NewSTEPs

A Program of the Association of Public Health Laboratories™

User Guide for the NewSTEPs Repository

Last Updated: April 1, 2025

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Association of Public Health Laboratories
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INTRODUCTION

Welcome to the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) Repository. NewSTEPs is a program of the Association of Public Health Laboratories (APHL) that was developed by funding from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U22MC24078. NewSTEPs is a national newborn screening (NBS) resource center designed to provide data, technical assistance, and training to NBS Programs.

The NewSTEPs Repository is a centralized and secure database that can be accessed by authorized users from anywhere and allows NBS programs to explore resources and data to meet local needs. NBS programs that enter data into the NewSTEPs Repository have access to their own data, plus aggregate data from other participating programs. NewSTEPs provides users with real-time interactive data visualizations for quality improvement purposes. Select data visualizations are public-facing, while access to quality indicator and case dashboards is based on your NewSTEPs user role.

NewSTEPs collects three types of data from NBS programs:

- Profile and programmatic information (e.g., fees, disorders screened, policies, program structure, etc.). This information is available to the public.
- Case data for infants diagnosed with a newborn screening condition. Confirmed cases should only be entered for disorders that were part of your program's routine screening panel during the year of birth.
    - Individual cases are confirmed cases providing demographic and screening information (e.g., time to medical intervention, time to diagnosis). Individual case collection plays an integral piece when examining health disparities.
    - Aggregate cases reflect the total confirmed case counts stratified by disorder. Given the time and resources to enter individual cases, the aggregate case collection serves as a complete condition count detected per year.
- Quality Indicators to monitor performance across the NBS system on an annual basis.

The NewSTEPs Repository is for non-human subject research as defined by policies and current regulations and is in accordance with the Office of Human Research Protections (OHRP) and the Food and Drug Administration (FDA) guidelines. Entering data into NewSTEPs is done voluntarily.

DATA SHARING AND PRIVACY

Memorandum of Understanding (MOU)

NBS Programs are required to sign a Memorandum of Understanding (MOU) with APHL before entering case and quality indicator data in the NewSTEPs Repository. The MOUs were developed in accordance with guidance provided by a Health Insurance Portability and Accountability Act (HIPAA) attorney, APHL's in-house legal counsel, and state public health laboratories.

The MOU describes aspects of data sharing including data ownership, data reporting, and data security. NewSTEPs provides a video on the benefits of signing the MOU. An example of the MOU can be found here.

Data Sharing and Oversight

APHL will not share state/territory-level quality indicator data or case data with investigators. Sharing aggregate, unpublished data with investigators must be approved by the NewSTEPs Steering Committee. For case data, NewSTEPs will follow the “Rule of 5” which prevents data sharing if there are five newborns or fewer for a given category in a given year.

Parental Consent

Parental consent is **not** needed to enter individual case data into the NewSTEPs Repository. Case-level information is de-identified and no identifiable information is stored. Policies and privacy controls are in place to ensure appropriate and ethical treatment of individual data. Further, the Office of Human Research Protection (OHRP) has determined that NewSTEPs is taking all the necessary proactive measures to safeguard this information.

Data Security

NewSTEPs works closely with the current vendor selected by a robust Request for Proposals (RFP) process and is subject to privacy and security policies outlined in an annual contract to ensure the security of data. The web application is available through web browsers via 128-bit secure socket layer (SSL) encryption. Information on the website is limited and is role-based. Program profiles are public, and only authorized users can access case and quality indicators data (Access Matrix by User Role).

Access to data is secured in Amazon Web Services (AWS) using security groups and network access control lists (NACLs). Ingress traffic is allowed only from selected application servers. Data traffic utilizes Secure Socket Layer (SSL) encryption and Transport Layer Security (TLS) version 1.2 while in transit. Access to specific case information is restricted by row-level security rules ensuring only authorized users with appropriate institution credentials can retrieve records. Data is backed up to an off-site encrypted storage location multiple times a day.

For individual case reporting, the web application asks programs to provide the infant’s birth date and screening dates, but these dates are solely collected for the purpose of calculating the time elapsed. Aside from birth year, no dates are stored in the database. No parties involved in the project will have access to records that would allow for the re-identification of babies.

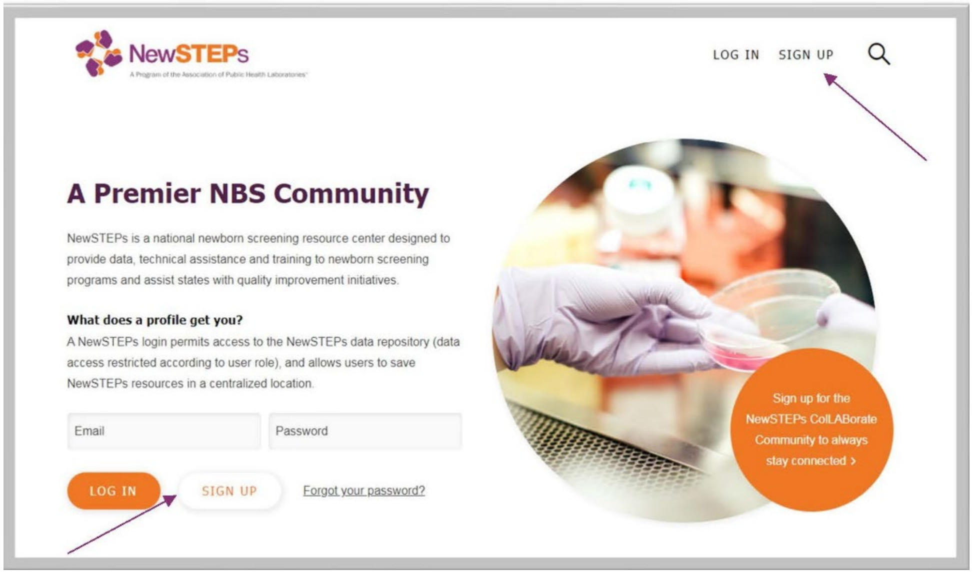
The current vendor is called Insomniac Design, Inc. which serves as an honest broker of the data and does not have the ability to share or identify data, newborns, or family information.

ACCOUNT MANAGEMENT

Account Registration

To enter and view data for your NBS Program, you must register for an account. Go to newsteps.org and follow these steps:

1. Click **SIGN UP**, which can be found on the NewSTEPs home page.

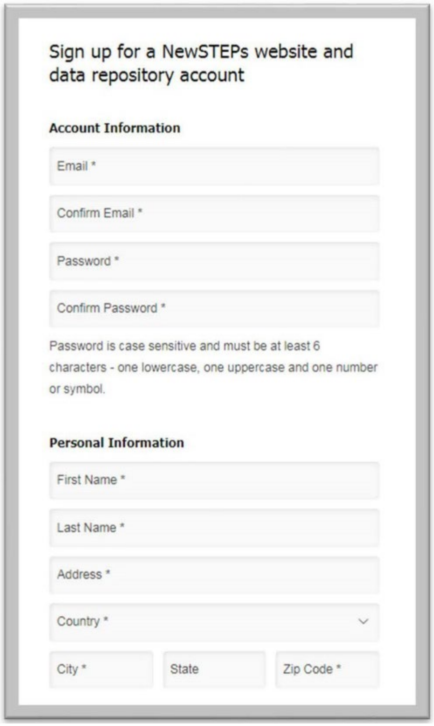


A Premier NBS Community

NewSTEPs is a national newborn screening resource center designed to provide data, technical assistance and training to newborn screening programs and assist states with quality improvement initiatives.

What does a profile get you?
A NewSTEPs login permits access to the NewSTEPs data repository (data access restricted according to user role), and allows users to save NewSTEPs resources in a centralized location.

2. The registration fields will appear on your screen next. Enter all required fields which are designated by an asterix (*).



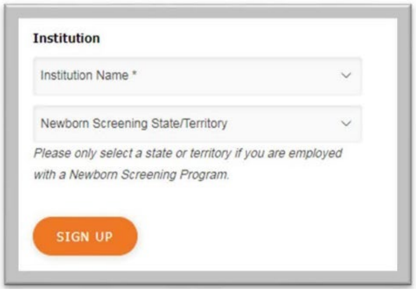
Sign up for a NewSTEPs website and data repository account

Account Information

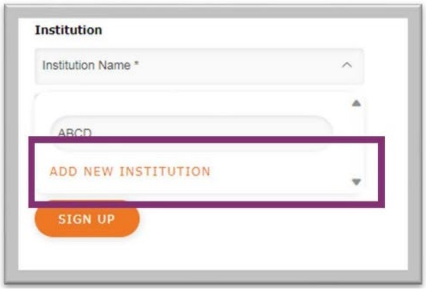
Password is case sensitive and must be at least 6 characters - one lowercase, one uppercase and one number or symbol.

Personal Information

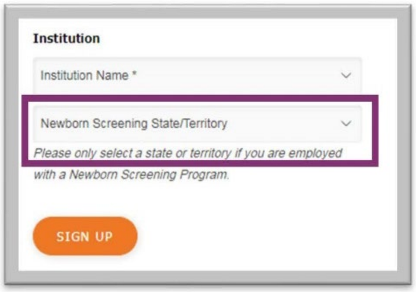
3. The list of institutions is pre-populated and should be selected by the new user. You can search by institution name. If you do not see your institution name or abbreviation, there is an option to add a new institution. *Note: Before creating a new institution, confirm that it does not already exist by searching for the abbreviated and full name of your organization*.



Please only select a state or territory if you are employed with a Newborn Screening Program.



4. Only select a state if you are employed by the state/territory newborn screening program. International NBS Programs and other organizations should leave this blank. This field is associated with access to state/territorial data and user roles.



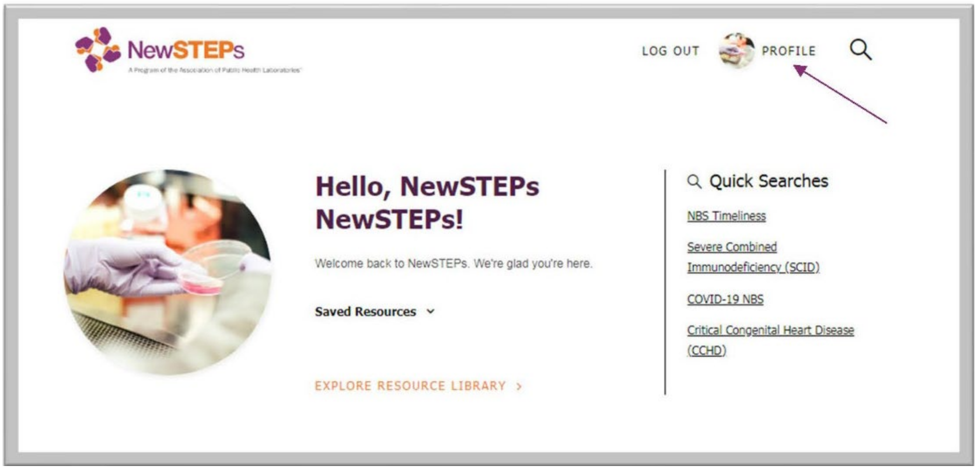
Please only select a state or territory if you are employed with a Newborn Screening Program.

5. After all required fields have been entered, click **SIGN UP** to complete your registration.

Updating Your Account

Your account information may change over time. You can edit your account details, including updating your password, email address, and institution. Users will be prompted to update their password annually.

1. **LOG IN** to the NewSTEPs Repository.
2. Click **PROFILE** in the top right-hand corner.



Welcome back to NewSTEPs. We're glad you're here.

3. Click **EDIT PROFILE** to edit.

Profile

Account Information

User Email
newsteps@aphl.org

Member since 03/31/2021

User Type
User

User Status
Active

Contact Information

Name

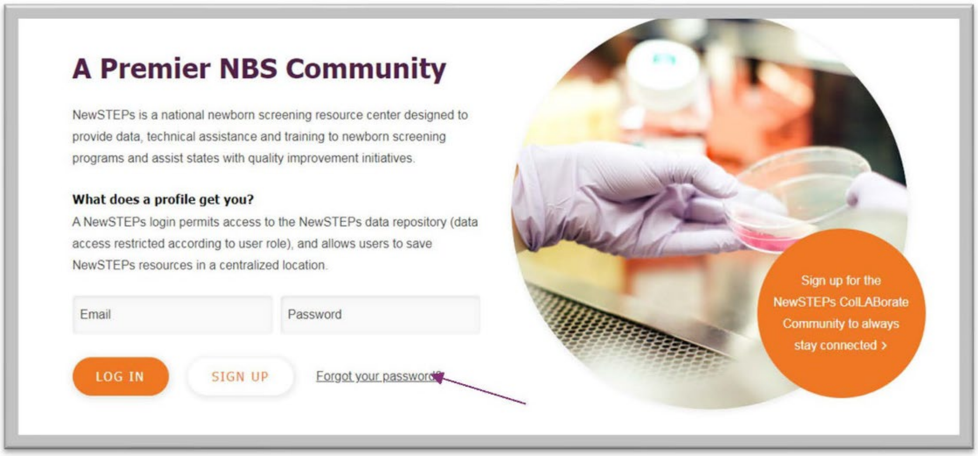
Address

4. Make the desired account changes.
5. Click the **SAVE PROFILE** button.

Resetting a Forgotten Password

If you forgot your password, you may reset it within the NewSTEPs Repository.

1. Go to [NewSTEPs.org.](https://NewSTEPs.org)
2. Click on **Forgot your password**.



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Sign up for the NewSTEPs CoLLABorate Community to always stay connected >

3. You will be asked to provide the email address associated with your account and then click **SUBMIT**.
4. You will receive an email with a link to change your password.
5. Once you successfully change your password, you will be able to sign in to the NewSTEPs Repository with your new password.

To ensure security, each user should reset their password annually. If you need help resetting your password, please contact newsteps@aphl.org.

ACCESS RIGHTS

User Roles

To abide by agreements detailed in the Memorandums of Understanding (MOU), NewSTEPs restricts access to quality indicator and confirmed case data in the repository to authorized users with the state/territorial program. Access to the NewSTEPs Repository is structured using well-defined user roles. Each state/territory will have at least one Program Administrator user who will manage all users for their state/territory.

Program Profiles can be accessed by the public. Only people who are assigned specific data user roles can enter profile data for their state/territory. The NewSTEPs User Role Descriptions (Table 1) and Access Matrix by User Role (Table 2) tables outline the different users, the primary function of the role, and the access rights.

Table 1: NewSTEPs User Role Descriptions

NewSTEPs User Role	User Role Descriptions
User	Users can manage their own account including, password, photo, and email address. All users have access to the resource library and can view NBS Program Profiles reports/dashboards.
Profile Data Manager	Ability to view and edit their own state/territorial NBS Program Profile.
Data Viewer	Data viewers can only **view** their state/territory data provided to NewSTEPs for: • NBS Program Profiles • Individual and aggregate case data • Annual and monthly Quality Indicator (QI) data and reports Data viewers are not able to enter or edit data.
Case Data Manager	Enter, edit, delete, and view their program's individual and aggregate cases data using the webform or CSV import file.
QI Data Manager	Enter, edit, delete, and view any Quality Indicator data, including annual and monthly data, for their assigned state/territory via the webform or CSV import file. Can view QI reports. .
Program Administrator	The Program Administrator has access to all data for their state/territory. Further, they can manage users within their state/territory, including adding or editing users, changing user access, and exporting users for their program. The Program Administrator can view, add, edit, and delete their program's data.

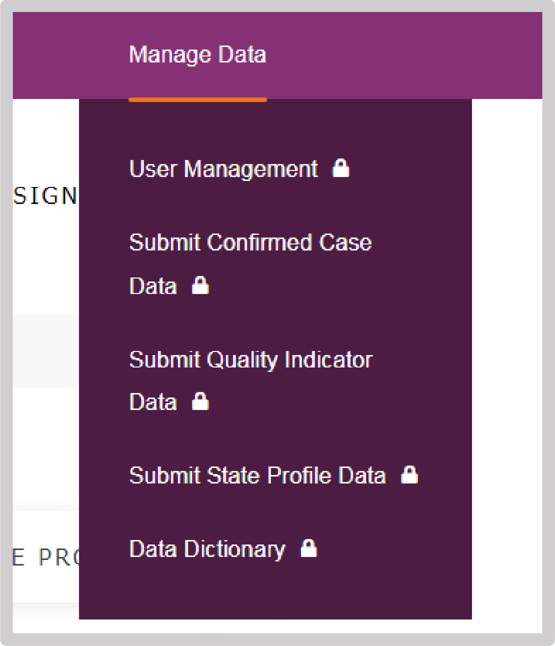
Table 2: Access Matrix by User Role

	Program Administrator	QI Data Manager	Case Data Manager	Data Viewer	Profile Data Manager	User
Account Profile Management						
Change password	X	X	X	X	X	X
Update account information	X	X	X	X	X	X
Edit photo	X	X	X	X	X	X
Can view profile	X	X	X	X	X	X
Can change email address	X	X	X	X	X	X
User Management						
Manage user roles for all assigned users in own state/territory	X					
Email and export assigned users	X					
Add/edit new users for the assigned program	X					
Change active status of users	X					
State Profile						
View any program profile	X	X	X	X	X	X
Edit the assigned program profile	X				X	
Cases						
Can view individual cases from assigned state/territory	X		X	X		
Add/ edit new individual cases for assigned state/territory via the webform	X		X			
Import individual cases using CSV import file	X		X			
Can see/ edit/ delete/ add aggregate cases for assigned state/territory	X		X			
Quality Indicators (QI)						
View/ download Quality Indicator Guide	X	X	X	X	X	X
View submitted QI data via the webform for	X	X		X		

	Program Administrator	**QI Data Manager**	**Case Data Manager**	**Data Viewer**	**Profile Data Manager**	**User**
assigned state/territory						
Enter QI data via the webform or CSV import file (annual and monthly data)	X	X				
View year-to-year comparisons report	X	X		X		
View QI monthly summaries for assigned program	X	X		X		
Tableau Dashboards						
Quality Indicator dashboards	X	X		X		
Confirm Cases dashboard	X		X	X		

NBS Programs may assign multiple user roles to a single individual (e.g., Profile Data Manager and QI Data Manager can be assigned to the same individual) and multiple individuals within the organization can have the same user role.

