NewSTEPs

Long-Term Follow-Up (LTFU) Feasibility Pilot Informational Webinar

February 25, 2026

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Informational Webinar

01

Process Measures Overview | Jennifer Hauser, MPH, RN, PHN

A brief background on the development of the process measures, including their purpose, framework, and intended use.

02

Survey Walkthrough | Sarah McKasson, MPH

A live demonstration of the Qualtrics survey platform, highlighting survey structure, question flow, and key features.

03

Oklahoma Case Study | Jennifer Baysinger, MSN, RN

An applied example demonstrating how Oklahoma operationalized and implemented the process measures in practice.

04

Next Steps | Noah Sinangil

Overview of upcoming office hours, survey distribution timeline, and time for questions and discussion.

Framework

Purpose

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) at the Association of Public Health Laboratories (APHL) is assessing a set of LTFU process measures to evaluate their validity, relevance, and feasibility for use by state and territorial newborn screening (NBS) programs.

Population

2024 birth cohort

Assessment

Outcomes at Age 1 (as of December 31, 2025)

Inclusion Criteria

Infants, residing in your state or territory, that were identified through newborn screening and confirmed by a clinical specialist to have a NBS disorder through diagnostic testing

Disorders

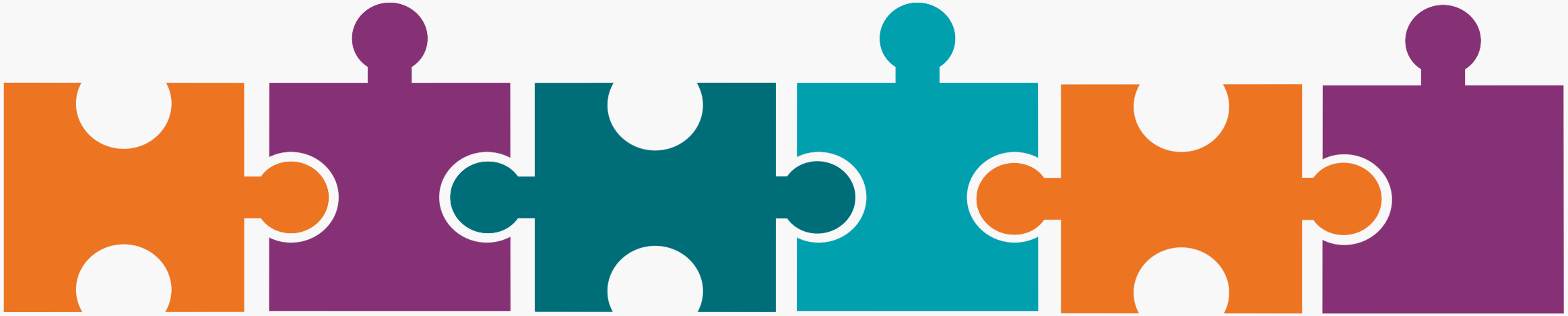
Seven disorders will be included:

- Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCADD)
- Phenylketonuria (PKU)
- Sickle Cell Disease (SCD)
- Congenital Hypothyroidism (CH)
- Pompe Disease
- Cystic Fibrosis (CF)
- Spinal Muscular Atrophy (SMA)

Development

Process measures were developed by the NewSTEPs Long-Term Follow-Up Data Taskforce and build on earlier work established by the **Health Resources and Services Administration (HRSA)** and the **Center for Public Health Innovation (CPHI)**

Process Measures (PM)



PM1	PM2A	PM2B	PM3	PM4	PM5
What is the number of children who are born and reside in your state or territory with a confirmed diagnosis of a core RUSP disorder?	How many children, who are diagnosed with a newborn screening disorder, have died (by disorder)?	How many of these deaths were attributable to the newborn screening disorder?	How many children with a confirmed newborn screening diagnosis have moved?	How many children had contact with a specialist for their disorder at age 1 (by disorder)?	How many children have an unknown status?

Process Measure (PM) Descriptors

PM1	The number of children-with a confirmed diagnosis by a clinical specialist to have the core RUSP disorder of interest through diagnostic testing **who were born and reside in your state at the time of diagnosis**
PM2A	The number of children diagnosed with a disorder identified through the newborn screening program **who have died**.
PM2B	The number of deaths that were caused by or **significantly related to the disorder** identified through newborn screening.
PM3	The number of children with a confirmed diagnosis identified through the newborn screening program who have **relocated out of the reporting jurisdiction** after diagnosis and before the completion of follow-up.
PM4	The number of children diagnosed with a newborn screening disorder who had at least **one documented intervention** for their disorder **within the first year of life (0 – 12 months).**
PM5	The number of children who were diagnosed with an NBS disorder but **did not complete the recommended clinical follow-up or treatment**.

