**ABSTRACT**

**Objective:** To identify the views of people with epilepsy (PWE), and their significant others, on the repurposing and trialling of statins as a potential antiepileptogenic or disease modifying treatment for those who have had a first seizure.

**Methods:** Online questionnaire. Participants needed to be aged ≥16 years, UK resident, and able to independently complete a questionnaire in English. User groups distributed study adverts. Embedded infographics explained repurposing, why anti-seizure treatment is not typically started after a first seizure and the nature of randomised placebo-controlled trials (RCTs).

The questionnaire asked participants to reflect and rate their expected willingness to have started an unspecified treatment after their first seizure/s (or that of the person with epilepsy they knew). They also rated willingness if the treatment were a statin, views of statins, the importance of an RCT of statins to their community, the outcomes it should assess, and their willingness to have taken part in it. The estimated number needed for the survey was 324.

**Results:** Responses from 213 persons were analysed; 111 (52.1%) were PWE and 102 (47.9%) significant others. Median years diagnosed was 10 and PWE suffered from relatively severe epilepsy.

One hundred and seventeen (54.9%) said they would have started an unspecified treatment after their first seizure/s (or supported the person with epilepsy they knew to have). A similar proportion (55.4%) said they would have started the treatment if it were a statin. Participants’ main concern about statins, expressed by 79%, were their possible side effects. Repurposing was a concern for only 25%. Most (85.8%) rated an RCT of statins as of extreme or high importance; 54.4% said they would have participated.

**Conclusion:** The PWE and SOs responding to our survey expressed views towards repurposing statins that were generally positive and indicate a trial in those who have had a first seizure might be feasible. Concerns regarding side effects are common. Our findings could help optimise a future trial’s design and the case for funding. Limitations include that we did not survey persons who had experienced a first seizure and did not go on to develop epilepsy. Also, persons with uncontrolled epilepsy were overrepresented.

**Keywords:**

Drug Repositioning; Epilepsy; Seizures; Disease-Modifying; Feasibility Studies; Outcome Assessment.

**1. INTRODUCTION**

Neither an antiepileptogenic, nor disease modifying compound has yet been discovered for epilepsy. Antiseizure medication (ASM) – usually only started after a person has had ≥2 unprovoked seizures 24 hours apart [1] – can reduce risk of seizures, but not epilepsy.[2] Moreover, 30% of people with epilepsy (PWE) continue to have seizures despite taking ASMs.[3] Prevention or modification of epileptogenesis has been called the ‘holy grail’ of epilepsy.[4] Additionally, calls have been made to broaden the search and consider the disease modifying potential of *existing* medications.[5-7]

A ‘repurposed’ medication could bring advantages.[8] Existing safety data might, for instance, permit the phase-1 trial stage to be bypassed.[9] Our group [10] thus completed an exhaustive examination of the literature to identify existing medications with potential antiepileptogenic effects.

Based on a favourable safety profile and compelling preclinical data and epidemiological observations, statins were identified as a promising candidate. A summary of the evidence collated by us [10] is presented here. There are three different types of animal models that can be used to study compounds’ disease-modifying effect on epilepsy; statins are disease-modifying in all three. At least 12 published clinical cohort studies have reported an association between statins and significantly reduced risk of epilepsy/seizures. At least four independently published meta-analyses of clinical cohort studies have found that statins are associated with a reduced risk of epilepsy.

A randomised placebo-controlled trial (RCT) recruiting people who have experienced a first unprovoked seizure/s and asking them to begin treatment would be needed to definitively determine a statin’s effects.

Our group proposes to conduct such a trial. Making the case for one is though, currently difficult. Why? A trial should only be initiated once foreseeable risks and inconveniences have been identified and weighed against anticipated benefits.[11] Moreover, research funders require evidence of patient and public involvement to help be assured that the proposed study is relevant, participant friendly and ethically sound.[12] At present, we have no indication as to the target population’s views of the proposed treatment, willingness to participate in the envisioned RCT or its perceived importance. This cannot be assumed. Public attitudes towards statins appear polarised [13], media coverage predominantly negative [14] and treatment after a first seizure represents a marked departure from current practice.[15]

To address these information gaps, we surveyed persons who had previously had a first seizure, with all the uncertainties that entails, as well as their significant others (SOs). Family and friends are often closely involved in treatment decisions, especially when the patient lacks capacity . Recruiting people who have had a single seizure and not developed epilepsy is challenging due to their heterogeneity and their lack of affiliation with a particular service or user group. Our survey thus focused on the epilepsy community.

