Haemoglobinopathy (Sickle Cell and Thalassaemia) (SCT) Screening and Counselling in Pregnancy

Classification :	Guideline
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Authors Division:	Women & Children's
Departments/Group this Document applies to:	Maternity

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Guideline to be followed by (target staff):
Primary Care Team
Maternity Services
Pathology
Antenatal & Newborn Screening Co-ordinator (ANSC)
Deputy Antenatal & Newborn Screening Midwife
Haemoglobinopathy Counsellor

To be read in conjunction with the following documents:
Newborn Bloodspot Screening guideline

CQC Fundamental standards:
Regulation 9 – person centred care
Regulation 10 – dignity and respect
Regulation 11 – Need for consent
Regulation 12 – Safe care and treatment

Disclaimer –

Since every patient's history is different, and even the most exhaustive sources of information cannot cover every possible eventuality, you should be aware that all information is provided in this document on the basis that the healthcare professionals responsible for patient care will retain full and sole responsibility for decisions relating to patient care; the document is intended to supplement, not substitute for, the expertise and judgment of physicians, pharmacists or other healthcare professionals and should not be taken as an indication of suitability of a particular treatment for a particular individual.
The ultimate responsibility for the use of the guideline, dosage of drugs and correct following of instructions as well as the interpretation of the published material **lies solely with you** as the medical practitioner.

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Guideline Statement

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the National Health Service (NHS) on the advice of the United Kingdom National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat (PHE, 2017).

The UK National Screening Committee (UK NSC) has responsibility for setting screening policy. The NHS Sickle Cell and Thalassaemia (SCT) screening programme (PHE, 2017) screens for:

- genetic carriers for sickle cell, thalassaemia and other haemoglobin disorders
- sickle cell disease
- thalassaemia
- haemoglobin disorders

It offers screening to:

- all pregnant women
- fathers-to-be, where antenatal screening shows the mother is a genetic carrier
- all newborn babies, as part of the Newborn Blood Spot Screening Programme

Objectives and outcomes of the SCT antenatal programme:

- to offer timely antenatal sickle cell and thalassaemia screening to all women (and couples), to facilitate informed decision-making
- for those women accepting prenatal diagnosis (PND), 50% of prenatal diagnoses to be performed before 12 weeks + 6 days

This guideline is to ensure that all professionals involved in the NHS SCT screening programme have an appropriate level of understanding, including benefits and risks of screening and haemoglobin disorders in order to minimise the adverse effects of screening.

Executive Summary

It is extremely important that antenatal screening for SCT is offered to all eligible women as early in pregnancy as possible and each woman accepting screening has a screening result (Standard 1). In order to, identify carrier and affected women by 10 weeks + 0 days of pregnancy (Standard 2) to allow the baby's biological father to be offered testing and to offer PND to women at risk of having an affected infant by 12 weeks + 0 days of pregnancy (Standard 5) (PHE, 2017).

This is to facilitate the offer of an informed choice to parents. If tests show that the baby is at risk of inheriting a major haemoglobin disorder then the parents need time to receive counselling and consider their options within the appropriate timescale; biological father screening and the offer of prenatal diagnosis (PND) by 12+0 weeks gestation (Standard 5), in order for PND to be completed by 12+6 weeks gestation (Standard 6). Some women/couples at high risk of being carriers may have strong religious or cultural beliefs that influence their decisions about having prenatal diagnosis or termination of pregnancy. They may also wish to take these decisions privately before announcing the pregnancy. It is therefore particularly important that this option is presented as early as possible in the pregnancy.

Definitions

Sickle cell disease: is the name given to a family of conditions. The most serious type of sickle cell disease is sickle cell anaemia (Hb SS). Other forms of sickle cell disease requiring treatment include Hb SC, Hb S beta thalassaemia and some more rare conditions.

Sickle cell disease affects the normal oxygen carrying capacity of red blood cells. When cells are de-oxygenated and under stress, they change from a flexible disc-like shape to a stiff, elongated sickle or crescent moon shape. When this happens, the cells cannot pass freely through small capillaries and form clumps which block the blood vessels. This in turn prevents oxygenation of surrounding tissue (hypoxia) causing pain known as a 'crisis'. Other symptoms of sickle cell disease can include severe anaemia, susceptibility to infections and damage to major organs.

Sickle cell disease affects approximately one in every 2,000 births in England. It is estimated that there are 380,000 healthy carriers of unusual haemoglobin variants. Most of these are sickle. More than 12,500 people have sickle cell disease. The highest prevalence of sickle cell disease is among Black Africans and Black Caribbeans.

