

## **Epilepsy Service Feedback Questionnaire, Chelsea and Westminster NHS Trust**

58 questionnaires returned

Response rate unknown.

### **Do you see a neurologist and / or epilepsy nurse practitioner?**

**Yes** 40

**No** 9

**Unanswered** 9

NB The aim had been to use this question to identify if patient's questionnaire responses varied between the different areas of the service (secondary / tertiary/ ANP). However, it was felt that the answers obtained were inaccurate. The patients did not understand that the secondary level consultants are paediatricians with a neurology interest and not a neurologist. In future feedback cycles this question would be reworded:

### **Did you see an epilepsy nurse today?**

### **Did you see a paediatrician with an interest in neurology today?**

### **Does your child see a specialist neurologist?**

It may be helpful to help patients fill in this question

### **Thinking about the epilepsy care you have had, what has been most useful?**

1. Access to a specialist (epilepsy nurse practitioner / neurologist / play specialist / psychologist)
  - ❖ **43** responses. 21 specifically referenced the ANP.
2. Access to advice on queries about epilep[sy between appointments
  - ❖ **26** responses
3. If an MRI scan was requested, quick (2-4 weeks wait) access to MRI
  - ❖ **9** responses
4. If an EEG was requested, quick (2-4 weeks wait) access to EEG
  - ❖ **18** responses
5. Being signposted to local support groups or epilepsy resources
  - ❖ **12** responses
6. Other – please tell us! (various free text replies)

### **Thinking about getting the help you need, what is most important?**

1. Getting a quick referral / appointment with a specialist
  - ❖ **29** responses

2. Being able to speak to a member of the epilepsy team when you need to  
❖ **43** responses
3. Getting quick access / results of an MRI scan if needed  
❖ **9** responses
4. Getting quick access / results of an EEG or videotelemetry if recommended  
❖ **17** responses
5. Having access to support between appointments (clinic / charity / support groups)  
❖ **12** responses
6. Other  
❖ **1** response (caring staff)

**Have you been referred for any of the following investigations, and if so, how long did you wait?**

	<b>MRI</b>	<b>EEG</b>	<b>Videotelemetry</b>
<b>Not referred</b>	8	3	15
<b>0-1 month</b>	16	28	2
<b>2-3 months</b>	10	16	3
<b>3-6 months</b>	5	3	0
<b>&gt;6 months</b>	1	1	5

**How confident do you feel in your knowledge of epilepsy and how to manage it?**

<b>Very Confident</b>	<b>19</b>
<b>Quite confident</b>	<b>27</b>
<b>Neither confident or uncertain</b>	<b>11</b>
<b>Quite uncertain</b>	<b>2</b>
<b>Very uncertain</b>	<b>0</b>

**Where do you prefer to get information about epilepsy?**

<b>Face to face with a doctor or epilepsy nurse</b>	<b>45</b>
<b>In a leaflet</b>	<b>4</b>
<b>Online</b>	<b>11</b>
<b>Other</b>	<b>2 (both preferred by phone)</b>

**Please tell us 5 words that sum up your experience of the epilepsy service;**

Various freetext responses

**Space for further comments**