**2. METHODS**

**2.1 Design**

An anonymous, piloted cross-sectional online survey hosted by Qualtrics.

**2.2 Recruitment**

Between January and June 2022, a participant advertisement was distributed using different social media platforms by UK epilepsy user groups (see Acknowledgments). To participate, patients needed to confirm they were aged ≥16 years, had a clinical diagnosis of epilepsy (any syndrome or seizure type; no restriction on time since diagnosis), lived in the UK, and could independently complete a questionnaire in English. SOs needed to confirm they were aged ≥16 years, lived in the UK, were able to independently complete a questionnaire in English and were a family member or friend of someone from the UK with a clinical diagnosis of epilepsy .

Approval was provided by the University of Liverpool's Health and Life Sciences Research Ethics Committee (Reference: 10779). All participants provided informed consent.

**2.3 Survey content**

We developed a unique questionnaire. It asked participants to reflect back to when they had experienced their first seizure/s and recall any uncertainties they had at the time regarding their chances of having another seizure. They were then asked a series of questions. Table 1 presents the questions used to estimate the key parameters. Supplementary Files 1, 3, 4 and 5 provide the other questions and the instructions used. Where possible, established scales and items deployed in previous studies were adapted.[16-21]

Epilepsy [22] and clinical trial knowledge amongst the target population [23] can be low. Therefore, we developed and embedded short animations into the survey. This ensured participants were aware of the differences between (i) standard treatment and treatment after a first seizure, (ii) what drug repurposing is; and (iii) what placebo RCTs are. Supplementary File 2 presents them.

SOs were asked the same questions as PWE, but they were rephrased so they referenced their own views and their willingness for the person with epilepsy they knew to have started treatment/ participated.

**TABLE 1** Main questions used by survey to estimate key parameters and participants responses

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Area** | **Questions1** | **Answer options** | **Participants** | | |
| **All**  (n=213) | **PWE**  (n=111) | **SOs**  (n=102) |
| ***Treatment after a first seizure/s*** | *Please think back… Imagine the new medication talked about in the video was available. If the doctor offered it to you, how willing would you be to start taking it?* | -Definitely willing to take it  -Probably willing to take it  -Maybe willing to take it  -Maybe not willing to take it  -Probably not willing to take it  -Definitely not willing to take it  Missing | 55 (25.82%)  62 (29.11%)  58 (27.23%)  16 (7.51%)  20 (9.39%)  2 (0.94%)  0 | 31 (27.93%)  30 (27.03%)  30 (27.03%)  11 (9.91%)  7 (6.31%)  2 (1.80%)  0 | 24 (23.53%)  32 (31.37%)  28 (27.45%)  5 (4.90%)  13 (12.75%)  0  0 |
| ***Statins after a first seizure/s*** | *Imagine the doctor asks whether you want to try a statin to try to cure (or least slow down) epilepsy. How willing would you be to start taking it?* | -Definitely willing to take it  -Probably willing to take it  -Maybe willing to take it  -Maybe not willing to take it  -Probably not willing to take it  -Definitely not willing to take it  Missing | 52 (24.41%)  66 (30.99%)  71 (33.33%)  7 (3.29%)  12 (5.63%)  5 (2.35%)  0 | 25 (22.52%)  32 (28.83%)  40 (36.04%)  4 (3.60%)  7 (6.31%)  3 (2.70%)  0 | 27 (26.47%)  34 (33.33%)  31 (30.39%)  3 (2.94%)  5 (4.90%)  2 (1.96%)  0 |
| ***Importance of trial*** | *In your opinion, how important do you think a trial of statins is for the epilepsy community?* 2 | -Extremely important  -High importance  -Low importance  -Not important  -No opinion  Missing | 91 (44.61%)  84 (41.18%)  5 (2.45%)  2 (0.98%)  22 (10.78%)  9 | 39 (36.45%)  50 (46.73%)  4 (3.75%)  1 (0.93%)  13 (12.15%)  4 | 52 (53.61%)  34 (35.05%)  1 (1.03%)  1 (1.03%)  9 (9.28%)  5 |
| ***Participation in RCT*** | *Please think back… Do you think you would have agreed to participate in a trial of a statin?* 3 | -Yes  -I am not sure  -No  Missing | 111 (54.41%)  70 (34.31%)  23 (11.27%)  9 | 58 (54.21%)  38 (35.51%)  11 (10.28%)  4 | 53 (54.64%)  32 (32.99%)  12 (12.37%)  5 |
| ***Outcome measures*** | *Please tick any of the things below that you think definitely should be looked at.* 4 | -side-effects that the treatment has on the person  -effect on how many seizures the person has  -effect on the person's quality of life  -effect on mental skills (such as, memory, concentration & thinking)  -effect on how severe the seizures are that the person has  -effect on the anxiety levels of the person  -effect on how depressed the person feels  -effect on how much support/ care the person needs from family & friends  -effect on how stigmatized the person feels  -How much the new treatment costs the health service  Missing | 180 (84.51%)  173 (81.22%)  170 (79.81%)  169 (79.34%)  165 (77.46%)  132 (61.97%)  124 (58.22%)  95 (44.60%)  62 (29.11%)  49 (23.00%)  0 | 91 (82.00%)  87 (78.40%)  81 (73.00%)  88 (79.30%)  80 (72.10%)  75 (67.60%)  75 (67.60%)  50 (45.10%)  36 (32.40%) 34 (30.60%)  0 | 89 (87.30%)  86 (84.30%)  89 (87.30%)  81 (79.40%)  85 (83.30%)  57 (55.90%)  49 (48.00%)  45 (44.10%)  26 (25.50%)  15 (14.70%)  0 |

