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A modified delphi study to determine the contents of a seizure diary for patients living with epilepsy in South Africa

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Availability of data and material: the corresponding author's data supporting this study's findings are available upon reasonable request.

Abstract

Background: Epilepsy is a debilitating chronic medical condition affecting many patients globally. A seizure diary is used in monitoring and managing patients with epilepsy. In South Africa, no standardized diary is currently being used.

Objective: This study intended to develop a consensus among experts managing patients with epilepsy on the content of a seizure diary.

Methods: The modified Delphi method consisted of three survey rounds spanning six months. Using a three-point Likert scale questionnaire, in round one, the panelists were required to choose an option (definitely required, optional, and not required) for 50 items and comment on the contents of the diary. In round two, three items were added based on comments from the panelists. In round three, panelists were allowed to deliberate further on unresolved items and change their responses in view of the group responses. The consensus was determined as a priori threshold of >70% on items definitely required, optional, or not required.

Results: Eleven local and two international panelists were enrolled in this study. Twelve completed all three rounds. The consensus was achieved in 21 of 50 items in round 1, three of seven items in round 2, and one of two items in round 3, of which 18 were definitely required as contents of a seizure diary.

Conclusions: Based on expert opinions, the modified Delphi study determined the essential contents of a seizure diary for use by patients with epilepsy in South Africa.

Introduction

The World Health Organisation (WHO) estimates that epilepsy affects over 50 million people worldwide, with 10 million residing in Africa.¹ The Global Campaign against epilepsy estimates the prevalence of epilepsy in Africa at 11.29 per 1,000 population and the prevalence of epilepsy in South Africa at 3.7 per 1,000.² Epilepsy South Africa estimates that epilepsy affects 1 per 1,000 South Africans, which is approximately 500,000 people.³

Patients living with epilepsy are unable to provide adequate seizure history in certain instances.⁴ The seizure diary can help in the management of patients with epilepsy; it helps with managing medication and other therapies, recognizing triggers and health events that may affect seizures and wellness, and communicating with patients' care providers.⁵

The seizure diary comes in either a paper or an electronic format. A seizure diary is a self-management tool that helps patients record their seizures, monitor the frequency of attacks, and promote medication adherence among its users.^{6,7} In developed countries like The United

States of America, the electronic diary is preferred due to easy access to personal electronic devices.⁸ In Africa, some people stay in rural communities², where internet access is limited, making it difficult to use electronic diaries. The paper-based diary is easier to use in a resource-poor setting as it does not require computer skills or internet access.⁹

In sub-Saharan Africa, the majority of people with epilepsy are treated by primary healthcare providers, such as family physicians at the community level and neurologists who are physicians specializing in epilepsy.¹⁰ The neurologist can help facilitate any required diagnostic testing such as EEG, CT, and MRI and recommend appropriate anti-epileptic medication. Primary care physicians are responsible for managing the patient's condition, such as tracking seizure frequency (using the seizure diary), monitoring medication compliance and side effects, ordering laboratory tests and drug levels, and providing education and social support.¹⁰

In South Africa and the rest of the African continent, we were unable to find any published studies concerning the creation of a seizure diary for the use of patients living with epilepsy.¹¹ However, some primary health care clinics, specialized epilepsy clinics in Bloemfontein, and other neurology clinics in South Africa use a basic paper calendar version distributed by pharmaceutical companies to help doctors monitor patients.¹² These paper diaries lack much information and ask basic questions about patients' seizure types and frequency, which is the industry standard.¹³ Most of these diaries were designed for patient use in developed countries such as the United Kingdom¹⁴ and may not have much relevance for patients in our African setting.

Most scientific papers explored support the concept that a properly designed seizure diary has a role in managing epilepsy patients and improving medication adherence in the clinical setting.^{6,15,16}

Aim

This study was initiated to help develop a standard seizure diary using a panel of local and international experts across various specialties conversant with managing patients with epilepsy.

Materials and Methods

This study is the 3rd phase of an extensive project. Other phases consisted of Phase 1, a scoping review of literature¹¹; Phase 2, a cross-sectional study of patients living with epilepsy¹⁷; Phase 4, six months of use of the new seizure diary by patients included in phase

2; Phase 5, a Patients' perceptions of the new seizure diary; Phase 5b Suggested final version of the new seizure diary.

