

AN IMPLEMENTATION TOOLKIT FOR STATE NEWBORN SCREENING PROGRAMS

A GUIDE TO IMPLEMENT NEWBORN SCREENING
EDUCATION FOR EXPECTING FAMILIES



Expecting **Health**

ABOUT

EXPECTING HEALTH

Born from Genetic Alliance, a nonprofit organization rooted in 37 years of community programs and representing national voices and family-centered experiences, Expecting Health shares science-based and policy-informed information that reflects the lived experiences of individuals and their families. We do this through the power of relationships, convening the top experts, working with key leaders in health, and engaging with families and communities at the center of the conversation.

The Newborn Screening Education and Communications Workgroup, run by Expecting Health, is a collaboration of newborn screening (NBS) system stakeholders, including families, newborn screening laboratory and follow-up staff. Through the convening and collaboration of this workgroup, this guide was developed. With this guide we aim to help states implement readily available program resources for expecting families to learn more about newborn screening during pregnancy.



This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$400,000 with 0 percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.



WHY DO WE NEED PRENATAL EDUCATION FOR NEWBORN SCREENING?

Successful education and engagement of families requires a multifaceted approach, including involvement at the local, state, and national levels. Despite a significant body of literature and guidance from professional societies such as the American College of Obstetricians and Gynecologists (ACOG) stating that education for newborn screening ideally occurs during pregnancy, this is not common practice among prenatal providers today.

Barriers to prenatal education implementation have historically included provider lack of comfort and confidence to provide information to patients and/or clients about newborn screening. Additionally, prenatal care providers, and families, are inundated with information during pregnancy, making the implementation of newborn screening education during this important time period challenging.



HOW TO USE THIS TOOLKIT

This toolkit is divided into 6 domains of implementation. Each domain contains a checklist to help guide you and your partners through implementation.


Each section also contains tips, resources, and templates that can be used and customized to support your implementation process.

If you need assistance accessing any of the resources, please contact the Expecting Health Team.

This Toolkit Includes:

- Checklists to support each stage of implementation
- Tips & tricks to strengthen planning
- Resources & templates to simplify the process

IMPLEMENTATION DOMAINS



01

Partner Identification

02

Develop a Project Plan

03

Workflow Design

04

Materials Development

05

Evaluation & Data
Collection

06

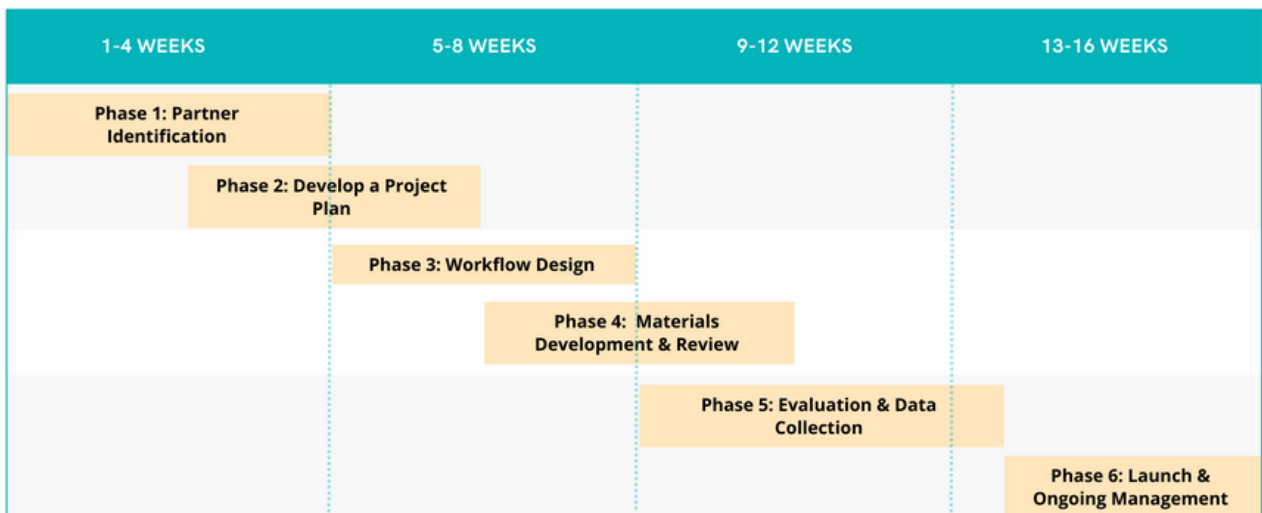
Program Launch &
Ongoing Management

Implementation Timeline

The following Gantt Chart provides a high-level overview of the estimated time to complete each domain of implementation. Times of implementation may vary based on your institution or organization's operations.

Internal review processes and procedures should always be considered when planning the anticipated timeline for implementation. Based on initial pilot experiences, the average length of time for implementation was 4-6 months. The most significant variations are related to internal review processes and variable print times.

Implementation Timeline



Tips for Successful Implementation:

- Identify a champion in each of the clinics you will be working with.
- Establish a regular bi-weekly check-in call throughout implementation
- Establish measures of success early in your project planning. How will you know you have reached your goals?
- Use the templates, tools, and resources on the following pages to track your progress towards your goals.

Tools to Support Project Planning

The following template is available to support your planning and tracking implementation efforts. Each section includes specific tasks for every implementation domain and can be edited to show the primary task owner and status. Project planning tools like this help ensure that users stay on track and complete tasks in a timely manner.

Use the link provided to download the template in Google Sheets or as an Excel workbook.

