Genomics and Newborn Screening is inclusive of the Early Hearing Detection and Intervention program and Indiana Birth Defects and Problems Registry.
This binder serves as a reference guide for those involved with Indiana’s State Mandated Genomics and Newborn Screening and its best practices, procedures, and follow-up. Introduction and references to the Indiana Birth Defects and Problems Registry are also included within its content.
### Narrative of Contents

**Acronyms**

**Genomics and Newborn Screening Program**

**Indiana’s Newborn Screening Law (16-41-17)**
- What is it?
- How much does it cost?

**Indiana’s Birth Defects and Problems Registry Law (IC 16-38-4)**
- What is it?
- Reports and Chart Audits

**Best Practices (410 IAC 3-3-6 Sec. 6)**
- NBS Log
- 3 Screens
- Dialogue

**Newborn Screening Lab Information**
- NBS Lab Process
- NOW Courier Information

**GNBS Results and Follow-up**
- Requesting GNBS Results
- INSTEP

**Monthly Summary Reports**
- MSR 101
- Exceptions
- Tips for Avoiding Error

**Newborn Screening**
- Religious Waiver for NBS (IC-41-17-2)
- Hearing Screen
- Pulse Oximetry Screen
- Heelstick Screen

**Birthing Facility Report Cards**
- Quality Improvement Initiative 2017
- Quality Indicators
- Summary and Report Card Example

### Appendices

**Genomics and Newborn Screening**
- Newborn Screening Law
- Indiana Administrative Code Article 3
- GNBS 49 Conditions List (en español)

**Indiana Birth Defects and Problems Registry**
- IBDPR Law
- Indiana Administrative Code Article 21
- Birth Defects Descriptions
- IBDPR Reportable Conditions List (en español)
- Physician Birth Defect Reporting System Form

**State Forms**
- Indiana Religious Refusal Waiver
- Storage Request of Dried Blood Spot
- Destruction Request of Dried Blood Spot
- Request for Newborn Screening Results
- Health information Access Request

**State Forms (en español)**
- GNBS Technique References and Protocols
- Hearing, Pulse Ox and Heelstick Reference Sheets
- Presumptive/Abnormal Heelstick Results
- Invalid Heelstick Results
- Special Cases for Pulse Oximetry and Heelstick

**Early Hearing Detection and Intervention Policy Manual**

**Current ISDH GNBS Grantees (TBD)**

**Maintaining a Centralized Program Form**

**GNBS Contacts**
ACRONYMS

CCHD – Critical Congenital Heart Disease
CHIP – Child Health Information Profile
DBS – Dried Blood Spot
EHDI – Early Hearing Detection and Intervention
FAQ – Frequently Asked Questions
GBYS – Guide by Your Side
GNBS – Genomics and Newborn Screening
IBDPR – Indiana Birth Defects and Problems Registry
IN – Indiana
INSTEP – Indiana Newborn Screening Tracking and Education Program
ISDH – Indiana State Department of Health
MCH – Maternal and Child Health
MCP – Maintaining a Centralized Program
MSR – Monthly Summary Report
PID – Patient Identification
PCP – Primary Care Provider
QI – Quality Indicator
RR – Religious Refusal
RUSP – Recommended Universal Screening Panel
SACHDNC – Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children
UNHS – Universal Newborn Hearing Screen
Genomics and Newborn Screening Program

Genomic medicine in neonatology, through newborn screening, allows for the rapid identification of various genetic structural deviations which result in disease that would otherwise go undetected until symptom onset. In today’s advancing medical science, detection of disease through genome sequencing is becoming more prevalent. Allowing, not only, for the identification of disease but also providing more effective treatments and in some cases, a cure.

What is Genomics?

Genomics is the medical practice of using an organism’s DNA to understand its physiological processes. This practice applies to all living organisms allowing for a comprehensive knowledge of how organisms interact and impact each other. In medical science, genomic medicine is considered a subset of precision medicine using a person’s genetic coding to identify diseases impacting healthy human physiology. Genomics is applicable to every medical field, however, there are a few well-known and widely utilized genomic practices in today’s medical fields including oncology, pathology, infectious disease, and pediatrics.

Identifying disease using genomic practices can be done a number of ways including whole genome sequencing, whole exome sequencing, or targeted gene sequencing. Whole genome sequencing is a scan of the full set of DNA’s base pairs (adenine, thymine, cytosine, and guanine or ATCG) for structural deviations where whole exome sequencing is a scan of only protein-coding RNA. Exome sequencing is a less broad view than genome sequencing, allowing for faster identification of diseases with known biomarkers. However, a targeted gene sequencing approach is most efficient and affordable for diseases with well-established locations for genetic mutations or deletions.

What is the difference between Genomics and Genetics?

Genomics focuses on physiological processes dictated by genetic coding. Genomics is a broader view of how genes interact and then how to use that interaction to identify and treat disease. Genetics is more narrowly focused on the coding process and DNA/RNA structure building. The differences are slight, but in short, genomics is a field of study and medical practice that uses genetics to understand physiology, health, and disease.
Indiana’s Newborn Screening Law (16-41-17)*

*Copy found in Appendix 1

What is it?

Newborn Screening is a set of three (3) tests that aims to detect health conditions in babies that would otherwise go undetected until the baby becomes symptomatic. This is important, as a newborn may look healthy, but can have a serious health condition, because if left undetected and untreated, these conditions result in severe developmental delays and fatalities. When caught early, the treatments for these conditions can lead to a stronger, healthier development and a longer life.

Indiana’s Newborn Screening law requires every baby to be tested for 49 different conditions including endocrine disorders, cystic fibrosis, inborn errors of metabolism, hemoglobinopathies, congenital heart defects and hearing loss*. In order to rapidly detect these conditions for early intervention, the following three (3) tests must be completed before the baby leaves the hospital:

1. **Universal Newborn Hearing Screen (UNHS)** detects hearing loss. This can be completed as soon as 6 hours after birth.
2. **Pulse Oximetry** measures pulse rate and oxygen levels to determine heart and lung function. This can be completed between twenty-four (24) and forty-eight (48) hours after birth.
3. **Heelstick**, a blood test, is used to screen for genetic conditions that would otherwise go undetected. This must be performed before the baby is discharged from care, twenty-four (24) hours after birth.

How much does it cost?

The cost of an initial newborn screen is $100, as of 2018. These funds go to ensuring that there are community resources and medical care available for the children who test positive for these conditions. Some of the expenses that result from these conditions include special medical foods, prescription medications, laboratory testing, frequent physician visits and specialized therapies, and surgeries. So even when a baby’s tests come back as negative, the fee goes to help a family whose baby tested positive and now needs expensive medical treatments.

