Appendix 1 The EpAID trial nurse self-completion diary version 1.4

Screening ID:	**W**						
Nurse TIN no:							

EpAID Epilepsy Nurse Self-Completion Diary Instructions

Thank you for agreeing to complete this diary. Your help is much appreciated.

If you have any problems with any aspect of the data collection then please contact: .

The diary will collect data for one month at a time and is to be returned to the university team at the end of each month in the freepost envelope provided or electronically to: ,

You will receive an adequate number of diaries during your training session.

SHEET 1 AND SUBSEQUENT SHEETS

Please use sheet one and continuation sheets to give details of each episode of care that you provide and the activity that you undertook during each intervention with that patient.

To minimise problems with recall, please complete the diary on a daily basis. If time permits and it does not compromise patient care, then please complete the individual patient entries after each consultation.

Date and time- please give details so that we can establish how often and for how long you saw the patient.

Location - Please specify where you saw the patient on that occasion (e.g. Home, Clinic, GP Surgery, Telephone, or Other (please specify this location).

Reasons For intervention – From the words provided, please describe the intervention **using the corresponding numbers**, selecting all that apply. **Please enter the main reason for the intervention in the first box and any other reasons in the second box.**

Details of care given – Please list ALL the activities that you have completed during the consultation, **using the numbers** that correspond to the list of words. We want to capture all the activities that you undertake with your patients however minor they might seem. **Please enter the main reason for the intervention in the first box and any other reasons in the second box.**

Screening ID: | W | | | | | |

Nurse TIN no: |

Sheet One Activity Details

Date of Intervention	Start time of Intervention	Location of intervention *(Home, Clinic, GP Surgery, Telephone, Other)*	Reason for Intervention (Please use numbers) *(**1**. Assessment; **2.** Counselling; **3**. Education; **4**. Health Facilitation; **5**. Management Planning; **6**. Monitoring Epilepsy; **7.** Monitoring Health/Behaviour; **8.** Monitoring Treatment; **9.** Responding to Urgent Health or Behavioural Concern; **10.** Other)*		Details of care given (Please use numbers) *(**1.** Education of Family Carer; **2.** Education of Paid Staff; **3**. Education of Patient; **4**. Health Facilitation; **5**. Investigation Request; **6**. Management Planning; **7**. Medication Issues; **8**. Prescribing; **9**. Review and Monitoring of Medication; **10**. Other)*		End time of Intervention
			Main Reason	***Other Reason(s)***	***Main Reason***	***Other Reason(s)***	

Appendix 2 The EpAID trial Epilepsy and Learning Disabilities Quality of Life questionnaire version 1.6

PIN	**P**	**Visit:**	**Screening ID Number:** **W**
Centre Name:		B1,B2,F1,F2	d d m m y y y y
Initials:		**Date form started:**	/ /

Modified ELDQoL Questionnaire - original courtesy of the Departments of Primary Care and Neurosciences, University of Liverpool.

EPILEPSY AND LEARNING DISABILITIES

QUALITY OF LIFE (ELDQoL) QUESTIONNAIRE

ABOUT THESE QUESTIONS

1. These questions ask about how the participant has been in the last four weeks. We are interested in how much the participant's daily life and activities have been affected by his/her epilepsy and its treatment.

2. We are interested in **your views** about how things have been for the participant. Your opinions are very important to us, and we hope you will take time to complete the questionnaire. We do not think it will take more than 15-20 minutes for you to do so.

3. Some people with epilepsy have more than one type of seizure. If the participant experiences different types of seizures, please answer the questions as they apply to the **most severe** seizures, in your opinion, that he/she has.

4. Most of the questions can be answered simply by ringing a number next to the answer that applies to the participant. Sometimes you are asked to write in a number.

5. We want to know how things have been **in the last four weeks**. If you cannot remember, do not know, or are unable to answer a particular question, please write that in.

6. Your name and address do not appear anywhere in this booklet. The information you give us will be treated as strictly confidential.

A. Has the participant had a seizure in the last four weeks? (*Please circle*)

Yes No

First some questions about the seizures the participant has. Please answer about seizures in the last four weeks. If the participant has more than one type of seizure, please think about the most severe seizures he/she has, when answering the questions. Please be sure to answer every question.

