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Epilepsy Information Record Standard: Phase 3

INTERIM REPORT

April 2025

Document Management

Revision History

Version	Date	Summary of Changes
0.1	17/04/2025	Initial draft.
0.2	01/05/2025	Updated document after review from the Board.

Reviewers

Reviewer name	Title / Responsibility	Date	Version

Approved by

Name	Title/Responsibility	Date	Version

Glossary of Terms

Term / Abbreviation	What it stands for
EIS	Epilepsy Information Standard
EPR	Electronic patient record
FHIR	Fast Healthcare Interoperability Resources
ILAE	International League Against Epilepsy
ISN	Information standards notice
MRHA	Medicines and Healthcare products Regulatory Agency
NHS E	National Health Service England
PRSB	The Professional Record Standards Body
RCPCH	The Royal College of Paediatrics and Child Health
SNOMED	Systemised nomenclature of Medicine Clinical Terms
SUDEP	Sudden Unexpected Death in Epilepsy

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for [3-year period], subject to agreement with NHS Digital as the commissioning body.

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

Contents

1 Executive Summary

Epilepsy is a common neurological condition, yet information about people living with epilepsy is often fragmented and inconsistently recorded across health and care settings. Currently, there isn't a nationally recognised, standardised way to capture epilepsy-related information digitally, which leads to duplication, missed patient safety risks, and poor communication between services and settings.

The Royal College of Paediatrics and Child Health (RCPCH) commissioned the Professional Record Standards Body (PRSB) to explore the development of an information record standard for epilepsy, for children, young people, and adults. This project has undergone two key phases: discovery and user-centred design. The focus of this third phase is to consult on the draft information record standard and ensure the model aligned with real-world requirements.

The development of the Epilepsy Information Standard (EIS) involved extensive stakeholder engagement through surveys, focus groups, and interviews, gathering input from over 100 individuals, including clinicians, service users, carers, charity representatives, and system suppliers. Clinical workshops were held to validate use cases, define essential data elements, and ensure the standard reflects real-world practice. An online public survey captured feedback from a broad range of professionals and people with lived experience.

The development of the Epilepsy Information Standard (EIS) has highlighted several key insights:

- Inconsistent Data Recording: Epilepsy-related information is often recorded inconsistently across various health and care settings, leading to fragmented care and communication challenges.
- Clinical Burden: Clinicians expressed concerns about the additional time required to input standardised data, emphasising the need for automation and integration with existing electronic patient records (EPRs).
- Patient and Family Engagement: There is a need for better tools and resources to help patients and their families understand and engage with their epilepsy care plans.
- Cultural and Psychosocial Considerations: Recognising and documenting cultural beliefs and psychosocial factors are essential for providing personalised and effective epilepsy care.

The following recommendations are proposed:

- Consider NHS England structural changes: Review how the abolishment of NHS England and wider management changes may affect the next phase of the EIS. Involving DHSE representatives in the Project Board will help maintain project momentum and secure national support for implementation.
- Standardised Data Structures: Develop clear, structured data elements using SNOMED-CT and FHIR to ensure compatibility across systems.
- Balanced Data Entry: Incorporate both structured fields and free-text options to allow clinical discretion and accommodate varying levels of digitisation.
- Implementation Support: Provide comprehensive training for health and social care professionals, along with an implementation toolkit and pilot programmes to test and refine the standard.

- Patient and Family Resources: Collaborate with charities and voluntary organisations to create resources that enhance patient and family understanding and involvement in care planning.

The EIS aims to improve the quality and consistency of epilepsy care by standardising the way information is recorded and shared.

2 Introduction

2.1 Background and Context

The Royal College of Paediatrics and Child Health (RCPCH) commissioned the Professional Record Standards Body (PRSB) to explore the development of an information record standard for epilepsy, for children, young people and adults. This project has undergone two key phases: discovery and user-centred design. The discovery report and draft information model are now published and available to download. The focus of this third phase is to consult on the draft information record standard and ensure the model aligned with real-world requirements.

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.

The key objectives are to:

- reach a consensus on the definition of epilepsy data items.
- develop an information standard defining epilepsy data items.
- facilitate reduction in the inconsistency of data through a standard that will enable interoperability.

The objectives of the information record standard phase are to:

- update use cases as required.
- agree issues to be tested in consultation.
- refine and iterate the model through consultation.
- log any points for inclusion in implementation guidance, safety case and hazard log.

3 Methodology and Consultation Approach

The PRSB methodology ensures broad engagement from service users, health and care professionals and system suppliers. We use various consultation techniques, including virtual discussions, semi-structured interviews, and an online survey.

The interim report summarises the findings associated with the delivery of the objectives described in the ‘Epilepsy Information Standard (EIS): Phase 3 Consultation plan’ (appendix 6.1), which included engagement with a broad range of clinicians, service users, suppliers, and other key stakeholders.

3.1 Project Objectives and Scope

3.1.1 Objectives

The objectives of the consultation are as follows:

- Undertake consultation on the draft EIS model with stakeholders to refine and iterate the model.
- Gather insights to ensure that the standard is robust and practical for future implementation.
- Raise awareness of the standard to support its future implementation when further funding is secured.