If are seeing locks in the NewSTEPs Repository, you either need to log in or you do not have the user permissions to view certain webpages for data entry and viewing. For questions about your user role permissions, please contact your Program Administrator or newsteps@aphl.org.



Note: No external user has access to the Data Dictionary, this is limited to NewSTEPs staff only.

Program Administrator User Role

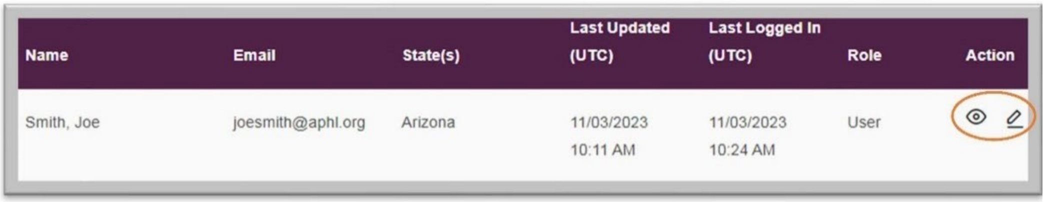
Each state/territory has at least one assigned Program Administrator; this is usually the newborn screening manager but can vary by program. The Program Administrator can make changes to the state/territory users based on their program needs. The Program Administrator may also email newsteps@aphl.org if changes need to be made for specific users.

Program Administrators can add, edit, and remove user access for their NBS Program via User Management. The Program Administrator can view users based on status (e.g., active, inactive, and locked) or user role. Additionally, Program Administrators can email and export all users for their state/territory.

How Program Administrators Can Assign/Edit User Roles

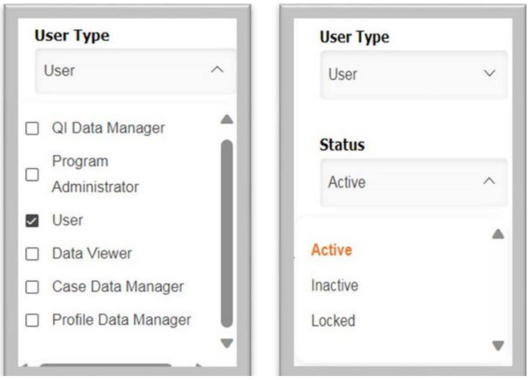
New users need to first create a NewSTEPs account by going to **SIGN UP** following the guidelines in Account Registration.

1. For new users or to edit existing user roles, go to Manage Data→ User Management.
2. Locate the user to be edited. Program Administrators will only see users assigned to their state/territory. Users can be filtered based on **Status** and **Role**. Users can also be found by using the **Search User** option.
3. Once the user has been located, click the **Pen** icon.



Name	Email	State(s)	Last Updated (UTC)	Last Logged In (UTC)	Role	Action
Smith, Joe	joesmith@aphl.org	Arizona	11/03/2023 10:11 AM	11/03/2023 10:24 AM	User	

4. Using the dropdown arrows, select the **User Type(s**) and **Status**.



User Type
User
☐ QI Data Manager
☐ Program Administrator
☑ User
☐ Data Viewer
☐ Case Data Manager
☐ Profile Data Manager

User Type
User
Status
Active
Active
Inactive
Locked

Note: For any user that is no longer employed by your organization, please change their user type to ***User*** *and status to* ***Inactive***

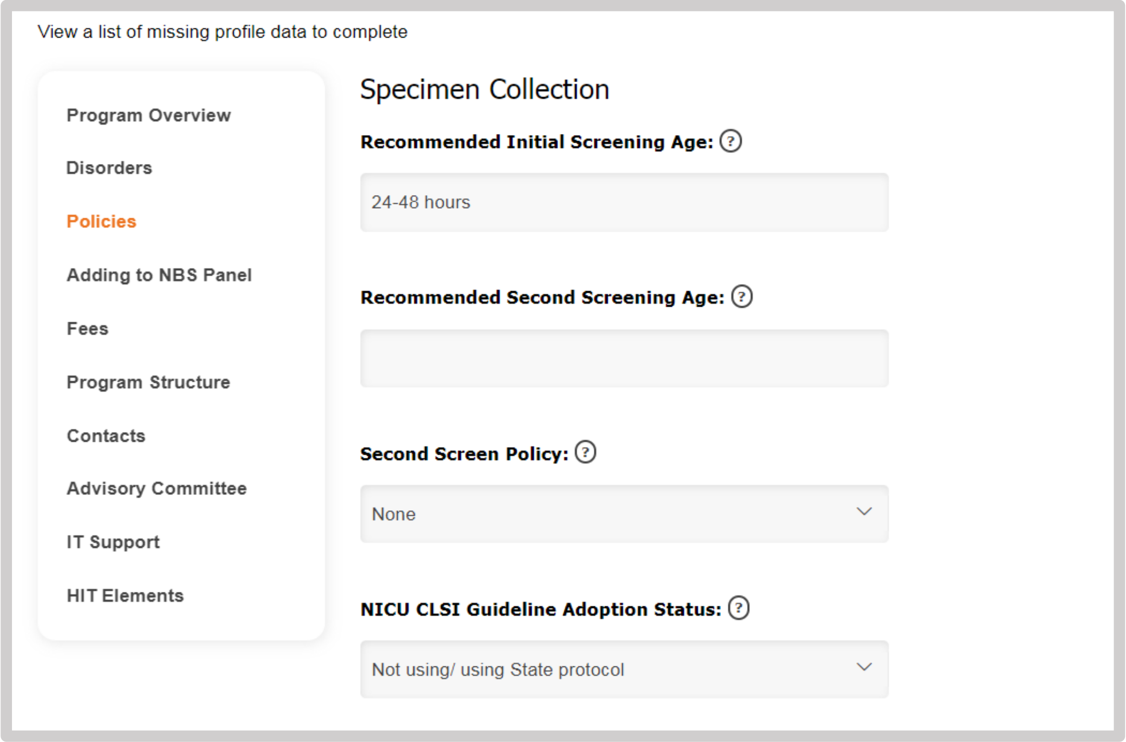
5. Once the edits have been made, click **SAVE PROFILE**.

DATA SUBMISSION

NBS Program Profiles

Program Profiles provide information that is specific to the state/territorial newborn screening program such as, disorders screened, policies, fees, and program structure. This information is shared with the public. NewSTEPs requires that states/territories update their profile data when changes occur and review their profiles for completion every August. Table 3 provides a detailed breakdown of the 10 sections collected within the program profiles.

1. Profile Data Managers can add/edit their profiles by going to Manage Data → Submit State Profile Data.
2. Select your assigned program to add/edit profile data using the dropdown arrow. Profile Data Managers will only see their assigned state/territory.
3. Using the sidebar menu, select the data elements on the side menu bar that you would like to add/edit/update.



Specimen Collection

Recommended Initial Screening Age: ?

24-48 hours

Recommended Second Screening Age: ?

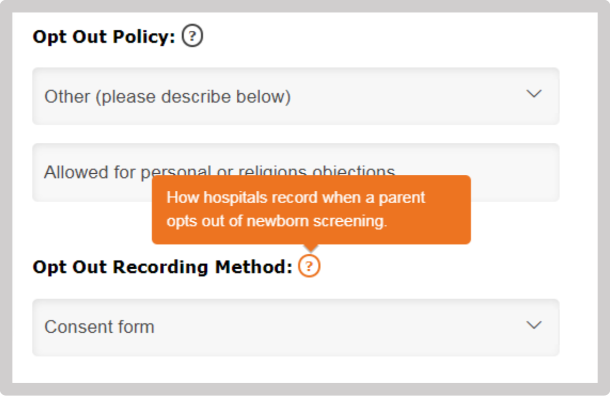
Second Screen Policy: ?

None

NICU CLSI Guideline Adoption Status: ?

Not using/ using State protocol

To access additional information about metrics collected within the Program Profiles, click on the question mark icon. An orange box will appear providing more information about the question.



Opt Out Policy:

Other (please describe below)

Allowed for personal or religious objections

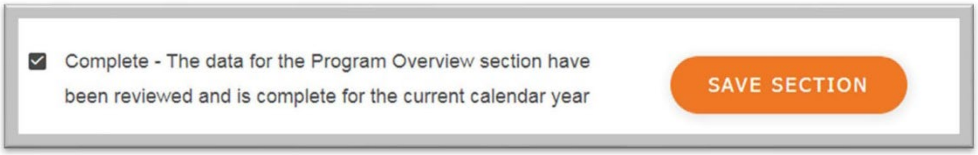
How hospitals record when a parent opts out of newborn screening.

Opt Out Recording Method:

Consent form

4. Once changes and updates have been made, click **SAVE SECTION.**

   Program Profile sections should be reviewed and marked **Complete** annually, even if changes were not made. Please ensure the **Complete** checkbox is selected once reviewed for each calendar year.



☑ Complete - The data for the Program Overview section have been reviewed and is complete for the current calendar year

Table 3: Data Elements Collected in Program Profiles

Program Profile Sections	Description of Data Collected
Program Overview	The program overview section collects general information about your NBS program: • Annual Births from the previous calendar year ○ *Note: This information is not entered by the NBS program, but data is pulled from the CDC Vital Statistics Rapid Release* • Name of the NBS Program • Region • Website • Number of required screens • Responsible laboratory • Screening card image • Hearing screening form
Disorders	The disorders section collects information about the disorders for which your state/territory screens. The disorders are organized according to the Recommended Uniform Screening Panel (RUSP) as core, secondary, and other conditions. • Screening Status (not screened, universally screened, likely to be detected/reported due to universal screening of another disorder, offered to select populations)

Program Profile Sections	Description of Data Collected
	o If a program selects **Not Screened**, they are asked to select if they are pursuing or not currently pursuing implementation. o If a program selects **Universally Screened** then they are asked if the condition is or is not required by law or rule. o *Note: Only select the month/year if the disorder is universally screened*. o *Note: If your program is piloting a disorder that is an **all-population pilot**, please select **Universal Screened** and **Not required by law/rule**.* • Screening Methodology for first and second screens for two-screen states o Method o Method's Target • Equipment • Implementation date for universal screening (month and year)
Policies	The policies section collects information about the newborn screening policies within your state/territory: • Recommended initial screening age • Recommended second screening age • Second screen policy • NICU CLSI guideline adoption status and description • Courier service usage status and provider • Definition of specimen receipt at lab and recording of specimen receipt at lab • Dried blood spot retention time • Dried blood spot storage conditions • Data retention policy • Consent for newborn screening and opt out policy • Residual specimen uses, including if specimens are consented for research • Short term follow-up definition, description, and method • Long term follow-up activities and description • Process for reporting missed diagnosis • Process for matching NBS records to find unscreened babies • Unsatisfactory specimen testing policy • Provide emergency/disaster support (agreement in place, testing frequency, support policy description, and continuity of operations plan (COOP))
Adding to the NBS Panel	This section collects information about the policies and procedures that your NBS program uses for adding conditions to the state/territory panel. There are three sections—general information, lab, and point-of-care (POC). Please make sure that you complete each tab.

Program Profile Sections	Description of Data Collected
	General Info • National recommendations followed and timeframe • Pilot studies requirement • Feasibility studies Lab • Lab test addition challenges • Lab test implementation period • Lab test addition requirements POC • POC addition challenges • POC test implementation period • POC test addition requirements
Fees	The fees tab collects information about NBS fees and related information: • Funding sources • Fee collection method • Fee holding location • Initial screen fee, and if repeat screen fee is included in the initial fee • Second screen fee • Fee use details • Fee notes
Program Structure	This section collects information about the NBS program structure, including operating hours, organizational chart, staffing levels, etc. You can also upload relevant documents. • Organizational chart (either upload file or can share a link) • Shared duties • Follow-up on unsatisfactory specimens (responsible party and description) • Follow-up on borderline results (responsible party and description) • Laboratory test performance evaluation (responsible party and description) • Formal communication structure • Staffing levels (% FTE) • Short term follow-up responsible party • Certification program • Proficiency tests • Program information (either upload document or provide link) • NBS educational information languages • Lab operating hours • Follow-up operating hours • Days of the week laboratory and follow-up activities occur • Days of the week tests are run for time-critical and non-time critical disorders

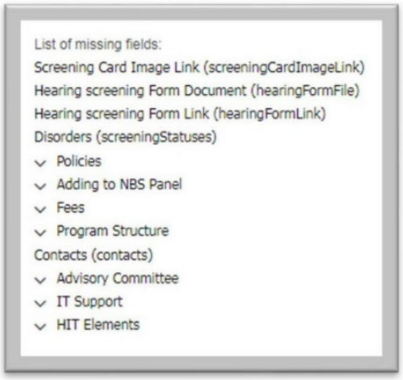
Program Profile Sections	Description of Data Collected
	• Inclement weather work policy
Contacts	The contacts tab collects contact information for the overall NBS program, Director, Program Manager, lab, follow-up, EHDI, CCHD, and HIT. For each contact and alternate contact, users are asked to provide the following information: • First and last name • Title • Credentials • Email • Country • State/Province/Region • Address • Phone • Fax
Advisory Committee	This section collects information on the details of the NBS advisory committee for the state/territorial NBS program: • Existing advisory committee • Advisory committee voluntary • Committee structure (text field and option to upload document or provide a link) • Charge/Bylaws (option to upload document or provide a link) • Meeting frequency • Link to meeting minutes
IT Support	The Information Technology (IT) section collects information on the types of information systems NBS programs use: • Lab information system • Follow-up information system • Staffing levels • IT support description • NBS data backup frequency • Data loss information • IT recovery time • Disaster recovery hardware • COOP information
HIT Elements	The Health Information Technology (HIT) section collects information on HIT processes and systems your NBS program is implementing. Please select “No” if certain processes are not applicable. • HL7 order messages accepted (if “yes” the program will be asked about the number of birthing facilities centers submitting and the number of HL7 orders received) • HL7 result messages sent (if “yes” the program will be asked about

Program Profile Sections	Description of Data Collected
	the number of birthing centers receiving results, number of HL7 specimen results sent) • HL7 implementation guides used • Terminology standards used • Web portal for sharing NBS data • Web portal for DBS test orders/demographic information • Number of birthing centers using web portal for DBS orders and demographic entry • Number of specimens entered into DBS order and demographic data entry web portal • Web portal for NBS result reporting • Number of birthing centers using NBS retrieval portal • Submitter performance feedback portal present and description • Alternative feedback method • Database integration information • Implementation status of statewide health information exchange (HIE) • Access to HIE and how results are shared

Information from the previous year will carry over into the new calendar year. States/territories will only have to enter missing data and data that needs to be revised. A comprehensive list of missing fields can be viewed by selecting **View a list of missing profile data to complete**.

[redacted] State Profile

View a list of missing profile data to complete



List of missing fields:
Screening Card Image Link (screeningCardImageLink)
Hearing screening Form Document (hearingFormFile)
Hearing screening Form Link (hearingFormLink)
Disorders (screeningStatuses)

Contacts (contacts)

Quality Indicators

NewSTEPs [Quality Indicators](#) (QIs) consists of eight different performance metrics which have undergone careful evaluation to assure agreement on definitions and are used to provide longitudinal comparisons within NBS programs as well as comparison to aggregate data across NBS programs. States and territories must have a signed Memorandum of Understanding (MOU) with APHL before QI data can be entered. QI data can only be entered by those assigned the QI Data Manager user role. See NewSTEPs Quality Indicator Webinar for definitions and a navigation tutorial.

Quality Indicator data may be entered annually or monthly (Table 4). If QI data is entered monthly, the data will be aggregated for the annual data submission (i.e., the program will not need to re-enter the annual data if all 12 months are provided). Quality Indicators are due each April for the previous year (e.g., 2021 quality indicator data is due in April 2022).

