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Maini, Rishma; Kirkpatrick, Martin; McCafferty, Aileen; Dunkley, Colin; Ogston, Simon; Williams, Fiona

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EVALUATION OF A QUESTIONNAIRE TO MEASURE PARENT/CARER AND CHILD/YOUNG PERSON EXPERIENCE OF NHS EPILEPSY SERVICES

Epilepsy12 National Audit

Rishma Maini,^{a,b} Martin Kirkpatrick,^a Aileen McCafferty,^c Colin Dunkley,^d Simon Ogston,^a Fiona Williams^a

- a. Ninewells Hospital and Medical School, University of Dundee, UK;
- b. Current address, British High Commission, Diplomatic Enclave, Islamabad, Pakistan
- c. Centre for Child Health, NHS Tayside, Dundee, UK;
- d. Department of Paediatrics, Sherwood Forest Hospitals, Nottinghamshire, UK

Corresponding author

Fiona Williams,
Population Health Sciences and Genomics
Mackenzie Building
University of Dundee
Dundee DD2 4BF

f.l.r.williams@dundee.ac.uk

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ABSTRACT

Purpose To validate a patient-reported-experience-measure, PREM, of the NHS paediatric epilepsy service.

Methods Section 1 of the PREM recorded demographic and clinical characteristics, and section 2 collected information about the users' experience with the service. Section 2 included eighteen statements around three constructs: communication and provision of information to service users, interpersonal skills of staff, and clinic visits and accessibility to the services. Face validity, construct validity, internal reliability, and internal consistency were used to examine the robustness of these statements. The PREM was completed by parents/carers and also children/young people.

Results PREMs were received from 145 of the 192 audit units; 2335 completed forms were returned; the attitude statements were completed by 750 children/young people and 1550 parents/carers. Face validity of the PREM was good. Construct validity was indecisive; confirmatory factor analysis of the hypothesised construct was weak. Exploratory factor analysis identified a four factor solution for the parent/carers dataset and a five factor solution for the children/young people's dataset. Internal reliability was good for the parent/carers dataset but less good for the children/young people. Internal consistency was moderately good for both datasets.

Conclusions These findings indicate that the PREM is likely to be a valid tool with the potential to elicit a wide variety of reliable views from parents/carers of children with epilepsy. The construct validity for the PREM should be reassessed with confirmatory factor analysis in a new dataset. More work needs to be undertaken with children/young people to design statements that capture their specific needs.

Keywords: Epilepsy, Children, Patient Reported Experience Measure, Factor Analysis, Measurement tool

INTRODUCTION

The “National Epilepsy 12 Audit” aimed to measure and improve the quality of care provided by the National Health Service (NHS) to children and young people with seizures and epilepsies in the United Kingdom (UK) [1]. The audit was co-ordinated by the Royal College of Paediatrics and Child Health in partnership with Epilepsy Action and the British Paediatric Neurology Association, and includes paediatric departments which see children aged 1 month to 16 years with suspected or diagnosed epilepsies [1]. A key component of the audit involved eliciting the views of service users using a Patient Reported Experience Measure (PREM).

Gaining an understanding of users’ views facilitates the development and shaping of health services, whereby enabling the service to be more responsive to the needs and preferences of the users [2]. A PREM is a type of survey which asks service users specific questions that are known to be important to them about their recent health care experience. Compared with a traditional patient satisfaction survey, a PREM allows for a more objective assessment of care by explicitly identifying aspects of service delivery requiring improvement [3]. There is no standard PREM instrument available which measures both patient and parent/carer experience of paediatric epilepsy services.

The purpose of this research was to develop and assess the validity of a PREM which captured the experience of users of the UK NHS paediatric epilepsy service over a defined 12 month period. An advantage of developing a robust tool which reliably and accurately measures the experience of parents/carer and young people is that it can then be used in future audits of paediatric epilepsy services.

METHODS

Development and pilot of the PREM

The composition and face validity of the PREM was informed by an extensive literature review which focussed on previous surveys of patient’s experiences and satisfaction [4-6], and experience

among patient users with epilepsy and other NHS services [7-9]. Face validity was ensured by consulting health professionals, young people with epilepsy, and parents of children and young people with epilepsy on the design of the questionnaire. Discussions by RM were initially undertaken with a consultant paediatric neurologist, two epilepsy specialist nurses, a clinical psychologist, and paediatric registrar. The views of 40 young people with epilepsy were captured through surveys coordinated by the Charity Epilepsy Action and the National Centre for Young People with Epilepsy, in 2010. In addition, three semi-structured interviews were undertaken by RM with parents and children attending a paediatric epilepsy clinic in Dundee. The development of the PREM was iterative.

The PREM consisted of two sections, the first to be completed by the parent/carer, and the second by the young person or, if that was not possible, by the parent/carer. The first section collected information about the young person with epilepsy: gender, age, frequency of seizures, associated comorbid conditions (such as cerebral palsy, intellectual disability, attention deficit hyperactivity disorder and autism), age at onset of epilepsy, prescribed anti-epilepsy medications, type of NHS services used, ease of contacting the service, and experience with the care received. The second section included eighteen statements around three constructs: communication and the provision of information to service users, interpersonal skills of the staff, and clinic visits and accessibility to the services. These statements were assessed on a 5-point Likert scale. To offset response bias negative and positive statements were developed. This section also asked whether more information was desired on a number of aspects of epilepsy care. The final question asked the respondent to list the three best things and the three worst things about the epilepsy service as free text responses. The overall results have been described in two publications [1,10].