Implementation Task	Owner (names to be filled in)	Target Completion Date	Status	Completion Date	Notes
1.0 Partner Identification & Discovery					
Generate a list of potential partners (suggestions may include: midwives, birthing centers and community clinics. TIP: reach out to your states PQC or other perinatal groups, medically underserved or excluded areas, areas where you wish to make a change in rate of NBS acceptance)	NBS Program				
1.1					
1.2 Initiate outreach to identified target clinics with aim to secure pilots in 1-3 clinics	NBS Program				
1.3 Share and Align on program overview (template available)	NBS Program				
1.4 Share pilot overview proposal/one pager to support internal partner discussions (template available)	NBS Program				
1.5 Set up introductory calls to gauge interest and assess current clinic workflow with potential partners	NBS Program				
1.6 Establish clinic needs and potential barriers	NBS Program & Partner				
1.7 Select clinic location (if large system with multiple locations, consider starting in 1 clinic and expand from there)	Partner				
1.8 Sign partnership MOU	Partner				
2.0 Develop a Project Plan					
2.1 Schedule & Host kick off meeting (template slides available)	NBS Program				
2.2 Establish regular calls with workgroup/site champion(s)	Partner				
2.3 Share brief program overview, lessons learned	NBS Program				
2.4 Discuss Current clinic workflow	NBS Program & Partner				
2.5 Discuss Implementation Timeline	NBS Program				
3.0 Workflow Design					
3.1 Determine how materials will be disseminated (virtual, paper, combination, sent in an email or posted on website/social)	NBS Program & Partner				
3.2 Determine when initiative will be introduced (third trimester, at home, specific clinic visit)	NBS Program & Partner				

<https://docs.google.com/spreadsheets/d/1iWiV7QAzO1bfWQssLYerkYuxHAQg291or8jYu1Sgy3l/edit#gid=0>

01

PARTNER IDENTIFICATION



IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	<p>Generate a list of potential partners (suggestions: midwives, birthing centers, and community clinics).</p> <p>TIP: reach out to your state's Perinatal Quality Collaborative (PQC) or other perinatal groups, and medically underserved or excluded areas, areas where you wish to make a change in rate of NBS acceptance)</p>
<input type="checkbox"/>	<p>Initiate outreach to potential partners with aim to secure pilots in 1-3 locations</p>
<input type="checkbox"/>	<p>Set up introductory calls to gauge interest and assess current clinic workflow with potential partners</p>
<input type="checkbox"/>	<p>Share pilot overview proposal/one pager to support internal partner discussions (template available)</p>
<input type="checkbox"/>	<p>Share and align on program overview (see page 14)</p>
<input type="checkbox"/>	<p>Establish clinic needs and potential barriers</p>
<input type="checkbox"/>	<p>Select clinic location (if large system with multiple locations, consider starting in one clinic and expanding from there)</p>
<input type="checkbox"/>	<p>Sign partnership Memorandum of Understanding (MOU). Template available upon request.</p>

Partner Identification

We believe the prenatal time period provides a unique opportunity to introduce newborn screening information to expecting moms at an optimal time prior to delivery. Additionally, we anticipate that expecting moms receiving this information from a trusted source, like their doctor, doula, midwife, or other birthing provider, will increase engagement, confidence and knowledge of what to expect with the newborn screening process.

The purpose of this initiative is to increase awareness of the process and importance of newborn screening (NBS) by introducing education during routine pregnancy visits.

Problem Statement:

Many families are unaware of newborn screening prior to their baby's delivery. Families from medically underserved communities are less aware than families from non-medically underserved communities.

TIPS FOR IDENTIFYING PARTNER SITES

- Evaluate the data sources you have and determine if there are particular hospital systems, birthing centers, or other areas where you would like to increase awareness of NBS during pregnancy.
- Connect with prenatal groups in your state, such as the Perinatal Quality Collaborative (PQC), doula groups, Federally Qualified Health Centers (FQHC), and large birthing centers or hospital systems.

USE THIS FRAMEWORK TO GENERATE PARTNER BUY-IN:

- **REFLECT:** Start with the **WHY**. Discuss and brainstorm the current state of prenatal education efforts already in place in your state. Have they been successful? Why or why not? Why is prenatal education for NBS important for your NBS program?
- **BUILD KNOWLEDGE:** Collect examples of data that support the need for prenatal education. Examples include:
 - Receiving NBS information prenatally and from a health care provider increases parent satisfaction. (1)
 - Parents state that NBS education should start prior to labor and delivery. (2, 3,4)
 - Prenatal NBS education is recommended by experts, including ACOG. (5,6)
 - Prenatal NBS education is not common practice among prenatal care providers. (7)
 - State-specific data
- **GENERATE ACTION:** Identify and write down your goals using the guide on the next page. Think about ideal partners and identify who to contact in each group.

1. Aria... & Potter. <https://www.nature.com/articles/gim201287>

2. Tluczek et al. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947955/>

3. Campbell & Ross. https://www.sciencedirect.com/science/article/abs/pii/S0002937803021689?casa_token=c2mtcWIGo5A4AAAAAzyF1YM94FpSpqjnd0ucNnc0IXuclmGnx6t5DKh890ILi6jkt_uUWRotX5Lk_E0CAHDR-1MPU

4. Davis, et al. https://www.publications.aap.org/pediatrics/article-abstract/117/Supplement_3/5326/68860/Recommendations-for-Effective-Newborn-Screening?redirectedFrom=fulltext

5. Botkin, Rothwell, et al. <https://jamanetwork.com/journals/jamapediatrics/article-abstract/2506139>

6. ACOG. [Add a little bit of body text](#)

7. Faulkner et al. https://www.sciencedirect.com/science/article/abs/pii/S0002937805007726?casa_token=5tQNGuqygcIAAAAA_gRoxXIB7ALFW-3ifsbQ_KeAIV0ZBSSA4xc5KlyjHFXBHEIYCa40pzlF9jQEV80IZ3ijyZMIs

Example Goals:

- *To increase awareness of the process and importance of newborn screening (NBS) in medically underserved populations by introducing education during routine pregnancy visits.*
- *To assess accuracy of knowledge regarding how, when and why newborn screening occurs.*
- *To provide families with additional information and resources regarding out-of-range newborn screening results.*
- *To reduce the rate of refusal in a particular region of the state.*

ESTABLISH YOUR PROGRAM GOALS

What do you hope to see happen as a result of this program?



Identify 1-3 Partner Sites:

Who will share these goals and be a champion for this project?