3.1.2 Scope

In scope

The project will:

- Provide a detailed opportunity for stakeholders to comment on the draft standard and their view of the completeness of the data content.

The following **exclusions** apply, the project will not:

- Include an Electronic Patient Record (EPR) system supplier webinar to provide an information update.
- Consider the issues related to standard finalisation and endorsement.
- Provide opportunity for EPR system suppliers to comment on the operationalisation of the standard at this stage of development. When funding is secured for the next phase, we will review any new initiatives in the market and consult with an expert group to establish if there is any requirement for additional data items.

3.1.3 Project team

The project team consisted of seven stakeholders, including one clinical lead (consultant paediatrician). The full breakdown of members can be found in Appendix 6.1.

3.2 Approach

The consultation approach involved a comprehensive, multi-stakeholder engagement to gather feedback for the EIS development. This included clinicians, services users, and advocacy groups to ensure both professional and lived experiences were incorporated.

Virtual discussions, interviews, and focus groups were ideal for capturing qualitative, in-depth feedback about users’ experiences, concerns, and suggestions. Whereas the survey allowed for broad quantitative feedback to validate and refine the proposed model. The online consultations ensured accessibility and minimised any geographical or time constraints.

3.2.1 Key Consultation Activities

- Expert Group Workshops for health professionals (Two sessions)
    - The expert group workshops facilitated discussions with subject matter (epilepsy) experts to identify key data requirements.
- Professional Webinar (One session)
    - The professional webinar was a structured session to engage health professionals, providing an opportunity to review and refine the proposed data model.
- Service User Representative Workshop (One session)
    - The service user representative workshop focused on validating and agreeing on the data required from a service user perspective to ensure it aligns with their needs and experiences.
- Lived Experience Focus Groups (Four sessions)
    - Dedicated discussions with individuals who have direct experience with the subject area to gather qualitative insights and highlight priority areas for data capture.
- Online Survey
    - The online survey was distributed widely to obtain feedback from a broad range of professionals, service users, and representatives to validate the draft standard.

4 Findings and Recommendations

Throughout the consultation process, we have carefully reviewed and considered all responses received from stakeholders, including clinicians, service users, and advocacy groups. Key insights from the consultations have shaped the recommendations, ensuring that:

- The standard balances structured and free-text data entry to maintain usability and complex detailed information that may not be coded.
- Existing implementation challenges, particularly interoperability, were highlighted and considered in our recommendations.
- The burden of data entry and workflow integration are addressed through automation and pre-populated fields from the system.
- The perspectives of patients and service users are reflected in the design of EIS, ensuring their needs are met through information records and better communication between care providers.

4.1 Expert group workshops

Two Expert group workshops were completed. One workshop (n=21) focused on the ‘Formulation’ section of the EIS and the other workshops (n=18) focused on the ‘Outcomes’ section. These sections were prioritised for consultation as they were new additions to the EIS compared to previous information standards. The attendee list can be found in the appendix (Appendix 6.3 and Appendix 6.4).

The summary of findings from the expert workshops focusing on the Formulation and Outcome sections are shown in table 4 and 5 (Appendix 6.5 and 6.6).

Burden of data entry

A significant concern raised during the EIS Formulation webinar was the burden of data entry. Participants highlighted concerns about who records information and when, which can lead to additional time requirements. To address this issue, it is recommended that systems explore automation and delegation, with data fields pre-populated using information from electronic patient records (EPR). Further clinical consultation is necessary to identify which data points should be mandatory to reduce the burden on healthcare professionals.

Data structure

In terms of data structure, the need to balance structured data (e.g., dropdown menus) with free-text fields to ensure usability was highlighted. While structured systems help standardise information, they may increase the time required for data input. To tackle this, the recommendation is to develop structured fields using SNOMED codes, while also allowing free-text options where necessary. Additionally, external coding for genotypic diagnosis should be explored to enhance the accuracy and comprehensiveness of data.

> *"The most important thing is who will enter and when that will be entered... New patient appointment varies between 30 minutes to 45 minutes in different settings... is it expected that once the standards data set has been created that will be entered in that clinical setting or... later on? If it has to be done same settings, obviously time will be the factor. And who enters and if it has to be done later on, then additional time will be required."*
>
> *"Who's doing the entry?... just hugely aware of the time pressures... I just want to find out if there's any thoughts about the practical maintenance of this data set."*

Prolonged seizures

A key point of discussion was the difficulty in defining what constitutes a prolonged seizure, as this varies from individual to individual. It was recommended that a data item be added to record the individual’s maximum seizure duration, rather than using the term "prolonged," which is variably defined and could lead to confusion.

Challenges with existing EPR systems

One of the major themes centred around implementation of information record standards. In particular, the existing interoperability issues that exist between and within systems, including SystmOne, Epic, and Cerner. One example highlighted the challenges of linking fertility and contraception data with Medicines and Healthcare products Regulatory Agency (MRHA) consent and medication status would be valuable but currently it is not possible. Therefore, standardisation across system suppliers should be mandated to ensure interoperability, particularly in alignment with ISN requirements. This will facilitate smoother data exchange and reduce the risk of information gaps when patients move between different healthcare settings.

