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Guidance

# NBSFS user guide

Updated 4 May 2021

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## 1. Overview

Please note that quick reference guides with detailed step-by-step actions for system functions are available on the resources section in the newborn blood spot failsafe solution (NBSFS).

### 1.1 Access the NBSFS

The system is only available on an N3 connection (NHS secure). Access the system (<https://www.bloodspot.northgate.thirdparty.nhs.uk/BloodspotWeb/nhsbaby>).

The NBSFS does not work with Internet Explorer (IE) versions older than IE 10. The system also works on the latest versions of Chrome and Firefox.

### 1.2 How it works

The NBSFS is an IT solution for England that reduces the risk of babies missing or having delayed newborn blood spot (NBS) screening. It supports the maternity service responsibility for ensuring that NBS screening is offered and that samples are taken and received in the laboratory on time.

This is a summary of how the system works (see also diagram below).

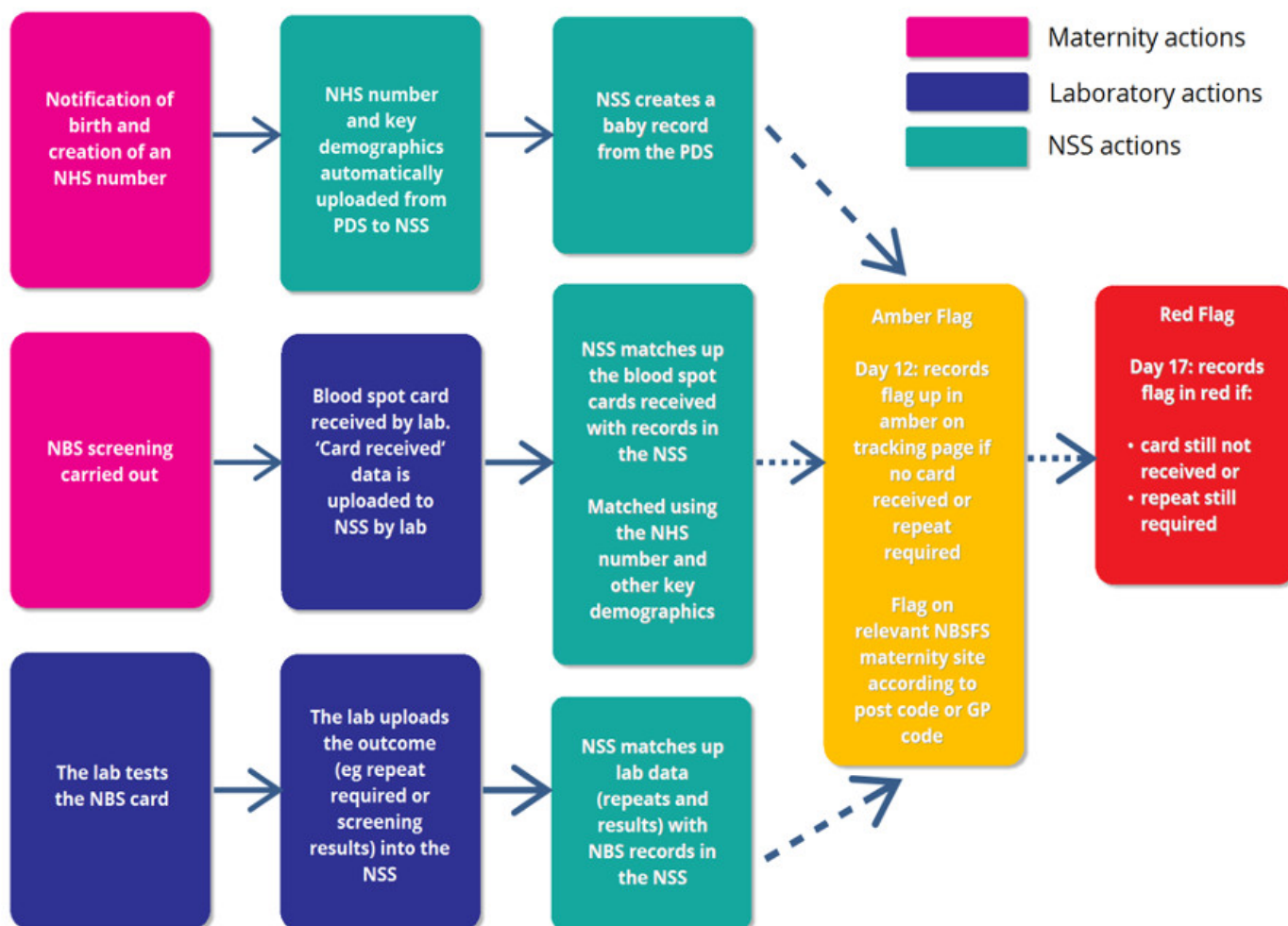
1. The midwife completes the baby's birth notification and an NHS number is automatically created via the Patient Demographic Service (PDS).
2. This NHS number and some demographic data entered by the midwife are automatically uploaded from the PDS into the national screening store (NSS) database.
3. A record for the baby is created in the NSS. This is allocated to the NBSFS maternity site responsible for screening the baby, based on the mother's postcode or GP code. For more details see mapping records to NBSFS sites (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/how-records-are-mapped-to-the-nbsfs-sites>).
4. The blood spot (BS) is taken, usually on day 5, and sent to the NBS screening laboratory.
5. Each working day, the NBS screening laboratory uploads a list of blood spot cards received into the NSS.
6. The NSS matches the blood spot cards received with records already existing in the NSS, using the NHS number and other demographic information. Because the NSS is a national database, blood spot cards from babies born anywhere in England can be matched to data uploaded from any of the 13 NBS screening laboratories.
7. The NBS screening laboratory tests the blood spot card.
8. The laboratory uploads the outcome – for example, 'repeat required' or screening results – into the NSS.
9. The NSS matches this outcome data with records as before, using the NHS number and other demographic information.
10. On day 12, records flag up amber on the NBSFS tracking page of the relevant NBSFS maternity site if no NBS card has been received for a record, or if a repeat is required. Each maternity site has designated users who log into the system each working day to check if there are any babies flagged