A modified Delphi method was used to obtain consensus among experts on the important contents of a seizure diary using an online questionnaire. The Delphi method is a consensus-building technique that seeks expert opinion on a topic in a structured and iterative manner.^{18,19} It is useful in areas where evidence-based literature is inadequate since it can unearth collective knowledge from experts in that area.^{20,21} A series of rounds are used to clarify, refine and ultimately achieve consensus on a given topic under discussion.²² Participants provide information anonymously (for participants) and independently with the overbearing influence of any individual or group during each round.^{18,20}

In the modified Delphi method, the expert panel does not generate the study question. The researcher generates the questions through literature reviews and expert consultation and presents them to the panel to begin the consensus-seeking process. The panellists can contribute through open-ended questions to the list prepared by the researcher.^{23,24}

The Delphi method involves 6 stages according to the approaches described by Humphrey-Murto, et al. (1) Identifying a research problem, (2) Completing a literature search, (3) Developing a questionnaire of statements, (4) Conducting an anonymous iterative mail or email questionnaire round, (5) Providing group feedback between rounds, (6) Summarising the findings.²¹ We reported our process following this guideline.

Step 1 – Identifying the research Problem /question

In numerous emergency departments and primary health care clinics across South Africa, patients living with epilepsy are seen, but they are unable to provide details about their seizures or medication use. Healthcare workers have to carry out expensive tests to help determine which drugs they are using in other to treat them. This often causes a delay in treatment. The existing seizure diaries are basic calendar diaries that fail to provide adequate information. The researchers (CKE, MA, WJS) are family physicians and a neurologist actively involved in caring for patients with epilepsy. The project was to determine the content of a seizure diary that can be used in monitoring and managing patients with epilepsy in SA.

Step 2 – Literature search

The protocol development and the 1st phase of this study required an extensive search of relevant literature on epilepsy and Delphi techniques describing the methodology for reporting a Delphi study.^{11,18,20,21}

Step 3 – Developing a questionnaire of Items

The first author (CKE), after an extensive search of relevant literature on the seizure diary¹¹, generated a list of possible relevant items as contents for the seizure diary. The research team met to review the generated items and add additional relevant items, resulting in a list of 50 items for the Delphi questionnaire.

The questionnaire had two sections; section 1 consisted of eight questions about the demographic information of the panellists, such as gender, speciality, country of practice, years of practice, and place of employment (public or private). They were also asked to answer yes or no if they worked with patients with epilepsy. Section 2 consisted of 50 stated items using a 3-point Likert scale with options (required, optional, and not required). Twelve items were grouped as items required once, while thirty-eight items were grouped as regularly required items. One of the items required the panellist to choose one from the A, B, or C options provided. An open comment space was provided for panellists willing to comment about what they felt was relevant to be included in the diary.²⁵ The consensus was set at 70% a priori for definitely required, optional, or not required items.

The round 2 questionnaire was developed after analysis of the round 1 results and the panellists' comments. The round 3 questionnaire was developed from the analysis of the round 2 questionnaire.

The study questionnaire was piloted with two specialists experienced in managing patients with epilepsy. The pilot was analysed, and minor changes were made to the questionnaire. The data from the pilot study was not used for the Delphi study. The questionnaires were in English, and all entries into the online questionnaire on Evasys were time-stamped.

Step 4 – Conducting anonymous three iterative rounds

We recruited 13 expert panellists from the fields of family medicine, neurology, and internal medicine. A total of 11 panellists were local, and two were international. In a Delphi study, a minimum of 10–18 respondents is generally sufficient to achieve consensus.^{19,24,26,27} Convenience sampling was used in selecting panellists.^{26,28} The number of international and local experts selected from each province in South Africa was based on the individuals' availability and willingness to partake in the study.²⁶

The specified inclusion criteria were as follows: Panellists must be proficient in English and registered with the relevant authorities in the country where they practice. They must have experience using the seizure diary to manage patients with epilepsy in their field of practice and sign an informed consent form to participate in the study.

