

Received: 20 December 2018

Revised: 23 January 2019

Accepted: 24 January 2019

DOI: 10.1002/epi4.12306

## FULL-LENGTH ORIGINAL RESEARCH

Epilepsia Open®

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# The provision of epilepsy care across Europe 2017: A 17-year follow-up survey

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## Funding information

European Union (Directorate General for Health and Food safety), Grant/Award Number: 2014/1/1995648

## Summary

**Objective:** To assess the resources available in the provision of epilepsy care across Europe and the developments since the International League Against Epilepsy (ILAE) survey published in 2003 (data collected in 2000).

**Methods:** An updated online version of the European Epilepsy Services Inventory was distributed to all European chapters of the ILAE (N = 47) and responses were obtained from 33 chapters (response rate 70%). To assess trends and allow comparisons with the survey published in 2003, the responding countries were divided into 4 groups (Western, Central, Southern, and Eastern). Responses from European Union (EU) member states are reported as a subgroup (N = 23), since the current survey is a part of the EU-funded European Study on the Burden and Care of Epilepsy (ESBACE, [www.esbace.eu](http://www.esbace.eu)).

**Results:** The total number of physicians involved in epilepsy care had increased since 2000, with the largest increase seen for neurologists. The gap between the best- and the least-provided areas with regard to the competence of the providers had diminished. However, the density of comprehensive multidisciplinary epilepsy teams had not changed to any greater degree. The main problems reported by the chapters were to a large extent the same as in 2000 and included lack of specialists and specialist care, lack or underuse of epilepsy surgery, and problems regarding financing and resource allocation. Several chapters also highlighted problems with healthcare structure and organization.

**Significance:** Although there have been some improvements concerning the availability of care for people with epilepsy in Europe over the last 17 years, there are still a number of problem areas with little improvement or where there are important regional differences.

## KEY WORDS

epilepsy, healthcare policy, public health

\*For ESBACE: refer to separate list of consortium collaborators in Appendix 1.

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## 1 | INTRODUCTION

The Commission of European Affairs (CEA) of the International League Against Epilepsy (ILAE) performed a survey of the provision of epilepsy care in Europe, which was published in 2003 (data collected in 2000).<sup>1</sup> The study assessed the needs and resources available in the provision of basic epilepsy care across Europe by use of a structured inventory, the European Epilepsy Services Inventory (EESI). The 2000 survey revealed differences between and within countries and shortage of resources for the provision of epilepsy care. The ongoing EU-funded European Study on the Burden and Care of Epilepsy (ESBACE, [www.esbace.eu](http://www.esbace.eu)) aims among other things to provide data on the current provision of epilepsy care in Europe, with emphasis on the European Union (EU) member states. One of the objectives was therefore to repeat the 2000 inventory to assess the current situation as well as to describe in what ways the provision of epilepsy care in Europe has changed over the last 17 years. Herein we report the findings of the repeat survey, with subgroup analyses of participating chapters from EU member states.

## 2 | MATERIAL AND METHODS

### 2.1 | European Epilepsy Services Inventory

The EESI questionnaire from the 2000 survey,<sup>1</sup> updated with current antiepileptic drugs (AEDs) and questions regarding the availability of registers of relevance for monitoring epilepsy care, was converted to an online form. The EESI contains 2 parts. The first part collects data on population size, number of physicians within different medical specialties, registered AEDs, and the economic availability of epilepsy care (reimbursements of visits and investigations). The second part of the EESI is more descriptive and asks responding chapters to assess which medical specialties of practitioners provide basic epilepsy care for different patient categories (children, adults, elderly, and learning disabled) in the best- and least-provided areas of the country, respectively. Categorization of the best- or least-provided areas was left to the discretion of the responding chapters. In addition, chapters were asked in an open-ended manner to describe obstacles to the provision of basic epilepsy care.

### 2.2 | Survey and analysis

Invitations were sent to all European chapters of the ILAE in October 2016, with reminders to nonresponders sent repeatedly (in total, 117 reminders were sent in 5 rounds) until June 2017. Twelve of the 14 nonresponders were from the Eastern

### Key Points

- The provision of epilepsy care was assessed in a survey of 33 European countries and compared to a similar survey 17 years ago
- There was an increase in the number of physicians involved in epilepsy care
- The gap between the least- and the best-provided areas was diminished
- More persons with epilepsy and learning disabilities were managed by neurologists
- The density of multidisciplinary epilepsy teams had not increased much
- There were still a few countries lacking epilepsy surgery programs

group and 2 were from the Western group. Responses were submitted by chapter board members, often the president. Data were analyzed using descriptive statistics and are presented at a group level. Participating countries were categorized into regions (Western, Southern, Eastern, and Central) according to the 2000 survey (new countries were categorized according to geographic location; see Table S1 for grouping). Because of the ESBACE objectives on the provision of epilepsy care in the EU, data are presented both for all ILAE European chapters and for the subgroup of EU member states.

