Professional Record Standards Body

Better records for better care

Epilepsy Information Standard: Phase 3 Survey Report

April 2025

Document Management

Revision History

Version	Date	Summary of Changes
0.1		Initial draft

Reviewers

Reviewer name	Title / Responsibility	Date	Version

Approved by

Name	Title/Responsibility	Date	Version
Project Board			
Assurance Committee			

Glossary of Terms

Term / Abbreviation	What it stands for

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 Introduction

This is an appendix to the final report for the Epilepsy Information Standard (EIS): Phase 3 project.

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.

2 Methodology and Consultation Approach

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 the epilepsy project.

2.1 Project Objectives and Scope

Objectives –

- Identify key data items that are critical for safe, coordinated epilepsy care.
- Understand current challenges and user needs from diverse stakeholder perspectives.
- Inform specific requirements for structuring and sharing information.

2.2 Survey Design

Survey design –

- The survey used a mixed-methods approach, combining quantitative and qualitative question types to capture both measurable trends and more detail insights. The design included:
    - Multiple choice questions – To gather structured data on respondent roles. For example. The survey consisted of two pathways depending on the type of respondent:
        - Clinical care providers/ social care providers/ educational provider/ charity provider
        - Service users
    - Likert scale question – to assess the importance or confidence of content of information.

The survey was open from Wednesday 26th March until Wednesday 2nd April 2025.

2.3 Scope

Scope -

The survey was:

- For testing the draft content of the EIS with the people who will use it by gathering evidence to support/oppose the inclusion of existing sections and elements and to identify any new areas to incorporate as required.
- A short and pragmatic exercise to engage stakeholders.

2.4 Limitations

Caution should be applied when drawing inferences that may not be generalisable to the wider population of the United Kingdom (UK) and four nations. The information may be representative of the views of some or even many clinical professionals or service users, but it was not the intention of this exercise to draw conclusions beyond those relevant to guiding us in the development of the standard's content.

The raw data was analysed by one PRSB analyst, conducting a thematic analysis on qualitative responses, and the findings presented in this report. Any requirements that arose from the survey were documented and reviewed by the project team.

3 Survey Analysis

Stakeholder breakdown

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 majority of respondents (78%) were clinical care providers, with additional responses from services users, social care providers, and charity representatives. One respondent was a clinical care provider and affiliated to specific epilepsy charities.