*Due to new rule promulgations this legislative session, there will be changes to certain rules and codes beginning July 1st, 2018. The new rule promulgations will be sent to each facility once in effect.*
NEWBORN SCREENING STAKEHOLDERS

Newborn Screening is a public health initiative aimed at identifying conditions that can affect a child’s long-term health or survival. Early detection, diagnosis, and intervention can prevent death or disability and enable children to reach their full potential.

Those who have a hand in ensuring that all babies born in IN receive a valid and timely screen and any follow-up necessary are very important to us here at ISDH. As of September 2017, Indiana has 90 birthing hospitals, and many birthing centers and midwiferies throughout the state. GNBS follow-up continues into the pediatricians’ offices, health departments, specialty groups, and more. It is important to recognize the work and maintenance that goes into ensuring all of IN newborns are well taken care of in regards to GNBS. Efforts are spread throughout the community and each of us has a crucial role to play in the early detection and intervention of these life threatening and life-altering diseases.

Our screeners, testers, reporters and follow-up teams include the following:

- Birthing Facility Managers
- Registered Nurses
- Unit Secretaries
- Laboratory Technicians
- Medical Records Staff
- Audiologists
- Nurse Practitioners
- Hospital Physicians
- Pediatricians
- Medical Assistants
- Specialists
- ISDH Grantees
- ISDH Vendors
- ISDH Staff
Indiana Birth Defects and Problems Registry Law (16-38-4)

Copy found in Appendix 2

What is it?

The Indiana Birth Defects and Problems Registry (IBDPR) is a population based surveillance system that seeks to promote fetal, infant, and child health. The purpose behind the IBDPR is to prevent childhood development disabilities, enhance the quality of life of affected children and their families, and reduce infant mortality. After conditions are diagnosed at birth, follow-up with referral to services and appropriate care can be provided to the children.

The Indiana Birth Defects and Problems Registry law allowed the Indiana State Department of Health to create the birth defects registry and gather relevant information for epidemiological and environmental studies as well as informing and providing resources to affected families.

How does the IBDPR receive reports?

The list of reportable conditions is mandated, and reports of confirmed cases are to be made to the IBDPR within sixty (60) days of diagnosis. Additionally, the IBDPR program has targeted conditions, which require a medical chart abstraction if reported through hospital discharge information. Targeted conditions can change based on the initiatives of the MCH programs and emerging public health threats. The IBDPR program receives reports through hospital discharge information, physician reporting, and newborn screening.

1. **Hospital reports** are received through specified file format in which IBDPR staff uploads into the IBDPR database. The IBDPR program hopes to implement data standards to reduce the burden on the reporting hospital staff.

2. **Physicians** are required to report to the IBDPR directly through the Physician Reporting Portal. This includes pediatricians, psychiatrists, psychologists, dentists, midwives, registered or licensed practical nurses, optometrists, podiatrists, chiropractors, physical therapists, local health departments, health maintenance organizations, and audiologists.

3. **Newborn screening reports**, such as failed pulse oximetry screens are reported to the IBDPR for follow-up purposes.

Information on how to register for the physician reporting portal, reportable condition list, and condition descriptions can be found in Appendix 2.
Why is the IBDPR important?

Birth defects are COMMON, COSTLY, AND CRITICAL.

- **1 in every 33** babies are born with a birth defect
- Birth defects cost over **$2.6 billion** in hospital costs each year
- **623 Hoosier infants died** before their first birthday in 2016, and **22%** of those deaths were due to congenital malformations

Current Public Health Initiatives Associated with Birth Defects

- Congenital Zika virus infection leading to microcephaly, brain abnormalities, neural tube defects and other early brain malformations, certain eye abnormalities, and consequences of central nervous system dysfunction such as arthrogryposis, clubfoot, congenital hip dislocation, congenital hearing loss.
- Critical Congenital Heart Disease (CCHD) includes 12 heart conditions; 7 of which the pulse oximetry screening may be able to detect.
- Neonatal Abstinence Syndrome (NAS) in relation to the opioid epidemic Indiana is currently facing.

IBDPR Chart Audit Process and Contacts

Medical chart reviews are required for select targeted conditions. Medical chart reviews take place either at the hospital or remotely. With advancements in technology, many hospitals and health networks have allowed Chart Auditors remote access to their EMR.

For more information on medical chart reviews or remote access to your facility’s EMR please contact the IBDPR Program at IBDPR@isdh.IN.gov
IBDPR STAKEHOLDERS

Birth defect surveillance is the first step in preventing birth defects by identifying and collecting information. The information collected through birth defects surveillance systems is used to understand the following:

- Prevalence rates
- Causes and risk factors for birth defects
- Education to the community
- Implement prevention strategies
- Referrals to service

Birthing facilities are the first contact for a baby born with a birth defect. As of September 2017, IN has 90 birthing hospitals, and many birthing centers and midwiferies throughout the state. GNBS Follow-Up continues into the pediatrician’s offices, health departments, specialty groups, and more. It is important to recognize the work and maintenance that goes into ensuring all of IN newborns are well taken care of in regards to GNBS. Efforts are spread throughout the community and each of us has a crucial role to play in the early detection and intervention of birth defects.

Key stakeholders in the birth defect surveillance include the following:

- Birthing Facility Managers
- Registered Nurses
- Unit Secretaries
- Laboratory Technicians
- Medical Records Staff
- Audiologists
- Nurse Practitioners
- Hospital Physicians
- Pediatricians
- Medical Assistants
- Specialists
- ISDH Grantees
- ISDH Vendors
- ISDH Staff
BEST PRACTICE (410 IAC 3-3-6 Sec. 6.)

NBS Log

Each hospital or birthing center, and midwife or physician should maintain a log that documents the following information for all infants born, transferred in, or screened at the facility:

- Name of newborn or infant
- Attending physician or midwife *(Follow-Up PCP is recommended)*
- Medical record number
- Form number of sample sent
- Date sample collected
- Date sample sent
- Date results received
- What the results were (hearing screen, pulse oximetry, heelstick)
- Name of person notified of positive results and date and time of notification

The *NBS Log* should be reviewed daily to ensure that they are in compliance and that results are recorded within fourteen days – if results are not received within fourteen days, the laboratory must be contacted by telephone. If a baby has been discharged prior to receiving mandated tests, the responsible health care provider and MCH/GNBS must be contacted immediately by telephone and written notification to inform them that a specimen must be taken within three days. MCH/GNBS must be contacted within three days if the responsible health care provider cannot be contacted. MCH/GNBS will then contact the local health officer who will ensure that the specimen is taken. If the health care provider is notified by the laboratory that a specimen is inadequate, they must obtain a repeat specimen within forty-eight hours.