## 3 | RESULTS

### 3.1 | Response rate and number of physicians

In total, 33 ILAE chapters responded (including 23 of 28 EU countries; Table 1). The number of physicians, neurologists, neuropsychiatrists, and other specialists involved in the treatment of epilepsy are presented in Table 2. There were considerable differences in the density of neurologists between countries. Within the EU, the reported number of neurologists per million inhabitants in each group was a median of (min-max): Western, 59 (12-81); Eastern, 109 (47-125); Southern, 49 (31-111); and Central, 102 (81-119). If countries outside the EU were included, there was more variability between countries in the Eastern region: Western, 63 (12-81); Eastern, 119 (20-299); Southern, 49 (31-111); and Central, 82 (81-119).

Compared to the survey conducted in 2000 and considering only the 26 countries responding to both surveys, the median number of practitioners was higher for all investigated medical specialties, with the exception of pediatric

**TABLE 1** Responding ILAE Chapters per geographic group

Albania	Latvia
Austria	Lithuania
Belgium	Malta
Croatia	Norway
Cyprus	Poland
Czech Republic	Portugal
Denmark	Republic of Moldova
Estonia	Romania
Finland	Russia
France	Serbia
Georgia	Slovenia
Germany	Sweden
Greece	Switzerland
Hungary	Turkey
Ireland	Ukraine
Italy	United Kingdom
Kazakhstan	

n = 33, EU countries in gray = 23.

ILAE, International League Against Epilepsy.

neurologists, for which the median number was unchanged between the surveys (Figure S1).

### 3.2 | Antiepileptic drug availability

The availability of AEDs is outlined in Table S3. Carbamazepine, clonazepam, diazepam, lamotrigine, and levetiracetam were registered in all responding countries. In addition to these drugs, gabapentin was registered in all

responding EU countries. Systems for reimbursement of drug costs are diverse, but free AEDs were reported most commonly by countries in the Southern (6/7) and Central (3/4) groups, and more seldom by countries in the Western (7/11) or Eastern groups (5/10). A similar pattern was seen if only EU countries were considered (Table 3). The remaining countries, within or outside the EU, reported that AEDs were associated with patient fees. No countries reported a total absence of financial support.

### 3.3 | Economic availability of epilepsy care

As illustrated in Table 3, outpatient visits, hospitalizations, and investigations associated with epilepsy (neuroimaging, electroencephalography [EEG], and therapeutic drug monitoring [TDM]) were free for patients in all responding countries belonging to the Central group. All other groups had countries reporting patient fees. For EU countries, investigations such as neuroimaging, EEG, and TDM were also free for the patients in all countries belonging to the Western group.

### 3.4 | Provisions of basic epilepsy care

Responding countries were asked which specialties most often provided basic epilepsy care in the best- and the least-provided areas of the country for adults, children, elderly, and learning disabled (Table 4). Several categories of physicians could be considered for each choice. Neurologists often provided for adults in the best-provided areas in 97% of responding countries (96% in EU countries), for elderly in 87% (83% in EU countries), and for the learning disabled in 81% (83%). In the least-provided areas, neurologists often provided for adults in 93% of responding countries (100% in

**TABLE 2** Number of physicians and certain specialists per million inhabitants

	All European ILAE chapters				EU			
	n	Median	Min	Max	n	Median	Min	Max
Total number of physicians	32	4280	1794	6517	23	4303	2218	6362
Speciality								
Neurologists	33	79	12	299	23	79	12	125
Neurosurgeons	32	16	5	39	22	15	5	39
Clinical neurophysiologists	15	5	1	68	8	6	2	15
Pediatricians	32	185	58	948	23	173	76	536
Pediatric neurologists	28	8	1	64	20	6	1	54
Psychiatrists	32	126	25	432	23	146	62	220
Child psychiatrists	30	16	2	77	21	17	2	47
General practitioners	32	636	65	1679	23	679	223	1679
Internists	30	304	35	1258	21	312	35	786
Geriatricians	22	14	1	72	15	19	2	72

n, number of reporting ILAE chapters.

