

2023-03

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<http://hdl.handle.net/10026.1/20157>

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10.1016/j.seizure.2023.01.007

Seizure

Elsevier BV

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## Journal Pre-proof

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PII: S1059-1311(23)00013-4  
DOI: <https://doi.org/10.1016/j.seizure.2023.01.007>  
Reference: YSEIZ 4487



To appear in: *Seizure: European Journal of Epilepsy*

Received date: 6 November 2022  
Revised date: 30 December 2022  
Accepted date: 10 January 2023

Please cite this article as: LV Watkins , S Ashby , J Hanna , W Henley , R Laugharne , R Shankar , An evidence-based approach to provide essential and desirable components to develop surveys on Sudden Unexpected Death in Epilepsy (SUDEP) for doctors: A focused review, *Seizure: European Journal of Epilepsy* (2023), doi: <https://doi.org/10.1016/j.seizure.2023.01.007>

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### Highlights

- SUDEP Counselling by clinicians is a recognised & important aspect of epilepsy care
- Surveys globally have identified challenges in clinicians delivering counselling
- It is important to have a common question set in this significant area of epilepsy care
- This review of 16 SUDEP counselling surveys covers 4000 doctors across 30 countries
- The study focus group including expert by experience outline 10 essential questions

# An evidence-based approach to provide essential and desirable components to develop surveys on Sudden Unexpected Death in Epilepsy (SUDEP) for doctors: A focused review

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**Acknowledgments:** none

**Word count:** **References:** 34 **Tables:** 3

## Statements and Declarations including competing interests:

WH is funded by the National Institute for Health and Care Research Applied Research Collaboration Southwest Peninsula. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care. SA and JH are CEO and deputy CEO of the national charity SUDEP Action. RS has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds grants from NIHR AI, SBRI and other funding bodies all outside this work. No other author has any declared conflict of interest related to this paper.

## Ethics Statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Author Contributions

All authors satisfy the ICMJE guidance by substantially contributing to the design, analysis and interpretation of the work, drafting of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

## Data statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## Abstract

Sudden Unexpected Death in Epilepsy (SUDEP) is a major concern for people with epilepsy, their families, their care givers, and medical professionals. There is inconsistency in the SUDEP counselling doctors provide, compared to what is recommended in clinical guidelines. Numerous national and international surveys have highlighted how epilepsy professionals, usually doctors, deliver SUDEP risk counselling, particularly, when they deliver it and to whom. These surveys help understand the unmet need, develop suitable strategies, and raise awareness among clinicians with the eventual goal to reduce SUDEPs. However, there is no standardised survey or essential set of questions identified that can be used to evaluate SUDEP counselling practice globally. This focused review analyses the content of all published SUDEP counselling surveys for medical professionals (n=16) to date covering over 4000 doctors across over 30 countries and five continents. It identifies 36 question themes across three topics. The questions are then reviewed by an expert focus group of SUDEP communication experts including three doctors, an expert statistician and SUDEP Action, an UK based charity specialising in epilepsy deaths with a pre-set criterion. The review and focus group provide ten essential questions that should be included in all future surveys inquiring on SUDEP counselling. They could be used to evaluate current practice and compare findings over time, between services, across countries and between professional groups. They are provided as a template to download and use. The review also explores if there is a continued need in future for similar surveys to justify this activity.

## Keywords

epilepsy risk; seizure risk communication; co-production; SUDEP counselling; risk counselling; SUDEP research

## Introduction

### Sudden unexpected Death in Epilepsy (SUDEP)

SUDEP can be defined as “sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death of patients with epilepsy with or without evidence of a seizure, excluding documented status epilepticus, and in whom post-mortem examination does not reveal a structural or toxicological cause of death”. [1]

Sudden unexpected death in epilepsy (SUDEP) is the most common cause of death for people with chronic epilepsy. [2,3] In a pooled estimate the incidence rate of SUDEP was found to be 1.4 per 1000 patient-years. For reference, this is 23 times higher than age matched controls without epilepsy. [4] This finding is likely an underestimate due to diagnostic challenges.

