Lothian NHS Board

NHS Lothian Headquarters
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Date 30 July 2026
Your Ref
Our Ref 11546

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – REFERRAL PATHWAYS

I write in response to your request for information in relation to referral pathways.

Question:

- We would be grateful if you could arrange for the attached questionnaire to be completed by the appropriate clinical service(s), such as Diabetes, Endocrinology, Obstetrics, Maternal Medicine, or Clinical Genetics teams, as applicable within your organisation.

  The information requested relates to service organisation, referral pathways, multidisciplinary working and genetic testing pathways for women with known or suspected monogenic diabetes during pregnancy.

Answer:

Please see enclosed which we have completed as fully as possible.

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.

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

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive

Background information:
Trust Name: NHS Lothian
Number of sites providing maternity care at the Trust:
Antenatal: 3
Intrapartum: 2
Postnatal care: 2

Annual Birth volume per site and overall for the Trust
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Annual birth rate (Health Board total)	9000
Site A Royal Infirmary of Edinburgh	6700
Site B St John's Hospital	2300

Tertiary level NICU? Yes
Tertiary level fetal medicine? Yes
Tertiary level Maternal Medicine Service Yes

Pre-pregnancy management of monogenic diabetes.
Do you have a written protocol or pathway of care for pre-pregnancy management of people with a known diagnosis of any form of monogenic diabetes?

No. All patients with monogenic diabetes are looked after in a dedicated genetic diabetes clinic run by an expert in monogenic diabetes. Pre-pregnancy discussions are managed on a case by case/ gene by gene basis.

Do you have a written protocol or policy for pre-pregnancy management of potential fathers with a known diagnosis of Monogenic diabetes?

No. All patients with monogenic diabetes are looked after in a dedicated genetic diabetes clinic run by an expert in monogenic diabetes. Pre-pregnancy discussions are managed on a case by case/ gene by gene basis.

If yes, are you happy for us to contact you to obtain a copy?
N/A

If no, would it be of value to you to have a protocol to refer to?
Yes / No Possibly – although there are many very rare forms of monogenic diabetes and it would be unlikely a protocol would cover all variations in care required.

Antenatal management of pre pregnancy diagnosis of monogenic diabetes.
Do you have a policy for management of pregnant people with a pre-pregnancy diagnosis of any form of monogenic diabetes?

No. Managing MODY requires a tailored approach based on the specific genetic subtype.

We have the following text in our general diabetes in pregnancy guideline:

Monogenic diabetes

Consider a diagnosis of monogenic diabetes for any new diagnosis of diabetes in pregnancy especially where there is a strong family history of diabetes or where the woman has an atypical phenotype for gestational or type 2 diabetes.

Glucokinase diabetes

Higher than usual home blood glucose test results (up to 10 mol/l) should be tolerated until 26 weeks' gestation. Growth scan should be offered at 26 weeks' gestation. If the fetus' abdominal circumference is >90th centile then assume the fetus does not also have the mutation and initiate trestment for the maternal hyperglycaemia (usually insulin). If the AC is normal, then assume the fetus also carries the mutation and do not lower the maternal blood glucose.

HNF1a/HNF4a diabetes

This is a sulfonyurea-sensitive form of monogenic diabetes. Glibenclamide is preferred to gliclazide, as it does not cross the placenta and cause fetal hyperinsulinism. Some patients may need insulin. Close liaison with the monogenic diabetes team at the WGH is advised.

If yes, are you happy for us to contact you to obtain a copy?

N/A

Antenatal management of monogenic diabetes diagnosed in the current pregnancy.

Antenatal Identification of pregnant people with undiagnosed monogenic diabetes in pregnancy

Do you have a policy for identifying pregnant people with monogenic diabetes in pregnancy (i.e. most commonly due to mutations in GCK, HNF1α, HNF4α and HNF1β genes)?

No.

If yes, are you happy for us to contact you to obtain a copy? We are currently offering gene testing to women who have been diagnosed with Gestational Diabetes based on their OGTT result who have a BMI of less than 30 when it is clinically indicated but we do not have a written policy.
If no, would it be of value to you to have a protocol to refer to?
Yes

Management of monogenic diabetes care in pregnancy

Which professional group leads on the management of pregnant people with monogenic diabetes during maternity care? Please indicate below: If this is a shared role, please include in the comments.

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	Yes	*No*	*Comments:*
Diabetes specialist midwife		*x*	
Obstetrician	*x*		*with special interest in diabetes*
Fetal medicine specialist		*x*	
Maternal medicine specialist (including obstetric physician)		*x*	

Diabetes/ endocrinology specialist	*x*		
Diabetes nurse specialist	*x*		
Clinical Geneticist/ Genetic Counsellor	*x*		
Other			

In which clinic are pregnant people with monogenic diabetes seen?
Please tick all that apply:
Diabetes clinic (separate to antenatal clinic)
Joint antenatal and diabetes clinic ***x***
Antenatal clinic
Specialist antenatal monogenic diabetes clinic
Other: Please indicate which other below:
Training and genomic testing

Do you have staff who are specifically trained to manage pregnant people with monogenic diabetes?