The UK has 197 distinct audit units defined and 192 agreed to participate in the PREM. Each participating unit was given 50 paper copies of the PREM and asked to distribute at least 25 of these to eligible young people across a range of different clinic provisions in their audit unit area, over a

fixed 3 month period. Eligible participants were defined as those submitted to the audit who had commenced anti-epilepsy drug treatment within 12 months of the first paediatric assessment and had not died. Respondents were asked to reflect on their experience of epilepsy care over the previous 12 months. The PREMs were completed and returned anonymously to clinic staff. Collation and data entry were undertaken by the research division of the UK Royal College of Paediatrics and Child Health.

Statistical Analysis

The data were transferred to a SafeHaven, which utilises a Citrix XenDesktop secure environment, at the University of Dundee for analysis and interpretation, and analysed using SPSS version 22 and SAS version 9.4.

Face validity, construct validity, internal reliability and internal consistency were used to evaluate the psychometric properties of the PREM. Face validity was examined through a pilot study that asked respondents about their understanding and views of the PREM and by analysing the general distribution of answers to the attitude statements in the PREM i.e. question 16 (Appendix A).

Construct validity was assessed using confirmatory factor analysis [11] of the attitude statements separately for the responses of the parent/carers and young persons. Exploratory factor analysis [11] was used to describe key features from both sets of responses. Internal reliability was assessed using Cronbach's alpha and an alpha of 0.70 or greater was taken as evidence of acceptable reliability [12].

Internal consistency was measured in three ways: by comparing responses to questions 16.3 (The information I was given was hard to understand) and 16.5 (Staff did not explain things in a way I could follow); question 10 (In the last 12 months have you been satisfied with the care your child receives for their epilepsy from the service?) and question 18 (Overall, are you satisfied with the care you receive from the epilepsy service?); and question 9 (In the last 12 months, have you found it easy to contact the health service looking after your child's epilepsy?) and question 16.10 (It is easy to contact someone in the epilepsy team). (Appendix A).

Prior to confirmatory and exploratory factor analyses, results obtained from respondents who had answered less than 90% of the attitude statements were excluded from the dataset [13]. For questionnaires with less than 10% of data missing, missing values were replaced with the mean value response for each statement.

Factor Analyses

Factor analysis was undertaken separately on the results obtained from the parents/carers and young people. Factor analysis is designed for interval data but it may be used on ordinal data such as scores assigned to Likert scales. Unordered categorical data are not suitable for factor analysis; hence, the data used for factor analysis in the PREM were the 18 attitude statements in question 16 (Appendix A), which were designed to measure satisfaction with the epilepsy service. *A priori*, it was thought that the PREM would have a three-factor structure, as the attitude statements were developed from three constructs. The three constructs were: communication and provision of information to service users, interpersonal skills of staff, and clinic visits and accessibility of services (Table 1).

Factor/Construct	Question numbers from the PREM
Communication and Provision of Information to Service Users	1,2,3,5,6,9
Interpersonal Skills of Staff	4,8,13,17,18
Clinic Visits and Accessibility of Services	7,10,11,12,14,15,16

Table 1 Hypothesised factor model for the PREM

Confirmatory factor analysis uses several tests to determine how well the statistical model fits the data. The CALIS procedure (Covariance Analysis of Linear Structural Equations) estimates parameters and tests the appropriateness of structural equation models generated by confirmatory factor analysis using covariance structural analysis [14]. As part of the output, a correlation matrix is produced which gives the correlations between factors. These matrix and goodness-of-fit statistics indicate whether the model is appropriate. A Root Mean Square Error of

Approximation (RMSEA) ≤ 0.06 implies a good fit [15]; a correlation of > 1.000 , a large χ^2 value with $p < 0.05$, and Root Mean Square Error of Approximation of ≥ 0.08 indicate that the model does not fit the data well.

Exploratory factor analysis is used if the factor structure is not confirmed by confirmatory factor analysis. Exploratory factor analysis helps to determine what the factor structure actually looks like according to how participants have responded to the attitude statements. As a result, it may reveal alternative underlying constructs or factors when compared to confirmatory factor analysis. A widely used method in factor analysis is principal axis factoring. This method seeks the least number of factors which can account for the common variance (correlation) of a set of variables. We used exploratory factor analysis by principal axis factoring in SPSS to detect the factor structure of the 18 statements. The Kaiser-Meyer-Olkin test and Bartlett's test of sphericity are generated automatically by SPSS when undertaking exploratory factor analysis using principal axis factoring. These tests indicate whether the size of the data-set is adequate for factor analysis. Values indicating an adequate sample size are a Kaiser-Meyer-Olkin test statistic of $\geq 0.5-0.7$ and significant Bartlett's test statistic ($p < 0.05$) [16].