1. How severe have the participant's seizures been in the last four weeks?

Very severe	.....	1	
Somewhat severe	.....	2	
Moderate	.....	3	
Mild	.....	4	
Can't say	.....	5	4

2. In the last four weeks, do you think the participant was aware of his/her surroundings during seizures?

Yes, during all seizures	.....	1	
Yes, during most seizures	.....	2	
Yes, during some seizures	.....	3	
No, not during any seizures	.....	4	
Can't say	.....	5	5

3. In the last four weeks, did the participant blank out/lose consciousness during any of his/her seizures? If yes, generally for how long?

Yes, for less than 1 minute	.....	1	
Yes, for between 1-2 minutes	.....	2	
Yes, for between 2-5 minutes	.....	3	
Yes, for more than 5 minutes	.....	4	
No, did not blank out or lose consciousness in any seizures	.....	5	
Can't say	.....	6	6

4. In the last four weeks, when the participant had seizures, how often did he/she fall to the ground?

Always	 1	
Usually	 2	
Sometimes/rarely	 3	
Never	 4	
Does not apply - participant does not stand independently/participant wheelchair bound	 5	
Can't say	 6	7

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5. In the last four weeks, was the participant ever confused, disorientated or non- responsive after seizures?

Yes, always	 1	
Yes, often	 2	
Yes, sometimes/rarely	 3	
No, never	 4	
Can't say	 5	8

---

6. In the last four weeks, **if** the participant was confused, disorientated or non- responsive after seizures, how long did this usually last?

Usually lasted less than 1 minute	 1	
Usually lasted for between 1-5 minutes	 2	
Usually lasted for between 6 minutes - 1 hour	 3	
Usually lasted for more than 1 hour	 4	
Participant never seemed confused/disorientated/non-responsive	 5	
Can't say	 6	9

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7. How often was the participant distressed after seizures in the last four weeks?

Always	 1	
Usually.	 2	
Sometimes/rarely	 3	
Never	 4	
Can't say	 5	10

---

8. In the last four weeks, how often did the participant wet him/herself during seizures?

Always	 1	
Usually	 2	
Sometimes/rarely	 3	
Never	 4	
Can't say – participant has no control of bladder	 5	11

9. In the last four weeks, how often did the participant soil him/herself during seizures?

Always	.....	1	
Usually	.....	2	
Sometimes/rarely	.....	3	
Never	.....	4	
Can't say – participant has no control of bowels	.....	5	12

10. In the last four weeks, did the participant suffer any injury to the mouth, cheek or tongue during a seizure?

Always	.....	1	
Usually	.....	2	
Sometimes/rarely	.....	3	
Never	.....	4	
Can't say	.....	5	13

11. In the last four weeks, did the participant suffer any injury other than to the mouth, cheek or tongue during a seizure?

Always	.....	1	
Usually	.....	2	
Sometimes/rarely	.....	3	
Never	.....	4	
Can't say	.....	5	14

12. How upset was the participant by the injury/injuries he/she suffered during seizures in the last four weeks?

Very upset	.....	1	
Somewhat upset	.....	2	
Not very upset	.....	3	
Not at all upset	.....	4	
Does not apply - no injuries	.....	5	
Can't say	.....	6	15

13. In the last four weeks, when the participant recovered from his/her seizures, how often did he/she appear sleepy or subdued?

Always	.....	1	
Usually	.....	2	
Sometimes/rarely	.....	3	
Never	.....	4	
Can't say	.....	5	16

14. In the last four weeks, when the participant had seizures, how quickly could he/she usually return to what he/she was doing?

In less than 1 minute	.....	1	
In between 1-5 minutes	.....	2	
In between 6 minutes - 1 hour	.....	3	
In over 1 hour	.....	4	
Can't say	.....	5	17

Now some more detailed questions about any injuries the participant experienced in the last four weeks, as a result of his/her seizures.

15. In the past four weeks, how many times did the participant injure him/herself during a seizure?

Not at all	.....	0	Go to Q 17
Number of times *(please write in)*	.....		Answer Q 16
			18

16. Did he/she suffer any of the following injuries as a result of having a seizure in the last four weeks?

a) An injury to his/her head which required assessment and/or treatment at hospital?

Yes	.....	1	
No	.....	2	19

b) An injury to his/her teeth or mouth which required dental or medical treatment?

Yes	.....	1	
No	.....	2	20

c) A fracture/broken bone?

Yes	.....	1	
No	.....	2	21

d) Bruising or friction burns to any part of the body?

Yes	.....	1	
No	.....	2	22

e) Cuts or grazes to any part of the body?