Qualtrics Survey Walkthrough

This survey is designed to allow all state and territorial newborn screening programs to participate, regardless of the development or maturity of your long-term follow-up system.

Even if you cannot provide data for the process measures, we ask that you complete part one of the survey.

Participation in this survey does not require a signed Memorandum of Understanding (MOU).

All data collected will be aggregated to protect your program's identity to ensure that no state or territory is individually identified in analyses or dissemination of results.

Oklahoma Long Term Follow-Up (LTFU) NewSTEPs Process Measures Case Study

OKLAHOMA State Department of Health

02/25/26

Agenda

- Background & Pilot Context
- Existing Infrastructure
- Operationalizing the Measures
- Results & System Stress Points
- Improvements & Next Steps
- Key Takeaways

The National LTFU Process Measure Feasibility Study

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- National effort to standardize long-term follow-up reporting
  - Focus: 2024 birth cohort, assessed at age 1
  - Seven core RUSP disorders
  - Required reporting of PM1–PM5 process measures
  - Goal: Assess feasibility, validity, and reporting burden

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Our Existing Infrastructure

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OK Current LTFU Program

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- Established LTFU program in place since 2024.
- Utilize REDCap for Annual Surveys to the providers and Neometrics software for documentation and timing reminders.

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LTFU Data Dissemination

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- LTFU data is captured using a program-built REDCap database.
- Each child has a unique case within REDCap built for longitudinal data capture.

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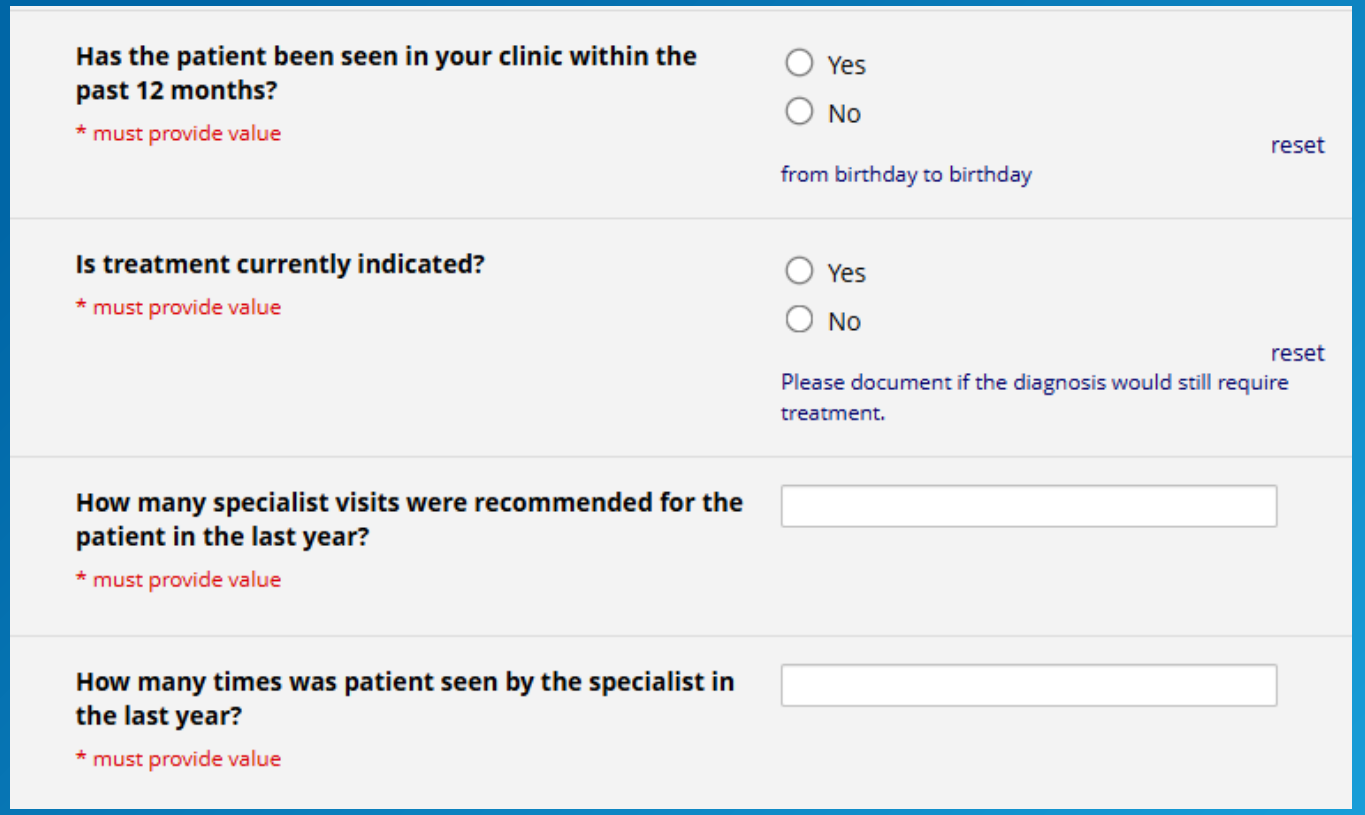
REDCap LTFU Annual Surveys

- Password protected.
- Ask common questions and disorder-specific questions.
- Branching logic based on previously given answers.
- Required responses before continuing.