Future proofing standards

Future-proofing the standards was another important theme. Participants acknowledged that the standards need to evolve as classifications, such as those from the International League Against Epilepsy (ILAE), are updated. Therefore, it was recommended that system suppliers update their systems in line with PRSB’s three-year maintenance cycle. Furthermore, the potential impact of evolving ILAE classifications should be assessed to ensure that the standards remain relevant and adaptable over time.

Epilepsy-specific data requirements

The expert group also emphasised the need for standardisation of epilepsy-specific data. This included seizure triggers, seizure duration, SUDEP considerations, and contextual episode data. To improve this, it was suggested that structured lists be limited to common seizure triggers, with free-text options provided for less common occurrences.

4.2 Professional workshop

The summary of findings for the professional workshop (n=20) are shown in table 7 (Appendix 6.8). The attendees list can be found in the appendix (Appendix 6.7).

Cardinality

In the EIS Wider Professional webinar, a key issue raised was the cardinality of episode descriptions. It was pointed out that multiple sources, such as witnesses, may contribute to the description of a seizure episode. To accommodate this, it was recommended that the episode description record entry cardinality be changed to allow multiple sources, reflected in a 0...* range.

Interoperability

Another concern involved the lack of interoperability between patient-used proformas, such as epilepsy passports and calendars, and the formal healthcare records. The recommendation is to update patient-used epilepsy documents, where possible, to align with the information standard to ensure continued interoperability between these documents and clinical systems.

Seizure clusters

The discussion also highlighted the need to address how seizure clusters will be represented in the data model. As seizure clusters differ from single seizures in both their frequency and impact, it was suggested that the data model be updated when counting seizure events to differentiate between single seizures and clusters. This differentiation will provide a clearer representation of the patient's condition and ensure quality data collection.

Prolonged seizures
Prolonged seizures were also a point of concern, with participants noting the difficulty in defining what constitutes a prolonged seizure. It was recommended that a data item be added to record the individual's maximum seizure duration, which would avoid ambiguity and provide more accurate data on seizure events. This would still allow the presence and absence of seizures (for example >5mins) of specific durations to be determined from entered data.

Epilepsy impacts
Epilepsy impacts were another important theme. It was noted that the standard should be able to record whether a patient is adhering to their prescribed medication, as non-adherence can trigger seizures and increase the likelihood of unplanned healthcare visits. It was also recommended that the data model be updated to include fertility and offspring impacts, with clear guidance to ensure these data items are completed for both male and female patients to align with national policy/guidelines.

Suspected diagnoses
Participants also highlighted the need for the data model to accommodate suspected diagnoses. Many patients with epilepsy do not have a clear, definitive diagnoses of causes / aetiology of their epilepsy diagnosis or co-morbidities, but instead have working or suspected diagnoses. The recommendation was to include a section in the model for recording suspected or working diagnoses, with further details to be developed in the next phase of the project.

Related diagnoses
Participants also highlighted the need for the data model to accommodate related diagnoses particularly where one diagnosis is felt to cause the other. The recommendation was to include a section in the model for recording causative relationships between diagnoses.

Following initial professional input, the requirements were further tested through a survey targeting a wider audience, including healthcare providers and service users, including individuals with epilepsy, their families, caregivers, and friends.

4.3 Service user representative group

A total of 9 people attended; there were representatives from SUDEP Action, Epilepsy Action, and the Epilepsy Research Institute.

The small discussion group allowed for rich, contextual discussions due to the participants' extensive experience advocating for service users. The webinar identified critical factors for improving epilepsy care, better information sharing, holistic care approaches, mental health tracking, and structured risk assessments.

The main themes to emerge from the discussions reflect a comprehensive approach to care, focusing on patient-centred, holistic, and personalised care, with an emphasis on effective communication and continuity of care.

Patient-centred Care and Information Sharing
The discussions highlighted the importance of collecting and sharing comprehensive information about patients, particularly those with epilepsy. The need for healthcare professionals to consider the patient's perspective and the impact of their condition on their daily life was emphasised. The integration of educational teams in care planning was discussed, with a focus on the need for consistent information sharing across different care providers. Additionally, the importance of clear documentation of the information provided to

patients, such as risk leaflets, and capturing feedback from patients about their care experiences, was stressed.

Impact on Patients' Lives

A significant theme was the impact of epilepsy and its treatment on patients' lives. The discussions focused on understanding how patients are coping with their condition, their challenges, and the overall effect on their education and daily activities. It was also highlighted that capturing comments from both patients and families, alongside the outcomes of care provided, is essential for a complete understanding of the patient's journey.

Reproductive Health and Pre-conception Advice

The need for better pre-conception advice and support for young people with epilepsy was raised. Participants emphasised the importance of addressing reproductive health impacts in the data model, which would better reflect the needs of those living with epilepsy who are planning a family.

> *"...one of the big things ....at the moment is there is no really good preconception, support, advice, direction. GPs aren't really doing it... we've got a cohort here of young people who need that advice..."*

Transition and Continuity of Care

The challenges faced during the transition from paediatric to adult epilepsy services were a key focus. Discussions highlighted the need to maintain continuity of information and ensure that care plans are communicated effectively during transition. Participants also called for greater support to ensure smooth transitions, allowing patients to continue receiving high-quality care as they move to adult services.