Following extraction of factors using principal axis factoring, the factors to be retained were selected. For this analysis, the Cattell scree test was used to determine the number of factors to be retained [17]. The scree test plots the eigenvalues, which indicate the amount of variance explained by each factor on the Y axis against the factor with which it is associated on the X-axis. If there is a point below which factors explain relatively little variance and above which they explain substantially more, this usually appears as an "elbow" in the plot. Cattell's guidelines recommend retaining factors above the elbow and rejecting those below. Factors appearing before the elbow were thus assumed to be meaningful and retained for 'rotation'. Rotation is the method used to simplify interpretation of factor analysis so that each individual variable has substantial loadings on as few

factors as possible (preferably only one). An oblique rotation was applied to retained factors because it was hypothesised that the factors would be correlated with one another [18]. The rotated solution was interpreted by identifying which statements loaded on each retained factor i.e. had coefficients ≥ 0.30 with a factor [13]. Those statements with zero or near-zero loadings were interpreted as unrelated to the factor. In circumstances where a statement had a factor-loading ≥ 0.30 for more than one factor, i.e. statements which 'cross-loaded' with more than one factor, the higher of the factor loadings was used to attribute the item to a factor. A descriptor was assigned to label each factor which best reflected the essence of the statements loading on it. Finally, all cross-loading statements were reviewed so that the statement was attributed to the factor judged to be most appropriate.

Global satisfaction

Responses to each attitude statement were scored so that a higher score indicated a more favourable attitude. For instance, the category 'strongly agree' scored five points whereas the category 'strongly disagree' scored only one point. Each of the 18 attitude statements received equal weight and responses were summed to give a global (total) score. Therefore, for positive attitude statements such as "Staff listened to what I had to say", strongly agree was weighted 5 points, agree was 4 points, unsure was 3 points, disagree was 2 points, and strongly disagree was 1 point. Scores were reversed for negative attitude statements such as "At times I felt I was not allowed to ask questions". The global satisfaction score could therefore range from 20 (least satisfaction) to 100 (most satisfaction).

RESULTS

Response Rates

PREMs were received from 145 of the 192 audit units who agreed to participate (75%); 2335 completed PREMs were returned, giving a return rate of between 24% (2335/9600) and 49% (2335/4800). The majority of PREMs were completed by parents/carers and they returned more

responses about male children/young people. Overall the responses were about children/young people aged 5-14 years and captured information mostly from the lower spectrum of seizure frequency (Table 2).

		Percentage PREM completed by	
		Young people (n=710)	Parents/carers (n=1550)
Gender	Female	380 (54%)	685 (44%)
	Male	329 (46%)	863 (56%)
Age group (yrs)	0-4	4 (0.6%)	403 (26%)
	5-9	103 (15%)	627 (31%)
	10-14	384 (54%)	371 (24%)
	15-19	216 (31%)	135 (9%)
Seizure frequency	<1 per month	206 (30%)	377 (25%)
	≥1 per month but not weekly	92 (13%)	234 (16%)
	≥1 per week but not daily	72 (10%)	220 (15%)
	≥1 per day	46 (7%)	286 (19%)
	Blank spells only	112 (16%)	224 (15%)
Co-morbidity*	Learning difficulties/delay	115 (17%)	813 (55%)
	Cerebral palsy	25 (4%)	177 (12%)
	Autism or autism spectrum	40 (6%)	197 (13%)
	Attention deficit hyperactivity disorder	22 (3%)	100 (7%)
	None of the above	494 (73%)	490 (33%)

* Categories are not mutually exclusive

Table 2 Characteristics of the young people with epilepsy

Face Validity

As the PREM neared its final version, it was sent to 6 families who completed it and provided written feedback on readability and clarity. RM also interviewed 10 families who completed the PREM while attending general outpatient paediatric clinics in Ninewells Hospital, Dundee and Perth Royal Infirmary; additionally, 6 six families were invited to participate while attending the paediatric epilepsy clinic at Ninewells Hospital. After completion, RM and the families discussed the responses with a view to ensure that all questions and answers were interpreted as intended. The development of the PREM was iterative and the face validity of the PREM (Appendix A) was believed to be good. The distributions of responses to the attitude statements, answered by both the parents/carers and young people, are mostly skewed (Tables 3a and b).

PREM question 16	Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Total
1. Overall, I received enough information about epilepsy	526	691	137	103	39	1496
2. Staff listened to what I had to say	736	653	55	35	15	1494
3. The information I was given was hard to understand	53	114	156	732	394	1449
4. Staff did not take time to get to know me	69	78	96	634	577	1454
5. Staff did not explain things in a way I could follow	51	86	72	649	581	1439
6. Staff took my thoughts into account when making decisions	575	661	111	61	28	1436
7. I felt the staff respected my need for privacy during clinic visits	632	686	54	21	20	1413
8. Overall, staff seemed to know what they were doing	720	640	56	25	18	1459
9. At times I felt I was not allowed to ask questions	49	76	76	524	715	1440
10. It is easy to contact someone in the epilepsy team	535	543	174	106	74	1432
11. Staff make sure it is easy to attend the clinic e.g. when making appointments	524	680	150	67	38	1459
12. I am not seen by the service often enough	72	140	178	596	461	1447
13. Staff tell me if my appointment is going to be late	255	552	194	267	79	1347
14. The waiting area does not have activities for my age	91	224	111	552	443	1421
15. Overall, the length of time spent with staff at the clinic is just about right	345	775	109	113	53	1395
16. Staff are not good at working together with others e.g. GP School or nursery, when looking after me	108	156	209	473	391	1337
17. Overall, staff are friendly and polite in the ward as inpatient	658	518	36	15	13	1240
18. Overall, staff are friendly and polite when going for tests e.g. EEG or MRI (if applicable)	702	560	29	15	8	1314