on their site. The maternity site makes sure that records which appear on the tracking page are followed up.

11. On day 17, records are displayed in red if they are still flagged.

Please note that:

- the NBSFS is not a tool for requesting repeat tests or to replace existing processes for communicating repeat requests or results
- data in the NBSFS should not be used as the primary source of data to populate the child health record or to give results to parents
- child health record departments (CHRDs) remain responsible for ensuring NBS screening coverage



Newborn blood spot failsafe solution flowchart

## 1.3 NBSFS data sources

### Demographic details

The demographic data in the NSS originates from the data provided when the NHS number is generated soon after birth, normally by the labour ward midwife.

NBSFS users can amend or update the demographic details. This will not update the PDS record (the 'spine') or NIPE SMART or SMART4Hearing.

The system provider and the NBS screening laboratories do not normally add or amend the demographic details in the NBSFS.

NBSFS users can print 22-digit barcode labels in the demographic details section.

## Results

The NBS screening laboratories provide the screening information in the results section.

## Notes

Any user can add notes. Notes can also be added by the system provider advisors, for example, a helpdesk operator, or may be added automatically, for example, when a record is transferred or the status has been changed. A list of automatic notes (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/an-explanation-of-the-notes-in-nbsfs>) is available.

To identify the user who added a note, hover the cursor over the user ID and their details will be shown. The details shown are those which the user has added in their 'user profile'.

## 1.4 Guidelines on using the NBSFS

NBS screening providers and other stakeholders must use the NBSFS. This is mandated in the section 7a service specification (<https://www.england.nhs.uk/publication/public-health-national-service-specifications>).

Operational level agreements (OLAs) describe how CHRDs (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/nbsfs-operational-level-agreements-for-chrd-users>), laboratories (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/nbsfs-operational-level-agreements-for-laboratory-users>) and maternity departments (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/nbsfs-operational-level-agreements-for-maternity-users>) should use the NBSFS and outline the responsibilities of the system provider and the NHS Newborn Blood Spot Screening Programme.

## 1.5 Feedback and change requests

The NBSFS User Group meets twice a year and reviews all requests and suggestions about improvements to the NBSFS.

You can feedback via the NBSFS Customer Portal (<https://npssupport.northgateps.com/production/core.aspx?lite&portal=NBSFS>).

