

# EPILEPSY12

United Kingdom collaborative clinical audit of health care for children  
and young people with suspected epileptic seizures

## **Epilepsy12 National Audit Round 2 Final Unit Report for:**

**Wirral**

Site specific report on the results for: Service Descriptor, Clinical Audit  
and Patient Reported Experience Measures

November 2014

Commissioned by the Healthcare Quality Improvement Partnership



## Background and methodology

This final unit report from Round 2 of Epilepsy12 contains results from the service descriptor, clinical audit and PREM questionnaire (if five or more PREM questionnaires received) audit domains. If a unit did not submit service descriptor or clinical audit data results will be shown as #N/A throughout those sections. Full details of the audit methodology can be found at: [www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)

### Unit details

Epilepsy12 Unit Name	Wirral
Name of audit unit lead	Adrian Hughes
Names of acute and community trusts	Wirral University Teaching Hospital NHS Foundation Trust
Names of component paediatric services/hospitals	Arrowe Park Hospital St Catherines Hospital: Birkenhead Victoria Central Hospital: Wallasey
Affiliated tertiary services	Alder Hey Children's Hospital Arrowe Park Hospital - Outreach Paediatric Neurology Clinic
EEG department(s)	Walton Neuroscience Centre The Walton Centre NHS Foundation Trust Lower Lane Fazakerley Liverpool L9 7LJ  Alder Hey Children's NHS Foundation Trust Eaton Road West Derby L12 2AP

### Case ascertainment in Round 2

	Your unit	UK
Children on list received from EEG department	-	14382
Children defined as 'excluded' (did not meet audit inclusion criteria)	-	9529
Children where it was not possible to identify whether they met the audit inclusion criteria	-	907
Children entered into the audit	0	3449
Children who were entered into the audit initially but not included in final analysis as their care was transferred to another unit at some point during the 12 months following the first paediatric assessment	0	31
Children entered into audit but not included in the data analysis as included inappropriate data	0	6
Children who met the audit criteria but were not successfully entered on web tool	-	281
Ascertainment completeness	-	92%
Data completeness	-	92%

## Service Descriptor Results

### Staffing and clinics

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
WTE general paediatric consultants (community or hospital based) employed in the audit unit	16.6	2026.9	17.8	1983.4
WTE general paediatric consultants with expertise in epilepsy employed in the audit unit	1	346.7	2	325.0
WTE epilepsy specialist nurses (ESNs) employed in the audit unit	1	100.9	1	124.3
Number of consultant (or associate specialist) led secondary level 'epilepsy clinics' for children or young people in the audit unit per week	1	189.9	3	215.8
Age outpatient adult services in the audit unit accepts referrals from primary care for young people with a seizure or seizures	16 years old	Median - 16 Min - 13 Max - 18	16 years old	Median - 16 Min - 14 Max - 18

### Services

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
The audit unit maintains a database or register of children with epilepsies	Yes for all children	26/193	Yes for all children	34/186
Audit unit hosts paediatric neurology clinics	Yes	164/193	Yes	159/186
Specific clinic for young people/teenagers with epilepsies	Yes	35/193	Yes	49/186
Handover' clinic	No	57/193	Yes	71/186
Other defined handover or referral to adult services	No	108/193	No	117/186
Local adult specialist epilepsy nurse	Yes	99/193	Yes	100/186
Youth worker	No	14/193	No	16/186

### Investigations

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
12 lead ECG	Yes	190/193	Yes	184/186
Awake' MRI	Yes	186/193	Yes	176/186
MRI with sedation	Yes	119/193	Yes	111/186
MRI with general anaesthetic	Yes	96/193	Yes	92/186
Routine EEG	No	115/193	No	112/186
Sleep-deprived EEG	No	114/193	No	111/186
Melatonin induced EEG	No	98/193	No	102/186
Sedated EEG	No	79/193	No	73/186
24-48 hour ambulatory EEG	No	80/193	No	82/186
Inpatient video telemetry	-	-	No	33/186
Outpatient video telemetry	-	-	No	15/186
Home video telemetry	-	-	No	4/186
Portable EEG on paediatric ward in audit unit	No	101/193	No	100/186