Yes	.....	1	
No	.....	2	23

f) Any other injury? (*please tell us what*):

Yes	.....	1	
No	.....	2	24

g) Please list other injuries:

1……..……..……

2……..……..……

Now a few questions about the drugs the participant takes for epilepsy

17. In the last four weeks, how well do you think the participant's seizures have been controlled by the drugs he/she is taking?

Very well controlled	.....	1	
Fairly well controlled	.....	2	
Not very well controlled	.....	3	
Not controlled at all	.....	4	
Can't say	.....	5	25

18. Below is a list of problems people sometimes have with the drugs they take for their epilepsy. During the last four weeks, has the participant had any of the problems listed **which you think may have been caused by the drugs** he/she takes for epilepsy?

For each of the things listed, if it has always been a problem in the last four weeks, ring 1; if it has often been a problem, ring 2; and so on. Please answer every item.

	Always a problem	Often a problem	Sometimes/ rarely a problem	Never a problem	Can't say	
A. Unsteadiness/dizziness	1	2	3	4	5	26
B. Tiredness	1	2	3	4	5	
C. Restlessness	1	2	3	4	5	
D. Hyperactivity	1	2	3	4	5	
E. Nervousness	1	2	3	4	5	
F. Headache	1	2	3	4	5	
G. Problems with skin, e.g. rash	1	2	3	4	5	
H. Disturbed vision	1	2	3	4	5	
I. Upset stomach/nausea	1	2	3	4	5	
J. Difficulty paying attention	1	2	3	4	5	
K. Trouble with mouth or gums	1	2	3	4	5	
L. Shaky hands/tremor	1	2	3	4	5	
M. Weight gain	1	2	3	4	5	
N. Weight loss	1	2	3	4	5	
O. Sleepiness/drowsiness	1	2	3	4	5	
P, Memory problems	1	2	3	4	5	
Q. Disturbed sleep	1	2	3	4	5	
R. Loss of appetite	1	2	3	4	5	
S. Behaviour problems (e.g. temper tantrums, irritability or agitation)	1	2	3	4	5	44

18T. Any other problems (please list in the spaces below):

1……1……2……3……4

2……1……2……3……4 46

Now some questions about how the participant has been generally. Please think about how the participant has been over the last four weeks, compared to how he/she is normally.

19. How aware has the participant been of his/her surroundings/things going on around him/her, in the last four weeks?

Very aware …… 1

Fairly aware …… 2

Not very aware	.....	3	
Not at all aware	.....	4	
Can't say	.....	5	47

20. How often, in the last four weeks, did the participant have problems sleeping (either difficulty falling asleep, waking during the night, or waking early)?

Always a problem	.....	1	
Often a problem	.....	2	
Sometimes/rarely a problem	.....	3	
Never a problem	.....	4	
Can't say	.....	5	48

21. How often was the participant's appetite a problem - either eating too much or too little?

Always a problem	.....	1	
Often a problem	.....	2	
Sometimes/rarely a problem	.....	3	
Never a problem	.....	4	
Can't say	.....	5	49

22. In the last four weeks, how good overall has the participant's bladder control been?

Very good	 1	
Good	 2	
Poor	 3	
Very poor	 4	
Does not apply - does not have control of his/her bladder	 5	
Can't say	 6	50

---

23. In the last four weeks, how good overall has the participant's bowel control been?

Very good	 1	
Good	 2	
Poor	 3	
Very poor	 4	
Does not apply - does not have control of his/her bowels	 5	
Can't say	 6	51

---

24. In the last four weeks, how well has the participant been able to let you know what he/she wants?

Very well	 1	
Fairly well	 2	
Not very well	 3	
Not at all well	 4	
Can't say	 5	52

---

25. In the last four weeks, how well has he/she been able to understand what you tell him/her?

Very well	 1	
Fairly well	 2	
Not very well	 3	
Not at all well	 4	
Can't say	 5	53

---

26. In the last four weeks, how well has the participant been able to pay attention to his/her favourite activities?

Very well	 1	
Fairly well	 2	
Not very well	 3	
Not at all well	 4	
Can't say	 5	54

27. How often in the last four weeks has the participant been prevented from taking part in his/her normal activities (e.g. seeing friends and relatives) by his/her seizures/epilepsy?