If they are not able to repeat the specimen within forty-eight hours, the GNBS team must be contacted immediately by telephone 888.815.0006 so they can try to follow up on all babies that have been reported as not having received a completed screening. This includes those discharged without NBS. Reporting these cases by phone does not take place of reporting within the MSRs.
**Hearing Screening**
A maximum of two inpatient hearing screens can be performed as early as 6 hours after birth and preferably before discharge. The Early Hearing Detection and Intervention (EHDI) program aims to screen by 1 month, have confirmatory evaluation by 3 months to identify hearing loss, and act on early intervention by 6 months.

When the hearing screen is not done prior to the DBS being sent to the lab, the pink carbon copy titled “Hearing Screen” should be submitted to the lab with the next set of NBS Cards to be picked up by the courier.

*For further information and best practices, please refer to the EHDI Policy Manual in Appendix 6*

**Pulse Oximetry Screening**
The pulse oximetry test needs to be complete within the first 24 and 48 hours of life to avoid false positives and take advantage of early interventions prior to the ductus arteriosus closing. During the test, the baby should be awake, calm, and warm with one probe placed on the baby’s right hand and the other probe placed on one of the baby’s feet. The results along with the date and time are to be documented on the NBS card and your facility’s NBS log. In the case of a religious exemption for the heelstick, the pulse oximetry results date and time need to be documented on the religious waiver in order for ISDH to know a valid test has been administered and documented.

When the pulse oximetry is not completed prior to the DBS being sent to the lab, the pink carbon copy titled “Hearing Screen” should be submitted to the lab with the next set of NBS Cards to be picked up by the courier with the results legibly written in. If there was an echocardiogram in place of the pulse oximetry, ensure to document the results in your facilities NBS Log for follow-up purposes.

*A protocol flow chart (insert) is available for pulse oximetry tests as reference to best practices.*

**Heelstick Screening**
The heelstick screening is state mandated to take place twenty-four (24) hours after birth and not later than forty-eight (48) hours after birth. In the event of discharge or transfer before twenty-four (24) hours, it is recommended that a heelstick occur prior to those events. This protocol is also relevant for NICU and other special scenarios. Current rule recommends a six (6), fourteen (14) and thirty (30) day collection timeline and monthly thereafter until discharge or 3 months of age, whichever comes first. For special cases it is best practice to still achieve the heelstick by twenty-four (24) hours old rather than delay detection, intervention, and follow-up care.
An appropriate heelstick procedure should start with warming the proper site with a soft moistened cloth and cleansed with alcohol towelette. A valid specimen requires all circles filled with blood soaked through to the other side of the filter paper while avoiding excessive layers. Take caution not to touch or smear the specimen and allow it to dry for four (4) hours prior to submission to the courier service.

Once the DBS is processed at the NBS Lab, all GNBS results will then be faxed from the NBS Lab to the submitting facility to ensure that NBS logs can be updated and resolved, rescreens can be scheduled per the birthing facility, and follow-up with the listed PCP can be initiated.

All information is to be completed legibly on the NBS card then mailed to the NBS Lab and documented in your facility’s NBS Log according to IN Administrative Code.
BEST PRACTICE: DIALOGUE

Best practice includes educating parents about GNBS conducting the screens and communication with ISDH. Parents must be informed of the DBS consent (opt in/out) portion!

This section is intended to be suggested dialogue pieces to communicate with the family PRIOR to GNBS. This will explain the process and procedures involved with GNBS, dried blood spot collection and storage, epidemiological research options, and aftercare.

Suggested Statement from Staff to Family:

Newborn screening is required by the state of Indiana and aims to protect the health of your baby. As of July 2018, Indiana screens for 49 different health conditions in your baby. The state screens for these different health conditions through three newborn screening tests. These tests include heelstick, which is a blood test that detects 47 different genetic (heritable) diseases, pulse oximetry which measures oxygen levels and heart rate to evaluate heart and lung function, and a hearing screen to detect hearing loss.

Newborn screening is important to protecting the health of your baby. If these conditions are left untreated, they may result in adverse health outcomes impacting the mental and physical growth and development of your baby. This can reduce the quality of life for your baby and lead to lifestyle restrictions. This can also lead to an increase in the use and cost of medical care for your baby.

The fees collected to conduct newborn screening are used to support families by ensuring that there are community resources and medical care available for the children who test positive for these health conditions. These fees might help pay for expenses that result from conditions including: special medical foods; prescription medications; laboratory testing; frequent physician visits; specialized therapies; and surgeries.

If newborn screening conflicts with your family’s religious beliefs, you have the right to decline any or all three (3) of the newborn screens including heelstick, pulse oximetry, and hearing. The religious waiver form must be used to indicate your decision to decline any of the newborn screens. The religious waiver is then submitted to the Indiana State Department of Health (ISDH) Genomics and Newborn Screening program.

For more information, please refer to the Newborn Screening pamphlets provided by your birthing facility or midwife.
GNBS LAB INFORMATION

As of Fiscal Year 2017, the GNBS Program contracts Indiana University Newborn Screening Laboratory as a vendor of ISDH. Beginning in 1991, this NBS Lab was selected as the centralized location for needs regarding the distribution, collection, and processing of the NBS Cards for the entire state. The NBS Lab serves all IN birthing facilities, midwives, and other NBS Card submitters across the state.

The following is a quick reference to the lab’s process once receiving an NBS Card:

NOTE: Submitters of an NBS Card with the heelstick portion completed will get a faxed or mailed report from NBS Lab once the screening process has been completed for normal results. If abnormal results or issues with the specimen arise then the NBS Lab will be in contact with the submitting facility immediately.

If you experience any issues in obtaining results from the NBS Lab, please contact the lab immediately to avoid lag in any follow-up or documentation in your facilities GNBS Log.

If your birth facility (hospital, birthing center, midwife / midwifery) needs more brochures or NBS Cards, please call the lab and request these materials. New GNBS Card submitters (facilities, birthing centers, midwife / midwifery) will need to set up an account with the lab and ISDH GNBS for submitting and reporting.

<table>
<thead>
<tr>
<th>NBS Lab</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone: 317.491.6678</td>
</tr>
<tr>
<td>Fax: 317.491.6679</td>
</tr>
</tbody>
</table>
**NOW Courier Information:**

*NOW Courier* is the statewide courier service used for all newborn screening specimens that ensures timely delivery to the NBS Lab, located in Indianapolis, from all IN birthing facilities. *NOW’s mission is to provide the most efficient, cost effective and value added courier services through quality service, people and proven technology while developing long-term partnerships with customers. NOW serves all IN birthing facilities six days a week to ensure all DBS cards are delivered in a timely manner to the NBS Lab. NOW offers a tracking system in order to track every DBS card that leaves a birthing facility and can be found at any point of the route, this ensures no cards are lost. It is best to become aware of your birthing facilities NOW courier service route and times to ensure your daily pick up is made with no delay.