All panellists were individually identified by the first author and supervisors based on their area of expertise and meeting the inclusion criteria. Local experts were Individually identified from different provinces in South Africa. International experts from various countries were identified via the International League Against Epilepsy (ILAE) website. Electronic mail was sent out to all the experts identified, informing them about the study and inviting them to participate. Those who responded in the affirmative were then sent a detailed background information letter providing details such as the study title, problem statement, aim of the study, description of the Delphi technique, how to use the online Evasys system, time frame for a response, what is consensus, the duration of the study and consent form. All emails were sent individually to the panellists to maintain the anonymity of every member of the panel to each other but not to the authors.^{25,27} They were required to respond to the email and return the completed consent. All panellists were required to participate in the prior round in order to be invited to participate in the subsequent round. The number of rounds required for the modified Delphi was not predetermined, and the study was terminated once adequate consensus or stability of responses on items was achieved. Stability is achieved when all panellists have the same response from round to round. A time frame of 4–6 months was allocated for the study. Electronic and telephonic reminders were used to encourage non-responders to complete the questionnaire.²⁵

Round 1 commenced from January to February 2021, round 2 was from March to April 2021, and round 3 was from May to June 2021. In each round, panellists were required to follow a provided online link²⁹ to complete the confidential survey questionnaire on Evasys. After completing the questionnaire, the survey was electronically submitted. The research team reviewed responses, consolidated and new items were incorporated into the list for the next round. After round 3, sufficient consensus was reached on the items to terminate the study.

Step 5 – Providing individual feedback to panellists

Each panellist after round 1 received an information sheet with feedback on consensus and further information that new items were added for deliberation based on expert recommendation. Panellists could change their opinions and were requested to follow the online link to participate in round 2. All panellists also received a comprehensive summary of

round 2 responses, consensus items so far, and which questions were returned for further deliberation in round 3. They also received a summary of their individual responses in the previous rounds via personalised emails with the option to change their opinions if they wished and an email request to participate in round 3 of the study.

Step 6 – Summarize the findings

The research team grouped the consensus items after each round, as reported in the result section. We report in Table 1 the quality criteria for the Delphi studies as proposed by Humphrey-Murto et al.²¹ with additional criteria from Diamond et al.¹⁸

Ethics

Ethical approval for the study was obtained from the Health Sciences Research Ethics Committee of the University of the Free State (HSREC) with reference number UFS-HSD2020/1385/2411. All panellists gave written informed consent to participate in the study and were free to withdraw at any point they wished. All data provided were confidential, and no names or identifiers were associated with the data.

Statistical analysis

Data was captured on an excel spreadsheet and analysed. Information obtained was analysed using descriptive statistics to describe demographic characteristics and responses during each round of the Delphi.

Results

In round 1 of the Delphi study, 13 email links were sent to the panellists; 12 out of the 13 panellists participated with a response rate of 92% and subsequently completed rounds 2 and 3 with a response rate of 100%. The majority of the panellists from all rounds were from South Africa, with some involvement of specialists from other countries. Almost all panellists were public sector employees – all with more than ten years of experience, and have worked with patients living with epilepsy.

Round 1

The modified Delphi in round 1 had 50 items, with item 32 subdivided into parts A and B. The total items with consensus definitely required, often, and not required responses from the panellists were (n=21; 42%) of all items. As indicated in table 3, most of the items on which

consensus was reached were definitely required. Item 32 was misunderstood in round 1 by the majority of the panellists. They only responded to part A, overlooking part B. The core research team met (3 specialists from family medicine and neurology) to review the responses and comments of the panellist. Items with 70% consensus responses definitely required, often, and not required were assumed to be finalised and were not returned for round 2.³⁰ Seven near consensus definitely not required items ($\geq 66\%$) were removed, new items were identified based on comments from the panellists, and misunderstood items were modified for inclusion in the round 2 questionnaires.³¹ Eighteen Items with near-even or split responses were also excluded because consensus will be unlikely in the next round.¹⁹ This ensures the diary is not large while remaining practical for patients.