Holistic and Personalised Care

There was a strong focus on the need to provide holistic care that goes beyond medical treatment. Discussions emphasised the importance of considering mental health, social interactions, and alternative therapies in care planning. The need for personalised care plans that reflect the individual needs and preferences of patients was also a key point. Specific areas of discussion included:

- **Alternative Therapies:** The importance of including alternative therapies, such as ketogenic diets, Vagus Nerve Stimulation (VNS), and other self-sourced treatments, in the data model was highlighted. This would ensure that all aspects of a patient's care are considered, giving a comprehensive view of the patient's treatment journey.
- **Holistic Care:** Holistic care, which considers the physical, emotional, and psychological well-being of the patient, was discussed as essential. This approach ensures that the care provided addresses all aspects of the patient's needs and improves overall well-being.
- **Potential Implications for the Data Model:** It was agreed that the current health model captures drug and non-drug therapies but needs to be expanded to include alternative treatments. The importance of patient-reported outcomes and tools to capture the impact of treatments on patients' lives was also discussed.

Mood and Mental Health

Capturing mood and mental health was seen as an essential part of the data model. The importance of recording mental health symptoms, even when they do not meet the threshold for a diagnosis, was stressed. This would provide a more complete picture of the patient's well-being. Discussions on this theme included:

- **Mood and Memory:** The significance of documenting mood and memory issues, which can impact daily life, was highlighted. There was a particular focus on the effects of stress and the potential risk of suicide, stressing the need for capturing these symptoms to understand their broader impact.
- **Symptom Recording:** It was noted that even if mood and memory symptoms do not meet the threshold for a diagnosis, capturing these details would help in understanding their impact on a patient's overall health and life.

End of Life and Palliative Care

The issue of learning from patient deaths and using this information to improve care for future patients was raised as a key point. The importance of capturing end-of-life and palliative care information in the data model was discussed. The need to ensure alignment with existing end-of-life care standards was also emphasised.

Risk Assessment and Impact

The importance of capturing risks and their potential impact on patients was discussed in detail. There was a clear need for a dedicated risk section in the data model to identify potential issues before they become critical. Specific areas of focus included:

- **Habits:** How lifestyle choices, such as smoking or alcohol consumption, may impact care.
- **Compliance:** Tracking patient adherence to treatment plans.
- **Safety:** Assessing the safety of the home environment during seizures.

Annual and Medication Reviews

There was a strong call for the inclusion of annual and medication reviews in the data model, particularly during the transition from paediatric to adult services. The need for an annual review section in the data model was suggested to ensure continuity of care and the effective monitoring of medication management over time.

4.4 Lived Experience Focus Groups

There were expressions of interest from fifteen people. In total discussion took place with eight people with direct experience of epilepsy either as a person with epilepsy or as a parent/care. Participants took part under Market Research Society guidelines and have chosen to exercise their right to remain anonymous. The broad participant demographics were -

1. A focus group discussion with three parent carers of people with epilepsy.
2. One-to-one discussions with two parent carers of people with epilepsy.
3. A discussion with a young person with epilepsy (aged 9), accompanied by their parent.
4. One-to-one discussions with two people of working age with epilepsy (with experience of transition from children to adult services).

Despite efforts to engage with individuals aged over 65 with epilepsy through advocacy and support agencies, direct contact was not achieved. This may be due to the complexities associated with engaging older adults, such as health conditions, accessibility barriers, or digital exclusion.

The main themes that arose from the focus groups included fragmented and inconsistent information management, the need for a universal digital health record, the burden on families and patients in managing epilepsy care, gaps in healthcare coordination, challenges in emergency care, issues with transitioning from paediatric to adult services, and the importance of self-tracking in epilepsy management.

Challenges in Information Sharing and Record-Keeping

The discussions emphasised that the current process of information sharing and record-keeping for epilepsy care is fragmented, inconsistent, and in need of universal digitalisation. Participants expressed concern about the lack of standardisation across NHS services, with epilepsy records being stored inconsistently. This inconsistency creates gaps in care, especially when patients move between different services, and forces patients and carers to repeat medical histories at every consultation, leading to frustration and delays. Additionally, many families are forced to maintain their own seizure diaries due to unreliable healthcare records, adding to the burden of manual record-keeping.

> *"When we go in the hospitals, I think they've got more or less up to date things now, but it was difficult because... we didn't see the same neurologist every time... I used to keep notes as when she was a child, I had her diary where I kept all the notes of what, when, how..."*
>
> *"...she (adult child) has made this chart where she records everything... and they were so amazed, the neurologists... it gave them a clear picture of what is happening... So maybe something like that could be introduced..."*

The need for a centralised digital epilepsy health record was a recurring theme. Participants proposed that a universal record should be accessible to a range of healthcare providers, including hospitals, GPs, emergency services, and pharmacies. Schools and workplaces should also be included in this system to ensure that seizure management plans are widely understood. This record would allow consultants and neurologists quick access to past treatments and triggers. Proposed solutions to facilitate this digital record include a seizure tracking mobile app that updates medical records in real time, an epilepsy "passport" for emergency access to medical details, and video telemetry storage for clinical teams to review seizures remotely.