SUDEP is associated with particular clinical characteristics that may be static or modifiable. Despite advances, the precise pathophysiological mechanisms involved are not clear. However, monitored SUDEP deaths have observed a theme of cardiorespiratory dysfunction with central apnoea followed by a terminal asystole. [5] SUDEP is essentially a diagnosis of exclusion following neuropathological post-mortem examination.

### Clinical Guidance

The National Institute for Health and Care Excellence Clinical Guideline NG217 on the Epilepsies (2022) and the American Academy of Neurology Practice Guideline on SUDEP (2017) state that SUDEP should be discussed at the earliest appropriate time. [6,7] Furthermore, good practice is for people with epilepsy to be counselled on SUDEP risk regularly and how it can be reduced based on the current evidence. [8,9,10]

### Clinical Implementation

There is a discrepancy between what professionals believe people with epilepsy should know, and what patients their families and care givers expect to discuss. [11] While structured communication tools exist, there is no consistent approach to the delivery of SUDEP discussions or an universal template for risk counselling [2,12,13]. The content of discussion or even absence of discussion is usually based upon the clinicians' opinion and may be influenced by fear of a negative reaction, not the evidence base or clinical guidelines. [13,14]

To better understand how clinicians deliver SUDEP discussion, in order to feedback and improve outcomes, a number of national and international surveys on SUDEP have been conducted and published in scientific literature generally among doctors particularly neurologists and paediatricians. However, the content of these surveys is variable. There is no standardised survey tool than can be applied to health care professional groups and services to evaluate and compare SUDEP counselling practice among health care professionals globally.

The aim of this focused review is –

- a. To identify all surveys considering views on SUDEP counselling by medical professionals. Then to analyse and compare the methodology and content of the selected surveys to identify common questions to develop a standardised survey tool that can be used internationally to evaluate SUDEP counselling.

- b. To examine if there is a continued need for SUDEP counselling surveys for clinicians to justify a standardised survey tool. This will be done by identifying if challenges of SUDEP counselling persist in the study population by cumulating the core outcome data of all included surveys.

## Methods

A focused literature search using PRISMA scoping review methodology as guidance was conducted on MEDLINE with the following search terms ((SUDEP OR sudden unexpected death in epilepsy) AND (survey OR questionnaire)) AND (neurologist OR paediatrician OR paediatrician OR health care professional) from 1<sup>st</sup> January 1990 to 23<sup>rd</sup> June 2022 (Figure 1).

Inclusion Criteria:

- Survey/questionnaire of clinicians' experience/opinions on SUDEP discussion.
- Medical Professionals (defined as neurologists, paediatricians, or other identifiable medical professional).
- Survey questions available.
- Excluding surveys of non-medical Professionals (patients, families and non-medical care givers.)

For those studies included the individual survey questions were collated and grouped into themes. Then inquiry was made to see the level of agreement in question themes between surveys. Attempt was then made to group the question themes into key topics. The methodological approach to the development of the survey content for each included study was analysed descriptively and captured.

Each survey's quantitative outcomes of number of respondents and their study population outcomes of SUDEP awareness was identified. It was felt important to understand the sample size engaged and the generalisability. Further, the outcome data on SUDEP counselling would enumerate if there is a continued requirement for similar future surveys thus justifying a uniform set of questions. A statistician was consulted who confirmed no quantitative statistical tests were recommended for analysis of this data.

## Results

The focused electronic literature search identified 42 results between the years 2003 to 2022. Following application of the inclusion criteria 16 results were included in the final analysis (Table 1). Twenty-two results were removed following title and abstract screening as they did not meet the inclusion criteria. Following full text review six were excluded as the surveys were not directed at medical Professionals. A further two studies that met the inclusion criteria were identified by reviewing the references of studies identified (supplementary figure 1).