Comments from panellists include adding items to the diary, namely, the use of folic acid, where to keep the diary at home, how soon after a seizure the diary should be completed, and not include too much in the diary, so it is not cumbersome for the patients.

Round 2

In round 2, seven items were included for deliberations; four were returned from round 1, one of which was rephrased and returned because it was misunderstood, while three new items derived from panellists' suggestions were included. A consensus of 70% was achieved for three of the seven items (See Table 3); the core research team reviewed the responses, and items with stability were not returned for round 3.

Round 3

In round 3, two unresolved items from the previous round were returned for deliberation. Panellists were asked to reconsider their responses in line with the group majority responses with the option of changing their answers. A consensus of $> 70\%$ was achieved for one item (See Table 3); the other item reached stability; hence a 4th round was unlikely to change their opinions. Some panellists provided comments supporting their response on how often the diary should be completed. These comments were, amongst others, "the practicality of completing the seizure diary immediately after a seizure and always having a family member around is difficult", "Not completing the diary daily may lead to non-documentation of subtle seizures", "Patients may lose interest due to being compelled to complete the diary daily", "daily completion of the diary may be cumbersome, but monthly will cause problems with recall", "The diary needs to be simple and mundane for patients, completing the diary after a seizure is adequate".

Based on the feedback of the expert panellists, 18 items were selected as the required contents of a seizure diary. They were ranked according to the strength of their consensus opinion (See Table 4).

Discussion

This study, with the use of a Delphi method, was focused on establishing the contents of a seizure diary for patients with epilepsy. Hasson et al. stated that for a Delphi method to maintain its rigours, a response rate of 70% must be maintained.³² The study met this with a reasonable response rate of 92% in round 1 and 100% in subsequent rounds. The total duration for the study was six months, which was a bit above the 45 days to 5 months recommended duration for completing a Delphi study.²⁷ This was due to the delay caused by waiting for some panellists to complete and return their completed questionnaires well outside the discussed time frame. Okoli et al. supported this assertion by reporting that in a Delphi study, delays may be caused by researchers waiting for the return of completed questionnaires before sending out another.²⁷

The study results demonstrate the strong agreement among the expert panel concerning the basic biodata of patients, such as name, address, date of birth, etc., as very important items for the diary. This is consistent with similar information found in other diaries from other organizations, such as the United Kingdom-based Epilepsy society.¹⁴ Information such as current medications, medication allergies, and chronic medications was also important enough to include in the diary. This is consistent with comments by Fisher et al. on what information should be recorded in a seizure diary.¹³ Information on the seizure type was not required by the expert panel, which is inconsistent with the findings of Fisher et al., who reported that the seizure types should be documented in the seizure diary.¹³ Patients' seizure frequency is one of the most reported findings from many articles on patient-reported seizures in Epilepsy.^{13,34-36} It is a key reported outcome measure important for individual treatment and pharmacological clinical trials.^{36,37} The expert panel recognized the importance and voted overwhelmingly to support this being included as an item in the seizure diary. Details about seizures, such as duration, time of occurrence, awake or sleeping, were also included in the diary in keeping with reports from most authors.^{13,36-39}

Our expert panel agreed that the seizure diary for patients with epilepsy must be completed immediately after each seizure. This statement is supported by the reports from other studies on epilepsy showing the reporting patterns of patients with epilepsy. In the study of Blachut

et al., 41% of patients reported recording their seizures after recovery, while a further 36% reported recording their seizures right after the seizure.³⁶ In another study, Blachut et al., looked at self-reported seizure counts by patients with epilepsy using a diary, 40.7% of patients documented seizures immediately after their seizures, 20.9% the same day in the evening, and 27.9% the next morning.³⁷

For the purpose of the Delphi method, the questionnaire presented to national and international professionals was in English. The questionnaires of phase 5 of the study that explored how the patients experienced the diary were available in the languages most commonly spoken in the study setting¹⁷, and the seizure diary can be made available in other languages if needed.

The responses from the expert panel and data obtained from patients' questionnaires from phase 2 about what information they think should be in a seizure diary will be merged and used to develop a seizure diary for use by patients with epilepsy in South Africa.