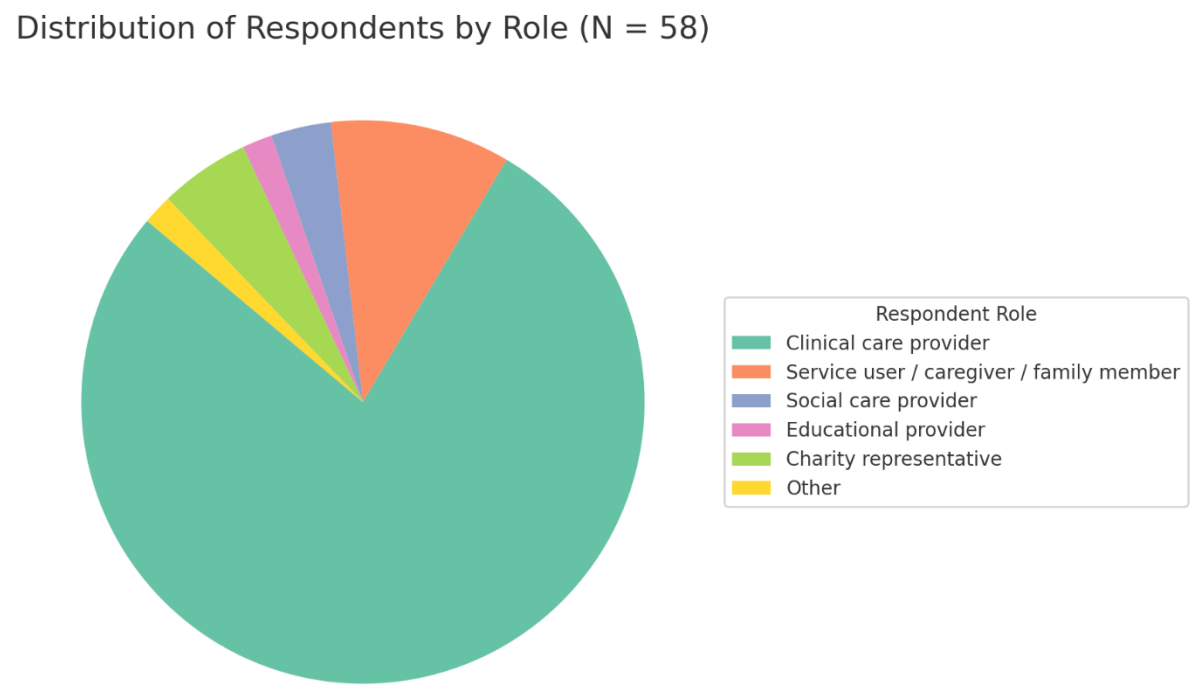

Figure 1. A pie chart presenting the stakeholder groups. Clinical care provider (n=45, 78%), service user (n=6, 10%), social care provider (n=2, 3%), education provider (n=1, 2%), charity representative (n=3, 5%), Other (n=1, 2%).

Most respondents (n=54) provided information about their profession/ job title; the majority of these respondents were consultants (n=25), specialist nurses (n=10) and nurses (n=8), or from resident doctors (n=2) and a scientist. Among the remaining respondents who answered 'Other', responses included the following –

- Clinical psychologist
- Physiologist
- Research manager
- Paediatric epilepsy nurse specialist
- Expert by experience

Among the service users (n=6), half of them were individuals living with epilepsy and the other half were a family member or friend.

All respondents answered the questions related to the content of the Epilepsy information standard. However, each group was analysed separately as they interact with epilepsy in different contexts, which often results in different priorities, varying levels of access to the systems, and using information in distinct ways. The view of service users was analysed separately to reveal individual experience and insight to inform service user-led requirements.

3.1 Which seizure triggers should be routinely included as options in the Epilepsy Information Standard (EIS)? (Tick all that apply)

The purpose of this survey question was to evaluate the potential value set items that could be available for selection in a clinical health and care record to support the management of epilepsy and personalised care planning.

The findings indicate a high level of consensus across service users, clinical care providers, and other professionals, that a broad range of environmental and lifestyle-related seizure triggers are relevant and should be captured in structured health records. These include medication adherence, stress, sleep patterns, illness, hormonal factors, and more.

The most relevant reported triggers were medication non-adherence, sleep deprivation, and stress, which was selected by 100% of respondents. Other frequently selected factors included short-term illness and the menstrual cycle (83%), followed by alcohol, recreational drugs, flashing lights, and weather changes (67%). Additional comments highlighted medication changes and side effects as important triggers for some individuals that should be recorded in the EIS. This feedback reinforces that the need for personalised seizure care plans and considerations of lifestyle and medication management are critical in epilepsy support.

Clinical care providers identified a range of common seizure triggers. The most frequently reported triggers were not taking medication as intended (96%), sleep deprivation (91%), and stress (89%). Other notable triggers included short-term illness, the menstrual cycle (both 89%), alcohol (87%), and recreational drug use (80%). Less frequently reported triggers included flashing lights (71%), exercise (33%), missing meals and weather (both 29%), and substances like caffeine, essential oils, smoking, and vaping (16–18%). A small proportion (13%) mentioned other triggers, such as over/ under arousal (stimulation), shock/ scare, sounds, anxiety, as well as heat (e.g. hot bath), and other medication. One respondent stated that some of the triggers could be grouped appropriately with an option to include ‘Other’ or ‘Further specification’ which was further supported by another comment suggesting that ‘no identifiable triggers’ should also be an option.

In general, social care providers reported high recognition of key triggers such as not taking medication, sleep deprivation, stress, short term illnesses, menstrual cycle, recreational drugs, and flashing lights (100%). Educational providers reported fewer triggers overall, which may be due to limited clinical exposure or small sample size. Furthermore, charity staff showed consistent awareness of a wide range of triggers, including environmental and lifestyle-related factors.