Partner 1

Partner 2

Partner 3



Action Steps:

Action Steps:

Action Steps:



02

DEVELOP A PROJECT PLAN

IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	Schedule & Host kick off meeting (template slides available)
<input type="checkbox"/>	Establish regular calls with workgroup/site champion(s)
<input type="checkbox"/>	Share brief program overview, lessons learned
<input type="checkbox"/>	Discuss Current clinic workflow
<input type="checkbox"/>	Discuss Implementation Timeline

Tips for Successful Implementation:

- Identify a "champion" and main point of contact in each of the clinics with whom you will be working.
- Establish a regular bi-weekly check-in call throughout implementation.
- Establish measures of success early in your project planning. How will you know you have reached your goals?
- Use the templates, tools and resources on the following pages to track your progress towards your goals.

Project Overview

BACKGROUND:

Successful education and engagement of families requires a multifaceted approach, including involvement at the local, state, and national levels. Despite a significant body of literature and guidance from professional societies such as the American College of Obstetricians and Gynecologists (ACOG) stating that education for newborn screening ideally occurs during pregnancy, this is not common practice among prenatal providers today.

Barriers to prenatal education implementation have historically included provider lack of comfort and confidence to provide information to patients and/or clients about newborn screening. Additionally, prenatal care providers, and families, are inundated with information during pregnancy, making the implementation of newborn screening education during this important time period challenging.

THE HOW

Expecting Health, in collaboration with several partner groups, including a community-based clinics in Texas and Indiana, developed and implemented a quality improvement program providing an NBS education initiative in community based prenatal settings. The program introduced an NBS educational opportunity during routine third-trimester clinic visits. This model has been piloted in two unique communities supporting families from medically underserved areas, including 1) a Latino group in Houston, Texas 2) Plain Community in Indiana. To evaluate, we conducted web-based surveys before (pre-test) and after (post-test) the participant reviewed a printed or digital educational Flip book.

RESULTS

Pilot 1: Latino/Urban (Spanish) Community in Houston, Texas

- Over 10 weeks, a total of **56 participants completed** the initiative and **79 participants read through the Flip book**.
- Approximately **90% of participants completed the initiative, digitally and in their preferred language (English or Spanish)**.
- The mean time spent reading the Flip book was **2.5 minutes**.

Pilot 2: Plain Community (Amish/Mennonite) in rural Indiana

- Over 10 weeks, a total of **27 participants completed** all three parts of the initiative.

All participants **completed the initiative on paper and in English**.

CONCLUSIONS

- This educational Flip book is a successful tool to raise awareness for and increase knowledge of newborn screening.
 - *Integrating into existing workflows is key*
 - *Leveraging relatable mechanisms for learning was also important*
- Prenatal groups AND state laboratories have shown interest in increasing efforts to educate families about newborn screening during pregnancy.
- Long-term studies are needed to demonstrate the impact of education on the NBS system.

M. Raia1, N. Bonhomme, B. Miller, J. Weirker; Expecting Health at Genetic Alliance, Damascus, MD, Children's National Hospital, Washington, DC, Indiana Community Health Clinic, Topoka, IN

BACKGROUND

Successful education and engagement of families requires a multifaceted approach including involvement at the local, state and national levels. Despite a significant body of literature, as well as guidance from professional societies such as ACOG, stating that education for newborn screening ideally occurs during pregnancy, this is not common practice among prenatal providers today).

Barriers to prenatal education implementation have historically included provider lack of comfort and confidence to provide information to patients and/or clients around newborn screening. Additionally, prenatal care providers as well as families are inundated with information during pregnancy making time for newborn screening education challenging to implement during this critical time period.

THE NEED

Receiving NBS information prenatally and from a health care provider increases parent satisfaction.¹ Parents state that NBS education should start prior to labor and delivery.^{2,3,4} Prenatal NBS education is recommended by experts, including ACOG.^{5,6} Prenatal NBS education is not common practice among prenatal care providers.⁷

*References available upon request

THE HOW

The program piloted the model in two unique communities supporting families from medically underserved areas including 1) a Latino group in Houston, TX 2) Plain Community in Indiana.



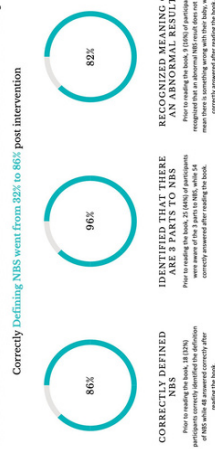
In an effort to increase awareness and knowledge of newborn screening in pregnant people, the program established a model for delivering newborn screening education in prenatal settings.

Key Strategies Used :

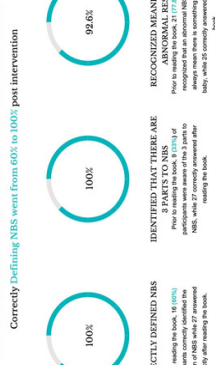


We developed and implemented a quality improvement program providing an NBS education initiative in a community based high-risk obstetrics and gynecology clinic. The program introduced an NBS educational opportunity during routine third-trimester clinic visits. To evaluate, we conducted web-based surveys before (pre-test) and after (post-test) the participant reviewed a printed or digital educational Flip book.

RESULTS FROM INITIAL PILOT PROGRAM AT LBJ



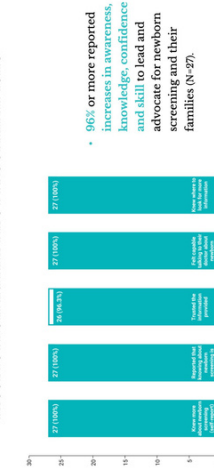
RESULTS FROM INITIAL PILOT PROGRAM AT ICHC



RESULTS FROM INITIAL PILOT PROGRAM AT LBJ



RESULTS FROM INITIAL PILOT PROGRAM AT ICHC



MATERIALS



RESULTS

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CONCLUSIONS

- This educational Flip book is a successful tool to raise awareness and increase knowledge of newborn screening. *Integrating into existing workflows is key*
- Important*
- Prenatal groups AND state laboratories have shown interest in increasing efforts to educate families about newborn screening during pregnancy.
- Long term studies are needed to demonstrate impact of education on the system.