Burden on Families and Patients

The discussions focused on the challenges faced by both parents and carers, as well as those managing epilepsy independently. Parents and carers often shoulder the responsibility of managing epilepsy care alone, tracking seizures, medications, and hospital visits. The emotional toll of ensuring medication availability, advocating for care, and dealing with changing seizure patterns can be mentally exhausting. Many parents feel isolated post-diagnosis, with minimal guidance on next steps.

> *"...I don't think we've once been signposted to any support, nothing since he's been diagnosed. It was literally; got the diagnosis and off we went... There was no support...it's only lucky that I kind of knew seizures and stuff from my job... I think for people that have never experienced that, it must be so scary."*

Individuals managing their own epilepsy face similar challenges. Transitioning to self-management can be overwhelming, especially when doctors require detailed recall of seizure patterns and medication history. Memory issues further complicate the process, making it difficult for patients to provide accurate information during consultations, which can result in misdiagnosis or ineffective treatments. It was suggested that a structured transition plan, with a named coordinator, could help young adults navigate the transition from paediatric to adult services more effectively.

Gaps in Healthcare Coordination

The breakdown of communication between different care settings and issues with medication management were identified as key challenges in healthcare coordination.

Changes in neurologists or epilepsy nurses disrupt continuity of care, forcing patients to repeatedly explain their medical history. GPs are often unaware of epilepsy-specific treatments, which can lead to incorrect medication adjustments. Additionally, the use of different health record systems across hospitals and community care settings delays access to critical information, especially in emergency situations.

> *"Today I had a call from the GP for me to talk through the consultation I had with my consultant at XXX Epilepsy Centre... Half of this stuff, I don't think he even read that letter. I have to dictate that entire letter, even though I was in this state... And then, of course, the pharmacy—if that drug was to get prescribed—should also make a checkpoint to say, 'Oh, have you had your ECG?'... But all the different trusts don't pull the same information... I'm just having to repeat it every time."*
>
> *"I think between hospitals it's... like delaying things, getting passed over... surely having just one thing for that patient should follow them across all settings."*

Medication management issues were also discussed. Frequent prescription errors occur due to a lack of communication between GPs, pharmacies, and specialists. Medication shortages, such as those related to Brexit, force patients to switch drugs, sometimes causing serious side effects. Better integration of pharmacy systems could prevent disruptions in epilepsy treatment and improve patient safety.

> *"We've had quite a lot of that... if you have got a specific brand written on [the prescription] and there is a shortage... the pharmacist then can't give you an alternative or a generic... I've literally stood in the doctor's surgery... saying please can you just reissue this prescription."*

Emergency Care and Epilepsy Awareness

One of the most significant issues discussed was the miscommunication and lack of understanding surrounding epilepsy in emergency care settings. Paramedics and A&E staff often lack knowledge of complex seizure types, leading to misidentification of seizures (e.g., absence seizures mistaken for fainting) and incorrect responses, such as unnecessary emergency interventions or the dismissal of symptoms. To improve emergency care, it was suggested that a centralised emergency epilepsy record should be accessible to ambulance and A&E teams. Additionally, video seizure logs could be used to help doctors assess seizure severity remotely. Mandatory epilepsy training for emergency responders was also recommended to improve treatment outcomes.

> *"...yes, if you're going into an appointment with your neurologist, your neurologist will have an understanding of what, how a focal seizure could present. But not necessarily all paramedics would have that... if they arrive in A&E... and either is acting as though they're drunk... particularly focal seizures... it's really important that there is some kind of flag that says... this could be actually the epilepsy, it could be a seizure."*

Transitioning from Paediatric to Adult Epilepsy Services

Participants shared their concerns regarding the transition from paediatric to adult epilepsy services. Many young people feel abandoned when they leave paediatric care, as adult services are less personalised.

> *"You go from paediatrics where everyone knows you, knows your story, checks in, talks to your mum – to adult services where you're just another person in the system. It feels like no one really cares anymore. You're left to figure it out on your own."*

The transition to self-management is overwhelming for many young adults, who are expected to manage their medication, recognise triggers, and seek help independently. Poor communication between paediatric and adult teams can result in lost medical records, forcing patients to start from scratch with new consultants.

> *"We didn't see the same neurologist every time... it lasted for a few months and then somebody else comes, and then you start from A again all the way through... I found that process... it was not very pleasant."*

To improve the transition process, it was recommended that a named transition coordinator be assigned to oversee the move from paediatric to adult services. Structured training on self-management should also be provided to families, including guidance on how to track seizures, what to do if medication is missed, and understanding restrictions around driving, alcohol, and workplace adjustments. Mental health support for young adults was also emphasised, as anxiety and depression are common post-transition.

> *"...if there's no dedicated individual to coordinate this, it falls through the cracks. A named transition coordinator could make a real difference—someone who knows the young person, who ensures the information is passed on, and that nothing is missed."*

Role of Schools and Workplaces in Epilepsy Management

Participants discussed their experiences of support in both educational and workplace settings. In schools, bullying and stigma due to a lack of epilepsy education were common issues. Despite epilepsy being a long-term condition requiring adjustments, schools often fail to follow medical guidance, creating unsafe environments for children with epilepsy. In workplaces, many employers lack awareness of epilepsy, which can lead to unsafe working conditions and limit career progression.