You can also get in touch via the NBSFS helpdesk.

Newborn blood spot failsafe solution helpdesk

Email [NBSFS.helpdesk@nhs.net](mailto:NBSFS.helpdesk@nhs.net)

Phone 0845 070 2778

Always direct urgent feedback or enquiries to the NBSFS helpdesk.

When submitting your feedback tell us your:

- name
- email address
- telephone number
- role (for example, lab technician, screening coordinator)
- hospital/CHRD
- trust (if relevant)
- suggestion or comment about NBSFS
- preference whether you would you like a response to your feedback

## 1.6 CHRD users

These users have 'CHRD access' to the NBSFS and include CHIS and CHIS hub users.

The NBSFS is a secondary source of NBS screening data for CHRDs and must not be used to populate the child health record or give results to parents. CHRD users can:

- view the full records on the CHRD user's site(s)
- filter records to match their area of responsibility
- use the national search to locate a record on any other site
- change the status of a record to deceased
- add notes to a record

## 1.7 Laboratory users

Guidance for NBSFS laboratory functions is not included in this publication.

## 2. Troubleshooting

This section explains what to do if problems occur with the NBSFS. You can contact the NBSFS helpdesk or customer portal. Email the NBSFS helpdesk using the record query form (RQF) ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) if your query is about a record. Ring them if the problem is urgent.

### 2.1 The baby has completed screening but the record remains on the tracking page

Complete the record query form (RQF) ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) and forward to the relevant NBS screening laboratory or NBSFS helpdesk as instructed on the form.

Records of screened babies can appear or remain on the tracking page for several reasons, for example:

1. Data provided at birth notification does not match the data on the NBS card. Matching is delayed because the NBSFS system will not automatically match the record and the card. Common data

errors include wrong date of birth (**DOB**) on the **NBS** card or the mother's NHS number appearing on the **NBS** card instead of the baby's.

2. The laboratory has tested the **NBS** card but has not uploaded the record into the **NBSFS**. Occasionally the laboratory upload is delayed, for example, if emergency situations or technical problems occur. The date and time of the most recent laboratory upload for the site's primary laboratory is displayed on the tracking page.
3. The laboratory has unsuccessfully attempted to upload the card details to the **NBSFS** database. Occasionally files contain errors and the record is not successfully uploaded.
4. A technical error may have occurred within the **NBSFS** system. A message will appear on the log-in page when the system provider is aware of an error affecting the running of the **NBSFS** system.

## 2.2 'Test patient' on tracking page

To remove 'test patient' records complete the **RQF**.

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) and forward to the **NBSFS** helpdesk as instructed on the form.

'Test patient' records can appear if there has been a local IT system test or change, or testing in the **PDS** by NHS Digital. These records are clearly identified, usually as 'test' or 'dummy' records. The **NBSFS** system provider does not add test records to the system.

## 2.3 Record for an older baby appears unexpectedly on tracking page

Outstanding records normally appear on the tracking page on day 12. Records for older babies, which were not previously on the tracking page, can appear in the following circumstances:

### Transferred from another **NBSFS** site

The record may have been transferred from another site. If so, the transfer icon will be highlighted. The originating site may have added a note to the 'notes' section of the record.

Accept or reject the transfer as appropriate (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

### Transferred by the system provider

A record may be transferred in by the system provider. This occurs when a record cannot automatically be placed – for example if the postcode, **GP** code and hospital of birth entered into the **PDS** are all incorrect. The transfer icon will be highlighted and there will be an explanatory note in the 'notes' section of the record. Accept or reject the transfer as appropriate (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

### Wrong date of birth (**DOB**)

If the wrong **DOB** is entered into the **PDS** when the NHS number is generated, this could result in the record immediately appearing on the **NBSFS** tracking page.

Maternity users can correct the **DOB** by editing the record (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))). Also inform the **NBSFS** helpdesk so the system provider can check for any previously uploaded sample cards which can be matched with the updated baby's record.

## Change to screening status

The record may have initially been marked as 'card received' or 'screening complete'. If a change to the record status is made after day 12 which indicates screening is not complete then the record will appear on the tracking page. This could happen if, for example, the laboratory was subsequently given new information about transfusion status or gestational age which invalidated the initial result.

