GUIDING QUESTIONS

What is the overall goal of the education?
What is the issue that needs to be addressed?
Are the plans people and purpose driven?
What type of information dissemination will meet the goal?

Why does the issue need to be addressed?
What is the cause of the issue?
What is the motivation to address the issue now?
How high is the priority?

Who is the target audience?
What is the geographical target area?
What special considerations are necessary for the target
population?

When does the intended change need to take place?
Is there an urgent need to address the issue? Provider needs,
family needs etc.

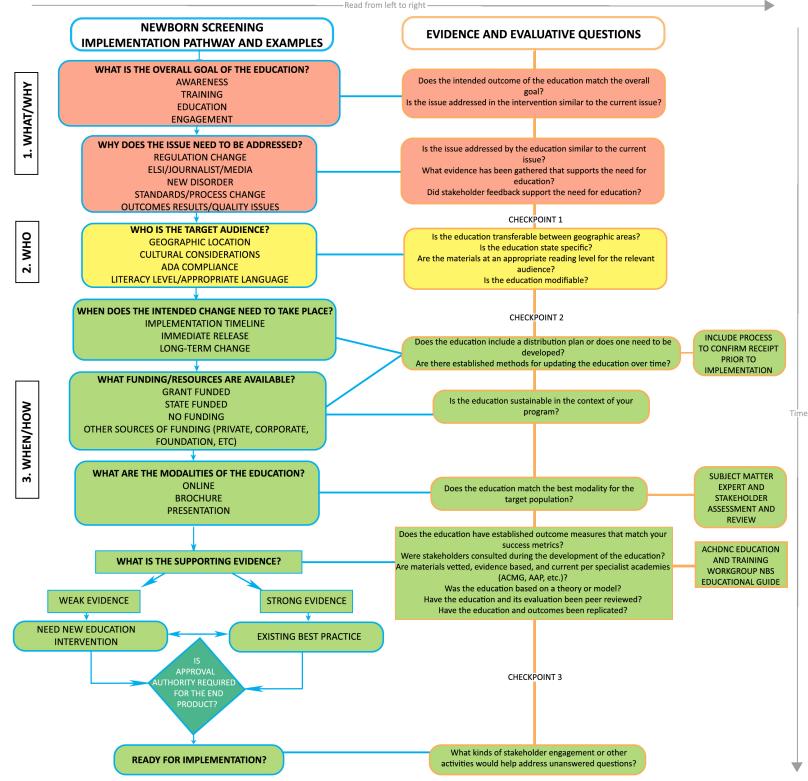
What modalities and distribution strategies are planned?

What resources are available for developing new materials or modifying existing materials?
What other barriers exist in developing/implementing?
What is the best modality for the target population?

Is the need, desired outcome, or audience unprecedented?

Are there existing education materials available to meet this need?







Newborn Screening Education Best Practices Framework: A User Guide

Getting Started

Baby's First Test developed this framework in partnership with our Best Practices Workgroup. Using evidence and input from a panel of experts from several fields, this framework will help you and/or your team determine if your education approach can be considered a best or promising practice. Newborn screening is a unique process with varying parts. For this reason, understanding the landscape surrounding a newborn screening education issue is essential to addressing it. This framework helps you define the traits of a newborn screening education issue and pair it with a best practice that matches those traits. The framework helps you decide if you should design an original approach to address the issue or apply an established strategy.

To begin, choose an education approach or practice that you want to use. An education approach can be a single education material, an education program, an education campaign, or any other strategy to improve a process, behavior, or health outcome.

There are **two parts** in this framework: a set of guiding questions and a flowchart.

Guiding Questions

Select your education approach and look over the guiding questions. The guiding questions show the overall concepts that form the core of the education approach. Answer all these questions then move to the flowchart. Use your answers to work through the flowchart. If you can't answer all the questions, it may be helpful to gather more information before moving to the flowchart.

Using the Best Practices Flowchart

The flowchart has three numbered levels: "1. What/Why"; "2. Who"; and "3. When/How." Each level has information on implementation and evaluation, as well as a checkpoint and associated color to assure everything has been properly evaluated. Read the information at each level from left to right, then move down to the next numbered level. As you pass through each checkpoint, you move closer to establishing the chosen education approach as a best practice. If the education approach fails a checkpoint, consider choosing a new approach or reworking components of the approach and start again.