Always	.....	1	
Often	.....	2	
Sometimes/rarely	.....	3	
Never	.....	4	
Can't say	.....	5	55

Now some questions about the participant's mood in the last four weeks

28. Here is a list of words that carers have used to describe patient's moods. In the last four weeks, has the participant appeared:-

	Always	Often	Sometimes/ rarely	Never	Can't say	
A. Happy	1	2	3	4	5	56
B. Aggressive	1	2	3	4	5	
C. Calm	1	2	3	4	5	
D. Irritable	1	2	3	4	5	
E. Tearful	1	2	3	4	5	
F. Friendly	1	2	3	4	5	
G. Hyperactive	1	2	3	4	5	
H. Relaxed	1	2	3	4	5	
I. Sad	1	2	3	4	5	
J. Agitated	1	2	3	4	5	
K. Cheerful	1	2	3	4	5	
L. Restless	1	2	3	4	5	
M. Tantrum-prone	1	2	3	4	5	
N. Frustrated	1	2	3	4	5	
O. Withdrawn	1	2	3	4	5	
P. Cooperative/helpful	1	2	3	4	5	71

Appendix 3 Safety procedures and adverse events

Reporting processes

It was not expected that there would be any major negative effects on participants resulting from participating in the EpAID trial. No clinically indicated treatments were withheld in either arm of the trial. However, SAEs that could have been expected in association with participation in the trial included an increase in seizure frequency or severity, occurrence of uncontrolled seizures requiring paramedic support or hospital admission and emergence of AED-related adverse effects.

The PI at each cluster site was responsible for recording all SAEs and reporting them to the chief investigator, via the trial co-ordinator, on trial SAE forms. The chief investigator then reported all SAEs to the sponsor. Any SAEs classified as 'related' and 'unexpected' were to be reported to the main research ethics committee within 15 days of the chief investigator becoming aware of them.

Adverse events

An adverse event was defined as any untoward medical occurrence in a participant involved in the trial. Adverse events occurring from time to time in patients participating in this trial in both the TAU arm and the intervention arm were generally not serious in nature and were not considered significant in terms of the safety assessment. They were not recorded unless considered serious, as defined in the following section.

Serious adverse events

A SAE was defined as any untoward medical occurrence that:

- resulted in death
- was life-threatening
- required hospitalisation or prolongation of existing hospitalisation
- resulted in persistent or significant disability or incapacity
- consisted of a genetic abnormality or birth defect
- was otherwise considered medically significant by the investigator.

Serious adverse events that might have been expected in the EpAID trial participants were:

- increased seizure frequency or severity
- the occurrence of uncontrolled seizures requiring paramedic support or hospital admission
- the emergence of AED-related adverse effects
- any event that the treating clinician would expect in a patient with an ID and epilepsy.

For each SAE identified the likely cause, in the view of the local PI (either EpAID trial related or not EpAID trial related), and the outcome (recovered, recovered with sequelae, ongoing, unknown and death) were recorded along with the start date, the criteria for designation, expectedness and causality.

Hospital admissions

In adults with an ID, regardless of whether or not they have epilepsy, there are several causes of hospital admission that are relatively common and would be expected and unrelated to participation in the trial. Admissions to hospital for these reasons were not reported as SAEs unless a participant's local clinical team considered that an admission primarily for one of the reasons on the list was nevertheless directly or indirectly associated with the participant's involvement in the trial. These causes of hospital admission are:

- constipation
- complications of diabetes mellitus
- respiratory infections
- asthma
- cellulitis
- dental infections
- kidney disease.

Serious adverse events reported

The complete list of adverse events reported is provided in *Table 32*.

TABLE 32 Complete list of SAEs reported

Site	Person identification number	SAE	Consequence	Caused by EpAID trial	Outcome
01	1	Admitted for prolonged seizures	Hospitalisation	No	Unknown
01	4	Admitted for prolonged seizures	Hospitalisation	No	Unknown
01	12	Hospitalised for management of deep-vein thrombosis	Hospitalisation	No	Resolved
01	12	Admitted following 2–3 weeks of poor eating and drinking	Hospitalisation	No	Unknown
01	19	Admitted for uncontrolled seizures secondary to poor food and fluid intake and medication compliance	Hospitalisation	No	Unknown
02	2	Admitted for back pain and laboured breathing	Hospitalisation	No	Resolved
02	3	Admitted because of coughing and general lethargy alongside associated foul-smelling urine	Hospitalisation	No	Resolved
02	3	Admitted following five seizures overnight	Hospitalisation	No	Resolved
02	4	Admitted because of increased seizure activity	Hospitalisation	No	Resolved
02	6	Percutaneous endoscopic gastrostomy tube had fallen out overnight. Admitted for re-siting. Discharged same day	Hospitalisation	No	Resolved
02	10	Admitted to hospital with community-acquired pneumonia	Hospitalisation	No	Resolved
02	10	Admitted to hospital following repeated seizures despite rescue medication	Hospitalisation	No	Resolved
02	14	Admitted for mental health breakdown	Hospitalisation	No	Ongoing
02	21	Pneumonia and multiple organ failure	Death	No	Death
02	21	Constipation	Hospitalisation	No	Resolved

