prior to the start of the clinical audit data entry phase. Copies of these materials will also be provided to participating Health Boards and Trusts to display in clinic areas and share with their patients and family members. HQIP may approve the sharing of pseudonymised Epilepsy12 data for the purpose of service improvement if stringent data protection policies and arrangements can be demonstrated by requestees and the aims of the service improvement are approved.

Epilepsy12 data may also be linked to data from the Hospital Episode Statistics (HES), Patient Episode Database for Wales (PEDW) and the Office for National Statistics (ONS). NHS Digital and the NHS Wales Informatics Service may provide HES, PEDW and ONS data to Epilepsy12 in an anonymous format. The linked data would then be analysed by the Epilepsy12 project team at the RCPCH to further help to measure standards of care.