## Clinical Audit Results - Characteristics of the audit cohort

### Demographic characteristics

		Round 1		Round 2	
		Your unit	UK	Your unit	UK
		N=16	N=4945	#N/A	N=3449
Sex	Female	8 (50%)	2280 (46%)	#N/A	1542 (45%)
	Male	8 (50%)	2665 (54%)	#N/A	1907 (55%)
Age	Infant	2 (13%)	1170 (24%)	#N/A	861 (25%)
	Pre-school	2 (13%)	984 (20%)	#N/A	831 (24%)
	School aged	9 (56%)	1841 (37%)	#N/A	1182 (34%)
	Young people	3 (19%)	950 (19%)	#N/A	572 (17%)
Setting of first paediatric assessment	Acute	8 (50%)	2154 (44%)	#N/A	1544 (45%)
	Non-acute	8 (50%)	2790 (56%)	#N/A	1889 (55%)
	Unknown	0 (0%)	1 (<1%)	#N/A	16 (0%)
Outcome	Presumed alive	16 (100%)	4931 (100%)	#N/A	3414 (99%)
	Died	0 (0%)	14 (<1%)	#N/A	10 (0.3%)

### Neurodisability

		Round 1		Round 2	
		Your unit	UK	Your unit	UK
Number with one or more neurodisability		3 (19%)	966 (20%)	#N/A	782 (23%)
Autistic spectrum disorder		1 (33%)	182 (19%)	#N/A	283 (36%)
Moderate, severe or profound learning disabilities or global development delay		2 (67%)	298 (31%)	#N/A	244 (31%)
Cerebral palsy		0 (0%)	100 (10%)	#N/A	99 (13%)
Neurodegenerative disease or condition		0 (0%)	15 (2%)	#N/A	12 (2%)
An identified chromosomal disorder with a neurological or developmental component		0 (0%)	57 (6%)	#N/A	68 (9%)
Attention deficit hyperactivity disorder		0 (0%)	89 (9%)	#N/A	82 (10%)
Other		0 (0%)	225 (23%)	#N/A	181 (23%)

Percentages are calculated with the number of children with evidence as a neurodisability as the denominator

### Diagnosis

		Round 1		Round 2	
		Your unit	UK	Your unit	UK
First paediatric assessment	2 or more episodes of epileptic seizures	9 (56%)	1488 (30%)	#N/A	1169 (34%)
	1 episode of epileptic seizure (single and cluster)	3 (19%)	766 (16%)	#N/A	334 (10%)
	Non-epileptic episode(s)	0 (0%)	899 (18%)	#N/A	512 (15%)
	Uncertain or unclear episode(s)	4 (25%)	1792 (36%)	#N/A	1434 (42%)
12 months after first paediatric assessment	2 or more episodes of epileptic seizures	15 (94%)	1775 (36%)	#N/A	1215 (35%)
	1 episode of epileptic seizure (single)	0 (0%)	259 (5%)	#N/A	422 (12%)
	Non-epileptic episode(s)	0 (0%)	2202 (45%)	#N/A	1513 (44%)
	Uncertain or unclear episode(s)	1 (6%)	709 (14%)	#N/A	299 (9%)

### Anti-epileptic drugs (AEDs)

		Round 1		Round 2	
		Your unit	UK	Your unit	UK
Commenced on 1 or more AED		13 (81%)	1538 (31%)	#N/A	334 (10%)
Commenced on 3 or more AEDs		1 (6%)	135 (3%)	#N/A	512 (15%)

## Clinical Audit Results - Characteristics of the audit cohort

### Seizure types

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
(Generalised) tonic-clonic seizures	8 (53%)	692 (39%)	#N/A	474 (39%)
Absence seizures (including typical or atypical)	3 (20%)	543 (31%)	#N/A	362 (30%)
Focal seizures	4 (27%)	290 (16%)	#N/A	253 (21%)
Secondarily generalized seizures	3 (20%)	111 (6%)	#N/A	111 (9%)
Myoclonic seizures	3 (20%)	129 (7%)	#N/A	89 (7%)
Focal motor seizures	0 (0%)	96 (5%)	#N/A	91 (7%)
Infantile spasms	1 (7%)	48 (3%)	#N/A	47 (4%)
No seizure type stated	1 (7%)	114 (6%)	#N/A	46 (4%)
Tonic seizures	0 (0%)	66 (4%)	#N/A	38 (3%)
Other seizure stated	-	-	#N/A	29 (2%)