Table 4: Quality Indicator Submission Details

Quality Indicator	Level	Submission
QI 1- Unacceptable Specimens	Specimen	Monthly or Annual
QI 2- Missing Essential Information	Specimen	Monthly or Annual
QI 3- Unscreened Newborns	Baby	Annual
QI 4- Lost to Follow-Up	Baby	Annual
QI 5- Timeliness	Specimen and Baby	Monthly or Annual
QI 6- Screen Positives	Baby	Annual
QI 7- Confirmed Positives	Baby	Annual
QI 8- Missed Cases	Baby	Annual

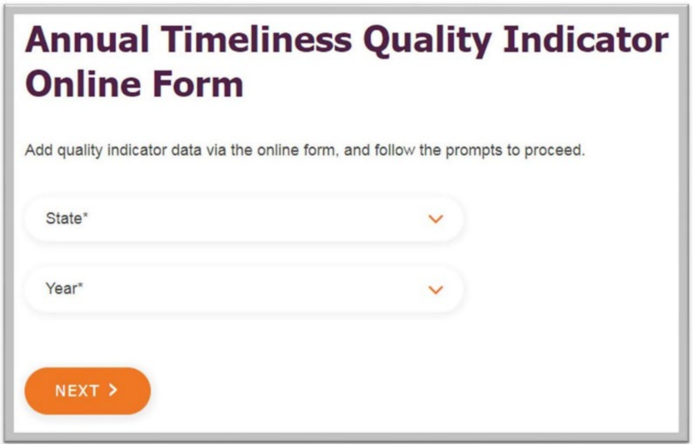
The Quality Indicator Source Document provides definitions and guidelines on how to query your program's data. It is important to follow the NewSTEPs definitions for national reporting. QI data may be entered via the webform or CSV import.

Quality Indicator Submission via Webform

The webform allows the user to manually quality indicator information. The annual and monthly QI data entry steps are the same. To enter/edit annual or monthly QI data using the webform follow the steps below:

1. Manage Data→ Submit Quality Indicator Data.
2. Click either **Annual** or **Monthly Quality Indicator Data**.

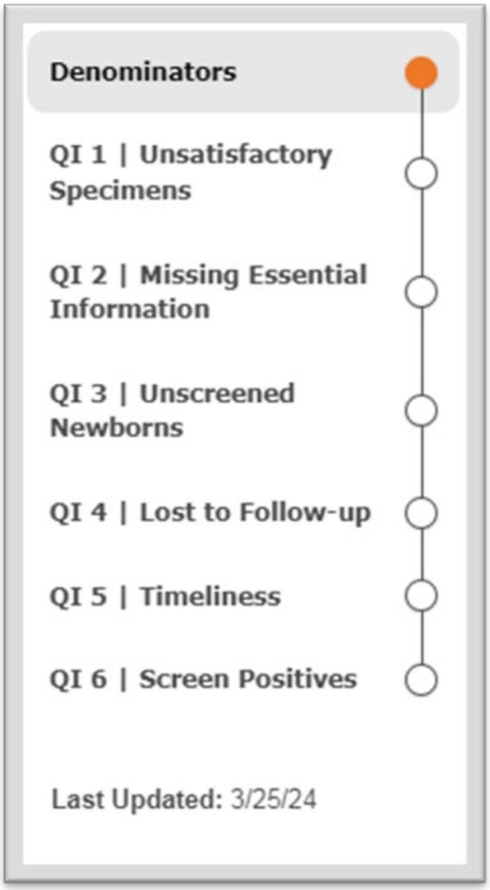
3. Click **ENTER/EDIT DATA USING OUR ONLINE FORM**.
4. Select the state/territory using the dropdown box. You will only see your assigned state/territory.
5. Select the year that data is being entered and click **NEXT**.



Annual Timeliness Quality Indicator Online Form

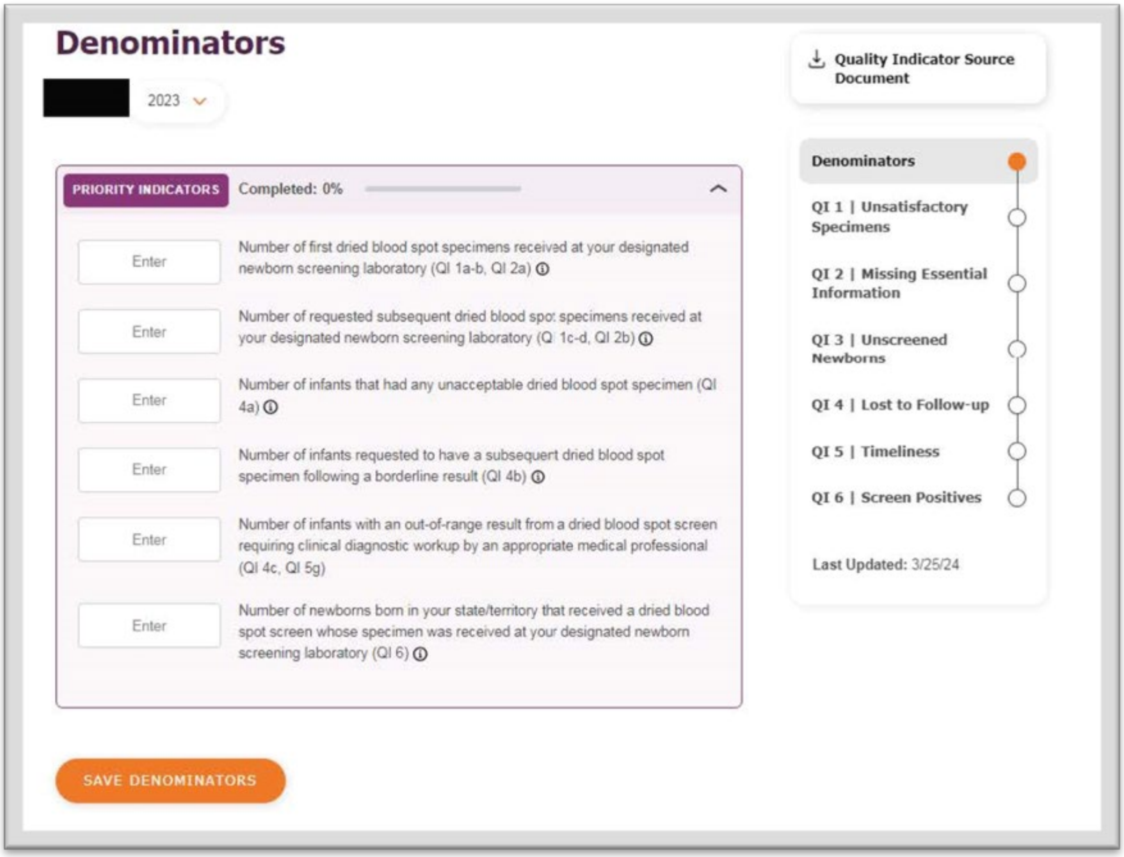
Add quality indicator data via the online form, and follow the prompts to proceed.

6. The sidebar to the right can be used to navigate. Click on the QI language to navigate to the desired quality indicator section.



Last Updated: 3/25/24

7. Denominators can be entered for all metrics on the **Denominators** page. Data entered here will carry over to their appropriate QI. If a denominator is edited on the QI page, the denominator page will automatically update to reflect the changed.



Denominators

[redacted] 2023

PRIORITY INDICATORS Completed: 0%

Enter | Number of first dried blood spot specimens received at your designated newborn screening laboratory (QI 1a-b, QI 2a) ⓘ

Enter | Number of requested subsequent dried blood spot specimens received at your designated newborn screening laboratory (QI 1c-d, QI 2b) ⓘ

Enter | Number of infants that had any unacceptable dried blood spot specimen (QI 4a) ⓘ

Enter | Number of infants requested to have a subsequent dried blood spot specimen following a borderline result (QI 4b) ⓘ

Enter | Number of infants with an out-of-range result from a dried blood spot screen requiring clinical diagnostic workup by an appropriate medical professional (QI 4c, QI 5g)

Enter | Number of newborns born in your state/territory that received a dried blood spot screen whose specimen was received at your designated newborn screening laboratory (QI 6) ⓘ

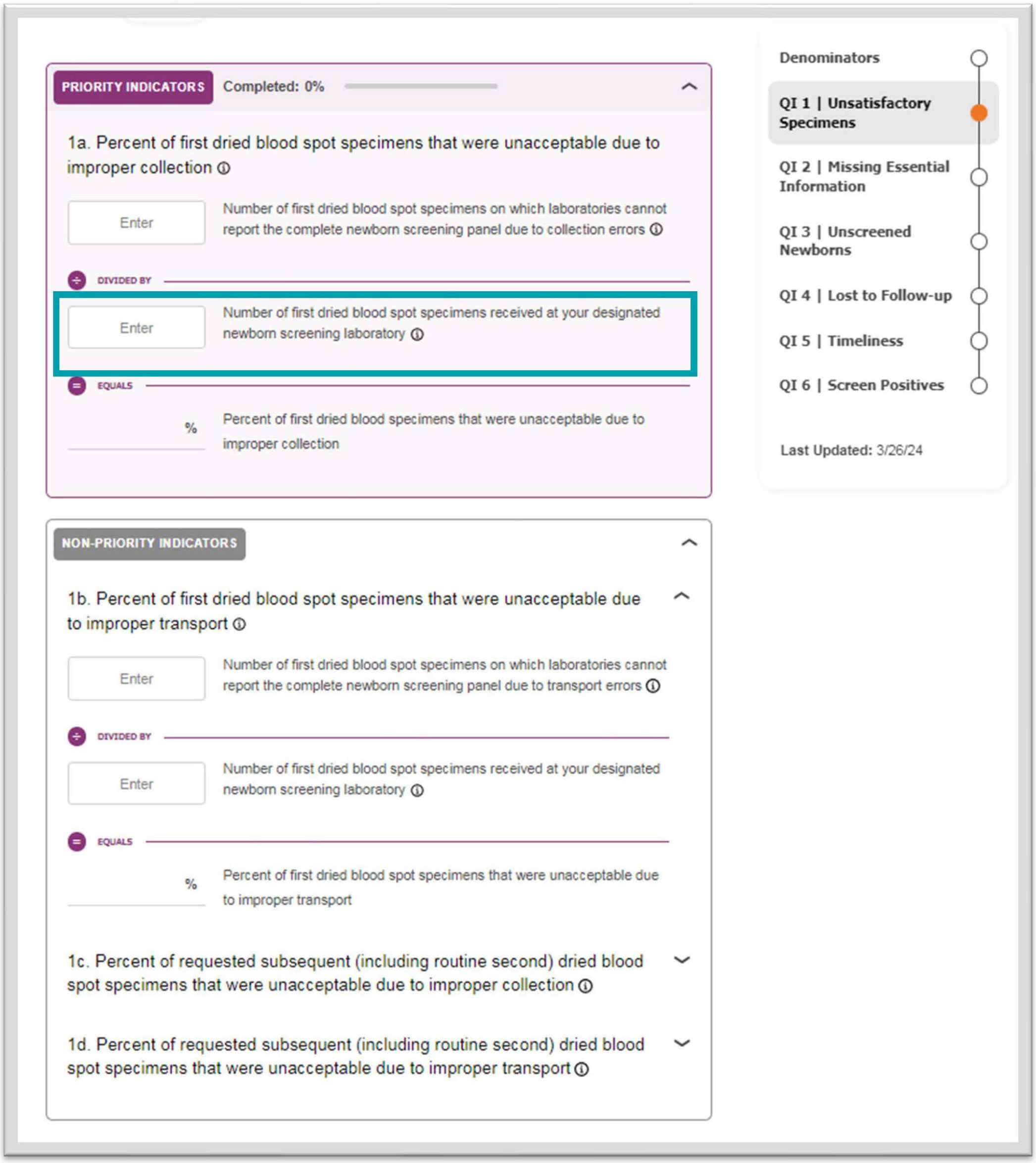
SAVE DENOMINATORS

Quality Indicator Source Document

- Denominators
- QI 1 | Unsatisfactory Specimens
- QI 2 | Missing Essential Information
- QI 3 | Unscreened Newborns
- QI 4 | Lost to Follow-up
- QI 5 | Timeliness
- QI 6 | Screen Positives

Last Updated: 3/25/24

8. To enter numerator data, select a QI and enter or change the data. The percent will automatically calculate when both numerator and denominator data is provided. *Note: each Quality Indicator page provides the purpose, definition, and tooltips. Hover over the tooltips* ⓘ *to see more information related to the QI and use the* *[Source Document]* *for complete definitions. Priority indicators will be purple, while non-priority indicators are in grey. The accordion may be used to consolidate and expand the QI as data is entered. A progress bar will track the level of completion. A note section is provided for each QI. Please provide any caveats associated with the QI. Quality Indicators 5e, 5f, 7, and 8 are entered via the case data.*



1a. Percent of first dried blood spot specimens that were unacceptable due to improper collection ⓘ

Number of first dried blood spot specimens on which laboratories cannot report the complete newborn screening panel due to collection errors ⓘ

Number of first dried blood spot specimens received at your designated newborn screening laboratory ⓘ

Percent of first dried blood specimens that were unacceptable due to improper collection

1b. Percent of first dried blood spot specimens that were unacceptable due to improper transport ⓘ

Number of first dried blood spot specimens on which laboratories cannot report the complete newborn screening panel due to transport errors ⓘ

Number of first dried blood spot specimens received at your designated newborn screening laboratory ⓘ

Percent of first dried blood spot specimens that were unacceptable due to improper transport

1c. Percent of requested subsequent (including routine second) dried blood spot specimens that were unacceptable due to improper collection ⓘ

1d. Percent of requested subsequent (including routine second) dried blood spot specimens that were unacceptable due to improper transport ⓘ

9. Once the information is entered click **SAVE** at the bottom of each page. *Note: you must hit SAVE for each webpage to save data for the specific quality indicator.*

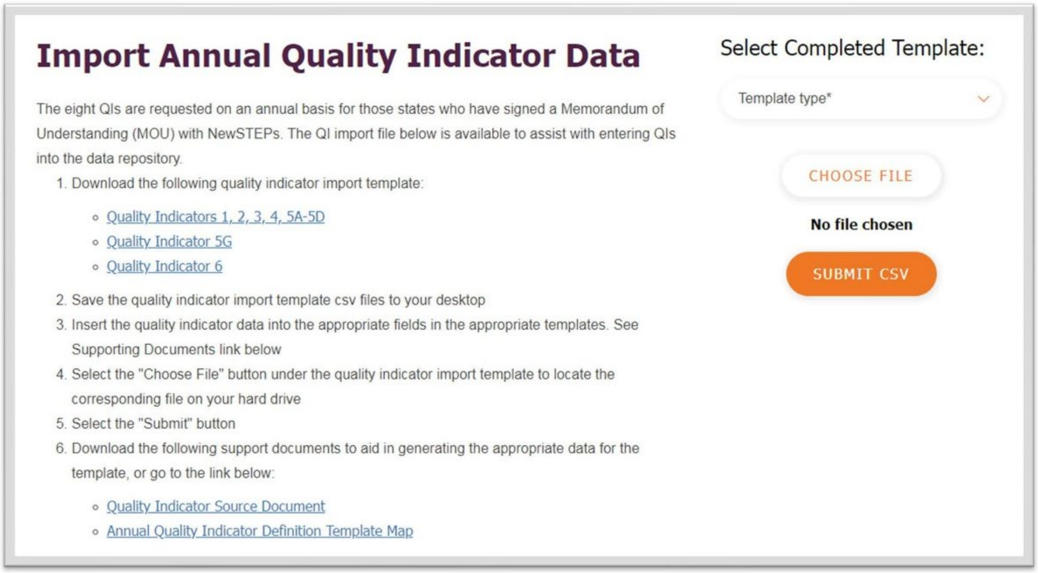
QI Submission via CSV Import File

The CSV Import allows the user to enter multiple quality indicators at the same time.

The annual and monthly QI CSV import steps are the same. To enter/edit annual/monthly QI data using the CSV import follow the steps below:

1. Manage Data→ Submit Quality Indicator Data.
2. Click either **Annual** or **Monthly Quality Indicator Data**.

3. Click **IMPORT ANNUAL DATA VIA CSV FILE.**
4. Download and review the appropriate template map.
    - Annual QI Template Map.
    - Monthly QI Template Map. Monthly QI metrics use numerical values for months.
5. Download the appropriate quality indicator import file.
    - Annual
        - Quality Indicators 1, 2, 3, 4, 5A-D
        - Quality Indicator 5G
        - Quality Indicator 6
    - Monthly Quality Indicators 1, 2, and 5A-D
6. Enter the data into the file that is being reported. Ensure that the required fields are filled out completely and that acceptable values are used (see template maps for more information).
7. Save the import file as a CSV file to your desktop.
8. On the sidebar, select **TEMPLATE TYPE** and **CHOOSE FILE**.



Import Annual Quality Indicator Data

The eight QIs are requested on an annual basis for those states who have signed a Memorandum of Understanding (MOU) with NewSTEPs. The QI import file below is available to assist with entering QIs into the data repository.

1. Download the following quality indicator import template:
    - Quality Indicators 1, 2, 3, 4, 5A-5D
    - Quality Indicator 5G
    - Quality Indicator 6
2. Save the quality indicator import template csv files to your desktop
3. Insert the quality indicator data into the appropriate fields in the appropriate templates. See Supporting Documents link below
4. Select the "Choose File" button under the quality indicator import template to locate the corresponding file on your hard drive
5. Select the "Submit" button
6. Download the following support documents to aid in generating the appropriate data for the template, or go to the link below:
    - Quality Indicator Source Document
    - Annual Quality Indicator Definition Template Map

9. Using the File Explorer on your desktop, select the desired CSV file.
10. Next, select **SUBMIT CSV**.
11. Do not navigate off the page until the import is successfully completed.