Check the results section and the notes page of the record which may give updates on the status of the record.

## Other

If none of the above applies and you are certain that the record has suddenly appeared, complete the **RQF** ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) and forward to the **NBSFS** helpdesk as instructed on the form.

This must be done without delay as the backup system must be investigated to find out why the record has appeared on the tracking page, and data is only held in the backup system for a limited period.

## 2.4 Duplicate record

Complete the **RQF** ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) and forward to the relevant **NBS** screening lab or **NBSFS** helpdesk as instructed on the form.

## 2.5 A record is on the wrong **NBSFS** site

The record should appear on the site responsible for screening the baby, usually based on the postcode or **GP** code of the mother's address. Records may appear on the wrong site for the following reasons.

### The mother and baby have moved

Maternity users can transfer records. If the baby has temporarily moved to a different location during the screening period, enter the temporary address in the relevant section, then transfer the record to the site responsible for screening, adding an explanatory note into the 'notes' section of the record (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).



If the baby has moved permanently to a different address, update the demographic details and transfer the record to the site responsible for screening, adding an explanatory note into the 'notes' section of the record (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

An **NBSFS** map (<https://www.google.com/maps/d/viewer?mid=zD-sEIC4d3W4.kjyulrZHflll>) shows the location of maternity hospitals and their associated **NBSFS** sites.

A list of postcodes and **GP** codes and the associated **NBSFS** sites is also available to help identify where to transfer a record (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

## Record has been incorrectly mapped

If a record has been wrongly allocated to your site (ie the postcode or **GP** code has been incorrectly mapped to your **NBSFS** site) then maternity users should transfer the record to the correct site (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))). You should then inform the **NBSFS** helpdesk using the **RQE**.

## 2.6 Shared postcodes

Usually, only the first part of the postcode is used for mapping: for example HA4 or NW14. If this part of the postcode is shared between more than one site then the record is mapped to the **NBSFS** site associated with the hospital of birth. This could result in records being wrongly mapped. A request can be made via the **NBSFS** helpdesk to have the full postcode mapped if this is a recurrent problem.

## 2.7 Incorrect repeat request or result

Complete the **RQE**.

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) and forward to the **NBS** laboratory or **NBSFS** helpdesk as directed on the form.

## 2.8 Wrong failsafe status

Maternity users can change the failsafe status (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

If you cannot change the failsafe status to the appropriate value please complete the **RQE**.

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) as directed and forward to the **NBSFS** helpdesk.

## 2.9 Demographic or data errors

### If details have changed since birth

Maternity users can update demographic information (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

You should also complete the [RQE](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'record has demographic or data errors' and adding the details in the 'additional notes' section. Forward to the [NBSFS](#) helpdesk as instructed on the form so the system provider can check for any previously uploaded sample cards which can be matched with the updated baby's record.

### **If demographic or data errors were made when the NHS number was generated**

Changes must be updated on the [NBSFS](#), even if updates have been made on the maternity IT system or [PDS](#). This is because corrections made to maternity IT systems or [PDS](#) do not update the [NBSFS](#). Maternity users can make simple demographic changes to a single record. More complex cases need to be referred to the [NBSFS](#) helpdesk using the [RQE](#).

### **Example: demographic changes to a single record**

Maternity users can update and correct demographic information such as NHS number, name, date of birth, gender and address (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))). Be particularly careful if changing the NHS number. Changes required to an NHS number tend to be more complex.

Whenever demographic details have been changed, please complete the [RQE](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'record has demographic or data errors' and add the details in the 'additional notes' section. Forward to the [NBSFS](#) helpdesk as instructed on the form in order for the system provider to check for any previously uploaded sample cards which can be matched with the updated baby's record.

Any changes made on [NBSFS](#) will not update the [PDS](#).

### **Example: removing a record from the [NBSFS](#)**

You must remove records from [NBSFS](#) when they were created in error, accidentally merged or are duplicates. Complete the [RQE](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'duplicate record' or 'other' as appropriate, and adding clear notes in the 'additional notes' section. Forward to the relevant [NBS](#) screening lab or [NBSFS](#) helpdesk as instructed on the form.