Table 3a Responses (N=1550) of the parents and carers to the attitude questions

PREM question 16	Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Total
1. Overall, I received enough information about epilepsy	224	349	85	25	10	693
2. Staff listened to what I had to say	362	291	34	2	6	695
3. The information I was given was hard to understand	22	108	146	285	122	683
4. Staff did not take time to get to know me	29	45	75	266	275	690
5. Staff did not explain things in a way I could follow	23	47	55	312	253	690
6. Staff took my thoughts into account when making decisions	237	315	88	29	14	683
7. I felt the staff respected my need for privacy during clinic visits	258	348	47	12	9	674
8. Overall, staff seemed to know what they were doing	398	251	26	9	8	692
9. At times I felt I was not allowed to ask questions	22	35	54	263	315	689
10. It is easy to contact someone in the epilepsy team	205	220	161	35	21	642
11. Staff make sure it is easy to attend the clinic e.g. when making appointments	221	303	104	34	11	673
12. I am not seen by the service often enough	16	48	122	284	212	682
13. Staff tell me if my appointment is going to be late	121	239	119	113	44	636
14. The waiting area does not have activities for my age	161	237	58	148	79	683
15. Overall, the length of time spent with staff at the clinic is just about right	155	384	85	37	16	677
16. Staff are not good at working together with others e.g. GP School or nursery, when looking after me	35	60	113	223	205	636
17. Overall, staff are friendly and polite in the ward as inpatient	265	213	22	5	7	512
18. Overall, staff are friendly and polite when going for tests e.g. EEG or MRI (if applicable)	342	269	18	7	4	640

Table 3b Responses (N=710) of the young people to the attitude questions

Construct validity

Confirmatory Factor Analysis –parent/carer responses

Attitude statements with less than 10% of missing responses were received from 1282 parent/carers. Running the three-factor structure model (Table 1) shows that the factors were all highly correlated with one another. The χ^2 value of 8653.4894 (df = 153, $p < 0.0001$), indicates a poor fit of the model to the data (Appendix B, Table 1a). The Root Mean Square Error of Approximation value obtained was 0.1181 (95% CI 0.1141, 0.1222) reaffirming that the model did not fit the data well.

Confirmatory Factor Analysis –young persons' responses

Attitude statements were received from 621 young people with less than 10% of missing responses. Running the same three-factor structure model as for the parents/carers shows that the factors were also all highly correlated with one another (Appendix B, Table 1b). The χ^2 value of 3021.6123 (df = 153, $p < 0.0001$) and Root Mean Square Error of Approximation value of 0.0828 (95%CI 0.089, 0.077) indicate a poor fit of the model to the data.

Exploratory factor analysis of the PREM completed by the parent/carers

There were sufficient PREM returns completed by the parent/carers (1282) to allow analysis of the data using exploratory factor analysis. The Kaiser-Meyer-Olkin measure was 0.909, (thus above the recommended value of 0.6), and Bartlett's test of sphericity was significant ($\chi^2 = 8607.328$, df = 153, $p < 0.0001$) implying that the sample size was adequate.

The exploratory factor analysis identified a four factor solution as the most appropriate for this dataset. These four factors explained 58% of the variance. The first factor (which mostly encompassed provision of information and clinical setting) explained 35.0% of the variance; the second factor (communication and respect) explained 11.0% of the variance; the third factor (clinic visits and accessibility) explained 6.2% of the variance; and, the fourth factor (general courtesy of staff) explained 5.9% of the variance. All items had primary loadings over 0.30 and were entered into

the exploratory factor analysis. With the exception of one attitude statement ('The waiting area does not have activities for my age') all items cross-loaded significantly with other items (Table 4a).

Statement	Factor 1 Provision of information and clinical setting	Factor 2 Communication and respect	Factor 3 Clinic visits and accessibility	Factor 4 General courtesy of staff
1. Overall, I received enough information about epilepsy	0.407*	0.598	0.637	0.365
2. Staff listened to what I had to say	0.463	0.775	0.643	0.424
3. The information I was given was hard to understand	0.649	0.301		
4. Staff did not take time to get to know me	0.772	0.368	0.364	
5. Staff did not explain things in a way I could follow	0.798	0.347	0.314	
6. Staff took my thoughts into account when making decisions	0.394	0.760	0.530	0.426
7. I felt the staff respected my need for privacy during clinic visits	0.317	0.729	0.504	0.390
8. Overall, staff seemed to know what they were doing	0.379	0.808	0.543	0.405
9. At times I felt I was not allowed to ask questions	0.665	0.375	0.342	
10. It is easy to contact someone in the epilepsy team	0.371	0.525	0.734	0.303
11. Staff make sure it is easy to attend the clinic e.g. when making appointments	0.303	0.514	0.718	0.415
12. I am not seen by the service often enough	0.612	0.404	0.596*	
13. Staff tell me if my appointment is going to be late		0.343	0.459	
14. The waiting area does not have activities for my age	0.362			
15. Overall, the length of time spent with staff at the clinic is just about right	0.329	0.404	0.390*	
16. Staff are not good at working together with others e.g. GP School or nursery, when looking after me	0.434		-0.375	
17. Overall, staff are friendly and polite in the ward as inpatient		0.442	0.421	0.709
18. Overall, staff are friendly and polite when going for tests e.g. EEG or MRI (if applicable)		0.457	0.418	0.856
% VARIANCE EXPLAINED BY FACTORS	35.0%	11.0%	6.2%	5.9%

* statement manually reassigned to the factor

Table 4a Factor loadings for parent/carer questionnaire (bold indicates highest loading)

Exploratory factor analysis of the PREM completed by the young persons

There were also sufficient PREM returns completed by the young people (621) to allow analysis of the data using exploratory factor analysis: Kaiser-Meyer-Olkin measure =0.886, and Bartlett's test of sphericity $\chi^2=2988.310$, $df=153$, $p<0.0001$.

