Newborn Screening Technical assistance and Evaluation Program (NewSTEPs)

USER GUIDE

August 9 2016

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1   Introduction

Welcome to the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) Data Repository. This user guide will help you get started with using the system.

Please note that entering the data into the NewSTEPs data repository occurs on a voluntary basis. All data elements do not have to be provided if they are not available. Please provide as much information as you can.

The high-level workflow diagram (Figure 1) shows an overview of how you can interact with the NewSTEPs Data Repository. After you have registered for an account, you should plan to:

1. Update state profile (annually or on an as-needed basis)

2. Enter cases (frequency to be determined by state; recommended that cases be entered at diagnosis and updated as changes are known)

3. Enter quality indicators (annually – by April 15th)

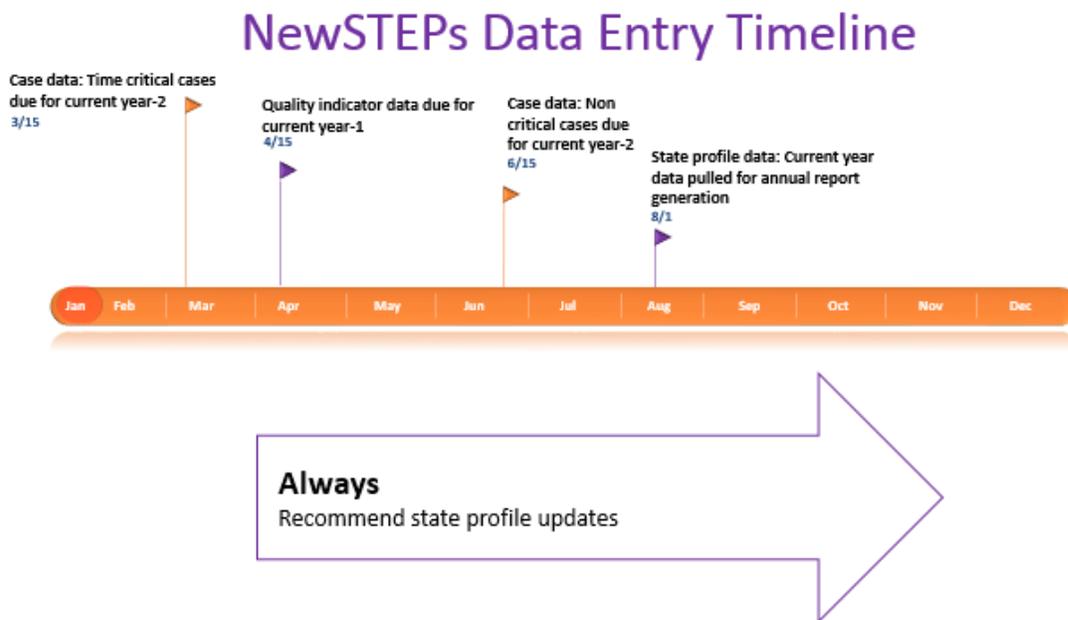This user guide will walk through these basic steps to get you started.

Figure 1: High Level Workflow

2 Document and application information

2.1 Legend

Within this document, we use two conventions to indicate system controls:

Italics – indicates a link

Bold – Indicates a button

2.2 Browser Compatibility

NewSTEPs makes use of new capabilities available in modern, up-to-date browsers, which also provide improved security and performance. The NewSTEPs Data Repository supports only current versions of Internet Explorer, Chrome, and Firefox.

2.3 System Messages

A red asterisk next to the data field name denotes required fields.

Warning messages are shown in red in a light red background.

Baby Demographic Information

State unique id *

State unique id must be set

If left blank

2.4 Getting Help

Although the NewSTEPs Data Repository was designed to be easily understood, we do include help and more detailed information within the system. To access this, click on the question-mark icons throughout the NewSTEPs Data Repository.

