# A review into how some people in Derby and Derbyshire were not informed their babies were carriers of sickle cell

## The issue

Between 2012 and 2024, some families in Derby and Derbyshire were not told that their newborns were carriers of sickle cell or other rare blood conditions.

Sickle cell is a group of inherited health conditions that affect the red blood cells. Those people most affected by sickle cell are from Black African or Black Caribbean heritage although those from Asia and Mediterranean countries can also be affected.

Carriers of sickle cell do not have the condition but can pass it on to their children.

The newborn blood spot test (the heel prick test) carried out at 5 days old tests for a number of inherited conditions. The issue was discovered in 2023 when NHS England became aware some families of babies who were carriers of sickle cell had not been informed after screening.

## How it happened

Following a detailed root cause analysis investigation to determine how this happened, the following causes were identified as contributing to the situation rather than there being one single cause:

* **Pathway change:** The pathway for communicating results changedin 2012when a specialist nurse whose role had included communication of carrier results for both Derby and Derbyshire patients left and was not replaced.This wasduring a period of significant organisational restructure when commissioning arrangements, roles and responsibilities were changed.
* **Processes changed without involving staff**: there is no evidence that GPs and Health Visitors were made aware that they needed to discuss results with families as a result of this pathway change.
* **It is not part of the GP contract**: As these sickle cell carrier results are rare in Derby and Derbyshire many GPs would never have seen a result like this before. GPs weren’t always trained or confident to explain these results. It wasn’t part of their contract, and they didn’t order the tests themselves so when letters were sent to practices often there was uncertainty about what to do with them.
* **No national letter**: There was no standard letter to send to families, which would have occurred if all the screening results in the newborn screening test had been negative. This meant many parents did not receive written confirmation of their child’s result which would have acted as a backup.
* **Difficulties with Health Visitors checking results**: Health Visitors were meant to check if families got their results—but they often saw families before GPs did, and there were limited opportunities for health visitors to do a follow-up check later.
* **Complex and confusing system**: The process involved many opportunities for communication midwives, laboratories, GPs, Health Visitors, and Child Health Information Services (CHIS)—with no single person responsible for making sure families got the result.
* **No monitoring**: There were no performance checks or audits to spot the problem earlier.
* **Organisational changes**: Over 12 years, many NHS structures changed, making it harder to track who was responsible for delivering the results and for checking they were delivered.

## What’s Changed

**Everyone Contacted**

In 2024, 839 families of babies who might not have received their results were contacted by letter with an apology. They were followed up with a phone call and offered the opportunity to talk to a GP about being a carrier of sickle cell. GPs were also informed.

Of the 557 people spoken to by phone, 475 (85%) already knew their babies’ sickle cell carrier results.

**New pathway in place**

From January 2025, a new system was introduced:

* **Specialist nurses at University Hospitals of Derby and Burton** now deliver all blood condition carrier results directly to families.
* **GPs do not have the responsibility** for sharing these results.

**National improvements**

* A **standard letter template** has been created and will be used across the East Midlands from September 2025.
* **National guidance** has been updated to make sure all families are informed, regardless of where they live.

**System fixes**

* The new pathway is **clearly documented**, with defined roles and responsibilities.
* **Regular audits** will check that results are being delivered.
* **Performance measures** are being introduced to track how well the system works.
* **Letters will act as a backup** by CHIS to make sure families are informed even if other steps fail.

**Community engagement**

* NHS England worked with The Sickle Cell Society and representatives of Caribbean and African communities (those communities most affected) on the letter and leaflet to be issued to those families affected
* Derby City Council Cabinet Member for Health and other councillors from affected communities were briefed on the incident and the approach being taken in spring 2024
* NHS England and NHS Derby and Derbyshire ICB attended a community event hosted at Derby West Indian Community Association in October 2024 where one family affected attended together with about 20 members of the community
* In May 2025 NHS Derby and Derbyshire ICB held two events took place in Derby and in Chesterfield. These were to update the community and gather feedback about the new service which now ensures all families are notified of sickle cell carrier results following newborn screening tests.
* The NHS is working to ensure that **future communications are clearer and more sensitive**, especially for communities that may already experience disadvantages.

**Ongoing commitment to community engagement**

* NHS Derby and Derbyshire have committed to continually engaging with the Black community to ensure that voices are heard and that the learnings from this journey are taken on board. This includes working closely with community representatives, listening to lived experiences, and putting infrastructure in place to ensure we build and maintain relationships. The ICB recognises that trust must be earned and maintained, and is committed to building stronger, more inclusive relationships with those communities.