If a new NHS number is created for a baby, it is essential to check that the new record has been entered into the [NBSFS](#). Use the 'national search' function, enter the NHS number and search for the record. If the record does not appear, complete the [RQE](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'record missing' and adding explanatory notes in the 'additional notes' section. Forward to the NBSFS helpdesk as instructed on the form.

Removed records are securely stored using an auditable process – for further details contact the NBSFS helpdesk.

## 2.10 If a baby dies

### A record for a deceased baby is on the tracking page

Maternity and CHRDP users can update the record to 'deceased' (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))). To avoid delay, this should normally be done by whichever NBSFS user receives the information first.

### Updating the NBSFS record when a baby has died

If NBS screening has not been completed for the deceased baby, the NBSFS must be updated without delay to minimise the risk of inappropriate contact being made with the family (for more information see operational level agreements and the quick reference guide ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))). Maternity and CHRDP users can update the record and, to avoid delay, it should normally be done by whichever NBSFS user receives the information first.

All providers, such as maternity units and neonatal units, which have a deceased baby checklist or protocol, should include an action to notify the appropriate NBSFS user of the death so that the NBSFS record can be updated.

Updating the NBSFS does not replace other forms of communication relating to a deceased baby. Local processes should be followed as usual.

If NBS screening is complete, it is not necessary to update the record to 'deceased' status when a baby dies, but you can do so if you wish.

### Babies who died soon after birth and still-born babies

NBSFS does not receive data about babies who are still-born. In addition, if a baby dies before the midwife generates an NHS number, and this is indicated on the birth notification, then details will not be uploaded to the NBSFS.

## 2.11 When a record cannot be located

Records can normally be located from within the user's own site or using the 'national search' option (for more information see operational level agreements and the quick reference guide ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/655643/NBSFS\\_quick\\_reference\\_guide.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655643/NBSFS_quick_reference_guide.pdf))).

### Babies born in England or Isle of Man (IOM)

If records cannot be located using the national search, complete the [RQF](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'Record cannot be located' and forward to the [NBSFS helpdesk](#).

## Babies born in Wales

The system identifies babies born in Wales to English residents on the Welsh failsafe site and creates a record for them in [NBSFS](#). The [GP](#) code and post code are used to map the record to an [NBSFS](#) maternity site. If this is unsuccessful, a manual process will be used. If a record is incorrectly matched to a site, it can be transferred out. The 'national search' option can be used to find a missing record.

For more details about Welsh babies see [NBS](#) processes between Wales and England

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/871035/NBS\\_failsafe\\_processes\\_between\\_Wales\\_and\\_England.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/871035/NBS_failsafe_processes_between_Wales_and_England.pdf)).

## Babies born outside England, Isle of Man and Wales

A record for a baby born outside England, Isle of Man and Wales can be added to the [NBSFS](#) on request. This is not normally done but might be advisable, for example, if an unscreened baby in midwifery care has moved to England or Isle of Man. This would ensure the baby is tracked on [NBSFS](#) in the same way as a baby born in England.

Complete the [RQF](#).

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)), selecting 'record missing', and add explanatory notes in the 'additional notes' section. Forward to the [NBSFS helpdesk](#) as instructed on the form.

See more details on [NBS](#) screening of babies with no available records

(<https://www.gov.uk/government/publications/movers-in-screening-babies-with-no-available-records>).

## Babies who died soon after birth and still-born babies

[NBSFS](#) does not receive data about babies who are still-born. In addition, if a baby dies before the midwife generates an NHS number then details may not be uploaded to the [NBSFS](#).

## 2.12 Baby resident/screened in Wales

If the baby was born in England but is the screening responsibility of Wales (temporarily or permanently resident in Wales), or was screened in Wales, transfer the record to the 'Wales' site. For more information, see operational level agreements and the quick reference guide in the resources section of the system.

For more details about [NBS](#) failsafe processes between Wales and England see [NBS](#) processes between England and Wales

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/871035/NBS\\_failsafe\\_processes\\_between\\_Wales\\_and\\_England.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/871035/NBS_failsafe_processes_between_Wales_and_England.pdf)).