> *"As a child, nobody understood X's focal seizures at school. And then the bullying comes from other children, and we've been through all that. If there is some kind of thing that the schools can be educated about... that would really, really make a difference to a child's life. It was very tough to go through all that on top of having the seizures and putting up with bullying."*

To address these issues, it was recommended that schools and workplaces implement better training and policy adjustments to support individuals with epilepsy. Raising awareness and providing reasonable accommodations would improve employment opportunities for people with epilepsy and foster safer, more inclusive environments.

The Role of Self-Tracking in Epilepsy Management

The need for patients and carers to track seizures was highlighted as a key tool in improving care. Patients and carers often find it difficult to recall seizure details during consultations, which can affect the accuracy of treatment. Digital seizure diaries were seen to improve consultations by providing structured data on seizure frequency, triggers, and medication effects. One respondent shared their experience of developing a custom seizure tracking system, based on tools like the Flow App, which improved doctor-patient relationships by providing quick, structured seizure insights. This approach also reduced consultation time by 15 minutes and enhanced treatment discussions.

The discussions emphasised the need for a more integrated and patient-centred system for epilepsy care. Poor information sharing across services was identified as a key issue, with patients and families experiencing frustration and delays. Transition periods and emergency care were highlighted as particularly problematic areas.

The following key recommendations emerged from the discussions:

- Develop a national standardised epilepsy health record to enable seamless information sharing across different care providers.
- Ensure smooth transitions to adult epilepsy services, with a named coordinator and structured self-management education.
- Improve emergency care by ensuring epilepsy records are instantly accessible to A&E staff and paramedics.
- Address medication management issues by integrating pharmacy and GP records to prevent prescription errors.
- Enhance epilepsy awareness in schools and workplaces through better training and policy adjustments.
- Provide mental health services for epilepsy patients and carers to reduce the emotional burden of managing care.

It is evident from the discussions with services users that there is a critical need for a standardised epilepsy information standard.

4.5 Online survey

Following the webinars and workshops, an online survey was conducted via Survey Monkey. The questionnaire intended to gather qualitative and quantitative data to inform the further development of the standard. The Professional Record Standards Body (PRSB) Communications, Engagement and Strategy team distributed the survey through social media channels, through email, and through existing lists of people connected to epilepsy and epilepsy projects.

One online survey was distributed to service users and clinical care providers to gather quantitative and qualitative data to inform the further development of the draft information standard.

The survey was open from Wednesday 26th March until Wednesday 2nd April 2025. Eighty individuals completed the survey. All available information and responses were analysed, although some questions were unanswered by respondents. Incomplete questionnaires were excluded from the final analysis due to the potential for bias, reduced sample size, and the difficulty of accurately analysing incomplete data. Therefore, a total of fifty-eight participants were included in the final analysis of the survey.

The full survey report can be found in the appendix (Appendix 6.9).

5 Recommendations and Conclusion

The following recommendations are a result of the analysis and findings in section 4.

Our approach considers the internal and external actions required to develop the EIS, with consideration of data modelling and implementation strategies in the next phase of the project. Also, the findings of the survey will help to inform the value sets for data items in the EIS.

5.1 Recommendations

Using structured data modelling is vital to the success of the Epilepsy Information Standard (EIS). It establishes a structured, consistent, and interoperable framework for capturing and sharing epilepsy-related health information across different systems and care settings.

Key recommendations for PRSB:

- **Standardised data structures:** This involves defining clear, structured data elements using SNOMED-CT and FHIR to ensure compatibility across different systems. See table 4 (Appendix 6.5) for further details.
  This would require further clinical consultation to define and validate appropriate reference value sets (e.g. lists for seizure types or medications).
- **Balance between structured and unstructured data**: Structured data elements ensure consistency; however, free text fields should be incorporated to allow clinical discretion where necessary. See table 5 (Appendix 6.6) for further details. This will also minimise the risk of digital exclusion where there are varying levels of digitisation across trusts. Designing the EIS model with inclusivity in mind is essential to ensure that information is accessible and usable for everyone.
- **Implementation guidance to automate data entry and pre-population:** To reduce the burden on clinicians, it is recommended to enable data fields to be auto populated from existing electronic patient records (EPRs), which will ensure accuracy and reduce duplication. See table 4 (Appendix 6.5) for further details.