The exploratory factor analysis identified a five factor solution as the most appropriate for the dataset. These five factors contributed 57.13% of the variance. The first factor (communication) explained 30.3% of the variance; the second factor (provision of information and respect) explained 8.1% of the variance; the third factor (clinic visits and accessibility) explained 6.9% of the variance; the fourth factor (general courtesy of staff) explained 6.2% of the variance; and the fifth factor (staff liaison) explained 5.7% of the variance (Table 4b). All statements had primary loadings over 0.30 and, with the exception of three statements ('The waiting area does not have activities for my age', 'The information I was given was hard to understand' and 'Overall, staff are friendly and polite when going for tests e.g. EEG or MRI (if applicable)'), cross-loaded with other factors (Table 4b).

Statement	Factor 1 Communication	Factor 2 Provision of information and respect	Factor 3 Clinic visits and accessibility	Factor 4 General courtesy of staff	Factor 5 Staff liaison
1. Overall, I received enough information about epilepsy	0.578	0.511*	0.530		
2. Staff listened to what I had to say	0.709	0.508	0.461	0.322	
3. The information I was given was hard to understand		0.472			
4. Staff did not take time to get to know me	0.472	0.652	0.393		0.390
5. Staff did not explain things in a way I could follow	0.418	0.725	0.368		0.406
6. Staff took my thoughts into account when making decisions	0.663	0.396	0.431		
7. I felt the staff respected my need for privacy during clinic visits	0.586		0.413	0.312	
8. Overall, staff seemed to know what they were doing	0.702	0.398	0.470		
9. At times I felt I was not allowed to ask questions	0.407	0.592	0.338		0.326
10. It is easy to contact someone in the epilepsy team	0.538	0.356	0.716	0.309	
11. Staff make sure it is easy to attend the clinic e.g. when making appointments	0.612	0.349	0.685	0.374	
12. I am not seen by the service often enough	0.421	0.485	0.637		0.413
13. Staff tell me if my appointment is going to be late		0.307	0.422		
14. The waiting area does not have activities for my age					
15. Overall, the length of time spent with staff at the clinic is just about right	0.378	0.362	0.389*		0.432
16. Staff are not good at working together with others e.g. GP School or nursery, when looking after me		-0.330			-0.673
17. Overall, staff are friendly and polite in the ward as inpatient	0.394	0.315	0.419	0.888	
18. Overall, staff are friendly and polite when going for tests e.g. EEG or MRI (if applicable)				0.664	
% VARIANCE EXPLAINED BY FACTORS	30.3%	8.1%	6.9%	6.2%	5.7%

* statement manually reassigned to the factor

Table 4b Factor loadings for children's questionnaire (bold indicate highest loadings)

Internal Reliability

Internal reliability for the items included in the hypothesised factor model (see Table 1) was examined using Cronbach's alpha. For the parents/carers data, the alpha for factor 1 (i.e. for communication and provision of information to service users) was 0.781 (based on 6 attitude statements), which is above the threshold indicating acceptable reliability. However, the alphas for factors 2 (i.e. for interpersonal skills of staff) and 3 (i.e. for clinic visits and accessibility of services) were below the threshold of acceptable reliability: Cronbach's alpha for factor 2 was 0.613 (based on 5 attitude statements), and 0.439 for factor 3 (based on 7 attitude statements).

The Internal reliability of the items included in the new factor structure of the parent/carers responses following exploratory factor analysis showed that Cronbach's alpha for the items with high loadings on each factor (shown in Table 4a) were good: 0.778 for provision of information and clinical setting (Factor 1, 7 items (i.e. statements), 0.848 for communication and respect (Factor 2, 4 items), 0.704 for clinical visits and accessibility to patients or other professionals (Factor 3, 5 items), and 0.757 for general courtesy of staff (Factor 4, 2 items). The items selected for each factor and used in the calculation of Cronbach's alpha are shown in Table 5a.

Factor	Statement numbers from the PREM
Provision of information and clinical setting	1,3,4,5,9,14,16
Communication and respect	2,6,7,8
Clinical visits and accessibility	10,11,12,13,15
General courtesy of staff	17,18

Table 5a Statements related to each factor for the PREM completed by the parent/carer following exploratory factor analysis

The internal reliability for the items included in the hypothesised factor model (see Table 1) using the young persons' responses was similar to that of the parents/carers, and only good for one factor. The alpha for factor 1 (Table 1) was 0.727, which is above the threshold indicating acceptable reliability.

However, as with the responses from the parents/carers, the alphas for factors 2 and 3 were below the threshold of acceptable reliability at 0.591 and 0.451 respectively.

The Internal reliability of the items included in the new factor structure of the child/young person’s responses following exploratory factor analysis showed that Cronbach’s alpha for the items with high loadings on each factor (as shown in Table 4b) were generally good: Factor 1, for communication, had a Cronbach’s alpha score of 0.729 (5 items); Factor 2, provision of information and respect had a Cronbach’s alpha score of 0.674 (4 items); Factor 3, clinical visits and accessibility had a Cronbach’s alpha score of 0.699 (5 items); Factor 4, general courtesy of staff, had a Cronbach’s alpha score of 0.729 (2 items); Cronbach’s alpha could not be calculated for factor 5 (staff liaison) as there was only one statement associated with this factor. The items selected for each factor and used in the calculation of Cronbach’s alpha are shown in Table 5b.