Table 1. Suggested seizure triggers selected by respondent groups.

This table presents the number and percentage of respondents from each stakeholder group who selected specific seizure triggers to be included in the EIS.

Seizure Triggers	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents
Not taking medication	43 (96%)	6 (100%)	2 (100%)	0 (0%)	3 (100%)	0 (0%)	54 (93%)
Sleep deprivation	41 (91%)	6 (100%)	2 (100%)	1 (100%)	3 (100%)	0 (0%)	53 (91%)
Stress	40 (89%)	6 (100%)	2 (100%)	0 (0%)	3 (100%)	0 (0%)	51 (88%)
Short term illness	40 (89%)	5 (83%)	2 (100%)	0 (0%)	3 (100%)	0 (0%)	50 (86%)
Menstrual cycle	40 (89%)	5 (83%)	2 (100%)	1 (100%)	2 (67%)	0 (0%)	50 (86%)
Alcohol	39 (87%)	4 (67%)	2 (100%)	0 (0%)	3 (100%)	0 (0%)	48 (83%)
Recreational drugs	36 (80%)	4 (67%)	2 (100%)	1 (100%)	3 (100%)	0 (0%)	46 (80%)
Flashing lights	32 (71%)	4 (67%)	2 (100%)	0 (0%)	3 (100%)	0 (0%)	41 (71%)
Exercise	15 (33%)	3 (50%)	1 (50%)	0 (0%)	3 (100%)	0 (0%)	22 (38%)
Missing meals	13 (29%)	1 (17%)	1 (50%)	0 (0%)	3 (100%)	0 (0%)	18 (31%)
Caffeine	8 (18%)	1 (17%)	1 (50%)	1 (100%)	2 (67%)	0 (0%)	13 (22%)
Essential oils	8 (18%)	2 (33%)	1 (50%)	0 (0%)	1 (33%)	0 (0%)	12 (21%)
Smoking	8 (18%)	2 (33%)	1 (50%)	1 (100%)	2 (67%)	0 (0%)	14 (24%)
Vaping	7 (16%)	2 (33%)	1 (50%)	0 (0%)	2 (67%)	0 (0%)	12 (21%)
Weather	13 (29%)	4 (67%)	1 (50%)	1 (100%)	2 (67%)	0 (0%)	21 (36%)
Other (please specify)	6 (13%)	2 (33%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	9 (16%)

3.1.1 Recommendation:

To support consistent and interoperable data capture, it is recommended that the appropriate value sets be reviewed and/or developed in SNOMED CT to reflect these triggers. Engaging with clinical terminologists and SNOMED experts is essential to validate the value sets.

This will ensure that information can be:

- Structured and coded appropriately.
- Consistently recorded and shared across systems and care settings.
- Effectively used in decision making support, monitoring, and person-centred care planning.

This will enable accurate, complete, and transferable documentation, supporting better care for people with epilepsy across the NHS and wider care system.

3.2 To what extent do you agree that the Epilepsy Information Standard (EIS) should capture information regarding the longest seizure duration for each seizure type.

The survey results reflect responses from different groups, including Clinical Care Providers, Service Users, Social Care Providers, Educational Providers, and Charity Representatives. The majority of Clinical Care Providers (53%) and Service Users (83%) strongly agreed with the statement, with fewer agreeing (38% for Clinical Care Providers and 17% for Service Users). Among other groups, Educational Providers (100%) and Charity Representatives (67%) strongly agreed. Very few respondents disagreed, with only 1 (2%) Clinical Care Provider and 1 (2%) Service User marking strong disagreement. No respondents were unsure or preferred not to answer.

Table 2. Level of agreement with statement "To what extent do you agree that the Epilepsy Information Standard (EIS) should capture information regarding the longest seizure duration for each seizure type." By respondent group.

