Reducing variation case studies 2023-2024

Improving SUDEP discussion with families

Organisation

Central North West London NHS Foundation Trust (Hillingdon Child Development Centre)

Project team

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Project aim

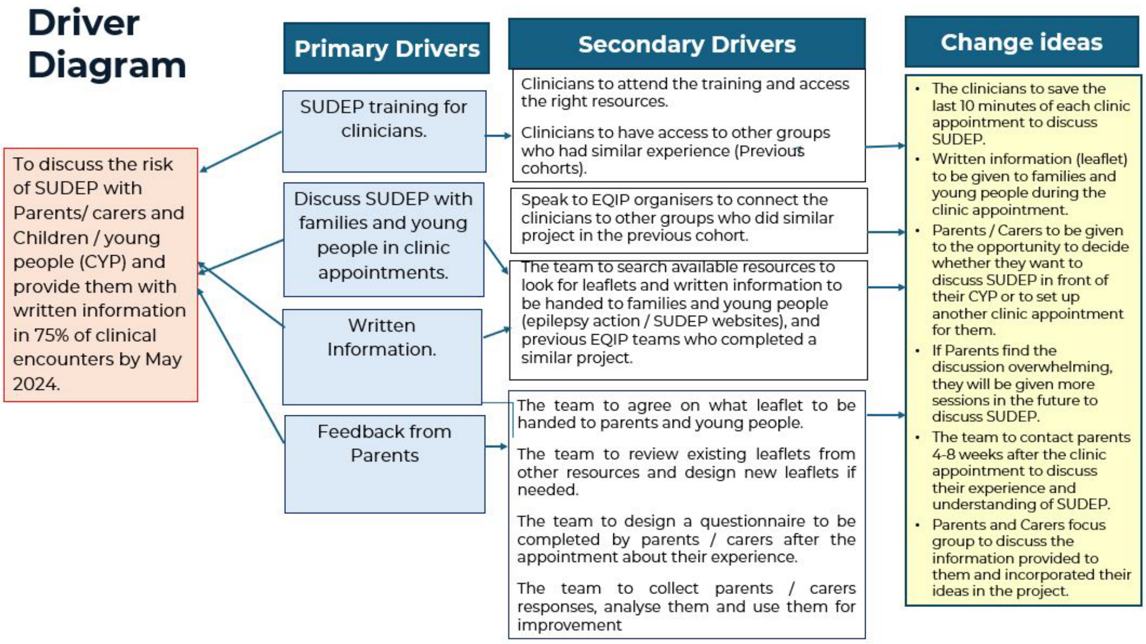
To discuss the risk of sudden death in epilepsy (SUDEP) with parents/carers and children/young people and provide them with written information in 75% of clinical encounters by May 2024.

Background/rationale

A total of four paediatricians provide care for children and young people with epilepsy in the community, aged 0-19 years with complex needs and most of them are attending special schools. All children and young people seen in clinic have associated special educational needs and disabilities. Clinics are also held on site in special schools, managing a caseload of 121 children, 98 of whom are over 13 years old and 21 over 16 years old. Our patients have access to acute care at Hillingdon Hospital for prolonged or uncontrolled seizures, and our medical team and epilepsy clinical nurse specialist review them in community based clinics. Support is received from the tertiary paediatric neurology teams at St Mary's and Great Ormond Street Hospital. The team work closely with the community nursing team to identify vulnerable children and families. Regular requests are made for a needs-based assessments for children with additional needs who require further funding for home-based care or hospice admission from NHS England and the Integrated Care Board (ICB).

What was the problem?

SUDEP is the leading cause of epilepsy-related mortality in children and young adults with epilepsy. Despite recommendations from consensus guidelines, many clinicians still do not follow practice in discussing with their patients and families about this risk. Risk factors for SUDEP include generalised tonic-clonic and nocturnal seizures, possible genetic predisposition, and non-adherence to medications. Developmental delay and intellectual disability are also potential risk factors for SUDEP in children and young people. Discussing SUDEP with parents and patients can be challenging, yet patients and their families want to be informed about this risk. Importantly, such discussions did not result in long-term anxiety or depression. The discussion of SUDEP with patients and families was inconsistent, as revealed by an internal audit. The audit reviewed the notes of 38 patients and found that SUDEP was mentioned in less than 10% of the cases.