Level 1: What/Why

In Level 1, start by establishing the overall goal for your education approach. Defining the traits of the issue and desired outcome(s) at the beginning will help determine the steps needed to reach your goal. Make sure there is a supported community need for the education approach. If there is no need, then no education approach is necessary. In newborn screening, some examples of evidence that support a need for education



are legislation, media coverage, adding new conditions to a panel, health outcomes, stories from stakeholders, or quality issues. Level 1 is colored red because it is best to stop at the highest level of planning if the approach doesn't pass *Checkpoint 1* and reconsider the approach.

Checkpoint 1

Before moving to Level 2, the education approach should pass the evaluation questions laid out in *Checkpoint 1*. Passing *Checkpoint 1* means the approach may be a best practice. The questions in this checkpoint are all "yes" or "no" questions. To move to Level 2, each of the questions in *Checkpoint 1* should have "yes" answers. If any answers are "no" or "maybe", the education approach may not be a best practice. Choose another approach or modify your current approach to pass *Checkpoint 1*.

Level 2: Who

Chart out the characteristics of the target audience. The education approach needs to fit the specific attributes and needs of the audience. Level 2 is colored yellow because your education approach may move to the next level if it fits the target audience or can be changed to fit the audience.

Checkpoint 2

Before moving to Level 3, the approach should pass *Checkpoint 2*. All questions at this checkpoint are "yes" or "no" questions. To pass, "yes" is not required for all questions. If the education approach matches the geographic area, state rules/laws, and reading level of the audience, the education approach may be a best practice and can move to Level 2. If the education approach can be changed to fit the audience, then it may be a best practice and can move to Level 2. If the education does not match any of the criteria and is not changeable, then it may not be a best practice.

Level 3: When/How

Identify any factors important in practical use of the approach. Each of these factors highlight the best, most practical course of action. Level 3 is colored green because once passing this checkpoint, you may move on to implement the education approach.

Checkpoint 3

Before making a final decision to use the chosen education approach, you should pass *Checkpoint 3*. The first six evaluation questions must have a "yes" answer. Together, measurements of success, stakeholder consultation, and evidence of need from stakeholders form a best practice for newborn screening education. The section below discusses how to apply the last four questions of *Checkpoint 3*.

Deciding on a New Approach or Existing Best Practice

The last step is to compare the chosen education approach with using a new program. To compare, weigh the quality the evidence supporting the chosen education approach as a best practice alongside the context of the newborn screening education issue. The last four questions of *Checkpoint 3* address the strength of evidence. If the need, desired outcome, or audience is unique in some way, then create a new approach to fit



the unique issue. For example, the addition of a new condition to the newborn screen may mean that there are no existing best practices. In these unique instances, a new education approach is best. For a unique case, skip the remaining four questions of *Checkpoint 3*. If there is no strong evidence to support an education approach as a best practice, then either a new approach or existing best practice is appropriate. If there is strong evidence to support an approach that passed through previous checkpoints, then that approach may be used as a best practice. Find supporting evidence in literature, specialist academies, and evaluations of other education programs that have similar approaches or audiences. The section below outlines how to use the last four questions of *Checkpoint 3* to decide if the supporting evidence is strong or weak.

Determining the Strength of Evidence

There are four fundamental "yes" or "no" questions used to determine strength. Strength is judged on a scale of 0-4, with 0 being the weakest evidence and 4 being the strongest. Each question answered with a "yes" gains a point.

- Are materials vetted, evidence based, and current per specialist, academies, known professionals in the topic or other trusted organizations?
- Was the education approach based on a theory or model?
- Has the education approach and its evaluation been peer reviewed?
- Has the education approach and its outcomes been replicated?

If the intervention scores a 0 or 1, revisit the approach to incorporate more evidence-based methods. If the approach scores a 2, stop and gather targeted stakeholder feedback on the approach. With positive stakeholder feedback, the approach may be used as a best practice. Conversely with negative stakeholder feedback, choose a different education approach. If the education approach scores a 3 or 4, the approach may be used as a best practice.