Response	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total respondents
5 – Strongly agree	24 (53%)	5 (83%)	1 (50%)	1 (100%)	2 (67%)		33 (57%)
4 – Agree	17 (38%)	1 (17%)	1 (50%)	0 (0%)	1 (33%)	1	21 (26%)
3 – Neither agree nor disagree	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)		2 (3%)
2 – Disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)		1 (2%)

1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)		1 (2%)
Not sure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)		0 (0%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)		0 (0%)

3.2.1 Recommendation

Including the longest seizure duration for each seizure type in the epilepsy information standard would enhance the accuracy and completeness of clinical data.

- This requires implementation considerations that would require system suppliers to create views or reports that allow healthcare providers to query and analyse seizure durations, particularly focusing on the longest seizure duration per type for patient cohorts or individual patients.
- Additionally, real-time updates require consideration depending on the implementation. The longest seizure duration could be updated in real-time or during batch updates at regular intervals (e.g., nightly processing).

3.3 For each seizure event, what information should be routinely included?

The data shows strong support across stakeholder groups for capturing contextual information about seizure events. Clinical care providers consistently endorsed all core data elements, with highest agreement for recording whether the seizure was witnessed (96%) and the time of day (87%). Service users similarly prioritised location, activity, and time of day (all 83%), though only 50% supported capturing whether the seizure was witnessed or providing additional details. Social care and educational providers showed unanimous support (100%) for all relevant fields they responded to. Charity representatives also showed high levels of agreement, especially for activity during onset, time of day, and witnessed status (all 100%). These findings suggest broad consensus on the importance of recording contextual seizure data, with slightly more varied perspectives on capturing free-text or additional detail.

Data Element	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents
Location (home/work/etc.)	31 (69%)	5 (83%)	2 (100%)	1 (100%)	2 (67%)	1 (100%)	42 (72%)
Activity during onset	34 (76%)	5 (83%)	2 (100%)	1 (100%)	3 (100%)	1 (100%)	46 (79%)
Time of day	39 (87%)	5 (83%)	2 (100%)	1 (100%)	3 (100%)	1 (100%)	51 (88%)

Witnessed? (Yes/No/Unknown)	43 (96%)	3 (50%)	2 (100%)	1 (100%)	3 (100%)	1 (100%)	53 (91%)
Other (please specify)	19 (42%)	3 (50%)	2 (100%)	0 (0%)	1 (33%)	1 (100%)	26 (45%)

A total of 26 additional responses were record, of which were 19 clinical care providers that stated additional detail against routine information for each seizure event. This included the importance of capturing detailed, non-technical descriptions of seizures to ensure clarity for all users, including people with epilepsy and their families. Key suggestions included triggers, which further supports the previous question about seizure triggers. Also, a step-by-step description of how the seizure started, evolved, and ended, and what it looked and felt like to the person affected. Several respondents recommended including videos where possible, as well as witness information, such as name, signature, actions taken, and whether the seizure was witnessed. Other contextual factors included the recovery period, any injuries sustained, and additional relevant observations.

Service user additional responses included – for women – menstrual cycle, time; type, presentation, witnessed, emergency meds or VNS used, and suspected triggers.

Social care providers suggested recovery – time/ post Ictal (time from initial symptoms to seizure end) presentation and the information related to what happened before, what happened during, and how was the recovery were important to capture.

One charity representative suggested to add anything concerning to the parent.

3.3.1 Recommendations

A series of epilepsy-specific data requirements were drawn from the responses to enhance the contextual capture of seizure events. For example, respondents highlighted the need for a non-technical narrative of each seizure, the ability to record suspected triggers, and a step-by-step description of seizure evolution and recovery. Additional requirements included capturing whether the seizure was witnessed, actions taken by the witness, injuries sustained, and the use of emergency interventions such as medication or VNS. Women-specific data items, such as the timing of seizures in relation to the menstrual cycle, were also noted. Further action on these requirements will be dependent on financial funding in the next phase. More detail can be found in the appendix A.

3.4 To what extent do you agree that the following factors should be routinely included in the Epilepsy information standard (EIS). The following factors describing seizure impact are based on the Personal Impact of Epilepsy Scale (PIES). It considers various factors beyond seizure frequency, helping to understand the psychosocial, cognitive, and emotional effects of epilepsy.