Strengths and limitations

The strength of this study is the inclusion of independent panellists from various disciplines and different provinces in South Africa who are conversant with the management of patients with epilepsy.

Including international experts in epilepsy helped broaden the variety of opinions and did not limit the conclusions in the study to a single geographic view. This may help bring the diary's contents in line with what is obtainable internationally.

Bias was minimized by maintaining the anonymity of the expert panel members to avoid dominance and conducting multiple rounds of the survey with controlled feedback of responses.⁴⁰

The small number of international panellists limited this study; this may make it difficult to generalize the study results, especially to western countries, since the focus was more on Africa.

Conclusions

The Delphi study recruited an independent panel of both local and international experts. Consensus was achieved on 18 items definitely required as the content of a seizure diary to be used in managing patients living with epilepsy in South Africa. Implementing the newly developed seizure diary should be encouraged among healthcare practitioners and health authorities responsible for managing patients with epilepsy. The outcome of this study will

help guide future research toward using an electronic diary, and cell phone application for patients living with epilepsy in South Africa should be done.

References

1. World Health Organization. Epilepsy. Facts about Epilepsy. 2019 [cited 2021 Feb 17]. Available from: <https://www.who.int/news-room/fact-sheets/detail/epilepsy>
2. World Health Organization. Epilepsy in the WHO African region: Bridging the Gap. World Health Organization. 2004 [cited 2021 Feb 17]. Available from: https://www.ecoi.net/en/file/local/1320358/432_1198069054_epilepsy-in-african-region.pdf
3. Epilepsy South Africa. Facts About Epilepsy [Internet]. <http://www.epilepsy.org.za>. 2004 [cited 2023 Jan 11]. Available from: <https://epilepsy.org.za/content/uploads/2020/07/002-Brochure-Facts-about-Epilepsy.pdf>
4. Fisher RS. Tracking epilepsy with an electronic diary. *Acta Paediatr.* 2010; 99(4):516–8. <https://doi.org/10.1111/j.1651-2227.2010.01694>
5. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia.* 2014;55(4):475–82. <https://doi.org/10.1111/epi.12550>
6. Ernst LL, Harden CL, Pennell PB, et al. Medication adherence in women with epilepsy who are planning pregnancy. *Epilepsia.* 2016;57(12):2039–44. <https://doi.org/10.1111/epi.13586>
7. Shafer PO, Fisher R, Schachter SC. Using Seizure Diaries [Internet]. Epilepsy Foundation. 2019 [cited 2020 Jul 11]. Available from: <https://www.epilepsy.com/manage/tracking/seizure-diaries>
8. Le S, Shafer PO, Bartfeld E, Fisher RS. An online diary for tracking epilepsy. *Epilepsy Behav.* 2011 Dec 1;22(4):705–9. <https://doi.org/10.1016/j.yebeh.2011.08.035>
9. Ohly S, Sonnentag S, Niessen C, Zapf D. Diary Studies in Organizational Research. *Journal of Personnel Psychology.* 2010;9(2):79–93. <https://doi.org/10.1027/1866-5888/a000009>