ILAE, International League Against Epilepsy.

**TABLE 3** Patient costs for epilepsy care in responding countries

All countries															
Group	Public (free of charge)					Partly free (patient fees)					No financial support				
	W	S	C	E	Total	W	S	C	E	Total	W	S	C	E	Total
<b>No. responses</b>	<b>11</b>	<b>7</b>	<b>4</b>	<b>10</b>	<b>32</b>	<b>11</b>	<b>7</b>	<b>4</b>	<b>10</b>	<b>32</b>	<b>11</b>	<b>7</b>	<b>4</b>	<b>10</b>	<b>32</b>
Outpatient visits	7	5	4	7	23	4	2	0	3	9	0	0	0	0	0
Hospitalizations	7	7	4	8	26	4	0	0	2	6	0	0	0	0	0
Antiepileptic drugs	7	6	3	5	21	4	1	1	5	11	0	0	0	0	0
Investigations															
Neuroradiology	10	5	4	5	24	1	2	0	5	8	0	0	0	0	0
EEG	10	5	4	6	25	1	2	0	4	7	0	0	0	0	0
Blood chemistry	10	5	4	7	26	1	2	0	3	6	0	0	0	0	0
TDM	10	5	4	5	24	1	2	0	3	6	0	0	0	2	2
EU															
Group	W	S	C	E	Total	W	S	C	E	Total	W	S	C	E	Total
<b>No. responses</b>	<b>9</b>	<b>5</b>	<b>4</b>	<b>5</b>	<b>23</b>	<b>9</b>	<b>5</b>	<b>4</b>	<b>5</b>	<b>23</b>	<b>9</b>	<b>5</b>	<b>4</b>	<b>5</b>	<b>23</b>
Outpatient visits	6	3	4	4	17	3	2	0	1	6	0	0	0	0	0
Hospitalizations	6	5	4	4	19	3	0	0	1	4	0	0	0	0	0
Antiepileptic drugs	6	4	3	3	16	3	1	1	2	7	0	0	0	0	0
Investigations															
Neuroradiology	9	3	4	3	19	0	2	0	2	4	0	0	0	0	0
EEG	9	3	4	3	19	0	2	0	2	4	0	0	0	0	0
Blood chemistry	9	3	4	4	20	0	2	0	1	3	0	0	0	0	0
TDM	9	3	4	3	19	0	2	0	2	4	0	0	0	0	0

W, Western; S, Southern; C, Central; E, Eastern; EEG, electroencephalography; TDM, therapeutic drug monitoring. The table shows in how many countries patients are required partly or completely to pay fees for certain aspects of their epilepsy care.

EU countries), for elderly in 77% of the countries (77% in EU countries), and for patients with learning disorders in 60% (73% in EU countries). Pediatric neurologists often provided epilepsy care for children in the best-provided areas in 93% of responding countries (100% in EU countries) and in the least-provided areas in 68% of all chapters (75% in EU countries).

### 3.5 | Multidisciplinary epilepsy teams

The density of epilepsy teams is illustrated in Figure 1 (see Table S2 for details). All countries in the Western group reported existence of teams with epilepsy surgery programs, whereas the Central, Southern, and Eastern groups had at least one responding country without such a program (overall 21%, EU countries 13%). The regional density of multidisciplinary teams with epilepsy surgery programs was one team per 9 million inhabitants for all ILAE chapters (range, no team to one team per one million inhabitants), and one team per 5.48 million inhabitants for EU countries (range, no team to one team per one million inhabitants). The regional density of multidisciplinary teams without epilepsy surgery programs was one

team per 3.94 million inhabitants for all ILAE chapters (range, no team to one team per 0.2 million inhabitants), and one team per 2.98 million inhabitants for EU-countries (range, no team to one team per 0.45 million inhabitants). Six of 33 countries (18%) reported no comprehensive multidisciplinary teams at all, including 5 of 23 EU countries (22%). The Southern, Central, and Eastern groups all contained at least one country reporting the absence of multidisciplinary teams with surgery programs, whereas all countries in the Western group reported existence of such teams. If only the 26 of 33 chapters that responded also to the 2000 inventory were considered, no clear differences in density of multidisciplinary teams with and without surgery programs could be seen<sup>1</sup>; the highest regional density in the present survey was 0.97 surgery teams per one million inhabitants (0.8 in 2000) and 4.4 nonsurgery teams per million inhabitants (5.3 in 2000).

