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South West PHE Screening and Immunisation Team

Good Practice Guidance for the communication of newborn screening Sickle Cell or other haemoglobin variant Carrier result

Communicating Newborn Screening Sickle Cell or other haemoglobin variant carrier results

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Communicating Newborn Screening Sickle Cell or other haemoglobin variant carrier results

This guidance covers babies born in NHS Hospital Trust maternity units that use the North Bristol Trust newborn screening laboratory and aims to clarify the roles and responsibilities of agencies and health professionals in communicating newborn screening sickle cell or other haemoglobin variant **carrier status** to parents.

Children who are diagnosed as carriers of sickle cell or other haemoglobin variants will not usually be affected by the condition and will only very rarely require any special treatment. However, carriers can pass on the altered gene to their children in later life so parents may wish to inform them at a later stage. Parents therefore need clear information about this result and the opportunity offered to discuss this further.

This guidance reflects national guidance: https://www.gov.uk/government/publications/sickle-cell-disease-report-screening-results-to-parents

Current practice of communicating carrier results varies across the region with some areas identifying specialist trained health visitors to carry out or advise on this role. This guidance allows for flexibility of delivery but offers clarity regarding overall responsibility. All provider Trusts and other local stakeholders involved should have written protocols and pathways that reflect this guidance and the standards specific to newborn screening. Training will be made available where necessary for health visitors and/or other health professionals to assist them in this role.

For health professionals needing support/information regarding Sickle Cell or other haemoglobin variants please use please contact:
Newborn and Antenatal Haemoglobinopathy Screening North Bristol NHS Trust: 0117 4148356

Overview of responsibilities

Where just the mother (when the father is unavailable for screening) or both parents have been diagnosed as carriers of or affected by these conditions during the antenatal screening pathway, prenatal diagnostic testing for their baby will have been offered. These parents may therefore already know that their baby is a carrier.

If the blood spot sample confirms the baby is a carrier of sickle cell or other haemoglobin variant -

Newborn screening laboratory will:

- Contact the child's health visitor (via child or parent's GP practice). The letter will include laboratory audit form and appropriate leaflet for parents and copy in GP.
- Inform Child Health Records Department of all newborn blood spot screening results

Child Health Records Department will:

- Record all newborn screening results on Child Health Information System
- Send all newborn screening results to health visitor

Health Visiting Service will:

- Decide who is best placed to communicate this result. This will most likely be the family health visitor but could be another designated health professional trained to communicate such results. If so, the health visitor will liaise with the health professional to ensure they are aware of the child's results and have the appropriate resources.

Designated health professional (normally the child's Health Visitor) will:

- Note the sickle cell and thalassaemia antenatal *parental* screening results which should be communicated in the letter from the lab (there needs to be sensitivity over the possibility of screening results revealing non-paternity)
- Contact the parent(s) and arrange to speak with them and/or see them as soon as possible
- Ensure the parent(s) understands the following information:
  -**that their child is healthy** but is a carrier of sickle cell or other haemoglobin variant
  -that carriers are not affected by this condition apart from in rare conditions such as during a general anaesthetic if they do not get enough oxygen
  -that if their child has a baby with another person who is also a sickle cell or other haemoglobin variant carrier, there is a one in four (25%) chance that their child (the parent's grandchild) could inherit sickle cell disease or other haemoglobin variant
  -that if they don't already know, it is recommended that both parents find out if they are carriers as if they are both carriers there is a chance they could pass on sickle cell disease or other haemoglobin variant to a future baby they may have
  -Discuss the role of genetic counselling and arrange referral via GP where requested
- Give parents the appropriate written information (available in English and other languages) – see links in table below.
  -Information for mums and dads: your baby carries a gene for sickle cell
  -Information for mums and dads: you baby carries a gene for unusual haemoglobin
- Record all blood spot screening results in the Personal Child Health Record (PCHR)
- Complete and return the Laboratory Audit form
- Inform child's GP that these results have been communicated to parent(s) and ensure they are recorded in the child's medical notes

GP will:

- Record the infant's carrier status in medical notes (information may become clinically relevant when they have children and/or if the child becomes unwell)

Education and Training

Training and continuing professional development including e-learning for people working in the sickle cell and thalassaemia screening programme in England is available at: http://cpd.screening.nhs.uk/sct-externaltraining

Resources

Sickle cell disease (including carrier)	Health Professionals	Reporting to parents guidance	https://www.gov.uk/government/publications/sickle-cell-disease-report-screening-results-to-parent
Sickle cell carrier	Parents	Leaflet	https://www.gov.uk/government/publications/baby-carries-a-gene-for-sickle-cell-description-in-brief
Carrier of unusual haemoglobin	Parents	Leaflet	https://www.gov.uk/government/publications/baby-carries-a-gene-for-unusual-haemoglobin-description-in-brief

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Target audience	Health Professionals working on this pathway including Maternity, Child Health Information Service, General Practice, Screening and Immunisation Teams, and Health Visiting Service.