Supplemental Guide to Using Performance Report Cards in Newborn Screening Programs

A performance report card is a simple way to show how a newborn screening (NBS) program or facility is doing on key measures like timeliness and specimen quality. It brings important data into one clear snapshot so teams can quickly see what's going well, where there may be challenges, and what steps could help improve performance. Ultimately, it's a tool to support shared accountability and continuous improvement.

This supplemental guide and checklist are designed to help NBS programs effectively develop and use a standardized performance report card (or score card) to monitor system performance, drive quality improvement, and strengthen communication with submitters, partners, and leadership. Recognizing that several NBS programs already have a report card they utilize, we collected feedback from over 30 NBS programs across the United States to gather tips, examples, and strategies to best utilize a performance report card. The following guide provides practical guidance across the full lifecycle of report card development, from defining measures to collecting data, visualizing results, sharing findings, and measuring impact. Additionally, a checklist was developed to help guide you as you create or iterate your program's report card.

1. Purpose & Scope

Building an effective newborn screening report card starts with being intentional about the primary purpose of the report card. Clarity around the purpose will help you better define what you plan to measure and how you measure it. The goal is not to track everything, but to focus on a set of meaningful, actionable indicators that reflect the most critical aspects of NBS program performance.

Thoughtful metric selection, clear definitions, and well-established benchmarks ensure that the report card drives improvement rather than confusion. This section outlines how to choose balanced measures, define them consistently, and set realistic yet motivating performance targets. When choosing metrics, many programs reported their top three reasons for implementing a submitter report card are as follows:

- **Quality Improvement:** Over 90% of surveyed NBS programs report that their main reason for implementing a submitter report card is for quality improvement purposes. They are focused on indicators that submitters or the program can influence through behavior or process changes.
- **Submitter Education:** Over 80% report they also implemented a report card to provide education to their submitting providers and institutions.
- **Alignment with program goals:** Over 70% report utilizing a report card to ensure compliance with program goals. Measures reflect statutory requirements, national benchmarks, internal quality improvement priorities, as well as submitter requests.

Define the Why

Clarify the primary purpose of the report card before selecting measures or designing the format. Determine whether the report card is intended to drive quality improvement, strengthen accountability, improve communication with submitters, inform leadership decision-making, or serve multiple purposes. A clearly defined purpose ensures that metrics, benchmarks, and reporting formats are aligned with intended outcomes.

Identify Target Audience

Determine who will receive the report card and how they will use it. Audiences may include submitters (e.g., birth facilities, midwives), program leadership, internal quality improvement teams, couriers, or external stakeholders. Identifying the audience early helps tailor the level of detail, terminology, and presentation style to ensure clarity and relevance.

Establish Governance and Approval Process

Define who must review and approve the report card prior to release. This may include data analysts, program managers, laboratory leadership, or quality assurance staff. A clear governance process ensures data accuracy, consistency in messaging, and alignment with program policies before dissemination.

2. Build Your Report Card

Selecting and Defining Your Measures

In an assessment including responses from over 30 states, we identified four common domains for performance measures. The shared template and checklist include suggested metrics for each of the four core domains commonly used in NBS performance monitoring. The metrics listed below were most commonly reported by programs that already have established performance report cards.

- **Demographics:** (samples with missing information such as collection time, date of collection, infant birth date, birth weight, submitter identifiers, primary care provider (PCP), and other relevant demographic information)
- **Specimen quality** (unsatisfactory samples due to uneven saturation, insufficient quantity, unsatisfactory collection times, expired kit, contamination, and/or damaged card)
- **Timeliness** (collection, shipment/transit times)
- **Results Summary** (normal/negative cases, out-of-range/presumptive positive, borderline, and/or confirmed cases, as well as any pending or unknown results)

Determining Who Collects Data

A reliable performance report card depends on a clearly defined, consistently executed data-collection process. Programs should establish transparent procedures that specify how each metric is calculated, the data elements included in the numerator and denominator, and the reporting period applied. Consistency over time is essential to ensure trend validity and meaningful comparisons.

