Professional Record Standards Body

Better records for better care

Epilepsy Information Standard Final Development Stage (Phase 4)

FINAL REPORT

December 2025

Document Management

Revision History

Version	Date	Summary of Changes
0.1	23/10/2025	Initial draft.
0.2	10/12/2025	Updated following feedback from project team
1.0	18/12/2025	Version uplifted following approval from project board

Reviewers

Reviewer name	Title / Responsibility	Date	Version
Steve Bentley	CSO/ Clinical Terminology Specialist	07/12/2025	0.1
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Oliver Lake	CEO (PRSB)	18/12/2025	0.2

Approved by

Name	Title/Responsibility	Date	Version
Project board	Project Board	18/12/2025	0.2

Glossary of Terms

Term / Abbreviation	What it stands for
E12	Epilepsy12
ED	Emergency Department
EHR	Electronic Health Record
EPR	Electronic Patient Record
EQIP	Epilepsy Quality Improvement Programme
ERUK	Epilepsy Research UK
HES	Hospitals Episodes Statistics
HIQA	Health Information and Quality Authority
HQIP	Healthcare Quality Improvement Partnership
NCAPOP	National Clinical Audit and Patient Outcomes Programme

PCSP	Personalised Care and Support Plan
PRSB	Professional Records Standard Body
RCPCH	Royal College of Paediatrics and Child Health

Route for User Feedback

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsb.org

Contents

1 Executive Summary

1.1 Background

Epilepsy is a complex, long-term neurological condition that requires coordinated, high-quality care across multiple settings and over the life course. Despite this, epilepsy-related information is not consistently recorded, structured, or shared across health and care systems in England and Wales. This lack of standardisation limits clinicians' access to accurate and timely information, increases reliance on patients and families to repeatedly provide the same information, and constrains the effective use of routine clinical data for service improvement, national audit, and research.

The need for a nationally agreed approach to recording and sharing epilepsy information has been consistently identified through the Epilepsy12 national audit. Variation in data quality, inconsistent coding of diagnoses, and limited interoperability between electronic patient record systems continue to present challenges to patient safety, continuity of care, and system-wide visibility of people living with epilepsy.

1.2 Purpose of the Epilepsy Information Standard

The Epilepsy Information Standard (EIS) has been developed to address these challenges by establishing a consistent, structured approach to recording and sharing epilepsy-related information across health and care settings. By defining a common set of data items and associated clinical terminology, the standard aims to improve communication between professionals, support person-centred care, and enable safer and more coordinated management of epilepsy.

The Professional Record Standards Body (PRSB) was commissioned by NHS England to deliver the final development and implementation phase (Phase 4) of the Epilepsy Information Standard, building on earlier discovery, user-centred design, and consultation phases led in partnership with the Royal College of Paediatrics and Child Health (RCPCH). The standard directly responds to long-standing issues identified through Epilepsy12 and aligns with national priorities for digital transformation, interoperability, and improved use of health data.

1.3 Project Approach

The project was delivered using an inclusive, user-centred approach. This phase focused on refining and finalising the Epilepsy Information Standard through structured engagement with clinical experts, and system suppliers. This included a series of supplier webinars, targeted follow-up discussions, and an expert group workshop to review the draft information model, agree data cardinality and conformance, and ensure clinical realism and usability.

Clinical terminology development was undertaken which included the alignment with International League Against Epilepsy (ILAE) classifications that was mapped to SNOMED CT wherever possible. The approach ensured that the standard reflects real-world clinical practice, remains proportionate, and can be implemented within existing digital infrastructures.

The outputs of this phase include the final Epilepsy Information Standard data model, supporting implementation guidance, and a set of recommendations to support adoption, assurance, and sustainability.

1.4 Findings

Consultation findings demonstrated broad support for the development of a national epilepsy information standard and confirmed the feasibility of implementation across systems.

Stakeholders consistently emphasised the importance of proportionality, flexibility, and longitudinal accuracy, recognising epilepsy as an evolving condition rather than a static diagnosis.

Key themes included the need for a shared and accessible epilepsy care record to reduce duplication and improve safety, particularly across emergency, acute, and shared-care settings. The structured capture of epilepsy formulation and outcomes was viewed as valuable in supporting clinical reasoning while allowing for narrative context and evolving diagnostic certainty.