*Notes* PWE, people with epilepsy; SO, significant other; RCT, randomised controlled trial. 1 See Supplementary File 1 for full questionnaire, including introductory text to the different questions. The phrasing of the questions was changed for SOs so the questions were in reference to the person with epilepsy they knew (e.g., “Imagine the new medication talked about in the video was available. If the doctor offered it to you, how willing would you be to start taking it?” was changed to “Imagine the new medication talked about in the video was available. If the doctor offered it to them, how willing would you be for them to start taking it?”). Order in which answers are presented does not necessarily align with that used in questionnaire. In some instances, it has been adjusted for presentation purposes; 2 Question adapted from Fernandez et al. 3 Adapted from Abu- Farha et al. (2020). 4 Adapted from Noble & Marson (2016).

**2.4 Analysis**

Given willingness to participate in the envisioned RCT would be the ultimate determinant of trial feasibility, this parameter informed the survey’s sample size calculation. Walters et al. [24]examined health technology trials conducted in the UK between 2004 to 2016. They had a median uptake rate of 70% (IQR 51–87%). Whilst most were not placebo controlled, this rate, together with a required confidence level of 95% and precision of ±5%, indicated our survey required 324 PWE/ SOs with complete data.

Analysis was largely descriptive, with 95% confidence intervals (CIs) calculated for the key parameters. Given data was largely ordinal, central tendency is described according to the median and interquartile range (IQR).

Mann-Whitney U tests compared the responses of those with and without controlled epilepsy (≥1 seizure in prior 12 months), whilst Kruskal-Wallis tests compared the responses of those who had been diagnosed for different time periods (0 to 4, 5 to 10, 11 to 17, or ≥18 years). We also compared responses of PWE and SOs and chi-square tests explored the association between the willingness participants reported in response to the different questions. For main analyses, alpha was set at .05. Only relationships that were statistically significant are reported.

Analyses were completed using data from participants who had completed the questionnaire sufficiently to mean they provided a response to the first key question of the survey – namely, willingness to consider starting a statin. Where available, the characteristics of individuals who were and were not included in the data-set are presented side by side to evaluate representativeness.

Analyses were conducted using SPSS (v27), with StatsDirect3 calculating CIs.

**3. RESULTS**

**3.1 Participant characteristics**

A total of 406 people responded to the survey, with 213 (52.5%) providing sufficient data for inclusion in the main analysis.

Of those with sufficient data, 111 (52.1%) were persons with epilepsy and 102 (47.9%) SOs. Participants were recruited from all UK nations; 78.4% came from England.

Participants’ characteristics are detailed in Table 2. In brief, the median age of PWE taking part (or being represented) was 23 years (IQR 15-36); 69.4% were female. Median years diagnosed was 10 (IQR 4-17). Most (56.3%) reported ≥10 seizures in the prior 12 months. Only 4 (1.9%) PWE in the sample reported, or were reported by a SO, to be prescribed a statin.