Driver Diagram

To discuss the risk of SUDEP with Parents/ carers and Children / young people (CYP) and provide them with written information in 75% of clinical encounters by May 2024.

Primary Drivers

SUDEP training for clinicians.

Discuss SUDEP with families and young people in clinic appointments.

Written Information.

Feedback from Parents

Secondary Drivers

Clinicians to attend the training and access the right resources.

Clinicians to have access to other groups who had similar experience (Previous cohorts).

Speak to EQIP organisers to connect the clinicians to other groups who did similar project in the previous cohort.

The team to search available resources to look for leaflets and written information to be handed to families and young people (epilepsy action / SUDEP websites), and previous EQIP teams who completed a similar project.

The team to agree on what leaflet to be handed to parents and young people.

The team to review existing leaflets from other resources and design new leaflets if needed.

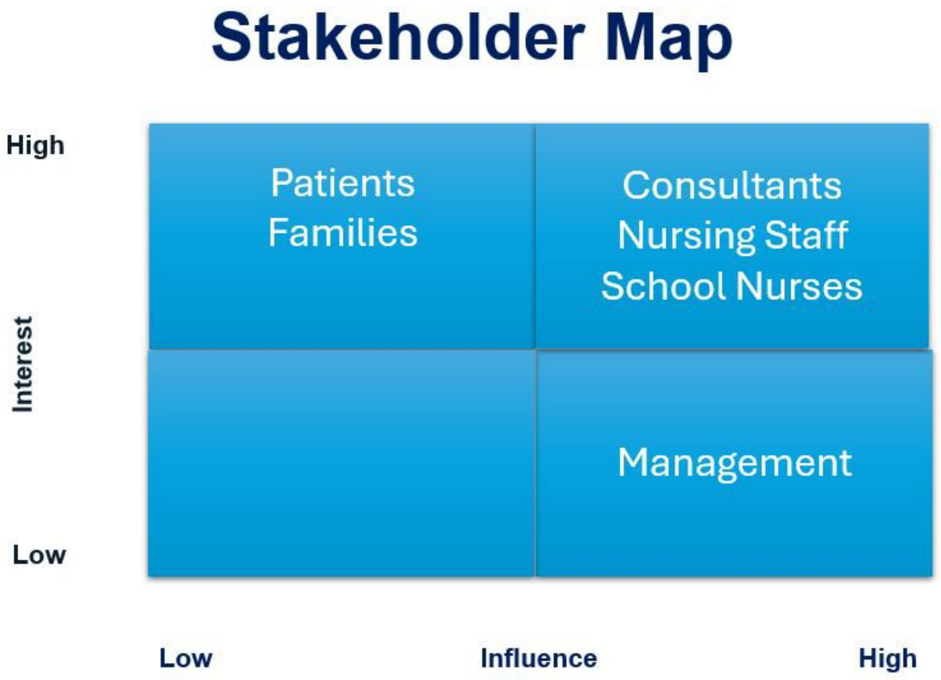
The team to design a questionnaire to be completed by parents / carers after the appointment about their experience.

The team to collect parents / carers responses, analyse them and use them for improvement

Change ideas

- The clinicians to save the last 10 minutes of each clinic appointment to discuss SUDEP.
- Written information (leaflet) to be given to families and young people during the clinic appointment.
- Parents / Carers to be given to the opportunity to decide whether they want to discuss SUDEP in front of their CYP or to set up another clinic appointment for them.
- If Parents find the discussion overwhelming, they will be given more sessions in the future to discuss SUDEP.
- The team to contact parents 4-8 weeks after the clinic appointment to discuss their experience and understanding of SUDEP.
- Parents and Carers focus group to discuss the information provided to them and incorporated their ideas in the project.

Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team's theory of what "drives". or contributes to, the achievement of a project aim.



Stakeholder Map

Interest / Influence	Low	High
High	Patients Families	Consultants Nursing Staff School Nurses
Low		Management

Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions you should take for involving and communicating with them.

What was the solution?