Only seizure types with more than 1% of patients are included in the table above

### Syndrome category identifiers

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
Genetic generalised	0 (0%)	13 (<1%)	#N/A	43 (4%)
Genetic focal/multifocal	0 (0%)	13 (<1%)	#N/A	27 (2%)
Idiopathic generalised	0 (0%)	391 (22%)	#N/A	339 (28%)
Idiopathic focal	4 (27%)	79 (5%)	#N/A	108 (9%)
Structural (metabolic) generalised	0 (0%)	4 (<1%)	#N/A	32 (3%)
Structural (metabolic) focal/multifocal	0 (0%)	23 (1%)	#N/A	32 (3%)
Probably symptomatic (or cryptogenic) or symptomatic generalised	1 (7%)	52 (3%)	#N/A	45 (4%)
Probably symptomatic (or cryptogenic) or symptomatic and focal/multifocal	3 (20%)	98 (6%)	#N/A	97 (8%)
Other	7 (47%)	1102 (62%)	#N/A	598 (49%)

### Epilepsy syndromes

	Round 1		Round 2	
	Your unit	UK	Your unit	UK
BECTS (benign rolandic epilepsy)	2 (13%)	160 (9%)	#N/A	95 (8%)
Other epilepsy syndrome stated	1 (7%)	128 (7%)	#N/A	229 (19%)
Childhood absence epilepsy (CAE)	1 (7%)	65 (4%)	#N/A	116 (10%)
Defined as unclassified	2 (13%)	54 (3%)	#N/A	75 (6%)
Juvenile absence epilepsy	0 (0%)	48 (3%)	#N/A	39 (3%)
Temporal lobe epilepsy	0 (0%)	41 (2%)	#N/A	37 (3%)
Frontal lobe epilepsy	0 (0%)	32 (2%)	#N/A	23 (2%)
Juvenile myoclonic epilepsy (JME)	0 (0%)	27 (2%)	#N/A	39 (3%)
West syndrome (infantile spasms)	0 (0%)	25 (1%)	#N/A	31 (3%)
Occipital lobe epilepsy	0 (0%)	17 (1%)	#N/A	9 (1%)
Doose syndrome	0 (0%)	16 (<1%)	#N/A	16 (1%)
Panayiotopoulos syndrome	0 (0%)	10 (<1%)	#N/A	11 (1%)
Dravet syndrome	0 (0%)	5 (<1%)	#N/A	2 (0%)
Parietal lobe epilepsy	0 (0%)	1 (<1%)	#N/A	0 (0%)
No epilepsy syndrome stated	9 (60%)	941 (53%)	#N/A	502 (41%)

Note: The figures in the table above may not add up to 100% as some children have more than one type, category or syndrome reported. Some less common seizure types have not been reported at unit level.

## Clinical Audit Results - Characteristics of the audit cohort

### Seizure free outcome data for those with epilepsy

	6 to 12 months after assessment		9 to 12 months after assessment	
	Your unit	UK	Your unit	UK
Known to be seizure free	#N/A	427 (35%)	#N/A	614 (51%)
Not seizure free	#N/A	709 (58%)	#N/A	464 (38%)
Not recorded	#N/A	79 (7%)	#N/A	137 (11%)

### Epilepsy12 indicators

There are 12 performance indicators that measure care over 12 months. Units are defined as a negative outlier if they are below two standard deviations from the UK value and a positive outlier if they are higher than two standard deviations from the UK value. The table below indicates the outlier status for your unit for each of the indicators.

Many of the indicators are based on small numbers of children at a unit level. This means that there will be a lot of natural variation in the percentage values for units, a difference of one or two children included (or not) in the indicator will make a big difference to the percentage value and units will have to have a percentage a long way from the UK value to be identified as an outlier. As the ideal for all indicators is 100% all units scoring less than this have scope for improvement.