Compared to PWE who took part themselves, those known by SOs were typically younger, male, had an intellectual disability, had more frequent seizures, and were less likely to be prescribed a medication beyond ASM.

Those who could not be included in the data-set for analysis due to insufficient data did not markedly differ from those who could (Table 2).

**3.2 Willingness to start an unspecified treatment after a first seizure/s**

One hundred and seventeen (54.9%; CI 47.9 to 61.7) participants said they would have been “definitely” or “probably” willing to have started a treatment after their first seizure/s or for the person with epilepsy they knew to have (Table 1). When including those who said they may have been willing, this rose to 82.2% (CI 76.5 to 87.1).

**3.3 Willingness to start statin treatment after a first seizure/s**

One hundred and eighteen participants (55.4%; CI 48.5 to 62.2) said they would have been “definitely” or “probably” willing to have started statin treatment (Table 1). It was 88.7% (CI 83.7 to 92.7) when including those who said they may have been willing.

Willingness was positively associated with the participant’s willingness to have started an unspecified treatment (*X*2= 41.25(1), p<0.001).

**3.4 Views on statins**

At least third of the sample said they “strongly” or “somewhat” agreed with were worry about side effects (79.8%; CI 73.8 to 84.9) and worry that a statin would interfere or interact with other medicines they take or might take (51.6%; CI 44.7 to 58.5) (Supplementary File 3).

What was also noteworthy is 29.1% (CI 23.1 to 35.7) “strongly” or “somewhat” agreed with the statement that they had read or heard negative or bad things about statins and 24.9% (CI 19.2 to 31.3) “strongly” or “somewhat” agreed that they would be concerned about becoming addicted. However, only 20.2% (CI 15.0 to 26.2) “strongly” or “somewhat” agreed that they would be less willing to take a drug they knew was not originally developed for their condition

**3.5 Importance of RCT**

Most (85.8%; CI 80.2 to 0.90.3) participants rated the importance of the envisioned trial as being “Extremely important” or of “High importance”.

SOs rated the trial of more importance than PWE (U= 4279, p<0.05). There was also a significant association with years diagnosed (*H*(3)9.021, p=0.02), with those who had been living with

**TABLE 2** Characteristics of participants

|  | **Analysis data-set** | **Excluded** |
| --- | --- | --- |
|  | **N=213** | **N=193**2 |
| ***Participant type,*** *n (%)* |  |  |
| Person with epilepsy | 111 (52.1%) | 89 (46.1%) |
| Significant other | 102(47.9%) | 104 (53.9%) |
| Missing | 0 | 0 |
| ***Age of PWE,*** *Median (range)* |  |  |
| Reported by people with epilepsy | 31 (25-45) | 30 (22-41) |
| Reported by significant others | 15 (8-20) | 18 (11.5-27.5) |
| Combined | 23 (15-36) | 24 (18-35.5) |
| Missing | 0 | 102 |
| ***Sex of PWE,*** *Female n (%)* |  |  |
| Reported by people with epilepsy | 92 (82.9%) | 38 (80.9%) |
| Reported by significant others | 56 (54.9%) | 20 (45.5%) |
| Combined | 148 (69.5%) | 58 (63.7%) |
| Missing | 0 | 102 |
| ***Intellectual disability in PWE,*** *n (%)* |  |  |
| Reported by people with epilepsy | 14 (12.6%) | 8 (18.2%) |
| Reported by significant others | 46 (45.1%) | 14 (35.0%) |
| Combined | 60 (28.2%) | 22 (26.2%) |
| Missing | 0 | 109 |
| ***Significant others relation to PWE,*** *Person with epilepsy is my… n (%)* |  |  |
| Partner/spouse | 4 (3.9%) | - |
| Sibling | 2 (1.9%) | - |
| Child | 92 (90.2%) | - |
| Other | 4 (3.9%) | - |
| Missing | 0 | - |
| ***Age at PWE’ diagnosis,*** *Median (range)* |  |  |
| Reported with people with epilepsy | 16 (11-22) | - |
| Reported by significant others | 5 (2-11 | - |
| Combined | 23 (15-36) | - |
| Missing | 0 | - |
| ***Currently prescribed ASM****, Yes n (%)* |  |  |
| Reported with people with epilepsy | 107 (96.5%) | - |
| Reported by significant others | 92 (91.1%) | - |
| Combined | 199 (93.9%) | - |
| Missing | 1 | - |
| ***Seizures in prior 12 months***1*, n(%)* |  |  |
| Reported by people with epilepsy |  | - |
| 0 | 25 (22.5%) | - |
| 1-3 | 21 (18.9%) | - |
| 4-6 | 7 (6.3%) | - |
| 7-9 | 5 (4.5%) | - |
| 10 or more | 53 (47.7%) | - |
| Missing | 0 | - |
| Reported by significant other participants |  |  |
| 0 | 9 (8.8%) | - |
| 1-3 | 11 (10.8%) | - |
| 4-6 | 13 (12.7%) | - |
| 7-9 | 2 (2.0%) | - |
| 10 or more | 67 (65.7%) | - |
| Missing | 0 | - |
| Combined |  |  |
| 0 | 34 (16.0%) | - |
| 1-3 | 32 (15.0%) | - |
| 4-6 | 20 (9.4%) | - |
| 7-9 | 7 (3.3%) | - |
| 10 or more | 120 (56.3%) | - |
| Missing | 0 | - |
| ***Any prescriptions beyond ASM?*** *Yes n (%)* |  |  |
| Reported by people with epilepsy | 71 (65.1%) | - |
| Reported by significant other participants | 39 (38.6%) | - |
| Combined | 110 (52.4%) | - |
| Missing | 3 | - |
| ***Is one of these a statin,*** *Yes n (%)* |  |  |
| Reported by people with epilepsy | 4 (3.7%) | - |
| Reported by significant other participants | 0 (0.0%) | - |
| Combined | 4 (1.9%) | - |
| Missing | 5 | - |