You can view more information about NOW Courier service at [http://nowcourier.com](http://nowcourier.com)

If your facility does not have high birth volumes that requires a set schedule for courier services, you are able to indicate the need for pick up by emailing: NewbornScreening@NowCourier.com

*This service for low volume facilities is only available Monday-Friday.*

The following lists the regional contact numbers in case your facility needs further information of your scheduled route or if an error has occurred, please contact your regional number or Barb Lesko at the NBS Lab.

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*The Newborn Screening Laboratory is subject to change at the end of every odd fiscal year as this is when the contract is up for renewal.*
INSTEP

Primary care providers have online access to newborn screening results, available through the Indiana Newborn Screening Tracking & Education Program (INSTEP)! The ISDH GNBS program highly recommends that a minimum of two people per office group have access to INSTEP in order to obtain GNBS results.

MSRs are submitted by hospital staff within INSTEP. ISDH strongly encourages assigning a minimum of two people to each mandatory reporting task. A two person minimum per each screening report task increases support with the additional work load, reduces delay when there is turn over or time off, and encourages collaboration resulting in fewer reporting errors.

To obtain INSTEP registration instructions, please send an e-mail to the GNBS team at their shared email ISDHNBS@isdh.IN.gov and include the following information:

1) Your full name as it appears on any licenses
2) The name of the physician’s office, hospital, or other medical facility with which you are affiliated
3) The primary care physicians within the medical facility that you are working with
4) The main telephone number of that medical facility
5) Your role at that facility (i.e., physician, nurse, medical assistant, audiologist, etc.)
6) The reason you are requesting to have access to INSTEP

Parents or healthcare professionals can also contact the ISDH Genomics and Newborn Screening Program by calling 888.815.0006
REQUESTING NBS RESULTS

If you do not have INSTEP access, and you would like to request Newborn Screening Results, please see the previous instructions on how to obtain INSTEP access in order to look for the results on your own and be able to verify information.

Facilities can also fax the lab with your office’s cover page to 317.491.6679 and include the following child information:

✓ Name
✓ Date of Birth
✓ Mom’s Name
✓ Birth Facility

Submitters of an NBS Card with the heelstick portion completed will get a faxed or mailed report from NBS Lab once the screening process has been completed for normal results. If abnormal results or issues with the specimen arise then the NBS Lab will be in contact with the submitting facility immediately.

If you experience any issues in obtaining results from the lab, please contact the lab immediately to avoid lag in any follow-up or documentation in your facilities GNBS Log.

For further questions regarding GNBS Results, please send an e-mail to the GNBS Program team at ISDHNBS@isdh.IN.gov or call the ISDH Genomics and Newborn Screening Program at 888.815.0006
Monthly Summary Reports (MSRs)

INSTEP allows birthing facilities and midwiferies to submit their monthly live birth totals, record of babies exempt from newborn screening for religious beliefs and/or other identified scenarios, and the total number of newborn screens completed. When this data is valid, ISDH is able to utilize the data for the following initiatives:

- Ensure Indiana babies are receiving valid screens
- Be alerted when there is missing information, an invalid heelstick, abnormal results, or no record prompting follow-up care
- Reduce lost to follow-up cases
- Complete quality indicator reports for each facility and midwifery
- Ensure that facilities and midwiferies are abiding the state mandated law
- Increase awareness in the community
- Improve the Newborn Screening Program
- Share reliable statistics
- Show the impact our screens have not only on Indiana babies, but public health initiatives

The overall purpose of adequate MSRs is to ensure that all babies born in Indiana are receiving valid screens, rescreens, and getting the follow-up care they need based on those results.

To ensure your facility is submitting accurate and valid data into the MSRs, please encourage collaboration between the hearing, pulse ox, and heelstick reporters and keep your NBS log up to date and available to all reporters.

MSRs are due by 5 pm EST on the 15th of each month.

If you have any questions about completing the MSR (either within INSTEP or on the hardcopy forms), please contact the Newborn Screening Follow-Up Care Coordinator.
MSR 101

Prior to submitting your MSR:

Gather information from your facilities Newborn Screening Log

Compare your numbers with other reporters within your facility. Each facility has a hearing, pulse ox, and heelstick reporter. *

Double check your information!

*Pay close attention to your live birth numbers, as this number should be the same for each reporter monthly. Exceptions and total number of screens can vary for many reasons.
Prior to submitting your Exceptions:

Resolve Holdovers
(Promote, Accept/Decline, Edit Transfer Detail)

Avoid Duplicate Exception Entries

Input Accurate Data with Supporting Documentation
The initial exception scenario should be priority. Additional information can always be documented in the notes/comments section to assist with follow-up.
When needing to update to another exception, ensure you are not creating additional CHIPs/PIDs.

If you have questionable data within your Exception Entry page, contact the NBS Follow-Up Care Coordinator prior to submitting for that month.
Exception Entry

- Ensure that you have the supporting documentation for the exception that you are reporting. Exceptions and their description are listed below:

<table>
<thead>
<tr>
<th>Transfer Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Transferred In- when valid, must accept or decline</td>
</tr>
<tr>
<td>• Transferred Out- must provide receiving facility for them to accept transfer in</td>
</tr>
<tr>
<td>• When a baby is transferred out of your facility and is not screened prior to transferring out, exception should be Transfer Only. In this scenario, NEVER mark baby as Finally Screened! Including when you know baby will be or has been screened. This verification is for the NBS Follow-Up Care Coordinator.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Finally Screened</th>
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</thead>
<tbody>
<tr>
<td>• Once exception is documented as Finally Screened for an exception, this number doesn’t tend to go towards your total screened number for that month. Although, the screen is documented within the exception report.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NICU</th>
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</thead>
<tbody>
<tr>
<td>• Used when in your facilities NICU, not when transferred out to another facilities NICU.</td>
</tr>
<tr>
<td>• Remember that there is a special protocol for screening NICU babies. When admitted in the NICU, the baby should remain as a NICU Exception until released and then you will promote the status within your MSR.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Initial Screen due Next Month</th>
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</thead>
<tbody>
<tr>
<td>• Used when there is a delay in screening or when the date and time of birth does not allow for a valid screen to take place within the same month. Applies to all babies born within the last 6-48 hours of the month and will prompt you to promote the baby in the next MSR.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Deceased</th>
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</thead>
<tbody>
<tr>
<td>• Always provide the date and time of death. Sometimes there is a lag in Vital Records, so providing this documentation within the CHIP’s General Notes section prevents reaching out to the family with NBS Follow-Up.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religious Refusal</th>
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<tbody>
<tr>
<td>• When documenting a RR, you will be prompted to upload the completed and signed form. This form must also be received by ISDH. You can submit via fax or send with your facilities’ NBS Cards to the NBS Lab, which will then forward them to ISDH.</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Discharged without NBS*</th>
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</thead>
<tbody>
<tr>
<td>• We never want this to occur, but when it does, alert the NBS Follow-Up Care Coordinator ASAP, and please document the scenario within the CHIP’s General Notes section.</td>
</tr>
</tbody>
</table>
Exception Entry for Pulse Oximetry

The previous exceptions are also utilized as options for the pulse oximetry MSR exceptions. Two additional exception options are valid for pulse oximetry MSRs:

- **Prenatally/Postnatally Diagnosed with CCHD**
  - When medical documentation supports this exception option, only this can be selected. When the pulse oximetry is seen to be unnecessary for this reason and an echocardiogram occurs, select this option as well as indicate when an echocardiogram occurred.