Implementation

To be sure the approach you chose truly worked as a best practice, measurements must prove that the approach made progress on the overall goal. You must track the education approach to measure progress. Monitoring and evaluation using relevant measurements and tools are essential to that process.

Example of Using the Framework

Below is an example of using the Newborn Screening Best Practices Framework. In this example, the newborn screening education issue is the use of the term "the PKU test" instead of the term "newborn screening" in clinical practice. This example will take the perspective of a state newborn screening program.

For this issue, here are the answers to the guiding questions:

- **Goal:** The goal is to raise awareness in clinicians about using the more current, correct term "newborn screening" rather than "PKU test".
- **Issue:** Clinicians frequently use the term "the PKU test" instead of the term "newborn screening". This can be misleading to families.



- People Driven: The issue has been discussed by both family and professional stakeholders.
- Type of Information Dissemination: Raising awareness among clinicians about the distinction between these terms will accomplish the goal.
- Target Audience: Clinicians within the state are the target audience.
- **Geographic Area:** The geographic area is the state.
- **Special Considerations:** In addressing this issue, it's important to acknowledge where clinicians are seeing or hearing the term "PKU test." Address all sources.
- When: Initiate the change as soon as possible to avoid further misinformation reaching families, but clinicians will need time to change their behavior.
- **Urgency:** Yes. Clinicians using this term are interacting with families every day.
- **Modalities/Distribution:** The chosen modality is an educational material. The material will be distributed through networks of hospital staff.
- Resources: The state has limited funding to pay for the development of new resources. The education approach must be inserted into current methods. The state does have access to design software and other materials that address this topic.
- **Barriers:** One significant barrier will be the behavior change necessary to increase the use of the term "newborn screening."
- Best Modality: The best modality for the target population would be a handout or a poster.
- **Precedence:** Baby's First Test addressed the desired outcome through an educational material.
- Existing Materials: The resource available is the "Newborn Screening: More Than a PKU Screen" document developed by Baby's First Test.

With these answers to the guiding questions, we will now use the flowchart to look at whether the example approach passes through the flowchart. The example approach is the document "Newborn Screening: More Than a PKU Screen" document.

Material 1: Newborn Screening: More Than a PKU Screen

Checkpoint 1

Material 1 was designed by Baby's First Test specifically to address the use of the term "the PKU test" by clinicians. The goal of Material 1 is to raise awareness of the term "newborn screening" in clinical use. Material 1 was created through collaboration with stakeholders from state newborn screening programs.

Since the goal, issue, and supporting evidence of Material 1 all match the relevant newborn screening education issue, this document passes *Checkpoint 1*.

Checkpoint 2

Material 1 is designed for a national audience but can be changed to include state specific statistics and stories. Material 1 is written in plain language

Since Material 1 can be changed to fit specific audiences, it passes *Checkpoint 2*.



Checkpoint 3

Material 1 was originally distributed through networks of state newborn screening staff, has methods for changing/updating content already in place, would be low cost to produce since it has already been developed by another organization, and is already in the best format for the target population. There are two outcome measures for Material 1 including number of copies distributed and awareness of the correct term through pre and post-tests at trainings. A state program can replicate both measurements. Material 1 was developed with family and professional stakeholder feedback. Material 1 passes the first six questions of *Checkpoint 3*.

Material 1 scores a 3 on the evidence scale as it is based on evidence, vetted, and current, per Baby's First Test. Material 1 accounts for the Transtheoretical Model of Health Behavior Changeⁱ, by raising awareness of underinformed individuals in the Precontemplation stage. Material 1 was also replicated in other states. With this score, Material 1 is a best practice for the context of this specific newborn screening issue and can move to implementation.

Technical Assistance

If you would like to learn more about the background of this framework or have support applying it, please contact Natasha Bonhomme at natasha@babysfirsttest.org for more information.

ⁱ Prochaska, J. O., & Velicer, W. F. (1997). The Transtheoretical Model of Health Behavior Change. American Journal of Health Promotion, 12(1), 38-48.