Has the patient been seen in your clinic within the past 12 months?

* must provide value

Yes
No

reset

from birthday to birthday

Is treatment currently indicated?

* must provide value

Yes
No

reset

Please document if the diagnosis would still require treatment.

How many specialist visits were recommended for the patient in the last year?

* must provide value

How many times was patient seen by the specialist in the last year?

* must provide value

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Neometrics

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- Generates action timing for sending annual surveys.
- Notebook entries are made for case documentation.

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Operationalizing the Measures

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Cohort Identification And Extraction

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- Identified the inclusion criteria and confirmed Oklahoma diagnosis using the REDCap built in filters.
- Filtered on birth year 2024, diagnosis, and survey year 1.

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Data Processing

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- Used SAS 9.4 to analyze the data and cross check diagnosis and treatment visits.
- Also verified against our final diagnosis report forms that all eligible cases were included.

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Mapping National Process Measures to State Data Systems

Process Measure	National Definition	OK Data Capture
PM1 Confirmed	Confirmed diagnosis	Report forms and provider surveys (REDCap)
PM2A Deaths	Died by age 1	Provider or parent report and death records (REDCap and VR Death Certificates)
PM2B Deaths due to Disorder	Died by age 1 due to NBS disorder	Unable to capture currently
PM3 Moved	Relocated Out of State	Provider or parent report in surveys (REDCap)
PM4 Specialist Contact	≥1 documented intervention	Provider surveys (REDCap)
PM5 Unknown	Did not complete follow-up	Derived from provider surveys or missing data logic (REDCap)

Main Data Variable Analyzed

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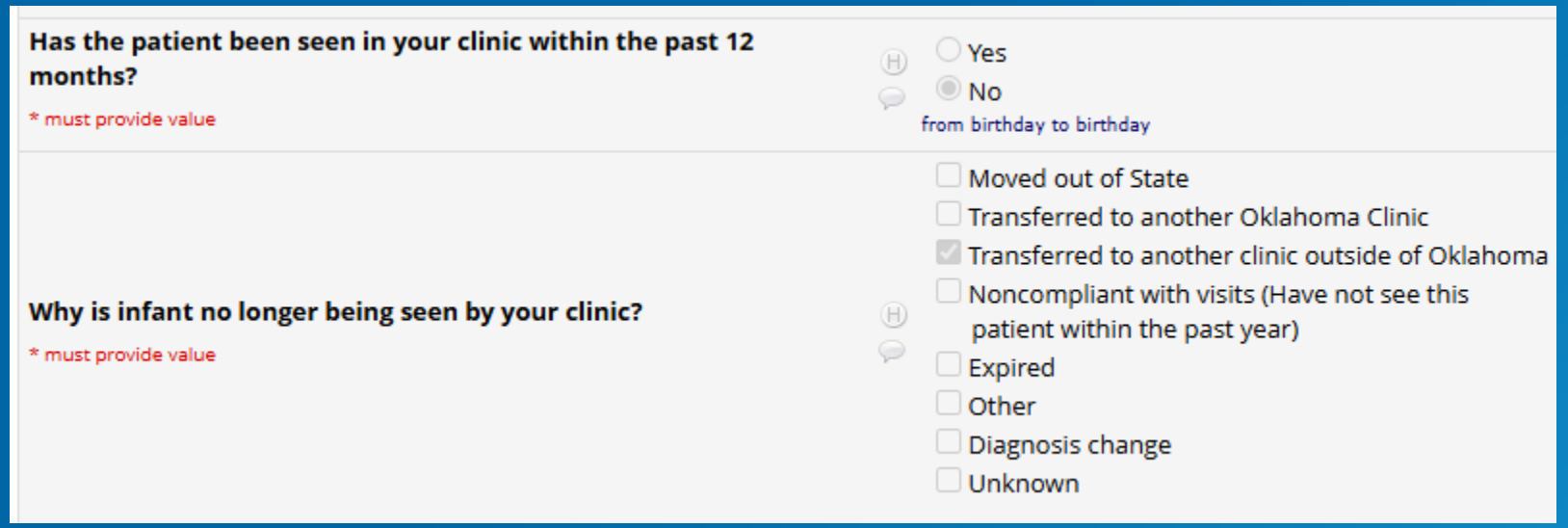
Has the patient been seen in your clinic in the last 12 months?