10. Chin JH. Epilepsy treatment in sub-Saharan Africa: closing the gap. *Afr Health Sci.* 2012;12(2):186–92. <https://doi.org/10.4314/ahs.v12i2.17>
11. Egenasi CK, Moodley AA, Steinberg WJ, Adefuye AO. Current norms and practices in using a seizure diary for managing epilepsy: A scoping review. *S Afr Fam Pract.* 2022;64(1),a5540. <https://doi.org/10.4102/safp.v64i1.5540>
12. Keikelame MJ, Swartz L. Lost opportunities to improve health literacy: observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town South Africa. *Epilepsy Behav.* 2013;26(1):36–41. <https://doi.org/10.1016/j.yebeh.2012.10.015>
13. Fisher RS, Blum DE, DiVentura B, et al. Seizure diaries for clinical research and practice: limitations and future prospects. Vol. 24, *Epilepsy Behav.* 2012; 24(3):304–10. <https://doi.org/10.1016/j.yebeh.2012.04.128>
14. Epilepsy society. Seizure diaries | Epilepsy Society [Internet]. Epilepsy society. 2019 [cited 2022 Dec 1]. Available from: <https://epilepsysociety.org.uk/about-epilepsy/epileptic-seizures/seizure-diaries>
15. Haut SR, Hall CB, Borkowski T, et al. Modeling seizure self-prediction: An e-diary study. *Epilepsia.* 2013;54(11):1960–7. <https://doi.org/10.1111/epi.12355>
16. Van Berge Henegouwen MTH, Van Driel HF, Kasteleijn-Nolst Trenité DGA. A patient diary as a tool to improve medicine compliance. *Pharm World Sci.* 1999;21(1):21–4. <https://doi.org/10.1023/a:1008627824731>
17. Egenasi CK, Moodley AA, Steinberg WJ, Joubert G. The perceptions and attitudes of patients with epilepsy to the use of a seizure diary, South Africa. *S Afr Fam Pract.* 2023;65(1), a5503. <https://doi.org/10.4102/safp.v65i1.5503>
18. Diamond IR, Grant RC, Feldman BM, et al. Defining consensus: A systematic review recommends methodologic criteria for reporting of Delphi studies. *J Clin Epidemiol.* 2014;67(4):401–9. <https://doi.org/10.1016/j.jclinepi.2013.12.002>
19. Vogel C, Zwolinsky S, Griffiths C, et al. A Delphi study to build consensus on the definition and use of big data in obesity research. *Int J Obes.* 2019;43(12):2573–86. <https://doi.org/10.1038/s41366-018-0313-9>

20. De Villiers MR, De Villiers PJT, Kent AP. The Delphi technique in health sciences education research. *Med Teach.* 2005;27(7):639–43. <https://doi.org/10.1080/13611260500069947>
21. Humphrey-Murto S, Varpio L, Wood TJ, et al. The Use of the Delphi and Other Consensus Group Methods in Medical Education Research: A Review. *Acad Med.* 2017;92(10):1491–8. <https://doi.org/10.1097/ACM.0000000000001812>
22. Van Schalkwyk SC, Kiguli-Malwadde E, Budak JZ, et al. Identifying research priorities for health professions education research in sub-Saharan Africa using a modified Delphi method. *BMC Med Educ.* 2020;20(1):443. <https://doi.org/10.1186/s12909-020-02367-z>
23. Keeney E, Thom H, Turner E, et al. Using a Modified Delphi Approach to Gain Consensus on Relevant Comparators in a Cost-Effectiveness Model: Application to Prostate Cancer Screening. *Pharmacoeconomics.* 2021;39(5):589–600. <https://doi.org/10.1007/s40273-021-01009-6>
24. Jünger S, Payne SA, Brine J, et al. Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliat Med.* 2017;31(8):684–706. <https://doi.org/10.1177/0269216317690685>
25. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm.* 2016;38(3):655-62. <https://doi.org/10.1007/s11096-016-0257-x>
26. Akins RB, Tolson H, Cole BR. Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. *BMC Med Res Methodol.* 2005;5(1):1–12. <https://doi.org/10.1186/1471-2288-5-37>
27. Okoli C, Pawlowski SD. The Delphi Method as a Research Tool: An Example, Design Considerations and Applications. *Inf Manag J.* 2004;42(1):15–29. <https://doi.org/10.1016/j.im.2003.11.002>
28. Toepoel V, Emerson H. Mathematical Population Studies An International Journal of Mathematical Demography Using experts' consensus (the Delphi method) to evaluate