Ethnic Distribution:

3 Registering for an Account

You must register for an account to enter information about your Newborn Screening (NBS) program into the NewSTEPs Data Repository. To register for a new account, follow the steps below:

1. On the home page, locate the Login box. Click on the *Register* link in this box.

2. You will be taken to the Register for an Account page. Enter in the required fields.

   Note that the Institution Name field will auto-populate with existing institutions when you begin typing. Take care to ensure you select a pre-populated institution, if one exists. This helps NewSTEPs to link people from the same organization.

3. Click the **Submit Registration Now** button to complete your registration.

4. When your account has been approved, you will receive an email at the email address you supplied during registration.

5. State Administrators: One person from each state will be designated as a state administrator and will have the ability to add additional users within the state program. To be designated as a state administrator, please contact Careema Yusuf (careema.yusuf@aphl.org) once you receive the approval email. Log into the NewSTEPs Data Repository using the email address and password you created during registration.

6. Other state users: Other individuals that would like to have access to enter, edit, or read data for their state should contact the state administrator. On the user registration form, you will be asked to indicate what state you represent. The state administrator is identified on the NewSTEPs State Profile page for each state. For more information on how state administrators can assign user roles, please see the State Administrator's User Guide on the Data Repository Landing page.

4   How to Manage Your Account

If your account information should change over time, you may edit your account details to make changes.

1. Sign in to the NewSTEPs Data Repository and click the *Account* link in the top navigation bar to access your account details.

2. Make the desired account changes to your account details and click the **Save** button to complete the operation.

5   Resetting a Forgotten Password

If you should forget your password, you may reset it from within the NewSTEPs Data Repository:

1. On the home page, locate the Sign In box. Click on the *Forgot Password?* link in this box.

2. You will be asked to enter the email address associated with your account. Enter it and click **Submit**.

    *   You will receive an email with a link to change your password.

3. Once you have successfully changed your password, you may sign in to the NewSTEPs Data Repository with your new password.

6   Home Landing Page

Once you are logged in you will see the landing page, below. The landing page will contain important information that NewSTEPs wants to share with the community about the program, events, and deadlines.

Welcome to the NewSTEPs Data Repository

The repository is now ready for data entry for basic state profiles, cases and quality indicators. We anticipate updates to occur on a quarterly basis, or sooner if needed. Please continue to check this page for announcements of new features. FAQs for the NewSTEPs Data Repository can be found linked **here**.

Case Definitions

Each state has the ability to review and enter **cases** through one designated state contact.

Quality Indicators

The 8 Quality Indicators that will be used to provide longitudinal comparisons within a program as well as comparisons to aggregate data across programs can be found linked here: **Quality Indicators**.

Reports

State Profile derived **reports/queries** are updated on a real-time basis. Additionally, sample reports depicting fictional data summaries demonstrating the range of responses in quality indicators throughout newborn screening systems in the country while protecting the confidentiality of each state newborn screening program can be found linked here: **Sample Reports**

Memorandums of Understanding

State Profile data can be entered prior to the ratification of the MOU. NewSTEPs has convened a series of **webinars** detailing the **Memorandums of Understanding (MOUs)** that will be entered into between APHL and newborn screening programs. NewSTEPs has contacted state representatives to help facilitate signatures. We request that all Quality Indicator and Infant level data entry be held until the MOUs are fully ratified.

Historical Data

Currently the historical data entered into the National Newborn Screening Information System (NNSIS) prior to June 1, 2012 has not been provided to NewSTEPs by the Health Resources and Services Administration (HRSA) in a manner that will allow for longitudinal comparisons.

Questions

We welcome feedback from you as we develop the repository and related reports. For any questions or feedback please contact Careema Yusuf at Careema.Yusuf@aphl.org or at 240-485-2761

Figure 2 - NewSTEPs Data Repository landing page

7 Managing Your State's Newborn Screening Program Information

NewSTEPs asks states to share information because the collection of data at the national level allows for quality improvement in the newborn screening system. When all states share data, each program will be able to compare outcomes and trends from their state or region to the national summary data. These data will also provide the ability to accurately calculate the birth prevalence of the rare disorders as detected by newborn screening.