Clearly defined roles are foundational to producing accurate and timely report cards. Programs should explicitly document who is responsible for each step in the data lifecycle to reduce ambiguity and ensure accountability.

- First, identify who is responsible for **gathering data** from primary systems such as the Laboratory Information Management System (LIMS), vital records, or follow-up databases. This role may fall to laboratory staff, epidemiologists, data analysts, or information technology (IT) personnel, depending on program structure.
- Second, designate who performs **data validation and quality assurance checks**. This includes reviewing numerator and denominator counts, confirming completeness of required fields, checking for anomalies or unexpected trends, and verifying that calculations align with documented metric definitions.
- Finally, clarify **who will be responsible for finalizing and releasing report card results**. This may involve program leadership, a quality improvement lead, or a designated data steward. Establishing formal

approval processes ensures consistency in messaging and prevents premature dissemination of unverified results.

Documenting these roles in a written workflow or standard operating procedure (SOP) supports continuity during staff turnover and promotes institutional knowledge retention.

Timing and Frequency

The credibility of a report card depends not only on what is measured, but also on when and how consistently it is reported.

Define Reporting Frequency

Establish how often the report card will be distributed (e.g., monthly, quarterly, annually). Reporting frequency should balance timeliness with operational feasibility and data stability. More frequent reporting may support rapid improvement efforts, while less frequent reporting may be appropriate for leadership summaries or long-term trend analysis.

It is also critical to build in adequate time for **data collection and review prior to dissemination**. Rushing directly from extraction to distribution increases the likelihood of errors, which can undermine trust with submitters and stakeholders.

Programs should establish and consistently apply **standard cut-off dates** for inclusion in each reporting period. Consistency in timing supports fair comparisons across reporting cycles and improves transparency.

In an assessment of over 30 programs: ~50% collect data monthly · ~25% collect quarterly · <10% collect every six months or as needed/as requested by submitters.

Data Sources

NBS report cards often draw from multiple data systems, each contributing a different piece of the performance picture. In our assessment, respondents shared that data is collected through automated extraction methods (78%), manual data collection (30%), and/or some combination of both (respondents could select multiple approaches; percentages are not mutually exclusive). Common sources include:

- **Laboratory Information Management Systems (LIMS)** for specimen receipt, testing timelines, and result classifications
- **Electronic birth records or vital records systems** for demographic and birth-related data
- **Follow-up or case management systems,** such as Tableau, for confirmatory testing and case resolution data

When metrics rely on multiple systems, programs should take deliberate steps to ensure consistency and data integrity. Programs should also **standardize submitter identifiers** (e.g., facility codes, submitter identifiers, etc.) to enable reliable linkage across datasets. Inconsistent naming conventions are a common source of reporting inaccuracies.

Where possible, **automating data extracts** reduces manual handling and lowers the risk of transcription errors. Automation also improves efficiency and ensures that calculations are reproducible over time.

Programs may also benefit from leveraging external benchmarking resources, such as the NewSTEPs Tableau Dashboards, which allow users to explore and compare quality practice metrics over time (e.g., unsatisfactory specimens, missing essential data, timeliness, percent unscreened). These tools can support programs in identifying trends, contextualizing performance, and informing quality improvement efforts.

Setting Benchmarks and Targets

Many states utilize their own benchmarks, but when possible, it is recommended to use national recommendations, historical state data, or peer comparisons where available.

Clearly distinguish between **minimum acceptable performance** and **aspirational targets.** Document assumptions so targets can be revisited as systems mature.

Measure Quality Check

When selecting metrics for a NBS performance report card, it is important to ensure that each measure is purposeful, actionable, and clearly defined. Each metric should **align with the program's goals and priorities** so that the information reported supports meaningful oversight and quality improvement efforts. Measures should also be **actionable**, meaning that submitters or program staff can influence performance through changes in workflow, training, or process improvements. To ensure consistency and transparency, all metrics should have written definitions that clearly describe how they are calculated, including the numerator and denominator.

