



# Newborn Bloodspot Screening Wales

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

February 2020

Issue 19

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

*It was a busy year for newborn bloodspot screening in Wales during 2019. There was a huge drive to improve the quality of bloodspot samples as a good quality sample is essential to allow early identification and referral of babies with a suspected condition. A huge thank you to all of you that have worked hard on improving the quality of samples.*

*A new, more robust, process for reporting results to parents started in February 2019. Newborn bloodspot screening results for babies living in Wales are now sent directly to parents by letter, together with a leaflet explaining the results. This means that parents now receive the results earlier. For babies who have a suspected result for any of the conditions, they will receive their results letter via the health visitor who will have been contacted by the programme. These babies would have already been seen by a clinician before the health visitor is contacted.*

*A key priority for 2020 is to sustain the sample quality improvement accomplished in the health boards during 2019 and to meet the avoidable repeat standard of  $\leq 2$  percent. Performance reports for individual sample takers are being developed and these will be available in February.*

## Included in this issue

- ✓ Sample Quality
- ✓ Annual Report/Conference
- ✓ Sample Takers
- ✓ Programme Handbook
- ✓ Parent Information



**Contact Us:** We hope you find this newsletter useful. If you have any queries or questions about the NBSW programme, 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.

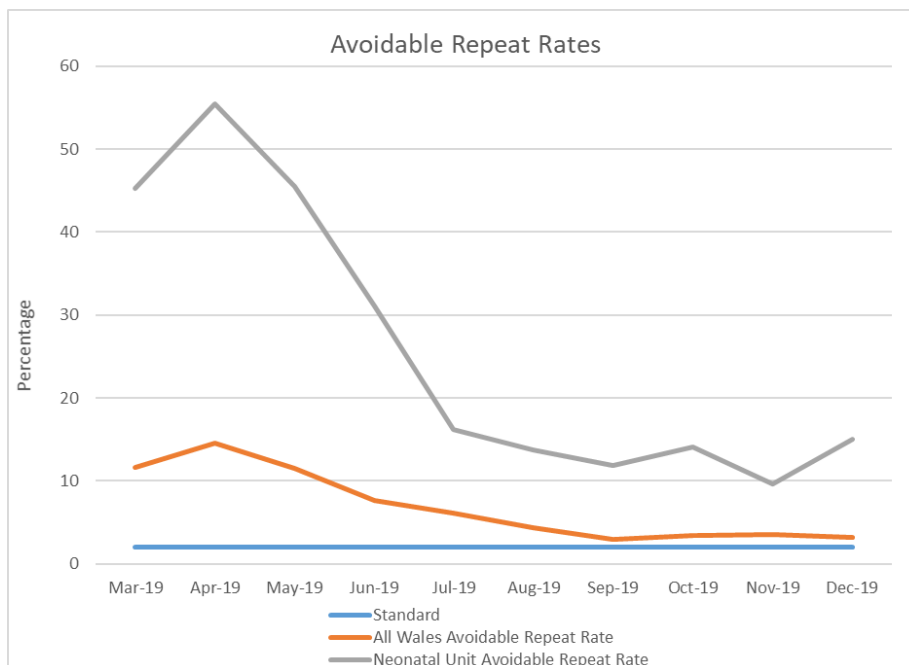


## Sample quality has significantly improved

We are pleased to announce that sample quality in Wales has significantly improved and the avoidable repeat standard has been met in five health boards. A task and finish group was set up by the programme in January 2019 with the aim of improving sample quality and sustaining the improvements already made. Membership includes representation from Maternity and Health Visiting, the Neonatal Network, Screening, Informatics and Improvement Cymru (formerly 1000 Lives).

Action has been taken in all the health boards to improve sample quality and a range of initiatives have been introduced including several pilots. The Quality Improvement Project undertaken in Betsi Cadwaladr University Health Board (BCUHB) led by Jan Quarmby, Improvement Midwife, has led to a significant improvement in sample quality and to the avoidable repeat rate standard being met for four consecutive months. This is the first time this has been achieved in any health board since the programme began in April 2014.

