



NewSTEPS

A Program of the Association of Public Health Laboratories™

Propel Awardee Forum Resources

<p style="text-align: center;">From Awareness to Action: Engaging Families in Newborn Screening</p>	<p>Resources from National Genetics Education and Family Support Center:</p> <ul style="list-style-type: none"> • Understanding Family Engagement in Genetic Services <p>Resources from Expecting Health:</p> <ul style="list-style-type: none"> • Navigate Newborn Screening: online educational module to help families navigate their child’s health during a critical period of development, • Navigate NBS Toolkit: implementation toolkit for Newborn Screening Programs containing multiple newborn screening resources to help raise awareness, educate and train and help support and engage families. <ul style="list-style-type: none"> ○ Poster Template: Learn More About NBS ○ Social media Graphic Templates • Implementation Guide to Prenatal NBS Education: guide to implement Newborn Screening education during pregnancy. <ul style="list-style-type: none"> ○ Patient Information Card Template ○ Establishing Evaluation Measures • Navigate NBS Ambassadors • Family Stories: NBS Ambassador Videos • Family Compensation and Incentives Tool: https://nationalhealthcouncil.org/fair-market-value-calculator <p>Resources from Hands and Voices Family, Language & Learning:</p> <ul style="list-style-type: none"> • Tips for Meaningful Family Participation • Family Leadership in Language & Learning Center Course <ul style="list-style-type: none"> ○ This course is designed to provide participants with knowledge and resources to enhance their development as leaders in the systems servng families. ○ Included in this curriculum are self-study activities covering three leadership domains: Personal Leadership, Leading Others, and Systems Leadership. • FL3 - Resource Toolbox
<p style="text-align: center;">Explore the Long-term Follow-up (LTFU) Landscape</p>	<ul style="list-style-type: none"> • CLSI Newborn Screening Follow-up and Education, 3rd Edition • Long-Term Follow-Up Taskforce Report NewSTEPS • Long-term follow-up after diagnosis resulting from newborn screening: Statement of the US Secretary of Health and Human Services' Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children • Introduction to Public Health Surveillance CDC PH 101

	<ul style="list-style-type: none"> • LTFU Dataset Publications <ul style="list-style-type: none"> ○ IJNS Defining the Minimal Long-Term Follow-Up Data Elements for Newborn Screening ○ IJNS Long-Term Follow-Up Cares and Check Initiative: A Program to Advance Long-Term Follow-Up in Newborns Identified with a Disease through Newborn Screening ○ IJNS Advancing Newborn Screening Long-Term Follow-Up: Integration of Epic-Based Registries, Dashboards, and Efficient Workflows
<p style="text-align: center;">NewSTEPs Quality Indicators and Improvement Strategies</p>	<p>Quality Indicator Resources:</p> <ul style="list-style-type: none"> • NewSTEPs Quality Indicator Webinar • Guide to Spotting Quality Improvement Opportunities Using NewSTEPs Data Visualizations • Quality Indicator Source Document • Dashboards and Reports NewSTEPs • Timeliness Toolkit for Expanding Newborn Screening Services • Resources available in the NewSTEPs Resource Library: <ul style="list-style-type: none"> ○ Reducing Late Collections Poster NY ○ NBS Online Educational Modules ND ○ Online NBS Education for Healthcare Professionals VA ○ Submitter Educational Activities CO ----- ○ Using CQI to Improve NBS Timeliness ○ IDEAL Project Using the Gemba Walk CA ○ NewSTEPs Quality Improvement Projects Collaborative Showcase Series ○ NBS Courier Fact Sheet OK <p>Quality Improvement Tools and Templates:</p> <ul style="list-style-type: none"> • ASQ Root Cause Analysis • ASQ Process Analysis Tools • Gemba Walk : Why Gemba Walks Matter & How to Make Them Work (kainexus.com) • Cause and Effect Diagrams: also known as Fishbone Diagrams or Ishikawa Diagrams <ul style="list-style-type: none"> ○ What is a Cause and Effect Diagram? Definition, Examples, Benefits, and Analysis (ideascale.com) ○ What is a cause and effect diagram? Miro • ASQ Force Field Analysis • Interrelationship Diagrams: also known as Interrelationship Diagrams or Influence Diagrams, Complex System Analysis: <ul style="list-style-type: none"> ○ Complexity is Made Simple Through Interrelationship Diagrams –CQI Toolkit (citoolkit.com) ○ ASQ Interrelationship Digraph Relations Diagram ○ By mapping out relationships, these diagrams facilitate pattern recognition. They help identify critical elements that significantly influence the system. In NBS, recognizing these patterns can guide decision-making and resource allocation.

Navigating New Disorder Implementation

Resources available in the [NewSTEPS Resource Library](#):

- [Newborn Screening Status for All Disorders | NewSTEPS](#)
- <https://www.newsteps.org/resource-library/webinars-events>
- New Disorder Toolkits:
 - [New Disorder Readiness Scale and Resources](#)
 - [New Disorders Checklist](#)
 - [Spinal Muscular Atrophy \(SMA\): New Disorder Resources and Tools | NewSTEPS](#)
 - [Mucopolysaccharidosis type II: New Disorder Resources and Tools | NewSTEPS](#)
 - [Guanidinoacetate Methyltransferase Deficiency: New Disorder Resources and Tools | NewSTEPS](#)
- [APHL NBS Subject-Matter-Expert-Support](#)
- [Request NewSTEPS Site Visit](#)
- [Molecular Resources for Newborn Screening \(aphl.org\)](#)
- [Assuring Laboratory Quality \(aphl.org\)](#)
- [NBS Cutoff-Determinations-and-Risk-Assessment-Methods.pdf](#)
- [Screening Methods and Targets Report | NewSTEPS](#)