7.1 How Will the Information Be Used?

NBS programs that enter data into the NewSTEPs repository will have access to their own data plus aggregate data from other participating NBS programs. Please see below for Table 1: NewSTEPs Data Repository: How will these elements be used?

Table 1: NewSTEPs Data Repository Data Elements: How will these elements be used?		
Data Element	**Publically Available (website and aggregate reports)**	**Other State Newborn Screening Programs Only (queries and reports)**
State Profile: Demographics		
State/ Territory Name	●	
Region	●	
Website URL	●	
Racial, Ethnic and Sex Distribution	●	
Annual Births	●	
Number of Eligible Births	●	
State Profile: Disorders		
Disorder Screened (Core, Secondary, Other)	●	
Disorder Screened Status (Core, Secondary, Other)	●	
Disorder Screened (month/ year);(Core, Secondary, Other)	●	
First Screen First Tier Method	●	
First Screen Second Method	●	
First Tier Target	●	
Second Screen First Tier Method	●	
Second Screen Second Tier Method	●	
Second Tier Target	●	
Equipment	●	

Table 1: NewSTEPs Data Repository Data Elements: How will these elements be used?		
Data Element	**Publically Available (website and aggregate reports)**	**Other State Newborn Screening Programs Only (queries and reports)**
General Info [Screening card image; hearing screening form; Number of required screens; Responsible Laboratory (Name and Type)]	●	
State Profiles: Policies		
Recommended Initial Screening Age	●	
Recommended Second Screening Age	●	
Second Screen Policy	●	
CLSI Guideline Adoption Status	●	
DBS Retention Time and Conditions	●	
DBS Specimen Uses; Consent for Research; Sharing Policies	●	
Data Retention Policy; Data Storage Period	●	
Courier Service Usage Status	●	
Consent of Newborn Screening	●	
Consent Recording Method	●	
Opt-out Policy	●	
Opt-out Recording Method	●	
Short-Term Follow-up Description; Unique Follow-up Methods; Follow-up Period for Inconclusive Diagnosis	●	
Long-Term Follow-up Participant? Long-Term Follow-up Description	●	
Missed Diagnosis Reported		●
Missed Diagnosis Reporting Process		●
Unscreened Babies Matched?		●
Result Matching Databases and Matching Method		●
Unsatisfactory Specimen Testing		●
Program Collaboration Policies around providing help and receiving help during emergencies	●	
State Profile: Adding to NBS Panel		
New Condition Decision Period; National Recommendations and Implementation Plan; Pilot Study and/or Feasibility Study?	●	
Lab Test Addition Challenges		●
Lab Test Implementation Period and Requirements	●	
Point of Care (POC) Test Addition Challenges		●

Table 1: NewSTEPs Data Repository Data Elements: How will these elements be used?		
Data Element	**Publically Available (website and aggregate reports)**	**Other State Newborn Screening Programs Only (queries and reports)**
POC Test Implementation Period and Requirements	●	
State Profiles: Fees		
Newborn Screening Funding Sources; Fee Collection Method; Fee Holding Location; Fees; Fee Notes	●	
Fee Use Details		●
State Profiles: Program Structure		
NBS System Organizational Chart; Shared Duties; Follow-up on Unsatisfactory and Borderline Specimens; Performance Evaluation; Formal Communication Structure; NBS Program Staffing Levels; Short-Term Follow-up Responsible Parties; Lab Certification and Proficiency Testing		●
Lab and Follow-up Operating Hours and Activities	●	
State Profiles: Contacts		
Overall, Director; Program Manager; Lab; Follow-up; EHDI; CCHD; HIT	●	
State Profiles: Advisory Committee		
Advisory Committee Present; Committee Structure; Charge/By-Laws; Meeting Frequency; Minutes	●	
State Profiles: IT and Labs		
Lab and Follow-up Information System	●	
Staffing Levels; Back-up Frequency; Recovery Time; Data Loss Amount-database failure, instrument failure; COOP Plan; Redundant Off-site and On-Site Operations		●
State Profiles: Health Information Technology (HIT)		
HL7 Orders, Messages; HL7 Interfacing Birthing Centers; HL7 Implementation information; NBS Data Sharing and Result Retrieval Portal and Use; CCHD and EHDI Result Integration Details; Health Information Exchange Implementation Status		●

7.2   State Profile

Your state's profile information collects program information and facts such as disorders screened, newborn screening fees, and annual births. This information is shared with the public through the NewSTEPs Data Repository, and should be updated annually.

