

# **RCPCH Censsus Platform Documentation**

---

## **User and Developer Manual**

The Royal College of Paediatrics and Child Health

Copyright © 2021-24 The Royal College of Paediatrics and Child Health (RCPCH)

## Table of contents

---

1. Home	3
1.1 Introduction	3
1.2 KPIs and Quality Improvement	4
1.3 Citing the Epilepsy12 audit	5
2. Contact	6
2.1 Contact Page	6
3. Legal	7
3.1 Intellectual Property	7
3.2 License (CC-BY-SA 4.0)	8
3.3 Clinical Safety	14
3.4 Privacy Overview	15
3.5 Privacy Notice	16
3.6 Data Protection Impact Assessment	17
3.7 Section 251 Exemption	18
3.8 Terms of Service	19

# 1. Home

---

## 1.1 Introduction

---

### Guidance for Clinicians

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

### 1.1.1 RCPCH Census Platform

---

## 1.2 KPIs and Quality Improvement

---

### 1.2.1 10 key performance indicators

---

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

---

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

---

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

---

You can use our Zenodo DOI button to cite this audit

DOI 10.5281/zenodo.6549072

## 2. Contact

---

### 2.1 Contact Page

---

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

---

## 3.1 Intellectual Property

---

### 3.1.1 Copyright

---

Copyright is asserted over all RCPCH intellectual property outputs by the Royal College of Paediatrics and Child Health. We will defend this copyright in all territories.

### 3.1.2 Open Source Licenses

---

#### Software

The RCPCH Audit Engine software is licensed under the GNU Affero General Public License v3.0

#### Documentation and textual outputs

All documentation and textual work (such as this documentation site) is licensed under a Creative Commons Attribution-ShareAlike 4.0 International license. See the [license](#) page for more detail.

#### Upstream components

Our licensing arrangements do not affect the licenses of any upstream technologies which we have used to build our platforms, such as Django ([3-clause BSD](#)) MkDocs ([BSD](#)) or Python ([PSF](#)). However our license choice is compatible with these upstream licensing arrangements.

## 3.2 License (CC-BY-SA 4.0)



### License for the textual and documentation portions of this work

The textual portions of this work, documentation, and all other included non-code written information is licensed under the [Creative Commons Attribution-ShareAlike 4.0 International](#) license, except where otherwise stated.

### 3.2.1 Creative Commons Attribution-ShareAlike 4.0 International

Creative Commons Corporation (“Creative Commons”) is not a law firm and does not provide legal services or legal advice. Distribution of Creative Commons public licenses does not create a lawyer-client or other relationship. Creative Commons makes its licenses and related information available on an “as-is” basis. Creative Commons gives no warranties regarding its licenses, any material licensed under their terms and conditions, or any related information. Creative Commons disclaims all liability for damages resulting from their use to the fullest extent possible.

#### Using Creative Commons Public Licenses

Creative Commons public licenses provide a standard set of terms and conditions that creators and other rights holders may use to share original works of authorship and other material subject to copyright and certain other rights specified in the public license below. The following considerations are for informational purposes only, are not exhaustive, and do not form part of our licenses.

- **Considerations for licensors:** Our public licenses are intended for use by those authorized to give the public permission to use material in ways otherwise restricted by copyright and certain other rights. Our licenses are irrevocable. Licensors should read and understand the terms and conditions of the license they choose before applying it. Licensors should also secure all rights necessary before applying our licenses so that the public can reuse the material as expected. Licensors should clearly mark any material not subject to the license. This includes other CC-licensed material, or material used under an exception or limitation to copyright. [More considerations for licensors.](#)
- **Considerations for the public:** By using one of our public licenses, a licensor grants the public permission to use the licensed material under specified terms and conditions. If the licensor’s permission is not necessary for any reason—for example, because of any applicable exception or limitation to copyright—then that use is not regulated by the license. Our licenses grant only permissions under copyright and certain other rights that a licensor has authority to grant. Use of the licensed material may still be restricted for other reasons, including because others have copyright or other rights in the material. A licensor may make special requests, such as asking that all changes be marked or described. Although not required by our licenses, you are encouraged to respect those requests where reasonable. [More considerations for the public.](#)

### 3.2.2 Creative Commons Attribution-ShareAlike 4.0 International Public License

By exercising the Licensed Rights (defined below), You accept and agree to be bound by the terms and conditions of this Creative Commons Attribution-ShareAlike 4.0 International Public License (“Public License”). To the extent this Public License may be interpreted as a contract, You are granted the Licensed Rights in consideration of Your acceptance of these terms and conditions, and the Licensor grants You such rights in consideration of benefits the Licensor receives from making the Licensed Material available under these terms and conditions.