- weighting techniques in web surveys not based on probability schemes. *Math Popul Stud.* 2017;24(3):161-71. <https://doi.org/10.1080/08898480.2017.1330012>
29. Avery AJ, Savelyich BSP, Sheikh A, et al. Identifying and establishing consensus on the most important safety features of GP computer systems: e-Delphi study. *Inform Prim Care.* 2005;13(1):3–11. <https://doi.org/10.14236/JHI.V13I1.575>
 30. Cassar Flores A, Marshall S, Cordina M. Use of the Delphi technique to determine safety features to be included in a neonatal and paediatric prescription chart. *Int J Clin Pharm.* 2014;36(6):1179–89. <https://doi.org/10.1007/s11096-014-0014-y>
 31. Woodcock T, Adeleke Y, Goeschel C, et al. A modified Delphi study to identify the features of high quality measurement plans for healthcare improvement projects. *BMC Med Res Methodol.* 2020;20(1). <https://doi.org/10.1186/s12874-019-0886-6>
 32. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs.* 2000;32(4):1008–15. <https://doi.org/10.1046/j.1365-2648.2000.t01-1-01567.x>
 33. Fisher RS, Bartfeld E, Cramer JA. Use of an online epilepsy diary to characterize repetitive seizures. *Epilepsy Behav.* 2015;47:66–71. <https://doi.org/10.1016/j.yebeh.2015.04.022>
 34. Hoppe C, Poepel A, Elger CE. Epilepsy: Accuracy of patient seizure counts. *Arch Neurol.* 2007;64(11):1595–9. <https://doi.org/10.1001/archneur.64.11.1595>
 35. Blachut B, Hoppe C, Surges R, et al. Counting seizures: The primary outcome measure in epileptology from the patients' perspective. *Seizure.* 2015;29:97–103. <https://doi.org/10.1016/j.seizure.2015.03.004>
 36. Blachut B, Hoppe C, Surges R, et al. Subjective seizure counts by epilepsy clinical drug trial participants are not reliable. *Epilepsy Behavior.* 2017;67:122–7. <https://doi.org/10.1016/j.yebeh.2016.10.036>
 37. Haut SR, Hall CB, Borkowski T, et al. Clinical features of the pre-ictal state: Mood changes and premonitory symptoms. *Epilepsy Behavior.* 2012;23(4):415–21. <https://doi.org/10.1016/j.yebeh.2012.02.007>

38. Ferastraoaru V, Goldenholz DM, Chiang S, et al. Characteristics of large patient-reported outcomes: Where can one million seizures get us? *Epilepsia Open*. 2018;3(3):364–73. <https://doi.org/10.1002/epi4.12237>
39. Hallowell MR. Techniques to minimize bias when using the Delphi method to quantify construction safety and health risks. *Building a Sustainable Future*. In *Construction Research Congress*. Seattle, Washington, USA. 2009;1489–98. [https://doi.org/10.1061/41020\(339\)151](https://doi.org/10.1061/41020(339)151)

Table 1. Quality characteristics for a Delphi study.^{18,21}

Reporting quality characteristics	Our Study
Literature review conducted	Yes
Background information provided to participants	Yes
Purpose is Item generation	Yes
No of participants indicated	Yes
No of respondents for round 1 indicated	Yes
No of respondents for round 2 indicated	Yes
Polling email described	Yes
Private decisions collected (Anonymity)	Yes
Formal feedback	Yes
Number of rounds 2 or more	Yes
Number of rounds determined a priority	No
Predetermined definition of consensus	Yes
Consensus forced	No
Were the criteria for participants reproducible?*	Yes
Stopping criteria other than rounds specified?*	Yes

Quality criteria according to Diamond et al. (18).*

Table 2. Demographic data of Delphi panelists.

<i>Demographic data</i>	n (%)
<i>Gender</i>	
<i>Males</i>	6 (50%)
<i>Females</i>	6 (50%)
<i>Specialties</i>	
<i>Family medicine</i>	6 (50%)
<i>Neurology</i>	6 (50%)
<i>Current positions</i>	
<i>Specialist Family med/Neurology</i>	8 (67%)
<i>Heads of academic departments</i>	4 (33%)
<i>Country of practice</i>	
<i>South Africa</i>	10 (83.3%)
<i>Malaysia</i>	1 (8.3%)
<i>Nigeria</i>	1 (8.3%)
<i>Place of Employment</i>	
<i>Public</i>	11 (92%)
<i>Private</i>	1 (8%)
<i>Years of experience</i>	
<i>0–4 years</i>	0
<i>5–10 years</i>	0
<i>More than 10</i>	12 (100%)
<i>Works with patients with epilepsy</i>	
<i>Yes</i>	12 (100%)
<i>No</i>	0

Table 3. Items with Consensus reached during rounds 1, 2 and 3.