This project was funded by the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA), grant no. U54MC23105.



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www.ExpectingHealth.org

What is the current state of the partner clinic? (ex: describe the audience)

What is the clinic currently doing to provide NBS education to patients?

Are there any existing newborn screening resources being shared?

What are the opportunities and/or gaps to NBS education in the clinic?

When will we meet again and how often? (suggest every other week)

03

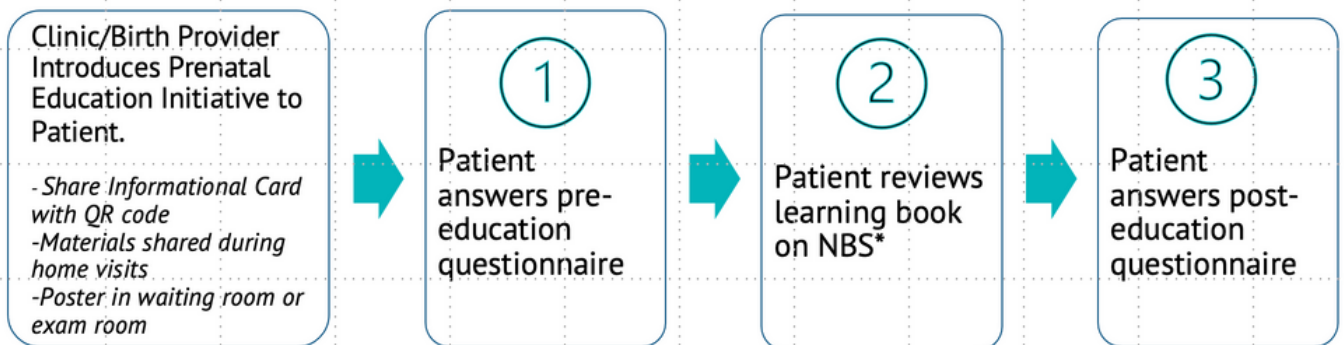
WORKFLOW DESIGN

IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	Determine when & where educational materials will be disseminated to patients (virtual, paper, combination, sent in an email, or posted on website/social media)
<input type="checkbox"/>	Determine when initiative will be introduced (third trimester, at home, or specific clinic visit)
<input type="checkbox"/>	Determine if specific data will be collected through the initiative (see evaluation section below)
<input type="checkbox"/>	Identify primary clinic/prenatal group to partner with

Incorporating this educational initiative into existing workflows will enable a seamless implementation. Introducing newborn screening during prenatal visits is simple; however, it is vitally important to ensure an active introduction from a trusted source rather than a passive experience, such as brochure or flyer. We have seen more engagement when there is an encouraging reminder that learning about NBS is important to both the patient and their baby, and that the educational flip book will help parents feel more prepared for what to expect. During your partner discussions, it is important to spend time discussing existing workflows and identify ways that newborn screening materials can be integrated into existing opportunities.

Example Workflow



**Materials and flipbook available in printed or digital formats in both English and Spanish*

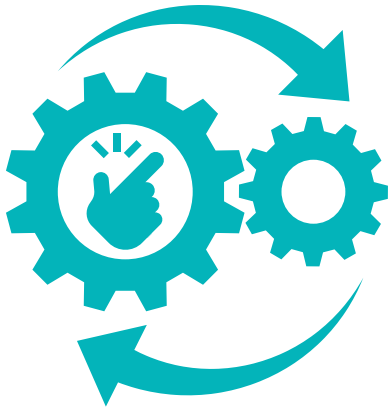
Determine, when, where and how patients are being seen? (ie-in a clinic/lab setting, at home, etc.)

Are there any other key milestones or assessments that are already in place? (ie-screenings, glucose testing, during vitals, in-home services, etc.)

Sketch Your Workflow

Questions to Consider When Designing Your Workflow:

1. When will patients be introduced to newborn screening?
2. Who will be discussing this education with patients/families?
3. What resources will we use to introduce the opportunity (i.e. info card with QR code, poster in lobby/examination room, printed flip book-see materials section for resources and scripts to utilize)
4. Will we need materials available in digital or printed forms? Both?
5. Is there an electronic or digital way to share/communicate the flip book with patients?
6. How will we identify which patients are visiting for a third trimester visit?
7. Is any documentation needed in the EMR or elsewhere to determine this education has been shared with the patient?
8. Determine the length for the pilot (recommend 12 weeks minimum)
9. What additional software platforms (if any) may be needed? (See next page for examples.
10. What evaluation measures will be collected and which tools will be used to collect this information?



Helpful Software Programs & Tools for Consideration

QR Code Generators



QR code generators are useful tools to easily and quickly direct patients to the online learning book. There are many QR code generators. The pilot program utilized QR Tiger (<https://www.qrcode-tiger.com/>).

TIP: Using “dynamic QR codes” allows for easy updates to a URL or content as it changes. Additionally, look for a QR code management tool that allows for tracking the number of scans and views.

Digital Flip book Platform



In order to facilitate a more engaging online learning experience, the learning book can be uploaded into an online flip book maker which converts pdf into a readable online book. Free versions of this are available through multiple software platforms. The pilot program utilized Flipsnack (<https://www.flipsnack.com/>).

TIP: Finalize your flip book, save as a pdf, to then upload into the platform. Paid subscription are available and have enhanced features as well as statistics/tracking options.

Evaluation Tools



A key part of monitoring your pilot program's success is to identify what information/data you will track and ensure that you have an ideal data collection tool. Examples may include Google Forms, SurveyMonkey, and other assessment tools you already have in place. See the Evaluation & Measures section for more information and tips on data collection.