### 3.6 | Registers

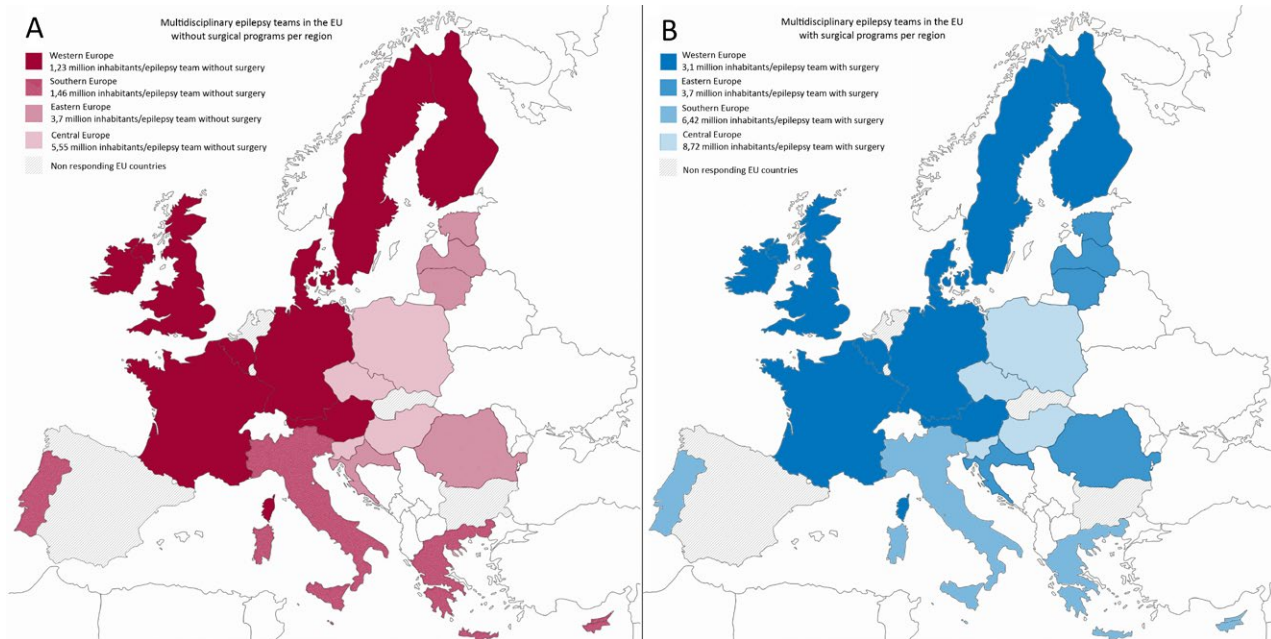
The updated EESI also assessed the availability of registers of value for monitoring epilepsy care, which was not done in

**TABLE 4** Provision of basic epilepsy care by different specialists in the best- and least-provided areas within each country across EU countries (A and B) and all countries (C and D)

<b>A. Best-provided areas: EU countries, n = 18-22<sup>a</sup></b>							<b>B. Least-provided areas: EU countries, n = 19-23<sup>a</sup></b>						
	Adults	Children	Elderly	Learning disabled			Adults	Children	Elderly	Learning disabled			
Physicians													
General practitioner	4	3	4	3		Physicians	6	5	4	5			
Internist	0	0	1	1		General practitioner	1	0	3	2			
Neurologists	22	3	19	19		Internist	22	4	17	16			
Pediatricians	0	9	0	5		Neurologists	0	11	0	4			
Pediatric neurologists	0	22	0	12		Pediatricians	0	15	0	6			
Psychiatrists	1	0	2	3		Pediatric neurologists	2	0	2	2			
Child psychiatrists	0	2	0	2		Psychiatrists	0	2	0	1			
Paramedics	0	0	0	0		Child psychiatrists	0	0	0	0			
						Paramedics	0	0	0	0			
<b>C. Best-provided areas: all countries, n = 27-31<sup>a</sup></b>							<b>D. Least-provided areas: all countries, n = 26-30<sup>a</sup></b>						
	Adults	Children	Elderly	Learning disabled			Adults	Children	Elderly	Learning disabled			
Physicians													
General practitioner	4	3	4	3		Physicians	9	8	7	8			
Internist	0	0	1	1		General practitioner	2	1	4	3			
Neurologists	30	8	27	25		Internist	28	7	23	18			
Pediatricians	0	12	0	6		Neurologists	2	17	2	7			
Pediatric neurologists	2	28	2	17		Pediatricians	1	19	1	9			
Psychiatrists	1	0	2	4		Pediatric neurologists	2	0	2	3			
Child psychiatrists	0	3	1	3		Psychiatrists	0	3	0	2			
Paramedics	1	1	1	1		Child psychiatrists	1	1	1	1			

EU, European Union.

