

Date: August 20, 2025

To: All newborn bloodspot screening (NBS) submitters (hospitals, clinics, community birth providers)

From: Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program

Subject: Request for changes to a baby's NBS result report

The NWRNBS program's identification of babies at high risk for a condition on the panel depends on the sample quality and the accuracy of the demographic information submitted on the specimen collection card. The NWRNBS program promotes submitter accuracy through education material on proper collection practices and guidelines on how to submit demographic information; completely, accurately, and legibly. (www.bitly.com/nbs-resource)

While we all strive for accuracy, at times the demographic information provided on the specimen collection card may not be correct or available at the time of collection. Likewise, data entry errors may occur, which are then transferred onto the patient's result report.

This letter outlines the permitted changes to NBS result reports, the instructions for requesting changes, and the expected timelines for the program to make the changes.

What changes to the baby's NBS report are permitted?

- Any discrepancy between the specimen collection card and the baby's NBS result report will be corrected promptly. These typographical errors result from the data entry process within the Oregon State Public Health Laboratory.
- Any inaccuracies in key data fields that impact test results will be corrected promptly. These errors typically result from inaccuracies in the health records of the baby at the time of collection or incorrect information on the specimen collection card.
 - Key Data Fields include:
 - Baby's date of birth
 - Baby's time of birth
 - Baby's birth weight
 - Date of specimen collection
 - Time of specimen collection
- If a parent or legal guardian of the baby requests a change to the NBS result report, the program will process the request in accordance with HIPAA. To amend the records, the requestor needs to attest to the NWRNBS that they have accepted a parent or legal guardian's amendment request under 45 CFR 164.256. A signature attesting the parent's request is required on the change request form.

What changes to the baby's NBS result report are **not** permitted?

- Baby's name: At the time of newborn bloodspot collection 24-48 hours after birth, the baby may not have received a name and facilities where the specimen is collected may have procedures to use the birth parent's name (in place of baby's name) or another alias (i.e. Baby boy / Baby girl).
 - Due to requirements for positive patient identification in laboratory testing (CLIA and Joint Commission), name changes are generally not permitted when the demographic information on the specimen collection card matches the result report.
 - The NWRNBS program recommends that submitters use identifiers other than the baby's name, such as the medical record number (MRN) and the date of birth when matching the NBS result report to the submitter's electronic health record for the baby.
- Any changes to the baby's NBS result report that calls into question the identity of the baby will generally not be permitted unless required by law. If the link between the baby and the collected specimen can no longer be confirmed, the testing will be canceled, and the report will be recalled.

How do I request a change to a baby's NBS report?

- Please fill out the change request form.
- Fax (503-693-5601) or email (NWRegional.NBS@odhsoha.oregon.gov) the form, along with a copy of the NBS result report for which changes are being requested, to the NWRNBS program.

How long will it take for a change to a NBS report to be available?

- The NWRNBS program prioritizes changes that directly impact the baby's test results.
- For corrections that do not impact the test results, it may take up to 30 days for the amended reports to be available in Secure Remote Viewer (SRV). We recommend checking SRV every two weeks for the updated record.