3. Data Visualization

Turning Data into Clear, Actionable Insights

Data visualization plays a critical role in transforming raw data into insights that can be quickly understood and acted upon. A well-designed report card should allow viewers to immediately recognize key performance patterns, identify areas needing improvement, and understand how their performance compares to benchmarks or targets.

Choosing Visualization Tools

NBS programs use a variety of tools to create and share report card visuals, with respondents able to select multiple options. The majority of programs utilize a **PDF document (80%)** that is sent to submitters. Some programs rely **on business intelligence platforms (12.5%)** such as Tableau or Power BI, which allow for interactive dashboards, automated data refreshes, and more advanced visual analytics. Others may use **Excel spreadsheet based files (20%)** or **web-based dashboards (17.5%),** which are often easier to implement and maintain with limited technical resources. In some cases, programs may also leverage **built-in reporting modules within Laboratory Information Management Systems (LIMS) or other public health data systems**.

The choice of tool should reflect the program's operational context. Important considerations include the **technical capacity and training of staff**, the **data security and privacy requirements** associated with newborn screening data, and the **ease with which reports can be updated and** shared with stakeholders. In many cases, the most effective tool is not necessarily the most complex one, but the one that allows the program to reliably produce clear and timely reports

Visualization Best Practices

Regardless of the platform used, following a few core visualization principles can greatly improve clarity and usability. Simple visual formats, **such as bar charts and line graphs**, are often the most effective for communicating performance and trends. These formats allow readers to quickly interpret differences across facilities or changes over time.

It is also helpful **to visually highlight benchmarks or performance targets**, for example, by adding reference lines or color-coded indicators that show whether performance meets, exceeds, or falls below expectations/benchmarks. To prevent information overload, each page or dashboard should focus on a **limited number of key metrics**, prioritizing those that are most relevant to the audience. In the provided template, separate pages are used for bloodspot, hearing, and heart screening performance metrics. Additionally, the submitter/facility metrics are compared to the overall state performance metrics, and the benchmarks are clearly indicated for each respective metric.

Consistency is equally important**. Using standardized colors, labels, and chart formats** across reporting periods helps users become familiar with the report card and makes it easier to compare results over time.

Designing for Different Audiences

Report cards are often shared with multiple audiences, and effective visual design should reflect the needs of each group. For **submitters**, such as birth facilities or midwives, reports should prioritize clarity and relevance. Visuals that show their performance relative to state or territorial benchmarks or peer facilities can help identify opportunities for improvement.

For **program leadership**, the focus may shift toward broader trends and system-level performance indicators that support strategic decision-making. Leadership audiences often benefit from high-level summaries and trend lines that illustrate progress over time.

Finally, **internal program teams** may require more detailed visualizations to support quality improvement efforts. These reports can include more granular data, such as facility-level breakdowns or detailed timelines, to help teams identify root causes and monitor the impact of interventions.

By thoughtfully selecting tools, applying clear visualization practices, and tailoring presentations to the intended audience, newborn screening programs can ensure that their report cards effectively communicate performance and support meaningful improvement data, facility-level breakdowns, or detailed timelines to support quality improvement efforts

Publicly Available Dashboard Examples

- Michigan's dashboard: https://www.michigan.gov/mdhhs/.../newborn-screening-dashboard
- Washington's dashboard: https://doh.wa.gov/.../newborn-screening/quarterly-report-dashboard

Performance Report Card Examples

- Indiana: https://www.newsteps.org/sites/default/files/resources/download/Indiana%20NBS%20Performance%20Report%20Template%20Example.pdf
- Minnesota: https://www.newsteps.org/sites/default/files/resources/download/MN%20QA%20Report%20example.pdf
- Oklahoma: https://www.newsteps.org/sites/default/files/resources/download/OK%20NBS%20Report%20Card%20for%20Birthing%20Hospitals.pdf
- Oregon: https://www.newsteps.org/sites/default/files/resources/download/OR%20QA%20Report%20example.pdf

4. Sharing and Disseminating Your Report Card

Making Distribution Simple and Sustainable

For a performance report card to be effective, programs must ensure that it **reaches the desired audiences in a clear and consistent manner**. Thoughtful dissemination helps turn performance data into a useful tool for communication, accountability, and quality improvement rather than simply a reporting exercise.