04

MATERIALS DEVELOPMENT

IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	Review educational “tool” (aka Flip book) & determine if customization is required
<input type="checkbox"/>	Determine what legal or organizational review is required by partner site
<input type="checkbox"/>	Review patient information card & determine if customization is required (cards are strongly suggested if using digital materials, generate custom QR code if needed)
<input type="checkbox"/>	Determine if translation of materials is needed
<input type="checkbox"/>	Test materials with smaller group of patients/staff informally & collect feedback (template survey available for use)
<input type="checkbox"/>	Finalize & approve materials (flip book, patient info card & assessment questions)
<input type="checkbox"/>	Create digital Flip book in software program (Flipsnack or alike)
<input type="checkbox"/>	Create unique QR code (suggested software program QR Tiger or alike)
<input type="checkbox"/>	Print and ship necessary materials

The following section includes resources and materials developed through initial pilot programs with diverse, high-risk, and medically underserved community groups. These resources were developed with, and alongside, our primary audiences to ensure we are **meeting our stakeholders where they are and addressing their needs**. These resources are available in downloadable and editable forms so that you can customize them to meet your community's needs.

Each of these resources should be reviewed by you and your partner teams to ensure that the communities you will be working with feel represented in the words, images, colors and depictions seen in each of these resources.

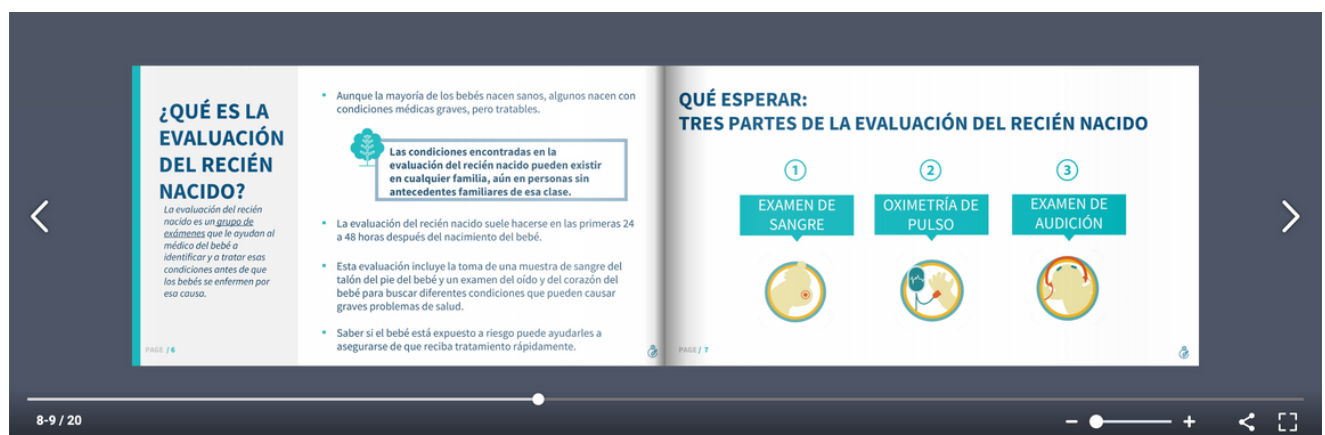
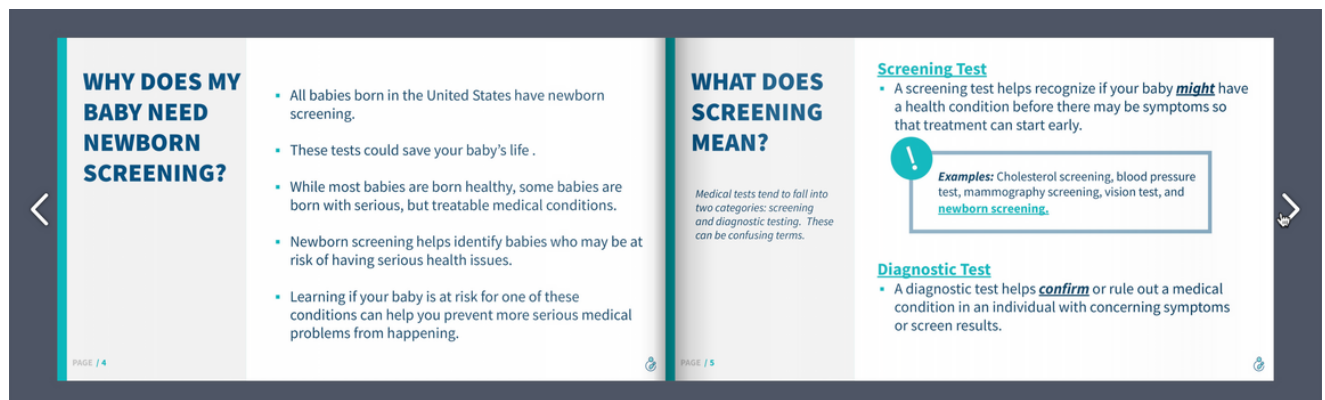
- Seek feedback from providers, staff, and families in the clinic before launch to ensure the educational tool is representative of the community.
- Update images to best fit community needs and perspectives.
- Add in links to state-specific resources and ensure all links are accurate.
- Before printing final materials, have someone who is not a part of the project planning team review all materials with fresh eyes to ensure accuracy and that all links are working properly.
- Account for review and printing time in your project planning.

Prenatal Education Flip book

The prenatal "Flip book" is available in both print and digital formats. Generate a QR code and use it to direct patients to the flip book using the dissemination resources previously shared. The flip book contains information about why newborn screening is important, when it is completed, possible results, as well as additional resources for families. This flip book can be tailored as needed to include state-specific information and links to local resources.



Currently, the flip book is available in English and Spanish. Additionally, images and graphics can be changed. It is important that the pictures included in the materials are representative of the community you will be working with.



To view the online version of the flip book, visit:

https://navigatenbs.expectinghealth.org/toolkit-Flip_book-english-nov-2021/full-view.html

Patient Information Card

The following patient information card is available in 4x6 or 5x7 and is a useful tool to help families gain access to prenatal education materials. These cards can be disseminated in a variety of locations.

Prenatal Clinic Visits

Distribute this card to patients as they are roomed and waiting to be seen by the clinician. Share it with them when they are having their vitals taken.

