



# NewSTEPS

A Program of the Association of Public Health Laboratories™

## Long Term Follow-up Taskforce Activities

### Landscape of Long Term Follow-up

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## Landscape of Long Term Follow-up

### Background

In May 2018, APHL hosted a national Short Term Follow-up stakeholders meeting to provide a forum for newborn screening follow-up personnel to share solutions for short- and long- term follow-up newborn screening (NBS). During this meeting, the NewSTEPs Short Term Follow-up Workgroup established five taskforces to address areas of need within the community, including a focus on long term follow-up (LTFU). All of the taskforces report to the Short Term Follow-up Workgroup.

### Long Term Follow-up Taskforce

The Long Term Follow-up Taskforce met monthly beginning in January 2019 and decided on two projects: develop a working definition of LTFU and assess the current state of LTFU activities across NBS programs. The working definition (p. 4) was created to guide the questions and data elements that would be included in a survey sent to NBS follow-up programs.

### National Survey

In order to assess the status of LTFU activities across NBS programs, the taskforce developed a survey with 20 questions to determine the type of activities performed, funding sources for LTFU, data collection methods, and program needs in the development and/or maintenance of LTFU. APHL's Quality Systems and Analytics program distributed the survey to 74 individuals identified as follow-up managers or coordinators representing 54 state and territorial NBS programs, including dried bloodspot, critical congenital heart disease (CCHD), and hearing screening programs. While the survey was open from January 9 to February 19, 2020, we received 42 responses. Of those, 32 were complete and the 10 incomplete surveys were excluded from analysis.

## Taskforce Members



Attendees of the Short Term Follow-up National Meeting were encouraged to volunteer for one of the five taskforces. The following individuals contributed to the activities of the Long Term Follow-Up taskforce.

#### Co-Chairs:

Jo Ann Bolick (Arkansas)  
Lani Culley (Washington)

#### Participants:

Nicole Brown (Minnesota)  
Amy Burke (North Dakota)  
Marie Burlette (Connecticut)  
Amy Gaviglio (Consultant)  
Carol Johnson (Iowa)  
Kristy Karasinski (Michigan)  
Sharon Linard (Ohio)  
Ruby Moore (Arkansas)  
Ellen Willmore (Texas)

#### APHL Staff Lead:

Erin Darby

#### Contact:

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## LTFU ACTIVITIES

Participants were asked to identify which long term follow-up activities their NBS program performs

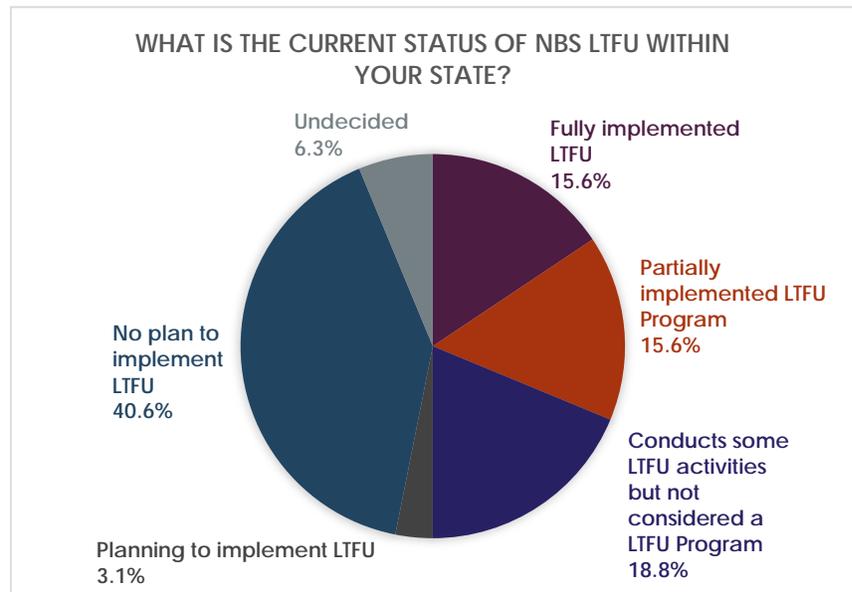
- Data collection from clinical providers
- Clinical care follow-up
- Connecting individual families to services and supports
- Data collection from the state health department/NBS Program
- Clinical care surveillance
- Public health surveillance
- Disease registries
- Data collection directly from families
- Research studies
- Other

## Results

The responses to the survey provided the taskforce with information on the types of LTFU activities NBS programs perform, funding sources, uses for LTFU data, and barriers to implementing or expanding LTFU.

