Public Health England

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South West PHE Screening and Immunisation Team
Good Practice Guidance for the communication of newborn screening Cystic Fibrosis Carrier result

Communicating Newborn Screening Cystic Fibrosis carrier results

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Communicating Newborn Screening Cystic Fibrosis 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 cystic fibrosis **carrier status** to parents as a result of the newborn blood spot.

Children who are diagnosed as carriers of cystic fibrosis have a low likelihood of being affected by the condition and will not need any special treatment. The family may however be concerned about the genetic implications of the result for the family and baby in which case referral to the Clinical Genetics service should be offered (pathway depends on families location, see below). Furthermore, if the family or GP are concerned that the baby has symptoms of CF (poor weight gain, recurrent chest infections, rectal prolapse, nasal polyps), the baby should be referred to a Regional CF Centre for further assessment.
This guidance reflects the following national guidance and standards
https://www.gov.uk/government/publications/clinical-referral-national-standard-protocol-for-cystic-fibrosis

Current practice of communicating 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 Cystic Fibrosis please use the following contacts (leaving a message where necessary):

Cystic Fibrosis Paediatric Specialist Teams:

Bristol, South Gloucestershire, Gloucestershire, N Somerset, Somerset:	0117 3428191
Devon:	01392 402726
Plymouth:	01752 439441
Cornwall:	01872 255008

Overview of responsibilities

When the result of the initial blood spot screening test for cystic fibrosis is inconclusive, the newborn screening laboratory will contact maternity to request a repeat blood spot which should be taken when the baby is 21 days old(the laboratory also notify the health visitor and GP of this request). The person collecting the second sample should provide the family with an information sheet outlining the reason for the request and possible outcomes. The information sheet for parents and guidance for healthcare professions is available via the following links

https://www.gov.uk/government/publications/repeat-blood-spot-test-for-cystic-fibrosis-information-sheet

https://www.gov.uk/government/publications/cystic-fibrosis-inconclusive-test-follow-up-form

If the second blood spot sample confirms the baby is a healthy cystic fibrosis carrier:

Newborn screening laboratory will:

- Contact the child's health visitor by phone. A letter will then be e-mailed/faxed to the health visitor and will include an information leaflet for the parents along with an audit proforma. The letter will be copied to the GP, local CF Centre, Genetics Screening Practitioner (Peninsula region only) and local Screening Midwife.
- Inform Child Health Information Service of all newborn blood spot screening results.

Child Health Records Department will:

- Record all screening results on Child Health Information System.
- Send results letter to the parents by 6 weeks of age.
- Send all screening results to the health visitor.

Health Visiting Service will:

- Decide who is best placed to communicate the result. This will most likely be the family health visitor but could be another designated health professional (e.g. midwife or screening nurse specialist) who is competent to communicate such results*. The local **Cystic Fibrosis Paediatric Specialist Teams** (contact details above) are able to provide advice and guidance to support the health professional to inform the family if required.
- Liaise, where necessary, with the designated health professional to ensure they are aware of the child's result and have the appropriate resources.

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

- Contact the parent(s) and arrange to see them as soon as possible – **ideally within 24hrs** - as the family will have raised anxiety after the second blood spot sample request.
- Give the parent(s) the following information:
    - **that their child is healthy** but is a carrier of the cystic fibrosis gene
    - that carriers are not affected by this condition
    - that carriers can pass on their altered gene to any children they may have
    - that if they (the parents) have another child, there is the possibility that their child could have cystic fibrosis
    - that on very rare occasions the screening test doesn't recognise uncommon alterations of the cystic fibrosis gene so there is a very small chance that their child could have cystic fibrosis. If they have any worries about their child's health they should contact their GP
- Give parent(s) the cystic fibrosis carrier leaflet (see link below).
- Advise the parent(s) to contact the family GP if they wish to discuss a possible referral for further genetic counselling. Note in the Peninsula (Devon & Torbay, North,East & West Devon and Kernow CCGs) families will be contacted by letter by the Genetics Screening Practitioner who is based in the Clinical Genetics Department at the Royal

Devon & Exeter Hospital, Heavitree, and offered an appointment with the Genetics Service.

- Record all blood spot screening results in the Personal Child Health Record (PCHR).
- Complete and return the Laboratory Audit form to the Bristol Newborn Screening Laboratory.
- Inform the child's GP that the results have been communicated to parent(s).

GP will:

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

*If the Antenatal and Newborn Screening Coordinator (ANSC) has the confirmatory result from the second sample, it may be appropriate for the ANSC to give the result to the parent at that stage, informing the health visitor that they have done so.

Resources

Cystic Fibrosis carrier	Health professionals	Guidance on reporting to parents (pg 19)	https://www.gov.uk/government/publications/clinical-referral-national-standard-protocol-for-cystic-fibrosis
Cystic Fibrosis carrier	Parents	Leaflet	https://www.gov.uk/government/publications/positive-screen-for-cystic-fibrosis-carrier-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.