Home Prenatal Visits

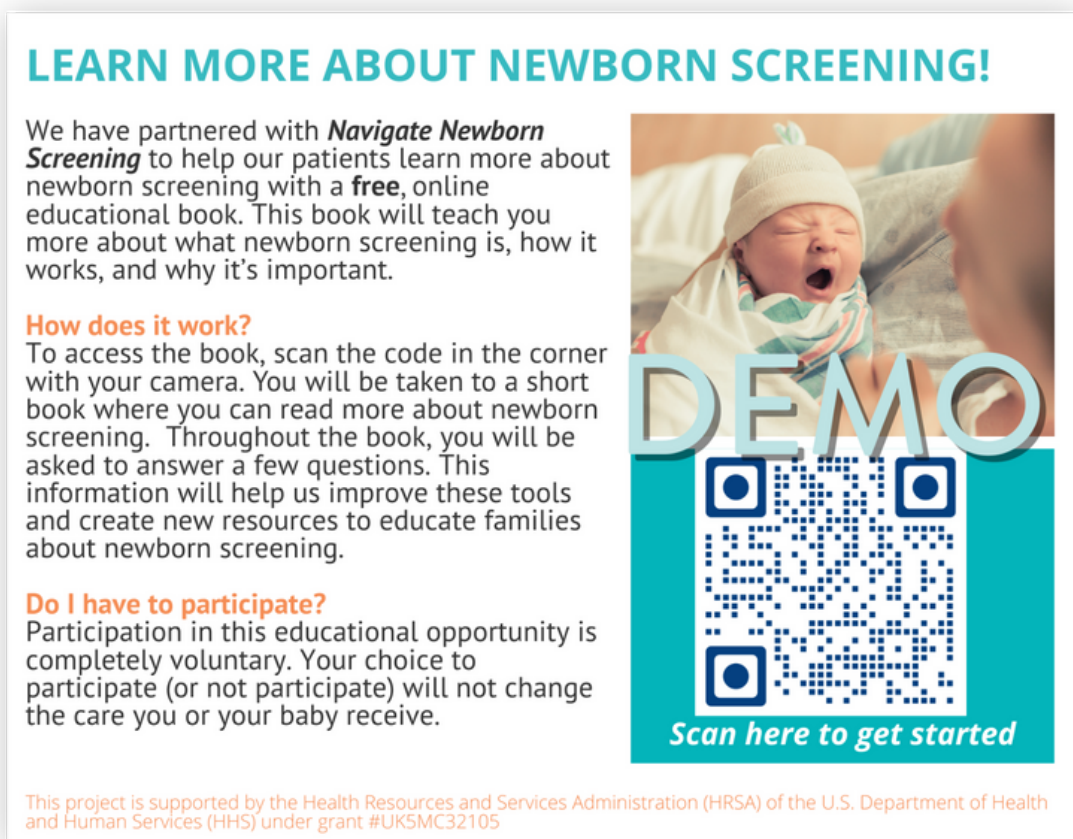
Partner with doulas, WIC offices, and other home visiting groups to share this card when visiting expecting moms in their homes.

Birthing Centers

Share with staff and families that are delivering at birthing centers. Encourage families to learn about newborn screening prior to delivery.

Hospitals

Have these cards available on delivery floors so that staff can disseminate to patients as they are administering newborn screening.




LEARN MORE ABOUT NEWBORN SCREENING!

We have partnered with *Navigate Newborn Screening* to help our patients learn more about newborn screening with a **free**, online educational book. This book will teach you more about what newborn screening is, how it works, and why it's important.

How does it work?
To access the book, scan the code in the corner with your camera. You will be taken to a short book where you can read more about newborn screening. Throughout the book, you will be asked to answer a few questions. This information will help us improve these tools and create new resources to educate families about newborn screening.

Do I have to participate?
Participation in this educational opportunity is completely voluntary. Your choice to participate (or not participate) will not change the care you or your baby receive.

DEMO



Scan here to get started

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant #UK5MC32105

Customize

Want to add local or state-specific information to this patient information card? Reach out to mraia@expectinghealth.org for technical assistance.

Learn More Poster

This poster (16 x 20 in) is designed to hang in waiting rooms, exam rooms, bathrooms, community centers, and other family hubs so that families can learn more about newborn screening BEFORE they deliver their baby.

Hang It Up

Hang in high-traffic areas such as prenatal, pediatric and specialty care offices, community centers, WIC offices, etc.

Print & Share

Send in the mail, share at in-person events, distribute in prenatal, pediatric and specialty clinics.



The poster is titled "LEARN MORE ABOUT YOUR BABY'S FIRST TEST" and features a teal and orange color scheme. It is divided into several sections: "WHAT IS NEWBORN SCREENING?" (orange background), "BLOOD SPOT SCREEN", "HEARING SCREEN", "HEART SCREEN", "WHEN WILL MY BABY HAVE NEWBORN SCREENING?", "WHAT CONDITIONS WILL MY BABY BE SCREENED FOR?", "WHY DOES MY BABY NEED NEWBORN SCREENING?", "GET PREPARED", and "LEARN MORE". It includes icons for a blood drop, an ear, and a heart, as well as a QR code and a photo of a family. The website www.expectinghealth.org is listed at the bottom.

LEARN MORE ABOUT YOUR BABY'S FIRST TEST

WHAT IS NEWBORN SCREENING?

Newborn screening is a 3-part test that checks babies to see if they are at increased risk of having a number of serious health conditions that can affect any baby. These tests are given to all babies born in the United States unless declined by a parent or guardian.

BLOOD SPOT SCREEN

A small blood sample is taken from your baby's heel, placed on a newborn screening filter card, and sent to a state laboratory for analysis

HEARING SCREEN

A quick and safe test of your baby's hearing will be completed to determine if your baby's brain and auditory brain stem respond to sound.

HEART SCREEN

A pulse oximetry or "pulse ox" test uses a small sensor to measure the amount of oxygen in your baby's blood and helps to detect Critical Congenital Heart Disease (CCHD).

WHEN WILL MY BABY HAVE NEWBORN SCREENING?

Babies typically receive newborn screening 24-48 hours after they are born. Tests done outside of this time may be less accurate or need to be redone.