#### Section 1 - Definitions.

a. **Adapted Material** means material subject to Copyright and Similar Rights that is derived from or based upon the Licensed Material and in which the Licensed Material is translated, altered, arranged, transformed, or otherwise modified in a manner



requiring permission under the Copyright and Similar Rights held by the Licensor. For purposes of this Public License, where the Licensed Material is a musical work, performance, or sound recording, Adapted Material is always produced where the Licensed Material is synched in timed relation with a moving image.

b. **Adapter's License** means the license You apply to Your Copyright and Similar Rights in Your contributions to Adapted Material in accordance with the terms and conditions of this Public License.

c. **BY-SA Compatible License** means a license listed at [creativecommons.org/compatiblelicenses](https://creativecommons.org/compatiblelicenses), approved by Creative Commons as essentially the equivalent of this Public License.

d. **Copyright and Similar Rights** means copyright and/or similar rights closely related to copyright including, without limitation, performance, broadcast, sound recording, and Sui Generis Database Rights, without regard to how the rights are labeled or categorized. For purposes of this Public License, the rights specified in Section 2(b)(1)-(2) are not Copyright and Similar Rights.

e. **Effective Technological Measures** means those measures that, in the absence of proper authority, may not be circumvented under laws fulfilling obligations under Article 11 of the WIPO Copyright Treaty adopted on December 20, 1996, and/or similar international agreements.

f. **Exceptions and Limitations** means fair use, fair dealing, and/or any other exception or limitation to Copyright and Similar Rights that applies to Your use of the Licensed Material.

g. **License Elements** means the license attributes listed in the name of a Creative Commons Public License. The License Elements of this Public License are Attribution and ShareAlike.

h. **Licensed Material** means the artistic or literary work, database, or other material to which the Licensor applied this Public License.

i. **Licensed Rights** means the rights granted to You subject to the terms and conditions of this Public License, which are limited to all Copyright and Similar Rights that apply to Your use of the Licensed Material and that the Licensor has authority to license.

j. **Licensor** means the individual(s) or entity(ies) granting rights under this Public License.

k. **Share** means to provide material to the public by any means or process that requires permission under the Licensed Rights, such as reproduction, public display, public performance, distribution, dissemination, communication, or importation, and to make material available to the public including in ways that members of the public may access the material from a place and at a time individually chosen by them.

l. **Sui Generis Database Rights** means rights other than copyright resulting from Directive 96/9/EC of the European Parliament and of the Council of 11 March 1996 on the legal protection of databases, as amended and/or succeeded, as well as other essentially equivalent rights anywhere in the world.

m. **You** means the individual or entity exercising the Licensed Rights under this Public License. **Your** has a corresponding meaning.

## Section 2 - Scope.

### a. License grant.

1. Subject to the terms and conditions of this Public License, the Licensor hereby grants You a worldwide, royalty-free, non-sublicensable, non-exclusive, irrevocable license to exercise the Licensed Rights in the Licensed Material to:
  - A. reproduce and Share the Licensed Material, in whole or in part; and
  - B. produce, reproduce, and Share Adapted Material.
2. **Exceptions and Limitations.** For the avoidance of doubt, where Exceptions and Limitations apply to Your use, this Public License does not apply, and You do not need to comply with its terms and conditions.
3. **Term.** The term of this Public License is specified in Section 6(a).
4. **Media and formats; technical modifications allowed.** The Licensor authorizes You to exercise the Licensed Rights in all media and formats whether now known or hereafter created, and to make technical modifications necessary to do so. The Licensor waives and/or agrees not to assert any right or authority to forbid You from making technical modifications necessary to exercise the Licensed Rights, including technical modifications necessary to circumvent Effective Technological Measures. For purposes of this Public License, simply making modifications authorized by this Section 2(a)(4) never produces Adapted Material.
5. **Downstream recipients.**
  - A. **Offer from the Licensor - Licensed Material.** Every recipient of the Licensed Material automatically receives an offer from the Licensor to exercise the Licensed Rights under the terms and conditions of this Public License.
  - B. **Additional offer from the Licensor - Adapted Material.** Every recipient of Adapted Material from You automatically receives an offer from the Licensor to exercise the Licensed Rights in the Adapted Material under the conditions of the Adapter's License You apply.
  - C. **No downstream restrictions.** You may not offer or impose any additional or different terms or conditions on, or apply any Effective Technological Measures to, the Licensed Material if doing so restricts exercise of the Licensed Rights by any recipient of the Licensed Material.
6. **No endorsement.** Nothing in this Public License constitutes or may be construed as permission to assert or imply that You are, or that Your use of the Licensed Material is, connected with, or sponsored, endorsed, or granted official status by, the Licensor or others designated to receive attribution as provided in Section 3(a)(1)(A)(i).