The handling of sensitive information, such as Sudden Unexplained Death in Epilepsy (SUDEP), was highlighted as an area requiring consistency while remaining clinically appropriate. Supplier engagement reinforced the importance of focusing the standard on essential clinical information required at the point of care, while ensuring that data can be reused across systems and settings.

1.5 Development of the Epilepsy Information Standard

The final Epilepsy Information Standard comprises 38 sections, including two newly developed epilepsy-specific sections: Epilepsy Formulation and Outcomes. The standard defines mandatory, required, and optional data items, alongside clear cardinality rules, from the perspective of the professional completing the record.

Existing PRSB data concepts have been reused wherever possible to support consistency across standards. SNOMED CT terminology has been embedded to enable interoperability and alignment with national clinical vocabularies. However, gaps between ILAE classifications and available SNOMED CT terms were identified, indicating the need for further terminological development to ensure full alignment with international clinical definitions.

1.6 Recommendations

- Address identified gaps between ILAE defined seizure types and epilepsy classifications, the E12 audit and Epilepsy Information Standard value sets, and the corresponding terminology in SNOMED CT, in order to ensure clinical alignment, and interoperability across systems.
- Seek assurance from the Data Alliance Partnership Board to support national adoption and establish clear expectations for conformance with the Epilepsy Information Standard.
- Develop an implementation support programme, including:
    - Agreement on ISN conformance assessment and implementation planning with procurement leads.
    - Facilitate training for health and social care professionals on using the standard, especially digital aspects like epilepsy formulation and outcomes.
    - Piloting the standard through a multi-stakeholder testing approach across key care settings.
    - Creation of an implementation toolkit to guide consistent application of the standard.
    - Support patient and family engagement through co-developed resources to improve understanding and encourage active involvement in care planning.
- Ensure the Epilepsy Information Standard is included in the NHS England data standards directory for national visibility, uptake, and sustainability.

1.7 Conclusions

The Epilepsy Information Standard represents a significant step towards improving the quality, safety, and consistency of epilepsy care. Through extensive collaboration with clinicians, patients, advocacy organisations, system suppliers, and national stakeholders, the PRSB has developed a standard that reflects real-world clinical practice while supporting interoperability and secondary use of data.

Adoption of the Epilepsy Information Standard will enable health and care professionals, and people living with epilepsy, to access the right information at the right time. This will support personalised care, service improvement, and better outcomes across the life course.

2 Background

Epilepsy12 (E12) was established in 2009 with the aim of supporting epilepsy services and those who commission health services to measure and improve the quality of care for children and young people with seizures and epilepsies. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

Epilepsy is the most common significant long-term neurological condition of childhood, affecting an estimated 112,000 children and young people in the United Kingdom. Epilepsy12 seeks to improve the quality and consistency of care for these children and young people across England and Wales by collecting and analysing patient-level data to identify areas of good practice and highlight opportunities for improvement.

In 2022, a further contract was awarded to the RCPCH to continue delivering the Epilepsy12 audit until 31 March 2025, with a further 2-year extension awarded until 31 March 2027. However, there continues to be considerable variation in the ability of different Health Boards and NHS Trusts in England and Wales to provide the necessary workforce capacity and resources to participate fully in the national audit. These challenges have been compounded by the impact of the COVID-19 pandemic.

2.1 The Structure of Epilepsy12

Epilepsy12 audit is comprised of three main components, which are reflected in its annual report:

1. Clinical Audit – Describing the care provided to children and young people newly diagnosed with epilepsy during their first year of care. Patients are grouped into cohorts based on the date of their first paediatric assessment and are followed for the subsequent 12 months.
2. Organisational Audit – Assessing paediatric epilepsy services and workforce provision at Trust or Health Board level, as they stand in November each year.
3. Quality Improvement Activities – Showcasing examples of local and national quality improvement initiatives, including case studies from NHS Trusts and Health Boards, outputs from the Epilepsy Quality Improvement Programme (EQIP), and activities led by the Epilepsy12 Youth Advocates.

2.2 The Case for an Epilepsy Information Standard

Through delivery of the audit, the Epilepsy12 team identified the need for an agreed national epilepsy information standard to facilitate the consistent recording and secure sharing of epilepsy-related data across health and care settings. This standard would also enable the use of routine clinical data for secondary purposes, such as national audit and research.