Individual Case Data

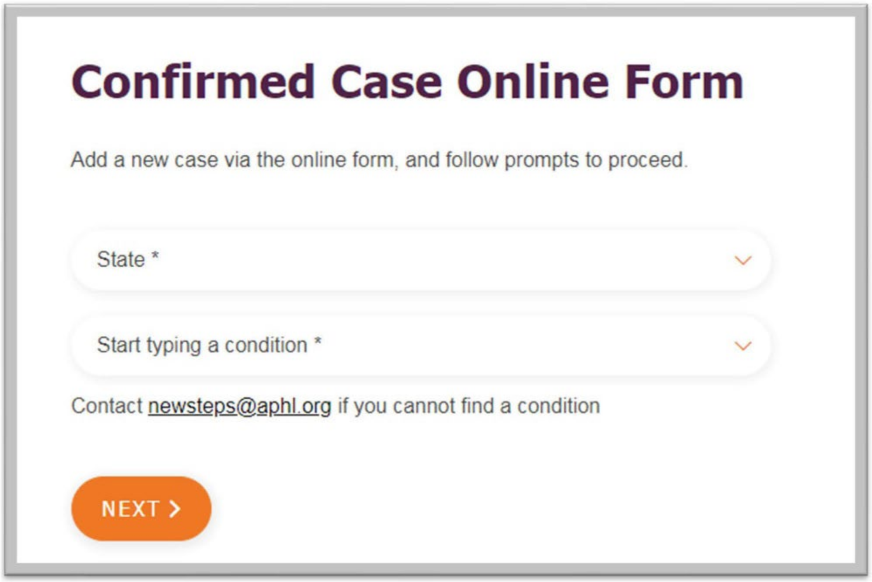
Individual cases are confirmed cases that provide demographic, screening, intervention, follow-up, and diagnosis details. States and territories must have a signed Memorandum of Understanding (MOU) with APHL before case data can be entered. Case data can only be entered by those who are assigned the Case Data Manager user role. Individual case data plays an integral piece in data analysis, particularly when examining health disparities and gaps. Confirmed cases should only be entered for disorders that were part of your program's routine screening panel during the year of birth.

Public health surveillance case definitions (i.e., case definitions) were developed by the newborn screening community to facilitate common classifications for diagnoses across programs for all core newborn screening conditions. NBS Programs may use these case definitions to allow for consistent categorization and tracking of short and long-term follow-up of identified newborns at the local, regional, and national levels. Note, diagnostic criteria are available on the case worksheets but diagnostic criteria are no longer collected within the NewSTEPs Data Repository, only the final diagnosis for each case.

Individual Case Entry via Webform

The case webform allows the user to enter one case at a time. To enter case data follow the steps below:

1. Manage Data → Submit Confirmed Case Data
2. Click **ENTER/EDIT DATA USING OUR ONLINE FORM**.
3. Select the state/territory using the dropdown. Case Data Managers will only see their assigned state/territory.
4. Start typing the condition or use the dropdown select the condition and click **NEXT.**
   Note: Core, secondary, and other RUSP conditions are listed separately



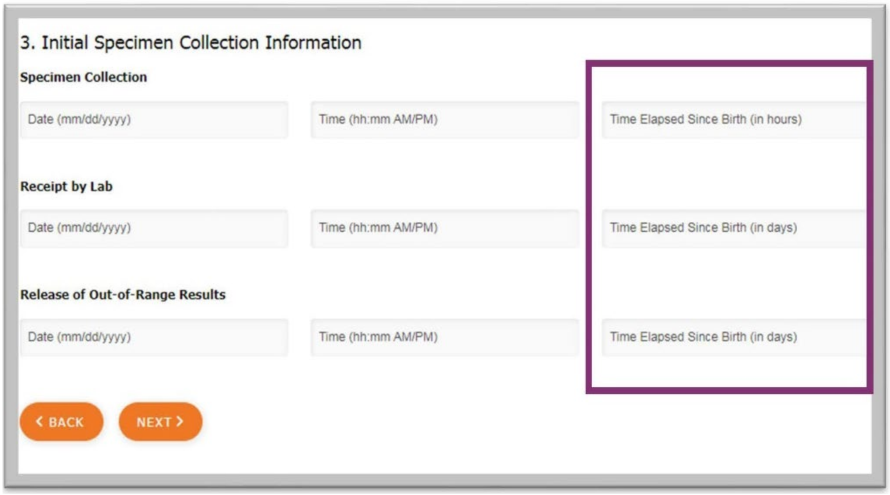
Confirmed Case Online Form

Add a new case via the online form, and follow prompts to proceed.

Contact newsteps@aphl.org if you cannot find a condition

5. Enter infant demographic information. State Unique ID and date of birth/year of birth is required. Click **NEXT**.
    - *Note: the state unique identification number is unique to the state/territory meaning that only a single case can have the same identification number.*
    - *If a baby is diagnosed with multiple conditions, the state-unique identification number should contain an **A** and **B** to differentiate between conditions**.** For example, when a baby is diagnosed with multiple conditions and the state-unique identification number is **APHL123**, the first condition would be entered as **APHL123A,** and the second condition would be entered as **APHL123B**.*
6. Provide screening information, then click **NEXT**.
7. Enter the initial specimen collection information, then click **NEXT**.

- Time elapsed will be calculated when dates are entered; however, time elapsed can be entered manually instead of dates. Dates are not stored in the repository and are only used for calculations.



3. Initial Specimen Collection Information

Specimen Collection

Date (mm/dd/yyyy) | Time (hh:mm AM/PM) | Time Elapsed Since Birth (in hours)

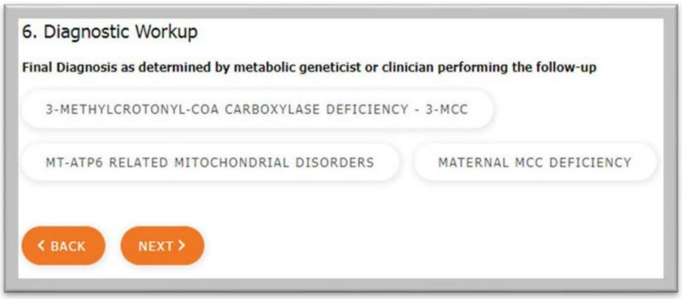
Receipt by Lab

Date (mm/dd/yyyy) | Time (hh:mm AM/PM) | Time Elapsed Since Birth (in days)

Release of Out-of-Range Results

Date (mm/dd/yyyy) | Time (hh:mm AM/PM) | Time Elapsed Since Birth (in days)

8. Enter the subsequent specimen collection information, then click **NEXT**.
9. Enter the intervention, follow-up, and diagnosis information, then click **NEXT**.
10. A final diagnosis may be applicable for some conditions and then click **NEXT**.



6. Diagnostic Workup

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

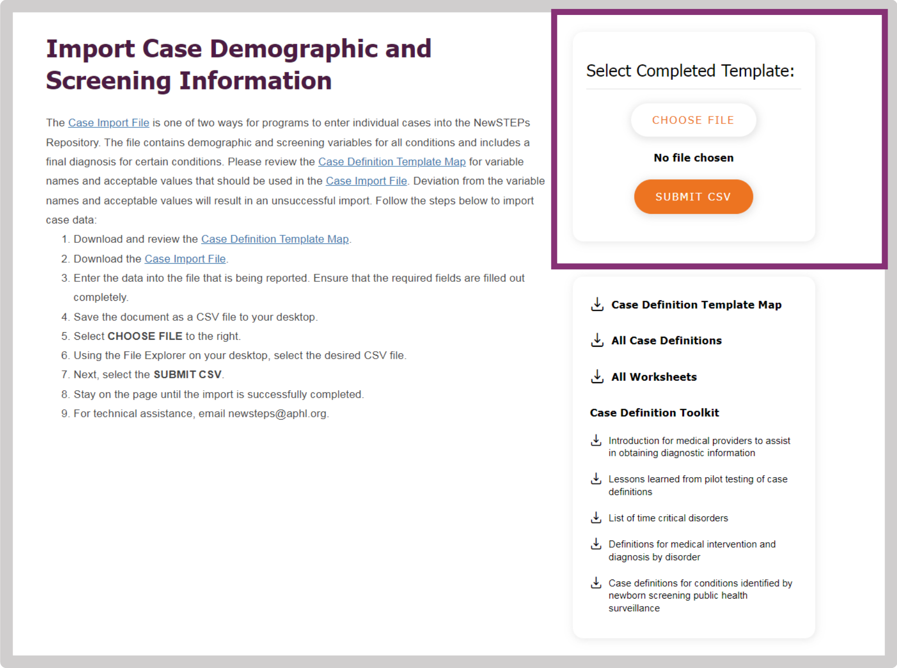
11. Additional notes about the case may be entered. Please do not include any personal identifiable information (PII) in the notes.
12. Click **COMPLETE FORM**. You will receive an error message if the individual case information was not entered properly.

Individual Case Entry via CSV Upload

The case data entry CSV Form allows the user to enter multiple cases at a time. To enter/edit case data follow the steps below:

1. Manage Data → Submit Confirmed Case Data
2. Click **IMPORT CASE DATA VIA CSV FILE**.
3. Download and review the Case Definition Template Map.
4. Download the Case Import File.
5. Enter the data into the file that is being reported. Ensure that the required fields are filled out completely.
6. Save the document as a CSV file to your desktop.
7. On the sidebar, select **CHOOSE FILE**.
8. Using the File Explorer on your desktop, select the desired CSV file.
9. Next, select **SUBMIT CSV**.

10. Do not navigate off the page until the import is successfully completed.



Import Case Demographic and Screening Information

The Case Import File is one of two ways for programs to enter individual cases into the NewSTEPs Repository. The file contains demographic and screening variables for all conditions and includes a final diagnosis for certain conditions. Please review the Case Definition Template Map for variable names and acceptable values that should be used in the Case Import File. Deviation from the variable names and acceptable values will result in an unsuccessful import. Follow the steps below to import case data:

1. Download and review the Case Definition Template Map.
2. Download the Case Import File.
3. Enter the data into the file that is being reported. Ensure that the required fields are filled out completely.
4. Save the document as a CSV file to your desktop.
5. Select **CHOOSE FILE** to the right.
6. Using the File Explorer on your desktop, select the desired CSV file.
7. Next, select the **SUBMIT CSV**.
8. Stay on the page until the import is successfully completed.
9. For technical assistance, email newsteps@aphl.org.

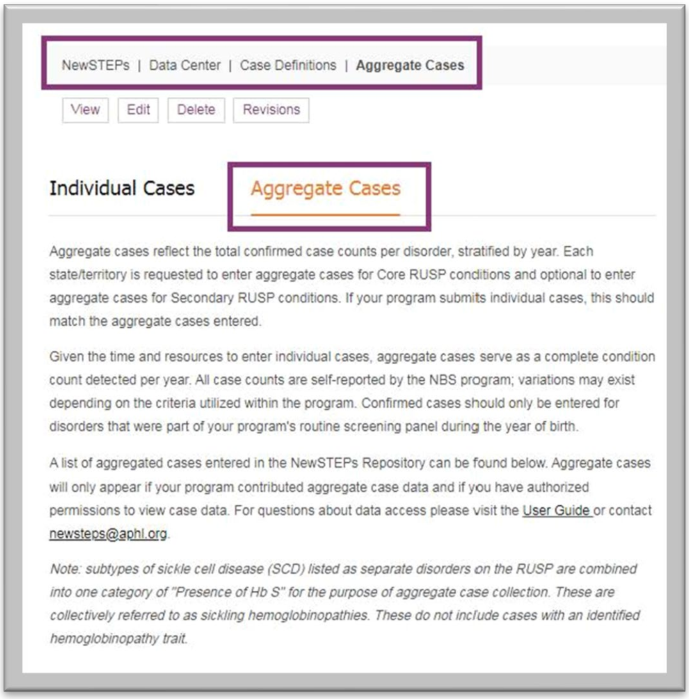
Aggregate Cases

Aggregate case data reflects the total number of confirmed case counts per disorder, stratified by year. Each state/territory is requested to enter aggregate cases for Core RUSP conditions and optional to enter aggregate cases for Secondary RUSP conditions. Aggregate cases serve as a complete count for conditions detected per year. If your program submits individual cases, this should match the aggregate cases entered for core RUSP conditions.

Given the time and resources to enter individual cases, aggregate cases serve as a complete condition count detected per year. Confirmed cases should only be entered for disorders that were part of your program's routine screening panel during the year of birth.

To enter aggregate case data, follow these steps:

1. Go to Data Center→NBS Cases→ Aggregate Cases



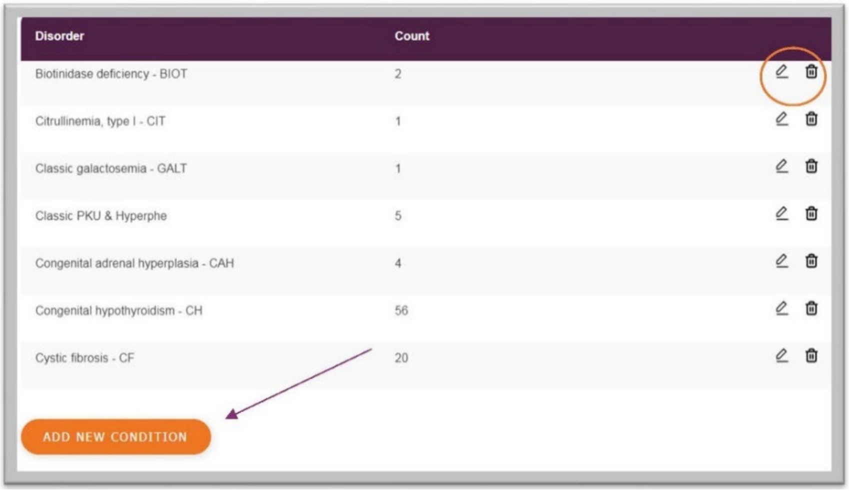
Aggregate cases reflect the total confirmed case counts per disorder, stratified by year. Each state/territory is requested to enter aggregate cases for Core RUSP conditions and optional to enter aggregate cases for Secondary RUSP conditions. If your program submits individual cases, this should match the aggregate cases entered.

Given the time and resources to enter individual cases, aggregate cases serve as a complete condition count detected per year. All case counts are self-reported by the NBS program; variations may exist depending on the criteria utilized within the program. Confirmed cases should only be entered for disorders that were part of your program's routine screening panel during the year of birth.

A list of aggregated cases entered in the NewSTEPs Repository can be found below. Aggregate cases will only appear if your program contributed aggregate case data and if you have authorized permissions to view case data. For questions about data access please visit the User Guide or contact newsteps@aphl.org.

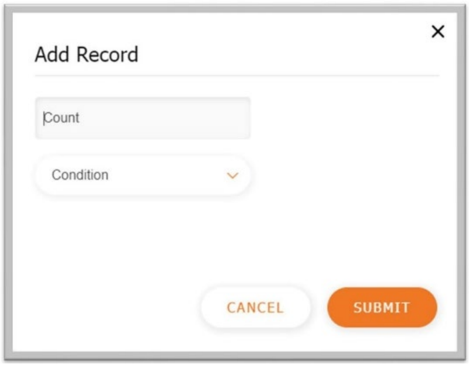
Note: subtypes of sickle cell disease (SCD) listed as separate disorders on the RUSP are combined into one category of "Presence of Hb S" for the purpose of aggregate case collection. These are collectively referred to as sickling hemoglobinopathies. These do not include cases with an identified hemoglobinopathy trait.

2. Select the state/territory using the dropdown. Case Data Managers will only see their assigned state/territory.
3. Select the birth year
4. Click **ADD NEW CONDITION**

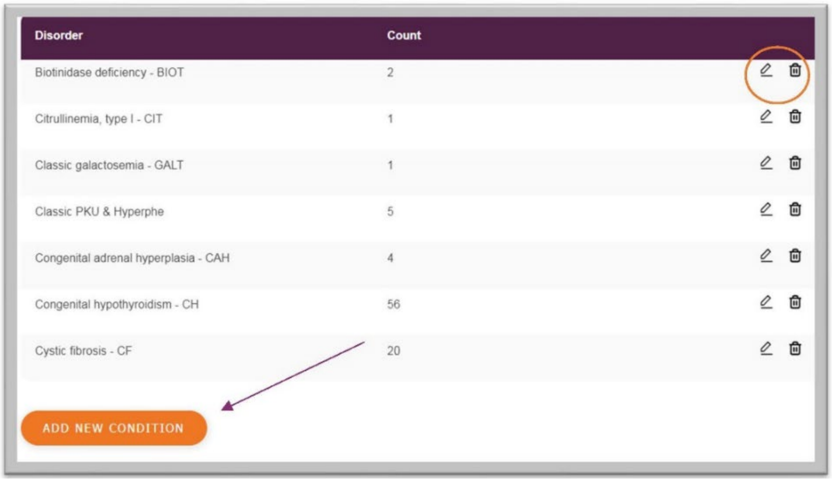


Disorder	Count
Biotinidase deficiency - BIOT	2
Citrullinemia, type I - CIT	1
Classic galactosemia - GALT	1
Classic PKU & Hyperphe	5
Congenital adrenal hyperplasia - CAH	4
Congenital hypothyroidism - CH	56
Cystic fibrosis - CF	20

5. The user will be prompted to enter the aggregate number of cases reported for the condition selected from the condition dropdown.



6. Repeat steps 3-4 until all aggregate case data has been submitted. All data entered will be visible on the aggregate case tab.
7. NBS Programs can edit or delete aggregate case data as needed by using the icons in the orange circle.



