

## Freedom of Information Questionnaire – Epilepsy in Pregnancy Services

**Hospital Name:** Royal Albert Edward Infirmary

**Trust:** Wroughtington, Wigan and Leigh NHS FT Teaching Hospitals

**Maternity Medicine Network:** The Trust is part of the Northwest Maternal Medicine Network for Safer Pregnancy

**Secondary/Tertiary Care:** Manchester University NHS Foundation Trust (they provide the pre-pregnancy clinics)

Pre-pregnancy planning in women with epilepsy		
1a	Do women with epilepsy have access to a pre-pregnancy counselling clinic in your centre?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No  There is a pre-pregnancy clinic in Manchester which any clinician in Wigan can access that clinic and refer patients.
1b	If pre-pregnancy counselling is available in your centre, who delivers this/these services?  (Please tick all that apply)	<input type="checkbox"/> A neurologist/ epilepsy specialist doctor <input type="checkbox"/> A neurology specialist nurse/ epilepsy specialty nurse <input type="checkbox"/> An obstetrician with an interest in neurology/ a maternal-fetal medicine obstetrician <input type="checkbox"/> An obstetrician physician <input type="checkbox"/> An epilepsy specialist midwife  N/A – clinic not available.
1c	If you have selected more than one practitioner in question 1b do they work separately or as part of a joint clinic?	<input type="checkbox"/> They work separately <input type="checkbox"/> They work together in a joint clinic  N/A – pre-conception clinic not available in Wigan.
1d	How are patients transferred into the pre-pregnancy clinic?  (Please tick all that apply)	<input type="checkbox"/> From their General Practitioner (GP) <input type="checkbox"/> From their secondary care epilepsy service <input type="checkbox"/> Other – please state:  N/A

Antenatal management		

2	Do your patients have access to written information on the management of epilepsy in pregnancy?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No There are no local patient information leaflets.
3a	Do women with epilepsy in your centre have access to regular planned antenatal care with a designated epilepsy care team?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
3b	If yes, which of the following healthcare professionals deliver the service?  <b>(Please tick all that apply)</b>	<input checked="" type="checkbox"/> A neurologist/ epilepsy specialist doctor <input checked="" type="checkbox"/> A neurology specialist nurse/ epilepsy specialist nurse <input checked="" type="checkbox"/> An obstetrician with an interest in neurology/ a maternal-fetal medicine obstetrician <input type="checkbox"/> An obstetric physician <input type="checkbox"/> An epilepsy specialist midwife
3c	If you have selected more than one practitioner in questions 3b do they work separately or as part of a joint clinic?	<input checked="" type="checkbox"/> They work separately <input type="checkbox"/> They work together in a joint clinic
3d	How do women with epilepsy enter the service?  <b>(Please tick all that apply)</b>	<input checked="" type="checkbox"/> Identified at their booking appointment <input type="checkbox"/> From their General Practitioner (GP) <input type="checkbox"/> From their secondary care epilepsy service <input type="checkbox"/> Other – please state:
3e	If yes, how often are they reviewed in your epilepsy pregnancy clinic?	<input type="checkbox"/> Fortnight <input type="checkbox"/> Monthly <input type="checkbox"/> Bimonthly <input type="checkbox"/> Once per trimester <input checked="" type="checkbox"/> Other – please state: Booking, 20 weeks, 32 weeks, 35 weeks, 38 weeks, or as dictated by clinical situation.
4	Are women with epilepsy risk stratified in your antenatal service?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No

4b	If yes, how is the risk assessment done?	<input type="checkbox"/> Using a risk stratification tool : please state which  <input checked="" type="checkbox"/> Other – please state: Clinical history.
4c	If so do those women considered 'higher risk' have a different care pathway to those considered 'lower risk'	<input checked="" type="checkbox"/> Yes  <input type="checkbox"/> No  <p>If yes, please detail how these pathways differ:</p> <p>High risk patients referred to Manchester or Neurologist in Salford.</p> <p>Women with a history of epilepsy who are not considered to have a high risk of unprovoked seizures can be managed as low-risk women in pregnancy. These are women who have been seizure free for 10 years (with the last 5 years off AEDs) and those with childhood epilepsy syndrome who have reached adulthood seizure and treatment free. A trained neurologist may make the diagnosis of Epilepsy resolution in these cases.</p>

Medication management		
5	How does your service manage folic acid use in women with epilepsy?	<input checked="" type="checkbox"/> Recommend 5mg folic acid for three months prior to pregnancy and throughout pregnancy  <input type="checkbox"/> Recommend 5mg folic acid for three months prior to pregnancy and for the first trimester of pregnancy, then drop to 400mcg for the remainder of the pregnancy  <input type="checkbox"/> Recommend 400mcg for three months prior to pregnancy and for the first trimester of pregnancy  <input type="checkbox"/> Recommend 400mcg for three months prior to pregnancy and throughout pregnancy  <input checked="" type="checkbox"/> Other – please state  <p>All women with epilepsy should be advised to take 5 mg/day of folic acid prior to conception and to continue the intake until at least the end of the first trimester to reduce the incidence of major congenital malformation.</p>
6	How does your service manage titration of antiseizure medications in pregnancy?  <b>(Please tick all that apply)</b>	<input type="checkbox"/> Using drug levels  <input type="checkbox"/> Using clinical symptoms  <input checked="" type="checkbox"/> Using both drugs levels and clinical symptoms  <input checked="" type="checkbox"/> Other – please state: Left to discretion of Neurologist.

7	Does your centre routinely measure drug levels in women with epilepsy?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
8a	Do you use long-acting benzodiazepines, such as clobazam, in the peripartum period for women with 'high risk' of seizures during this period?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No With discretion of Neurologist.
8b	If yes, what is your routine drug/dose/regimen	Long-acting benzodiazepines such as clobazam can be considered if there is a very high risk of seizures in the peripartum period. In individual cases if labour is thought to be likely to precipitate a major seizure, the care plan may include use of additional clobazam 10-20mg orally 12 hourly to reduce the risk. (The patient's own AED should be continued in labour).
8c	If yes, what are the criteria for women being considered 'high risk'?	Potential indications for clobazam include recent convulsive seizures and a history of seizure provocation by sleep deprivation, stress or previous labour.  Patients with recurrent seizures even whilst on AED.

Postpartum follow up for women with epilepsy		
9	How are women with epilepsy in your service followed up postpartum?	<input type="checkbox"/> In a postpartum pregnancy clinic <input checked="" type="checkbox"/> In their usual epilepsy clinic <input checked="" type="checkbox"/> By their GP <input type="checkbox"/> There is no routine follow-up

Thank you for taking the time to complete this survey.