While Epilepsy12 focuses on children and young people, it is recognised that any information standard must also meet the needs of adults with epilepsy, ensuring interoperability and continuity across the life course.

There are multiple drivers across the epilepsy community for developing and embedding standardised data for epilepsy. For example, the RCPCH Epilepsy Passport, published in 2015, was designed to help families maintain up-to-date copies of their child's epilepsy-related health information. However, implementation proved challenging due to the absence of standardised routes to derive and update this information directly from Electronic Health Records (EHRs). Similar barriers persist across epilepsy care planning, where maintaining accurate and consistent diagnostic information remains critical.

The Epilepsy12 (2024) report found that 55.3% (63/114) of Trusts and Health Boards maintain some form of local database or registry for epilepsy patients. However, there is no evidence that diagnoses, or care data are recorded in a consistent, standardised way, nor are these datasets routinely linked to EHR systems. The multi-axial, complex, and evolving nature of epilepsy, its associations with co-morbidities, and variations in disease progression further compound challenges in ensuring interoperability and data aggregation.

Within primary care and across Trust or Health Board EHRs, epilepsy diagnoses are not consistently coded or recorded. This lack of standardisation limits system-wide visibility of patients with epilepsy and constrains several key activities, including:

- Accurate coding of hospital admissions and emergency department attendances related to epilepsy within Hospital Episode Statistics (HES) data.
- Development of national activity and outcome dashboards to inform commissioning, which currently rely heavily on admission data and lack comprehensive epilepsy-specific indicators.
- Research and innovation, which increasingly depend on large, multi-centre population cohorts. The ability to identify and recruit specific subgroups or to undertake approved research using routinely collected clinical data is essential to drive the advances needed to improve outcomes. Epilepsy Research UK (ERUK) has identified *big data analysis* as one of its ten key research priorities.

Furthermore, the Core20PLUS5 framework for Children identifies epilepsy, particularly in children with learning disabilities and/or autism, as a key priority for reducing health inequalities.

2.3 Commissioning of the Epilepsy Information Standard

The Professional Record Standards Body (PRSB) was commissioned by the Royal College of Paediatrics and Child Health (RCPCH) to undertake a Discovery Phase, User-Centred Design Phase, and Consultation Phase to develop the first draft of an Epilepsy Information Standard (EIS).

Following this initial work, NHS England has now commissioned the PRSB to deliver Phase 4 of the project, focused on finalising and preparing for implementation the Epilepsy Information Standard.

2.4 Purpose of the standard

The Epilepsy Information Standard (EIS) aims to establish a consistent, structured approach to recording and sharing information about the diagnosis, treatment, and ongoing management of epilepsy across all health and care settings. By defining a common set of data items and terminologies, the standard seeks to improve communication between professionals, enhance patient safety, and support more coordinated, person-centred care.

The EIS will enable interoperability between systems, ensuring that essential information about an individual's epilepsy, such as seizure history, medication, and comorbidities, can be accurately and efficiently shared between clinicians, services, and digital platforms. This will facilitate timely decision-making, reduce duplication, and minimise the risk of errors.

In addition to improving clinical care, the EIS will provide a robust foundation for secondary uses of data, including national audit, research, and service improvement. By ensuring that information is recorded in a consistent and standardised way, the EIS will strengthen the evidence base for policy, commissioning, and quality improvement initiatives, ultimately contributing to better outcomes for people living with epilepsy.

3 Aim and objectives

The overall aim of the project is to support the integrated and continuous care of epilepsy across settings by developing an information standard for epilepsy data items which can be utilised across all settings to facilitate sharing of data between these settings. This work will also contribute to the delivery of the NHS England 10-Year Plan by supporting national strategic priorities for digital transformation and could enable the development of a Single Patient Record.

The key objectives are to:

- Develop an information standard (clinical record specification).
- Facilitate reduction in the inconsistency of data through a standard that will enable interoperability.

The objectives of the Standard Development Phase are to:

- Build the Epilepsy Information Standard into PRSB's Data Modelling Tool.
- Engage expert group in defining cardinality and MRO for the information standard.
- Define clinical terminology (SNOMED CT) for relevant value sets.
- Further consultations with system suppliers to test the design and feasibility of implementation of Epilepsy Information Standard.
- Apply for an Information Standard Notice (ISN).

