

NEWBORN SCREENING LONG-TERM FOLLOW-UP QUESTIONNAIRE

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Introduction:

The Association of Public Health Laboratories (APHL) is interested in better understanding the activities and characteristics of Newborn Screening (NBS) Long Term Follow-up (LTFU), both for Public Health and Clinical Care. NBS LTFU pertains to newborn screening for hearing loss, critical congenital heart disease, and those conditions screened for through the dried blood spot. APHL has developed the following questionnaire to assess current state practices and to identify LTFU services and activities that are currently being conducted in the states. Please note that APHL will make efforts to reconcile all information received in this questionnaire with the recently issued Association of Maternal and Child Health Programs (AMCHP) [LTFU August 2018 Issue Brief](#) as well as with information in the NewSTEPS Data Repository (State Profiles) to ensure that all stakeholders are reporting uniform information. Specific states will not be identified in any presentations or publications as a result of this survey unless specific permission is granted.

Instructions:

The name of your state and/or NBS LTFU Program are essential to summarizing the results. The name of person completing the questionnaire, their role, and contact information would be very helpful; however, these are optional. If a state has both public health and clinical LTFU programs, we welcome more than one questionnaire being submitted from the state. If there is other information you want to share with APHL that is not addressed by one of these questions, please include it in the comments section. We sincerely appreciate your time and effort in completing this questionnaire.

Thank you.

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Newborn Screening Long-Term Follow-Up Questionnaire

1. State (drop down)
2. Contact information (optional)
 - a. Name
 - b. Title
 - c. Email Address
 - d. Phone Number
3. What is the current status of NBS LTFU within your state?
 - a) Fully implemented NBS LTFU Program within your state (established, stand-alone program with continual funding)

- b) Participates with another NBS LTFU Program within another state
 - c) Partially implemented LTFU Program within the state (providing LTFU in only certain parts of the state or limiting LTFU to only a certain number of NBS Conditions)
 - d) Provides some LTFU services/activities; however not considered a LTFU Program
 - e) In the planning stage to implement a NBS LTFU Program within the state
 - f) No plan to implement, but believe LTFU is an important NBS service/activity ([skip to Needs & Barriers](#))
 - g) No plan to implement and believe LTFU is not an important NBS service/activity ([skip to Needs & Barriers](#))
 - h) Undecided ([skip to Needs & Barriers](#))
4. Name of NBS LTFU Program (Note: Enter NA, if not applicable.)
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LTFU Activities

5. Does your state currently engage in any NBS LTFU activities with the following entities? (e.g. collecting data and/or providing follow-up services). Check all that apply.
- a. State Health Department/ Newborn Screening Long-Term Follow-up
 - b. Long term follow-up through a Children with Special Care Needs (CSHCN) Program
 - c. University/Medical Center program/Physician Group
 - d. Other: Please describe
6. Describe the type of LTFU activities provided by this entity(ies) by checking all the activities or services that apply.
- a. Data collection from clinical providers
 - b. Data collection directly from families
 - c. Research studies
 - d. Public Health Surveillance
 - e. Clinical Care follow-up
 - f. Clinical Care Surveillance
 - g. Disease registries
 - h. Connecting individual families to services and supports
 - i. Data collection from the state health department/NBS Program
 - j. Other (Please specify)
7. How are these activities funded? (Select all that apply)
- a. NBS Fee
 - b. Grant
 - c. Other (Please specify)
8. Is Institutional Review Board (IRB) approval required?
- a. Yes
 - b. No

Application of LTFU

9. Approximately what percentage of the conditions on your state NBS Panel are receiving LTFU services or activities? (Slider scale indicator 0-100%)
10. Approximately what percentage of individuals identified through newborn screening are receiving LTFU services or activities? (Slider scale indicator 0-100%)
11. Through what age do your NBS LTFU activities provide follow-up. Please select all that apply.
 - a. 0 through 2 years old
 - b. 3 through 5 years old
 - c. 6 through 10 years old
 - d. 7 through 18 years old
 - e. Up to 21 years old
 - f. Lifetime
 - g. Length/Type of LTFU services depends on the diagnosed condition (Please briefly explain)
12. What types of professionals are providing the LTFU activities? Please check all that apply.
 - a. Genetic Counselors
 - b. Social Workers
 - c. Nurses
 - d. Psychologists
 - e. Nutritionists
 - f. Respiratory Therapists
 - g. Childhood Developmental Specialist (e.g. Child Life Specialist)
 - h. Health Educator/Educator
 - i. Clinic Coordinator
 - j. Administrative Support
 - k. Other (Please specify)

LTFU Data

13. What types of LTFU data are being collected? Please check all that apply.
 - a. Whether the patient is currently being seen by a specialty provider
 - b. Whether the patient is currently being seen by a primary care physician (PCP)
 - c. Date of the last visit with the specialty provider
 - d. Date of the last visit with the PCP
 - e. Current patient treatment regimen
 - f. Changes to treatment regimen
 - g. Updated patient clinical data
 - h. Patient's developmental progress
 - i. Contact information of current PCP

- j. Other (Please specify)
14. How is your state NBS program using the collected data? Please check all that apply.
- a. Track number of individuals lost to follow-up
 - b. Track clinical outcomes of patients
 - c. Evaluate the performance of specialty providers (physicians, Nurses, and allied health professionals)
 - d. Assess the needs of individuals/families for services
 - e. Conduct research (e.g. cost-benefit analysis of testing)
 - f. Other (Please specify)
15. Is the collected data entered into an Electronic System or Database?
- a. Yes
 - b. No
 - c. N/A
16. What Electronic System or Database do you use?
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Needs & Barriers

17. What do states need when establishing a NBS LTFU program? Please select your top three choices. **(LIMIT TO 3 CHOICES)**
- a. Staff devoted to LTFU
 - b. A clear definition of LTFU
 - c. Legal authority or legislative mandate to conduct LTFU
 - d. Buy-in from NBS program leadership
 - e. Adequate funding for start-up
 - f. Adequate funding for sustaining the program
 - g. Trained staff
 - h. Recommended minimum data set to standardize data collection
 - i. Electronic system (ES such as a database) to input, monitor, and evaluate data
18. Please identify any additional needs of states in establishing a NBS LTFU program.
19. How could NewSTEPS assist your state in implementing LTFU?
20. Please include any other information about LTFU in your state that you feel is important.