Public Health England

Protecting and improving the nation's health

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Guidance for reporting newborn blood spot screen positive results from laboratories to Child Health Information Service (CHIS) and Newborn Blood Spot Failsafe Solution (NBSFS)

1. Introduction

Reporting newborn screen positive results from the laboratory to CHIS varies across the country. Some laboratories release a positive result to CHIS without confirmation that the clinical team has contacted the family, others do not.

Unfortunately, there have been incidents where a health visitor has informed a family of a positive result before the clinical team had contacted the family. With the introduction of the dPCHR (digital Personal Child Health Record), there is also the potential for a positive result to be conveyed to parents before contact with the clinical team.

To avoid this, some laboratories already wait for confirmation from the relevant clinical team that the parents have been contacted before a positive results is released to CHIS.

The Newborn Blood Spot (NBS) Screening Programme convened a working group in June 2020, including representatives from Birmingham, Sheffield, Viapath, Manchester and GOSH (Great Ormond Street Hospital) laboratories and the Sickle Cell and Thalassaemia (SCT) Screening Programme, to discuss the options for a uniform policy and provide guidance.

2. Guidance for reporting newborn screen positive results from laboratory to CHIS/CHRD

Laboratories should notify the relevant clinical team of a positive result. The expectation would be that the clinical team would inform the laboratory when the parent has been contacted. Only when the laboratory has confirmed that this has been achieved should laboratories release a positive result to CHIS and NBSFS. **This guidance applies to all screen positive results including CF carrier status but does not apply to sickle cell carrier results.**

This will help ensure that:

i. Any questions the family has will be answered adequately at the time the result is communicated, thus reducing anxiety for the family
ii. The family have been contacted by the clinical team before receiving the result via a letter or electronically (dPCHR)
iii. The risk of families receiving positive results from a health visitor, before being contacted by the clinical team, is reduced
iv. There is a consistent approach across all newborn screening laboratories when reporting screen positive results

With effect from Tuesday 1st June 2021, laboratories must, as a minimum, seek to ensure that the family has been contacted before releasing a positive screening result (including CF carriers) to CHIS and NBSFS.

If, in rare instances, the clinical team do not respond with confirmation, the laboratory should document two attempts over the period of two weeks to gain a response and then release the results to CHIS and NBSFS without further delay.

The Programme will review this guidance in six months.

The programme is aware that the above guidance does not close the reporting pathway as 'contact' does not mean that the baby has been seen but it does provide a minimum workable standard and takes the view that knowing that the clinical team has contacted the family is sufficient to release the positive result to CHIS and NBSFS.

The clinical team continues to be responsible for informing the screening laboratory when the newborn has been seen in clinic and the diagnostic outcome. The Programme will raise this with the Clinical Chairs of all condition specific Screening Advisory Boards to see how communication can be improved between the clinical teams and the laboratories.

3. Informing maternity, health visitors and GPs of a positive result

Some laboratories inform maternity, health visitors and GPs of positive results. To keep in line with the above guidance, laboratories are requested to **only release a positive release** to other appropriate health care professionals after confirmation from the relevant clinical team that the family has been contacted.

4. Releasing results on a condition by condition basis

In light of the Severe Combined Immunodeficiency (SCID) evaluation and the BCG vaccination pathway, all laboratories are permitted to release results on a condition by condition basis. All laboratories must release SCID results (including 0911-not offered) by 21 days of age to facilitate timely offer and uptake of the BCG vaccination.

5. Sickle cell carrier results

Whilst the NBS Screening Programme is aware of variation in sickle carrier result reporting, at this stage laboratories are not required to make any changes to their current processes. The Sickle Cell and Thalassaemia (SCT) Screening Programme will provide guidance, once the carrier reporting pathway has been reviewed and service user needs identified.