TABLE 32 Complete list of SAEs reported (*continued*)

Site	Person identification number	SAE	Consequence	Caused by EpAID trial	Outcome
04	1	Participant admitted as had been difficult to rouse and was not taking food or fluids	Hospitalisation	No	Unknown
04	2	Seizures at respite care, rescue medication administered, further seizures and raised temperature	Hospitalisation	No	Resolved
04	2	Cluster of seizures	Hospitalisation	No	Resolved
04	3	Unwitnessed seizure/fall	Hospitalisation	No	Resolved
05	5	Previously diagnosed with malignant tumour. Epilepsy relapsed as could not tolerate medication	Hospitalisation	No	Unknown
05	5	Inoperable abdominal tumour	Other	No	Unknown
05	5	Patient had a terminal illness	Death	No	Death
05	22	Prolonged seizures that required hospitalisation to stabilise	Hospitalisation	No	Resolved
06	5	Routine change of baclofen, no complications	Hospitalisation	No	Resolved
06	5	High temperature with possible underlying renal infection	Hospitalisation	No	Resolved
06	11	Admitted to hospital because of breathing difficulties arising from chest infection	Hospitalisation	No	Resolved
07	19	Mini stroke	Hospitalisation	No	Resolved
07	19	Participant fell and hit head. Admitted but no cause found	Hospitalisation	No	Unknown
07	19	Participant fell and hit head. Admitted but no cause found	Hospitalisation	No	Unknown
07	19	Participant fell downstairs while carrying a bag of rubbish and sustained small fracture to the skull	Hospitalisation	No	Unknown
08	13	Death from natural causes: aspiration of blood following bleeding oesophagitis	Death	Yes	Death
08	14	Seizures continued after administration of rescue medication	Hospitalisation	No	Resolved
08	14	Seizures continued after administration of rescue medication	Hospitalisation	No	Resolved
08	16	Admitted for low pulse rate and hypertension; treated for infection	Hospitalisation	No	Unknown
08	16	Treated for infection	Hospitalisation	No	Resolved
08	16	Hospitalisation for re-siting of percutaneous endoscopic gastrostomy tube	Hospitalisation	No	Resolved
08	16	Admitted for treatment of chest infection	Hospitalisation	No	Resolved
08	17	Admitted for further administration of rescue medication	Hospitalisation	No	Unknown
08	17	Admitted for administration of further rescue medication to control seizures	Hospitalisation	No	Resolved
09	1	Admitted to hospital following blood test. Patient aspirated, resulting in pneumonia and collapsed lung	Death	No	Death

continued

TABLE 32 Complete list of SAEs reported (*continued*)