<sup>a</sup>Not all chapters answered all possibilities.



**FIGURE 1** The map shows the regional density of multidisciplinary epilepsy teams without (A) and with (B) surgical programs in the responding European Union (EU) countries. Hatched countries on the maps represent nonresponding EU countries; white countries are not member states in the EU

2000. Existence of an International Classification of Diseases (ICD)–based register of patient visits was reported by 73% of all ILAE chapters (70% of chapters within in the EU), a drug database was reported by 70% of all ILAE chapters (74% within EU), and other registers of relevance for epilepsy care were reported by 30% of ILAE chapters and 26% of EU chapters. Chapters belonging to the Western group most frequently reported the existence of other registers of value for the monitoring of epilepsy care, for instance, national quality registers.

### 3.7 | Problems in the provision of care

Responding chapters were asked to list the main obstacles to the provision of epilepsy care. Problems regarding financing and resource allocation were reported as most important by 7 chapters (4 EU chapters), lack of specialists and specialist care was reported as most important by 6 chapters (5 EU chapters), and lack or underuse of epilepsy surgery was reported as most important by 5 chapters (3 EU chapters). Also reported as most important was lack of comprehensive care (4 chapters, 3 EU chapters), insufficient professional education or expertise (4 chapters, 3 EU chapters), high costs of AEDs (4 chapters, 1 EU chapter), and stigma or social problems (3 chapters, 2 EU chapters). Other problems mentioned concerned healthcare structure and organization and included lack of structural quality criteria, lack of formal standards for care, lack of follow-up from the National Board of Health and Welfare, delays and gaps in care pathways, and lack of epidemiologic surveillance.

## 4 | DISCUSSION

Herein we report the results of a pan-European inventory of epilepsy care. The European Epilepsy Services Inventory (or EESI) concentrates on the prerequisites for and the provision of basic epilepsy care. The results give several important insights into the current state of basic epilepsy care in Europe and the challenges faced by its providers. There are few reports on the provision of epilepsy care in Europe. In the United Kingdom, there had been little improvement in the provision of epilepsy care between 2009 and 2012,<sup>2</sup> a finding that is in line with our results.

By re-use of the previously developed EESI form, our findings can be compared to data from 2000, and therefore at least to some extent allow reflections on the development of epilepsy care in Europe over the last 17 years. It must be remembered, however, that the European countries responding to the survey were not identical between the first and the second survey. Of the 33 answering countries in 2017, a total of 26 also participated in the 2000 survey. Another 6 countries answered the 2000 survey only, whereas still another 7 countries answered the 2017 survey only.

As in the earlier survey, there were large variations across Europe—somewhat less in EU countries—concerning the number of physicians and specialists per million inhabitants. For certain specialties (neurology, clinical neurophysiology, pediatrics, psychiatry, and internal medicine) the ranges were larger, with higher maximal numbers in non-EU countries (Table 2).

Positive changes include higher numbers of physicians involved in epilepsy care, especially neurologists and pediatricians, but also to some extent pediatric neurologists. The reported total number of physicians per million inhabitants in Europe has increased since the 2000 inventory. The increased availability of neurologists may be reflected in the diminished gap between the best- and the least-provided areas with regard to the competence of the providers, as seen in Table 4. The majority of adults with epilepsy are reported to be often treated by neurologists both in the best- (97%) and least-provided areas (93%) as compared to the 2000 survey where the proportions were 88% and 47%. Persons with learning disorders are also more commonly treated by neurologists today: 81% in the best-provided vs 60% in the least-provided areas, compared to 53% and 34% in the 2000 survey. Although the numbers show an improvement, the findings nonetheless demonstrate a remaining gap in the care provided to persons with learning disabilities, who remain a relatively neglected group. This observation is in agreement with a recent national survey on the care of this patient group.<sup>3</sup> Treatment of the epilepsy aside, neurologists are often paramount in ensuring that epilepsy does not hamper adequate attention to somatic or psychiatric/neuropsychiatric comorbidities, family support, and meaningful occupation. Children with epilepsy were often treated by pediatric neurologists in the best-provided areas, but this was not the case in the least-provided areas in many chapters, indicating substantial room for improvement.

