



Newborn Bloodspot Screening Wales

Sgrinio Smotyn Gwaed Newydd-anedig Cymru

Issue no.17 : March 2018

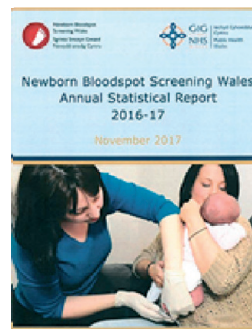
Welcome to the seventeenth edition of the Newborn Bloodspot Screening Wales (NBSW) bulletin from the Screening Division of Public Health Wales. This bulletin will provide information and updates on the Newborn Bloodspot Screening Wales Programme.

First Newborn Bloodspot Screening Wales Annual Report shows more than 99% uptake

The first annual statistical report from Newborn Bloodspot Screening Wales (NBSW) was published in November 2017. It showed that 99.6 per cent of newborn babies in Wales were tested for a number of serious but rare conditions in 2016/17.

The screening programme, managed by the Screening Division of Public Health Wales, offers eligible babies a test for the following conditions as recommended by the UK National Screening Committee:

- Congenital hypothyroidism (CHT)
- Cystic fibrosis (CF)
- Inherited metabolic disorders:
 - Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
 - Phenylketonuria (PKU)
 - Maple syrup urine disease (MSUD)
 - Isovaleric acidaemia (IVA)
 - Glutaric aciduria type I (GAI)
 - Homocystinuria (HCU)
- Sickle cell disorders (SCD)



In the period covered by this report, 1 April 2016 to 31 March 2017, 33,505 babies were tested. The programme identified 39 babies with serious conditions.

Headline Statistics

April 2016 to March 2017

- The number of eligible births across Wales was 33,627
- The number of these babies tested was 33,505 (99.6%)

Completeness of offer and coverage (eligible newborns)

- Completeness of offer – 97.3% of babies had a bloodspot card (for screening or decline) received in the laboratory by day 14 of life (*standard 95%*)
- Coverage – 94% of babies had conclusive bloodspot screening results by day 17 of life (*standard 95%*)

Timeliness of sample collection

- Timely collection of sample (day 5-8 of life) – 98.0% (*standard 95%*)
- Timely collection of sample (day 5 of life) – 75.3% (*standard 90%*)

The programme is working with the health boards to improve timeliness of sample collection.

Avoidable repeat rate

- Avoidable repeat rate – 5.5% (*standard ≤ 2%*)

Improving performance in collecting good quality samples remains a high priority for the programme to avoid delays in the referral of babies.

NHS number on bloodspot card

- 99.1% of bloodspot cards received in the laboratory had a valid NHS number for the baby recorded (*standard 100%*)

Timely receipt of card in laboratory

- 95.6% of bloodspot cards were received within 4 working days of sample collection (*standard 99%*)

A copy of the report can be downloaded from: <http://www.wales.nhs.uk/sitesplus/888/news/46847>
<http://www.wales.nhs.uk/sitesplus/888/newyddion/46848>

NBSW holds its second Annual General Meeting

The second Annual General Meeting (AGM) for the Newborn Bloodspot Screening Wales Programme was held in November 2017 in Cardiff. The focus of the day was around the first Annual Report and the performance of the programme in the year 2016/2017. Presentations were given looking at performance and aspects of the programme from the failsafe, programme, laboratory and governance leads perspectives.

There were also sessions covering the screening pathways and timelines for screen positive babies from both the laboratory and clinician perspectives, and these included the discussion of case histories. The importance of sample quality and timely sample collection and receipt were highlighted.

Two films were shown. In the first, a mother talked about newborn bloodspot screening from her perspective following the referral of her baby to clinical care after a screen positive result. This was positively received and the programme aims to develop more 'parent stories' to obtain service users perspectives and feedback. The second film has been developed for sample takers to show the processing of samples in the laboratory and why a good quality sample is important.



This was a positive day which was well attended by our clinician, midwifery, health visiting and neonatal colleagues, and by other health professionals involved in newborn bloodspot screening. There were productive discussions which raised good points and ideas to consider for service improvement. We would like to thank everyone who attended for their valuable contribution.

Redesigned bloodspot screening card is now available

The bloodspot screening card for use in Wales has been redesigned. The changes have been made to include additional information now required, and to allow more room to record some of the demographics.

The expiry date is now printed in red on the front of the card to make it more visible to sample takers.



The expiry date must be checked before a sample is taken because the laboratory will request a repeat sample if the card is out of date.

Other changes include the addition of information fields for the GP telephone number, alternative surname for the baby and type of transfusion. To improve legibility of sample taker name, there is now an instruction to print this.

'Parent telephone number' has now been replaced with 'parent contact number'. This is to encourage staff to ask for a current contact number (mobile preferably) to enable the timely referral of babies into clinical care.

The new redesigned cards will be sent out to the health boards when they are next due to be distributed in April. Stocks of the existing bloodspot cards should be used first, before using the new cards.

Please contact us via NBSW@wales.nhs.uk if you have any queries about your supply of bloodspot cards.