Yes

If yes, please tick below to indicate which professional group/s have received ***specific training*** *in management of pregnant people with monogenic causes of diabetes? Please tick all that apply:*
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	Training Yes/ No	***Comments:*** *Type of training and venue eg: inclusion in a module, training day, specific training event*
Diabetes specialist midwife		
Obstetrician		
Fetal medicine specialist		
Maternal medicine specialist (including obstetric physician)		
Diabetes/ endocrinology specialist	*YES*	
Diabetes specialist nurse		

Are you aware of how to request genomic tests for monogenic diabetes in your UK country as below: yes

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Country	***Genomic Testing***
England	*NHS England » National genomic test directory*
Northern Ireland	*Requesting genetic testing | Belfast Health & Social Care Trust website*
Scotland	*Home - Scottish Strategic Network for Genomic Medicine*
Wales	*AWMGS - Download Services*

For those working in England, Wales and Northern Ireland only:
Are you aware of how to request non-invasive prenatal diagnosis in pregnancy where knowledge of fetal genotype will impact pregnancy management, delivery and immediate postnatal care?:

N/A

If you do not currently provide genomic tests for monogenic diabetes in pregnancy, what would you need to enable this to occur? Please tick as many options as apply and complete the free text box below for any additional comments:
Staffing:
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Professional group	*Please indicate Whole time equivalent (WTE) or numbers of staff you anticipate needing to provide this addition to your service*
Diabetologists trained and able to manage pregnant people with monogenic diabetes	
Obstetricians trained and able to manage pregnant people with monogenic diabetes	
Diabetes specialist midwives trained and able to manage pregnant people with monogenic diabetes	
Diabetes specialist nurses trained and able to manage pregnant people with monogenic diabetes	

Training:
Sufficient dedicated time for training in monogenic diabetes.
Funding for training
Availability of training
If your responses differ by professional group, please indicate below in the free text box.
Patient knowledge
Improved pregnant people's knowledge and understanding of testing and implications for their ongoing maternity or diabetes care
Other

<u>Postnatal management.</u>
Do you have a policy or protocol for postnatal management for individuals and their babies following a diagnosis of monogenic diabetes?
Yes
They are offered follow up in the MODY clinic diabetes specialist.
Do you have a policy or protocol to inform health professionals of the potential implications of a monogenic diabetes diagnosis on the pregnant person's/ patient's wider family?
No

If yes, are you happy for us to contact you to obtain a copy? N/A
If no, would it be of value to you to have a protocol to refer to?
Yes

Multidisciplinary team working
Does your maternity Information Technology (IT) system allow for the recording of monogenic diabetes maternal, paternal or fetal genotype results (tick one)?

Yes - in part

If 'in part', please indicate which in the free text box below:

Which electronic Maternity IT system does your Trust use?

MaternityTrak

Do you have a pathway to share maternal and fetal monogenic genomic test results with members of the multi-disciplinary team?
Please indicate yes or no below for each section/subtype of monogenic diabetes:

The result of any genetic testing is usually dictated so that patient and GP are aware and also entered onto TRAK and SCI Diabetes which is accessible to all MDT team. (for all below)

Glucokinase hyperglycaemia (GCK)
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	Glucokinase hyperglycaemia (GCK) Maternal genotype result	***Glucokinase hyperglycaemia (GCK) Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*
Community Midwife	*Yes /No*	*Yes /No*
Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*

Hepatic Nuclear Factor 4 Alpha (HNF4A)
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	Hepatic Nuclear Factor 4 Alpha (HNF4A) Maternal genotype result	***Hepatic Nuclear Factor 4 Alpha (HNF4A) Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*

Community Midwife	*Yes /No*	*Yes /No*
Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*

Hepatic Nuclear Factor 1 Alpha (HNF1A)

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	Hepatic Nuclear Factor 1 Alpha (HNF1A) Maternal genotype result	***Hepatic Nuclear Factor 1 Alpha (HNF1A) Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*
Community Midwife	*Yes /No*	*Yes /No*
Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*

Hepatocyte Nuclear Factor-1 Beta (HNF1B)

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	Hepatocyte Nuclear Factor-1 Beta (HNF1B) ***Maternal genotype result***	***Hepatocyte Nuclear Factor-1 Beta (HNF1B*** ***Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*
Community Midwife	*Yes /No*	*Yes /No*
Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*

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	KCNJ11 Neonatal diabetes ***Maternal genotype result***	***KCNJ11 Neonatal diabetes*** ***Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*
Community Midwife	*Yes /No*	*Yes /No*

Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*

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	ABCC8 Neonatal diabetes ***Maternal genotype result***	***ABCC8 Neonatal diabetes*** ***Fetal Genotype result***
Diabetes/endocrinology	*Yes /No*	*Yes /No*
Obstetrician	*Yes /No*	*Yes /No*
Community Midwife	*Yes /No*	*Yes /No*
Screening Midwife/ultrasound	*Yes /No*	*Yes /No*
Neonatology/NICU	*Yes /No*	*Yes /No*
GP	*Yes /No*	*Yes /No*
Health Visitor	*Yes /No*	*Yes /No*