Site	Person identification number	SAE	Consequence	Caused by EpAID trial	Outcome
09	2	Fell during seizure, sustained a broken leg in two places	Hospitalisation	No	Unknown
09	5	In hospital since November 2015, death from respiratory causes	Death	No	Death
09	5	Feeding tube dislodged, pneumonia delayed surgical re-implantation	Other	No	Ongoing
09	9	Admitted to hospital because of prolonged clonic seizures	Hospitalisation	No	Unknown
09	9	Long clonic seizure, GP thought patient was dehydrated	Hospitalisation	No	Resolved
09	14	Hospitalisation after seizure during which the participant fell to the floor and broke an ankle	Hospitalisation	No	Unknown
09	20	Lump in breast	Other	No	Unknown
11	5	Multiple infections, acute bronchiolitis, enterocolitis (*Clostridium difficile*), urinary tract infection	Hospitalisation	No	Ongoing
11	5	Attended A&E for low oxygen saturation. Suffered respiratory arrest	Death	No	Death
11	10	Head injury following a fall after a seizure	Hospitalisation	No	Resolved
13	13	Admitted because of epilepsy episode but diagnosed with a chest infection	Hospitalisation	No	Resolved
15	29	18 seizures in 24 hours, which did not respond to rescue medication	Hospitalisation	No	Resolved
15	29	Assumed post-ictal state	Hospitalisation	No	Resolved
16	5	Multiple seizures, chest infection, constipation	Hospitalisation	Response not provided by respondent	Ongoing
16	5	Continuation of condition	Hospitalisation	Response not provided by respondent	Ongoing
16	5	Increase in seizures, bowel perforation	Hospitalisation	Response not provided by respondent	Ongoing
16	12	Participant died in her sleep of a heart attack	Death	Response not provided by respondent	Death
16	16	Diagnosis of community-acquired pneumonia – CURB-65 pneumonia severity score of 2, chronic type 2 respiratory failure	Hospitalisation	No	Resolved
16	16	Admitted to hospital because of a cough. Diagnosis was community-acquired pneumonia	Hospitalisation	Response not provided by respondent	Ongoing
16	16	Admitted to hospital with a chest infection. Died of pneumonia	Death	Response not provided by respondent	Death
17	12	Participant attended A&E because of uncontrollable pain. Changes made to insulin medication	Hospitalisation	No	Ongoing

CURB-65, confusion, uraemia, respiratory rate, blood pressure, age ≥ 65 years.

Appendix 4 Scoring instructions for the Epilepsy and Learning Disabilities Quality of Life questionnaire

Scoring instructions for the 4 subscales of the re-validated version of ELDQOL

A. Seizure Severity Scale (Qs. 1 – 14)

Qs. 1, 5, 7, 8, 9, 10, 11, 13

Reverse the individual item scoring so that

1 = 4
2 = 3
3 = 2
4 =1
5 - define as a missing value so that it is not included in the calculation of the scale score

Qs. 4, 12

Reverse the individual item scoring so that

1 = 4
2 = 3
3 = 2
4 =1
5 = 0
6 - define as a missing value

Qs. 2, 14

5 - Define 5 as a missing value.
Other scores unchanged.

Qs. 3, 6

5 = 0
Define 6 as a missing value.
Other scores unchanged

Total scale score range = 10-56

B. Side-effects Profile (Qs. 17 & 18) (Only items in Q.18 used to compute sub-scale.)

Reverse the individual scoring of each of the 19 items in Q.18 so that:

1 = 4
2 = 3

3 = 2
4 =1
5 - define as a missing value

Any additional problems itemised by respondents should be recorded, but are not added to the total scale score.

Total scale score range = 19-76

C. Behaviour (Qs. 19 – 27)

Qs.19, 24, 25, 26

Define 5 as a missing value
Other scores unchanged

Qs. 20, 21, 27

Reverse scoring so that:

1 = 4
2 = 3
3 = 2
4 =1
5 - define as a missing value

Qs.22, 23

Recode so that:

5 = 4
6 – define as a missing value
Other scores unchanged

Total scale score range = 9-36

D. Mood Scale (Q. 28)

Reverse scoring of negative items (aggressive, irritable, tearful, hyperactive, sad, agitated, restless, tantrum-prone, frustrated, withdrawn), so that:

1 = 4
2 = 3
3 = 2
4 =1
5 - define as a missing value

Total Scale score range = 16-64

Appendix 5 Missing data

TABLE 33 Epilepsy and Learning Disabilities Quality of Life SSS missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n*/*N*	%	*n*/*N*	%	*n*/*N*	%
Present	Present	100/184	54.3	72/128	56.3	172/312	55.1
Present	No seizures (4 weeks)	26/184	14.1	16/128	12.5	42/312	13.5
Present	Missing	10/184	5.4	14/128	10.9	24/312	7.7
< 50% answered	No seizures (4 weeks)	1/184	0.5	1/128	0.8	2/312	0.6
< 50% answered	Missing	0/184	0.0	1/128	0.8	1/312	0.3
No seizures (4 weeks)	Present	13/184	7.1	10/128	7.8	23/312	7.4
No seizures (4 weeks)	No seizures (4 weeks)	21/184	11.4	11/128	8.6	32/312	10.3
No seizures (4 weeks)	Missing	6/184	3.3	0/128	0.0	6/312	1.9
Missing	Present	0/184	0.0	1/128	0.8	1/312	0.3
Missing	Missing	7/184	3.8	2/128	1.6	9/312	2.9