To improve discussions of SUDEP with patients and families, the team explored the following:

- Collected feedback from families on the usefulness of SUDEP discussions held during clinic appointments and evaluated whether to include children in SUDEP discussions. Given that many patients have severe disabilities or learning difficulties, these children are typically not included in discussions. However, the team recognised the need to co-produce solutions with parents/carers on how to involve patients who might not understand the discussions.
- To address identified challenges, the team informed families about the SUDEP discussion prior to their clinic appointment. Families were contacted via a phone call and mentioned within appointment letters. This advance notice helped families prepare and provide consent regarding the presence of their child during the discussion.
- Feedback was collected via telephone conversations two weeks after the discussion, with more information or appointments provided if needed, and the team acted upon parents/carers' suggestions.
- The team began to address areas of health inequalities; they researched and sourced translated resources in a number of languages to test the usefulness with families according to their language spoken and arranged for translators to attend clinics to reduce language barriers.

- Initial consultations did not result in high levels of anxiety among parents/carers. In one case, an 18-year-old participated due to a parent's learning difficulties. The team planned to form a focus group of parents/carers to be involved in identifying and addressing gaps in the SUDEP discussion process. Six parents agreed to join this group.
- Responses from 15 parents/carers were analysed, revealing mixed feedback. While most parents and carers found the information useful and easy to understand. Some reported feeling anxious or found the discussion unnecessary. The team will continue to collect feedback to address any issues.
- Engagement with the Oxford University EQIP team resulted in discussions to develop a structured, individualised plan for SUDEP discussions, detailing what will be covered and informing families about risk areas and considering the needs and challenges of children with intellectual disabilities and autism.

What were the challenges?

- With a small caseload of 120-130 patients and their families, the team runs only two epilepsy clinics a month (one every fortnight), seeing a total of 10 patients and their families each month, once a year. This limited number of clinics restricts opportunities for regular SUDEP discussions.
- Follow-up calls revealed that many parents and carers did not read or engage with the written information provided during the clinic, potentially due to various reasons. A significant proportion of families (63%) were not accessing the information provided to them, which affected efforts to improve understanding and management of SUDEP risks.
- This indicated a need to explore other strategies to ensure that families understand and utilise the information.
- The initial difficulties included a lack of interest from families in participating in a focus group and challenges in engaging and co-designing processes with children who have intellectual disabilities and autism.
- Only 5% of patients attend public schools, 30% are verbal, and 70% are non-verbal, with the majority having autism. This highlighted the need for a careful approach in communication, requiring the team to engage with parents and carers first to avoid causing any stress or problems.
- There is still a lack of research on supporting families with children who have intellectual disabilities and autism, although there has been some increase in research over the last decade. This gap makes it challenging to develop evidence-based strategies for SUDEP discussions.
- The diverse population presents language issues, complicating effective communication. Some families felt uncomfortable discussing SUDEP in front of their children. These families require further follow-up phone consultations by the epilepsy nurse specialist to address their concerns.

What were the results?

- Total patients seen: 55.
- Patients excluded: 19 (mostly because the appointments happened over the phone).
- Patients who refused to have the conversation: 3.
- Total patients who participated in the project: 33 (91.6%)

Question: How did you feel about it?