Factor	Statement numbers from the PREM
Communication	2,6,7,8
Provision of information and respect	1,3,4,5,9
Clinical visits and accessibility	10,11,12,13,15
General courtesy of staff	17,18
Staff liaison	16

Table 5b Statements related to each factor for the PREM completed by the parent/carer following exploratory factor analysis

Internal Consistency

The responses to the question ‘the information I was given was hard to understand’ and ‘staff did not explain things in a way I could follow’ yielded dissimilar proportions for each category whether completed by the parent/carer or the young people, indicating that the responses were not internally consistent (Tables 3a and 3b, questions 16.3 and 16.5); (for parent/carer responses paired T test, $t=-8.967$, degree of freedom (dof) 1413, 95% CI -0.273, -0.175; for young people responses $t=-11.102$, dof 677, 95% CI -0.597, -0.417). Similarly, the responses to question 9 (In the last 12 months, have you found it easy to contact the health service looking after your child’s epilepsy?) and question

16.10 (It is easy to contact someone in the epilepsy team) were not consistent. (For parent/carer responses paired T test, $t=-29.566$, dof 1398, 95% CI -0.860, -0.753; for young people responses $t=-22.906$, dof 629, 95% CI -0.979, -0.824). However, the responses to question 10 (In the last 12 months have you been satisfied with the care your child receives for their epilepsy from the service?) and question 18 (Overall, are you satisfied with the care you receive from the epilepsy service?) were consistent. (For parent/carer responses paired T test, $t=0.093$, dof 1408, 95% CI -0.028, 0.031; for young people responses $t=-1.143$, dof 657, 95% CI -0.066, 0.017).

Relationships between variables and global satisfaction

The mean global satisfaction score obtained from the PREM attitude statements completed by the parent/carers was 72.1% (sd 8.8), and 70.0% (sd 8.1) for the PREM completed by the young people.

DISCUSSION

Most surveys about the experiences of paediatric epilepsy services in the literature have focused on the views only of the parents or carers and have not been validated. However, the ratification of the United Nations Convention on the Rights of the Child in 1991 led to the NHS consulting children about their health needs and their opinions on the planning of services. It is increasingly apparent that almost all children, whatever their age and circumstances, can provide valuable perceptions that can improve clinic care. Studies have demonstrated that children's views do not always mirror those of their parents and other adults with respect to health and health services [19]. Our aim was to develop a robust tool (Appendix A) that would reliably and accurately measure the experience of parent/carers and young people using the UK NHS epilepsy service. The methodology used to develop the Epilepsy12 PREM was robust and used four approaches (face validity, construct validity, internal reliability, and internal consistency) to examine the robustness of a key component of the PREM (question 16, which aimed to determine how satisfied users were with the epilepsy service).

The face validity of the attitude statements was judged to be good during the pilot studies with questions perceived as clear and relevant to the users and stake holders. The distributions of some of the responses (both parent/carer and young person's) to the attitude statements were skewed, mostly towards positive experiences of the service. This may indicate that while the users were generally satisfied with the service that some statements were not discriminatory and should be more complex in order to understand fully the responses; alternatively, it might indicate that the sample was unrepresentative of the users as a whole. Two statements (staff tell me if my appointment is going to be late, Q16.13, and staff are not good at working together with others e.g. GP School or nursery, when looking after me Q16.16) identified by both the parent/carer and young person's and an additional statement identified only by the young people (the waiting area does not have activities for my age Q16.14) showed roughly equal distributions of responses across the Likert scale. These responses spotlight potential areas for improvement in services. Global satisfaction was around 70% for both the parent/carers and the young people. Given the likely biased sample of respondents this nevertheless shows that a fairly wide spread of responses was elicited from the respondents, supporting good face validity.

The construct validity was assessed through the confirmatory and exploratory factors analyses. The hypothesised structure based on three constructs did not fit the responses of either the parents/carers or the young people. The exploratory factor analysis suggested a four factor construct for the parent/carers data and a five factor construct for the young person's data. Allocating an overall descriptor for the factors identified through exploratory factor analysis is subjective, but with some researcher reassignment of items, defining the descriptors was reasonably straightforward. The parent/carers factor structure resembled the hypothesised structure (communication and provision of information, interpersonal skills of staff and clinic visits, and accessibility of services), with provision of information clearly important. However in a departure from the hypothesised structure, parent/carers responses in this dataset placed equal

emphasis (with provision of information) with aspects of the clinical setting, with elements of respect and general courtesy also identified as important. The young person's responses were similar but with most emphasis on communication. The items making up the factor structure differ between the parents/carers and young people, and while these differences might challenge service change they nevertheless have the common theme of good communication. Overall, in this dataset (aspects of) communication was the single most important factor to determine the satisfaction of the epilepsy service users reported by both the parent/carers and the young people.

Internal reliability (assessed by Cronbach's alpha) for the hypothesised factor model showed that only one of the three factors was reliable i.e. Factor 1, communication and provision of information to service users. The outcome from the exploratory factor analysis showed improvement using the parents/carers responses, as each of the four factors identified were reliable. However, only two of the five factors were reliable for the young people's responses. There are several possible explanations for this lack of reliability. For instance it may be explained by variance in the cognitive developmental stage of the children/young people completing the survey. Proxy indicators of cognitive development (years in education, reading ability, working memory capacity) have all been found to impact on data quality including reliability of responses and internal consistency in survey-based research [20,21]. In the current study there was marked variation in the age range of the children/young people who completed the survey and it is possible younger children struggle to process and retain responses to individual survey items and the wider questionnaire focus.