WHAT CONDITIONS WILL MY BABY BE SCREENED FOR?

Every state requires newborn screening. Each state is different and decides which conditions will be included in their screen based on the recommended list provided by the United States Secretary of Health and Human Services.

WHY DOES MY BABY NEED NEWBORN SCREENING ?

A baby can have the conditions included in newborn screening even if they look and act healthy at birth. These conditions must be identified early and treated quickly to prevent serious health outcomes, disability, and even death.

GET PREPARED

We have partnered with *Navigate Newborn Screening* to help our families learn more about newborn screening with a free online educational book. This book will teach you more about what newborn screening is, how it works, and why it's important.

LEARN MORE

Scan the code to learn more about newborn screening.

www.expectinghealth.org

Customize

Want to add local or state-specific information? Want to add your unique enrollment link? Reach out to mraia@expectinghealth.org to discuss.

05

EVALUATION &
DATA
COLLECTION

IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	Identify a main point person on the team to establish & manage data collection
<input type="checkbox"/>	Define specific aims of pilot program
<input type="checkbox"/>	Define program evaluation plan (share question template & determine if partner would like to collect pre & post-test data, post only or no data collection)
<input type="checkbox"/>	Set up data collection tools: pre & post-test evaluations (Google Form or printed paper copies)
<input type="checkbox"/>	Determine frequency of data analysis & outcomes

Establishing Evaluation Measures

The purpose of this section is to support and help you establish an outcome evaluation to determine if this educational initiative (Pilot Program) is successful. This section will be based on the specific goals and objectives you set during your project planning. Examples are listed below but can be modified to meet you and your partner's needs to increasing awareness, knowledge, and perceived importance of newborn screening among pregnant women.



- To what extent does the Pilot Program increase awareness of newborn screening among medically underserved pregnant women?
- To what extent does the Pilot Program increase knowledge related to newborn screening among medically underserved pregnant women?
- To what extent does the Pilot Program increase perceived importance of newborn screening among medically underserved pregnant women?
- To what extent does the Pilot Program increase self-efficacy to find additional information about newborn screening among medically underserved pregnant women?

To evaluate the Pilot Program, you can elect to conduct a web-based or paper survey before the participant reviews the flip book and a second web-based or paper survey after the participant reviews the flip book. Responses from these pre- and post-tests can then be compared to assess to what extent the Pilot Program was successful.

The following pages share a copy of the questions that were used with the initial two pilot sites, and are available in both English and Spanish translations.

QUESTIONS TO CONSIDER:

- Will your patients/families need to complete this questionnaire on paper or online?
- What evaluation tool will work best for your community (Google Form, SurveyMonkey, etc.?)

Navigate Newborn Screening

An Expecting Health Program

Welcome! You are here to learn more about newborn screening and why it is important to your baby's health. Many moms do not know about newborn screening before their baby is born. By sharing this information now, we hope you will feel more prepared for one of the first tests your baby will have.

You will be asked to answer a few questions about what you may already know about newborn screening. It is ok if you have not heard of this before. Then, you will look at a short book to learn more about newborn screening. After you've read the book, we will ask you to answer a few more questions. This will help us understand if the booklet is helpful to parents.

This should take you about 10-15 minutes to finish. You may choose to skip any question or stop at any time. Your midwife or doctor will not see your answers.

This program is being managed by the Indiana Community Health Clinic and Expecting Health, a non-profit organization focused on supporting families and health professionals in pregnancy and newborn health. If you have questions about this program, you may call Marianna Raia, at (281) 728-2196.

First, we would like to ask you a few questions about you and your pregnancy.

1. How many times have you given birth?

- 0
- 1
- 2
- 3
- More than 3 Times
- I don't know

2. How far along are you in this pregnancy?

- 28-31 weeks (6 months pregnant)
- 32-35 weeks (7 months pregnant)
- 36-39 weeks(8 months pregnant)
- 40 or more weeks (9 months pregnant)
- I am less than 28 weeks(0-5 months pregnant)
- I don't know

Next, we will ask you some questions about what you may already know about newborn screening.

3. Before today, had you ever heard of newborn screening?

- Yes
- No
- I don't know

Navigate Newborn Screening

An Expecting Health Program

Please tell us how much you agree or disagree with the following statement. Circle your answer.

4. It is important for me to know about newborn screening.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
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5. What is newborn screening?

- A test given 1 minute and 5 minutes after birth to quickly check a baby's health.
- Tests performed 24-48 hours after birth that tests babies for serious, but treatable conditions.
- A vitamin K shot given soon after birth to prevent bleeding in babies.
- All of the above
- None of the above
- I don't know

Please tell us if you think each statement below is true or false. Don't worry if you are not sure about the answer, you can say you don't know.

6. There are 3 parts to newborn screening.

- True
- False
- I don't know

7. Newborn screening helps identify babies who may be at risk of having serious health issues.

- True
- False
- I don't know

8. Newborn screening usually takes place one week after a baby is born.

- True
- False
- I don't know

9. An abnormal result always means there is something wrong with my baby.

- True
- False
- I don't know

Navigate Newborn Screening

 An Expecting **Health** Program

Please take time to read the booklet about newborn screening. On the next page, we will ask you some questions about what you learned.

Navigate Newborn Screening

An Expecting Health Program

Please tell us how much you agree or disagree with the following statements. Please circle your answer.

1. After reading the booklet, I know more about newborn screening.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
-------------------	----------	----------	-------	----------------

2. It is important for me to know about newborn screening.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
-------------------	----------	----------	-------	----------------

3. What is newborn screening?

- A test given 1 minute and 5 minutes after birth to quickly check a baby's health.
- Tests performed 24-48 hours after birth that tests babies for serious, but treatable conditions.
- A vitamin K shot given soon after birth to prevent bleeding in babies.
- All of the above
- None of the above
- I don't know

Please tell us if you think each statement below is true or false based on the booklet you just read. Don't worry if you are not sure about the answer, you can mark you don't know.