Feedback collected across a range of epilepsy-related domains revealed strong consensus on the importance of clinical indicators such as seizure recency, severity, loss of awareness, injury, and seizure clustering. These were consistently rated as highly relevant by respondents, with over 90% selecting "Agree" or "Strongly Agree."

There was also widespread agreement on the impact of epilepsy on mood, anxiety, cognitive function, and overall quality of life, highlighting the significance of psychosocial and emotional factors in epilepsy care.

Medication side effects—such as tiredness, confusion, and aggression—were acknowledged, though responses were more varied, reflecting individual patient experiences and perceptions of severity.

Functional and social aspects, including school, work, and transportation, were viewed as relevant but showed greater variability in responses. Financial concerns and seizure bothersome-ness were noted, though with a broader spread across the scale, indicating these may be more context specific.

Overall, the findings reinforce the need for a holistic, person-centred approach to epilepsy care that captures both clinical and quality of life factors. There was a consensus that the factors describing seizure impact based on the Personal Impact of Epilepsy Scale (PIES) were very important to capture in the EIS, with mainly clinical providers, suggesting it is highly relevant for understanding a patient's condition and guiding treatment.

Detailed breakdown of the respondents' data can be found in Appendix B.

3.5 To what extent do you agree that when counting or recording seizures, that there should be a data element to differentiate between a single seizure and a cluster of seizures.

Clinical care providers and service users tended to show higher levels of agreement, suggesting strong alignment with the statement or concept being assessed. Over half of respondents agreed that differentiating between a single seizure and a cluster of seizures was important. Service users seemed to show the most variability, with 17% disagreeing and 0% unsure, suggesting a potential area for further exploration into why they might be in less agreement.

Table 3. Level of agreement with statement "To what extent do you agree that when counting or recording seizures, that there should be a data element to differentiate between a single seizure and a cluster of seizures." By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Total respondents
5 – Strongly agree	21 (47%)	3 (50%)	2 (100%)	1 (100%)	2 (67%)	29 (50%)
4 – Agree	19 (42%)	2 (33%)	0 (0%)	0 (0%)	1 (33%)	23 (23%)
3 – Neither agree nor disagree	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
2 – Disagree	0 (0%)	1 (17%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)

1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Not sure	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.6 The following page contains an optional question regarding Sudden Unexpected Death in Epilepsy (SUDEP), which may be a sensitive topic. You are not required to answer this question, and you may skip it without affecting your participation in the survey. If you would like further information or support, this is available from SUDEP Action. Do you want to skip this question?

Among the total respondents, only two clinicians decided to skip the question regarding Sudden Unexpected Death in Epilepsy (SUDEP). In addition, no service users skipped the question regarding SUDEP.

3.6.1 What information should routinely be recorded regarding discussions that a professional has with a person with epilepsy about SUDEP risk? (Tick all that apply)

Table 4. Breakdown of what information should be routinely recorded regarding discussions that a professional has with a person with epilepsy about SUDEP risk by respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total respondents
Whether discussion occurred	43 (98%)	6 (100%)	2 (100%)	1 (100%)	3 (100%)	1 (100%)	56 (98%)
Who was present at the consultation	34 (77%)	5 (83%)	1 (50%)	1 (100%)	2 (67%)	1 (100%)	44 (77%)
Whether a leaflet/tool was used	28 (64%)	6 (100%)	1 (50%)	1 (100%)	2 (67%)	0 (0%)	38 (67%)
Type of leaflet/tool used	23 (52%)	6 (100%)	0 (0%)	1 (100%)	3 (100%)	0 (0%)	33 (58%)

Whether there was a standardised SUDEP risk score used	20 (45%)	5 (83%)	2 (100%)	1 (100%)	3 (100%)	0 (0%)	31 (54%)
Agreed interventions/management	32 (73%)	6 (100%)	2 (100%)	1 (100%)	3 (100%)	1 (100%)	45 (79%)
Other (please specify)	5 (11%)	2 (33%)	1 (50%)	0 (0%)	1 (33%)	1 (100%)	10 (18%)

Several clinicians added the following considerations about SUDEP, such as if the person has an increased risk of SUDEP and why, response from consultation, who's responsible for actions, how regular reviews/ discussions are held, signposting to agencies, reminders to find ways to reduce risk and timing of delivering information depending on their condition. Additionally, it was highlighted that the patient's understanding of the information should be documented as well as the reason for not discussing SUDEP with the patient.