Considerations for the next phase of the EIS development include:

- **NHS E & DHSC changes:** With the recent abolishment of NHS England and changes to national management structures, it is important to review how these changes may affect the next phase of the EIS development. Maintaining traction for the project alongside the NHSE/ DHSE changes – including members of DHSE in the Project Board will be key to maintaining and securing support for implementation.
- **Supplier engagement:** Early engagement in the next phase with system suppliers and EPR providers is essential to ensure feasibility and practical integration of the standard. Working with the PRSB Implementation Lead will also mitigate any potential implementation challenges and increase success of conformance.
- **Testing and validation:** Suppliers should pilot the standard within different care settings to refine its implementation before full-scale rollout. The EIS can also be tested with the application of AI supported ambient scribing, which could populate confirmed information to the EIS to reveal if it is effective as an inputting solution in clinical settings.
- **User-friendly interfaces**: This is outside of the remit of PRSB; however, as a result of our consultations, our implementation guidance suggests that using dropdown menus, auto-filling fields, voice-to-text features, and ambient AI scribing would reduce the burden of data entry and workload. The PRSB must define and clinically validate reference value sets for suppliers to implement.
- **System supplier compliance with EIS:** Upon completion of the EIS, the PRSB will seek Data Alliance Partnership Board (DAPB) assurance. DAPB assurance would require providers to comply with the standards and to comply they will require systems that conform to the standards.
- Consider an implementation support programme to include:
    - Consideration of how conformance with the ISN should be assessed and work with procurement framework leads to agree an implementation approach.
    - Training for health and social care professionals in all systems within their organisation that use the EIS, including how to complete digital elements of care and support plans, and how to use different sections of the record to ensure personalised and effective care.
    - Development of an implementation toolkit and pilot sites that can test the standard use, measure benefits, and share learning with the system.
    - Support for patients and families to engage with the model, 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.

5.2 Conclusion

The development of the Epilepsy Information Standard (EIS) represents a critical opportunity to improve the quality, safety, and personalisation of care for children, young people and adults living with epilepsies. The recommendations outlined in this section reflect the insights and findings gathered from stakeholder engagement, data analysis, and practical feedback from clinical and non-clinical contributors. A robust data modelling approach, coupled with inclusive implementation guidance, will be essential to ensure the standard is clinically relevant, interoperable, and usable in real-world settings.

6 Appendix

6.1 Communications plan

https://theprsb.org/wp-content/uploads/2025/05/EIS-Consultation-Plan-V3.pdf

6.2 Project team

Table 1. Names and roles of project team members.

Name	Role
Alison Brown	Project Support Manager
Andy Wright	Communications Lead
Caitlin O’Donnell	Project Analyst
Kelly Cheng	Project Analyst
Kingsley Ejeh	Project Manager
Colin Dunkley	Clinical Lead
Niky Raja	Epilepsy12 Project Manager
James Mitchell	Clinical Lead

6.3 EIS Expert Group – Formulation attendees list

Table 2. Organisation and role of Non-PRSB Formulation webinar attendees

Organisation	Role
Sherwood Forest Hospitals NHS Foundation Trust	Consultant Paediatrician
Royal Devon University Healthcare NHS Foundation Trust	Speciality Registrar
Great Ormond Street Hospital	Consultant Paediatric Neurologist
South tees NHS trust	Consultant
Sussex Community NHS Foundation Trust	Consultant Community Paediatrician with special interest epilepsy
Barts Health NHS Trust	Consultant Paediatrician
Lewisham And Greenwich NHS Trust	Consultant Paediatrician with special interest in epilepsy

RCPCH	Head of Audits
Ashford And St Peter's Hospitals NHS Foundation Trust	Epilepsy Specialist Nurse
York And Scarborough Teaching Hospitals NHS Foundation Trust	Consultant Paediatrician
Belfast Health and Social Care Trust	Consultant paediatrician
East and North Herts NHS Trust	Regional Clinical Nurse Specialist - Children's Epilepsy
Ashford and St Peter's Hospital	Epilepsy Specialist Nurse
Buckinghamshire Healthcare NHS Trust	Lead nurse for epilepsy
RCPCH	Head of Audits
Epilepsy Research Institute	Chief Executive

6.4 EIS Expert Group – Outcome attendee list

Table 3. Organisation and role of Non-PRSB Outcome webinar attendees

Organisation	Role
Sherwood Forest Hospitals NHS Foundation Trust	Consultant Paediatrician
Hull University Teaching Hospitals NHS Trust	Clinical lead for Paediatric epilepsy service
Great Ormond Street Hospital	Consultant Paediatric Neurologist
Aminu Kano Teaching Hospital	Paediatrician
LEWISHAM AND GREENWICH NHS TRUST	
Bristol Royal Hospital for Children	Consultant General Paediatrician with Special Interest in Epilepsy
SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	Consultant Paediatrician with Expertise in Epilepsy
Barts Health NHS Trust	Consultant Paediatrician
NHS NORTH EAST AND NORTH CUMBRIA ICB - 00P	Network Delivery Manager CYPT
Buckinghamshire Healthcare NHS Trust	Lead nurse for epilepsy
York And Scarborough Teaching Hospitals NHS Foundation Trust	Consultant Paediatrician
RCPCH	Head of Audits

6.5 Findings and recommendations from the EIS Formulation webinar.

Table 4. Findings and recommendations from the EIS Formulation webinar.