New presentation developed for Health Visitors

A PowerPoint presentation has been developed specifically for health visitors and their teams. It covers the conditions screened for, gaining informed consent including the decline process, and arranging sample collection. It also includes the different aspects of newborn bloodspot screening that are specifically relevant to health visitors.

This new presentation can be accessed via the NBSW website:

<http://www.newbornbloodspotscreening.wales.nhs.uk/training-and-education-presentations>

The presentations 'How to take a good quality sample' and 'Laboratory requests for further newborn bloodspot screening samples' are recommended for health visitors and other staff in their teams who take samples. These presentations can be accessed via the NBSW website: [Newborn Bloodspot Screening Training Presentations](#)

There are also plans to develop a newborn bloodspot screening presentation specifically for neonatal unit staff.

New film produced for sample takers

NBSW has produced a short film for sample takers. The film 'Good quality newborn bloodspot screening samples – understanding laboratory requirements and processes' is to be launched later this month and will be available on the NBSW website.

<http://www.newbornbloodspotsscreening.wales.nhs.uk/training-film>
<http://www.newbornbloodspotsscreening.wales.nhs.uk/ffilm-hyfforddi>

This new 10 minute film shows the processes involved in the testing of newborn bloodspot screening samples once they have been received in the Wales Newborn Screening Laboratory. It highlights why good quality samples are important, and provides examples of poor quality samples and the reasons why they are unsuitable for testing.

NBSW is also developing a film for sample takers in neonatal units. It will look at aspects of newborn bloodspot screening for babies who are being cared for in neonatal units, and the additional requirements needed for screening these babies.

Easy read leaflet has been launched

An easy read version of the newborn bloodspot screening information for parents leaflet was launched at the NBSW Annual General Meeting in November. This leaflet has been developed for people who have a learning disability or who do not have Welsh/English as their first language.

A copy of the leaflet can be downloaded from the NBSW website:

[Easy Read leaflet](#)
[Taflen Hawdd ei Ddarllen](#)

Laminated versions of the easy read leaflet have been sent out to the health boards for use in the postnatal wards and neonatal units.



Secondment opportunity for Governance Leads



The Maternal and Child screening programmes have been pleased to offer a funded secondment as a development opportunity for the governance leads. Secondtees will work for two weeks with the Programme Co-ordinators on an education project and learn more about the day to day working of the screening programmes.

To date, two governance leads have taken up this opportunity and have worked with the Antenatal Screening Wales Co-ordinators. There was positive feedback following their experience, and the programmes would like to thank them for their contribution and hard work during the secondment.

Sample quality

The aim of newborn bloodspot screening is to enable early referral of babies for diagnostic tests and treatment. To achieve this, good quality samples need to be taken at the right time and sent to the laboratory with out delay.

NBSW is continuing to work with health boards to improve performance by education and training of sample takers. Training sessions specifically focusing on sample quality are being rolled out by NBSW across Wales, and monthly sample quality feedback to governance leads and Heads of Midwifery continues.

Maternal and Child screening programmes welcomes two new team members

Jemma Muggeridge and Rebecca Jones have joined the Maternal and Child screening programmes in administrative support roles.

Jemma and Rebecca will be pleased to help with any enquiries about parent information leaflets, bloodspot cards or envelopes and can be contacted via nbsw@wales.nhs.uk.



Contact numbers for the Newborn Screening Administration Failsafe Teams

South East Wales Cardiff and Vale, Cwm Taf and Aneurin Bevan University Health Boards:
Tel – 029 2074 3568

Mid and West Wales Abertawe Bro Morgannwg and Hywel Dda University Health Boards
and Powys Teaching Health Board: Tel – 01656 754085

North Wales Betsi Cadwaladr University Health Board: Tel – 01978 727005

Contact numbers for the Wales Newborn Screening Laboratory

Health professionals should use the following telephone numbers to contact the laboratory:

1. To check that a sample has been received, or for any queries about demographic information on a bloodspot card:

Telephone – 029 2074 4032

Laboratory Fax number – 029 2074 4065

2. For all clinical enquiries (including interpretation of screening results) or enquiries about the quality of a bloodspot sample please contact:

Dr Stuart Moat (Consultant Clinical Biochemist), Director of Wales Newborn Screening Laboratory:

Telephone – 029 2074 3562

Email: stuart.moat@wales.nhs.uk

Contact numbers for the NBSW Programme

The address and telephone numbers for the NBSW Head of Programme, Co-ordinators and Administration Support Team are:

Ruth Lawler, Head of Maternal and Child Screening: Telephone – 029 2010 4432

Email: ruth.lawler@wales.nhs.uk

Catherine Boyce, NBSW Programme Co-ordinator: Telephone 029 2010 4399

Email: catherine.boyce2@wales.nhs.uk

Chris Bovington, NBSW Programme Co-ordinator: Telephone 029 2010 4401

Email: Christine.bovington@wales.nhs.uk

Administration Support Team: Telephone 029 2010 4427

Email: nbsw@wales.nhs.uk Address: Newborn Bloodspot Screening Wales, Floor 4, Number 2
Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ

Contact Us: If you have any queries or questions about the Newborn Bloodspot Screening Wales programme, or would like to be added to our circulation list, please contact us at nbsw@wales.nhs.uk



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