

# ***Newborn Screening Education Best Practice Framework***

## ***An Innovation Station Emerging Practice***

**Purpose:** This document is intended to support MCH professionals to implement a practice found in Innovation Station. This resource provides the information needed to replicate the practice and is divided into two sections: the first section provides a high-level overview of the practice while the second section describes how to implement the practice. For additional information on any of the content provided below, please reach out to the practice contact located at the bottom of this document.

### **Section I: Practice Overview**

<b>Location:</b>	National	<b>Title V/MCH Block Grant Measures Addressed</b>
<b>Category:</b>	Emerging	<b>NOM #9.1:</b> Infant Mortality <b>NOM #9.2:</b> Neonatal Mortality <b>NOM #9.3:</b> Postneonatal Mortality <b>NOM #9.4:</b> Preterm-Related Mortality <b>NOM #9.5:</b> SUID Mortality <b>NOM #12:</b> Newborn Screening Timely Follow-Up
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### **Practice Description**

The Newborn Screening Education Best Practice Framework is intended to help users design and evaluate approaches to newborn screening awareness building and education efforts. This framework will guide them through the process of selecting contextually appropriate newborn screening education approaches.

### **Purpose**

In today’s media-centric world, families are constantly inundated with health messages – filtering through these messages to find important, accurate information is challenging. As a result, public health education must be targeted, clear, and accessible. The time-sensitive nature of newborn screening results compounds the need for effective education. For families to make informed health decisions, they need to understand newborn screening and what the results mean for them. In a recent study, 76% of survey participants stated they knew “very little” or “a little” about newborn screening, indicating that newborn screening education could be improved.<sup>1</sup>

In 2017, Baby’s First Test, the nation’s resource center for newborn screening information, hosted an educational summit called *Beyond the Bloodspot: Education and Engagement Summit*. The goals of the summit were to:

- Identify and evaluate best practices that improve family and healthcare provider understanding of the newborn screening system;
- Identify best practices that increase family and healthcare professional involvement in the newborn screening system; and
- Evaluate family and healthcare professional involvement in the newborn screening system.

Over 100 newborn screening, public health, and health communication experts attended the summit. While the summit illustrated clear gaps in newborn screening education, it also demonstrated the exponential need for guidance on how to identify and evaluate programs as best practices. As a follow-up to the summit, Baby's First Test convened a panel of experts to develop a system for identifying best practices in newborn screening education. This panel collaboratively created the Newborn Screening Education Best Practice Framework. The framework responds to the need for improved newborn screening education by providing a systematic process for designing and evaluating education approaches for newborn screening educators.

1. DeLuca, J. M. (2018, Jan - Feb). Public attitudes toward expanded newborn screening. *Journal of Pediatric Nursing*, 38, e19-e23. <http://dx.doi.org/10.1016/j.pedn.2017.10.002>

## Practice Foundation

Using the Newborn Screening Education Best Practice Framework, those designing and implementing newborn screening education approaches will benefit from shared data/practices that result in a more efficient use of resources. Downstream, families will benefit from more effective education efforts that successfully reach intended audiences with information that is needed and relevant to them.

To develop the Newborn Screening Education Best Practice Framework, we looked at several tools and models including:

- Community Tool Box's [Developing a Framework Model of Change](#);
- Community Tool Box's [Implementing Effective Interventions](#);
- Genetic Alliance's [Trust It or Trash It? Creating and Assessing Genetic Health Information](#);
- CDC's [Seeking Best Practices: A Conceptual Framework for Planning and Improving Evidence Based Practices](#);
- The Secretary's Advisory Committee on National Health Promotion and Disease's [Evidence-Based Clinical and Public Health: Generating and Applying the Evidence](#);
- WHO: Regional Office for Africa's [Guide for Documenting and Sharing "Best Practices" in Health Programmes](#);
- AHRQ's [Grading the Strength of a Body of Evidence When Assessing Health Care Interventions for the Effective Health Care Program of the Agency for Healthcare Research and Quality: An Update](#); and

- AMCHP's [Innovation Station Submission Form](#).