There also seems to be some regional catch-up in the provision of epilepsy care. Although differences between the regions still exist, for instance, regarding the availability of AEDs, a finding in agreement with another recent report,<sup>4</sup> regional differences seem less evident than in the last survey, especially within the EU. For countries within the EU, the high cost of AEDs did not seem to be the most important problem and was reported as such by only 1 of 23 (4%) EU chapters, in contrast to the whole group, from which 4 of 33 chapters considered this an important problem (12%).

However, although the reported total number of physicians has increased, the density of epilepsy teams—with or without surgery programs—has not changed to any greater degree. At least one chapter in each region reported total absence of multidisciplinary teams without a surgical program. The lack of such comprehensive teams indicates that people with epilepsy do not obtain the services needed to optimize treatment, consider comorbidity, and give necessary psychosocial support.<sup>5</sup> In addition, use of epilepsy specialist nurses and nurse practitioners may constitute cost-effective ways of providing epilepsy care.<sup>6,7</sup>

In all regions outside the Western group, some chapters also reported total absence of epilepsy surgery programs, which highlights the need for international collaboration in the management of medically refractory patients. Cross-border cooperation is a commitment from the EU commission within the frame of the European Reference Networks

(<https://www.eurordis.org/content/about-european-reference-networks>), which include EpiCARE, the European Reference Network for Complex and Rare Epilepsies.

The lack of multidisciplinary epilepsy teams and the qualitative reports from several chapters of a lack of epilepsy specialists are the most important obstacles to providing basic epilepsy care. This finding indicates that the increased number of neurologists has not been paralleled by an increase in the resources devoted to epilepsy care, despite epilepsy being the most common chronic neurologic disorder. This situation contrasts with several commitments from policymakers, for example, the European Written Declaration on Epilepsy, which was adopted by the EU parliament in 2011 and which calls on the European Commission and European Council to prioritize epilepsy as a major disease that imposes a significant burden across Europe (<https://www.epilepsy.org.uk/news/news/european-written-declaration-epilepsy-adopted-european-parliament>). Providing adequate resources for epilepsy care is a national responsibility, and our findings should spur efforts from policymakers to this effect. One possible measure could be national guidelines stipulating lowest acceptable level of care. Another important area is further studies on how to increase access to care in the least-provided areas.

The strengths of this study include that the chapter representatives answering the survey probably are those most updated on the provision of basic epilepsy care in their countries. In addition, because this was a repeat survey, it offered some possibilities for comparison with the situation in Europe in 2000 when the first survey was performed. The weaknesses include lower response rate than the first survey, different chapters in the regions participating in each survey, and that some of the answers may be assessments not always based on published data. The survey was undertaken with the aim of providing aggregated regional data, in line with the ESACE objective, whereas developments in individual countries are a national responsibility.

In conclusion, there have been some improvements concerning the availability of care for people with epilepsy in Europe over the last 17 years, but there are still a number of problem areas where there has been little improvement or where there are important regional differences.

## ACKNOWLEDGMENT

Funded by the European Union (DG SANTE C-Public health—Directorate General for Health and Food Safety grant no: 2014/1/1995648).

## DISCLOSURE OF CONFLICTS OF INTEREST

J.Z. is organizing a scientific meeting at Gothenburg University in 2019 sponsored by UCB and Eisai and has

been a subinvestigator in clinical trials sponsored by GW Pharmaceuticals and SK Life Science. T.T. is an employee of Karolinska Institutet; is associate editor for *Epileptic Disorders*; has received speaker's honoraria to his institution from Eisai, UCB, Sandoz, and Actavis, honoraria to his institution for advisory boards from UCB and Eisai, and research support from Stockholm County Council, CURE (Citizens United for Research in Epilepsy), GlaxoSmithKline, UCB, Eisai, Bial and Novartis. Jakob Christensen has received honoraria for serving the Scientific Advisory Board of UCB Nordic and Eisai AB. Jakob Christensen has also received honoraria from UCB Nordic and Eisai AB for giving lectures and has received funding for a trip for UCB Nordic. Jakob Christensen is involved in clinical trials involving the following companies: Pfizer, Novartis, Eisai AB, and Sage Therapeutics, Inc. The other authors report no disclosures relevant to this research activity. 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.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**How to cite this article:** Zelano J, Klecki J, Christensen J, Tomson T, Malmgren. The provision of epilepsy care across Europe 2017: A 17-year follow-up survey. *Epilepsia Open*. 2019;4:144-152. <https://doi.org/10.1002/epi4.12306>

## APPENDIX 1

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