*Notes* ASM, anti-seizure medication; n, number; 1Thapar’s seizure frequency scale [25]for the prior

12 months. It asks, “How many epileptic attacks (of any type) have you had in the last 12 months?”; 2Those who responded to the survey but who are excluded completed the demographic question to varying extents, hence the different levels of missing data for some of the fields.

epilepsy for 5 to 10 years assigning greater importance to the trial than those who had been living with epilepsy for ≥18 years (p=0.03).

**3.6 Participation in RCT**

One hundred and eleven (54.4%; CI 47.3 to 61.4) participants anticipated they would have said “Yes” to trial participation. Most of the remainder (34.3%; CI 27.8 to 41.3) were unsure.

Willingness to participate was positively associated with a participant’s willingness to start a statin (*X*2= 38.69(1), p<0.001) and start an unspecified treatment (*X*2= 19.25(1), p<0.001).

Of those saying they would have participated, the statement most often endorsed to account for this was a belief that the trial results could benefit others in the future (82.9%; CI 74.6 to 89.4) ( Supplementary File 4). The most common prepared reason offered for saying they would not or were unsure if they would have participated was a concern about the risks of statins (46.2%; CI 35.8 to 56.9).(Supplementary File 5).

The reasons PWE and SOs offered for their willingness to participate were broadly similar. Exceptions were that PWE more often (36.7% vs 4.6%) cited not participating because they did not believe those close to them would have be keen for it, whilst SOs more often (20.5% vs 12.2%) cited a view that the person with epilepsy they knew would not have been able to cope with the study burden.

**3.7 Outcome measures for RCT**

Table 2 shows the extent to which participants said the different domains required measurement within the envisioned trial. The one which was most selected was treatment side-effects (84.5%, CI 78.9 to 89.1).

The proportions of PWE and SOs selecting the different outcome domains were similar. PWE did though select the domains anxiety and depression more frequently than SOs, whilst SOs selected seizure severity more often than PWE.

**4. DISCUSSION**

**4.1 Main findings**

Before a trial can be completed to definitively determine whether a statin could stop or ameliorate the course of epilepsies, for both pragmatic and moral reasons it was necessary to engage with the target population.[12] Our study indicates a trial is indeed feasible and considered of high importance to the epilepsy community. Our findings can be used by groups such as our own to optimise trial design and support the case for funding it.

**4.2 Starting treatment after a first seizure/s and repurposing statins**

Only 40-50% of people who experience a first seizure go on to have further seizures.[26] Treatment after a first seizure, as proposed with statins, would mean some people would be asked to receive a medication with the potential negative consequences this may have for little benefit since they were never going to experience further seizures. This was not sufficient to deter most in our sample from believing they would have started treatment after their first seizure. Over 80% said they either definitely, probably or may have been willing to take it.

