



# Newborn Bloodspot Screening Wales

Welcome to the Newborn Bloodspot Screening Wales (NBSW) newsletter. This provides information and updates on the NBSW Programme.

September 2021

Issue 21

## Message from Ruth Lawler, Head of Maternal and Child Screening

*"Since the start of the Covid-19 pandemic, staff involved in newborn bloodspot screening have worked tirelessly to ensure that all eligible babies have timely good quality bloodspot samples taken despite the huge challenges they faced. This is a credit to you all and I would like to say a huge **THANK YOU** to everyone involved in taking newborn bloodspot screening samples.*

*Moving forward it is essential that you continue to take timely good quality samples to prevent repeat samples and unnecessary workload.*

*Thank you once again for all your hard work and dedication in ensuring that timely good quality bloodspot samples are taken for all eligible babies".*

## Included in this issue

- ✓ New e-learning packages
- ✓ Sample taker registration
- ✓ SCID Evaluation study in England – Implications for Wales
- ✓ New screening letter – babies moving into Wales
- ✓ NBSW conference
- ✓ Website



**Contact Us:** We hope you find this newsletter useful. If you have any questions about the NBSW programme or any of the resources, or would like to be added to our circulation list, please contact us at [nbsw@wales.nhs.uk](mailto:nbsw@wales.nhs.uk). Telephone: 029 2010 4427.



## New e-learning packages for health professionals

NBSW provides educational resources for health professionals to improve their knowledge on the newborn bloodspot screening programme in Wales.

To provide easy access to online education, NBSW are pleased to announce the launch of 2 new e-learning modules:

- Introduction to newborn bloodspot screening
- Taking a good quality newborn bloodspot screening sample

It is recommended that sample takers complete both packages before taking any samples. The first package is recommended for staff who do not take samples but have involvement in any part of the newborn bloodspot screening pathway.

These e-learning packages are both available via ESR (Electronic Staff Record) and Learning@Wales.

Further information and Guides for accessing this e-learning can be found on the [NBSW website](#).



## Website

Following the redesign of the [NBSW website](#) last year, the website is undergoing further changes. This is to ensure that there is website consistency across the screening programmes in Public Health Wales.

## NBSW Annual Conference

We are pleased to announce that the NBSW conference will take place on **24<sup>th</sup> November 2021**, via Microsoft Teams. The focus will be on Congenital Hypothyroidism (CHT) and will include an overview of the condition, the screening and referral pathways and the impact of a suspected CHT screening result. All are welcome.

Please [click here](#) to book your place at the conference.



## Mandatory registration of sample takers planned for 2022

The NBSW programme is planning to introduce the Mandatory Registration of Sample Takers in Wales to start in 2022 (start date to be confirmed).

This would mean that sample takers will need to be registered on the NBSW sample taker database and have completed training before they can take any samples. Sample takers would also need to ensure that their sample taker ID code (NMC PIN or NBSW ID code) is recorded on the bloodspot cards.

The benefits of mandatory sample taker registration will be:

- All registered sample takers will have completed training which is essential for good quality samples
- All sample takers will be able to access their individual newborn bloodspot screening (NBS) performance reports via the NBSW website
- Monthly health board NBS performance reports will show accurate performance data for samples taken in maternity units, neonatal units, paediatric units and by health visiting staff.
- NBSW will be able to directly communicate with sample takers and provide updates from the programme

NBSW is working with the governance leads and department managers in preparation for mandatory registration. We would like to thank everyone for all the hard work in the health boards to support this and to all the sample takers who have registered. We are pleased to report that the percentage of samples taken by registered sample takers has increased from 74 percent in July 2020 to 88 percent in June 2021.

We recommend that all sample takers complete the two e-learning packages, in addition to the practical training in sample collection. We also recommend accessing the [NBSW Programme Handbook](#) which includes the NBS guidelines and brings together the NBS resources in one place.



Learning@Wales



Electronic Staff Record  
NHS Electronic Staff Record

Sample Takers




## Sample taker registration

To register, please complete the [NBSW sample taker registration form](#) which can be accessed via the NBSW website.

If already registered, please let us know if any of your details, including your health board, have changed since you completed your sample taker registration form.

Please [contact us](#) if you have any questions about registration.



 Iechyd Cyhoeddus Cymru Public Health Wales

 Sgrinio Smotyn Gwaed Newydd-anedig Cymru Newborn Bloodspot Screening Wales

### Newborn Bloodspot Screening Wales Sample Taker Registration Form

Newborn Bloodspot Screening Wales (NBSW) is establishing a database of all newborn bloodspot screening sample takers in Wales as part of its quality assurance processes. All sample takers should complete newborn bloodspot screening training before taking any samples.

