



**East Sussex Healthcare**  
NHS Trust

Eastbourne District General Hospital

Kings Drive  
Eastbourne  
East Sussex  
BN21 2UD

FOI REF: 26/382

1<sup>st</sup> July 2026

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Further to your recent request for information made under the Freedom of Information Act (FOIA) 2000, I now set out our answers to your specific questions, and any clarifications sought and provided, within the attached document - 'FOI 26-382 Response'.

I trust this information is helpful in its detail or explanation however, if you are dissatisfied with the response, then you have the right to request an internal review. If you wish to seek an internal review, please write to the Freedom of Information Team at [esh-tr.foi@nhs.net](mailto:esh-tr.foi@nhs.net) quoting the above FOI reference number, within 40 working days. Please note the Trust is not obliged to accept a request for an internal review after this time period.

Yours faithfully

Freedom of Information (FOI) Team  
East Sussex Healthcare NHS Trust  
0300 131 4716  
Core Hours of Business: Monday to Friday 9.00am to 4.00pm

**Re: Freedom of Information request.**

Please see below a survey of the services provided for pregnant women or birthing people (hereafter referred to as pregnant people) who may have a genetic form of diabetes or diabetes-type conditions. We are specifically interested in the ways that different hospitals manage monogenic diabetes, and particularly those caused by mutations in the genes GCK, HNF1 $\alpha$ , HNF4 $\alpha$  and HNF1 $\beta$ , as each of these can have different implications for management of an affected pregnancy.

The information provided will be used to benchmark maternity services across the United Kingdom to identify what services are currently offered and how these services are managed within the Trust (this information will inform a national project which aims to support the embedding of testing for the common forms of monogenic diabetes in pregnancy).

As the care of pregnant people with monogenic diabetes commonly involves diabetes and maternity services, it may be helpful for the response to be a joint venture between the diabetology and maternity teams.

**1. Background information:**

**Trust Name:** [East Sussex Healthcare NHS Trust \(ESHT\)](#)

**Number of sites providing maternity care at the Trust:** 2

**Antenatal:** 2

**Intrapartum:** 2

**Postnatal care:** 2

**Annual Birth volume per site and overall for the Trust**

<b>Annual birth rate (Trust total)</b>	<a href="#">2788 Women (2791 registerable babies)</a>
<b>Site A (Conquest Hospital)</b>	<a href="#">2697</a>
<b>Site B (named)</b>	<a href="#">4</a>
<b>Site C (named)</b>	

**Tertiary level NICU?** [No](#)

**Tertiary level fetal medicine?** [No](#)

**Tertiary level Maternal Medicine Service** [No](#)

**2. 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, but care falls under guidance for per existing diabetes.*

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

*No.*

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

*Not applicable.*

**Free text for email address:**

*Not applicable.*

If no, would it be of value to you to have a protocol to refer to?

*Yes.*

**3. 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, but care falls under guidance for per existing diabetes.*

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

*Not applicable.*

**Free text for email address (if different from the email addresses above):**

*Not applicable.*

4. **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, HNF1 $\alpha$ , HNF4 $\alpha$  and HNF1 $\beta$  genes)?

East Sussex Healthcare NHS Trust follows South East genomic medicine guidelines.

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

*Not applicable.*

<p><b>Free text for email address:</b></p> <p><i>Not applicable.</i></p>
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If no, would it be of value to you to have a protocol to refer to?

*Yes.*

5. **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.

	Yes	No	Comments:
Diabetes specialist midwife	Yes		
Obstetrician	Yes		
Fetal medicine specialist	Yes		
Maternal medicine specialist (including obstetric physician)	Yes		
Diabetes/ endocrinology specialist	Yes		
Diabetes nurse specialist	Yes		
Clinical Geneticist/ Genetic Counsellor		No	None at ESHT.
Other			

<p>Free text for other to specify:</p> <p><i>Care would be by the joint antenatal and endocrine team.</i></p>
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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](#)
- Antenatal clinic
- Specialist antenatal monogenic diabetes clinic
- Other: Please indicate which other below:

Free text for other to specify: .....
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## 6. Training and genomic testing

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

[Yes \(attended the South East genomic medicine training day\).](#)

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:

	<b>Training Yes/ No</b>	<b>Comments:</b> Type of training and venue eg: inclusion in a module, training day, specific training event
Diabetes specialist midwife	<a href="#">No</a>	
Obstetrician	<a href="#">No</a>	
Fetal medicine specialist	<a href="#">No</a>	
Maternal medicine specialist (including obstetric physician)	<a href="#">No</a>	
Diabetes/ endocrinology specialist	<a href="#">Yes</a>	<a href="#">Attended the South East genomic medicine training day).</a>
Diabetes specialist nurse	<a href="#">Yes</a>	<a href="#">Attended the South East genomic medicine training day).</a>

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

Yes.

Country	Genomic Testing
England	<a href="#">NHS England » National genomic test directory</a>
Northern Ireland	<a href="#">Requesting genetic testing   Belfast Health &amp; Social Care Trust website</a>
Scotland	<a href="#">Home - Scottish Strategic Network for Genomic Medicine</a>
Wales	<a href="#">AWMGS - Download Services</a>

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?:

Yes.

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:

**7. Staffing:**

Approximate number as follows as this is not quantifiable:

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	0.25
Obstetricians trained and able to manage pregnant people with monogenic diabetes	0.25
Diabetes specialist midwives trained and able to manage pregnant people with monogenic diabetes	0.25
Diabetes specialist nurses trained and able to manage pregnant people with monogenic diabetes	0.5

Free text: Other/Comments:  
.....

**8. 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.*

Free text: Other/Comments:  
.....

**9. Patient knowledge**

- Improved pregnant people’s knowledge and understanding of testing and implications for their ongoing maternity or diabetes care

Free text: Other/Comments:  
Yes.

**10. Other**

Free text: Other/Comments:  
None.

**11. Postnatal management.**

Do you have a policy or protocol for postnatal management for individuals and their babies following a diagnosis of monogenic diabetes?

No.

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?

*Not applicable.*

Free text for email address (if different from the email addresses above):

*Not applicable.*

If no, would it be of value to you to have a protocol to refer to?

Yes.

## 12. 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- all
- Yes- in part
- No.

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

Free text box: Recording of monogenic diabetes results in maternity IT systems

.....

Which electronic Maternity IT system does your Trust use?

Free text box: Which maternity IT system/s is in use in your organisation

Badgernet

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:

13. Glucokinase hyperglycaemia (GCK)

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

14. Hepatic Nuclear Factor 4 Alpha (HNF4A)

	Hepatic Nuclear Factor 4 Alpha (HNF4A) Maternal genotype result	Hepatic Nuclear Factor 4 Alpha (HNF4A) Fetal Genotype result
Diabetes/endocrinology	No.	No.
Obstetrician	No.	No.
Community Midwife	No.	No.
Screening Midwife/ultrasound	No.	No.
Neonatology/NICU	No.	No.
GP	No.	No.
Health Visitor	No.	No.

15. Hepatic Nuclear Factor 1 Alpha (HNF1A)

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

16. Hepatocyte Nuclear Factor-1 Beta (HNF1B)

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

	KCNJ11 Neonatal diabetes Maternal genotype result	KCNJ11 Neonatal diabetes Fetal Genotype result
Diabetes/endocrinology	No.	No.
Obstetrician	No.	No.
Community Midwife	No.	No.
Screening Midwife/ultrasound	No.	No.
Neonatology/NICU	No.	No.
GP	No.	No.
Health Visitor	No.	No.

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

Thank you very much for responding to this FOI and completing the information.