Additional service user responses included occupational therapy input and signposting for support.

3.7 To what extent do you agree that the Epilepsy information standard (EIS) should record possible causes of epilepsy as well as confirmed causes.

Over half of respondents (33-57%) strongly supported the recoding of possible causes of epilepsy, as well as confirmed causes across all groups.

Table 5. *Level of agreement with statement "To what extent do you agree that the Epilepsy information standard (EIS) should record possible causes of epilepsy as well as confirmed causes." By respondent group.*

Response Option	**Clinical care provider (n=45)**	**Service user (n=6)**	**Social care provider (n=2)**	**Educational provider (n=1)**	**Charity representative (n=3)**	**Other**	**Total respondents**
5 – Strongly agree	24 (53%)	5 (83%)	1 (50%)	1 (100%)	2 (67%)	0 (0%)	33 (57%)
4 – Agree	16 (36%)	1 (17%)	1 (50%)	0 (0%)	0 (0%)	1 (100%)	19 (33%)
3 – Neither agree nor disagree	3 (7%)	0 (0%)	0 (0%)	0 (0%)	1 (33%)	0 (0%)	4 (7%)
2 – Disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)

1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Not sure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.8 To what extent do you agree that the following fertility-related data is recorded in the Epilepsy Information Standard (EIS).

All respondents strongly agreed that the following fertility-related data should be recorded in the EIS.

3.8.1 Anti-seizure medication impact on fertility

Table 6. Level of agreement with statement "To what extent do you agree that the Epilepsy information standard (EIS) should record Anti-seizure medication impact on fertility" By respondent group.

Response Option	**Clinical Care Provider**	**Service User**	**Social Care Provider**	**Educational Provider**	**Charity Representative**	**Other**	**Total Respondents (Number)**
5 – Strongly agree	22 (49%)	6 (100%)	2 (100%)	1 (100%)	1 (33%)	0 (0%)	32 (55%)
4 – Agree	13 (29%)	0 (0%)	0 (0%)	0 (0%)	1 (33%)	1 (100%)	14 (65%)
3 – Neither agree nor disagree	4 (9%)	0 (0%)	0 (0%)	0 (0%)	1 (33%)	0 (0%)	5 (9%)
2 – Disagree	3 (7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	3 (5%)
1 – Strongly disagree	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
Not Sure	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Prefer Not to Say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.8.2 Contraception/ ASM interactions

Table 7. Level of agreement with statement "To what extent do you agree that the Epilepsy information standard (EIS) should record Contraception/ ASM interactions" By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents (Number)
5 – Strongly agree	25 (56%)	6 (100%)	2 (100%)	1 (100%)	2 (67%)	0 (0%)	36 (62%)
4 – Agree	14 (31%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (100%)	15 (26%)
3 – Neither agree nor disagree	3 (7%)	0 (0%)	0 (0%)	0 (0%)	1 (33%)	0 (0%)	4 (7%)
2 – Disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
1 – Strongly disagree	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
Not Sure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Prefer Not to Say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.9 To what extent do you agree that it is important to link a person's epilepsy record with their parent or their child.

Over half of respondents (21-35%) agreed and strongly agreed that it is important to link a person's epilepsy record with their parent or child. A quarter of all respondents selected 'Neither agree nor disagree' with a further 9% selecting 'Not sure', which suggests further clarity on the question may have been required, elaborating on the impact of linking family records.