Thalassaemia: is the name given to a family of conditions where less haemoglobin than normal is produced. Of these the most serious are beta thalassaemia major and alpha thalassaemia major. Beta thalassaemia major is caused by a defect in the normal haemoglobin gene, which prevents the body from producing haemoglobin. The result is life threatening anaemia, and the condition usually becomes apparent during the first few months after birth. People with beta thalassaemia major need regular blood transfusions for survival and therapeutic treatment to clear excess iron from the body throughout their lives. There are currently an estimated 300,000 healthy carriers of the beta thalassaemia gene variant in England, and over 800 people with beta thalassaemia major. The highest prevalence is among Pakistanis, Cypriots, Italians, Greeks, Indians, Bangladeshis, Chinese, and other South East Asian groups.

Alpha thalassaemia major: is incompatible with life and babies do not usually survive the pregnancy. Diagnosis of this condition during pregnancy is very important to preserve the mother's health. Sickle cell anaemia and beta thalassaemia major can sometimes be cured with bone marrow or stem cell transplantation. However, the associated risks are high and suitable donors should ideally be a close family member.

Haemoglobin Disorders: There are many other milder forms of haemoglobin disorders where the individual does not have any normal haemoglobin A. Many of these may not be clinically significant for the individual but will be significant for genetic inheritance of offspring. If in doubt consult the local haematology team for further advice and information.

High Prevalence: Where the percentage of booking bloods received by the laboratory which are screen positive is greater than or equal to 2%. In high prevalence trusts all pregnant women are offered screening followed by a blood test for sickle cell and other haemoglobin variants. The Family Origin Questionnaire (FOQ) should also be completed and sent to the laboratory with the sample to facilitate interpretation of results by laboratory staff and identify those at risk of severe alpha thalassaemia; Milton Keynes University Hospital NHS Foundation Trust (MKUH) is a high prevalence trust.

1. Roles and Responsibilities:

1.1 Role of the General Practitioner

- To encourage pre-conceptual screening and counselling if individuals are at risk
- To ensure early recognition of couples at risk in the antenatal period and refer appropriately for antenatal screening and prenatal diagnosis
- To arrange for appropriate follow up as necessary

1.2 Role of Community Midwife

- As soon as possible in pregnancy offer all eligible pregnant women Sickle Cell and Thalassaemia screening and provide the '*Screening tests for you and your baby in pregnancy*' leaflet.

  Available online in several languages at:
  https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief

In order to identify carrier and affected women by 10 weeks + 0 days of pregnancy to allow the baby's biological father to be offered testing and to offer PND to women at risk of having an affected infant by 12 weeks + 0 days of pregnancy (Standard 2); in order to maximise the opportunity for informed choice.

If the biological father is available at the booking appointment and the woman is a known carrier, then screening should be offered (irrespective if screening has previously been completed). If he declines a retest, this should be documented on eCare along with the result and the ANSC and/or deputy notified.

- If an expectant mother is known to have a haemoglobinopathy variant, the Antenatal and Newborn Screening Co-ordinator (ANSC) and/or deputy needs to be urgently informed, together with details of the biological father, who will be offered screening regardless of previous known result.

    - Either by phone: 01908 995236/ 07790 935490
    - In person or email: mkg-tr.mkscreeningmidwives@nhs.net

- The ANSC and/or the deputy screening midwife can arrange an early pregnancy scan in the Early Pregnancy Unit (EPAU) if required, to date the pregnancy, in order to expedite the completion of PND within the appropriate timeframe.

- Complete screening for SCT (using a lilac EDTA blood specimen bottle) and send with a completed Family Origin Questionnaire (FOQ) (Standard 3) (Appendix 2) ticking boxes for all family ancestry that apply, for both the pregnant woman and the biological father.

  The FOQ is used to interpret screening results in high prevalence areas and to identify women at higher risk to be offered further testing in low prevalence areas; MKUH is a high prevalence area.

- If the woman declines screening an FOQ form should still be completed and sent to the laboratory with the reason for decline and the antenatal & newborn screening team should be notified.

Assisted Conceptions:

- If a woman has had fertility treatment, it is important to establish the source of both egg and sperm to assess the potential risk of the baby inheriting a major haemoglobin disorder. If both egg and sperm are from the baby's biological parents, the risk to the baby can be assessed as for any other carrier woman/couple.

- If either the sperm or the egg has been donated to the couple, it is not possible to do a risk assessment of the pregnancy based on the parental screening results. If the donor sperm and/or egg have been screened for a haemoglobinopathy and the results are available, then this can be discussed with the couple.

- If pregnancy has been achieved through a donor egg then the screening results on the woman will not be informative. Even if she is not the baby's biological parent, it is best practice to always test the pregnant woman for a haemoglobinopathy to ensure optimal maternal care during pregnancy. The baby's biological father must also be tested, irrespective of the woman's result and, if screen positive, the fertility clinic should be contacted to obtain the biological mother's haemoglobinopathy results.