### Survey Methodologies

The review identified 14 surveys that were sent out to medical practitioners (mainly neurologists and paediatric neurologists), and two investigations that conducted in depth interviews. The number of questions, depth of questions, and style of questions varied between the included studies. In nine of the 14 surveys the content of the survey was

developed by consensus of the expert research team. Three of the included studies performed a literature review in the development of the survey content. [14,16,24] One outlined a piloting stage before dissemination.[16] The other two indicated an additional expert review stage to check content validity. [14,24]

Two studies have been used as a template for the content of other survey development, although there is limited explanation regarding the development of the original questions themes. [15,20] One contributed to the survey content of two studies [15,18,23] and another to two others. [20,26,28]

It is worth highlighting that two of the surveys undertaken in Brazil were conducted with the same population, by the same study team, and have the same number of respondents. To our knowledge these surveys were completed separately, at different periods of time, with different content. It is not known whether the responding population is the same or if this is coincidental. [19, 27]

### Survey Content analysis

From the 16 studies a total of 36 question themes were identified and the percentage of consistency for each question across the surveys captured (table 2). The level of agreement on each question theme ranged from 6% i.e., used only in one survey) to 94% i.e., used in 15 of 16 surveys. The question themes were broadly allocated into three topics; Demographics (n= 8); Clinical Experience (n=3); and SUDEP specific (n=25).

The cumulative data includes feedback from over 4000 clinical practitioners across over 30 countries and 5 continents. Studies varied in range across the responses for the fundamental question around whether SUDEP is discussed. Studies found it was “never discussed” (7.5% to 79%), to “rarely discussed” (30% -76%), “discussed with majority” (8.7% to 36%) and “always discussed” (2.7% to 16%). Newer studies and/or studies from economically developed countries were more likely to have higher levels of discussion. Two clear reasons for why SUDEP discussion took place was identified by the responders. Firstly, that it is clinician led based on the clinician’s subjective interpretation of the SUDEP risk factors. Secondly, when a patient initiates questions regarding SUDEP.

These findings are in contrast to a SUDEP counselling survey of clinical nurse specialists in epilepsy that was not identified through this focused literature review as the focus was on medical professionals. [30]

While not directly relevant to the current review aims this study showcased interesting results as compared to those studies on medical professionals. Of the 103 respondents, (41% of the targeted cohort) 56% discussed SUDEP with most or all of their patients. The SUDEP discussion was considered part of a wider general and specific risk assessment process. The large majority of the responding specialist nurses felt that everyone should be informed about SUDEP risk, and that it is the role of nurses and medical professionals to counsel patients regarding risk. The results of this survey indicate that this role has become a focus of the epilepsy specialist nurse over the medical practitioner.

### Discussion

#### Is creating an evidence-based survey tool possible and relevant?

This focused review summarises the contents of SUDEP surveys targeted at medical practitioners published worldwide. The methodology of content development in each survey is summarised in table 1. The content of each survey was usually developed by the



research team by expert consensus. This process was also sometimes preceded by a formal review of the evidence base in the literature. Encouragingly there is a significant overlap across all the surveys on the core question themes. These findings suggest that the questions that are included in multiple surveys have been thoroughly considered as important repeatedly by different expert consensus groups. In addition, given the numbers, diversity and heterogeneity of study population, services, and cultures surveyed the 36 question themes appear to cover all key aspects of inquiry into SUDEP counselling for clinicians and are generalisable. It can also be inferred from the replies on the range of SUDEP counselling discussions the need for such surveys will continue in the foreseeable future to examine clinician attitudes and awareness to SUDEP. It is evident that the respondents are not currently aligned with national and international evidence-based guidelines on SUDEP counselling, that indicate risk should be discussed at the earliest appropriate opportunity.

### Creating the survey tool

From the data reviewed the 36 question themes could be stratified into questions that are *essential* separating them from questions that may be of relevance dependent upon the surveys aims, location or service set up. It was agreed by consensus, among the study authors who included three doctors, an expert statistician and experts by experience (SUDEP Action) that any question theme included in 10 (63%) or more of the surveys should be considered *essential*. Nine question themes which met the criteria.

