

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: **Powys Teaching Health Board (PTHB)**

Number of sites providing maternity care at the Trust: **PTHB does not have obstetric units and commission to other health boards for this service. This includes pregnant women and birthing people who are identified as diabetic.**

Antenatal: **Not applicable.**

Intrapartum: **Not applicable.**

Postnatal care: **Not applicable.**

Annual Birth volume per site and overall for the Trust

Annual birth rate (Trust total)	Average of 900-1100 births annually between commissioned services and local births which are either in birth centres or patients home.
Site A (named)	
Site B (named)	
Site C (named)	

Tertiary level NICU? **No**

Tertiary level fetal medicine? **No**

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?

No. PTHB follow NICE guidelines and refer pregnant women and birthing people who are either already diabetic or who develop diabetes in pregnancy to one of our District General Hospital (DGH) commissioned services.

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

No. PTHB follow NICE guidelines and refer pregnant women and birthing people who are either already diabetic or who develop diabetes in pregnancy to one of our DGH commissioned services.

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

Not applicable.

Free text for email address:

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

No. PTHB do not provide the care for pregnant women and birthing people with diabetes, we refer in; it would not be helpful as all units have their own protocols they follow.

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?

Not applicable.

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?

Not applicable.

Free text for email address:.....

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

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.

PTHB refer pregnant women and birthing people who are either already diabetic or who develop diabetes in pregnancy to one of our District General Hospital commissioned services for a plan of care and ongoing assessments.

	Yes	No	Comments:
Diabetes specialist midwife		x	
Obstetrician		x	
Fetal medicine specialist			
Maternal medicine specialist (including obstetric physician)		x	
Diabetes/ endocrinology specialist		x	
Diabetes nurse specialist		x	
Clinical Geneticist/ Genetic Counsellor		x	
Other			

Free text for other to specify:

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:

We refer pregnant women and birthing people who are either already diabetic or who develop diabetes in pregnancy to one of our District General Hospital commissioned services.

Training and genomic testing

Do you have staff who are specifically trained to manage pregnant people with monogenic diabetes? **No.**

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	Not applicable	
Obstetrician	Not applicable	
Fetal medicine specialist	Not applicable	
Maternal medicine specialist (including obstetric physician)	Not applicable	
Diabetes/ endocrinology specialist	Not applicable	
Diabetes specialist nurse	Not applicable	

Are you aware of how to request genomic tests for monogenic diabetes in your UK country as below: **No**

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?: **No**

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	Not applicable

Obstetricians trained and able to manage pregnant people with monogenic diabetes	Not applicable
Diabetes specialist midwives trained and able to manage pregnant people with monogenic diabetes	Not applicable
Diabetes specialist nurses trained and able to manage pregnant people with monogenic diabetes	Not applicable

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

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:

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?

No – a management plan would be agreed with the pregnant women and birthing people and specialist services in obstetric unit / specialist services.

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):

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

No – a management plan would be agreed with the pregnant women and birthing people and specialist services in obstetric unit / specialist services.

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 can record all risk factors

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)

	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

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

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

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.