Professionals	1	Paediatrician with expertise in epilepsies	#N/A
	2	Epilepsy specialist nurse	#N/A
	3	Tertiary involvement	#N/A
Assessment and classification	4	Appropriate first clinical assessment	#N/A
	5	Seizure classification	#N/A
	6	Syndrome classification	#N/A
Investigation	7	ECG	#N/A
	8	EEG	#N/A
	9	MRI	#N/A
Management and outcome	10	Carbamazepine	#N/A
	11	Accuracy of diagnosis	#N/A
	12	Water safety	#N/A

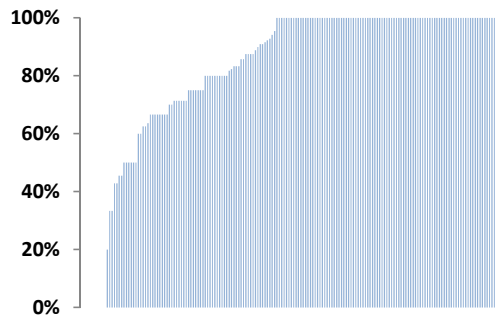
For full details of the definitions of the Epilepsy12 indicators please see the methodology document at [www.rcpch.ac.uk/epilepsy12](http://www.rcpch.ac.uk/epilepsy12)

## Epilepsy12 Performance Indicators

The charts below show the achievement of the Epilepsy12 indicators compared to all units in the audit. Your unit is shown by the black line.