In developing our framework, we looked at each of these tools and models to understand the elements typically used in best practice development and evaluation. We researched these tools to determine which elements were relevant to newborn screening and which should be included in the framework. While none of these tools and models were a singular guide to our framework, we strove to include broad, vetted best practice concepts in our framework and make sure they fit a newborn screening context specifically. For a full description of the elements of the framework, please read our [academic publication](#).

Further, the Newborn Screening Education Best Practice Framework does account for established public health models and theories within the framework itself. Although we do not stipulate that users apply a specific theory or model, we do recommend they consider several of the models and theories mentioned in the above list. In this way, the framework allows the user to make a determination on which model or theory is most relevant to their unique newborn screening education issue, while still promoting their use overall.

## Core Components

The goal of the Newborn Screening Education Best Practice Framework is to help users identify evidence-based education approaches to address issues in newborn screening education. The core components of using the framework are the guiding questions, flowchart, implementation, and evaluation of the selected approach.

## Practice Activities

Core Component	Activities	Operational Details
Guiding Questions	Collaboratively answer the guiding questions of the framework	Select an education approach that addresses a particular newborn screening education issue. The guiding questions show the overall concepts that form the core of the education approach. Work collaboratively with relevant staff and stakeholders.
Flowchart	Collaboratively work through the flowchart of the framework using the answers to the guiding questions	Use the flowchart to determine if the selected approach may be a best practice considering the context of the newborn screening education issue. Work collaboratively with relevant staff and stakeholders.
Implementation	Implement the selected approach	Based on the discussion of the guiding questions and flowchart, implement the education approach that was ultimately selected.
Evaluation	Evaluate the effectiveness of the selected approach	Evaluate the implementation of the selected education approach to determine if the approach used may be a best practice.

## Evidence of Effectiveness (e.g. Evaluation Data)

Our primary method of evaluation is to gather qualitative data through interviews with known users of the Newborn Screening Education Best Practice Framework. We designed an interview guide to structure this process.

In addition to the qualitative feedback, we are tracking some quantitative data. We are tracking the number of states we know have used the Newborn Screening Education Best Practice Framework, traffic to materials related to the framework in the [Resource Center](#) on BabysFirstTest.org, response to social media posts, and the number of views on our academic publication.

- Overall evaluation question:
  - Was the Newborn Screening Education Best Practice Framework helpful in selecting a newborn screening education approach?
- Participant selection:
  - Since the Newborn Screening Education Best Practice Framework is available for free to download on our website, we set up a qualitative interview with users who contact us to let us know they used the framework.
- Baseline values:
  - We will consider our baseline data collection complete one year after the release of the Newborn Screening Education Best Practice Framework, which has been available since January 18, 2019. Since then, we know of three state programs who have applied the framework. All three state programs have informed us they would use the framework again in a relevant situation. We know of one additional international user of the framework, but this user was unavailable for an interview or to provide further information.
  - 100% of users interviewed would use the framework again.
- Outcome measures:
  - The main outcome measures for the Newborn Screening Education Best Practice Framework are the percentage of states who have taken up the framework (6%), the percentage of known users interviewed who would use the framework again (100%), and the overall number of known users of the framework (4).
- Data collection:
  - We collected qualitative data through interviews with known users. These interviews were conducted using a standard interview guide over Zoom, an online meeting software.
  - For our quantitative evaluation measures, we collected data from our qualitative interviews as well as Google Analytics, social media insights, and academic article metrics.
- Data analysis:
  - Data analysis has so far focused on tracking the number of users to monitor uptake and qualitative feedback for quality improvement of the framework and related materials. Once we have interviewed more users, data analysis may include using methodologies such as emergent coding and a more systematic assessment of recurring themes. At a later date, we may also expand evaluation efforts to take a more active approach, as well as examine our dissemination methods.

For further details on how users have applied the framework, please see this one-page sheet we developed ([Real Life Examples](#)).

## Replication

The Newborn Screening Education Best Practice Framework has so far been used in three states and one international newborn screening program. Inherently, each user had different settings and populations to consider due to legislation and geographic location. Each user addressed a different newborn screening education issue, such as adding a condition to the newborn screening panel or updating regulations, so the framework has been useful in several different contexts within newborn screening education.