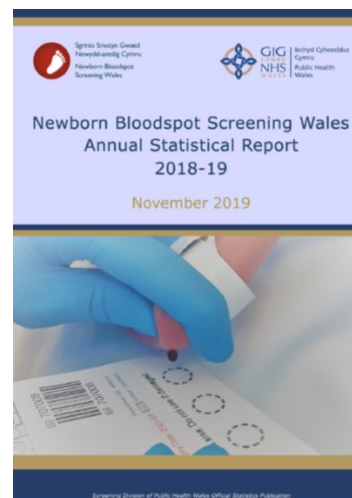
### This chart demonstrates the huge improvement across Wales



There is still work to do but with further training, education and collaboration with health boards the programme is confident that the standard will be met across Wales.



**The NBSW Annual Statistical Report for 2018-2019 was published in November 2019.** A copy of the report can be downloaded from the [NBSW website](#).



## NBSW holds its Fourth Annual Conference

Sgrinio Smotyn Gwaed Newydd-anedig Cymru  
Bedwaredd Gynhadledd Flynyddol  
Blwyddyn ym mywyd Sgrinio Smotyn Gwaed Newydd-anedig Cymru

Newborn Bloodspot Screening Wales  
4<sup>th</sup> Annual Conference  
A Year in the Life of Newborn Bloodspot Screening Wales

Ruth Lawler, Pennaeth Sgrinio Mamau a Phlant/  
Head of Maternal and Child Screening  
26 Tachwedd/November 2019



The NBSW Annual Conference was held in November 2019 in Cardiff. This was a positive day which was well attended by our clinician, midwifery, health visiting, neonatal colleagues, and by other health professionals involved in newborn bloodspot screening.

The focus of the day was the performance of the programme in the year 2018/2019 and the journey of the baby and parents from screening

through to diagnosis of cystic fibrosis (CF). There was an emphasis on the importance of good quality samples and the work that has been undertaken across Wales to improve sample quality.

A session on CF took us through the journey from the initial CF suspected newborn bloodspot screening result to the diagnostic result and the follow on care by the CF team in Cardiff. We heard from a clinician, CF specialist nurse, and health visitor. The session included a powerful, emotional and positive family story from a father whose son was diagnosed with CF. This session was very well received, and we would like to thank the father and his family once again for sharing their story.

There were productive discussions during the day which raised good points and ideas to consider for service improvement. We would like to thank everyone who attended for their valuable contribution.

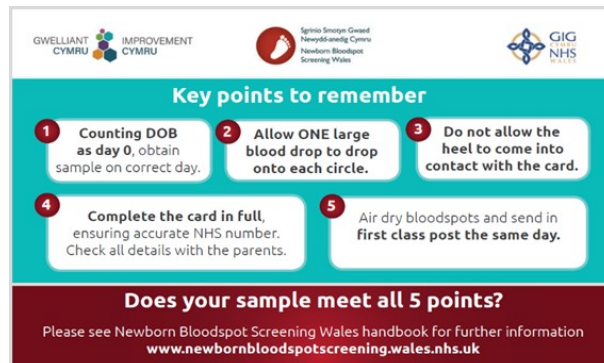




## New data card for sample takers

A new data card for sample takers has been produced with collaboration between NBSW and Improvement Cymru. The purpose of this data card is to act as an aide memoire to ensure that a good quality sample is taken. It is credit card sized and will fit into an ID badge holder which will make it handy for double checking bloodspot samples before posting.

To obtain your card please contact the Newborn and Antenatal Screening Governance Lead in your health board.



## Sample takers soon to receive their own performance reports

Registered sample takers in Wales will be able to access their own NBS performance reports later this month. These reports, generated every three months, will show the number of samples they have taken each month, the number of avoidable repeats and a breakdown of the reasons for any repeat samples. Individual reports, when provided in other screening programmes, are positively received by sample takers.

Reports will be accessible via the NBSW website by entering the sample taker ID code (NMC number or ID number issued by NBSW for those without an NMC number). A password is also required to access the reports and this can be obtained from the governance lead or by contacting the NBSW programme. Further instructions will be sent out to sample takers before the start date. Sample takers will need to be registered on the NBSW sample taker database and ensure that their name and sample taker ID code are legibly recorded on the bloodspot card. The use of stamps to record the sample taker name and ID are used by some staff and this is welcomed by the laboratory.