- **Did Not Pass Pulse Oximetry Screen -- Referred For Additional Follow-Up**
  - In these scenarios, always indicate if and when the echocardiogram occurred and a brief description in the notes of the exception to support follow-up needs.

*Discharged HOME without Pulse Oximetry Screen*

Summary Data Entry:

The numerical value of exceptions you entered into the Exception Entry portion will automatically populate within the table on the MSR Summary Data table. These exceptions, including *Finally Screened*, will deduct from your total number of screens once the following information is manually inputted into the tables, prompting your total number of screens to automatically populate.

- **Live births**
  - number of births in which the baby is born alive within the reporting facility
  - ALL ports of NBS should be reporting the same live birth number!

- **Home births**
  - number that received screening are those born at a non-hospital location and come into your facility to complete their initial GNBS

- **Walk ins**
  - number that received screening are those who need initial or rescreens due to various reasons including being discharged without GNBS, whether they were born at the reporting facility or not a different facility, possibly discharged without GNBS, and come into your facility to complete valid GNBS

*Notify the Follow-Up Care Coordinator if you view any discrepancies once you have completed your MSR Summary Data entry.*
**MSR: Tips for Avoiding Error**

- Share this responsibility with a designated backup reporter for your specific screen in addition to the other screen reporters
  - Verify contact info is up to date on MCP form
- Encourage accurate recording within your facility’s GNBS Log as births and screens occur
- Review your facility’s GNBS Log prior to data submission
- Collaborate with other GNBS reporters and share GNBS Log data
- Compare your data with other reporters data when applicable (i.e., live births)
- Ask questions when unsure about data entry or unusual cases by calling ISDH or another reporter
- Review PIDs and CHIPs for any conflicting data
  - Screenshot errors when noticed and send to ISDH. Alert ISDH as this can be a technical error that will need analyzed and corrected in a timely manner
- Double check your GNBS Log and what you entered into your MSR exception page prior to moving forward with the overall summary entry
- Once live birth number is confirmed accurate and inputted into the summary page and you move to the next field, confirm auto populated numbers are accurate with your facility
- Save and Close the MSR which will submit the report. Saving will only allow you to return to the entry at a later time
- Check your email for reminders from INSTEP to submit your MSR or that your MSR may be late
- Provide necessary attachments for religious refusal exceptions
- Provide the hospital name that is accepting the transfer. Notify ISDH if it is not an option within INSTEP and input it within the notes as well.

*ISDH will email and or call you with questions regarding your MSR data entry as needed.*
Newborn Screening
Religious Waiver for the Newborn Screening (IC 16-41-17-2)
*Copy found in Appendix 3*

The State of Indiana has mandated newborn screening, which consists of the hearing screen, pulse oximetry, and heelstick.

Per law (IC 16-41-17-2), a family is able to refuse one, two, or all three portions of the newborn screening due to religious beliefs. For a religious exemption, please have the parent/legal guardian clearly fill in, indicate which screen(s) they are refusing to be administered to the infant, and sign the form (along with a witness).

Always report religious refusals by submitting the waiver(s) to ISDH by faxing the forms directly to the GNBS Program or by mailing a copy of the waiver(s) with your facilities NBS Cards. Note that this does not bypass the requirement of submitting religious exemptions as an exception in your MSR. If one screen is refused it does NOT change the value in reporting the other two portions of NBS to ISDH.

Note: There are no guidelines for specified religious affiliation. Regardless of the family’s beliefs the ISDH GNBS program needs a signed copy of the religious refusal waiver. Ensure the family indicates which screen (hearing, pulse ox and heelstick) is being waived for religious purposes. Upon receipt of the signed and indicated waiver, the family can be assured that no further contact regarding GNBS and follow-up will be made. *It is important to note that this waiver serves as a protective measure for healthcare providers and health organizations in the event of adverse outcomes.*

*If your facility needs more waivers, please refer to the “Forms” section of this Toolkit or contact the GNBS Follow-Up Care Coordinator.*
Hearing Screen

EHDI Manual found in Appendix 6
See Technique References in Appendix 5

Each year in the United States, approximately 3 of every 1,000 babies are born with permanent hearing loss; in Indiana, this accounts for 250 babies annually. Additionally, Indiana has a unilateral (one ear) hearing loss rate of nearly 40%. While not all hearing loss can be reversed or prevented, newborn screening provides the opportunity for early detection and intervention for improved growth, development and social-emotional health. By including hearing screening in Indiana’s newborn screen, most of these children can be identified before 3 months of age and enrolled in appropriate intervention services for them to achieve the best outcomes. It is important to find hearing loss early so that early intervention services and language development can begin as soon as possible.

Mandated by Indiana Statute IC 16-41-17-2, the Universal Newborn Hearing Screening (UNHS) can be performed as early as six (6) hours after birth and it is best practice that not more than two inpatient hearing screens are done. Similar to the heelstick and pulse oximetry screens, the UNHS needs to be completed prior to discharge.

The Early Hearing Detection and Intervention (EHDI) program aims to screen by 1 month, have confirmatory evaluation by 3 months to identify hearing loss, and act on early intervention by 6 months. All babies can and should have their hearing screened before they leave the birthing facility. When an infant has not passed two newborn hearing screens prior to discharge, hospitals and birthing facilities are responsible for providing a referral to a diagnostic audiologist, and/or to the primary care physician. It is not recommended to re-screen the infant who did not pass the initial two screenings. The birthing facility is also required to report the hearing screening results to Indiana’s Early Hearing Detection and Intervention (EHDI) program.

Following a failed newborn hearing screen, the diagnostic evaluation should be completed prior to three months of age in order to identify a hearing loss within the recommended time frame to reduce parental anxiety, decrease the need for sedation, reduce the lost-to-follow up rate and ensure appropriate early intervention services in a timely manner.
Indiana was the second state to have pulse oximetry newborn screening added to the state newborn screen beginning January 1, 2012. Since then every baby born in Indiana is required to have a valid pulse oximetry, unless the baby's parents object to newborn screening based on their religious beliefs.