## 2.13 Placing a record 'out of England'

The 'out of England' status is only for records of babies who have been confirmed as no longer the responsibility of the English screening programme or [JQM](#). This is babies who:

- are resident in Scotland
- are resident in Northern Ireland
- are resident in the Channel Isles
- have moved to another non-UK country
- are the responsibility of United States Air Force (USAF) Lakenheath

Do not use the 'out of England' status for any other reasons. Records marked as 'out of England' do not flag up on the NBSFS (even if screening is not complete) although they can still be located using the search functions.

## 2.14 Baby resident/screened in Scotland

If the baby was born in England but is the screening responsibility of Scotland, update the record status to the 'out of England – Scotland'.

The record will no longer be followed up in the NBSFS so records must only be set to 'out of England – Scotland' status if the baby is being screened in Scotland.

We cannot transfer records to an NBSFS site in Scotland in the same way as we do for Wales as there is no electronic failsafe system in Scotland.

For other NBS failsafe processes between Scotland and England see NBS processes between Scotland and England

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/872401/NBS\\_failsafe\\_processes\\_between\\_Scotland\\_and\\_England.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/872401/NBS_failsafe_processes_between_Scotland_and_England.pdf)).

## 2.15 Baby resident in England but screened elsewhere

See the guidance for Wales and Scotland.

For babies born in England and screened elsewhere, refer to NBS guidelines

(<https://www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines>) to see if they should be offered screening in England:

If they are not eligible for screening or do not require screening, complete the RQF

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) as indicated and submit it to the NBSFS helpdesk.

Otherwise, screening should be offered, as indicated in the guidelines, and the record should remain on the NBSFS tracking page until there is a screening outcome. Explanatory notes should be added to the 'notes' section of the baby's record.

## 2.16 Baby is in hospital

### In a maternity hospital or neonatal unit attached to a maternity hospital

The maternity hospital or neonatal unit can transfer the record into their own site (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

The record should be transferred to the relevant maternity hospital NBSFS site if it flags up on the tracking page of the home site (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

## In a paediatric hospital or children's ward

A limited number of paediatric hospitals are being set up as NBSFS sites. These hospitals will appear in the transfer drop-down list and the record should be transferred (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

Most paediatric centres are not NBSFS sites and the record should remain on the home site until screening is complete. Babies in paediatric care have an increased risk of missed screening and must remain visible on NBSFS until screening is complete.

If there are arrangements for the local maternity unit to oversee NBS screening in a paediatric unit, the NBSFS record should be transferred to the overseeing site if it flags up on the home site tracking page. Where this arrangement is in place, the local team should inform the relevant stakeholders and the NBSFS helpdesk.

If there are problems following up babies in paediatric care, please seek advice from your regional SQAS team.

## 2.17 Care by a private or independent midwife

Some private or independent midwife services are set up as NBSFS sites. Their service will appear in the transfer drop-down list and the record should be transferred (for more information see operational level agreements and the quick reference guide

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814151/NBSFS\\_quick\\_reference\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814151/NBSFS_quick_reference_guide.pdf))).

Most private or independent midwives do not use the NBSFS, but the babies in their care are entitled to cover by the NBSFS. The record will, therefore, remain on the home site and be visible until screening is complete. If there are problems following up babies cared for by a private or independent midwife, please seek advice from your regional SQAS team.

## 3. New users and training

### 3.1 Registering new users

Site leads can add and manage site users locally through the NBSFS. Site leads need to contact the helpdesk once to have the permissions added to their account.

Alternatively, each NBSFS has a named site lead who is responsible for authorising access. The site lead completes a new user access form

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814165/NBSFS\\_new\\_user\\_request\\_form.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814165/NBSFS_new_user_request_form.pdf)). This must be emailed to the NBSFS helpdesk from the site lead's email address.

## 3.2 Training materials for new users

Training films are available.

Please contact the NBSFS helpdesk if you need any further assistance.

Local arrangements should be made for training new users. External training is not usually necessary but can be arranged via the NBSFS helpdesk. This is likely to incur a cost for the site requesting training.

## 4. Administration queries

### 4.1 Problems accessing the NBSFS

Forgotten password: there is a 'forgotten password' link on the login page of NBSFS.

Password reactivation: accounts are deactivated if not used for 90 days. To reactivate an account, contact the NBSFS helpdesk.