New monthly performance reports for the governance leads and Heads of Midwifery are also planned. Instead of reporting on the avoidable repeat samples only, these new reports will also include the total number of samples taken by the sample takers in the health board.

**To register as a sample taker, please complete the [NBSW sample taker registration form](#) and return it to us via [nbsw@wales.nhs.uk](mailto:nbsw@wales.nhs.uk) or send it to us at: Newborn Bloodspot Screening Wales, Floor 4, Number 2 Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ.**

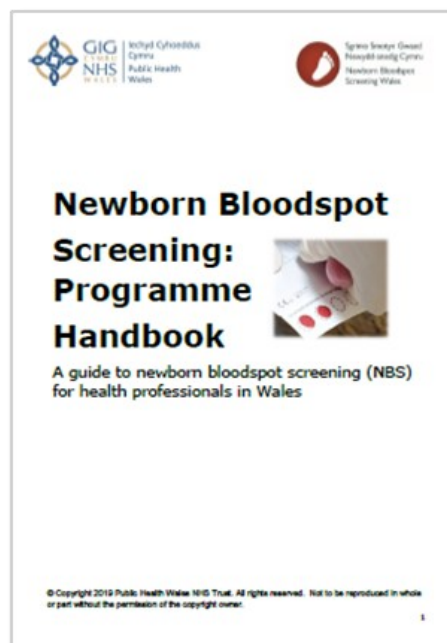
**If you have any questions about registration please contact us.**



## Programme Handbook Updated

The [Newborn Bloodspot Screening Wales Programme Handbook](#) has been updated (December 2019) to include information about new formats of the parent information leaflet and changes to the contact details for the NBS Administration Failsafe Teams. A full list of the changes can be found on page 3 of the [handbook](#).

It is recommended that all sample takers access the handbook which includes the NBS guidelines and guidance for taking good quality bloodspot samples. It is accessible via the [NBSW website](#) and contains links to allow easier access to further information. Guidance for accessing information in the handbook can be found on the second page.



## Update to NBS Administration failsafe team contact details

Following the restructuring in Swansea Bay and Cwm Taf Morgannwg University Health Boards, the contact details for the regional NBS administration failsafe teams have been updated. The telephone number for the Mid and West Wales Team has changed and the team boundaries have been clarified.

The teams can be contacted (office hours Monday - Friday) by health professionals who have queries about the follow up of babies identified by the Newborn Bloodspot Screening Wales System (NBSWS) failsafe. They can also be contacted to request the NHS number for a baby if it is not available prior to taking the sample.

The updated contact details can be found in the [NBS Programme Handbook](#) together with the contact information for the Wales Newborn Screening Laboratory and NBSW Programme.






## New formats of the parent information leaflet now available

The information for parents leaflet is now available in British Sign Language (BSL) and Audio versions.

Parents can find this [Accessible Information](#) on the [NBSW website](#). The easy read version of the parent leaflet can also be found on the [Accessible Information](#) page.

Please could you share this information with your colleagues so that parents who would benefit from the Accessible Information can be made aware of it and how it can be accessed.

Please let us know if you have any queries.

Accessible Information	
This leaflet explains the conditions screened for and how the sample is taken.	
<b>Bloodspot tests</b> An easy guide to screening tests for your new baby 	<b>Information for parents leaflet - Easy Read format</b> The information for parents leaflet is available in an easy read format
	<b>Information for Parents leaflet - British Sign Language (BSL) format</b> The information for parents leaflet is available in BSL format.
	<b>Information for Parents leaflet - Audio format</b> The information for parents leaflet is available in audio format.

## New version of parent information leaflet available from April 2020



The newborn bloodspot screening information for parents leaflet has been updated and this new version 8 will be sent out to health boards from April this year.

The main changes are the inclusion of information about the other formats of the leaflet which are Easy Read, British Sign Language (BSL), audio, Braille and large print.

We are pleased to include lovely new pictures of babies in the leaflet and would like to thank the parents for giving us permission to do this.