- If donor sperm has been used and the mother has a positive screening result then, where possible, the fertility clinic should be contacted to obtain the biological father's haemoglobinopathy results.

- In the case of surrogacy the fertility clinic should be contacted to obtain the haemoglobinopathy results of both biological parents.

- If no screening results are available for either donor sperm or egg, then the process for dealing with this situation should be determined locally, with discussions between maternity services, specialist nurses and consultant haematologist.

- At the 16 week routine antenatal appointment the community midwife should ensure a screening result is available and document the result. If no evidence of a completed SCT result, re-offer screening and complete accordingly; failsafe officer, ANSC and/or deputy to be notified.

1.3 Role of the Antenatal Screening Co-ordinator and Deputy Screening Midwife

The screening team is notified of any positive haemoglobinopathy screening results by MKUH laboratory via the generic email: mkg-tr.mkscreeningmidwives@nhs.net. A read receipt is sent to the laboratory to acknowledge, by the ANSC and/or deputy, and then immediately actioned.

On receipt of a positive haemoglobinopathy result the ANSC and/or deputy will complete the Haemoglobinopathy record sheet (Appendix 3) and HBO screening spreadsheet.

The ANSC and/or deputy will complete a community midwife notification slip (Appendix 4) and also provide a copy of the Haemoglobinopathy Record to the Haemoglobinopathy Counsellor.

In the first instance the woman is contacted directly via telephone by the ANSC and/or deputy to invite in along with the biological father to discuss the result. If there is no contact with the woman within two days a patient carrier status letter (Appendix 5) is sent to the woman along with the applicable PHE haemoglobinopathy carrier leaflet and information for fathers leaflet; requesting the woman to contact the ANSC and/or deputy to arrange a face-to-face appointment.

Leaflets are available online at: https://www.gov.uk/government/collections/adult-carriers-sickle-cell-thalassaemia-unusual-haemoglobin

If the woman does not contact the screening team within 2 days of the letter being sent, the community midwife is asked to complete a wellbeing check and give or post a letter with the date and time of an appointment to attend antenatal clinic with the screening team.

At this appointment the ANSC and/or deputy will discuss and offer biological father screening and obtain a blood specimen sample with consent. This is sent along with a completed FOQ clearly stating partner of (woman's name and MRN).

Alternatively, the woman and biological father can attend the community midwife or General Practitioner (GP) for screening to be completed.

Every effort should be made to obtain a blood sample from the biological father of the unborn baby; however, in cases where the couple is no longer together or where the biological father

is abroad or declines testing, the pregnant woman is offered ***prenatal diagnosis.*** The pregnancy is considered to be potentially high risk unless there is a negative partner result.

If both biological parents are found to be a carrier of a Haemoglobin variant or the baby's father is unavailable or declines screening; the ANSC and/or deputy are to discuss and offer PND. If PND is declined, and the baby is ***at risk,*** an Oxford University Hospital NHS Foundation Trust Notification of Couples at Risk alert form is completed (Appendix 6) and sent via email to: hbopathy.screening@nhs.net

If PND is requested, then the ANSC and/or deputy will arrange for the woman to attend either MKUH or OUH fetal medicine department within the appropriate timeframe; either chorionic villus sampling (CVS) or amniocentesis. If completed at MKUH, then they are to ensure the PND sample is sent to the specialist laboratory (John Radcliff, Oxford) along with parental EDTA blood samples by 13.30 for the courier service to OUH screening laboratory.

If the prenatal diagnosis proves positive for a major haemoglobin disorder the couple will be seen by the ANSC and/or deputy for a full discussion of all options; continue or terminate the pregnancy. If a termination of pregnancy is requested, the ANSC and/or deputy will arrange this. Dependent on gestation feticide maybe required and should be discussed with the couple.

The local Health Visitor will also be informed and will provide or arrange longer term counselling, information and support.

1.4 Role of the Haemoglobinopathy Nurse Counsellor

- To liaise with the ANSC and/or deputy screening midwife to collect information and referrals
- To give individuals or couples written information on the counselling given
- To arrange a face-to-face counselling appointment with the individual/couple
- To ensure that written confirmation of result and explanatory information is given to clients, (e.g., haemoglobinopathy card) together with patient information leaflet
- To inform the appropriate General Practitioner (GP) and send a copy of information given
- To keep records of contacts and information given
- To liaise with relevant health professionals and clinicians as necessary; e.g., Health Visitor, where a child with a major haemoglobinopathy is expected

2.0 Implementation and dissemination of document

This policy will be uploaded onto the intranet and hard copies will be made available in key areas of the hospital and community. Teaching sessions will also be provided to key members of staff involved in antenatal screening.