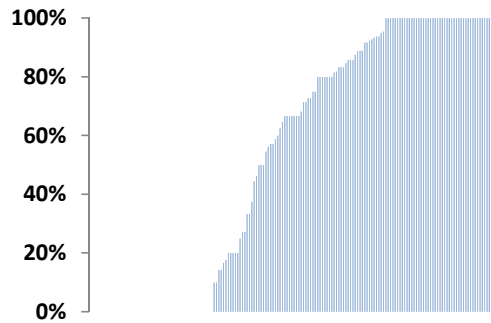
### Professionals

1. Paediatrician with expertise in epilepsies



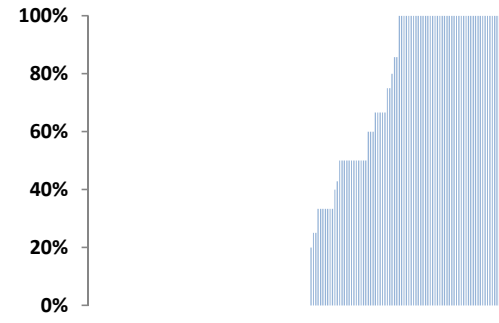
#N/A

2. Epilepsy specialist nurse



#N/A

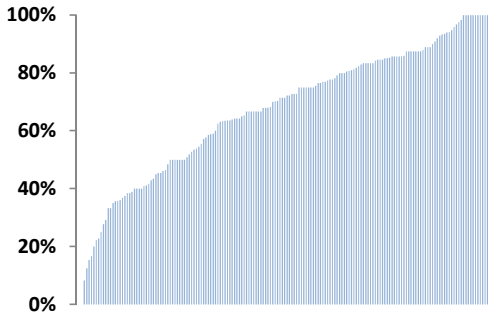
3. Paediatric neurologist



#N/A

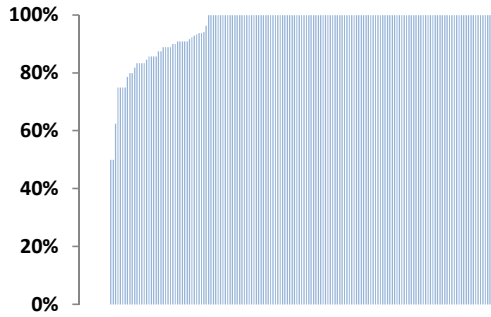
### Assessment and classification

4. Appropriate first clinical assessment



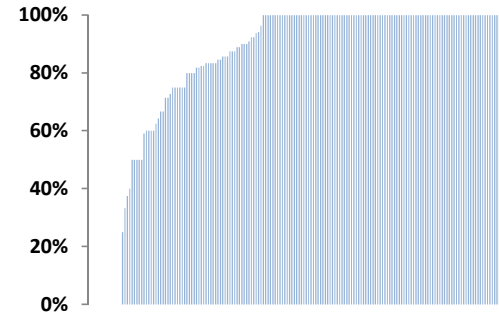
#N/A

5. Seizure classification



#N/A

6. Syndrome classification

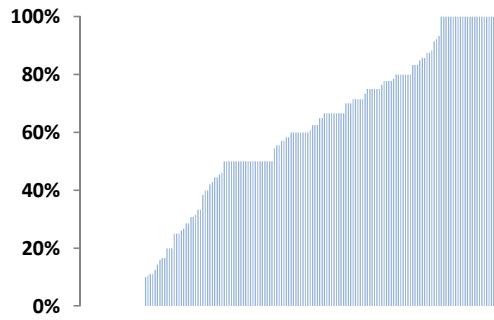


#N/A

# Epilepsy12 Performance Indicators

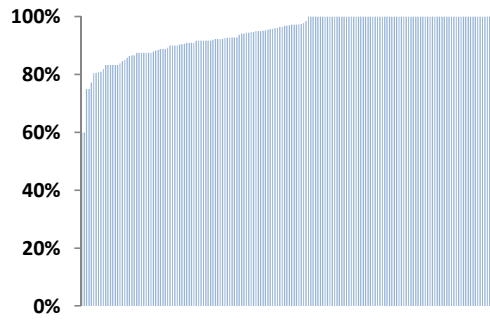
## Investigations

7. ECG



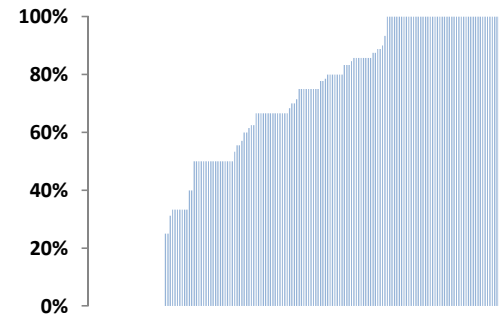
#N/A

8. EEG



#N/A

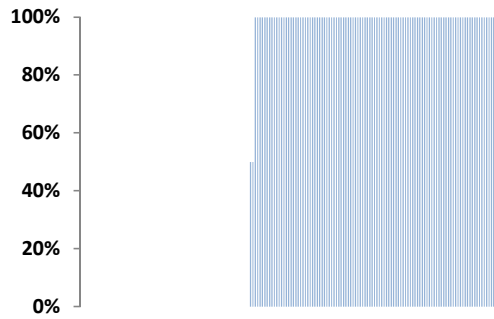
9. MRI



#N/A

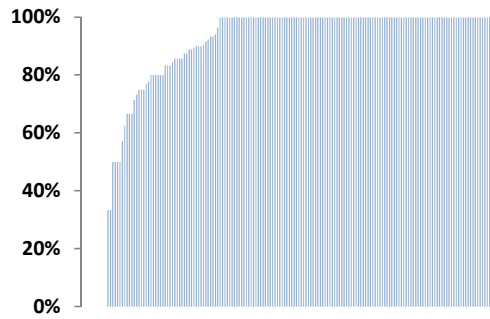
## Other

10. Appropriate carbamazepine



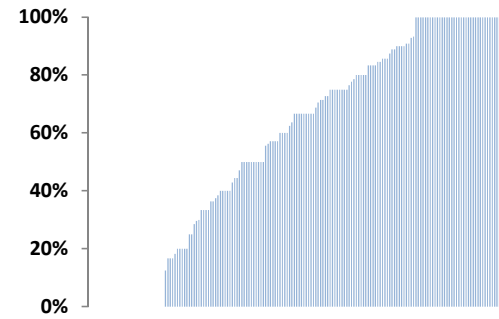
#N/A

11. Accuracy of diagnosis



#N/A

12. Information and advice



#N/A



## Detailed Performance Indicators

			Your unit				Liverpool & North Wales				England				All units in UK							
			Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	25th centile	75th centile	% in Round 1	25th centile in R1	75th centile in R1
Professionals	1a	% of children with epilepsy with input by a consultant paediatrician with expertise in epilepsies by one year	#N/A	#N/A	0%	93%	61	67	91%	79%	877	1019	86%	78%	1053	1215	87%	71%	100%	79%	57%	100%
	1b	% of children with epilepsy who are commenced on AEDs with input by a consultant paediatrician with expertise in epilepsies by one year	#N/A	#N/A	0%	100%	48	52	92%	80%	726	813	89%	80%	875	976	90%	75%	100%	81%	64%	100%
	2a	% of children with epilepsy referred for input by an epilepsy specialist nurse by one year	#N/A	#N/A	0%	93%	44	67	66%	57%	555	1019	54%	42%	717	1215	59%	0%	100%	46%	0%	77%
	2b	% of children with epilepsy who were commenced on AEDs referred for input by an epilepsy specialist nurse by one year	#N/A	#N/A	0%	100%	34	52	65%	60%	474	813	58%	45%	617	976	63%	0%	100%	51%	0%	87%
	3	% of children meeting defined criteria for paediatric neurology referral with input of tertiary care by one year	#N/A	#N/A	0%	33%	11	19	58%	47%	115	214	54%	59%	145	253	57%	0%	96%	60%	33%	100%
Assessment & classification	4	Appropriate first clinical assessment	#N/A	#N/A	0%	13%	101	142	71%	72%	1971	2907	68%	65%	2361	3449	68%	50%	85%	65%	50%	79%
	4a	% of children with descriptions of episode	#N/A	#N/A	0%	94%	138	142	97%	98%	2863	2907	98%	98%	3394	3449	98%	100%	100%	98%	98%	100%
	4b	% of children with descriptions of age of child/timing of first episode	#N/A	#N/A	0%	100%	135	142	95%	99%	2739	2907	94%	94%	3246	3449	94%	91%	100%	94%	91%	100%
	4c	% of children with descriptions of frequency	#N/A	#N/A	0%	100%	127	142	89%	98%	2703	2907	93%	91%	3205	3449	93%	88%	100%	92%	88%	100%