To enter your state profile information, click on the *State Profile* tab. There are eleven tabs within the state profile. Click on the **Edit** button on the right-hand side of the screen.

If you are certain that the information you have provided is complete for the year, please also check the **Complete** box before saving.

Program Overview

The Program Overview tab collects general demographic information about your state's program – program details; your program name; website URL; racial, number of required screens, responsible laboratory and other details. Complete all the information and click the **Save** button.

Disorders

The disorders tab collects information about the disorders for which your state screens. The disorders are organized according to the Recommended Uniform Screening Panel (RUSP), as core, secondary, and other conditions.

1. To complete the disorders, select the screening status of the condition in your state. Statuses are shown in the image below.

2. After you select a screening status, select a subcategory and fill additional data elements that ask about screening methodologies, equipment used and the date of implementation (month and year, or year) of the screening population-wide where known.

Recommended Uniform Screening Panel

Core Conditions

The core conditions presented are those listed on the Secretary's Advisory Committee for Heritable Disorders in Newborn and Children Recommended Uniform Screening Panel (RUSP) and are disorders that should be included in every Newborn Screening Program. Current information for each disorder, along with the dates of implementation can be updated by individuals within each state screening program.

For each condition, select the status of screening for the condition in your state. Please also select the year and month in which population based screening began (not pilot or feasibility studies), if known.

Organic Acid Disorders

Propionic acidemia - PROP   Universally Screened | - Select subcategory -
                                                        Required by law or rule
                                                        Not required by law or rule

First Screen

First Tier Method | First Tier Method Target | Second Tier Method | Second Tier Method Tar

Second Screen

First Tier Method | First Tier Method Target | Second Tier Method | Second Tier Method Tar

Equipment   Proposed/Actual Implementation Date for Universal Screening

Equipment   Year | Month

Methylmalonic acidemia (methylmalonyl-CoA mutase) - MUT   Not Screened | - Select subcategory -

Proposed/Actual Implementation Date for Universal Screening

Year | Month

Methylmalonic acidemia (cobalamin disorders) - Cbl A,B   Not Screened | - Select subcategory -

Proposed/Actual Implementation Date for Universal Screening

3. When you complete the entries for core conditions, click the **Save** button, or click on the tabs to enter information for secondary and other conditions, clicking the **Save** button when completed. (Clicking **Save** will return you to the screen that will list all the selections you have made; click on any tab to return and edit it.)

Policies

The policies tab collects information about the NBS policies that your state program has. These policies include those around recommended age at initial screening and second screening; consent; follow-up services; missed cases; storage of specimens; storage of data; sharing of specimens; and other details.

Complete all the information and click the **Save** button.

Adding to the NBS Panel

The adding to the NBS panel tab collects information about the policies and procedures that your state program has with regard to adding conditions to the NSB panel.

1. The General Info section collects for example, the time frame typically seen for adoption of a new condition, once a decision has been made; whether or not a pilot study and/or feasibility study is done before adoption of population wide screening; and other details. Complete all the information and click the **Save** button.

2. The Lab section collects information about any challenges that the laboratory may have in adding a new DBS condition to the panel. Complete all the information and click the Save button.

3. The Point Of Care (POC) section collects information about any challenges that the laboratory may have in adding a new POC condition to the panel. Complete all the information and click the Save button. If you are certain that the information you have provided is complete for the year, please also check the **Complete** box before saving.

Fees

The fees tab collects information about the state NBS fees and related information. Complete all the information and click the Save button.