For other access problems contact the NBSFS helpdesk.

Accounts are deleted if not used for 12 months.

### 4.2 Access to additional NBSFS sites

Users normally access one NBSFS site.

Some CHRDs cover a large geographical area and access a 'hub' of NBSFS sites. This is arranged through the NBSFS helpdesk.

CHRD users can also request access to neighbouring sites if their screening coverage overlaps.

For access to additional sites, the cross border access form ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814166/NBSFS\\_cross\\_border\\_access\\_authorisation\\_form.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814166/NBSFS_cross_border_access_authorisation_form.pdf)) is completed and sent to the site lead of the site to which access is requested. The authorising site lead agrees or declines the request and returns the form to the NBSFS helpdesk.

Some NBSFS maternity sites are part of the same trust and maternity users have screening responsibility for babies at all the sites. These are known as 'linked sites' and users have access to all the linked sites. Linked sites can be set up through the NBSFS helpdesk.

### 4.3 A NBSFS user is changing role

The NBSFS helpdesk should be informed of a site lead change, preferably in advance by the existing site lead changing role.

If a user no longer requires access to NBSFS, the NBSFS helpdesk must be contacted to deactivate their account. A successor must be appointed to take on NBSFS responsibilities (for more information see operational level agreements).

## 5. Record query form (RQE) guide

## 5.1 When to use the RQE

The RQE

([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814149/NBSFS\\_record\\_query\\_form.xlsx](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814149/NBSFS_record_query_form.xlsx)) is used for queries such as:

- record on the tracking page when a BS sample has been taken
- error in a NBSFS record
- record has been assigned to the wrong site
- NBSFS record cannot be found

The RQE should not be used for:

- administration enquiries such as password queries, new user requests
- training queries such as help using the system
- technical problems such as the system not operating correctly - contact the NBSFS helpdesk instead
- urgent issues such as an issue which may have a direct and immediate effect on patient safety or care - contact the NBSFS helpdesk instead

## 5.2 Maintaining confidentiality

Always send the RQE via secure nhs.net email (sender and recipient) to protect patient identifiable information.

Avoid giving sensitive or clinical details unless essential.

State the helpdesk reference number in subsequent emails to avoid using identifiable data.

Do not forward the RQE on to others and avoid copying others into emails, so that patient identifiable information is not inadvertently shared.

The confidential identifier can be used if a non-secure email address has to be used. To see the confidential identifier, hover the cursor over the baby's first name on the NBSFS tracking page. To copy and paste the confidential identifier, open the baby's details and click on the envelope icon in the top right hand corner. Do not add any other identifying details.

## 5.3 When a query involves more than one record

If a query involves more than one record, only use one RQE. For example:

- records which have become mixed up, for example, twins records muddled, two babies with one NHS number, duplicate records
- several records on the tracking page with a probable common underlying cause

Include all the affected NHS numbers in 'Baby NHS Number' section, separated by a comma but do not complete the DOB and surname sections.

Give the details of the query clearly in the 'Additional Notes' section.



In some circumstances it is not possible or necessary to list every NHS number involved; discretion can be applied but communication must be clear.

## 5.4 Where to send the RQE.

When the 'enquiry reason' is selected from the drop-down list, the 'action to be taken' will appear below. This indicates whether to forward the RQE to the screening laboratory, to the NBSFS helpdesk or whether the query can be resolved by the user.

Remember to maintain confidentiality when sending the RQE.

## 5.5 Is the RQE compulsory?

The RQE is not mandatory but using it:

- ensures that the necessary information is provided and correct actions are taken to speed up a response
- helps the helpdesk to prioritise and respond to queries consistently
- allows the NBS laboratories to respond to queries efficiently
- provides an audit trail which cannot be captured by ad hoc phone calls

The NBSFS helpdesk will continue to respond to queries made by email or phone.

## 5.6 What to do if the query is unresolved

If queries are not resolved the escalation process can be found in the operational level agreements (<https://www.england.nhs.uk/publication/public-health-national-service-specifications/>).