Report cards are often shared with a variety of stakeholders, including birth facilities, midwives who collect specimens, courier services responsible for specimen transport, program leadership and funders, and internal quality improvement committees.

Establish a Simple and Sustainable Distribution Process

Many programs streamline dissemination through the following channels:

- **Automated email distribution lists (77.5%)**
- **State program website (20%)**
- **Secure data portals or dashboard platforms (12.5%)**
- **Site visits (12%)**
- **Mail or courier systems (7.5%)**

*Respondents could select multiple channels; percentages are not mutually exclusive.

Establishing a predictable reporting cadence, such as quarterly releases, can also help build trust and familiarity among recipients.

Clearly Defined Interpretations

Programs should take steps to support the interpretation of the report card. Providing a brief cover page or summary that explains what the report shows can help readers quickly understand the purpose and key takeaways. Including definitions or a legend for metrics ensures that recipients interpret measures consistently.

Provide Contact Information for Technical Assistance

Offering contact information for program staff creates an opportunity for submitters or partners to ask questions, request clarification, or seek technical assistance. Together, these practices help ensure that report cards are not only distributed effectively, but also understood and used to support system improvement.

5. Measuring the Impact of Report Cards

Using Data to Drive Improvement

A performance report card is most valuable when it drives measurable improvement rather than simply tracking metrics. Programs should clearly define what "impact" looks like, which may include improvements in specimen timeliness, reductions in unsatisfactory sample rates, increased completeness of demographic data, or stronger engagement and collaboration with submitters.

To evaluate impact, programs should **track performance over time**, comparing data before and after report card implementation. Linking observed changes to specific interventions, such as targeted training, process updates, or policy changes, helps demonstrate the effect of the report card on program outcomes. Annotating trend charts to indicate when changes were introduced can make improvements easier to interpret and communicate.

State Examples: Report Cards Driving Improvement

> *We've definitely seen improvements in timeliness. Several hospitals were drawing bloodspots later than 48 hours — we provided these data and the hospitals adjusted their orders to ensure babies had their bloodspots drawn earlier.*

> *Yes, the report cards have helped with timeliness, especially during hospital mergers.*

> *Absolutely. Since implementing the report card in 2016, our Early Hearing Detection and Intervention (EHD) Program has observed improvement in the number of hospitals attaining 100%. In 2016, five birth hospitals attained 100%. In 2024, 31 hospitals attained 100%. Additionally, since 2022, there are no hospitals scoring below the 80–89% attainment range.*

Starting in 2019, specific benchmarks were established along other quality improvement initiatives including assigning grades for these performance measures. Since the inclusion of these performance grades, our annual unsatisfactory rates dropped from 1.92% in 2019 to 0.98% in 2025. Our transit rates also fell from 21.10% in 2019 to 11.71% in 2025.

Finally, it is important to **close the loop** by sharing successes with submitters and leadership. Positive reinforcement, combined with constructive feedback, encourages ongoing engagement and improvement. Programs should also periodically reassess metrics to ensure they remain relevant and continue to reflect meaningful performance priorities.

Conclusion

A well-designed performance report card is more than a reporting requirement, it is a strategic tool for transparency, accountability, and continuous improvement. By investing in clear measures, reliable data collection, effective visualization, and thoughtful dissemination, newborn screening programs can use report cards to strengthen systems and improve outcomes for newborns and families.

The Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS) provided financial support for this activity. The award provided 100% of total costs and totaled $2,300,000. The contents are those of the author. They may not reflect the policies of HRSA, HHS, or the US Government.