Based on this categorisation the theme of 'SUDEP experience', or experience of a SUDEP death, would fall outside of the *Essential* category. This question theme was present in 7(43%) of the included surveys. However, the views of our collaborators and experts by experience, SUDEP Action acting on behalf of bereaved families, and the impact a SUDEP death can have on everyone involved, it was agreed that this question theme should be considered *Essential*. In addition, only 2(13%) of surveys asked whether clinicians should discuss SUDEP with everyone with epilepsy. However, this question is aligned with the guidance from NICE and AAN as outlined, and given the discrepancy between clinical practice and guidance it was felt it must be included as an essential question. Therefore, in total we propose 11 Essential Question Themes for any SUDEP counselling survey focused on health care professionals (Table 3). Interestingly, on comparing the content of the nursing survey [30] with the essential question themes identified from this review 10 of the essential question themes are included within the 12-question survey.

Further, it is recognised that there are nuances to individuals' workloads and services. Therefore we have also included additional question themes that are considered *Relevant*. Relevant questions are any question theme represented in seven (44%) or more of the surveys included in this investigation, based on consensus opinion of the group. Some of these question themes may not be applicable to all clinician groups or services and depend on geographic variation.

### How could the new evidenced survey tool be improved?

The creation of a standardised survey on SUDEP/Risk communication practice that can be used across clinical settings, has the potential to provide insight into current practices that can inform future practice for the benefit of people with epilepsy [31]. It is important such surveys go beyond the topic of SUDEP and are widened to encompass the communication of risk factors known to be associated with epilepsy-related deaths, else these risks, and the population in danger may fall through the gap. The voice of people with epilepsy and bereaved families has too often been lost in the past in the design and outputs of research

on communication of risk, ever since the first national guidelines on communication of risk were published in the UK. The recommendations on SUDEP and Risk discussion good practice included in the NICE [6] followed the stark concerns identified in The National Sentinel Clinical Audit on Epilepsy-Related Death, where they found that there had been communication in less than 1% of deaths. [32] Similar recommendations were made in Scotland by a Fatal Accident Inquiry in 2002. [33] The value of charities who work in the field of SUDEP/risk communication practices who can support the involvement of experts by experience to inform the design and outputs from research cannot be underestimated. In the UK this is recognised good practice by nationally funded research. If the above can be achieved by improvement of the presented standardised survey, it has the potential to have real world impact, improving patient outcomes and quality of life for the epilepsy population.

From the different survey results identified in this review we can observe that SUDEP counselling is a global problem. The majority of surveys are conducted where there is expertise in the area and well-developed specialist neurology services. Even in this context clinicians are not meeting the desired criteria for SUDEP discussion, or the expectations of bereaved families and care givers.

Significant disparities also exist between epilepsy professionals globally particularly in developing and developed countries with regard to SUDEP awareness matters. A global survey of ILAE chapters of 77 countries highlighted that two-third had no research or audits on SUDEP in their country in the last decade [34].

There has been limited progress over time with regard to SUDEP communication. The results of the included surveys show that a key factor leading to SUDEP discussion is patient request. In order to achieve successful action there is a need to better understand the views of clinicians and identify the barriers to overcome, and the facilitators that can be enhanced. The development of tailored educational programmes to improve clinician knowledge of SUDEP is an essential factor in this process. This should be fundamental to the curricula of any specialist training programme, alongside updates for more senior clinicians. It is important that specialists in epilepsy take ownership of SUDEP counselling as a core part of management, and lead the responsibility for appropriate delivery. Wider than this, there is a need to empower people with epilepsy with knowledge that is readily accessible.

### Limitations

Only published research in MEDLINE has been looked into. There could be other surveys which have taken place which have not been published as scientific literature but possibly as reports etc. However, this has been largely mitigated as generally the researchers working in the area of SUDEP are small and well known and recognised. Thus, going over the identified surveys it is unlikely any major influential work has been missed.