Online e-learning available at: https://www.e-lfh.org.uk/programmes/nhs-screening-programmes/

3.0 Processes and procedures

3.1 Pre-Pregnancy Screening

Although not always possible or appropriate, it is naturally much better if haemoglobinopathy screening and counselling can be provided before conception and pregnancy takes place.

Every opportunity should therefore be taken at infertility clinics, after miscarriages, or at times of pre-conception counselling to make sure that all ***"at risk"*** women and their long term partners who may

in future have children are offered testing for haemoglobin anomalies. All those working in the Health Care system (including GPs, Gynaecology, Maternity Care and Family Planning Clinics) should be aware of the importance of haemoglobinopathy pre-conception screening and counselling.

Screening can be requested through haematology and a blood sample taken in a lilac EDTA bottle and sent with a completed FOQ.

3.7 Counselling

It is good practice to offer information and counselling pre and post testing. Counselling must be non-directive, but those providing counselling must always be aware that screening for haemoglobinopathies may lead parents to find them-selves considering the possibility of opting for permanent voluntary childlessness.

Because of this, before any test, the mother and her partner will require careful counselling. In order to do this to the standard required, it is essential that all those involved at each stage should have sufficient knowledge for them to provide appropriate information. It is especially important that the implications both of testing, and of all results, are adequately understood, and that inappropriate anxieties are as far as possible allayed, especially some information on why these disorders are more common in certain ethnic groups. Opportunity for further counselling contact and follow up is also very important.

3.5 Newborn Screening

All newborn babies are offered Haemoglobinopathy Screening included in the Newborn Blood Spot Screening Programme. This should take place on day 5 after birth.

(see *Newborn Bloodspot Screening* guideline)

4.0 Statement of evidence/references

NHS public health functions agreement 2015-16 Service specification no. 18 NHS Sickle Cell and Thalassaemia Screening Programme (2014) vPublic Health England. Department of Health

Information for health care professionals: sickle cell and thalassaemia screening (2012) Public Health England

Statement of evidence:

References:

Public Health England (PHE) (2019) NHS public health functions agreement 2019-20 Service specification no. 18 NHS Sickle Cell and Thalassaemia Screening Programme

Public Health England (PHE) (2019) NHS Sickle Cell & Thalassaemia Screening Programme Standards for data collected from 1st April 2018

External weblink references:

Please note that although Milton Keynes University Hospital NHS Foundation Trust may include links to external websites, the Trust is not responsible for the accuracy or content therein.

5.0 Governance

5.1 Document review history

Version number	Review date	Reviewed by	Changes made
1	March 2003	Ann Foakes and Eileen Bowen	
	June 2005	Ann Foakes and Susan Mew	Reviewed – no change required
2	September 2008	Louise Abbott and Susan Mew	Reviewed and updated
3	October 2010	Louise Nicol	Reviewed and updated
4	January 2014	Louise Nicol, Susan Mew and Karen Ayre	Reviewed and updated
5	August 2020	Anita Males	Reviewed and significant changes

5.2 Consultation History

Stakeholders Name/Board	Area of Expertise	Date Sent	Date Received	Comments	Endorsed Yes/No
Nicolette Petrou	Haemoglobinopathy Counsellor	19.09.2019		Comments acknowleged and included.	
Erum Khan	Consultant Obstetrician				
Caroline Midgeley	Quality Assurance Advisers for Antenatal & Newborn Screening	11.2019	04.06.2020	Comments acknowledged and included	
Anita Males	Antenatal & Newborn Screening Co-ordinator			Guideline reviewed and significantly updated.	
Julie Cooper	Head of Midwifery		19.08.2020	Comments acknowledged and included	
Janice Styles	Matron for Community, ANC and ANNB Screening		19.08.2020	Comments acknowledged and included	

5.3 Audit and monitoring

Audit/Monitoring Criteria	Tool	Audit Lead	Frequency of Audit	Responsible Committee/Board
Screening Uptake	National KPI template	ANSC	Quarterly	Antenatal and Newborn Programme Management board
Number of women screened by 10 weeks gestation	National KPI template	ANSC	Quarterly	Antenatal and Newborn Programme Management board
Number of FOQ's correctly completed	National KPI template	ANSC	Quarterly	Antenatal and Newborn Programme Management board

5.4 Equality Impact Assessment

As part of its development this Guideline and its impact on equality has been reviewed. The purpose of the assessment is to minimise and if possible remove any disproportionate impact on the grounds of race, gender, disability, age, sexual orientation, religion or belief, pregnancy and maternity, gender reassignment or marriage and civil partnership. No detriment was identified. Equality Impact assessments will show any future actions required to overcome any identified barriers or discriminatory practice.