Theme/Finding	Recommendations
Burden of Data Entry	
Concerns about who will be responsible for data entry and the risk of poor-quality recordings due to increased data requirements.	Explore automation and delegation. Systems should pre-populate fields using EPR data.
Potential Duplication	

Risk of duplicating data within records, increasing data entry burden.	Pre-populate fields from existing EPR data and map all epilepsy-specific requirements to the standard model.
Time and Resources	
Healthcare staff, such as epilepsy nurses or consultants, need dedicated time for record maintenance. Time pressures affected Epilepsy 12 implementation.	Define clear responsibilities within the standard. Consider financial feasibility to prevent staff overload.
Capturing Broader Seizure Impacts	
Qualitative data using free-text fields is needed to describe patient impacts across different life phases (e.g., elderly, paediatric, transition).	Include transition data for young adults, DVLA guidance, and health-specific challenges for older adults
Epilepsy-Specific Data Requirements	
Standardisation needed for seizure triggers, seizure duration, SUDEP considerations, and contextual episode data.	Limit structured lists to common triggers but allow free text. Conduct a survey to refine seizure frequency recording.
Seizure Frequency Categorisation	
Sample time periods (daily, weekly, monthly, <1 month) and significance should consider individual baselines.	Review existing guidance and refine seizure frequency data collection to avoid loss of detail.
Addressing Health Inequalities	
Need to assess broader impacts on epilepsy diagnosis and care, including language barriers and transport access.	Review and update health inequalities data model. Capture first language, non-attendance reasons, and medication compliance.
Practical implementation insights	
Linking fertility and contraception data with MRHA consent and medication status is valuable.	Ensure EPR systems can pre-populate consent information. Incorporate into the entity-relationship diagram.

6.6 Findings and recommendations from the EIS Outcome webinar.

Table 5. Findings and recommendations from the EIS Outcome webinar.

Theme/Finding	Recommendations
Burden of Data Entry	
Concerns about who records information and when, highlighting the additional time required.	Explore automation and delegation. Systems should pre-populate fields using EPR data. Further clinical consultation on mandatory data points.

Data Structure	
Need to balance structured data (e.g., dropdowns) with free text for usability. Concerns about structured systems increasing input time.	Develop structured fields with SNOMED codes and free text options. Investigate external coding for genotypic diagnosis.
Prolonged Seizures	
Difficulty defining what a prolonged seizure is as it varies between individuals. This would make it difficult to record whether a seizure is prolonged, or whether the person has a history of prolonged seizures.	Add a data item recording what the individual's maximum seizure duration is, rather than using the word prolonged.
Epilepsy-Specific Data Requirements	
Standardisation needed for seizure triggers, seizure duration, SUDEP considerations, and contextual episode data.	Limit structured lists to common triggers but allow free text. Conduct a survey to refine seizure frequency recording.
Future-Proofing Standards	
Need to maintain up-to-date standards with evolving classifications (e.g., ILAE updates) and ensure long-term system interoperability.	Ensure system suppliers update according to PRSB's three-year maintenance cycle. Assess the impact of evolving ILAE classifications.
Challenges with Existing EPR Systems	
Interoperability issues exist between and within systems, including SystmOne, Epic, and Cerner.	Standardisation across system suppliers should be mandated to ensure interoperability, aligning with ISN requirements.

6.7 EIS Professional workshop attendee list

Table 6. Organisation and role of Non-PRSB Professional workshop attendees.

Organisation	Role
Royal College of Paediatrics and Child Health	Epilepsy12 Manager
Mid-Yorkshire Teaching Hospitals NHS Trust	Consultant Paediatrician
Royal College of Nursing	Professional Lead, Learning Disability and Neuroscience at PBS4
Pertemp Medicals	Consultant Community Paediatrician
King's College London	Clinical Lecturer
Epilepsy Research Institute	Research Programme Manager
University of Eastern Finland	Postdoctoral Researcher
University of Glasgow	Senior Clinical Research Fellow

The Walton Centre NHS Foundation Trust	Consultant nurse in epilepsy
South Eastern Health and Social Care Trust	Consultant Paediatrician
Bolton NHS Foundation Trust	Epilepsy Specialist Nurse

6.8 Findings and recommendations from the EIS Wider Professional webinar.

Table 7. Findings and recommendations from the EIS Wider Professional webinar.

Theme/Finding	Recommendations
Cardinality	
There may be multiple sources of episode descriptions to record (e.g., multiple witnesses).	Episode description record entry cardinality to be changed to 0...*.
Interoperability	
Concerns around lack of interoperability of data with patient-used proformas (e.g., epilepsy passports/calendars).	It is recommended that any patient-used epilepsy documents are updated where possible to align with the information standard for continued interoperability.
Seizure Clusters	
Queries as to how seizure clusters will be represented within the model, compared to single event seizures.	The data model should allow for differentiation between record single seizures and a cluster of seizures.
Prolonged Seizures	
Difficulty defining what a prolonged seizure is as it varies between individuals. This would make it difficult to record whether a seizure is prolonged, or whether the person has a history of prolonged seizures.	Add a data item recording what the individual's maximum seizure duration is, rather than using the word prolonged.
Epilepsy Impacts	
Ensure that the standard can record whether medication is not being adhered to – this can trigger seizures and lead to an increased risk in unplanned healthcare visits.	Add data item to record whether medication is being adhered to as intended.
Requirement that fertility and offspring impact data items are also completed for males.	Add implementation guidance that explains that these data items should be completed regardless of the person's sex.
Suspected Diagnoses	

The cause of epilepsy may not have a diagnosis but may have a working/suspected diagnosis. There was a requirement that this should be recordable.	Model to allow record of working diagnosis. Specifics of how this may be recorded to be devised in the next phase of this project.