Program Structure

The program structure tab collects information about the state NBS program structure. This includes laboratory operating hours; follow-up operating hours; organizational chart; staffing levels (%FTE); and related information. You can also upload and relevant documents. Complete all the information and click the Save button.

Program Overview
Disorders
Policies
Adding to NBS Panel
Fees
Program Structure
Contacts
Advisory Committee
IT Support
HIT Elements

NBS system organizational chart: ⊕

Document

[   ] [Browse...]

Link

[   ]

Shared Duties: ⊕

[   ]

Follow-Up on Unsatisfactory Specimens: ⊕

Responsible Party

[- Select -   ▾]

Description

[   ]
[   ]

3999 characters remaining.

Follow-Up on Borderline Results: ⊕

Responsible Party

NBS Program Staffing Level: ⊕

Laboratory Scientists

[   ] FTE

STFU Personnel

[   ] FTE

Clerical Support Personnel

[   ] FTE

EHDI Personnel

[   ] FTE

CCHD Personnel

[   ] FTE

STFU Responsible Parties: ⊕

[None selected ▾]

Certification Program: ⊕

[- Select -   ▾]

Proficiency Tests: ⊕

[None selected ▾]

Program Information: ⊕

Contacts

The contacts tab collects contact information for the following: the overall NBS program, the Director and/ or Program Manager, the NBS state laboratory, the NBS follow-up program, the Early Hearing Detection and Intervention (EHDI) program, Critical Congenital Heart Disease (CCHD) program, and the Health Information Technology (HIT) person(s) in your state. Complete all the information and click the **Save** button.

Advisory Committee

The advisory committee tab collects information on the details of the NBS advisory committee for your state NBS program. This includes, if applicable, the make-up of the advisory committee; how often the committee meets; and other details. You can also upload and relevant documents. Complete all the information and click the **Save** button.

Program Overview
Disorders
Policies
Adding to NBS Panel
Fees
Program Structure
Contacts
Advisory Committee
IT Support
HIT Elements

Existing Advisory Committee?: ❓

○ Yes
○ No
◉ Unknown

Advisory Committee Voluntary?: ❓

○ Yes
○ No
◉ Unknown

Committee Structure: ❓

Description

3999 characters remaining.

Document

Browse...

Link

Charge/Bylaws: ❓

Document

Browse...

Link

Meeting Frequency: ❓

- Select -

Meeting Minutes Link: ❓

IT Support

The Information Technology (IT) Support tab collects information on the types of information systems your state NBS program uses. This includes the type of information system in the laboratory; the type of information system in the follow-up program; information on Continuity of Operation Plans (COOP); and other details. Complete all the information and click the **Save** button.

| Program Overview |
| Disorders |
| Policies |
| Adding to NBS Panel |
| Fees |
| Program Structure |
| Contacts |
| Advisory Committee |
| **IT Support** |
| HIT Elements |

Lab Information System: ⊘
- Select -

Follow-up Information System: ⊘
- Select -

Staffing Levels: ⊘

LIMS Management
[   ] FTE

Desktop Support
[   ] FTE

Network Support
[   ] FTE

HL7 Messaging/Terminology Support
[   ] FTE

Follow-Up Support
[   ] FTE

IT Support Description: ⊘
[   ]
3999 characters remaining.

NBS Data Backup Frequency?: ⊘
- Select -

Data Loss Amount from Database Failure: ⊘
☐ Unknown
[   ]

Data Loss Amount from Instrument Failure: ⊘
☐ Unknown
[   ]

IT Infrastructure Recovery Time: ⊘
☐ Unknown
[   ]

Disaster Recovery Hardware: ⊘
None selected ▾

IT Part of COOP? ⊘
○ Yes
○ No
◉ Unknown

Redundant Off-site Operations Exists? ⊘
○ Yes
○ No
◉ Unknown

Redundant On-site Operations Exists? ⊘
○ Yes
○ No
◉ Unknown

HIT Elements

The Health Information Technology (HIT) elements tab collects information on the HIT processes and systems (if applicable) your state NBS program is implementing. This includes details on the type of messaging used (e.g., HL7 messaging); any coding used within the information systems (e.g., LOINC, SNOMED, etc.); information on data integration efforts with other NBS systems; and other details. Complete all the information and click the **Save** button.