Equality Impact Assessment			
Division	Women & Children's	Department	Maternity
Person completing the EqIA	Anita Males	Contact No.	01908 995236
Others involved:		Date of assessment:	12.08.2020
Existing policy/service		New policy/service	

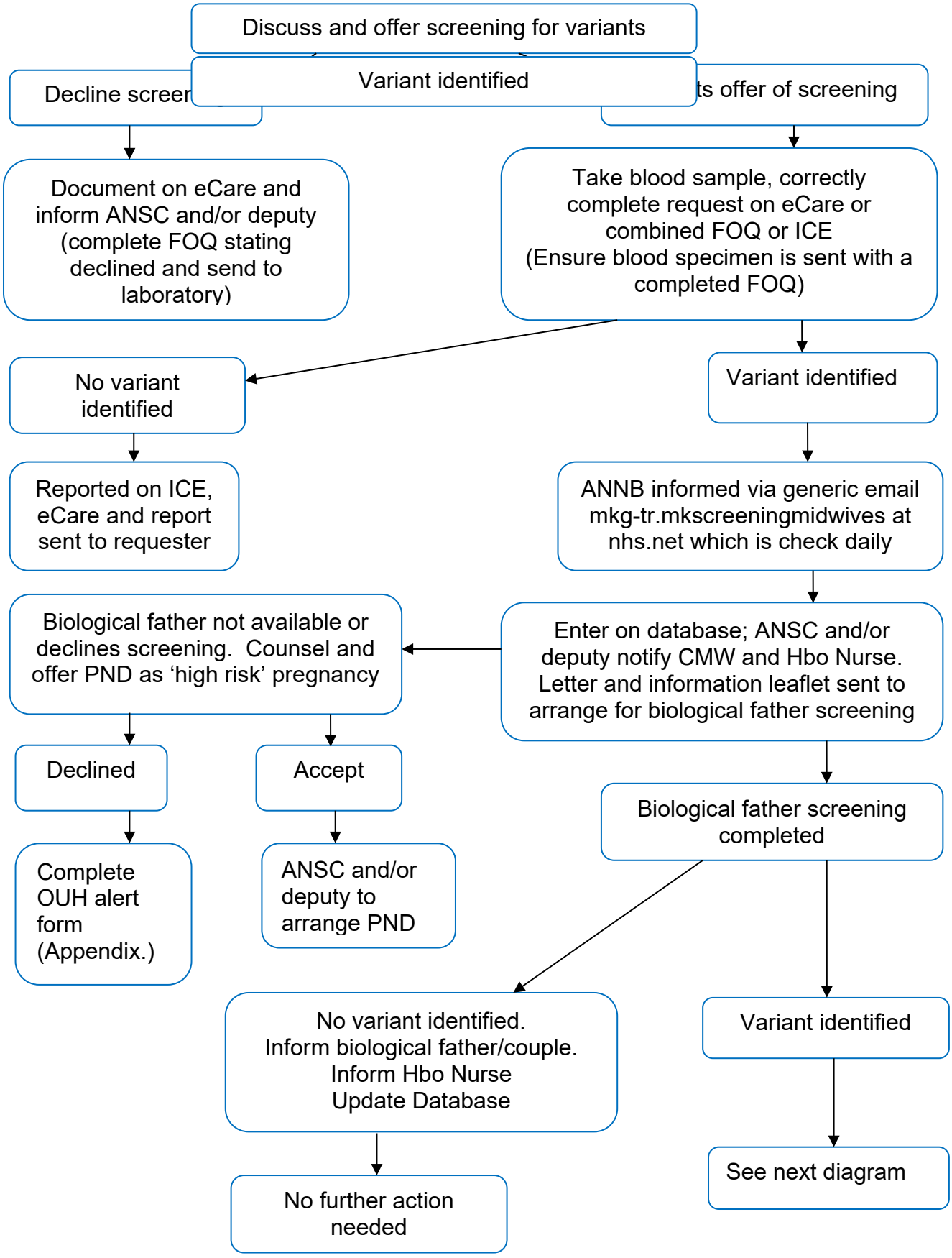
Will patients, carers, the public or staff be affected by the policy/service?	Yes
If staff, how many/which groups will be affected?	Community Midwives, Haemoglobinopathy Specialist Nurse, Antenatal & Newborn Screening Midwives