4 Benefits

A standard which facilitates sharing of epilepsy data between settings will:

- Ensure that care providers have the information they need to inform shared decision making about follow up care and enhancing health outcomes for people with epilepsy.
- Provide an accurate record of epilepsy data.
- Deliver efficiency gains by reducing the need for manual investigation between settings.
- Reduce reliance on patients being a source of information and potentially repeating information in multiple settings.

- Facilitate the improvement of the accuracy of data submitted for national audit and approved research purposes and reduce manual/duplicative data entry.
- Align with NHS England's 10-Year Plan ambitions for digitisation and interoperability by enabling consistent, structured epilepsy data to flow seamlessly across care settings.

5 Scope

5.1 In scope

The scope of the project covers both children and adults with epilepsy. Scope includes data relating to epilepsy which:

- might be required at point of care.
- might be shared between different settings.
- a patient might wish to share.
- might be required for national audit and approved research purposes.
- might be required to support care planning.

5.2 Out of Scope

The use of artificial intelligence (AI) technologies including tools or systems designed to automatically generate, populate, or summarise patient records are out of scope for this project.

6 Project approach

This phase focused on developing and finalising the Epilepsy Information Standard, building on the completed discovery, user-centred design, and consultation phases.

The key steps involved are:

- Establish the team and project advisors (clinical and citizen leads).
- Draft the Project Initiation Document including exploration of scope and identification of the key stakeholders to be involved found in Appendix 10.2.
- Confirm the use case(s)
- Exchange information with 4 nations stakeholders (in collaboration with NHSE) and seek agreement on potential for implementation across the UK, bringing issues back to the Project Board for resolution.
- Undertake consultation with system suppliers.
- Develop Information Standard (clinical record specification).
- Develop the relevant Epilepsy-specific clinical terminology and value sets.
- Develop supporting documentation and materials.
- Publish draft standard on the PRSB website.
- Seek endorsement from relevant stakeholders.

6.1 Consultation Approach

As part of Phase 4, we consulted with system suppliers to test the feasibility and design of the proposed Epilepsy Information Standard. This built on consultations carried out in the previous phase and ensured the standard is practical and implementable across care settings.

PRSB hosted a series of webinars in October and November 2025 to support this work.

The Epilepsy supplier webinar was held on Tuesday, 21 October 2025. The webinar gathered supplier feedback on the draft standard model to discuss implementation considerations and ensure alignment with existing systems and interoperability frameworks. Our aim was to work collaboratively with suppliers to refine the standard and support its practical adoption across health and care environments.

Following the Epilepsy supplier webinar, two additional webinars were held to allow for further conversation with those that were interested. These stakeholders were identified to be relevant to the development of the EIS model.

6.2 Clinical terminology and value sets development

The development of the value sets was led by the clinical terminologist at PRSB with support from the consultant paediatrician on the team. All value sets were guided by the International League Against Epilepsy (ILAE) classifications. The ILAE strives to provide definitions for key concepts and classification schemes that will help the global epilepsy community in developing a common language to communicate effectively regarding the many facets of epilepsy. All available ILAE classifications of epilepsy and seizures were searched in the SNOMED CT browser to ensure consistency and usability in the EIS model.

7 Findings

7.1 Epilepsy supplier webinar 1 findings and recommendations

There was a total of 18 attendees at the Epilepsy information standard supplier webinar, including PRSB and project team members. The webinar engaged 10 external stakeholders, representing a broad range of expertise across clinical practice, patient advocacy, academia, and digital health technology. The attendees list can be found in Appendix 10.3.

The feedback was generally neutral. However, Sudden Unexplained Death in Epilepsy (SUDEP) Action provided a specific recommendation to make the SUDEP risk assessment more explicit, suggesting that each query within the assessment be expanded on to capture more detailed information.

This feedback reflects wider patient body concerns that SUDEP is not consistently discussed during clinical consultations, despite its association with increased mortality risk among individuals with epilepsy. Strengthening the standard's guidance in this area could therefore help promote consistent and proactive risk assessment across care settings.