4. There are 3 parts to newborn screening.

- True
- False
- I don't know

5. Newborn screening helps identify babies who may be at risk of having serious health issues.

- True
- False
- I don't know

6. Newborn screening usually takes place one week after a baby is born.

- True
- False
- I don't know

7. An abnormal result always means there is something wrong with my baby.

- True
- False
- I don't know

Navigate Newborn Screening

An Expecting Health Program

8. I trust the information that was shared in the book.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
-------------------	----------	----------	-------	----------------

9. I feel more capable talking to my doctor about newborn screening.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
-------------------	----------	----------	-------	----------------

10. After reading the book, I know where to look for more information about newborn screening.

Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
-------------------	----------	----------	-------	----------------

Thank you for your time. We hope you feel ready for when your baby will have newborn screening. If you have any questions, you can ask your doctor. Please return this questionnaire to the nurse.

Navigate Newborn Screening

An Expecting Health Program

The following is a listing of the questions and the correct answers. You may keep this page.

What is newborn Screening?

The correct answer is: Tests performed 24 - 48 hours after birth that tests babies for serious, but treatable conditions.

There are 3 parts to newborn screening.

The correct answer is: True. The 3 parts to newborn screening are blood test, pulse oximetry and hearing screens.

Newborn screening helps identify babies who may be at risk of having serious health issues.

The correct answer is: True. Newborn screening helps identify babies who may be at risk of having serious health issues.

Newborn screening usually takes place one week after a baby is born.

The correct answer is: False. Newborn screening happens around 24-48 hours after your baby's birth.

An abnormal result always means there is something wrong with my baby.

The correct answer is: False. An abnormal result indicates your baby may have a condition. It is important to complete any follow up testing that is recommended.

06

**PROGRAM
LAUNCH &
ONGOING
MANAGEMENT**

IMPLEMENTATION CHECKLIST

<input type="checkbox"/>	Set target launch date Date: _____
<input type="checkbox"/>	Schedule an in-person staff training Date: _____
<input type="checkbox"/>	Soft launch: test materials with small group of patients/clinic staff (optional but strongly suggested)
<input type="checkbox"/>	Full "launch" on designated date
<input type="checkbox"/>	Identify & implement Quality Improvement methods as needed.

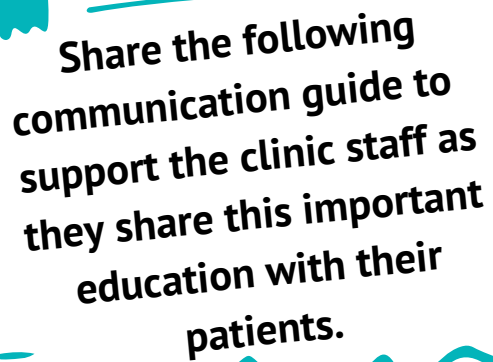
As you prepare for the launch of this prenatal education initiative, take a few moments to address these final questions. These will ensure a timely and efficient launch.

How much time is needed to review, print ,and disseminate all materials to the appropriate locations/individuals? Who needs to be involved in the final review?

What additional training/communication is needed to ensure everyone is prepared?

How often do we want to check-in with clinics/partners after launch? (recommend once a month for the first 12 weeks).

Any outstanding questions or concerns?



Share the following communication guide to support the clinic staff as they share this important education with their patients.

Communication Guide

For Providers & Staff

- We have put together a free, online educational booklet for expecting parents to learn more about what newborn screening is, how it works, and why it's important for you and your baby.
- We would like you to read this book to learn more about newborn screening BEFORE you deliver.
- **Newborn screening is important** because:
 - All babies in the US are screened, but many families are unaware of what this screening consist of.
 - Newborn screening can **identify babies who may be at risk for serious, but treatable health conditions.**
 - 24 hours after your baby is born, they will have **three types of tests:** a heel prick blood test, a pulse oximetry test to check for heart conditions, and a hearing test.
 - An out-of-range result does not mean your baby has the condition. It does mean that **your baby will need additional follow-up testing.**
- To access the book, please scan the QR code with your camera.
- To help us continue to improve this book and learn how helpful this book is to our patients, we will be asking you some questions about your experience along the way. It is OK if you do not know the answer to these questions.
- If you like the booklet or have suggestions for improvement, please let us know!
- Participation is entirely voluntary. Your choice to participate (or not participate) will not change the care that you or your baby receive.

ADDITIONAL TIPS

- Information cards should be shared with all patients during third-trimester visits
- Patients only have to participate once-when they come back for subsequent appts, if they say they've already participated, they don't need to participate again.
- If patients have trouble opening the QR code, you can:
 - Check Camera settings in phone: QR code reader needs to be turned ON.
 - If doesn't work, give patients a paper copy of the flip book to take home.
- Any patient is welcome to have a paper copy of the book
- Consider including a note within the EMR to indicate which patients have received NBS education. (i.e.: "Patient given NBS pilot card.")

FAMILY STORIES HELP RAISE AWARENESS



To learn more about our Newborn Screening Ambassadors, you can read more about their newborn screening journeys in our first edition of the "Meet Our Ambassadors" book.



<https://navigatenbs.expectinghealth.org/meet-our-ambassadors-volume-1/full-view.html>

You can also watch the following videos to hear more from our ambassadors and connect with others in the newborn screening system. Feel free to share these videos with other families, providers, and stakeholders in NBS.

- Meet Our Ambassadors
- Newborn Screening in One Word
- Family Leadership in Newborn Screening
- Community Leadership
- Changing the System



<https://youtube.com/playlist?list=PL6M2gEwQoV25pYKKTWn7GnK1cf1kiDL40>

What is the PDSA Cycle?

A "Plan, Do, Study, Act" model (PDSA) is a quality improvement tool used to guide small tests of a change to determine if the change was an improvement. In your ongoing work to implement prenatal education for newborn screening, PDSA cycles can guide the way you process and make decisions. Using the template below, take a few moments to reflect on your initial implementation and how you may want to use this model to impact continued growth and success.

PDSA Cycle

Plan

What exactly are we going to do?

Do

When and how did we do it?

Study

What were the results?

ACT

What changes are we going to make based on our findings?

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