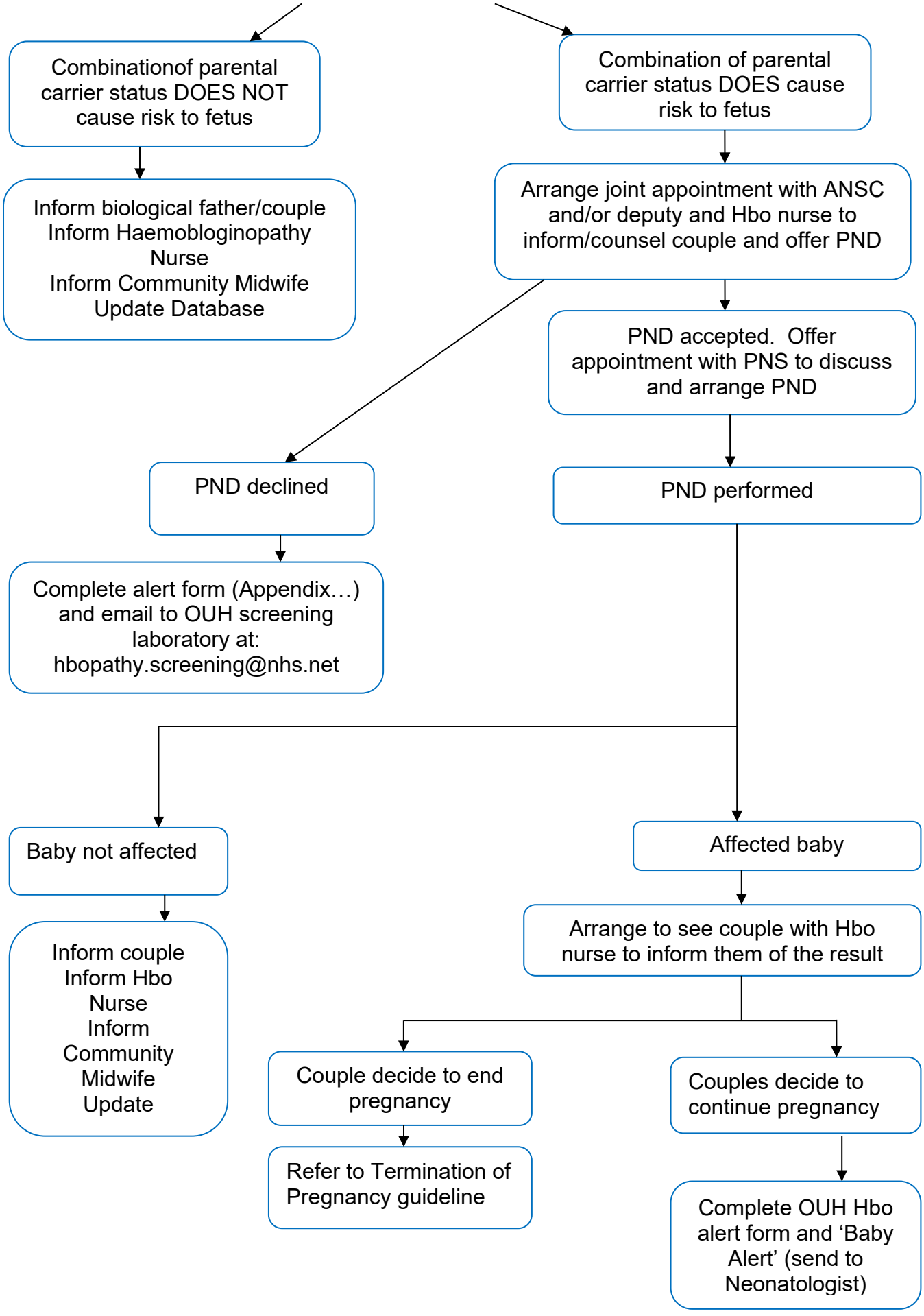
Protected characteristic	Any impact?	Comments
Age	NO	Positive impact as the policy aims to recognise diversity, promote inclusion and fair treatment for patients and staff
Disability	NO	
Gender reassignment	NO	
Marriage and civil partnership	NO	
Pregnancy and maternity	NO	
Race	NO	
Religion or belief	NO	
Sex	NO	
Sexual orientation	NO	

What consultation method(s) have you carried out?
Circulated for comments via email.
How are the changes/amendments to the policies/services communicated?
email, community midwife meetings, intranet post
What future actions need to be taken to overcome any barriers or discrimination?

What?	Who will lead this?	Date of completion	Resources needed
Review date of EqIA			

Appendix 1: Flow chart of screening pathway





Appendix 2: Family Origin Questionnaire (FOQ)

This form is only to be used for Antenatal booking bloods.

At least four points of matching identification including the NHS number must be used on forms and sample tubes – see over

Please write clearly inside text boxes. One character per box and mark option boxes as appropriate.