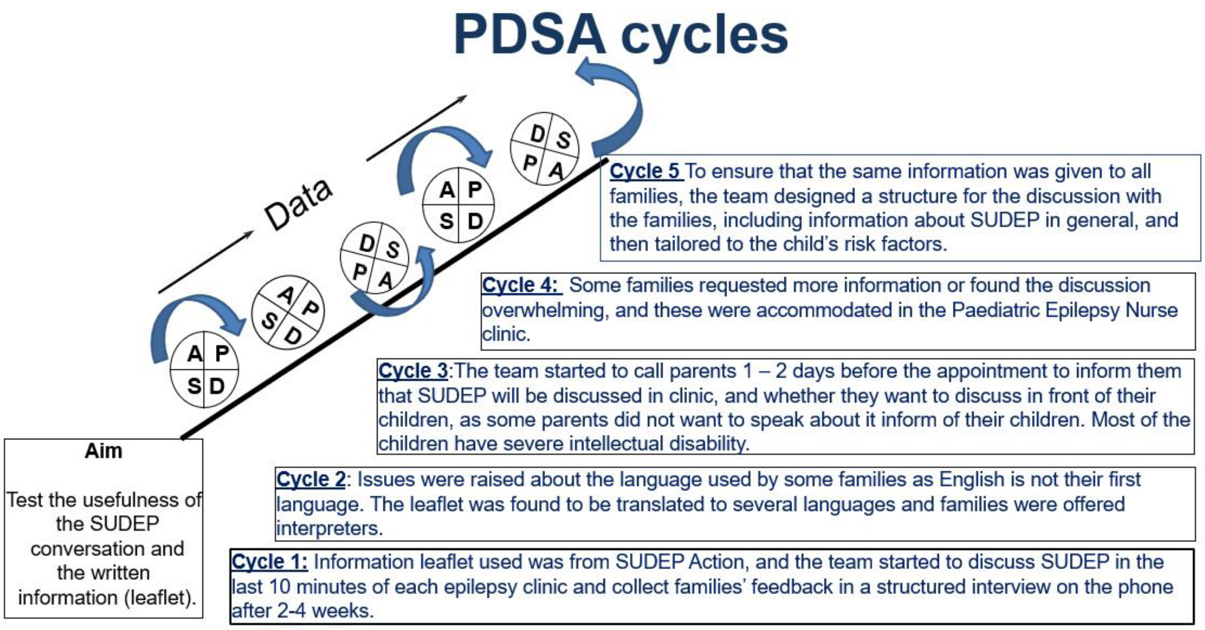
- Worried/stressed – came up in 9 interviews.
- Happy/ The discussion of SUDEP (Sudden Unexpected Death in Epilepsy) with patients and families was inconsistent, as revealed by an internal audit. The audit reviewed the notes of 38 patients and found that SUDEP was mentioned in less than 10% of the cases. Comfortable/content – came up in 17 interviews.
- Risk/aware – came up 12 times.
- More information needed – came up 3 times.
- Not relevant – came up 4 times.

Question: Was there anything not covered?

- They don't want any further conversation – came up 4 times.
- They would like more details – came up 2 times.

Other results

- It is possible to discuss SUDEP during routine epilepsy clinics.
- Although interpreters were provided, families could not access SUDEP Action resources, which were mainly available in English. This highlighted the need for translated resources.
- Some parents require further meetings for additional information, prefer not to discuss SUDEP in front of their children, or found the initial discussion overwhelming.
- Feedback from families was essential for improving the service. It helps the team understand the needs and preferences of parents and carers.
- Contacting parents and carers before the clinic appointment to confirm whether their children should be included in the discussion has proved successful. No issues were raised by parents about this pre-clinic contact.
- Two families requested to discuss SUDEP with the staff alone, without involving their children, demonstrating the importance of accommodating individual family preferences.



PDSA cycles

Cycle 5 To ensure that the same information was given to all families, the team designed a structure for the discussion with the families, including information about SUDEP in general, and then tailored to the child's risk factors.

Cycle 4: Some families requested more information or found the discussion overwhelming, and these were accommodated in the Paediatric Epilepsy Nurse clinic.

Cycle 3:The team started to call parents 1 – 2 days before the appointment to inform them that SUDEP will be discussed in clinic, and whether they want to discuss in front of their children, as some parents did not want to speak about it inform of their children. Most of the children have severe intellectual disability.