Participants’ willingness did not reduce when informed the treatment would be a statin. Some did express concerns about the potential risks of statins and interactions with other medications, but these were not sufficient to mean statins do not remain a promising candidate.

That statins would have been ‘repurposed’ for the target population was also not a key concern. To our knowledge, this is the first evidence from the epilepsy community about drug repurposing. It indicates repurposing should not automatically been seen as a barrier to uptake. Clearly our findings are specific to statins. The community might have more or less concerns with another drug that has a different ‘legacy’.

**4.3 Views on a trial of statins**

Just over ~50% of our sample anticipated they would have participated in a placebo RCT of statins. The rate is within the range seen within publicly funded UK health trials.[27] Importantly, from a generalisability perspective, we did not find that willingness to participate was not associated with any participant characteristic. This, together with the fact that first seizures are a common presentation, indicates a trial of statins is feasible. What is also encouraging is many in our sample (34%) remained undecided regarding participation. Thus, with appropriate counselling, even more might participate.

We explored participants views of statins and their reasons for wanting or not wanting to participate. Our findings identify avenues by which recruitment might be increased. For instance, ~35% strongly agreed with the statement that they would be worried about side effects. And 25% strongly or somewhat agreed with the statement about being concerned about becoming addicted to the statin. Statins are not known to be addictive and the rates of side-effects from statins (within controlled trials) are low.[28] A nocebo effect has though been noted.[29] It would be important to share rigorous evidence on these topics with potential participants to address misconceptions.

In terms of views of the trial, it is noteworthy that many willing to participate were motivated by a desire to help others This has been reported by others participating in trials, including on epilepsy.[30] That PWE and SOs both cited each other as a reason for not participating highlights the importance, where possible, of having discussions with both patients and SOs and surfacing their concerns.

**4.4 Strength and weaknesses**

Study strengths include the national sample. The involvement of SOs also permitted access to a unique part of the target population. The study is not though without potential limitations.

Firstly, due to the timeline within which the evidence was required, the lack of funding for this sort of formative work and the challenges of identifying and recruiting a large number people who have recently had their first seizure, we recruited a retrospective sample of persons and asked them to reflect back and try to recall feelings and concerns at the time. It is unclear how well they could do this and how concordant the views they expressed would be if asked closer to the time of their first seizure/s. Surveying patients to explore willingness to participate in a trial and/or accept a novel treatment is an established approach (e.g.,[31, 32]). How stated willingness aligns with actual behaviour is relatively unexplored. Halpern et al.[33] at least found stated willingness to participate in a HIV vaccine trial had modest predictive ability for actual participation.

Secondly, we recruited people who had a first seizure who went on to be diagnosed with epilepsy. It was not possible to readily identify those who had experienced a single seizure, but not developed epilepsy. Consequently, we only secured an approximation of the views of around half of the target population. The views of those who have had a first seizure and developed epilepsy might differ in important ways from those of people for whom a seizure did not lead to epilepsy.

Thirdly, participants were recruited via user groups and online. We do not know how the views of our sample will generalise to the wider epilepsy community. Whilst 96% of UK households have internet access [34], our approach could have excluded the less privileged minority [35]. The approach also meant that people with poorly controlled epilepsy were overrepresented. Given in other fields the severity of one’s experience of a condition can be related to one’s willingness to participate in a trial of a treatment for that condition (e.g., [36]), we note that we did not find our participants views to be associated with a measure of seizure control, nor, for the most part, how long they had been living with epilepsy.

Finally, a high proportion of participants started the survey but did not complete it. This meant the survey did not achieve its required sample size and so in some instances the confidence intervals for estimates are wide. Importantly, though those who did and did not finish the survey did not appear to differ. Future endeavours looking to inform the design of their trials could use shorter surveys. They could remove questions on the importance of their trial since they could use the findings from the UK’s research priority setting exercise currently underway [37]. They could also remove questions on which outcome domains to measure since a ‘core outcome set’ for epilepsy will soon be available.[21, 38]

**5. COnclusions**

This UK survey indicates a placebo controlled RCT of a statin to determine its antiepileptogenic and/or disease modifying effect in those who have experienced a first seizure/s would be of high importance to the epilepsy community and feasible. Our findings can help optimise trial design and support the case for funding.

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**COMPETING INTERESTS**

Declarations of interest: none.

**Role of the funding source**

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