All surveys brought a level of subjectivity in their question setting. However, these at the minimum had face validity while some had expert consensus groups and a few others had a full ethical review. Further, the current review consensus committee ensured any obvious blind spots were identified and addressed. Thus, it is unlikely that any major aspect of SUDEP counselling has been missed.

A potential weakness of our study design is that we have included studies across two decades. However, it is positive to know that there is significant overlap across the studies reviewed. An area of challenge would be to give assurance on the study population results. Studies which were older and from non-economically developed countries had poor levels of SUDEP counselling results. This though is of peripheral interest to our study aims.

A further issue is that the new proposed survey tool will not reach a broad audience and stakeholder group. To ensure we can have the tool disseminated further we recognised the importance of developing it with a patient facing organisation i.e., SUDEP Action. SUDEP action have national and international research across patient, clinical, commissioning and political bodies. It is hoped that working with them and through our own clinical – academic networks such as the ILAE the tool can be promoted to further trial and use.

## Conclusion

This focused literature review has identified SUDEP counselling surveys targeted at medical professionals in different contexts and settings worldwide. Analysis of the content of the surveys demonstrates significant overlap in the questions themes, including the fact that previous surveys have been used as templates for future content. The content of the surveys were based on the existing evidence base and developed by expert consensus. By comparing the content in each of the surveys included an expert focus group has reached an agreement of 11 Essential Question Themes that should be included in any SUDEP counselling survey targeted at health care professionals. The results of the surveys demonstrates that medical professionals are not currently following NICE and AAN guidelines to counsel all patients on SUDEP risk. There also appears to be a discrepancy between professional in groups providing SUDEP counselling which requires further exploration. All this suggests that there is a continued need for future similar surveys. A standardised SUDEP Counselling survey allows the evaluation of current practices, in different settings that can be compared over time and between services, and professions.

conflict of interest

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**Table 1. Summary of results included in survey content analysis.**

Study	Year of publication	Region/ Country (organisation)	Title	Methodology of survey development	Summary of results
Morton et al [15]	2006	United Kingdom (Association of British Neurologists)	Sudden unexpected death in epilepsy (SUDEP): don't ask, don't tell?	Items developed by research team.	Responders=387 5% discuss SUDEP with all patients, 26% with majority 61% with a few, 7.5% with none.  Commonest reason for discussion is person request.
Gayatri et al [16]	2010	United Kingdom (British Paediatric Neurology Association)	Parental and physician beliefs regarding the provision and content of written unexpected death in epilepsy (SUDEP) information	Literature review, peer review, and piloting of questions. Items developed by research team.	Responders=46  20% provide SUDEP information to all patients 93% in some cases.  Risk factors were an indicator for initiating SUDEP discussion.
Akhtar et al [17]	2010	Pakistan (Neurology society)	Knowledge, attitude and practice about "Sudden Unexpected Death in Epilepsy Patients" among neurologists and paediatricians	Items developed by research team (Interview based)	Responders=41  37% responders were aware of SUDEP, 20% observed a case  Most/all never discussed SUDEP
Vegni et al [18]	2011	Italy (Italian Association)	Sudden unexpected death	Items developed by research team adapted	Responders=195

		Against Epilepsy)	in epilepsy (SUDEP): a pilot study on truth telling among Italian epileptologists	from Morton et al, 2006.	9% discuss SUDEP with all patients, 20% with majority 62% with few 8% with none.  Risk factors and patient request most likely reason for discussion.
Abdalla et al [19]	2013	Brazil (Brazilian League of Epilepsy)	Attitudes of Brazilian epileptologists to discussion about SUDEP with their patients: Truth may hurt, but does deceit hurt more?	Items developed by research team	Responders=44  76% discuss SUDEP with a minority of patents  14% discuss with majority of patients
Friedman et al [20]	2014	United States and Canada (The Epilepsy Therapy Project)	Sudden unexpected death in epilepsy: Knowledge and experience among U.S. and Canadian neurologists	Literature review. Items developed by research team.	Responders=1200  6.8% discussed SUDEP with nearly every patients, 14% most of the time 33.4% sometimes 30% rarely 11.6% never discuss SUDEP.  Most respondents reported a negative reaction from patients following SUDEP discussion.
Suna et al [21]	2015	Latvia (Society of Latvian Neurologists)	Awareness of sudden unexpected death in epilepsy among neurologists in Latvia	Items developed by research team.	Responders=84  79% do not discuss SUDEP with patients 17% informed some 4% informed all  93% believe patients should be informed.