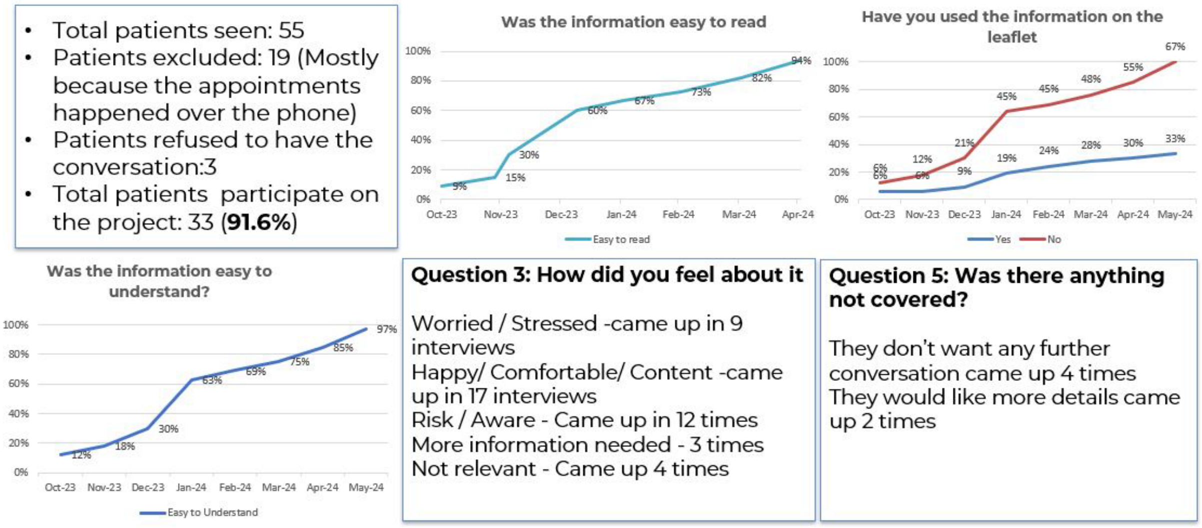
Cycle 2: Issues were raised about the language used by some families as English is not their first language. The leaflet was found to be translated to several languages and families were offered interpreters.

Cycle 1: Information leaflet used was from SUDEP Action, and the team started to discuss SUDEP in the last 10 minutes of each epilepsy clinic and collect families' feedback in a structured interview on the phone after 2-4 weeks.

Aim

Test the usefulness of the SUDEP conversation and the written information (leaflet).

Figure 3: Shows the Plan, Do, Study, Act (PDSA) cycles of change ideas to engage with young people and families within the driver diagram being tested.



- Total patients seen: 55
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Question 3: How did you feel about it

Worried / Stressed -came up in 9 interviews
Happy/ Comfortable/ Content -came up in 17 interviews
Risk / Aware - Came up in 12 times
More information needed - 3 times
Not relevant - Came up 4 times

Question 5: Was there anything not covered?

They don't want any further conversation came up 4 times
They would like more details came up 2 times

Figure 4: Shows examples of the data captured from patients and families the team engaged with and feedback received.

What was the outcome?

- The majority of families agreed to discuss SUDEP during their consultations.
- SUDEP was successfully discussed at every consultation, and feedback was collected from families.
- There has been a noticeable improvement in the frequency of SUDEP discussions during clinical encounters.

- The majority of families found the leaflets easy to read and understand.
- The entire team, including administrative staff, doctors, nurses, and managers, became involved in the project.
- The changes implemented are sustainable and have been integrated into day-to-day practice.
- Within 12 months, the team aims to complete SUDEP conversations with the vast majority of their clients.
- Interviews indicated that people are becoming more aware of the risks associated with SUDEP and revealed that some families would benefit from psychological support to cope with the stress related to SUDEP discussions.
- Efforts were made to improve the effectiveness of video and phone consultations.
- The project expanded to include counselling for parents, carers, children and young people on broader epilepsy-related issues beyond SUDEP.

What were the learning points?

- Even small changes require time to implement effectively.
- Gained knowledge of quality improvement principles, which has been instrumental in driving the project's success.
- The project will be sustained within our day-to-day practice, ensuring ongoing improvements in SUDEP discussions.
- The project will be extended to include other aspects of epilepsy care, broadening its impact and enhancing overall patient and family support.
- The team planned to introduce additional clinics to discuss various topics, such as safety advice, alcohol, smoking, and medication, alongside SUDEP.

Next steps and sustainability

- Presenting the project and its outcomes in governance meetings to ensure continued oversight and support.
- Implementing a SUDEP checklist for each consultation to standardise discussions and ensure all relevant points are covered.
- Enhancing the use of electronic communication to update clinical encounters, improving efficiency and record-keeping.
- Applying the principles of this project to address various other aspects of epilepsy care, thereby broadening its impact.
- Organising social events to train families and provide them with opportunities to give feedback on our services, with the first event scheduled for July 2024.

Want to know more?

If you would like to know more about this project, please contact:

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