7.1.1 Follow-up conversations

A follow-up conversation with a paediatrician at King's College and a software developer who completed the tagging implementation for the E12 audit identified several value sets that are highly relevant to the Epilepsy Information Standard (EIS) model. It is not expected that all E12 value sets will be directly applicable to the EIS. This reflects the differing purposes of the two initiatives. The E12 audit was designed to measure service performance

and quality outcomes, using simplified or service-level indicators, whereas the EIS focuses on structured clinical information recorded at the point of care. Consequently, some audit value sets describe processes, such as whether an assessment occurred, rather than the underlying clinical data captured in the clinical record, or they rely on categorical rather than coded terminology. As a result, only a subset of E12 value sets will directly inform the EIS, although the mapping activity remains essential for identifying clinically important data items and ensuring semantic alignment across both initiatives.

Additionally, we furthered the conversation with SUDEP Action, which highlighted the critical importance of explicitly including the SUDEP and Seizure Safety Checklists in the Epilepsy information standard. Embedding the checklist in the standard would align with NICE guidelines, which recommends that all patients be informed about SUDEP in a sensitive and appropriate way. We sought access to the checklist to complete an analysis of the data items to explicitly build in the EIS.

7.2 Epilepsy supplier discussion

The discussion on implementing the EIS focused on how epilepsy care plans and related data can be effectively shared across health and care settings through existing digital infrastructure. The need for a single, centralised care plan was emphasised as key to reduce duplication and ensure consistent, safe care during seizure emergencies. The conversation explored interoperability challenges, ownership of shared records, and the importance of making data accessible, rather than constantly transferring it. It was highlighted that epilepsy data standards should define the essential clinical elements required for direct care, rather than relying solely on aggregated or secondary data to ensure that all professionals have timely, accurate, and shared information to support patient safety and continuity of care.

7.3 Epilepsy supplier webinar 2 & 3

The second supplier webinar was attended by representatives from Graphnet, and Seizure Tracker. The third session brought together a group from Central London Community Healthcare NHS Trust and System C Healthcare. Both sessions provided the opportunity to review and discuss the Epilepsy Information Standard in its draft form, to ask questions on its development, and to consider its practical application. Across the two meetings, participants explored how the standard is expected to improve data consistency, interoperability, and patient care across systems. The smaller group format supported open discussion, shared understanding, and constructive feedback to help shape the standard ahead of its final release.

7.4 Expert Group Workshop

The workshop formed part of the final review stage of the Epilepsy Information Standard. Participants were invited in recognition of their specialist expertise and their roles across the clinical pathways that interact with epilepsy information systems. Fourteen (14) attendees took part, providing representation from across paediatric and adult epilepsy care, Implementation specialists, and patient and nursing perspectives. The attendees list can be found Appendix 10.8.

The primary purpose of the session was to review the draft data items within the standard and to agree their cardinality and conformance. At the outset, these concepts were explained to ensure a shared understanding. The group then worked systematically through the draft standard, focusing on the two new sections, Epilepsy Formulation and Outcomes. The review was undertaken from the perspective of users of epilepsy information systems,

considering how the data items would be recorded and used in routine clinical practice. Each data item was assessed to determine whether it should be mandatory, required, or optional, and to confirm how frequently it may need to be recorded. This structured clinical review provided essential assurance that the standard is practical, clinically relevant, and ready for finalisation and publication.

8 Development of EIS

8.1 The Standard

The Epilepsy information standard includes 38 sections overall, with two sections newly developed to capture the epilepsy-specific requirements. The information model delineates conformance levels (mandatory, required, and optional) and the cardinality for each data element. The conformance and cardinality have been determined from the viewpoint of the person completing the record. System providers are anticipated to integrate all items outlined in the standard.

Section name	Definition
Person demographics	The person's details and contact information.
GP practice	Details of the person's GP practice.
About me	The most important details that a person wants to share with professionals in health and social care.
Alerts	Details of significant information meriting a specific and highly visible warning to any user.
Legal information	The legal information relating to the person.
Safeguarding	The safeguarding details of the person.
Professional contacts	The details of the person’s professional contacts.
Personal contacts	The details of the individual's personal contacts.
Participation in research	
Referral	The details of referrals made for the individual.
Admission details	The information regarding any admission to hospital or services.
Discharge details	The information regarding any discharge from hospital or services.
Future appointments	The record of all pending appointments with health or social-care services.