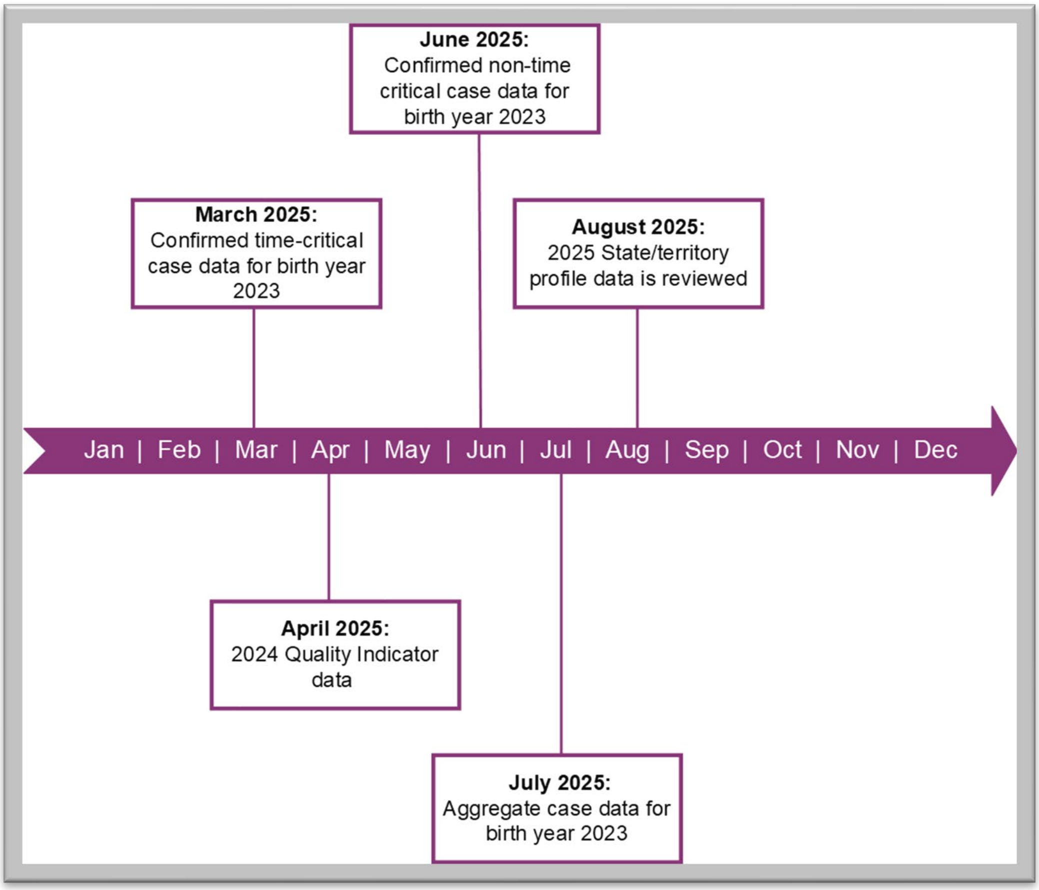
Disorder	Count
Biotinidase deficiency - BIOT	2
Citrullinemia, type I - CIT	1
Classic galactosemia - GALT	1
Classic PKU & Hyperphe	5
Congenital adrenal hyperplasia - CAH	4
Congenital hypothyroidism - CH	56
Cystic fibrosis - CF	20

Data Submission Deadlines

All data is voluntary. Ideally, data would be entered by the due date; however, it may not be feasible for some programs. When data is entered by the specified due date, it helps with the data review and reporting process.

Quality Indicator data for the ***previous*** year (current year – 1) is due every April. Reporting for case data is entered ***two years*** behind (current year – 2). Case data for time-critical cases is due in March, non-time-critical cases in June, and aggregate confirmed cases in July. State/territory program profile data is due for the current calendar year in August. Figure 1 summarizes the due date for each data metric. *Note: due dates may change slightly. For the most up-to-date due dates please see the Manage Data timeline.*

Figure 1: Data Submission Timeline



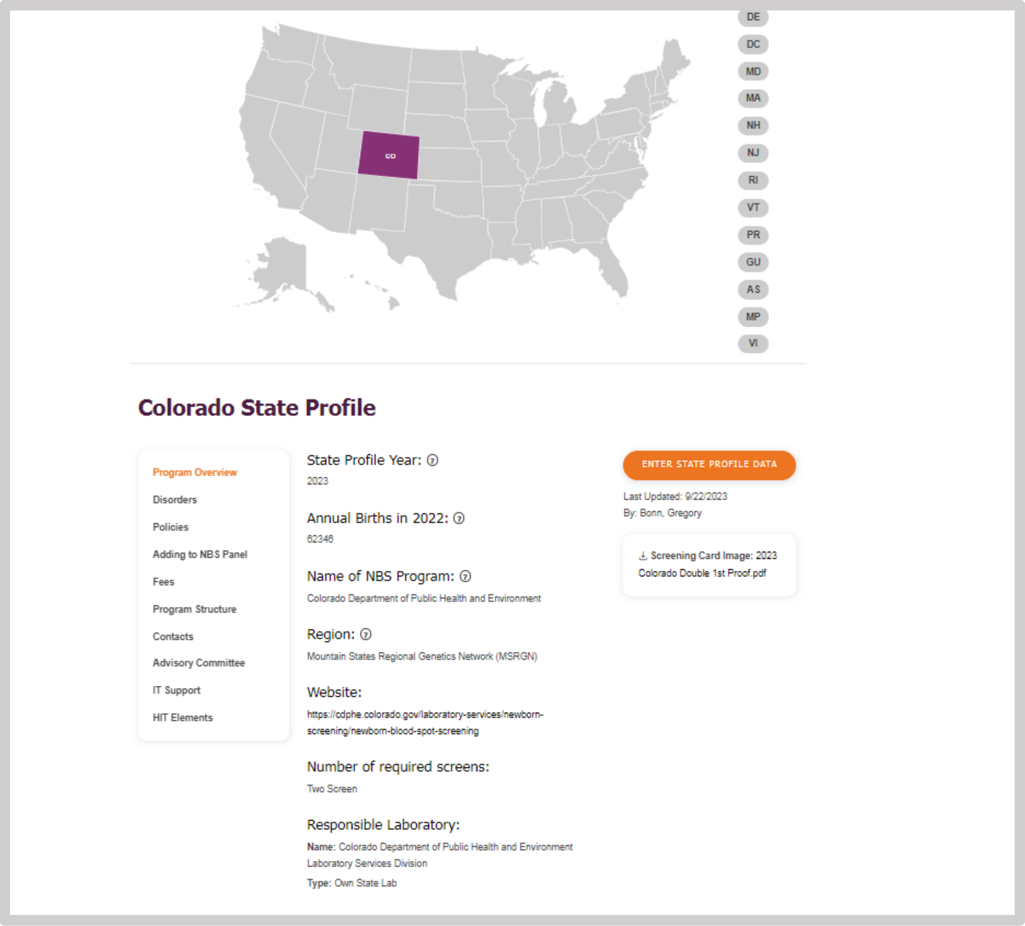
ACCESSING SUBMITTED DATA

Interactive dashboards and reports utilize data that has been entered into the NewSTEPs Repository. There are three categories of dashboards and reports: State/Territory Profiles, Quality Indicators, and Confirmed Cases. State profile data dashboards and reports are public-facing, while quality indicator and case dashboards require permission-based user roles.

Publicly Available Dashboard and Reports

Program Profile data can be viewed by:

1. Go to Data Center→ State Profiles
2. Select the state/territory in which you want to see their program profile information
3. On the left-hand side, users can select the different program profile sections (see Table 3 for more information)



Colorado State Profile

State Profile Year: 2023

Annual Births in 2022: 62346

Name of NBS Program: Colorado Department of Public Health and Environment

Region: Mountain States Regional Genetics Network (MSRGN)

Website: https://cdphe.colorado.gov/laboratory-services/newborn-screening/newborn-blood-spot-screening

Number of required screens: Two Screen

Responsible Laboratory:
Name: Colorado Department of Public Health and Environment Laboratory Services Division
Type: Own State Lab

Last Updated: 9/22/2023
By: Bonn, Gregory

Further, the state/territory profile dashboards and reports are public-facing. Reports are automatically refreshed each evening, and dashboards are updated as needed, but at least at the end of every month. See Table 5 for a complete list of the state profile dashboards and reports.

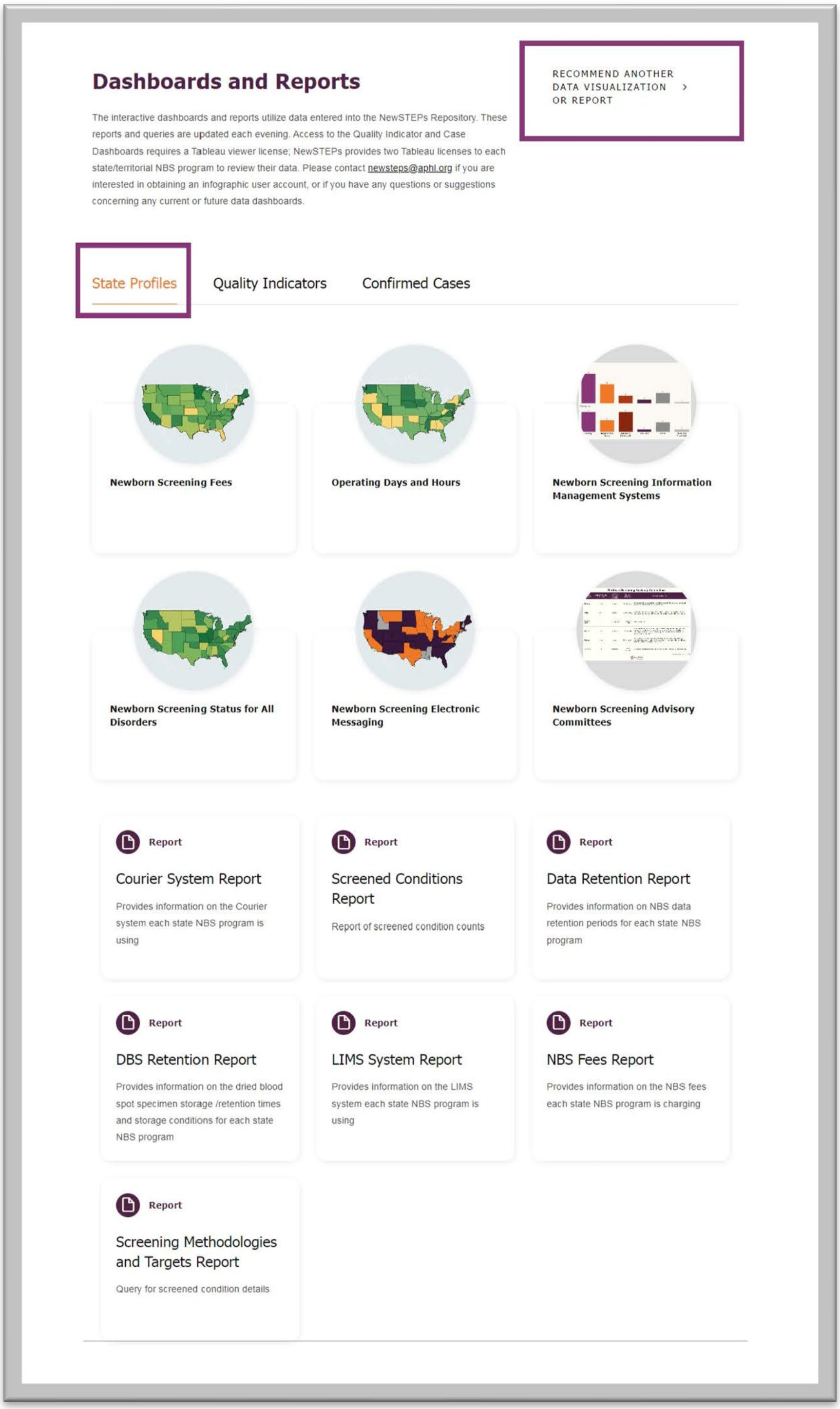
Table 5: List of State Profile Dashboards and Reports

Name of Dashboard/Report	Description
Newborn Screening Fees	Heat maps for initial NBS fee, repeat NBS fee, and fee activity.
Operating Days and Hours	Heat map for laboratory and follow-up hours by day of week.
Newborn Screening Information Management Systems	Bar charts display the number of NBS Programs using the different laboratory and follow-up information systems. Hover over the bar chart to see a list of states/territories using each system.
Newborn Screening Status for All Disorders	Provides a heat map of the number of disorders screened, a measles chart of the status of core RUSP conditions, and a map of screening status for each condition status for each condition.

Name of Dashboard/Report	Description
Newborn Screening Electronic Messaging	Heat map of HL7 orders accepted, HL7 results sent, and a terminology standard chart.
Newborn Screening Advisory Committees	A table of newborn screening advisory Committee structure and meeting frequency by NBS Program.
Screened Conditions Report	Users can access the number of programs universally screening or not screening for each condition. There are tabs for core, secondary and other RUSP conditions.
Screening Methodologies and Targets	Click on the filters to choose the condition, screening method, target, and equipment. The report will the list the states/territories that meet the criteria of the filter.
Data Retention Report	Provides information on NBS data retention periods for each state/territorial NBS program.
DBS Retention Report	Provides information on the dried blood spot specimen storage/retention times, as well as storage conditions for each NBS program.
Laboratory Information (LIMS) System	Provides information on the laboratory information system each NBS program is using.
NBS Fees	Provides information on the NBS fees each NBS program is charging as well as fee notes.
Courier System	Provides information on the courier system for each NBS program.

To access these dashboards and reports:

1. Go to Data Center→ Dashboards and Reports
2. Select the State Profile Tab
3. Select the dashboard or report that you would like to see (see Table 5 for the complete list); for any missing dashboards/reports you have the option to recommend one to NewSTEPs.



Dashboards and Reports

The interactive dashboards and reports utilize data entered into the NewSTEPs Repository. These reports and queries are updated each evening. Access to the Quality Indicator and Case Dashboards requires a Tableau viewer license; NewSTEPs provides two Tableau licenses to each state/territorial NBS program to review their data. Please contact newsteps@aphl.org if you are interested in obtaining an infographic user account, or if you have any questions or suggestions concerning any current or future data dashboards.

- Newborn Screening Fees
- Operating Days and Hours
- Newborn Screening Information Management Systems
- Newborn Screening Status for All Disorders
- Newborn Screening Electronic Messaging
- Newborn Screening Advisory Committees

Report
Courier System Report
Provides information on the Courier system each state NBS program is using

Report
Screened Conditions Report
Report of screened condition counts

Report
Data Retention Report
Provides information on NBS data retention periods for each state NBS program

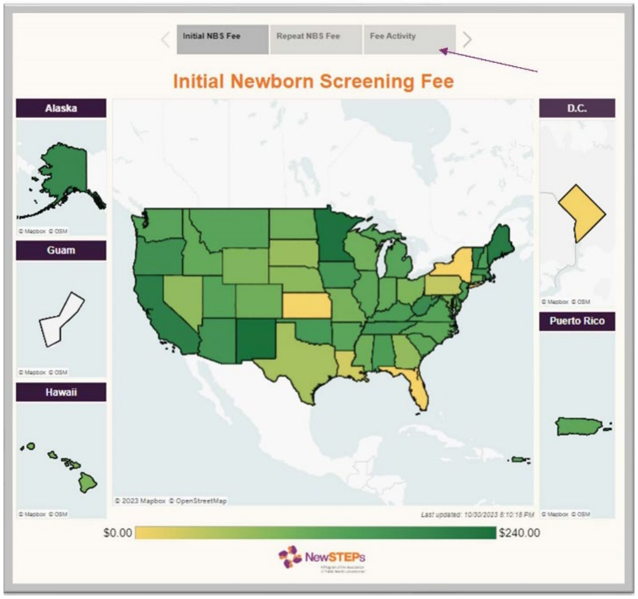
Report
DBS Retention Report
Provides information on the dried blood spot specimen storage /retention times and storage conditions for each state NBS program

Report
LIMS System Report
Provides information on the LIMS system each state NBS program is using

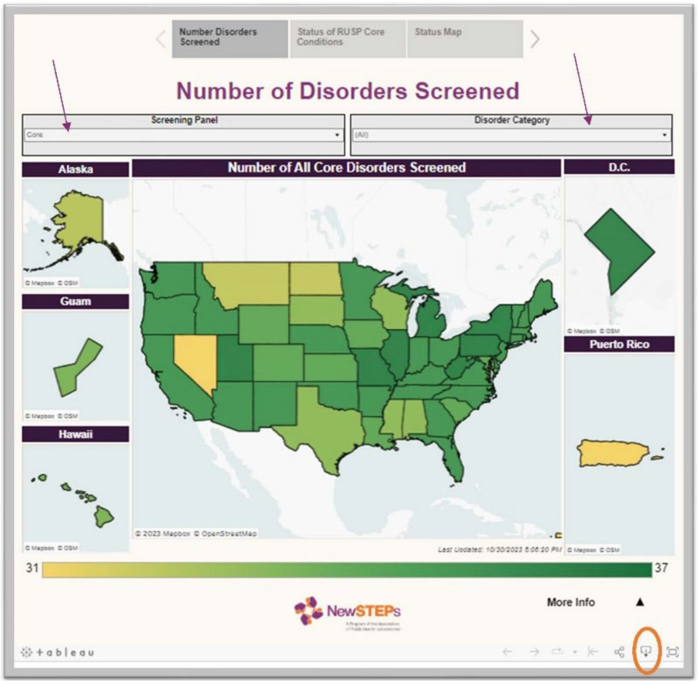
Report
NBS Fees Report
Provides information on the NBS fees each state NBS program is charging

Report
Screening Methodologies and Targets Report
Query for screened condition details

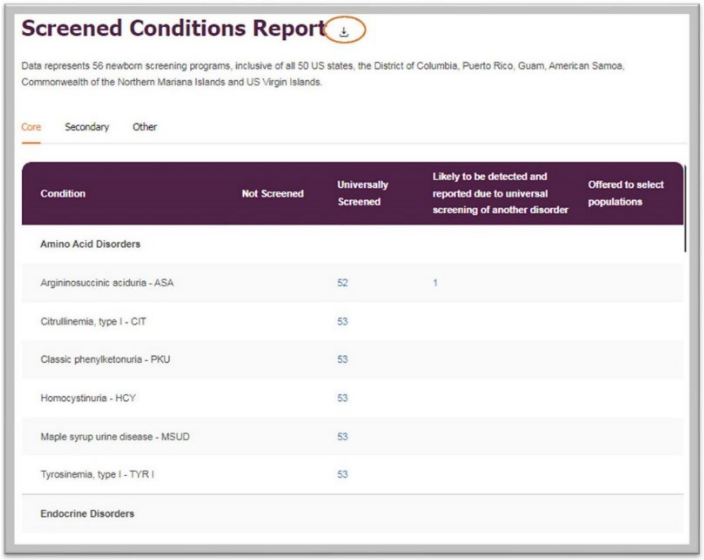
Some dashboards may require the user to click the different tabs to change the visual. For example, on the Newborn Screening Fee dashboard, the user will need to click **Repeat NBS Fee** or **Fee Activity** as the graphic will default to **Initial NBS Fee**.