Table 8. Level of agreement with statement "To what extent do you agree that it is important to link a person's epilepsy record with their parent or their child." By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents

5 – Strongly agree	7 (16%)	3 (50%)	0 (0%)	1 (100%)	1 (33%)	0 (0%)	12 (21%)
4 – Agree	17 (38%)	1 (17%)	2 (100%)	0 (0%)	0 (0%)	1 (100 %)	21 (35%)
3 – Neither agree nor disagree	11 (24%)	1 (17%)	0 (0%)	0 (0%)	2 (67%)	0 (0%)	14 (25%)
2 – Disagree	4 (9%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	4 (7%)
1 – Strongly disagree	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
Not sure	4 (9%)	1 (17%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	5 (9%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.10 To what extent do you agree that the following offspring health data is included in the Epilepsy information standard (EIS).

Overall, there was strong agreement for information about the presence/absence of neonatal seizures, neurodevelopmental disorders, and congenital disorders to be included in the EIS.

3.10.1 Neonatal seizures

Table 9. Level of agreement with statement "To what extent do you agree that it is important to record information about neonatal seizures." By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents
5 – Strongly agree	22 (49%)	4 (67%)	0 (0%)	1 (100%)	3 (100%)	1 (100 %)	30 (53%)
4 – Agree	12 (27%)	1 (17%)	2 (100%)	0 (0%)	0 (0%)	0 (0%)	15 (26%)
3 – Neither agree nor disagree	6 (13%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (10%)

2 – Disagree	3 (7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	3 (5%)
1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Not sure	1 (2%)	1 (17%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.10.2 Neurodevelopmental disorders

Table 10. Level of agreement with statement "To what extent do you agree that it is important to record information about neurodevelopmental disorder." By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents
5 – Strongly agree	29 (64%)	5 (83%)	1 (50%)	1 (100%)	3 (100%)	1 (100 %)	40 (69%)
4 – Agree	11 (24%)	1 (17%)	1 (50%)	0 (0%)	0 (0%)	0 (0%)	13 (22%)
3 – Neither agree nor disagree	4 (9%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	4 (7%)
2 – Disagree	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Not sure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.10.3 Congenital disorders

Table 11. Level of agreement with statement "To what extent do you agree that it is important to record information about congenital disorders." By respondent group.

Response Option	Clinical Care Provider	Service User	Social Care Provider	Educational Provider	Charity Representative	Other	Total Respondents
5 – Strongly agree	27 (60%)	6 (100%)	1 (50%)	1 (100%)	3 (100%)	1 (100%)	39 (67%)
4 – Agree	12 (27%)	0 (0%)	1 (50%)	0 (0%)	0 (0%)	0 (0%)	13 (22%)
3 – Neither agree nor disagree	5 (11%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	5 (9%)
2 – Disagree	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
1 – Strongly disagree	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Not sure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

3.11 Is there any additional information that you think should be included for the minimum dataset in the Epilepsy Information standard?

Respondents also had the opportunity to submit any additional information that should be included in the EIS.

Among the 21 responses, 14% (n=3) stated that the content of the survey was comprehensive and no further information was required in the EIS. The remaining responses highlighted several key themes essential for the holistic and safety considerations of people with epilepsy. These include medication and treatment history, risk and safety considerations, cultural and social context, mental health and wellbeing, and diagnostic background.

Also, the themes included acute care and service utilisation (need for admission, A&E attendance), social support networks (carer or family involvement), and cultural or religious beliefs that may influence engagement with conventional treatment. These should be mapped to relevant EPR sections such as unplanned care or admission history, social support or next of kin details, and cultural or spiritual considerations within the social history or care planning modules.

Additionally, the EIS must accommodate broader psychosocial, developmental, and communication factors in the care of people with epilepsy. Key themes included the psychosocial impact of the condition—such as mental health risks and lifestyle limitations—

the need to record functional (non-epileptic) seizures, and the importance of making health information accessible to individuals with diverse communication needs. One respondent highlighted the need to differentiate between adult and paediatric care tools to ensure age-appropriate engagement. Additionally, one respondent highlighted that clinicians need direct links to resources like the Paediatric Epilepsy Checklist to ensure all necessary topics are addressed in clinical encounters and to streamline access to relevant information for both professionals and families.