## Section II: Practice Implementation

### Internal Capacity

To implement the Newborn Screening Education Best Practice Framework, gather any relevant staff that are involved in planning or implementing newborn screening education and meet for a discussion session. Although the staff needed may vary, it may be helpful to include newborn screening program staff, lab staff, and local providers to discuss the framework questions. Gaining support from leadership is important before moving into implementation of the selected education approach.

Moving into the implementation and evaluation phases, the staff needed may vary depending on the specific context of the newborn screening education issue and the education approach selected.

### Collaboration/Partners

Relevant stakeholders must be included in the process of applying the Newborn Screening Education Best Practice Framework. Baby's First Test is available to partner for technical assistance. Stakeholders from various fields and relevant consumer communities should be consulted about decisions or present during discussion sessions.

Additional partners will be necessary during implementation of the selected newborn screening education approach. These partners will vary depending on the scope of the newborn screening education issue and the education approach selected.

### Practice Cost

The Newborn Screening Best Practice Framework itself can be accessed for free on the Baby's First Test [Resource Center](#). Baby's First Test does also offer customized technical assistance on using the framework for a fee. The exact practice budget will vary depending on the scope of the newborn screening education issue and the education approach selected.

Budget			
Activity/Item	Brief Description	Quantity	Total
Newborn Screening Best Practice Framework	Obtain a copy of the Framework Guiding Questions and Flowchart. This can be accessed free on the Baby's First Test <a href="#">Resource Center</a> .	1	\$0
Technical Assistance from the Baby's First Test Team	For a fee, Baby's First Test can provide technical assistance on how to use and apply the framework.	1	Varies
Discussion Sessions	Gather relevant staff and stakeholders for a discussion session. Account for meeting space, staff time, stakeholder compensation, and other meeting considerations. For example, providing food for attendees during the discussion would create an additional cost	Varies	Varies
Implementation	The cost of implementing the selected education approach will vary depending on the chosen approach and the duration of implementation. For example, creating a brochure would be much cheaper and quicker than launching a training program.	Varies	Varies
Evaluation	The cost of evaluating the selected education approach will vary depending on the chosen approach. For example, hosting an online survey may be cheaper than designing a randomized trial.	Varies	Varies
Total Amount:			Varies

### Practice Timeline

The Newborn Screening Best Practice Framework can be applied in a short amount of time. Typically, users have scheduled 1-2 short discussion sessions to go over the guiding questions and flowchart. The implementation timeline is much more variable. The exact practice timeline

will vary depending on the scope of the newborn screening education issue and the selected education approach.

Practice Timeline				
Phase	Description of Activity	Date/Timeframe	# of hours needed to complete/oversee activity	Person(s) Responsible
Planning/ Pre-implementation	Discussion Session(s) Scheduling	Before Discussion Session	1	Administrative Staff
Implementation	Discussion Session(s)	Before Implementation	1-4	Program Manager
	Implementation of Selected Approach	Varies	Varies	Program Manager
	Evaluation	During/After Implementation	Varies	Evaluation Manager
Sustainability	Technical Assistance on Selected Approach	After Evaluation	Varies	Program Manager

### Resources Provided

We developed a User Guide and a one-page sheet on Real Life Examples. Both of these are available on the Baby's First Test Website.

- [User Guide](#)
- [Real Life Examples](#)

We published one academic article about this work in the International Journal of Neonatal Screening. The publication can be found at the following link: <https://www.mdpi.com/2409-515X/5/2/22>.

### Lessons Learned

We found that all of our users have applied the Newborn Screening Education Best Practice Framework in a team-based discussion session. Subsequently, we now recommend that users take a team-based discussion approach and include all relevant stakeholders.

In interviews, some users discussed using the Newborn Screening Education Best Practice Framework for unexpected purposes. One of the users that we interviewed informed us that the New Zealand newborn screening program was using the framework and associated academic publication to appeal the discontinuation of their follow-up program. We intended the framework to be primarily used to support educational programs and materials, so we did not expect the

framework would be used to support advocacy for program funding. We interpreted this as a positive indicator that the framework has broader uses than the original intent of impacting programmatic work.

## Next Steps

Expecting Health will build out technical assistance around the Newborn Screening Education Best Practice Framework. Expecting Health currently offers support to states, hospitals, or other organizations interested in newborn screening education who want to apply the framework. Further, the framework will be incorporated into designing approaches for all of Expecting Health's newborn screening projects.

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