In the **Newborn Screening Status for All Disorders** dashboard, various filters can be applied that change the information provided. For example, on the **Number of Disorders Screened Map**, the user can filter based on **screening panel** (i.e., core, secondary, and other) and **disorder category** (i.e., all, amino acid, endocrine, fatty acid, hemoglobin, lysosomal storage, organic acid, and other).



The maps can be downloaded by clicking the download icon circled in the bottom right corner in the image above. Further, each of the reports have a download option and will export to Excel.



Screened Conditions Report

Data represents 56 newborn screening programs, inclusive of all 50 US states, the District of Columbia, Puerto Rico, Guam, American Samoa, Commonwealth of the Northern Mariana Islands and US Virgin Islands.

Condition	Not Screened	Universally Screened	Likely to be detected and reported due to universal screening of another disorder	Offered to select populations
Amino Acid Disorders				
Argininosuccinic aciduria - ASA		52	1	
Citrullinemia, type I - CIT		53		
Classic phenylketonuria - PKU		53		
Homocystinuria - HCY		53		
Maple syrup urine disease - MSUD		53		
Tyrosinemia, type I - TYR I		53		
Endocrine Disorders				

Non-Publicly Available Dashboards

Tableau Dashboards

Access to the Tableau dashboards has been integrated with your NewSTEPs user account. The single sign-on feature means that users only need to log into NewSTEPs.org and permission to view the quality indicator and case dashboards is based on your NewSTEPs user role.

Quality Indicator Reports and Dashboards

Quality Indicator reports are NOT available to the public and only to users assigned Data Viewer, QI Data Manager, or Program Administrator user roles. Please note that some visualizations will have a **Program ID**. If you do not know your program's identification number, please email newsteps@aphl.org.

Table 6 describes the available QI dashboards and reports. All QI dashboards and reports are automatically updated each night to reflect the most current data in the repository. See Guide to Spotting Quality Improvement Opportunities Using NewSTEPs Data Visualizations for a tutorial on the functionality of the dashboards.

Table 6: Quality Indicator Dashboards and Reports

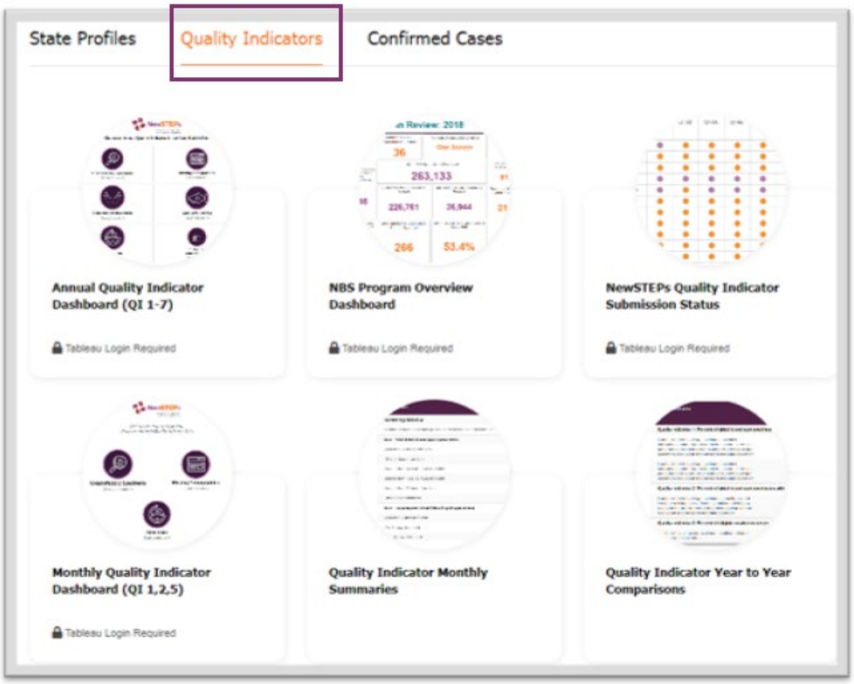
Name of Dashboard/Report	Description
Annual Quality Indicatory Dashboard (QI 1-7) *NewSTEPs user roles Data Viewer, QI Data Manager or Program Administrator*	This dashboard features various visualizations (line chart, bar chart, box plots, tables) for annual Quality Indicators 1-7. Dashboards are accessible via state-based permissions, eliminating the need to assign random ID to each viewer. Users can filter data on their preferred

Name of Dashboard/Report	Description
	indicator and other metrics, including year and number of screens.
NBS Program Overview Dashboard *NewSTEPs user roles Profile Data Manager, QI Data Manager, Case Data Manager and Program Administrator*	This dashboard summarizes quality indicator data provided to the NewSTEPs Repository. Programs will need to select their ID and year. Programs can download the dashboard and insert their program logo.
NewSTEPs Quality Indicator Data Submission Status *NewSTEPs user roles Data Viewer, QI Data Manager or Program Administrator*	A measles chart shows the submission status for Quality Indicators 1-5d and 6. There are two views: • Status of All Quality Indicators allows users to select the year and can view submission status for each QI • Quality Indicators by Year allows users to select the QI and shows the submission status for each year For both views, users can filter by Propel Grantee.
Monthly Quality Indicator Dashboard QI 1, 2, and 5) *NewSTEPs user roles Data Viewer, QI Data Manager or Program Administrator*	This dashboard features various visualizations (line chart, bar chart, box plots, tables) for monthly Quality Indicators 1,2, and 5a-d. Dashboards are accessible via state-based permissions, eliminating the need to assign random ID to each viewer. Users can filter data on their preferred indicator and other metrics, including year and number of screens.
Quality Indicator Monthly Summary *NewSTEPs user roles Data Viewer, QI Data Manager or Program Administrator*	This provides monthly quality indicator via table. Users can view tables for their state/territory by month and year. For each QI, the user can view the count (i.e., numerator) and the percentage for each month and year. Users can download these tables at the bottom of the report.
Quality Indicator Year to Year Comparisons *NewSTEPs user roles Data Viewer, QI Data Manager or Program Administrator*	This table provides cross-year comparison of annual quality indicator data submitted to NewSTEPs. The count and percent is provided for each QI, by year.

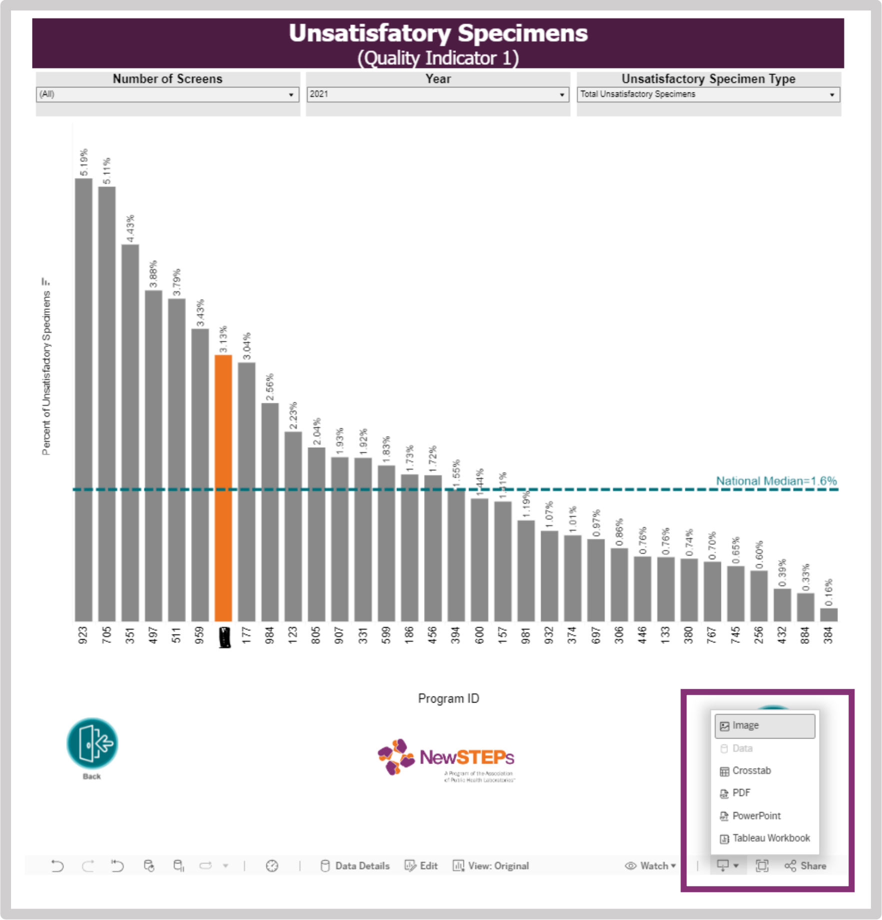
Name of Dashboard/Report	Description
	Users can download these tables at the bottom of the report.

To access the Quality Indicator dashboards and reports:

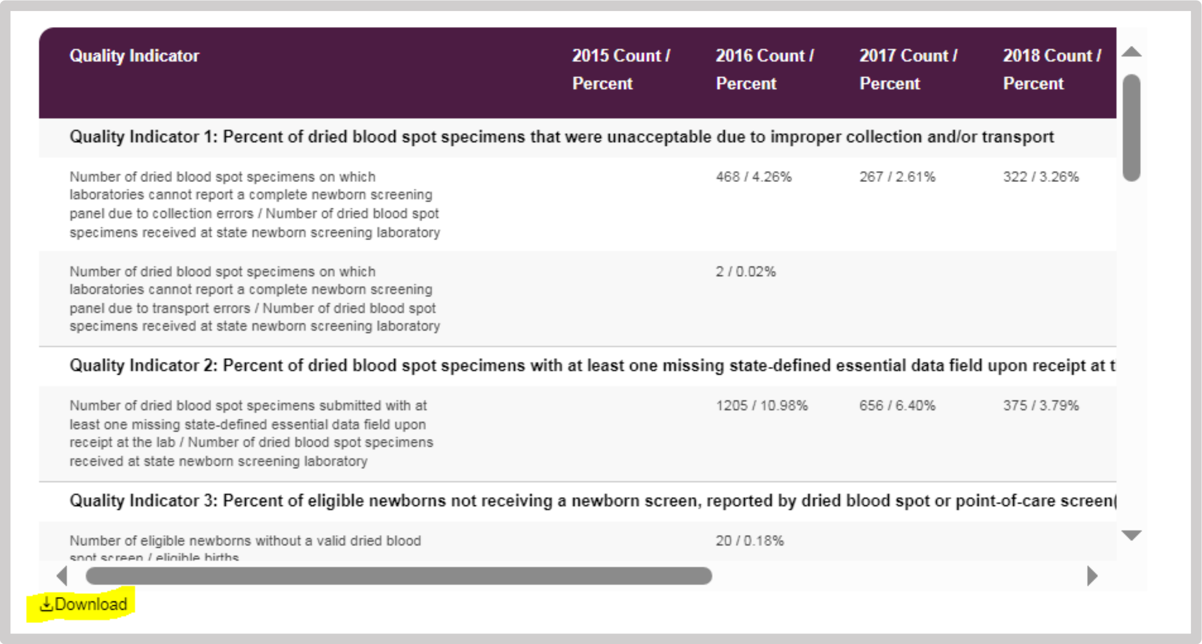
1. Go to Data Center→ Dashboards and Reports
2. Select the Quality Indicator tab
3. Select the dashboard or report that you would like to see (see Table 6 for complete list)



Quality Indicator dashboards and reports are available for download. For the Tableau dashboards, users can download an image of their preferred view.



For the Quality Indicator reports, hit the download button at the bottom of the table.

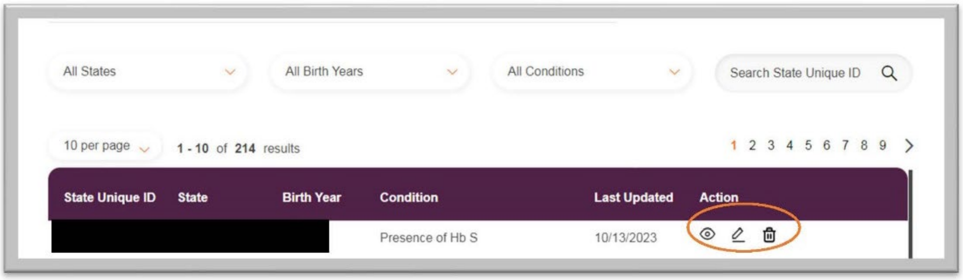


Quality Indicator	2015 Count / Percent	2016 Count / Percent	2017 Count / Percent	2018 Count / Percent
Quality Indicator 1: Percent of dried blood spot specimens that were unacceptable due to improper collection and/or transport				
Number of dried blood spot specimens on which laboratories cannot report a complete newborn screening panel due to collection errors / Number of dried blood spot specimens received at state newborn screening laboratory		468 / 4.26%	267 / 2.61%	322 / 3.26%
Number of dried blood spot specimens on which laboratories cannot report a complete newborn screening panel due to transport errors / Number of dried blood spot specimens received at state newborn screening laboratory		2 / 0.02%		
Quality Indicator 2: Percent of dried blood spot specimens with at least one missing state-defined essential data field upon receipt at t				
Number of dried blood spot specimens submitted with at least one missing state-defined essential data field upon receipt at the lab / Number of dried blood spot specimens received at state newborn screening laboratory		1205 / 10.98%	656 / 6.40%	375 / 3.79%
Quality Indicator 3: Percent of eligible newborns not receiving a newborn screen, reported by dried blood spot or point-of-care screen				
Number of eligible newborns without a valid dried blood spot screen / eligible births		20 / 0.18%		

How to View, Edit, and Delete Individual Cases

If a state/territory has entered individual case data they can access the case details via the NBS Case webpage. Individual cases will be displayed in a table format. The user may filter individual cases by birth year, condition, or unique identifier. The Case Data Manager and Program Administrator may view, edit, or delete the individual case.

1. Go to Data Center→ NBS Cases
2. Select the tab for **Individual Cases**
3. A table will display showing each case for the state/territory. Use the filters to select birth years and conditions. Programs can also search for a case by using the state-unique ID.
4. Users can view (👁), edit, (✎), and delete (🗑) a case from the table as needed.