Vaccinations	
Problem list	The record of all active and historical diagnoses or health issues.
Epilepsy Formulation (NEW)	The record of seizure descriptions and summary, epilepsy diagnoses, and important comorbidities.
Outcomes (NEW)	The details about the clinical, functional, and quality-of-life impact of epilepsy and its management. This section complements the Epilepsy formulation.
Shared decision point	The record of the collaborative process where clinicians and individuals consider treatment options together, to enable the person to decide the best course for themselves.
Consent form details	This contains the individual's consent forms. It records consent type, date, scope of consent, withdrawal status, and any restrictions or conditions.
Procedures and therapies	This records all procedures, interventions, and therapies delivered
Social context	This section provides an overview of the person's social circumstances.
Services and care	This section captures all services currently supporting the individual
Primary support reason	This documents the primary reason the individual is receiving support.
Family history	This summarises relevant medical, psychosocial, and hereditary information from the person's family
Investigation results	This records all completed investigations such as blood tests, imaging, neurophysiology, and genetic studies. It includes dates, findings, and interpretations where available.
Investigations requested	This section identifies pending investigations.
Examination findings	This documents findings from physical, mental state, or functional examinations.
Pregnancy status	The record of the pregnancy status of the person.
Assessments	This captures all completed assessments on the person.

Risks	This section captures details of any risks related to the person.
Allergies and adverse reactions	This section records all known allergies and documented adverse reactions.
Medications and medical devices	This documents all medications, and any medical devices prescribed to the person.
Equipment and adaptations	This section lists equipment or environmental adaptations provided to support daily living or clinical management
Plan and requested actions	The record of all plans and requested actions.
Care and support plan	This records the decisions reached during conversation between the individual and health and care professional about future plans and also records progress.
Additional support plan	This section records any supplementary plans.
End of life care	This records Information relating to end-of-life care. N.B. This is not an end-of-life care plan but contains information that would be found in an end-of-life care plan.
Documents (including correspondence, audio and images)	The record of documents related to the person.

8.2 The Reuse of other PRSB data concepts

Existing PRSB data concepts were reused during the design of the standard. These have either been developed for the Core Information Standard or are part of PRSB's data reference library. It is also probable that concepts that have been specifically developed for the EIS may be used for new standards.

8.3 Terminology

Where possible, terminology including SNOMED CT and NHS Data Dictionary terms has been provided against relevant data items. These terminologies have been embedded within the information model and will be made available to system suppliers through the implementation guidance. This ensures consistency, interoperability, and alignment with established clinical vocabularies across systems.

Gaps were identified between the ILAE-defined seizure types and epilepsy classifications and the terminology currently available within SNOMED CT. Addressing these gaps will require further terminological development work to ensure closer alignment between international clinical definitions and the coding structures used within national systems.

Once these terminological gaps have been resolved, the agreed terms should be incorporated into the epilepsy standard. At that point, an updated version of the standard should be released to ensure that suppliers and clinical users have access to the most accurate and comprehensive terminology set. This update will be available to review in Spring 2026 with the publication expected in September 2026.

8.4 Implementation guidance

The standard's implementation guidance was developed through the series of consultations and discussions with project clinical leads, to enhance understanding of how the standard can be applied practically. Most of this guidance has been incorporated into the standard at both section and element levels. A document titled "General implementation guidance for PRSB standards" provides overarching guidance and clarifies the standard's structure and content.

9 Recommendations and Conclusions

9.1 Recommendations

a) Further terminological development work should be undertaken to address the gaps identified between ILAE-defined seizure types and epilepsy classifications, the E12 Audit and EIS value sets, and the corresponding terminology currently available within SNOMED CT.

b) Data Alliance Board assurance is undertaken for the Epilepsy Information Standard. Such assurance would support clarity and consistency in adoption by establishing a clear national expectation for conformance, helping providers and suppliers to plan implementation in a more aligned and coordinated way.

c) Consider an implementation support programme to include:

   i. Consideration of how conformance with the Information Standard Notice should be assessed and work with procurement framework leads to agree and implement approach
   ii. Facilitate the training for Epilepsy care professionals in all systems within their organisation that use the Epilepsy Information Standard, including how to complete digital elements of epilepsy formulation and outcomes, and how to use different sections of the record to ensure personalised and effective care.
   iii. Piloting standard through a structured, multi-stakeholder testing approach that reflects real world shared care record use. Involving primary care, acute neurology, emergency care, and regional shared care record platforms would help confirm that the standard can be implemented consistently across systems while remaining clinically meaningful and usable.
   iv. Develop implementation toolkit
   v. Support for patients and families to engage with the information recording approach, including resources co-developed with charities and voluntary organisations to raise awareness, improve understanding of the information being recorded, and encourage meaningful involvement in their care planning and decisions.

d) Epilepsy Information Standard, including its Data Model and accompanying documentations, is included in the NHS England standards directory.