Patient ID stickers may be used on the form

Lab Use Only | Sample Number

IRREGULAR ANTIBODIES KNOWN	YES / NO	IF LABELS USED PLEASE ADD NHS NUMBER	
ANTI-D ADMINISTERED DURING PREGNANCY	YES / NO	NHS NO.	
IF YES GIVE DATE		HOSPITAL NO.	
PREVIOUS TRANSFUSION	YES / NO	SURNAME	
ANY HISTORY OF HDN / NAITP?	YES / NO	FORENAME	
EDD		D.O.B	ADDRESS
GEST @ TEST		POSTCODE	

	Accepted		Declined		Priority Status:					Tick
FBC					**INITIAL** antenatal screening sample					
SCT Screening					**REPEAT** antenatal screening sample (inadequate first sample)					
Groups & Abs					**REPEAT** sample to exclude recent infusion					
	Status Unknown		Known Positive		**INITIAL** sample taken after previous decline					
	Accepted	Declined	Accepted	Declined	**Clinical indications for urgent sample request:**					
Hepatitis B										
Syphilis					Form completed by	Date	Location	Sample completed by	Date	Location
HIV										

Reason why declined: ………………………………………………………………………………………… **Signature of woman:** ………………………………………………………….......

Is pregnancy the result of IVF? If yes, complete the form including **SECTION H**

What are you and your family's origins?

Please tick all boxes in ALL sections that apply to the woman and the baby's biological father

	Woman	Biological father
A. AFRICAN OR AFRICAN-CARIBBEAN (BLACK)	Woman	Biological father
Caribbean Islands	☐	☐
Africa (excluding North Africa)	☐	☐
Any other African family origins	☐	☐
B. SOUTH ASIAN (ASIAN)	Woman	Biological father
India or African-Indian	☐	☐
Pakistan, Bangladesh, Sri Lanka	☐	☐
C. SOUTH EAST ASIAN (ASIAN)	Woman	Biological father
China including Hong Kong, Taiwan	☐ #	☐ #
Singapore, Thailand, Indonesia	☐ #	☐ #
Malaysia, Vietnam, Philippines	☐ #	☐ #
Cambodia, Laos, Myanmar	☐ #	☐ #
Any other Asian family origins	☐ #	☐ #
D. OTHER NON-EUROPEAN (OTHER)	Woman	Biological father
North African, South America	☐	☐
Middle East, Saudi Arabia, Iran	☐	☐
Any other Non-European family origins	☐	☐
E. SOUTHERN & OTHER EUROPEAN (WHITE)	Woman	Biological father
Sardinia	☐ #	☐ #
Greece, Turkey, Cyprus	☐ #	☐ #
Italy, Portugal, Spain	☐	☐
Albania, Czech Republic	☐	☐
Poland, Romania, Russia	☐	☐
Any other Mediterranean family origins	☐	☐
F. UNITED KINGDOM (WHITE) Refer to list on the back	Woman	Biological father
England, Scotland, Northern Ireland, Wales	☐	☐
G. NORTHERN EUROPEAN (WHITE) Refer to list on the back	Woman	Biological father
Austria, Belgium, Switzerland, Scandinavia	☐	☐
Eirie, France, Germany, Netherlands	☐	☐
Australia, North America, South Africa	☐	☐
Any other European family origins	☐	☐
*Hb Variant Screening Requested by (F) and/or (G)	☐	☐

Higher risk for alpha zero thalassaemia

	Woman	Biological father
H. DON'T KNOW	Woman	Biological father
Adoption/unknown ancestry	☐	☐

Donor egg/sperm (if pregnancy results from donor egg, order test for mother and offer biological father test immediately)	☐	☐
Bone marrow transplant (if mother has had a bone marrow transplant, order test for mother and offer biological father test immediately)	☐	☐
I. DECLINED TO ANSWER	☐	☐

Guidance for Healthcare Professionals

In low prevalence areas the family origin questionnaire (FOQ) is principally used to identify women who are at high risk of being a haemoglobin variant carrier.

In high and low prevalence areas the FOQ is used to help with the interpretation of results, particularly in the interpretation of results indicating possible alpha or beta thalassaemia. The family origin is useful for accurate prenatal diagnosis. More information about its use can be found in the laboratory handbook. Search for 'SCT handbook for laboratories' on www.gov.uk

Therefore you need to ask for the family origins of both the women AND the baby's biological father going back at least 2 generations (or more if possible).

Women with sickle cell disease
Screening will also identify women with sickle cell disease, who will require specialist care during pregnancy from an obstetrician and haematologist, and who should be booked for a hospital delivery.

'Low risk' family origins
People with family origins from the countries listed below are considered at low risk for haemoglobin variants.

United Kingdom (white)
England, Scotland, Northern Ireland, Wales.

Northern European (white)
Austria, Belgium, Denmark, Greenland, Iceland, Ireland (Eire), Finland, France, Germany, Luxembourg, Netherlands, Norway, Sweden, Switzerland.