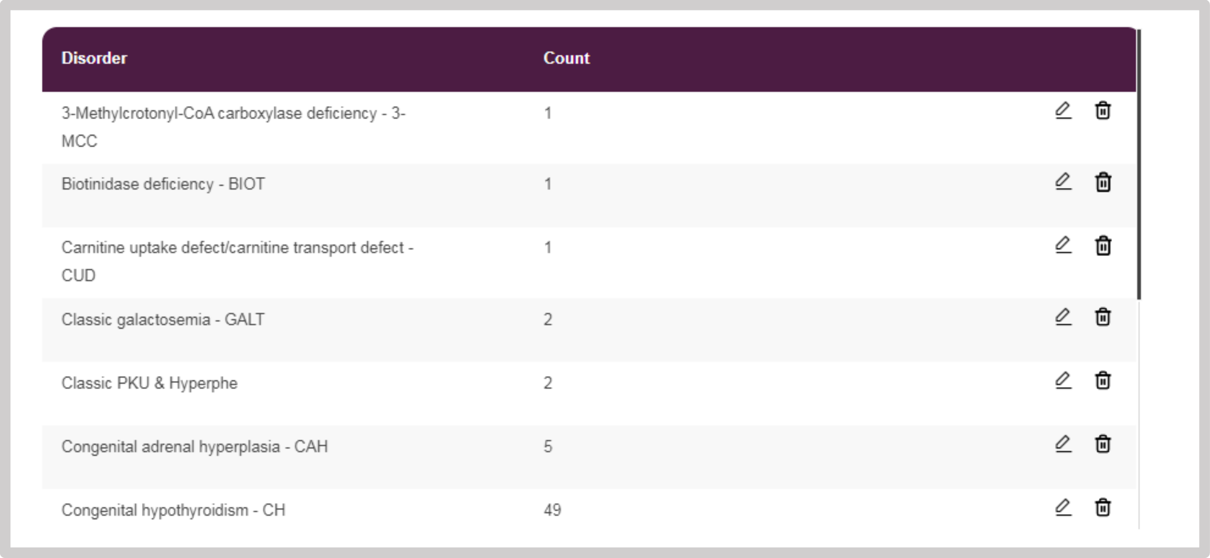


State Unique ID	State	Birth Year	Condition	Last Updated	Action
[redacted]	[redacted]	[redacted]	Presence of Hb S	10/13/2023	👁 ✎ 🗑

How to View, Edit, and Delete Aggregate Cases

If a state/territory has entered aggregate case data they can access the cases via the NBS Case webpage. Aggregate cases will be displayed in a table format. The user may filter aggregate cases based on birth year. The Case Data Manager and Program Administrator may view, edit, or delete the aggregate case count.

1. Go to Data Center→ NBS Cases
2. Select the tab for **Aggregate Cases**
3. Select the birth year
4. A table listing the conditions and associated case count will appear for that specific birth year.
5. Users can edit, (✎), and delete (🗑) aggregate case information, by condition.

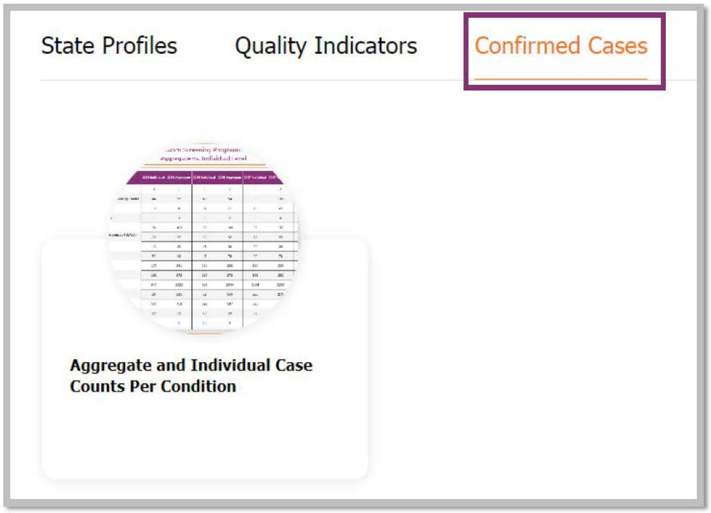


Disorder	Count	
3-Methylcrotonyl-CoA carboxylase deficiency - 3-MCC	1	✎ 🗑
Biotinidase deficiency - BIOT	1	✎ 🗑
Carnitine uptake defect/carnitine transport defect - CUD	1	✎ 🗑
Classic galactosemia - GALT	2	✎ 🗑
Classic PKU & Hyperphe	2	✎ 🗑
Congenital adrenal hyperplasia - CAH	5	✎ 🗑
Congenital hypothyroidism - CH	49	✎ 🗑

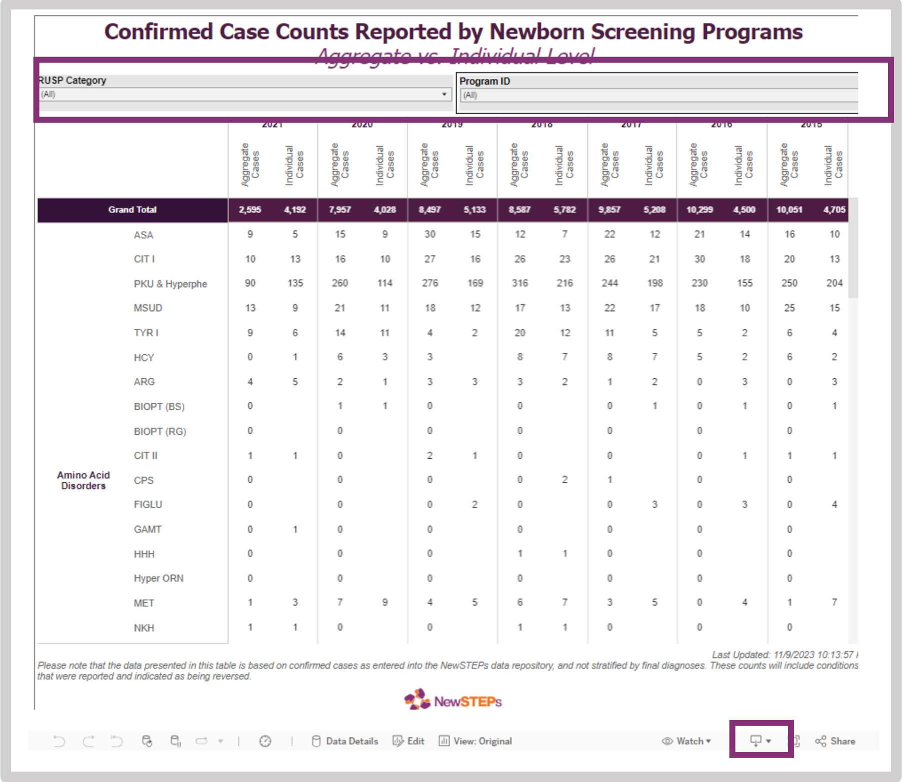
Case Dashboards

Confirmed cases are NOT available to the public and are only available to users that have been assigned Data Viewer, Case Data Manager, or Program Administrator user roles. The case dashboards are automatically updated each night to reflect current data in the repository.

1. Go to Data Center→ Dashboards and Reports
2. Select the tab for **Confirmed Cases**



3. Select the dashboard of interest; users can download an image of their preferred view.
   - Aggregate and Individual Case Counts Per Condition compares case counts entered in the NewSTEPs for both individual and aggregate case counts. Users can filter by their program ID and by the RUSP category. Aggregate and individual case counts should match. This dashboard is updated every night.



Confirmed Case Counts Reported by Newborn Screening Programs

Aggregate vs. Individual Level

RUSP Category: (All)

Program ID: (All)

		2021		2020		2019		2018		2017		2016		2015	
		Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases	Aggregate Cases	Individual Cases
Grand Total		2,595	4,192	7,957	4,028	8,497	5,133	8,587	5,782	9,857	5,208	10,299	4,500	10,051	4,705
Amino Acid Disorders	ASA	9	5	15	9	30	15	12	7	22	12	21	14	16	10
	CIT I	10	13	16	10	27	16	26	23	26	21	30	18	20	13
	PKU & Hyperphe	90	135	260	114	276	169	316	216	244	198	230	155	250	204
	MSUD	13	9	21	11	18	12	17	13	22	17	18	10	25	15
	TYR I	9	6	14	11	4	2	20	12	11	5	5	2	6	4
	HCY	0	1	6	3	3		8	7	8	7	5	2	6	2
	ARG	4	5	2	1	3	3	3	2	1	2	0	3	0	3
	BIOPT (BS)	0		1	1	0		0		0	1	0	1	0	1
	BIOPT (RG)	0		0		0		0		0		0		0	
	CIT II	1	1	0		2	1	0		0		0	1	1	1
	CPS	0		0		0		0	2	1		0		0	
	FIGLU	0		0		0	2	0		0	3	0	3	0	4
	GAMT	0	1	0		0		0		0		0		0	
	HHH	0		0		0		1	1	0		0		0	
	Hyper ORN	0		0		0		0		0		0		0	
	MET	1	3	7	9	4	5	6	7	3	5	0	4	1	7
	NKH	1	1	0		0		1	1	0		0		0	

Last Updated: 11/9/2023 10:13:57

Please note that the data presented in this table is based on confirmed cases as entered into the NewSTEPs data repository, and not stratified by final diagnoses. These counts will include conditions that were reported and indicated as being reversed.

REQUESTING DATA

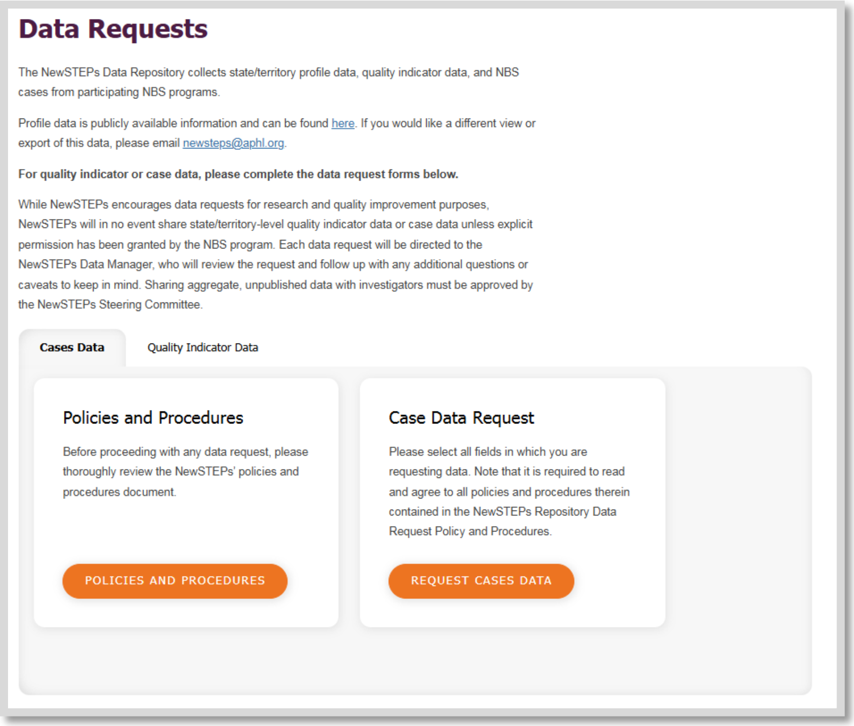
While NewSTEPs encourages data requests for research and quality improvement purposes, NewSTEPs will in no event share state/territorial-level quality indicator or case data unless explicit permission has been granted by the NBS program. Investigators can submit a data request for quality indicator or case data via the webform. Each data request will be redirected to the NewSTEPs Steering Committee which is charged with providing recommendations to NewSTEPs regarding sharing data collected within the repository.

Before submitting data requests, please review NewSTEPs Data Request Policies and Procedures.

Requesting Case Data

For case data, NewSTEPs will follow the “Rule of 5” which prevents data sharing if there are five newborns or fewer for a given category.

1. Go to Data Center→Request Data
2. Select the tab for **Case Data**
3. Review Policies and Procedures
4. Select **Request Cases Data**



Data Requests

The NewSTEPs Data Repository collects state/territory profile data, quality indicator data, and NBS cases from participating NBS programs.

Profile data is publicly available information and can be found here. If you would like a different view or export of this data, please email newsteps@aphl.org.

For quality indicator or case data, please complete the data request forms below.

While NewSTEPs encourages data requests for research and quality improvement purposes, NewSTEPs will in no event share state/territory-level quality indicator data or case data unless explicit permission has been granted by the NBS program. Each data request will be directed to the NewSTEPs Data Manager, who will review the request and follow up with any additional questions or caveats to keep in mind. Sharing aggregate, unpublished data with investigators must be approved by the NewSTEPs Steering Committee.

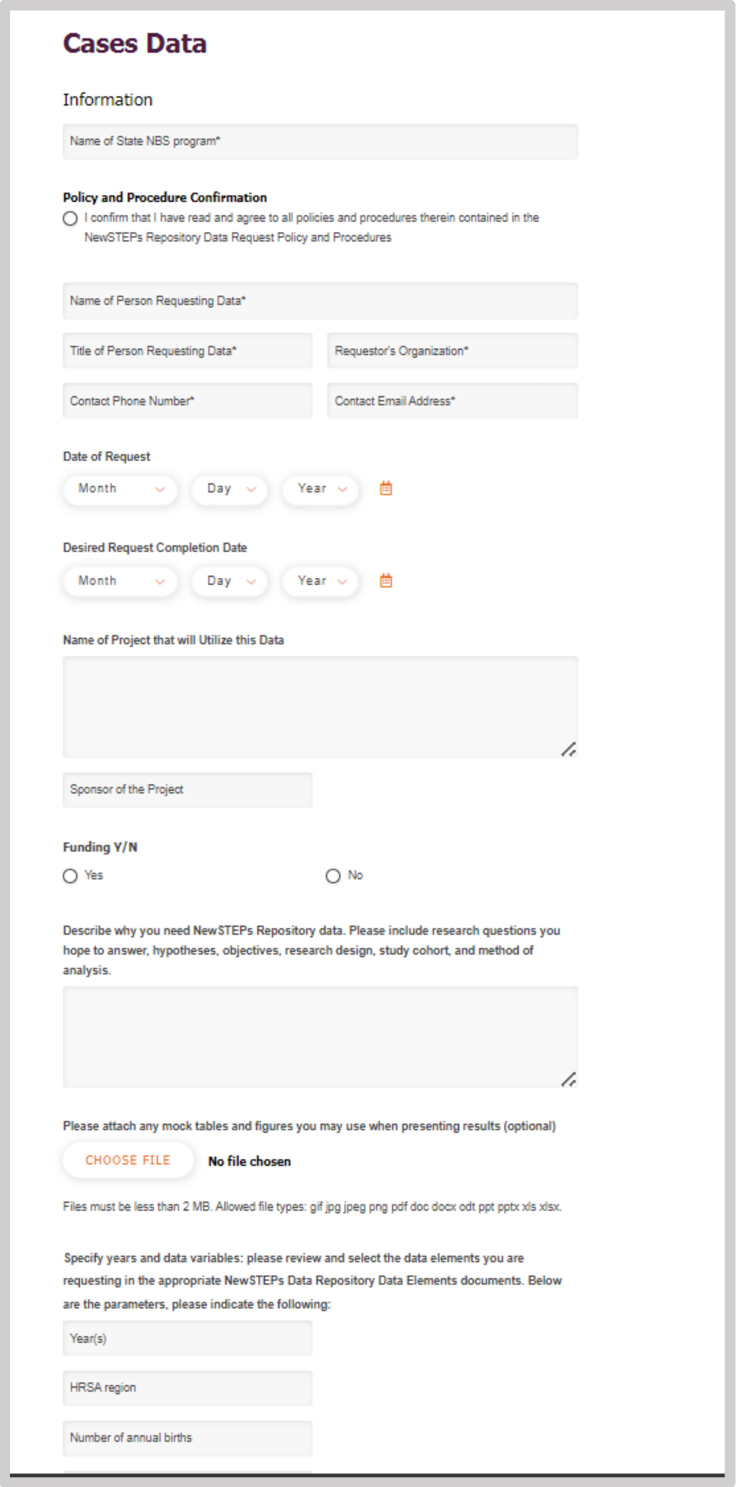
Policies and Procedures

Before proceeding with any data request, please thoroughly review the NewSTEPs' policies and procedures document.

Case Data Request

Please select all fields in which you are requesting data. Note that it is required to read and agree to all policies and procedures therein contained in the NewSTEPs Repository Data Request Policy and Procedures.

5. Complete the form; all required fields are indicated with an asterix *
6. Explain how the project plans to utilize the data and the research questions you plan to answer.
7. Attach mock tables and figures that you plan to use when presenting results.
8. Specify the years and case variables that you are requesting (birth years, HRSA regions, conditions)



Cases Data

Information

Name of State NBS program*

Policy and Procedure Confirmation

○ I confirm that I have read and agree to all policies and procedures therein contained in the NewSTEPs Repository Data Request Policy and Procedures

Name of Person Requesting Data*

Title of Person Requesting Data*

Requestor's Organization*

Contact Phone Number*

Contact Email Address*

Date of Request

Month Day Year

Desired Request Completion Date

Month Day Year

Name of Project that will Utilize this Data

Sponsor of the Project

Funding Y/N

○ Yes ○ No

Describe why you need NewSTEPs Repository data. Please include research questions you hope to answer, hypotheses, objectives, research design, study cohort, and method of analysis.

Please attach any mock tables and figures you may use when presenting results (optional)

No file chosen

Files must be less than 2 MB. Allowed file types: gif jpg jpeg png pdf doc docx odt ppt pptx xls xlsx.