# 6. Resources

## 6.1 Training films

Training films (<https://vimeopro.com/phescreening/blood-spot-failsafe-videos>) include:

- logging in and forgotten password
- basics of the tracking page part 1
- basics of the tracking page part 2
- how do edit or update a failsafe record
- how to find a record in your failsafe site
- how to carry out a national NHS number site
- how to cancel a transfer
- how to set a record to deceased
- how to set a record to 'out of area'

## 6.2 Newborn blood spot guidelines

See blood spot sampling guidelines (<https://www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines>) and procedures for screening babies with no available records (<https://www.gov.uk/government/publications/movers-in-screening-babies-with-no-available-records>).

## 7. Contacts

### 7.1 NBSFS helpdesk

Newborn blood spot failsafe solution helpdesk

Email [NBSFS.helpdesk@nhs.net](mailto:NBSFS.helpdesk@nhs.net)

Phone 0845 070 2778

### 7.2 NBS screening laboratories – England

#### Bristol

0117 32 35566 [nbn-tr.newbornscreening@nhs.net](mailto:nbn-tr.newbornscreening@nhs.net)

#### Cambridge

01223 217160 [add-tr.newbornscreening@nhs.net](mailto:add-tr.newbornscreening@nhs.net)

#### GOSH (North Thames)

020 7813 8383 [gos-tr.enquiriesgosnbs@nhs.net](mailto:gos-tr.enquiriesgosnbs@nhs.net)

#### Leeds

0113 2065087 (or 0113 2065806 - newborn screening reception) [leedsth-tr.LeedsScreeningLab@nhs.net](mailto:leedsth-tr.LeedsScreeningLab@nhs.net)

#### Liverpool

0151 252 5489 [screening.laboratory@nhs.net](mailto:screening.laboratory@nhs.net)

#### Manchester

0161 7012262 [cmm-tr.NBSL@nhs.net](mailto:cmm-tr.NBSL@nhs.net)

#### Newcastle

0191 2820339 [Tnu-tr.NewcastleNewbornScreening@nhs.net](mailto:Tnu-tr.NewcastleNewbornScreening@nhs.net)

#### Oxford

01865 220488 [s.laboratory@nhs.net](mailto:s.laboratory@nhs.net)

#### Portsmouth

02392 286000 ext 1765 or 02392 286903 pho-tr.PortsouthScreening@nhs.net

## Sheffield

0114 271 7346 newborn.screening@nhs.net

## South East Thames

02071881267 gst-tr.SEThamesNBSLab@nhs.net

## South West Thames

0208 296 2991 est-tr.SWTNewbornScreening@nhs.net

## West Midlands

0121 333-9900 nsbg.bch@nhs.net

NBS laboratory contacts are also available from the UK Newborn Screening Laboratories Network (<http://www.newbornscreening.org/site/laboratory-directory.asp>).

## 7.3 NBS screening - Wales

### General NBS screening enquiries

NBSW@Wales.nhs.uk. This is not a secure email address so do not send confidential or identifiable information.

### Wales Newborn Screening Laboratory

029 2074 4032 (phone), 029 2074 4065 (fax)

NBS laboratory contacts are also available from the UK Newborn Screening Laboratories Network (<http://www.newbornscreening.org/site/laboratory-directory.asp>).

## 7.4 NBS screening: Scotland and Northern Ireland contacts

Contact details for NBS screening in Scotland and Northern Ireland are available from the UK Newborn Screening Laboratories Network (<http://www.newbornscreening.org/site/laboratory-directory.asp>).

## 7.5 SQAS regional team contacts

Contact SQAS teams in London, Midlands and East, North or South (<https://www.gov.uk/government/publications/nhs-population-screening-regional-quality-assurance-teams-in-england>).

## 7.6 PHE helpdesk

Population screening helpdesk

PHE Screening  
Floor 5  
Wellington House  
133-155 Waterloo Road  
London  
SE1 8UG

Email [PHE.screeninghelpdesk@nhs.net](mailto:PHE.screeninghelpdesk@nhs.net)

Helpdesk phone number 020 3682 0890

The helpdesk is not for media enquiries and does not have access to screening results. For queries about results, contact your GP or local screening service. Order screening leaflets at [www.gov.uk/phe/screening-leaflets](http://www.gov.uk/phe/screening-leaflets) (<http://www.gov.uk/phe/screening-leaflets>).

Use for any screening queries not related to ~~NBSFS~~.

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