The pulse oximetry is used as part of newborn screening to determine how healthy a baby’s cardiovascular and pulmonary functions are by detecting oxygen levels in the blood. Babies who have low oxygen levels may have CCHD. This critical test is crucial when CCHD is not detected in utero and can be detected before major signs and symptoms occur after birth.

The pulse oximetry screening must take place between the first twenty-four (24) to forty-eight (48) hours after birth. This test can occur a maximum of three times, with a minimum of one hour in-between screens, before further assessment is needed. There are scenarios when this screen is bypassed and an echocardiogram is done in place.

Please document both results and when an echocardiogram has taken place instead of a valid pulse oximetry screening in order to help with follow-up processes. Documentation can be done either on the GNBS Card, within INSTEP on their CHIP in the general notes section, Religious Waiver and or on your MSR submission.

In order to pass the pulse oximetry screen, a baby must have results of 95% or higher and no difference equal to or greater than 3% between the right hand and foot.

A failed pulse oximetry screen consists of results in either the hand or foot lower than 95% and/or a difference greater than 3% between the right hand and foot.

It is important for parents to know that pulse oximetry cannot identify every child with CCHD, but most babies who pass the pulse oximetry screen will not have CCHD. Therefore, it is important for parents to know the signs of CCHD (including cyanosis of the skin/fingernails/lips, fast breathing, & poor feeding or poor weight gain). Encourage a family to contact their baby’s doctor if they notice any of these signs in their baby.
Heelstick Screen
See Technique References in Appendix 5

It is the mission of the ISDH GNBS program to use the RUSP as guidelines for adopting conditions to the IN GNBS panel. As the SACHDNC recommends new conditions for GNBS, it is the responsibility of states to perform cost benefit analyses identifying the local community’s ability to support and sustain screening and follow-up services. As of 2018, the IN GNBS panel detects 47 different conditions with the heelstick.

Without this heelstick screen, these conditions would remain undetected until symptom onset, at which point, severe developmental delays or death will have already occurred. If a child has one or more of these 47 different conditions, it can be confirmed up to as early as one week of life allowing for rapid detection, early intervention and lifesaving treatment.

Once detection has occurred, early intervention and lifesaving treatment need to take place. The birthing/submitting facility should receive the heelstick results via fax from the GNBS lab within seven (7) days of the birth prompting the receiver to complete “Results Received” column of the NBS log. The receiver must review the results and follow the recommendations provided by the NBS Lab immediately.

Heelstick Results Protocol:

**Normal valid results** should be received by the birthing/submitting facility within seven (7) days of birth. These results received should then be documented in your NBS log to consider the screen resolved. No further action needs to be taken when a heelstick result is normal and valid.

**Presumptive positive or abnormal results** will also be documented in your GNBS log and this follow-up process includes phone notification from the NBS Lab and contacting the PCP on file. Please refer to ISDH NBS Lab recommended guidelines. See process map Appendix 5.

**Invalid results**, for the wellbeing of the child, it is imperative to acquire the rescreen and without further delay repeat the collection of specimen within five (5) business days of initial screen. Please review the table below listing quality indicators for invalid results. See process map Appendix 5.

**NICU and other special cases** such as preterm delivery, please refer to the ISDH GNBS recommended guidelines. This protocol aids in follow-up and can identify abnormalities even when the heelstick is not considered a valid test. See process map Appendix 5.
DRIED BLOOD SPOT:

The heelstick screens for these conditions by collecting a DBS. According to IN NBS Law, the remaining DBS can be made available for epidemiological research to identify new conditions, treatments and preventative measures. All research will be conducted on de-identified specimen, per Indiana Code 16-41-17-10.

ISDH requests written consent from parents or guardians of newborns if they would like to make their child’s DBS available for research purposes.

**If consent is granted, the DBS of the child will be stored and made available for epidemiological research for a period of three (3) years and then destroyed.**

**If parents do not consent to making their child’s DBS available for research, their child’s DBS is kept for six (6) months to ensure all GNBS testing has been completed and then is destroyed.**

Within the six (6) months, parents or legal guardians can request that their child’s DBS be stored for research purposes by completing and sending in a form to the GNBS Program. This form can be found in Appendix 3 and online at [www.isdh.in.gov](http://www.isdh.in.gov)

Within the three (3) years, parents or legal guardians may request that their baby’s DBS be destroyed by completing and sending a form to the GNBS Program. This form can be found in Appendix 3 and online at [www.isdh.in.gov](http://www.isdh.in.gov)

**Cards for any child born before June 1, 2013, have not been made available for research and have been destroyed in a secure manner. Other cards will be destroyed on a schedule in accordance with the three-year retention policy.**

More information, including a full list of the conditions currently tested for, can be found at [www.NBS.in.gov](http://www.NBS.in.gov)

If you encounter any questions regarding the status of a child’s DBS, please do not hesitate to contact the Indiana Genomics and Newborn Screening Program.
Birthing Facility Report Cards

Quality Improvement Initiative 2018

ISDH GNBS Program has revitalized this program with tools and suggestions provided by the NewSTEPs360 program. NewSTEPs is a program of the Association of Public Health Laboratories with an objective to reduce infant mortality and morbidity through GNBS by assisting states in being timely and accurate.

You can view more information on the NewSTEPs program at http://www.newsteps.org/

The mission of this revitalization is to improve timeliness, accuracy, collaboration, education, and reporting between all of IN GNBS stakeholders. With this, the GNBS program aims to aid in reducing infant mortality and morbidity through IN state mandated GNBS (hearing screen, pulse oximetry, and heelstick).

The following Quality Indicators will be used by ISDH GNBS in creating your facilities report card and are subject to change. These report cards will be electronically distributed to a designated person and or group within your facility and identified on the MCP Form quarterly and annually.

If you have any questions, please feel free to email GNBS Quality Coordinator or Special Projects Coordinator at ISDHNBS@isdh.IN.gov
Quality Indicators:

Quality Indicator 1: Total number of reported MSRs by facility for the year, including hearing, pulse oximetry and heelstick MSRs, the number received on time, and overall rank among birthing facilities in the State of Indiana.

Purpose: To rank all institutions based on Newborn Screening MSR quality indicators.

Screening Data Denominators:

i. Number of Hearing MSRs received from facility for the Quarter.

ii. Number of Pulse Oximetry MSRs from facility for the Quarter.

iii. Number of Heelstick MSRs from facility for the Quarter.

ii. Number of MSRs that were received on time to the ISDH.

iii. Overall rank of all birthing facilities based on the institution’s received MSRs.

Definitions:

i. Total number of MSRs received by ISDH through INSTEP database system

ii. Total number of Months that MSRs were received on time through the INSTEP database system.

   a) MSRs are due by 5 pm EST on the 15th of the following month.

iii. Overall rank of institution compared to all other institutions that report to the ISDH through the INSTEP system.

   a) Rank of one is the highest rank available
Quality Indicators:

Quality Indicator 2: Total number of infants who did not pass their initial hearing screening and are referred due to high risk factors.