Alternatively it is possible that the children/young people found the questions of the survey less pertinent than the parents/carers, and consequentially lost interest in completing the survey.

The internal consistency was assessed through a comparison of responses to three pairs of similar questions. The statistical outcome suggested that the responses to two of the pairs were not consistent. However, the responses were broadly similar and the statistical difference is exaggerated

by a large sample size. Furthermore, the questions were not identical and the nuances of each may have been interpreted differently by the respondents.

This study has two major limitations, the sampling method and response rates. The sample, while very large, is essentially a convenience sample and unlikely to be representative of the population treated for epilepsy. Indeed the characteristics of the sample indicate a bias towards a sample aged 5-14 years, with a majority recording blank spells only or a seizure frequency of <1 per month. Future surveys should purposely sample children under 5 years and young people aged 15-19 years, and ensure that the views of those with more frequent seizures are adequately represented. The response rate of between 24%-49% is also low, which compounds weak sampling. A response rate of 70% or above is considered acceptable [22]; although this is challenging for questionnaire based studies. Garratt et al. successfully developed a six-factor questionnaire to evaluate parent experiences of paediatric in-patient care [8] and achieved a response rate of 53.8%. Low response rates are problematic as those who do not respond may be very different from those who do, thereby creating sampling bias. The low response rate obtained suggests that only a minority of the parent/carers and young person's attending paediatric epilepsy services answered the PREM. The minority who answered are likely to be those with very strong views [23,24]. This could lead to polarised responses which will impact on the validation of the questionnaire. It is probable that although the sample sizes met minimum requirements for analysis, the results of the confirmatory and exploratory factor analyses were adversely affected by the non-representativeness of the sample population.

The major strength of this study is that the methodology used to develop the questionnaire was very robust. Several approaches were used to examine the validity of the questions. The PREM had good face validity, good internal reliability - particularly for the parent/carer responses, and moderately good internal consistency. The confirmatory factor analysis did not confirm the

hypothesised constructs. The exploratory factor analysis identified for the parent/carers resembled the hypothesised structure, with provision of information important but with more emphasis placed on aspects of the clinical setting with elements of respect and general courtesy also identified as important. The young person's responses were similar with but with more emphasis on communication. A variety of modalities for communication exist. In this survey we used paper questionnaires and it may be that web, telephone or text based surveys are more attractive to young people. Identification of the most appropriate modalities for this population is an obvious next step for research. The construct validity for the PREM will now have to be reassessed by confirmatory factor analysis in a new dataset.

CONCLUSION

Overall our findings indicate that the PREM is likely to be a valid and robust tool with the potential to elicit a wide variety of reliable views from parents/carers of children with epilepsy provided it is circulated to a representative population. More work needs to be undertaken with children/young people to design a valid tool to capture their specific need.

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Table 1a Covariance matrix produced by CFA* for the parent/carers responses

		Factor 1 Communication and Provision of Information to Service Users	Factor 2 Interpersonal Skills of Staff	Factor 3 Clinic Visits and Accessibility of Services
Factor 1	Correlation	1.0000	1.0245	0.9293
	SE		0.0147	0.0138
	T-value		69.6389	67.4161
	p		<0.0001	<0.0001
Factor 2	Correlation	1.0245	1.0000	0.9782
	SE	0.0147		0.0173
	T-value	69.6389		56.6712
	p	<0.0001		<0.0001
Factor 3	Correlation	0.9293	0.9782	1.0000
	SE	0.0138	0.0173	
	T-value	67.4161	56.6712	
	p	<0.0001	<0.0001	

SE – standard Error * Confirmatory Factor Analysis

Table 1b Covariance matrix produced by CFA* for the young persons' responses

		Factor 1 Communication and Provision of Information to Service Users	Factor 2 Interpersonal Skills of Staff	Factor 3 Clinic Visits and Accessibility of Services
Factor 1	Correlation	1.0000	0.9881	0.8278
	SE		0.0289	0.0281
	T-value		34.1314	29.4832
	p		<0.0001	<0.0001
Factor 2	Correlation	0.9881	1.0000	0.9519
	SE	0.0289		0.0305
	T-value	34.1314		31.1615
	p	<0.0001		<0.0001
Factor 3	Correlation	0.8278	0.9519	1.0000
	SE	0.0281	0.0305	
	T-value	29.4832	31.1615	
	p	<0.0001	<0.0001	

SE – standard Error * Confirmatory Factor Analysis

Autism or autistic spectrum disorder {
FORMCHECKBOX }

Attention Deficit Hyperactivity Disorder (ADHD) {
FORMCHECKBOX }

None of the above { FORMCHECKBOX }

Other

5. When was your child's first assessment by a paediatrician for their epilepsy? (*Tick one option only*)

Less than 1 year ago { FORMCHECKBOX }

Between 1 and 2 years ago {
FORMCHECKBOX }

2 years ago, or more { FORMCHECKBOX
}

6. What was the age of your child at their first assessment (years and months).....

7. What clinics or services has your child attended for their epilepsy and how often have they been in the last 12 months? *Tick all that apply*

Type of service	Number of visits in last 12 months
Hospital general paediatric clinic { }	{ FORMCHECKBOX }
Community paediatric clinic { }	{ FORMCHECKBOX }
Teenage epilepsy clinic { }	{ FORMCHECKBOX }

Specific epilepsy clinic { FORMCHECKBOX }

 Paediatric neurology clinic { FORMCHECKBOX }

 A & E { FORMCHECKBOX }

 GP { FORMCHECKBOX }

 Other.....