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Results & System Stress Points

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Process Measure 1

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Has the patient been seen in your clinic in the last 12 months?

- PM1 What is the number of children who are born and reside in your state or territory with a confirmed diagnosis of a core RUSP disorder?
  - This is captured when the answer to this question above is yes.
    - Currently 109 children born in OK in 2024 and diagnosed with a core RUSP disorder still live in OK.

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Process Measure 2

Has the patient been seen in your clinic in the last 12 months?

- PM2A How many children, who are diagnosed with a newborn screening disorder, have died (by disorder)?
  - This is captured when the answer to this question is no and expired is selected.
    - There have been no reports that a child within this cohort have expired.
- PM2B How many of these deaths were attributable to the newborn screening disorder?
  - We do not currently capture this but is something that we are going to look at implementing.

Process Measure 3

Has the patient been seen in your clinic in the last 12 months?

- PM3 How many children with a confirmed newborn screening diagnosis have moved?
  - This is captured when the answer to this question is no and transferred to a clinic outside of Oklahoma is selected.
    - 4 children have moved out of state.

Process Measure 4

Has the patient been seen in your clinic in the last 12 months?

- PM4 How many children had contact with a specialist for their disorder at age 1 (by disorder)?
  - This is captured when the answer to the question above is yes. We then follow up with two questions - how many visits were recommended and how many the patients attended.
    - 96 saw provider at least 1 time during the year.

Process Measure 5

Has the patient been seen in your clinic in the last 12 months?

- PM5 How many children have an unknown status?
  - This is captured when the question is answered no and either unknown or noncompliant is selected.
    - 7 surveys have not been completed by the specialist at the time of data extraction.
    - 1 child is seen by a PCP that does not report annual data.
      - This leaves 8 with an unknown status.

System Stress Points

- Enrollment and Exclusion Gaps
- Diagnostic Classification Limitations
- Provider Response Variability

Enrollment and Exclusion Gaps

- No direct REDCap field to capture "born out of state" for exclusion.
- Children who moved out of state prior to age 1 were not entered into our Annual Survey database.

- Lesson:
  - This required cross-system review to ensure accurate cohort inclusion and exclusion.

Diagnostic Classification Limitations

- No differentiation between CRMS and confirmed CF within REDcap.

- Lesson:
  - Required manual review to ensure accurate disorder categorization.

Provider Response Variability

- Some specialists did not complete Annual Survey in a timely manner.
- Delayed responses are counted as unknown.

- Lesson:
  - No system in place to remind providers that surveys have not been completed at this time.

Strengths and Opportunities Identified

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Strengths

- Established LTFU infrastructure already in place.
- REDCap allows for structured data extraction.
- Data validation by tracking the number of visits a child was seen during the previous year.
- Able to generate all but 1 process measure.

Areas for Optimization

- Not all children were seen by a specialist that participates in LTFU program.
- Need to add structured fields for exclusions and disorders.
- Provider survey timeliness variability.
- PM2B (deaths due to disorder) is not currently collected.

Next Steps and Strategic Improvements

Short Term	Medium Term	Long Term
• Add exclusion field in REDCap Annual Survey • Add differentiation between CRMS and CF • Reinforce provider completion timelines	• Create and automated cohort extraction process in SAS • Reduce manual reconciliation steps • Create a process to remind specialist of incomplete surveys	• Increase automation of annual reporting • Enhance provider engagement strategy • Strengthen readiness for future age reporting

Key Takeaways

- Feasibility of reporting PM1–PM5 was demonstrated.
- Cohort definition integrity requires structured exclusion fields.
- Diagnostic classification precision is essential for accurate reporting.
- Automation potential is limited without system integration.
- Running the pilot functioned as a real-world infrastructure stress test.
- The evaluation directly informed targeted improvements.

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Contact

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Next Steps

Informational Webinar

Overview of the process measures, survey structure, and a state case study highlighting implementation in practice.

February 25, 2026

Survey Launch

Survey and supplementary materials distributed, with instructions for completion.

March 2, 2026

Office Hour 1

A 60-minute session to hear from programs with LTFU experience and to ask questions.

March 11, 2026

Office Hour 2

A second 60-minute session featuring early responders who will share insights, questions, and considerations.

April 8, 2026

Survey Close

Survey submission deadline and wrap-up of the pilot response period.

June 15, 2026

NewSTEPs

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