TABLE 34 Epilepsy and Learning Disabilities Quality of Life AED side effects missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n*/*N*	%	*n*/*N*	%	*n*/*N*	%
Present	Present	82/184	44.6	62/128	48.4	144/312	46.2
Present	< 50% answered	5/184	2.7	3/128	2.3	8/312	2.6
Present	No seizures (4 weeks)	18/184	9.8	17/128	13.3	35/312	11.2
Present	Missing	9/184	4.9	14/128	10.9	23/312	7.4
< 50% answered	Present	7/184	3.8	4/128	3.1	11/312	3.5
< 50% answered	< 50% answered	6/184	3.3	3/128	2.3	9/312	2.9
< 50% answered	No seizures (4 weeks)	9/184	4.9	0/128	0.0	9/312	2.9
< 50% answered	Missing	1/184	0.5	1/128	0.8	2/312	0.6
No seizures (4 weeks)	Present	10/184	5.4	10/128	7.8	20/312	6.4
No seizures (4 weeks)	< 50% answered	3/184	1.6	0/128	0.0	3/312	1.0
No seizures (4 weeks)	No seizures (4 weeks)	21/184	11.4	11/128	8.6	32/312	10.3
No seizures (4 weeks)	Missing	6/184	3.3	0/128	0.0	6/312	1.9
Missing	Present	0/184	0.0	1/128	0.8	1/312	0.3
Missing	Missing	7/184	3.8	2/128	1.6	9/312	2.9

TABLE 35 Epilepsy and Learning Disabilities Quality of Life behaviour missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n/N*	%	*n/N*	%	*n/N*	%
Present	Present	99/184	53.8	71/128	55.5	170/312	54.5
Present	< 50% answered	0/184	0.0	1/128	0.8	1/312	0.3
Present	No seizures (4 weeks)	27/184	14.7	17/128	13.3	44/312	14.1
Present	Missing	10/184	5.4	15/128	11.7	25/312	8.0
< 50% answered	Present	1/184	0.5	0/128	0.0	1/312	0.3
No seizures (4 weeks)	Present	13/184	7.1	10/128	7.8	23/312	7.4
No seizures (4 weeks)	No seizures (4 weeks)	21/184	11.4	11/128	8.6	32/312	10.3
No seizures (4 weeks)	Missing	6/184	3.3	0/128	0.0	6/312	1.9
Missing	Present	0/184	0.0	1/128	0.8	1/312	0.3
Missing	Missing	7/184	3.8	2/128	1.6	9/312	2.9

TABLE 36 Epilepsy and Learning Disabilities Quality of Life mood missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n/N*	%	*n/N*	%	*n/N*	%
Present	Present	97/184	52.7	72/128	56.3	169/312	54.2
Present	< 50% answered	1/184	0.5	0/128	0.0	1/312	0.3
Present	No seizures (4 weeks)	27/184	14.7	17/128	13.3	44/312	14.1
Present	Missing	10/184	5.4	15/128	11.7	25/312	8.0
< 50% answered	Present	1/184	0.5	0/128	0.0	1/312	0.3
< 50% answered	< 50% answered	1/184	0.5	0/128	0.0	1/312	0.3
No seizures (4 weeks)	Present	11/184	6.0	10/128	7.8	21/312	6.7
No seizures (4 weeks)	< 50% answered	2/184	1.1	0/128	0.0	2/312	0.6
No seizures (4 weeks)	No seizures (4 weeks)	21/184	11.4	11/128	8.6	32/312	10.3
No seizures (4 weeks)	Missing	6/184	3.3	0/128	0.0	6/312	1.9
Missing	Present	0/184	0.0	1/128	0.8	1/312	0.3
Missing	Missing	7/184	3.8	2/128	1.6	9/312	2.9

TABLE 37 Tonic–clonic seizures missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n*/*N*	%	*n*/*N*	%	*n*/*N*	%
Present	Present	153/184	83.2	98/128	76.6	251/312	80.4
Present	Missing	20/184	10.9	20/128	15.6	40/312	12.8
Missing	Present	3/184	1.6	2/128	1.6	5/312	1.6
Missing	Missing	8/184	4.3	8/128	6.3	16/312	5.1