Program Overview
Disorders
Policies
Adding to NBS Panel
Fees
Program Structure
Contacts
Advisory Committee
IT Support
HIT Elements

HL7 Order Messages Accepted? ⊙
○ Yes
○ No
◉ Unknown

HL7 Interfacing Birthing Center Count: ⊙
[   ]

Electronically Ordered Sample Count: ⊙
[   ]

HL7 Result Messages Sent? ⊙
○ Yes
○ No
◉ Unknown

HL7 Result Message Recipient Count: ⊙
[   ]

Electronically Reported Sample Count: ⊙
[   ]

Implementation Guide and HL7 Version: ⊙

NBS Data Sharing Portal Exists? ⊙
○ Yes
○ No
◉ Unknown

DBS Data Entry Portal Exists? ⊙
○ Yes
○ No
◉ Unknown

Count of Birthing Centers Using Entry Portal: ⊙
[   ]

Count of Samples Entered Using Entry Portal: ⊙
[   ]

NBS Result Retrieval Portal Exists? ⊙
○ Yes
○ No
◉ Unknown

Count of Birthing Centers Using Retrieval Portal: ⊙
[   ]

NBS Activities Feedback Portal? ⊙

Databases Integrated with NBS Systems: ⊙
[None selected ▼]

Hearing Result Integration Method: ⊙
[- Select -   ▼]

CCHD Result Integration Method: ⊙
[- Select -   ▼]

HIE Implementation Status: ⊙
[- Select -   ▼]

HIE Data Exchange Status: ⊙
[- Select -   ▼]

HIE Interfacing Funds Received? ⊙
○ Yes
○ No
◉ Unknown

NBS Result Accessor: ⊙
[- Select -   ▼]

NBS Result Sending Method: ⊙
[- Select -   ▼]

7.3 Cases identified by newborn screening

The conditions detected by newborn screening are rare, therefore it is only with the combined births across the U.S. that we will be able to identify trends in the true birth prevalence of disorders, and also understand trends over time. Consistent data collected across all programs in the country will provide valuable data for state public health departments, Title V reporting requirements, reports to legislators, and clinical care providers caring for children with these rare disorders.

* Please note that your state must have a signed Memorandum of Understanding (MOU) with NewSTEPs/APHL before case information can be entered. For more information about the MOU process, please contact NewSTEPs at newsteps@aphl.org.

1. To enter a case, click on the *Cases* tab, then click on the **Add New Case** button.

2. First, select the condition, either by typing it in the text field on the left side, or selecting it on the right side (where conditions are organized by category). Click the **Next** button.

3. After a condition is selected, the form for entering case details will load. The system will require you to input a state unique identifier and the infant's date of birth. Note that the NewSTEPs Data Repository does ask for date of birth and dates and times of service, which are collected only in the browser for the purpose of calculating differences in dates and times (i.e., days elapsed between birth and screening) – other than birth year, NO date or time is stored in the NewSTEPs Data Repository.

Enter as much information as you can with infant detailed information, screening details, and collection information.

Some conditions include diagnostic workup data, including enzymatic test details and molecular genetic testing results. As a public health surveillance program, it is critically important for NewSTEPs to have accurate definitions of each disorder.

NewSTEPs has partnered with HRSA to provide case definitions for use in public health newborn screening. A tool kit that includes the case definition worksheets, a sample letter to a medical provider, etc. are provided for your use on the NewSTEPs website and are linked here and should be completed in collaboration with the clinical care providers. For those conditions with an attached Diagnostic Workup within the repository, you can find a PDF version of the worksheet on the NewSTEPs website here. You can print out and fill out the worksheet by completing demographic information and any data available from within the newborn screening program. These worksheets are intended to be tools to help in the collection of the data elements within the case definitions. The case definitions are not intended to change the diagnosis from the clinicians, but to allow categorization of the certainty of the public health surveillance reported case. Please use the provided worksheets to collect the appropriate information. When possible, please collect the laboratory results for your internal records. These will never be shared beyond your program, but will help to support the case definition.