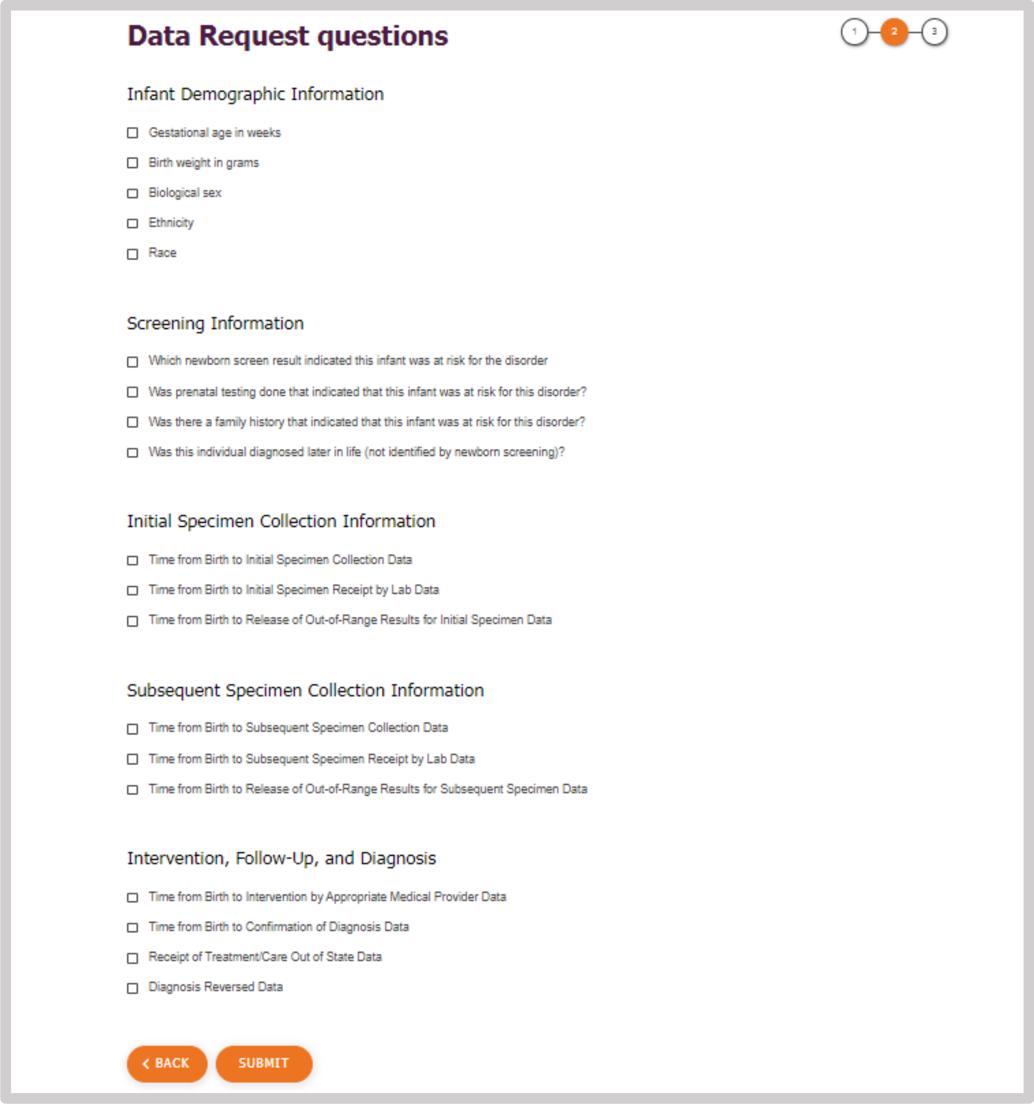
Specify years and data variables: please review and select the data elements you are requesting in the appropriate NewSTEPs Data Repository Data Elements documents. Below are the parameters, please indicate the following:

Year(s)

HRSA region

Number of annual births

9. If you want data on individual cases, select the appropriate demographic and screening information variables needed to answer your research questions.



Data Request questions

Infant Demographic Information

☐ Gestational age in weeks
☐ Birth weight in grams
☐ Biological sex
☐ Ethnicity
☐ Race

Screening Information

☐ Which newborn screen result indicated this infant was at risk for the disorder
☐ Was prenatal testing done that indicated that this infant was at risk for this disorder?
☐ Was there a family history that indicated that this infant was at risk for this disorder?
☐ Was this individual diagnosed later in life (not identified by newborn screening)?

Initial Specimen Collection Information

☐ Time from Birth to Initial Specimen Collection Data
☐ Time from Birth to Initial Specimen Receipt by Lab Data
☐ Time from Birth to Release of Out-of-Range Results for Initial Specimen Data

Subsequent Specimen Collection Information

☐ Time from Birth to Subsequent Specimen Collection Data
☐ Time from Birth to Subsequent Specimen Receipt by Lab Data
☐ Time from Birth to Release of Out-of-Range Results for Subsequent Specimen Data

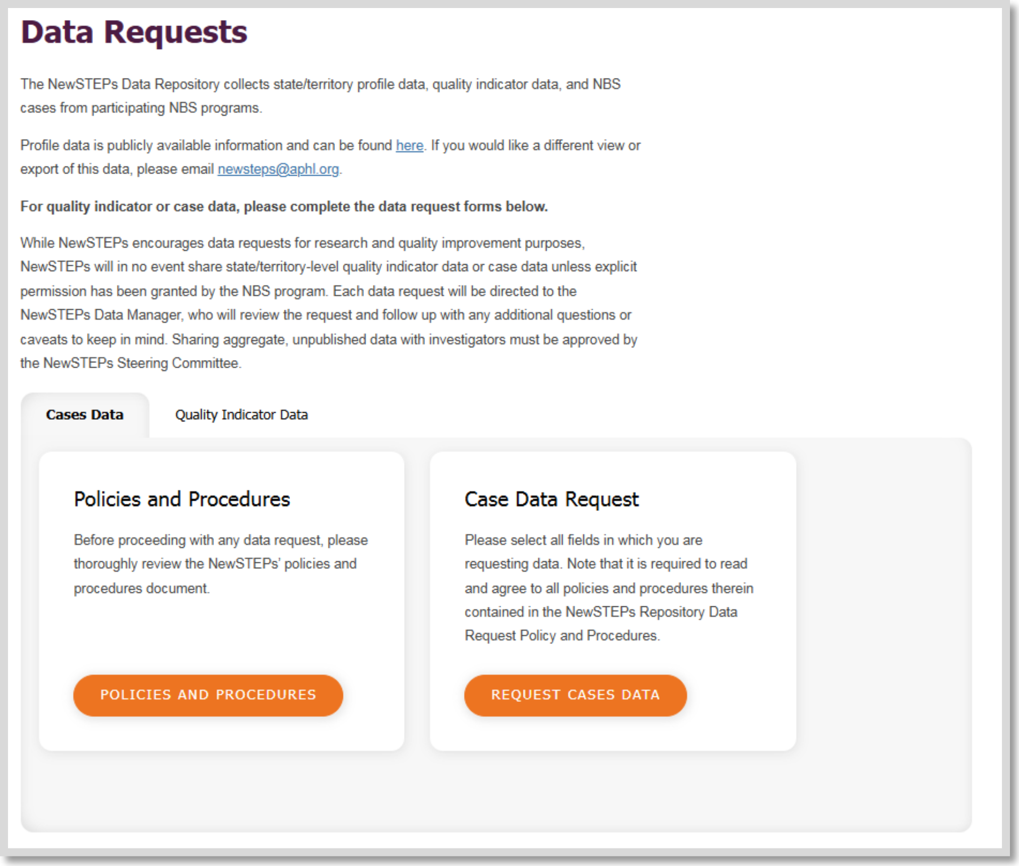
Intervention, Follow-Up, and Diagnosis

☐ Time from Birth to Intervention by Appropriate Medical Provider Data
☐ Time from Birth to Confirmation of Diagnosis Data
☐ Receipt of Treatment/Care Out of State Data
☐ Diagnosis Reversed Data

10. Hit **Submit**.

Requesting Quality Indicator Data

1. Go to Data Center→ Request Data
2. Select the tab for **Quality Indicator Data**
3. Review Policies and Procedures
4. Select **Request QI Data**



Data Requests

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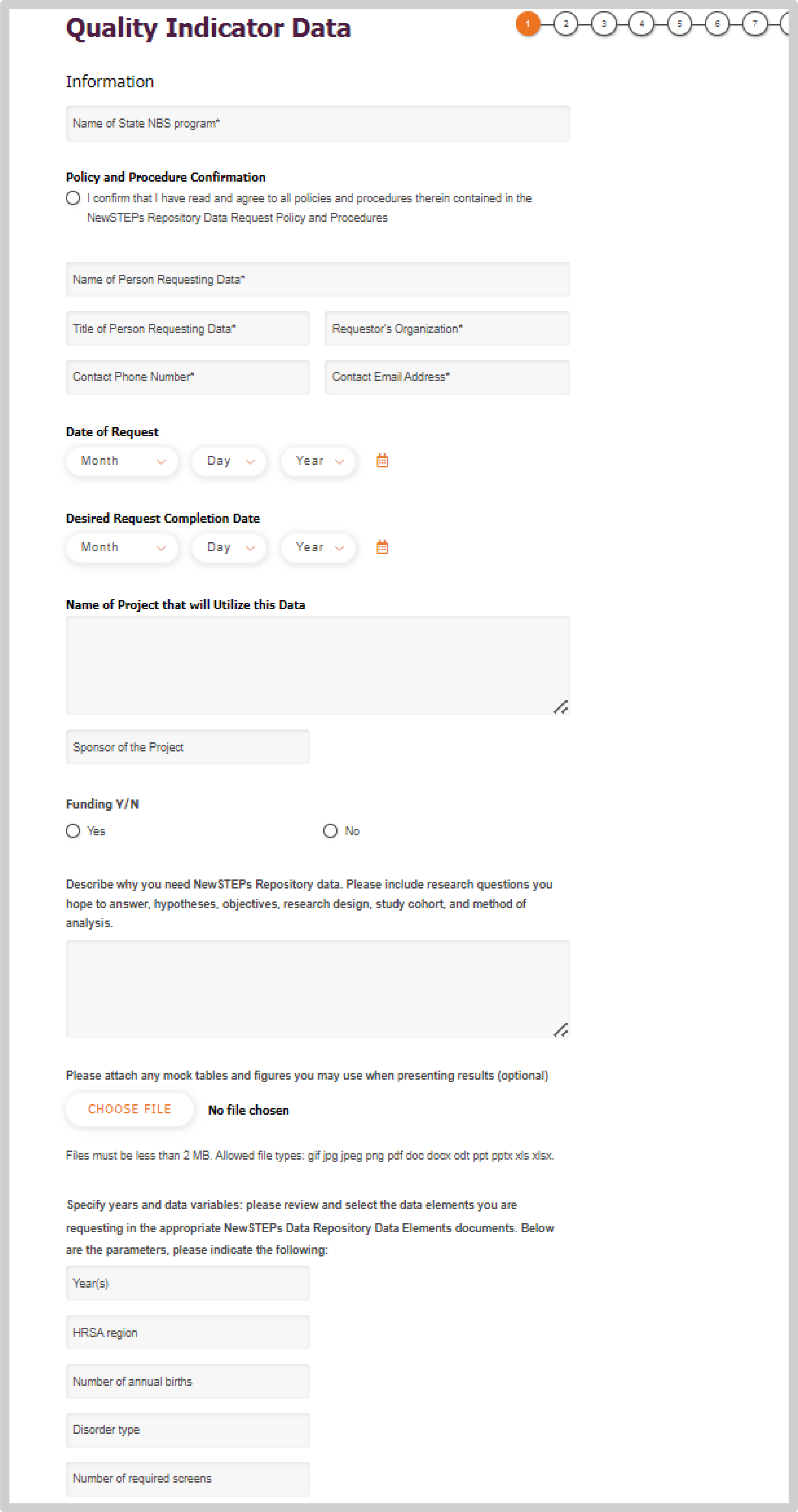
Case Data Request

Please select all fields in which you are requesting data. Note that it is required to read and agree to all policies and procedures therein contained in the NewSTEPs Repository Data Request Policy and Procedures.

5. Complete the form; all required fields are indicated with an asterix *
6. Explain how the project plans to utilize the data and the research questions you plan to answer.
7. Attach mock tables and figures that you plan to use when presenting results.
8. Specify the years and case variables that you are requesting (birth years, HRSA regions, conditions)



Quality Indicator Data

Information

Name of State NBS program*

Policy and Procedure Confirmation

○ I confirm that I have read and agree to all policies and procedures therein contained in the NewSTEPs Repository Data Request Policy and Procedures

Name of Person Requesting Data*

Title of Person Requesting Data*

Requestor's Organization*

Contact Phone Number*

Contact Email Address*

Date of Request

Desired Request Completion Date

Name of Project that will Utilize this Data

Sponsor of the Project

Funding Y/N

○ Yes ○ No

Describe why you need NewSTEPs Repository data. Please include research questions you hope to answer, hypotheses, objectives, research design, study cohort, and method of analysis.

Please attach any mock tables and figures you may use when presenting results (optional)

No file chosen

Files must be less than 2 MB. Allowed file types: gif jpg jpeg png pdf doc docx odt ppt pptx xls xlsx.

Specify years and data variables: please review and select the data elements you are requesting in the appropriate NewSTEPs Data Repository Data Elements documents. Below are the parameters, please indicate the following:

Year(s)

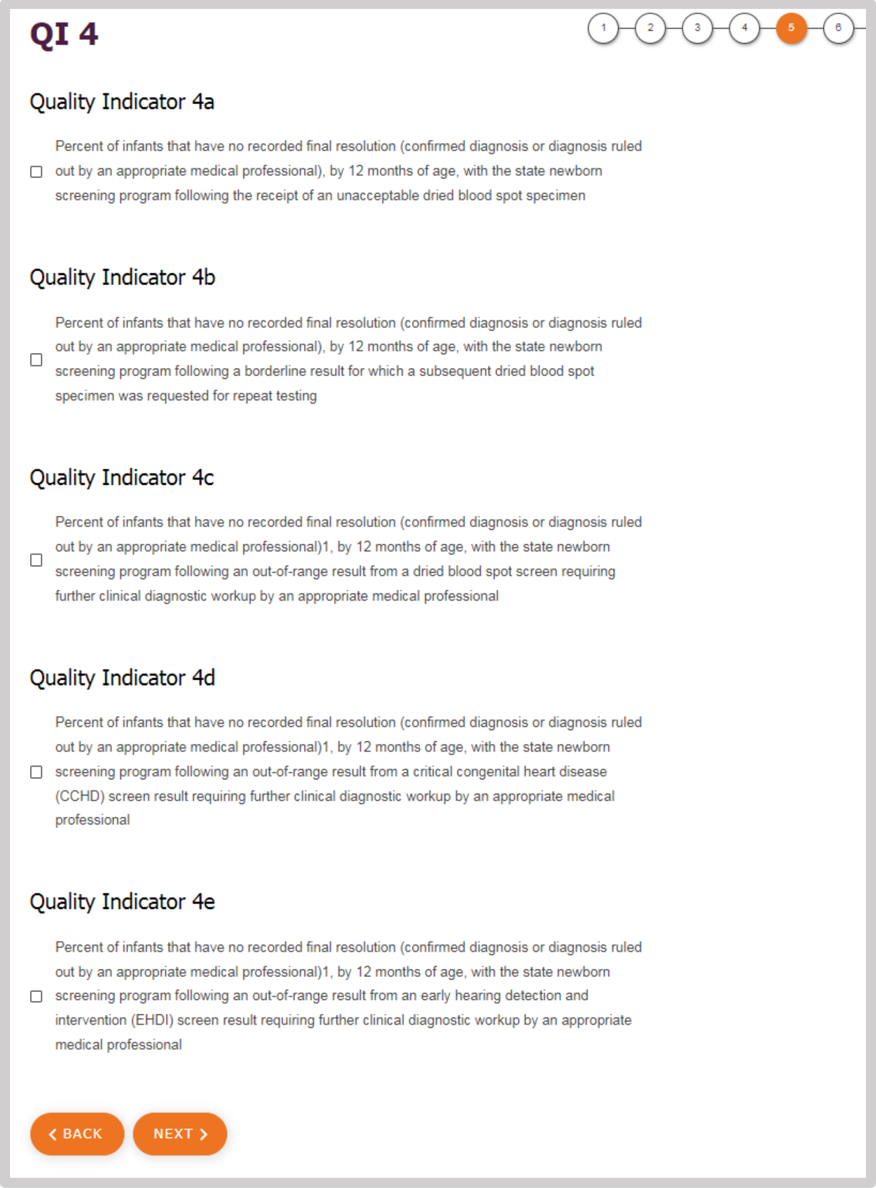
HRSA region

Number of annual births

Disorder type

Number of required screens

9. Click **Next**.
10. The following pages will have you select which QI data is needed to answer your research questions. Review the [Quality Indicator Source Document]() for more information. Select **Next** to go through each of the eight QIs.



QI 4

Quality Indicator 4a

☐ Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional), by 12 months of age, with the state newborn screening program following the receipt of an unacceptable dried blood spot specimen

Quality Indicator 4b

☐ Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional), by 12 months of age, with the state newborn screening program following a borderline result for which a subsequent dried blood spot specimen was requested for repeat testing

Quality Indicator 4c

☐ Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional)1, by 12 months of age, with the state newborn screening program following an out-of-range result from a dried blood spot screen requiring further clinical diagnostic workup by an appropriate medical professional

Quality Indicator 4d

☐ Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional)1, by 12 months of age, with the state newborn screening program following an out-of-range result from a critical congenital heart disease (CCHD) screen result requiring further clinical diagnostic workup by an appropriate medical professional

Quality Indicator 4e

☐ Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional)1, by 12 months of age, with the state newborn screening program following an out-of-range result from an early hearing detection and intervention (EHDI) screen result requiring further clinical diagnostic workup by an appropriate medical professional