					77% subjective SUDEP knowledge as minimal and insufficient
Strzelczyk et al [22]	2016	Austria, Germany, Switzerland (ILAE chapters)	Predictors of attitudes toward counselling about SUDEP and other epilepsy risk factors among Austrian, German, and Swiss neurologists and neuropsychiatrists	Items developed by research team.	<p>Responders=519</p> <p>2.7% discuss SUDEP all the time 8.7% most of the time, 20.8% sometimes, 44.5% rarely 23.3% never.</p> <p>Less experience and training were associated with lower levels of SDEP discussion.</p>
Galli et al [23]	2017	Italy (neurology and paediatric neurology societies)	Sudden unexpected death in epilepsy (SUDEP) disclosure in pediatric epilepsy: An Italian survey on "to tell or not to tell".	Items developed by research team, adapted from upon Morton et al 2006	<p>Responders=114</p> <p>16% state all patients should be counselled on SUDEP, 20% majority should 52% minority 12% none.</p> <p>Main reasons for discussion were risk factors, and patient request.</p>
Nisbet et al [24]	2017	United Kingdom (West of Scotland Neurology Service)	'Breaking Good News': Neurologists' experiences of discussing SUDEP with patients in Scotland	Literature review. Items developed by research team. Items reviewed by expert. Additional questions developed based on responses. <b>(Interview based)</b>	<p>Responders=10</p> <p>Identified standard script for SUDEP discussion. Clinicians regularly discuss SUDEP at diagnosis.</p>
Keller et al [25]	2021	Canada (Child Neurology Society)	Why child neurologists talk about SUDEP:	<b>(Two surveys)</b> Items developed by research team.	<p>Responders=396</p> <p>12% discuss SUDEP with most of their</p>

			Results from two cross-sectional surveys		patients 36% at least half.  Discussion increased to 89% of participants at second survey following education.
Hakami and Hakami [26]	2021	Saudi Arabia (Saudi Neurology Society)	Sudden unexpected death in epilepsy: Experience of neurologists in Saudi Arabia	Items developed by research team, adapted from Friedman et al, 2014.	Responders=60  25% discussed SUDEP most of the time 65% sometimes or rarely 10% never.  Risk factors (poor compliance) main reason for discussion.  Responders note a positive patient reaction if neurologist was well informed.
Mosini et al [27]	2022	Brazil (Brazilian League of Epilepsy)	Discussion of the Brazilian neurologists about sudden unexpected death in epilepsy	Items developed by research team.	Responders=44  82% have discussed SUDEP with patients in the past.  59% believe early SUDEP discussion must be considered.  80% aware of SUDEP risk factors.  18% of neurologists responding had no knowledge of SUDEP risk factors.
Saleh et al [28]	2022	Eastern Mediterranean-UAE, Saudi Arabia, Egypt. (Emirati League	Sudden unexpected death in epilepsy: A pilot study on neurologists knowledge and	Items developed by researchers, adapted from Friedman et al 2014	Responders=132  1.5% discuss SUDEP with most patients 55.3% rarely or never discuss SUDEP.  81% had Limited knowledge of SUDEP