Clinicians highlighted the importance of ensuring that any data collection system introduced must be mindful of the existing clinical workload. There was a strong recommendation to safeguard clinician time and consider redistributing EIS-related data entry tasks to dedicated staff. Respondents called for clear guidance on which data elements are essential versus optional, and when these should be collected, depending on the clinical context. A lean, flexible dataset that supports both clinical care and research was strongly advocated for, alongside consistent use of terminology aligned with current seizure classifications.

The full breakdown of themes can be found in the appendix (Appendix 5.3).

4 Conclusions

The general conclusion from the survey data is that there is strong cross-sector support for structured and standardised epilepsy information, particularly regarding safety, medication, and risk discussions like SUDEP. The findings of the survey will help to inform the value sets for data items in the EIS.

The key takeaways are:

- High agreement across all groups (clinical staff, service users, social care, education, and charities) on the importance of capturing detailed information such as seizure frequency, medication side effects, and social/ functional impacts.
- Stakeholders called for greater clarity on what is essential vs optional.

5 Appendix

5.1 Survey requirements

https://theprsb.org/wp-content/uploads/2025/05/Survey-report-Appendix-5.1-Survey-requirements.xlsx

5.2 Summary data

https://theprsb.org/wp-content/uploads/2025/05/Data_All_250416-1.pdf

5.3 Themes from additional suggestions

Theme	Mapped to EIS	Relevant points/ quotes from comments
Medication and treatment history	- Medical history - Adverse reactions - Treatments - Clinical notes/ neurology review templates	- List of previous antiseizure medications tried with reasons of discontinuation. - Diagnosis - Treatment - Previous ASM and whether they were beneficial, max dose, side effects. - Foetal exposure to ASM - Previous exposure to emergency parenteral benzodiazepines - Record of emergency medications (e.g. buccal midazolam)
Risk and safety	- Allergies - Adverse reactions - Care plan/ seizure management plan - Emergency care - Safeguarding	- Allergies/ anaphylaxis from ASM - Whether clinically significant respiratory depression/apnoea occurred - Is the patient prescribed emergency rescue meds (e.g., buccal midazolam)?
Cultural, spiritual and social context	- Social history - Cultural/spiritual beliefs or preferences - Reasonable adjustments / accessibility flags - Barriers to engagement / Non-medical factors	- Use of alternative/spiritual/religious healing interfering with conventional care - If the individual has disabilities (e.g., ASD) that affect understanding or management of epilepsy

Mental health and wellbeing	- Mental health history - Mood or behavioural health assessments - Wellbeing goals / patient-stated outcomes	- Mental health status - Personal goals (e.g. seizure freedom) - Impact of epilepsy on life
Diagnostic and investigation results	- Diagnosis/ problem list - Investigation results - Neurology assessments	- Diagnosis and treatment - Relevant prior investigations
Acute care and service utilisation	- Encounters - Admission history - Emergency care/ A&E attendance records - Care planning/ escalation protocols	- Need for admission - A&E attendance
Social support and care network	- Next of kin/ carer information - Social context - Care planning	- Carer or family supporting the person
Cultural and religious beliefs	- Social context - Reasonable adjustment	- Religious or cultural beliefs…may have an adverse effect on their care and management e.g. black magic, evil eye, or jinn/ spirit possession
Psychosocial impact and risk management	- Social history	- Psychosocial impacts – risk of secondary mental health issues, impact on social life/driving etc; technology that is available to support and manage risk
Development, education, work and support neds	- Social history - Functional assessment	- Need to holistically record how epilepsy affects the person's development, education, employment opportunities, and the level of support they receive, especially in paediatric and transition settings. These domains help inform care coordination and planning.
Seizure classification	- Diagnosis/ seizure classification	- Recording functional (non-epileptic seizures)

	- History	
Accessibility	- Reasonable adjustments - Communication preferences	- Wide range of communication needs e.g. different language, easy read, BSL
Age appropriateness	- Demographics	- Need to differentiate between paediatric and adult tools
Individualised risk discussions (including SUDEP)	- Safeguarding - Risk management	- The SUDEP (Sudden Unexpected Death in Epilepsy) discussion should be framed within an individualised risk conversation. EPRs should support documentation of what was discussed, when, and with whom, allowing for dynamic risk profiling based on seizure type, frequency, and underlying causes.