### b. Other rights.

1. Moral rights, such as the right of integrity, are not licensed under this Public License, nor are publicity, privacy, and/or other similar personality rights; however, to the extent possible, the Licensor waives and/or agrees not to assert any such rights held by the Licensor to the limited extent necessary to allow You to exercise the Licensed Rights, but not otherwise.
2. Patent and trademark rights are not licensed under this Public License.
3. To the extent possible, the Licensor waives any right to collect royalties from You for the exercise of the Licensed Rights, whether directly or through a collecting society under any voluntary or waivable statutory or compulsory licensing scheme. In all other cases the Licensor expressly reserves any right to collect such royalties.

## Section 3 - License Conditions.

Your exercise of the Licensed Rights is expressly made subject to the following conditions.

**a. Attribution.**

1. If You Share the Licensed Material (including in modified form), You must:

A. retain the following if it is supplied by the Licensor with the Licensed Material:

- i. identification of the creator(s) of the Licensed Material and any others designated to receive attribution, in any reasonable manner requested by the Licensor (including by pseudonym if designated);
- ii. a copyright notice;
- iii. a notice that refers to this Public License;
- iv. a notice that refers to the disclaimer of warranties;
- v. a URI or hyperlink to the Licensed Material to the extent reasonably practicable;

B. indicate if You modified the Licensed Material and retain an indication of any previous modifications; and

C. indicate the Licensed Material is licensed under this Public License, and include the text of, or the URI or hyperlink to, this Public License.

2. You may satisfy the conditions in Section 3(a)(1) in any reasonable manner based on the medium, means, and context in which You Share the Licensed Material. For example, it may be reasonable to satisfy the conditions by providing a URI or hyperlink to a resource that includes the required information.

3. If requested by the Licensor, You must remove any of the information required by Section 3(a)(1)(A) to the extent reasonably practicable.

**b. ShareAlike.**

In addition to the conditions in Section 3(a), if You Share Adapted Material You produce, the following conditions also apply.

1. The Adapter's License You apply must be a Creative Commons license with the same License Elements, this version or later, or a BY-SA Compatible License.
2. You must include the text of, or the URI or hyperlink to, the Adapter's License You apply. You may satisfy this condition in any reasonable manner based on the medium, means, and context in which You Share Adapted Material.
3. You may not offer or impose any additional or different terms or conditions on, or apply any Effective Technological Measures to, Adapted Material that restrict exercise of the rights granted under the Adapter's License You apply.

**Section 4 - Sui Generis Database Rights.**

Where the Licensed Rights include Sui Generis Database Rights that apply to Your use of the Licensed Material:

- a. for the avoidance of doubt, Section 2(a)(1) grants You the right to extract, reuse, reproduce, and Share all or a substantial portion of the contents of the database;
- b. if You include all or a substantial portion of the database contents in a database in which You have Sui Generis Database Rights, then the database in which You have Sui Generis Database Rights (but not its individual contents) is Adapted Material, including for purposes of Section 3(b); and
- c. You must comply with the conditions in Section 3(a) if You Share all or a substantial portion of the contents of the database.

For the avoidance of doubt, this Section 4 supplements and does not replace Your obligations under this Public License where the Licensed Rights include other Copyright and Similar Rights.

**Section 5 - Disclaimer of Warranties and Limitation of Liability.**

**a. Unless otherwise separately undertaken by the Licensor, to the extent possible, the Licensor offers the Licensed Material as-is and as-available, and makes no representations or warranties of any kind concerning the Licensed Material, whether express, implied, statutory, or other. This includes, without limitation, warranties of title, merchantability, fitness for a particular purpose, non-infringement, absence of latent or other defects, accuracy, or the presence or absence of errors, whether or not known or discoverable. Where disclaimers of warranties are not allowed in full or in part, this disclaimer may not apply to You.**

**b. To the extent possible, in no event will the Licensor be liable to You on any legal theory (including, without limitation, negligence) or otherwise for any direct, special, indirect, incidental, consequential, punitive, exemplary, or other losses, costs, expenses, or damages arising out of this Public License or use of the Licensed Material, even if the Licensor has been advised of the possibility of such losses, costs, expenses, or damages. Where a limitation of liability is not allowed in full or in part, this limitation may not apply to You.**

c. The disclaimer of warranties and limitation of liability provided above shall be interpreted in a manner that, to the extent possible, most closely approximates an absolute disclaimer and waiver of all liability.

