



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

Document title:

Communicating Newborn Screening Cystic Fibrosis carrier results

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Author: Sara Dove, Screening and Immunisation Coordinator

Verified by: Matthew Dominey, Screening and Immunisation Manager

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Version	Date	Comments
1.0	November 2016	Consultation completed. Guidance signed off.
1.1	November 2016	Telephone contact detail amended.

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 will not be affected by the condition and will not need 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 the following national guidance and standards

<https://www.gov.uk/government/publications/cystic-fibrosis-carrier-communication-sheet>
<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 between 21 and 28 days of age (the laboratory also notify the health visitor and GP of this request)

<https://www.gov.uk/government/publications/repeat-blood-spot-samples-description-in-brief>

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 (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 screening results on Child Health Information System
- Send all screening results to the 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 (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 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 (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. 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 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)

Resources

Cystic Fibrosis carrier	Health professionals	Guidance on reporting to parents	https://www.gov.uk/government/publications/cystic-fibrosis-carrier-communication-sheet
Cystic Fibrosis carrier	Parents	Leaflet	https://www.gov.uk/government/publications/positive-screen-for-cystic-fibrosis-carrier-description-in-brief

*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.