8. What drug(s) is your child currently prescribed for their epilepsy? *Tick all that apply*

Sodium Valproate (Epilim) { FORMCHECKBOX }
 Carbamazapine (Tegretol) { FORMCHECKBOX }
 Lamotrigine (Lamictal) { FORMCHECKBOX }
 Levetiracetam (Kappa) { FORMCHECKBOX }
 Other { FORMCHECKBOX }

If other, state drug(s).....

9. In the last 12 months, have you found it easy to contact the health service looking after your child's epilepsy?

Yes { FORMCHECKBOX }
 No { FORMCHECKBOX }

Unsure { FORMCHECKBOX }

10. In the last 12 months have you been satisfied with the care your child receives for their epilepsy from the service?

Yes { FORMCHECKBOX }

No { FORMCHECKBOX }

Unsure { FORMCHECKBOX }

11. Over the last 12 months, what are the **three** best things about the epilepsy service?

1.

2.

3.

12. Over the last 12 months, what are the **three** worst things about the epilepsy service?

1.

2.

3.

B: To be answered by child/young person or if this is not possible, by parent/carer

*If possible please now give the questionnaire to your child to complete. If your child does not or cannot answer the questionnaire themselves, **please answer the remainder of the questionnaire yourself***

13. Who is completing this section (questions 13-16)?

I am the child/young person { FORMCHECKBOX }

I am the parent or carer { FORMCHECKBOX }

Both of us { FORMCHECKBOX }

14. If you are a parent or carer completing this section, why is this? *Tick all that apply*

My child is too young {
FORMCHECKBOX }

The questions are too difficult {
FORMCHECKBOX }

My child is too unwell {
FORMCHECKBOX }

Other:

15. This questionnaire is being completed

before the appointment today {
FORMCHECKBOX }

Page {

after the appointment today {
FORMCHECKBOX }

before and after the appointment today {
FORMCHECKBOX }

16. Please let us know how strongly you agree or disagree with the statements given in this section. We are interested in your **overall** impressions over the last year.

Strongly Agree Unsure Disagree Strongly Disagree Not Applicable

- Overall, I received **enough** information about epilepsy
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
- Staff **listened** to what I had to say
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
- The information I was given was **hard** to understand
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {

- Staff **did not** take time to get to know me { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX }
- Staff **did not** explain things in a way I could follow { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX }
- Staff **took my thoughts into account** when making decisions { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX }
- I felt the staff **respected** my need for privacy during clinic visits { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {
FORMCHECKBOX }
- Overall, staff seemed to **know what they were doing** { FORMCHECKBOX } {
FORMCHECKBOX } { FORMCHECKBOX } {

FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {

- At times I felt **I was not allowed** to ask questions

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- It is **easy to contact someone** in the epilepsy team

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- Staff make sure **it is easy to attend** the clinic e.g. when making

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

appointments

- I am **not seen by the service often enough**

FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {

Strongly Agree Agree Unsure Disagree Strongly Disagree Not Applicable

- Staff **tell me** if my appointment is delayed

{ FORMCHECKBOX } {

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- The waiting area **does not have activities** for my age

{ FORMCHECKBOX } {

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- Overall, the length of time spent with staff at the clinic is

about right

{ FORMCHECKBOX } {

FORMCHECKBOX }
FORMCHECKBOX }
FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- Staff are **not good at working together** with others e.g. GP

School or nursery, when looking after me

FORMCHECKBOX }

FORMCHECKBOX }

FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- Overall, staff are friendly and polite

- In the ward as inpatient

FORMCHECKBOX }

FORMCHECKBOX }

FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

- When going for tests e.g. EEG or MRI (if applicable)

FORMCHECKBOX }

FORMCHECKBOX }

FORMCHECKBOX }

{ FORMCHECKBOX } {
{ FORMCHECKBOX } {
{ FORMCHECKBOX } {

If you would like to explain an answer or tell us about other concerns, please do so in this space:

17. Which areas, if any, would you like more information on? *Tick all that apply*

- Guidance on what I can or can't do {
FORMCHECKBOX }
- Contact with other young people with epilepsy {
FORMCHECKBOX }
- What to tell other people about my epilepsy {
FORMCHECKBOX }
- Possible side effects of medication {
FORMCHECKBOX }
- Support groups { FORMCHECKBOX }
- Cause of my epilepsy { FORMCHECKBOX }
- Reasons for changing medication {
FORMCHECKBOX }
- Reasons for, and results of, tests {
FORMCHECKBOX }

18. Overall, are you satisfied with the care you receive from the epilepsy service?

- Yes { FORMCHECKBOX }
- No { FORMCHECKBOX }
- Unsure { FORMCHECKBOX }

Now please put your completed questionnaire in the envelope provided, seal it and return to the clinic staff.

If you prefer, you can post the envelope directly to the Epilepsy12 Audit team. It is Freepost so does not require a stamp.

Thank you very much for taking the time to complete
this questionnaire



Thanks to Chetna, Lisa, Catherine, Ravi, Sohail, Jane, Katie and Philip from the RCPCH Youth Advisory Panel, for their feedback when making this questionnaire