#### **Section 6 - Term and Termination.**

a. This Public License applies for the term of the Copyright and Similar Rights licensed here. However, if You fail to comply with this Public License, then Your rights under this Public License terminate automatically.

b. Where Your right to use the Licensed Material has terminated under Section 6(a), it reinstates:

1. automatically as of the date the violation is cured, provided it is cured within 30 days of Your discovery of the violation; or
2. upon express reinstatement by the Licensor.

For the avoidance of doubt, this Section 6(b) does not affect any right the Licensor may have to seek remedies for Your violations of this Public License.

c. For the avoidance of doubt, the Licensor may also offer the Licensed Material under separate terms or conditions or stop distributing the Licensed Material at any time; however, doing so will not terminate this Public License.

d. Sections 1, 5, 6, 7, and 8 survive termination of this Public License.

#### **Section 7 - Other Terms and Conditions.**

a. The Licensor shall not be bound by any additional or different terms or conditions communicated by You unless expressly agreed.

b. Any arrangements, understandings, or agreements regarding the Licensed Material not stated herein are separate from and independent of the terms and conditions of this Public License.

#### **Section 8 - Interpretation.**

a. For the avoidance of doubt, this Public License does not, and shall not be interpreted to, reduce, limit, restrict, or impose conditions on any use of the Licensed Material that could lawfully be made without permission under this Public License.

b. To the extent possible, if any provision of this Public License is deemed unenforceable, it shall be automatically reformed to the minimum extent necessary to make it enforceable. If the provision cannot be reformed, it shall be severed from this Public License without affecting the enforceability of the remaining terms and conditions.

c. No term or condition of this Public License will be waived and no failure to comply consented to unless expressly agreed to by the Licensor.

d. Nothing in this Public License constitutes or may be interpreted as a limitation upon, or waiver of, any privileges and immunities that apply to the Licensor or You, including from the legal processes of any jurisdiction or authority.

Creative Commons is not a party to its public licenses. Notwithstanding, Creative Commons may elect to apply one of its public licenses to material it publishes and in those instances will be considered the “Licensor.” The text of the Creative Commons public licenses is dedicated to the public domain under the [CC0 Public Domain Dedication](#). Except for the limited purpose of indicating that material is shared under a Creative Commons public license or as otherwise permitted by the Creative Commons policies published at [creativecommons.org/policies](https://creativecommons.org/policies), Creative Commons does not authorize the use of the trademark “Creative Commons” or any other trademark or logo of Creative Commons without its prior written consent including, without limitation, in connection with any unauthorized modifications to any of its public licenses or any other arrangements, understandings, or agreements concerning use of licensed material. For the avoidance of doubt, this paragraph does not form part of the public licenses.

Creative Commons may be contacted at [creativecommons.org](https://creativecommons.org).

## 3.3 Clinical Safety

---

### 3.3.1 Clinical Safety

---

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

---

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

---

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)

---

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

---

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

### 3.4.3 Data Protection Impact Assessment

---

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

## 3.5 Privacy Notice

---

### 3.5.1 Privacy Notice

---

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

---

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

---

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

### Important

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

### 3.8.1 Key points

- 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.

### 3.8.2 Acceptance of Terms

The RCPCH ("we", "us" or "our") provides access (the "Site") subject to your acceptance of these Terms. These Terms may be updated by the RCPCH from time to time without prior notice. By accessing, browsing, entering data or otherwise accessing the Site, you become a User and assert that you have read and understand and agree to be bound by the terms of this Agreement. If you have any questions about this Disclaimer, please contact us.

### 3.8.3 Your Account Obligations

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

The medical data and other contents of the Site ("Contents") were furnished by and entered into the RCPCH site by third parties with the permission of the RCPCH and are presented for informational purposes only. Content contained within or reported by the RCPCH does not supersede the official patient medical record.

The RCPCH makes no representations, warranties, or assurances as to the accuracy, currency or completeness of the Content provided. You accept the responsibility to verify any contents obtained from the site. Contents should be verified with the official patient medical record before making medical decisions. You should not rely on anything contained on this site to suggest a course of treatment for any medical condition.

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

---

The RCPCH does not make any express or implied warranties, presentations, or endorsements whatsoever (including, but not limited to, warranties of title or non-infringement, or the implied warranties of merchantability or fitness for a particular purpose) with regard to the site, the content, any reports provided through the site, and the RCPCH shall not be liable for any cost or damage arising either directly or indirectly from any content or use of the site.

It is solely your responsibility to evaluate the reliability, accuracy, timeliness, completeness or usefulness of all services and content provided through the site. The RCPCH does not warrant that the site will be uninterrupted or error-free or that defect in the site will be corrected. The site and the content made available on the site are provided on an 'as is' and 'as available' basis.

### 3.8.6 Fair Processing Statement

---

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.