Many positive newborn screening results take significant time for resolution. We ask that the case definitions be closed after a year from the child's birth and all relevant data be entered by this point.

Diagnostic Workup

Enzymatic

Final Diagnosis as determined by metabolic geneticist or clinician performing the follow-up

- Select - ▾

Were urine organic acids tested?
○ Yes ○ No ◉ Unknown

Were plasma acylcarnitines tested?
◉ Yes ○ No ○ Unknown
    Was C3 level:
      ○ Elevated
      ○ Normal
      ○ Unknown
    Was C5-OH level:
      ○ Elevated
      ○ Normal
      ○ Unknown

Were infant chemistries (biotinidase) studies completed?
○ Yes ○ No ○ Unknown

Was enzyme analysis for holocarboxylase synthetase deficiency enzyme activity completed?
○ Yes ○ No ○ Unknown

Molecular Genetics

Was mutation analysis done?
◉ Yes ○ No ○ Unknown
    What genes were included in the mutation analysis?
    ☑ HLCS Gene
      Check the types of variants found on:
      Allele 1:
        ○ Variant known to be disease causing
        ○ Variant of unknown significance
        ○ Wild Type (Normal)
        ○ Unknown
      Allele 2:
        ○ Variant known to be disease causing
        ○ Variant of unknown significance
        ○ Wild Type (Normal)
        ○ Unknown
    ☐ Other Gene

☐ Complete - The case data entry is complete. All available data related to this diagnosis (obtained through one year of age) has been entered. ⍰

Save | Cancel

4. After all information has been entered, click the **Save** button. If you are certain that the information you have provided is complete for the year, please also check the **Complete** box before saving.

5. The new case will then be visible in the table of cases on the *Cases* tab.

6. To edit an existing case, click on the edit icon from the cases table, as shown below.

State Unique ID	Birth year	Condition	Last Updated	Action
trg-10312-1-q104	2012	S,S disease (Sickle cell anemia) - Hb SS	09/16/2013	👁 ✎
trg-8446-1-q81	2012	Cystic fibrosis - CF	09/16/2013	👁 ✎
trg-9873-1-q76	2012	3-Methylcrotonyl-CoA carboxylase deficiency - 3-MCC	09/16/2013	👁 ✎

7.4   Quality Indicators

The eight Quality indicators (QI) has undergone careful evaluation by stakeholders to assure agreement on definitions and will be used to provide longitudinal comparisons within a program as well as comparisons to aggregate data across programs. QIs are calculated using information from state profiles, cases, and QI-specific information.

* Please note that your state must have a signed Memorandum of Understanding (MOU) with NewSTEPs/APHL before QI information can be entered. For more information about the MOU process, please contact NewSTEPs at newsteps@aphl.org

To enter QIs, click on the *Quality Indicators* tab. This will display a list of all quality indicators. Select the year for which you're entering quality information, then select *Demographics* to enter state demographic data.

State *

- Select -

Year *

- Select -

Section *

Quality Indicator 1 - Percent of dried blood spot specimens that were unacceptable due to improper collection and/or transport
Quality Indicator 2 - Percent of dried blood spot specimens with at least one missing state-defined essential data field upon receipt at the lab
Quality Indicator 3 - Percent of eligible newborns not receiving a newborn screen, reported by dried blood spot or point-of-care screen(s)
Quality Indicator 4 - Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional) with the
                newborn screening program
Quality Indicator 5 - Timeliness of newborn screening activities
Quality Indicator 6 - Percent of infants with an out-of-range newborn screen result requiring clinical diagnostic workup reported by disorder category
Quality Indicator 7 - Percent of disorders detected by newborn screening with a confirmed diagnosis by an appropriate medical professional
Quality Indicator 8 - Percent of missed cases, reported by disorder
Additional Screening Data - Additional state-level data that provides peripheral annual screening information
Demographics - State Demographic Data
View QI Summary - A Summary of all QI data for the year and state selected with regional and national data for comparison.
Year to Year Comparison - A Summary of all QI data for the state selected compared by year.