The sample taker database is used as a mechanism to monitor the quality of the newborn bloodspot screening programme and distribute information to sample takers. Individual sample taker performance reports are now produced for registered sample takers. The database holds information about health professionals as sample takers. Personal details are held securely and confidentially and are not released outside of the programme.

The Nursing and Midwifery Council have given their approval for health professionals to use their NMC PIN as a unique identifier. Please use this as your 'sample taker ID code' which should be recorded in the 'sample taker ID' field on the bloodspot card.

If you do not have an NMC PIN you will be issued with a unique identifier (sample taker ID code) by NBSW after you have completed and returned this registration form.

| Personal Details |           | Staff Group              |                          |
|------------------|-----------|--------------------------|--------------------------|
| Title            | Type Here | Midwife                  | <input type="checkbox"/> |
| Surname          | Type Here | Health Visitor           | <input type="checkbox"/> |
| Forename(s)      | Type Here | Nursery Nurse            | <input type="checkbox"/> |
| NMC number       | Type Here | RNU nurse                | <input type="checkbox"/> |
|                  |           | Maternity Support Worker | <input type="checkbox"/> |
|                  |           | Paediatric Nurse         | <input type="checkbox"/> |
|                  |           | Other (please specify)   | Type Here                |

**Location details:** please give full details of the main location where you work and NOT your home address.

|                                 |           |
|---------------------------------|-----------|
| Department/Ward                 | Type Here |
| Hospital/Clinic/Surgery address | Type Here |
| Post Code                       | Type Here |
| NHS Email address               | Type Here |
| Signature: Type Here            | Type Here |

**Please email the completed form to:**  
nbsw@wales.nhs.uk  
Alternatively, please post to: Newborn Bloodspot Screening Wales, Floor 4, Public Health Wales, Number 2 Capital Quarter, Tyndall Street, Cardiff CF10 4BZ.

**Please keep us informed about changes to your details by contacting us at:**  
nbsw@wales.nhs.uk

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## SCID Screening Evaluation in England – Implications for Wales

An evaluation of screening babies for severe combined immunodeficiency (SCID) is due to start in England on 6.9.2021 and will run for 2 years. The UK National Screening Committee (UKNSC) will then consider the evidence and make a recommendation as to whether SCID screening should be included in the NHS Newborn Blood Spot (NBS) Screening Programme in England.

The SCID evaluation will cover around two-thirds of the newborn population in England and the laboratories included are Birmingham, Great Ormond Street hospital (GOSH), Manchester, Newcastle, Sheffield and South East Thames.

**It is important to note that welsh babies who are screened in Wales will not be offered SCID screening as the Wales Newborn Screening Laboratory is not included in the evaluation.**

Babies affected by SCID have major abnormalities of the immune system which lead to significantly increased risks of infection and other complications that are life-threatening. These babies rarely survive beyond one year of age without treatment. Screening would help to identify and treat babies with SCID early.

There are implications for the areas not screening for SCID in England and for babies moving in and out of Wales. BCG vaccinations cannot be given to babies with SCID as it can be fatal. It must therefore be ensured that for Welsh babies it is known whether or not they have been screened for SCID in England and that if so the result is known and confirmed as 'SCID not suspected' before a BCG vaccination is given in Wales.

New guidance has been issued to the BCG Immunisation Teams in Wales and this includes how to access the results for Welsh babies screened in England. All SCID screening results enquiries should be made to the [Welsh NBS failsafe teams](#) who will be able to make checks on the English NBS IT system. The NBSW programme coordinators can be contacted if there are any queries about the SCID evaluation or about babies who have had screening in England.





## New screening letter for babies moving into Wales

A new letter has been developed for parents of all babies who have moved into Wales and have been identified as eligible for newborn bloodspot screening. These babies are usually those who have moved into Wales from outside the UK.

The purpose of this 'Movement in – eligible for screening' letter is to inform parents that their baby is eligible for the screening at the earliest opportunity, and to let them know what to do if they would like their baby screened. It will be sent for eligible, movement in babies who are identified on the Newborn Bloodspot Screening Wales System (NBSWS) on or after **2.8.2021**.

When babies who have moved into Wales are identified as being eligible the failsafe team contacts the health visitor and confirms the need to offer the screening. Delays in the offer of screening sometimes occur if a health visitor has not yet been allocated or there are difficulties contacting the family. The new letter will enable parents to be aware of the screening at the earliest opportunity.

The 'not screened' letter sent out to parents of eligible 'movement in' babies if attempts by the health visitor to offer/arrange screening have been unsuccessful, will continue. This letter confirms to the parents that their baby has not been screened and lets them know what to do if they would like their baby screened.