9.2 Conclusions

The PRSB has an inclusive approach to the development of information standards. As such, a rich mixture of information, opinions, experiences, and knowledge has been shared throughout the course of this consultation by members of the public, epilepsy service professionals, advocacy groups, suppliers, general practice, and many other organisations with vested interests in epilepsy care.

A detailed analysis of all the information gathered has been undertaken in the production of this final report and the epilepsy information standard and the PRSB is deeply grateful to everyone who contributed.

With so much information, producing a concise and cogent final report that reflects all the dimensions of epilepsy care shared with us has been challenging. We would like to thank everyone that took the time to support the development of this standard for their valuable input in helping shape and define this standard.

It is vital that epilepsy service professionals and, in most instances, those people using epilepsy services themselves, have access to an electronic patient record system that contains the right information at the right time, to support epilepsy care provision. This will enable health and care providers to plan appropriately personalised care.

This report should be read in conjunction with the Epilepsy Information Standard and additional material that supported the development of this report that will be placed on the PRSB website.

10 Appendix

10.1 Project team

Name	Role
Alison Brown	Project Support Manager
Andy Wright	Stakeholder engagement lead
Holly Kearn	Communications lead
Steve Bentley	Clinical Terminology Specialist
Kelly Cheng	Project Analyst
Kingsley Ejeh	Project Manager
Colin Dunkley	Clinical Lead (Paediatrics)
Niky Raja	Epilepsy12 Project Manager
James Mitchell	Clinical Lead (Adult)

10.2 Stakeholder engagement and endorsement

The following professional and patient organisations have been identified as key stakeholders for this project. We identify the key stakeholders including endorsers at the outset of the project

so that they can be proactively managed through the whole process including finalisation and endorsement. Not all organisations are able to formally endorse (as they do not have capacity to do so). The organisations able to endorse are marked with an asterisk:

- Association of British HealthTech industries*
- Association of British Neurologists
- Association for Real Change*
- Association of Directors of Adult Social Services
- Association of Directors of Children's Services
- Association of Mental Health Providers
- Association of Neurophysiological Scientists
- British Academy of Childhood Disability
- British Paediatric Neurology Association
- British Psychological Society
- British Society for Clinical Neurophysiology
- Care Provider Alliance*
- Carers UK
- CASPA
- Chartered Society of Physiotherapy*
- Digital health and care Northern Ireland
- Digital health and care Scotland
- Digital health and care Wales
- Epilepsy Action
- Epilepsy Research UK
- Epilepsy Scotland
- Epilepsy Specialist Nurse Association
- Health Data Research UK
- Healthcare Quality Improvement Partnership*
- International League against Epilepsy UK Chapter*
- National Association of independent Schools & Non-Maintained Special Schools
- National Institute of Health and Care Excellence (NICE)
- National Voices
- Neurological Alliance
- Office for Health Improvement and Disparities
- OPEN UK
- Patient Information Forum*
- RCPCH &Us Network
- Royal College of Emergency Medicine*
- Royal College of General Practitioners*
- Royal College of Nursing*
- Royal College of Occupational Therapists*
- Royal College of Paediatrics and Child Health*
- Royal College of Pathologists*
- Royal College of Psychiatrists*
- Royal College of Physicians*
- Royal College of Speech and Language Therapists*
- Royal Pharmaceutical Society*
- SUDEP Action
- techUK
- UK Epilepsy Board
- Young Epilepsy