TABLE 38 Modified Carer Strain Index missingness

		Treatment arm					
		Active		TAU		Overall	
Baseline	Follow-up	*n*/*N*	%	*n*/*N*	%	*n*/*N*	%
Present	Present	37/165	22.4	30/118	25.4	67/283	23.7
Present	Missing	12/165	7.3	19/118	16.1	31/283	11.0
Missing	Present	0/165	0.0	2/118	1.7	2/283	0.7
Missing	Missing	116/165	70.3	67/118	56.8	183/283	64.7

TABLE 39 Covariate missingness

	Treatment arm					
	Active		TAU		Overall	
Variable	*n*/*N*	%	*n*/*N*	%	*n*/*N*	%
Age	7/184	3.8	2/128	1.6	9/312	2.9
Accomodation	7/184	3.8	6/128	4.7	13/312	4.2
Level of ID	11/184	6.0	21/128	16.4	32/312	10.3
Deprivation Index	5/184	2.7	2/128	1.6	7/312	2.2
Number of tonic–clonic seizures	11/184	6.0	10/128	7.8	21/312	6.7

Appendix 6 Community intellectual disability team epilepsy service availability questionnaire version 1

EpAID epilepsy clinical ID questionnaire version 1.0 21 Oct 2014

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1. What catchment area does your service look after?

_____

2. Approximately how many adults are looked after within your service?

_____

3. Approximately how many adults have a diagnosis of epilepsy within your service?

Number _____ Not sure

4. Does your service maintain an updated epilepsy register? Yes / No

5. Does your service run an epilepsy clinic? Yes / No

If yes, what does it consist of?

_____

__

6. Does the LD Consultant in your team have a particular interest in epilepsy? Yes / No

COMMUNITY INTELLECTUAL DISABILITY EPILEPSY

SERVICE AVAILABILITY QUESTIONNAIRE

Name of the Community Learning

(Intellectual) Disability Team:

_____

Address: _____

_____

_____

Date: ____ / ____ / _____

7. Relevant LD Team members How many?

Consultant Psychiatrists……..

Non-consultant doctors……

Community LD nurses……. ……..

Epilepsy Nurse Specialists (ENS) ……

LD Nurses with a specialist interest in epilepsy……..

8. In general, what role does the ENS/LD nurse have in the management of someone's epilepsy?

Please tick all that are relevant

Initial assessment……

Ongoing follow-up…….

Training/care plan writing for emergency medication……

Telephone contact to support and advise families……..

Visits to support and advise families……

Liaison with other services……

Other _____

8. If there are no ENS's in your team do you have access to neurology or general hospital-based

Epilepsy Nurse Specialists?

Yes / No

If yes, what sort of access?

_____

—

9. Does your LD service have direct access to epilepsy investigations, for example EEG and brain scans? Yes / No

10. Does your service provide training to carers about the emergency treatment of prolonged seizures? Yes / No

Please continue overleaf

_____

_____

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11. Is the local learning disability service the main provider of epilepsy care to *any* of your patients?

Yes / No

If yes, please estimate the percentage of patients where this is the case: _____%

12. Is the local neurology service the main provider of epilepsy care to *any* of your patients?

Yes / No

If yes, please estimate the percentage of patients where this is the case: _____%

What are the referral criteria for neurology services?

All patients with LD and epilepsy.....

Those with the most difficult to treat epilepsy.....

Other:_____

13. Is there a shared management approach between neurology and LD services for any of your patients that involves joint discussions about management?

Yes / No

If yes, please estimate the percentage of patients for whom this is the case: _____%

14. Does your learning disability service play a role in diagnosing new cases of epilepsy?
Yes / No

If yes, please give details:

_____

____

15. Please list any other services that you liaise with regarding epilepsy care. For example, voluntary organisations, private health providers, specialist epilepsy centres (e.g. David Lewis Centre, Chalfont).

_____

_____

16. Does your service follow any sort of epilepsy care pathway that makes explicit reference to people with LD? Yes / No

If yes, is this pathway used for diagnosis or continuing treatment? Diagnosis / Treatment / Both

Who was responsible for its design? Your local team / PCT / SHA

17. Are there any plans to change or restructure the epilepsy services that you provide?

Yes / No

If yes, please give details:

_____

__

18. Please add any other comments you would like to make about the epilepsy services provided by your team.

Thank you for completing this questionnaire.

Developed by members of the CIDDRG. University of Cambridge, UK

We may wish to discuss your responses to the questionnaire. If this is acceptable, please would you provide your contact details:

Name:_____ Contact email/telephone no.:_____

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