	4d	% of children with descriptions of general examination	#N/A	#N/A	0%	31%	129	142	91%	88%	2704	2907	93%	93%	3211	3449	93%	89%	100%	92%	89%	100%
	4e	% of children with description of neurological examination	#N/A	#N/A	0%	19%	122	142	86%	80%	2471	2907	85%	83%	2951	3449	86%	78%	97%	83%	77%	93%

			Your unit				Liverpool & North Wales				England				All units in UK							
			Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	% in Round 1	Numerator	Denominator	%	25th centile	75th centile	% in Round 1	25th centile in R1	75th centile in R1
Assessment & classification	4f	% of children with description of developmental history or educational progress	#N/A	#N/A	0%	81%	124	142	87%	88%	2376	2907	82%	82%	2843	3449	82%	73%	94%	82%	74%	94%
	4g	% of children three years and over with descriptions of emotional or behavioural problems	#N/A	#N/A	0%	8%	56	90	62%	61%	1160	1938	60%	55%	1376	2280	60%	42%	76%	55%	38%	67%
	5	% of children with epilepsy with seizure classification by one year	#N/A	#N/A	0%	93%	63	67	94%	95%	973	1019	95%	87%	1159	1215	95%	91%	100%	87%	78%	100%
	6a	% of children with epilepsy with epilepsy syndrome by one year	#N/A	#N/A	0%	40%	33	67	49%	44%	556	1019	55%	38%	678	1215	56%	28%	75%	87%	78%	100%
	6b	% of children with epilepsy with epilepsy syndrome or category identifiers by one year	#N/A	#N/A	0%	-	60	67	90%	-	911	1019	89%	-	1088	1215	90%	80%	100%	-	-	-
Investigation	7	% of children with convulsive seizures with an ECG by one year	#N/A	#N/A	0%	17%	40	67	60%	26%	654	1113	59%	38%	760	1291	59%	27%	78%	40%	22%	53%
	8	% of children who had an EEG in who there are no defined contraindications	#N/A	#N/A	0%	100%	139	142	98%	96%	2740	2907	94%	92%	3247	3449	94%	91%	100%	92%	88%	100%
	9a	% of children with defined indications for an MRI who had an MRI by one year	#N/A	#N/A	0%	88%	31	44	70%	68%	458	630	73%	64%	544	751	72%	43%	100%	64%	50%	80%
	9b	% of children with defined indications for an MRI who had an MRI or CT by one year	#N/A	#N/A	0%	88%	36	44	82%	70%	493	630	78%	70%	583	751	78%	50%	100%	70%	50%	87%
Other	10	% of children given carbamazepine in who there were no defined contraindications	#N/A	#N/A	0%	100%	7	7	100%	100%	188	189	99%	94%	226	228	99%	0%	100%	95%	100%	100%
	11	% of children diagnosed with epilepsy who still had that diagnosis at one year	#N/A	#N/A	0%	100%	65	69	94%	92%	1007	1080	93%	88%	1200	1286	93%	88%	100%	89%	82%	100%
	12a	% of females over 12 years given AEDs who had documented evidence of discussion of pregnancy and contraception	#N/A	#N/A	0%	0%	3	5	60%	50%	48	86	56%	38%	52	97	54%	0%	0%	38%	0%	100%
	12b	% of children diagnosed with epilepsy with documented evidence of communication regarding water safety	#N/A	#N/A	0%	-	35	67	52%	-	660	1019	65%	-	774	1215	64%	26%	90%	-	-	-