Item no from questionnaire	Items	Definitely required n (%)	Optional n (%)	Not required n (%)
Round 1				
1	Name of patient	11 (91.7%)	1 (8.3%)	0
2	Date of birth	11 (91.7%)	1 (8.3%)	0
3	Gender of patient	10 (83.3%)	2 (16.6%)	0
5	Highest educational qualifications	2 (16.7%)	9 (75%)	1(8.3%)
6	Current home address	9 (75%)	1 (8.3%)	2 (16.6%)
7	Patients phone number	11 (91.7%)	1 (8.3%)	0
8	Emergency phone number for next of kin	9 (75%)	3 (25%)	0
9	Name of local clinic and contact number	9 (75%)	3 (25%)	0
11	Medication allergies	11 (91.7%)	1 (8.3%)	0
13	Patients chronic conditions	9 (75%)	3 (25%)	0
15	Current epilepsy medications	12 (100%)	0	0
16	Patients' current medication dosages	11 (91.7%)	1 (8.3%)	0
22	Frequency of patients' seizures	12 (100%)	0	0

25	Duration of seizures	9 (75%)	3 (25%)	0
35	Instruction to circle days of the months with seizures on the calendar	9 (75%)	3 (25%)	0
38	Space for comments on EEG reports	1 (8.3%)	10 (83.3%)	1 (8.3%)
44	Commercial adverts on every page of diary	0	1 (8.3%)	11 (91.7%)
45	Commercial adverts on selected pages only	0	2(16.6%)	10 (83.3%)
46	Different dairy colours for males & females	0	2 (16.6%)	10 (83.3%)
47	Coloured diary background	0	2 (16.6%)	10 (83.3%)
48	Background pictures in the diary	0	3 (25%)	9 (75%)
Round 2				
14	Patients' other chronic medications	11 (91.7%)	8.3%	0%
24	Time of the day patient had a seizure.	9 (75%)	25%	0%
27	Seizures occurred while sleeping or awake	11 (91.7%)	8.3%	0%
Round 3				

32	How often should the diary be completed?	Daily regardless of seizures (A) = 25%	Immediately after a seizure (B) = 9 (75%)	Monthly (c) = 0%
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Table 4: Final list of the selected items from highest consensus rating to lowest.

No	Items	(%) Definitely required
1	Current epilepsy medications	100%
2	Frequency of patients' seizures	100%
3	Name of patient	91.7%
4	Date of birth	91.7%
5	Patients phone number	91.7%
6	Medication allergies	91.7%
7	Patients' current medication dosages	91.7%
8	Patients' other chronic medications	91.7%
9	The seizure occurred while sleeping or awake	91.7%
10	Gender of patient	83.3%
11	Current home address	75%
12	The emergency phone number for the next of kin	75%
13	Name of a local clinic and contact number	75%
14	Patients' chronic conditions	75%
15	Duration of seizures	75%
16	Instruction to circle days of the months with seizures on the calendar	75%
17	Time of the day patient had the seizure.	75%
18	How often should the diary be completed (Immediately after a seizure)	75%

Attachment: Seizure Diary

<p>Name and surname: <input type="text"/></p> <p>Patient's hospital number: <input type="text"/></p> <p>Date of birth: <input style="width: 100%;" type="text" value="..... / /"/></p> <p>Gender: <input type="text"/></p> <p>Current home address: <input type="text"/></p> <p>Patient's phone number: <input type="text"/></p> <p>Emergency phone number for next of kin: <input type="text"/></p> <p>Name of local clinic and contact number: <input type="text"/></p> <p>Medication allergies: <input type="text"/></p> <p>Patient's chronic conditions: <input type="text"/></p> <p>Current medication & dosages: <input type="text"/></p>	<p style="text-align: center;">Instructions</p> <p>After each seizure, encircle the day on the Seizure Calender and provide more information in the Seizure Details section.</p> <p>Complete the diary immediately after each seizure.</p>	<p style="text-align: center; color: orange; font-size: 2em; font-weight: bold;">Seizure Diary</p> <div style="text-align: center; margin-top: 100px;"><input type="text"/></div>
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