Some populations of the following countries have Northern European origin (countries listed above) and are also at low risk for haemoglobin variants:

Northern European origin (white)
Australia, North America (USA, Canada), South Africa, New Zealand.

Obtaining a supply of FOQ forms
For more information on how to order additional FOQ forms see www.gov.uk/phe/screening-leaflets

Appendix 3: Haemoglobinopathy Record Sheet

HAEMOGLOBINOPATHY RECORD

Attach Mother's Patient Details Sticker here

Booking Date:		Gestation:	

Mothers contact tel. no:		Mothers Ethnicity:
GP:	Surgery:	
Father's Name: Tel No:	NHS No: Hospital No:	Date of Birth: Ethnicity:

	Haemoglobin Genotype:	Date Tested:	Date Reported:	Gestation at Test:
Mother:				
Father:				
Child:				

Father refused testing: ☐ Father Not Available: ☐ Father Declined Retest: ☐ No details of Father given: ☐

Comment:

Scan Date:	**EDD:**	First Pregnancy in Milton Keynes?: Yes/No *(delete as applicable)*

Offer of PND (Pre-natal Diagnosis)**:**

Date offered:	**Gestation:**	☐ ACCEPTED	☐ DECLINED

	Date	Result/Comment
CVS (Chronic Villus Sampling)		
Amniocentesis		

Decision from PND: **Continuing Pregnancy:** ☐ **TOP:** ☐ **Comment:**

Result of PND given by 5 working days: ☐ **OXFORD 'AT RISK' ALERT COMPLETED:**

Date Haemoglobinopathy Counsellor informed:

Haemoglobinopathy Service:

Registered on SystmOne: Baby's Risk Level: L / M / H / Known Affected

Letter Sent: Moved to Risk Waiting List:

If Parent Affected: Check Known to HAS: ☐ Referral request to GP for HAS:

Appendix 4: Community Midwife Notification Slip

To Community Midwife

Re;-

Is a carrier of

Please arrange partner testing as soon as possible, either by yourself, ANNB or GP. We need the father's results by 12 weeks gestation to enable us to complete PND by 12+6 if required.

The patient has been informed of the result.

With Thanks

Antenatal and Newborn Screening Team

Appendix 5: Haemoglobinopathy Status Letter

Antenatal and Newborn Screening
Tel: 01908 995236 or
07790 935490
Email: mkg-tr.mkscreeningmidwives@nhs.net

Standing Way
Eaglestone
Milton Keynes
MK6 5LD
01908 660033
www.mkhospital.nhs.uk

For people who have hearing loss
Minicom 01908 243924

Private and Confidential

Date:

Dear

Your recent antenatal blood results indicate that you are a carrier of:

_____

Your baby is potentially at risk of inheriting a blood disorder, affecting the haemoglobin (part of the blood that carries oxygen around the body). People who have these conditions will need specialist care throughout their lives. Your partner needs to have a blood test to identify whether he is also a carrier.

Please contact the Antenatal & Newborn Screening team on the above number to arrange a blood test.

We strongly advise that this appointment is arranged as soon as possible.

Information leaflets enclosed

Yours sincerely,

Antenatal and Newborn Screening Team

Appendix 6: Oxford Notification of Couples at Risk Form

Oxford University Hospitals NHS
NHS Foundation Trust

NATIONAL HAEMOGLOBINOPATHY REFERENCE LABORATORY

Haemoglobinopathy Screening, Department of
Haematology, Level 4, Oxford University Hospitals
NHS Foundation Trust, Headley Way
Oxford OX3 9DU

Tel: 01865 572825
Email: hbopathy.screening@nhs.net

NOTIFICATION OF COUPLES AT RISK
SICKLE CELL & THALASSAEMIA SCREENING

(Attached to SOP HC 2028. Version 5 , issued Aug 2012, amended 29-03-2018)

Please complete and return by post to the regional Newborn Screening Laboratory (details at top of the sheet) or secure email to **hbopathy.screening@nhs.net**

Sent by (name) …… Contact number ……..……

Sent by (establishment) …….. Date Sent …….

MOTHER'S DETAILS

SURNAME:	**FORENAME:**
DOB:	**NHS number:**
EDD:	**ETHNIC ORIGIN:**
GP NAME/ADDRESS:	
HAEMOGLOBINOPATHY STATUS:	

PARTNER'S DETAILS

SURNAME:	**FORENAME:**
DOB:	**NHS number:**
	ETHNIC ORIGIN:
HAEMOGLOBINOPATHY STATUS:	

PRENATAL DIAGNOSIS

Has prenatal diagnosis been undertaken? **YES** ☐ **NO** ☐

PRENATAL DIAGNOSIS RESULT:

Appendix 7: Risk of inheritance