

Dear Sir/Madam

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 α , HNF4 α and HNF1 β , 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.

Background information:

Trust Name: Belfast Health and Social Care Trust

Number of sites providing maternity care at the Trust:

Antenatal: 2

Intrapartum: 1

Postnatal care: 1

Annual Birth volume per site and overall for the Trust

Annual birth rate (Trust total)	4500-5000
Site A (named)	Royal Jubilee Maternity hospital
Site B (named)	
Site C (named)	

Tertiary level NICU? Yes

Tertiary level fetal medicine? Yes

Tertiary level Maternal Medicine Service? No

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?

Yes

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

Yes

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

No

Free text for email address:

.....

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

Yes

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

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

No

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

.....
.....

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 α , HNF4 α and HNF1 β genes)?

No

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

No

Free text for email address:

.....

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.

	Yes	No	Comments:
Diabetes specialist midwife		x	
Obstetrician	x		
Fetal medicine specialist	x	x	Available to the team for consult
Maternal medicine specialist (including obstetric physician)		x	
Diabetes/ endocrinology specialist	x		
Diabetes nurse specialist	x		
Clinical Geneticist/ Genetic Counsellor		x	Available to the team for consult
Other	x		Diabetes Specialist Dietician

Free text for other to specify:

.....
.....

In which clinic are pregnant people with monogenic diabetes seen?

Please tick all that apply:

☐ x 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:

Free text for other to specify:

.....
.....

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:

	Training Yes/ No	Comments: Type of training and venue eg: inclusion in a module, training day, specific training event
Diabetes specialist midwife	Yes	Masters in Diabetes including monogenetic diabetes
Obstetrician		
Fetal medicine specialist		
Maternal medicine specialist (including obstetric physician)		
Diabetes/ endocrinology specialist	Yes	
Diabetes specialist nurse	Yes	

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

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?:

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:

Staffing:

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	
---	--

Free text: Other/Comments:

.....

Training:

- ☐ X Sufficient dedicated time for training in monogenic diabetes.
- ☐ x Funding for training
- ☐ x Availability of training

If your responses differ by professional group, please indicate below in the free text box.

Free text: Other/Comments:

.....

Patient knowledge

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

Free text: Other/Comments:

.....

Other

Free text: Other/Comments:

.....

Postnatal management.

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

Yes

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?

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

.....
.....

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- all

☐

X 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

Snomed

Which electronic Maternity IT system does your Trust use?

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

EPIC, Stork

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:

Glucokinase hyperglycaemia (GCK)

	Yes /No	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)

	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)

	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)

	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

	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

	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

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