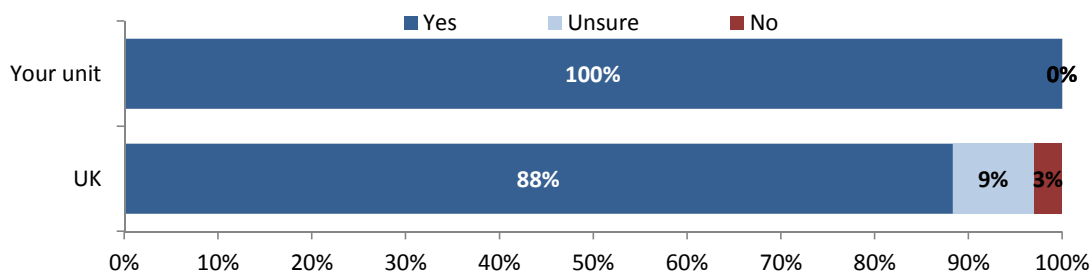
## Patient Reported Experience Measures

13 completed PREM questionnaires, were received for this unit. Parents or carers completed Section A. Section B was to be answered by the child or young person or, if that was not possible, by their parent or carer. Of the 13 questionnaires 7 (54%) had Section B completed by parents/carers and 5 (38%) had Section B completed by children or young people. There were 1 questionnaires where the respondent for Section B could not be identified.

Characteristics of children		Your unit N=13	UK N=2335
Year of birth	1994-1998	7.7%	15.5%
	1999-2003	53.8%	33.2%
	2004-2008	30.8%	32.2%
	2009-2013	0.0%	18.2%
	Not answered	7.7%	0.9%
Gender	Female	46.2%	47.1%
	Male	46.2%	52.3%
	Not answered	7.7%	0.6%
Diagnosis	Learning difficulties/developmental delay	30.8%	43.6%
	Cerebral palsy	7.7%	9.4%
	Autism or autistic spectrum disorder	0.0%	9.0%
	Attention deficit hyperactivity disorder (ADHD)	0.0%	5.3%
	None of the above	53.8%	40.6%
Timing of first assessment by paediatrician	Less than one year ago	15.4%	19.5%
	Between one and two years ago	15.4%	18.7%
	Two or more years ago	46.2%	57.3%
	Not answered	23.1%	4.4%
Age at first assessment	Infants (< 2 years)	15.4%	23.6%
	Pre-school (2 - <5 years)	23.1%	22.7%
	School (5 - < 12 years)	38.5%	31.4%
	Young people (12 - <16 years)	15.4%	9.5%
	Not answered	7.7%	12.8%
Services attended	Hospital general paediatric clinic	7.7%	12.7%
	Community paediatric clinic	7.7%	12.7%
	Teenage epilepsy clinic	15.4%	2.9%
	Specific epilepsy clinic	53.8%	19.5%
	Paediatric neurology clinic	46.2%	28.8%
	A&E	30.8%	23.6%
	GP	15.4%	21.7%
Drugs currently prescribed	Sodium Valproate	30.8%	41.2%
	Carbamazepine	0.0%	17.9%
	Lamotrigine	7.7%	19.8%
	Levetiracetam	38.5%	18.6%