### *How many states perform LTFU?*

Half of the 33 states surveyed perform at least some LTFU activities while 41% indicated no plans to implement a LTFU program.



### *What activities are states doing as part of LTFU?*

The components of a LTFU program vary greatly between states, with 42% of respondents performing more than four distinct follow up activities. Nearly three quarters of programs provide clinical care follow-up but only 32% conduct public health surveillance. Over half of respondents perform between two and four activities, while 85% perform between 2 and 6 distinct activities. Clinical care follow up and data collection from clinical providers were the most commonly reported in tandem with each other.



### What do programs need in order to implement LTFU?

In addition to determining current LTFU activities, this survey was designed to identify challenges and barriers to implementation. States were asked to indicate their top three needs in establishing a LTFU program. Of the 32 responses the most common selection was adequate funding for sustaining the program at 53.1% and an equal number of states (37.5%) identified the need for a clear definition of LTFU and a recommended minimum data set to standardize data collection.

### How could NewSTEPS assist states in implementing LTFU?

We also asked states to identify how NewSTEPS could provide assistance in developing or maintaining a LTFU program. Most topics identified in the previous question were also identified in this one. Again, standardized recommendations, definitions, and guidelines were selected in over half of the responses. This alignment of topics may indicate that most respondents are under the impression that they may not be able to address or satisfy those needs through other avenues.

## Next Steps

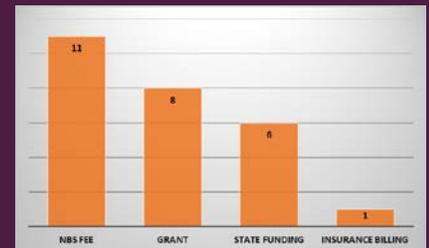
The taskforce intends to develop a publication on the current status of long term follow-up and submit the manuscript for consideration in the NBS Follow-up special issue of the *International Journal of Neonatal Screening*. In addition to publishing the results of this survey, the taskforce is also working toward or considering the following deliverables:

- Develop a presentation on the current landscape and barriers to follow-up for the upcoming February 2021 ACHDNC meeting.
- Develop a position paper identifying a role for APHL in LTFU
- Develop a definition of LTFU or essential elements of a LTFU program
- Create a LTFU Fact Sheet for programs to demonstrate the value of LTFU to their leadership

## How are LTFU activities funded?



NBS Fees  
Grants  
State Funding  
Insurance Billing



Over 50% of respondents who reported utilizing the NBS Fee also reported it as their only funding source in higher proportions than grants or state funding (38% and 50%, respectively, for the other two funding sources).

Are states that utilize particular funding sources able to do more activities? There is less apparent correlation between state funding and most activities compared to other funding sources.



## Working definition of Long-term Follow-up | Developed May 2019

Long-term follow-up (LTFU) is an essential component of the Newborn Screening (NBS) system that begins after an infant has been diagnosed with a condition screened for by NBS and may extend throughout the lifetime of the individual. Long-term follow-up serves to:

- Evaluate health and developmental outcomes in affected children and their families,
- Assess whether there are appropriate benefits to early detection and treatment for all conditions,
- Continually improve upon the NBS, public health, and medical systems to maximize benefits, and
- Reduce condition-associated morbidity and mortality through ongoing care, connection to services, and management.

LTFU relies on the collaboration and integration of both public health and clinical follow-up. LTFU may include care coordination, assuring the availability of evidence-based treatment, continuous quality improvement, and new knowledge discovery, as well as periodic assessment of the clinical and developmental outcomes in affected individuals.

### *What are the overarching goals of Public Health LTFU?*

- To improve life-time health and developmental outcomes for children identified with a condition screened for by NBS
- To identify how the NBS system is achieving the primary aims of preventing mortality and mitigating morbidity
- To assure equitable access, effective NBS programs, and interventions for children with conditions screened for by NBS and their families
- To use surveillance data to inform public health actions such as policy change, targeted outreach, or additional resources to address barriers

### *What are the overarching goals of Clinical Care LTFU?*

- To improve life-time health and developmental outcomes for children identified with a condition screened for by NBS
- To ensure appropriate care coordination across the clinical system
- To collect data for the purposes of evaluating and improving evidence-based treatment/care effectiveness