		Against Epilepsy (UAE chapter)	experience in the Eastern Mediterranean region		risk factors.
Venegas et al [29]	2022	Latin America (Paediatric Neurology Societies for 20 countries)	How the characteristics of pediatric neurologists in Latin America influence the communication of sudden unexpected death in epilepsy to patients and caregivers	Items developed by research team.	<p>Responders=367,</p> <p>17.9% communicate SUDEP risk frequently, or always</p> <p>73.8% felt SUDEP discussion was relevant</p> <p>80% felt SUDEP should be discussion when SUDEP risk is high</p> <p>18% felt SUDEP should be discussed at diagnosis</p>
Asadi-Pooya et al [14]	2022	Global (50 countries)	Counseling about sudden unexpected death in epilepsy (SUDEP): A global survey of neurologists' opinions	Literature review. Theme developed by research team. Expert validation to assess clarity of relevance of items to construct.	<p>Responders=1123,</p> <p>55% 'rarely' or never discuss SUDEP with patients,</p> <p>29.5% with some patients</p> <p>12% with most</p> <p>3.7% with all</p> <p>Main reason for SUDEP discussion was specific risk indications.</p>

Table 2. % Of questions identified in surveys

Demographics of studies	Number
Age	7 (44%)
Sex	7 (44%)
Relationship status	1(6%)
Occupation	12(75%)
Area of specialization	12(81%)
Nationality	4(25%)
Country/location	7(44%)
Academic affiliation	2(13%)
<b>Clinical Experience</b>	
Level of experience	11(69%)
Epilepsy workload	9(56%)
SUDEP Deaths (experience)	7(44%)
<b>SUDEP specific</b>	
SUDEP Knowledge	12(75%)
SUDEP clinical risk factors	11(69%)
SUDEP Discussion (do you?)	15(94%)
What profession leads discussion	2(19%)
Who do you discuss SUDEP with?	15(94%)
What proportion of patient do you discuss SUDEP with?	5(31%)
When do you discuss SUDEP?	12(88%)
Why do you discuss SUDEP	10(63%)
What response do you get from discussion?	11(69%)
Do you discuss medication compliance?	7(44%)
Do you use any SUDEP discussion support tools?	7(44%)
Are you comfortable discussing SUDEP?	4(25%)
Is your approach different for children/adolescent?	7(44%)
People with Intellectual Disability?	
Have you had any training on SUDEP/How do you keep up to date?	3(19%)
Do you discuss other risk associated with epilepsy?	2(13%)
Should people with epilepsy have MDT support?	1(6%)
Should all members of the MDT be aware of SUDEP?	1(6%)
Should SUDEP discussion be incentivised?	1(6%)
Should the patient decide how much information to receive?	1(6%)
What do clinical guidelines state?	1(6%)
What is the local policy for SUDEP discussion?	1(6%)
How do you approach discussion/what information do you provide?	5(31%)
Should everyone be told about SUDEP?	2(13%)
What is the annual incidence of SUDEP?	1(6%)
What are the commonest causes of Mortality in Epilepsy?	1(6%)

**Table 3. Question themes identified as essential template for any SUDEP counselling survey for health care professionals to use.**

<b>ESSENTIAL QUESTION THEMES</b>	
<b>Demographics</b>	Occupation Area of specialization
<b>Clinical Experience</b>	Level of experience in epilepsy SUDEP deaths (first-hand experience)
<b>SUDEP specific</b>	SUDEP Knowledge SUDEP Risk Factors SUDEP Discussion (do you discuss with All/majority/few/none?) Do certain factors influence who you discuss SUDEP with?(example – young adults, caregivers, people with intellectual disability and/or their carers, those with treatment resistance, those with low concordance etc.) When do you discuss SUDEP? SUDEP counselling- a positive or negative process for people with epilepsy? Should you discuss SUDEP with every person with epilepsy as recommended by all major international guidance (American Academy of Neurology (AAN), National institute of Excellence (NICE) etc. ?
<b>OTHER RELEVANT QUESTION THEMES</b>	
<b>Demographics</b>	Age Sex Country/location
<b>Clinical experience</b>	Epilepsy workload
<b>SUDEP specific</b>	Does compliance with anti-seizure medication influence SUDEP counselling? Do you use SUDEP discussion support tools/other support materials How do you approach SUDEP counselling in children How do you approach SUDEP counselling for people with Intellectual Disability

Figure 1. Search Strategy