Purpose: To track and maintain total number of infants who do not pass the initial hearing screen and were referred due to high risk conditions.

Screening Data Denominators:

i. Number of infants who did not pass the initial screening for the newborn screening for hearing loss.

ii. Number of infants who were referred due to high risk factors due to newborn screening results.

Definitions:

i. Total number of infants who did not pass the initial hearing screen test.

ii. Total number of children referred due to high risk factors found during the hearing part of the NBS.
**Quality Indicators:**

**Quality Indicator 3:** The amount of missing information from the medical record that is needed for chart reviewers to appropriately report to the IBDPR to confirm diagnosis of reportable conditions.

**Purpose:** To increase the percentage of information that is put into the medical records for infants who have reportable conditions so that chart reviewers can more easily identify and confirm conditions that need reported to the IBDPR.

**Definitions:** List of all necessary components for a complete and accurate chart patient medical record. See similarities in requirements of NBS Card and Log within the list below.

<p>| <strong>Infant’s Name</strong> | The full name of the newborn |
| <strong>Infant’s DOB</strong> | The date of birth of the newborn |
| <strong>Infant’s Gender</strong> | The gender of the newborn |
| <strong>Infant’s Race</strong> | The race of the newborn |
| <strong>Infant’s Ethnicity</strong> | The ethnicity of the newborn |
| <strong>Infant’s Follow-Up PCP</strong> | The infant’s Follow-Up PCP name and contact information. Hospitalist should never be the listed PCP unless NICU statues or will see in outpatient setting. |
| <strong>Mother’s name</strong> | The full name of the mother |
| <strong>Mother’s maiden name</strong> | The maiden name of the mother |
| <strong>Mother’s Race</strong> | The race of the mother |
| <strong>Mother’s DOB</strong> | The date of birth of the mother |
| <strong>Mother’s address</strong> | The address of the mother at the time of delivery |
| <strong>Mother’s phone number</strong> | The phone number of the mother |
| <strong>Mother’s email</strong> | The email address of the mother |
| <strong>Time of Birth</strong> | The time of birth for the newborn |
| <strong>Birth order</strong> | The order in which infants of a multiple gestation pregnancy are delivered |
| <strong>Birth facility</strong> | The location where the birth took place |
| <strong>Gestational age</strong> | Gestational age of the newborn at the time of birth |
| <strong>Plurality</strong> | The number of infants resulting from a single pregnancy |
| <strong>Birth Weight</strong> | The weight of the newborn at delivery in grams |
| <strong>Birth length</strong> | The length of the newborn at delivery in centimeters |
| <strong>Head Circumference</strong> | The head circumference at delivery in centimeters |</p>
<table>
<thead>
<tr>
<th><strong>Date of Death</strong></th>
<th>The date of death for an infant</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transfused</strong></td>
<td>Whether the baby was transfused or not</td>
</tr>
<tr>
<td><strong>Birth Defect(s)</strong></td>
<td>The ICD-10 code for the diagnosed birth defect</td>
</tr>
<tr>
<td><strong>Procedures performed for diagnosis of birth defect(s)</strong></td>
<td>All procedures performed for diagnostic evaluation. Procedures required for confirmation of diagnosis differ depending on the condition, but may include echocardiograms, imaging studies, surgeries, specialist consults, and physician consults.</td>
</tr>
<tr>
<td><strong>Prior Infant Deaths</strong></td>
<td>The number of previous infant deaths experienced by mother</td>
</tr>
<tr>
<td><strong>Prior Stillbirths</strong></td>
<td>The number of previous stillbirths</td>
</tr>
<tr>
<td><strong>Prior Spontaneous Abortions</strong></td>
<td>The number of previous spontaneous abortions</td>
</tr>
<tr>
<td><strong>Prior Induced Terminations of Pregnancy</strong></td>
<td>The number of previous induced terminations</td>
</tr>
<tr>
<td><strong>Prior Preterm Deliveries</strong></td>
<td>Whether mom experienced any preterm deliveries previously</td>
</tr>
<tr>
<td><strong>Prior Multiple Gestations</strong></td>
<td>Whether mom experienced any multiple gestations previously</td>
</tr>
<tr>
<td><strong>Gravidity</strong></td>
<td>The number of times a woman has been pregnant</td>
</tr>
<tr>
<td><strong>Parity</strong></td>
<td>The number of pregnancies carried to a viable gestational age</td>
</tr>
<tr>
<td><strong>Prenatal care start date</strong></td>
<td>The date prenatal care visits started</td>
</tr>
<tr>
<td><strong>Number of prenatal care visits</strong></td>
<td>The total number of prenatal care visits completed by mother</td>
</tr>
<tr>
<td><strong>Mother’s Substance Use History</strong></td>
<td>The type and name of substance(s) used prior to and during pregnancy: alcohol, tobacco, prescription and illegal drugs. The trimester substances were used and the tests performed for confirmation.</td>
</tr>
</tbody>
</table>
**Quality Indicators:**

**Quality Indicator 4:** The amount of time it takes facilities to collect and submit valid and sufficient NBS Cards to the NBS Lab for processing.

**Purpose:** To improve the amount of correctly labeled and correctly collected NBS Cards that the NBS Lab receives.

**Definitions:**

i. Correct and fully filled out NBS Card that the NBS Lab receives to run the test for the infant

ii. The code that is affixed by the NBS Lab to the NBS Card based on the sample given numbered 1-34

iii. Unsatisfactory rate percentage is the number of specimens sent to the NBA Lab that were not sufficient to run test divided by the total number of specimens sent to the lab.

**Quality Indicators:**

**Quality Indicator #5:** Number of infants who did not have Pulse Oximetry results who had suspected critical congenital heart disease (CCHD) on the NBS Card.

**Purpose:** To improve the amount of NBS Cards that have Pulse Oximetry results for infants who have suspected CCHD conditions.

**Definitions:**

i. Number of infants who have suspected CCHD conditions and the NBS Card did not have the Pulse Ox information on the card.

ii. Number of infants who have suspected CCHD conditions and the NBS Card did have the Pulse Oximetry information on the cards.
Summary Page

QI#1-Total number of reported MSRs:

**Report Information:** The statistics in this report are based on the data submitted by you for the year of **2018**.

**Reports Submitted:** Lists the percentage and rank of the reports that have been received by ISDH GNBS at the time of this report.

**Received on time:** Lists the percentage and rank of submitted reports that were received by 5 pm EST on the 15th of the month following the report month.

**Rank:** Ranking based on number of reporting institutions. Rank one is the highest rank available.

QI#2-Total not Passing Initial Hearing Screen:

The total number of infants who did not pass their initial hearing screen and were not referred to a specialist.

