

Date 12/06/2025
Your Ref
Our Ref 10064

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
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richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION - EPILEPSY DURING PREGNANCY

I write in response to your request for information in relation to epilepsy during pregnancy.

Question:

- The confidential enquiry into maternal deaths has highlighted the increased risk of maternal morbidity and mortality in women with epilepsy during pregnancy. This survey aims to enhance our understanding of the services currently in place to manage these women.

We will be very grateful for your completion of the attached survey. If you have any queries, please do not hesitate to contact us.

Answer:

Please see enclosed completed survey.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
*Lothian NHS Board is the common
name of Lothian Health Board*

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive

Freedom of Information Questionnaire – Epilepsy in Pregnancy Services

Hospital Name: Royal Infirmary of Edinburgh

Trust: NHS Lothian

Maternity Medicine Network:

Secondary/Tertiary Care: Tertiary

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 Not routinely but it can be requested
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 checked="" type="checkbox"/> A neurology specialist nurse/ epilepsy specialty nurse <input checked="" 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
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 checked="" type="checkbox"/> They work together in a joint clinic
1d	How are patients transferred into the pre-pregnancy clinic? (Please tick all that apply)	<input checked="" type="checkbox"/> From their General Practitioner (GP) <input type="checkbox"/> From their secondary care epilepsy service <input type="checkbox"/> Other – please state:

Antenatal management		
2	Do your patients have access to written information on the management of epilepsy in pregnancy?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
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	<p>If yes, which of the following healthcare professionals deliver the service?</p> <p>(Please tick all that apply)</p>	<input 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	<p>If you have selected more than one practitioner in questions 3b do they work separately or as part of a joint clinic?</p>	<input type="checkbox"/> They work separately <input checked="" type="checkbox"/> They work together in a joint clinic
3d	<p>How do women with epilepsy enter the service?</p> <p>(Please tick all that apply)</p>	<input checked="" type="checkbox"/> Identified at their booking appointment <input checked="" type="checkbox"/> From their General Practitioner (GP) <input type="checkbox"/> From their secondary care epilepsy service <input type="checkbox"/> Other – please state:
3e	<p>If yes, how often are they reviewed in your epilepsy pregnancy clinic?</p>	<input type="checkbox"/> Fortnight <input checked="" type="checkbox"/> Monthly <input type="checkbox"/> Bimonthly <input type="checkbox"/> Once per trimester <input type="checkbox"/> Other – please state:
4	<p>Are women with epilepsy risk stratified in your antenatal service?</p>	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4b	<p>If yes, how is the risk assessment done?</p>	<input type="checkbox"/> Using a risk stratification tool : please state which <input type="checkbox"/> Other – please state:
4c	<p>If so do those women considered 'higher risk' have a different care pathway to those considered 'lower risk'</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <p>If yes, please detail how these pathways differ:</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 type="checkbox"/> Other – please state
6	How does your service manage titration of antiseizure medications in pregnancy? (Please tick all that apply)	<input checked="" type="checkbox"/> Using drug levels <input type="checkbox"/> Using clinical symptoms <input type="checkbox"/> Using both drugs levels and clinical symptoms <input type="checkbox"/> Other – please state:
7	Does your centre routinely measure drug levels in women with epilepsy?	<input checked="" type="checkbox"/> Yes <input 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
8b	If yes, what is your routine drug/dose/regimen	Clobazam 10mg 5 days peri partum
8c	If yes, what are the criteria for women being considered 'high risk'?	Continued seizures in pregnancy, previous peri-partum seizures, poor compliance and recent diagnosis

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 type="checkbox"/> By their GP
	<input type="checkbox"/> There is no routine follow-up

Thank you for taking the time to complete this survey.