10.3 Epilepsy supplier webinar 1 attendees list

Organisation	Role
PRSB	Project Support Manager
PRSB	Communications Lead
PRSB	Business Analyst
PRSB	Project Manager
PRSB	Clinical Lead
PRSB	Implementation Lead
Sherwood Forest Hospitals NHS Foundation Trust	Consultant Paediatrician
Health Information and Quality Authority	Senior Business Analyst
SUDEP Action	Director of Policy and Influencing
SUDEP Action	Research Manager
NHS Greater Glasgow and Clyde	Consultant Paediatric Neurologist
NightWatch Epilepsy Detection	CEO
Patients Know Best	Head of Sales/ Lead for Life Sciences & Sustainability
Royal College of Paediatrics and Child Health	Lead Software Developer
Graphnet Health	Product Director
vCreate	Founder
King's College London	Professor
Accessible-Info	Health Informatics & Data Accessibility – Blind Visionary, Deaf Listener

10.4 Follow-up conversation 1

Organisation	Role
King's College London	Consultant paediatrician/ E12 Developer

10.5 Follow-up conversation 2

Organisation	Role
SUDEP Action	Director of Policy and Influencing

10.6 Epilepsy supplier discussion

Organisation	Role
Graphnet Health	Product Director
SeizureTracker.com	Director

10.7 Epilepsy supplier webinar 3

Organisation	Role
Central London Community Healthcare NHS Trust	Physiotherapist Practitioner
System C Healthcare	Product Director

10.8 Epilepsy Expert Group Workshop

Role
Consultant paediatrician, Wales
Implementation specialist & retired GP (PRSB)
Project clinical lead (paeds) & consultant paediatrician
Patient & nurse representative
Project clinical lead (adult), registrar (neurology)
Consultant Paediatric Neurologist
Representative of BPEG
Consultant Paediatrician,
Consultant Paediatrician, Wales
Standard Assessor and retired GP
Clinical lead (adult) & Registrar - neurologist
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10.9 Epilepsy Expert Group Workshop Analysis

Theme / Area	Discussion Focus	Key Considerations Raised	Analytical Interpretation
Clinical realism and usability	Ensuring the standard reflects how epilepsy is managed in practice	Participants repeatedly emphasised that clinicians work with evolving information,	The group emphasised the importance of supporting longitudinal accuracy and clinical reasoning, favouring data structures that can

		uncertainty, and narrative context rather than fixed labels	evolve over time rather than static or overly rigid data capture that could misrepresent a patient's clinical journey.
User perspective	Reviewing data items from the viewpoint of system users	Clinicians highlighted workflow burden, visibility of key information, and ease of reuse across care settings	The discussion consistently framed decisions around "what would be useful when seeing a patient" rather than technical completeness
Epilepsy formulation	Purpose and scope of the formulation section	The formulation was seen as a dynamic, multi-layered construct rather than a one-off diagnostic event	Participants aligned around the need for a structured but flexible formulation that evolves over time
Diagnostic certainty	Handling confirmed, provisional, and refuted diagnoses	Strong concern about mandating actions when epilepsy is unconfirmed or later excluded	Diagnosis must be capable of being updated without loss of historical context
Cardinality	How often data items should be recorded	Discussion focused on avoiding duplication while preserving clinical meaning	One-to-one versus one-to-many decisions were framed in terms of clinical coherence
Mandatory, required or optional data	Balancing safety with clinical burden	Participants cautioned against excessive mandatory fields that could undermine clinical interaction	Mandatory data should be limited to information with clear clinical value
Outcomes	Maturity of outcome measurement in epilepsy	Consensus that outcome measurement is heterogeneous and context-dependent	A generic "assessment section" was favoured over prescriptive outcome sets
Date of last seizure	Clinical importance of seizure recency	Widely viewed as the most universally meaningful outcome measure	Seen as a minimal anchor for understanding disease control
SUDEP	Appropriate handling of SUDEP-related data	Acknowledged as critically important but clinically sensitive and context-specific	Participants were cautious about premature standardisation
Social and contextual factors	Lifestyle, psychosocial, and	Clinicians stressed their relevance to	Contextual information should be visible and updateable

	environmental context	seizure control and risk	
Narrative vs structured data	Risk of losing clinical story	Concern that structured records can obscure patient narratives	Structured data must coexist with narrative, not replace it
Proportionality	Size of the dataset versus required completion	The group consistently returned to the principle of “minimum necessary data”	Large datasets can exist, but few elements should be mandatory