QI#3-Missing information from medical record:

The information missing from medical record that is needed for chart reviews to appropriately report to IBDPR.

QI#4- Time for valid NBS Card for DBS to be received and processed:

The amount of time it takes for facilities to collect and submit valid and sufficient NBS Cards to the NBS Lab for processing.

QI#5- Number of children without pulse oximetry:

The number of infants who did not have a pulse oximetry result with suspected CCHD on the NBS Card.

**Unsatisfactory Rate Percentage:** This is the percentage of unsatisfactory NBS Lab DBS compared to total DBS submitted.
Quality Codes:

<table>
<thead>
<tr>
<th>1. Oversaturated</th>
<th>2. Oversaturated; spotted on both sides</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Oversaturated; Double Spotted</td>
<td>4. Minimal Specimen to Assay</td>
</tr>
<tr>
<td>5. Minimal Specimen to Assay; Circle Underfilled</td>
<td>6. Minimal Specimen to Assay; Uneven Saturation</td>
</tr>
<tr>
<td>7. Minimal Specimen to Assay; Multiple Small Dots</td>
<td>8. Uneven Saturation</td>
</tr>
<tr>
<td>9. Uneven Saturation; Overlapped Spots</td>
<td>10. Uneven Saturation; Filter Paper Scratched</td>
</tr>
<tr>
<td>11. Inadequate Saturation</td>
<td>12. Circles Underfilled</td>
</tr>
<tr>
<td>13. &lt;3 Circles Filled</td>
<td>14. Double Spotted</td>
</tr>
<tr>
<td>15. Spotted on Both Sides</td>
<td>16. Multiple Small Dots</td>
</tr>
<tr>
<td>17. Filter Paper Scratched by Capillary Tube</td>
<td>18. Clotted</td>
</tr>
<tr>
<td>19. Paperwork Incomplete</td>
<td>20. Specimen Received &gt;5 days After Collection</td>
</tr>
<tr>
<td>25.* Specimen Unacceptable; Clots on Card</td>
<td>26.* Specimen unacceptable; Contaminated with Tissue Fluid</td>
</tr>
<tr>
<td>27.* Specimen Unacceptable; Contaminated with Liquid</td>
<td>28.* Specimen Unacceptable; Multiple Overlapped Spots</td>
</tr>
<tr>
<td>29.* Specimen Unacceptable; Grossly Oversaturated</td>
<td>30.* Specimen Damaged</td>
</tr>
<tr>
<td>31.* Specimen QNS (Quality Not Sufficient)</td>
<td>32.* No Blood on Card</td>
</tr>
<tr>
<td>33.* Specimen Received&gt;10 days After Collection</td>
<td>34.* ID Doubtful</td>
</tr>
</tbody>
</table>

* Denotes a rejected code. Specimen is not resulted if this code is used; Another Specimen is required.
2018 Status Report Example
Newborn Screening Report
Quarterly Summary Report

Reporting Facility: FACILITY NAME

<table>
<thead>
<tr>
<th>FACILITY NAME</th>
<th>Overall Ranking is: CURRENT RANK /90</th>
</tr>
</thead>
</table>

Point of Contacts:

<table>
<thead>
<tr>
<th>Heelstick Contact</th>
<th>Hearing Contact</th>
<th>Pulse Oximetry Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAME</td>
<td>NAME</td>
<td>NAME</td>
</tr>
</tbody>
</table>

The following data listed is based solely on your institution's reports.

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Heelstick MSR</th>
<th>Pulse Ox MSR</th>
<th>Hearing MSR</th>
<th>Number of reports received on time</th>
<th>Overall Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1/3</td>
<td>1/3</td>
<td>1/3</td>
<td>1/3</td>
<td>1/90</td>
</tr>
</tbody>
</table>

Hearing Screen:

<table>
<thead>
<tr>
<th>Total not Passing Initial Hearing Screen</th>
<th>Total Infants Referred due to High Risk Factors</th>
</tr>
</thead>
</table>

Chart Reviews:

<table>
<thead>
<tr>
<th>Quality Code</th>
<th>Quality Code Description</th>
<th>Unsatisfactory Rate Percentage</th>
</tr>
</thead>
</table>

Pulse Oximetry readings for kids with suspected CCHD:

<table>
<thead>
<tr>
<th>Number of NBS with missing Pulse Oximetry information</th>
<th>Number of NBS with Pulse Oximetry information</th>
</tr>
</thead>
</table>

Year to date status:

<table>
<thead>
<tr>
<th>Heelstick</th>
<th>Pulse Oximetry</th>
<th>Hearing</th>
<th>Number of Reports on time</th>
<th>Overall Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>1/3</td>
<td>1/3</td>
<td>1/3</td>
<td>1/9</td>
<td>1/90</td>
</tr>
</tbody>
</table>
2018 Status Report Example
Newborn Screening Report

Annual Summary Report

Reporting Facility: FACILITY NAME

FACILITY NAME Overall Ranking is: CURRENT RANK/90

Point of Contacts:

<table>
<thead>
<tr>
<th>Heelstick Contact</th>
<th>Hearing Contact</th>
<th>Pulse Oximetry Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAME</td>
<td>NAME</td>
<td>NAME</td>
</tr>
</tbody>
</table>

The following data listed is based solely on your institutions reports.

January-December

<table>
<thead>
<tr>
<th>Heelstick MSR</th>
<th>Pulse Ox MSR</th>
<th>Hearing MSR</th>
<th>Number of reports received on time</th>
<th>Overall Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>/12</td>
<td>/12</td>
<td>/12</td>
<td>/36</td>
<td>/90</td>
</tr>
</tbody>
</table>

Hearing Screen:

<table>
<thead>
<tr>
<th>Total not Passing Initial Hearing Screen</th>
<th>Total Infants Referred due to High Risk Factors</th>
</tr>
</thead>
</table>

Chart Reviews:

<table>
<thead>
<tr>
<th>Lab Information</th>
<th>Quality Code</th>
<th>Unsatisfactory Rate Percentage</th>
</tr>
</thead>
</table>

Pulse Oximetry readings for kids with suspected CCHD:

<table>
<thead>
<tr>
<th>Number of NBS with missing Pulse Oximetry information</th>
<th>Number of NBS with Pulse Oximetry information</th>
</tr>
</thead>
</table>

Summary of Quarterly Performance:

**Overall Rank for 2018: RANK/90**

<table>
<thead>
<tr>
<th>1st Quarter Rank:</th>
<th>2nd Quarter Rank:</th>
<th>3rd Quarter Rank:</th>
<th>4th Quarter Rank:</th>
</tr>
</thead>
<tbody>
<tr>
<td>/90</td>
<td>/90</td>
<td>/90</td>
<td>/90</td>
</tr>
</tbody>
</table>

This will denote your facilities specific results.