The data import tool for the quality indicator data is currently disabled while we implement changes to the quality indicator fields. We anticipate this tool being available again by late summer. Sorry for any inconvenience.

Select a completed Annual Births csv file:

| Browse... |

Submit File

Select the Year and then click on Demographics.

State Demographic Data

Save | Cancel

Demographic information entered below provides details on the racial, ethnic, and gender distributions for your state.

Demographics Official?
○ Yes
○ No

Racial Distribution

White
[   ] %

Black or African American
[   ] %

American Indian or Alaska Native
[   ] %

Asian
[   ] %

Native Hawaiian or other Pacific Islander
[   ] %

Not Reported
[   ] %

Unknown
[   ] %

Ethnic Distribution

Hispanic, Latino/a, or Spanish origin
[   ] %

Not of Hispanic, Latino/a, or Spanish origin
[   ] %

Not Reported
[   ] %

Unknown
[   ] %

Sex Distribution

Female
[   ] %

Male
[   ] %

Unspecified
[   ] %

Unknown
[   ] %

Navigation sidebar:
Quality Indicator 1
Quality Indicator 2
Quality Indicator 3
Quality Indicator 4
Quality Indicator 5
Quality Indicator 6
Quality Indicator 7
Quality Indicator 8
Additional Screening Data
Demographics

Next, select Additional Screening Data and enter or confirm the information. Remember to click the Save button before moving on the next tab.

Additional Screening Data

Save | Cancel

The information entered below provides additional screening data including the number of birthing hospitals in your state, number of infants transferred to hospitals out of state and screening performed by another NBS program, number of infants who came in from other states for screening and cared for by specialists in your state, etc

Birth Statistics

[   ] How many infants screened were born in your state?

[   ] How many birthing centers are in your state?

Dried Blood Spot Screening Statistics

[   ] How many infants born in your state received DBS NBS at an out of state NBS program?

[   ] How many infants born out of state received DBS NBS through your NBS program?

Early Hearing Detection and Intervention Screening Statistics

[   ] How many infants born in your state received EHDI screening at an out of state NBS program?

[   ] How many infants born out of state received EHDI screening through your NBS program?

Critical Congenital Heart Disease Screening Statistics

[   ] How many infants born in your state received CCHD screening at an out of state NBS program?

[   ] How many infants born out of state received CCHD screening through your NBS program?

Navigation sidebar:
Quality Indicator 1
Quality Indicator 2
Quality Indicator 3
Quality Indicator 4
Quality Indicator 5
Quality Indicator 6
Quality Indicator 7
Quality Indicator 8
Additional Screening Data
Demographics

Then, select each QI and enter or confirm the information for each. For each, click the **Save** button before moving onto the next.

Please note that for each QI, enter the "Number of" the system will calculate the "Percent". Additionally, QIs 5e, 5f, 7 and 8 will be pre-calculated based on the case data entered in the "Cases" tab.

7.5 Next Steps

The NewSTEPs Data Repository will continue to be updated with new features. We anticipate that these updates will occur on a quarterly basis, with more frequent updates as needed.

7.6 Further Assistance

Contact information for Assistance: If you have any questions or feedback on the NewSTEPs Data Repository, please contact Careema Yusuf at 240-485-2761 or at careema.yusuf@aphl.org or Joshua Miller at 303-724-4438 or at joshua.i.miller@ucdenver.edu.

Revision History

Changes to this document are reflected in this Revision History table.

Date	Version	Description	Revised by
09/30/2013	Version 1.0	Initial draft	Leslie Power
03/04/2014	Version 1.1	Revised draft	Careema Yusuf
05/07/14	Version 2.0	Updated to reflect new tabs	Careema Yusuf
8/09/2016	Version 3	Updated to reflect new tabs and revised QIs	Sari Edelman