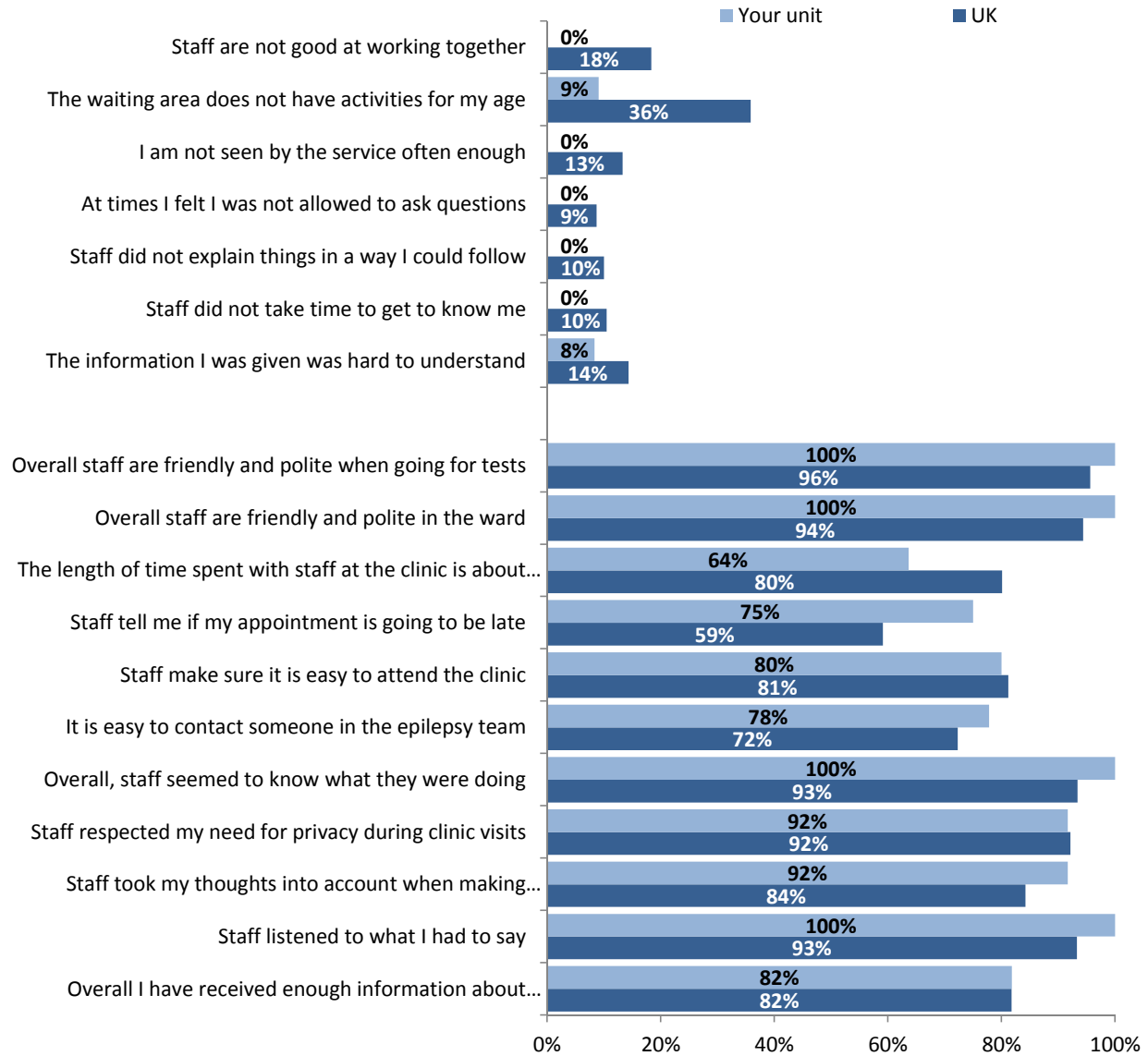
### Overall satisfaction

In your unit 11 (100%) of those who answered the question indicated yes to: 'Overall, are you satisfied with the care you receive from the epilepsy service?' compared to 88% across the UK.



## Patient Reported Experience Measures

Impressions of service over past year showing the percentage who agreed or strongly agreed



## Information needs

Respondents were asked 'What would you like more information on?' and could select multiple answers.

