NewSTEPs Annual Report 2020

NewSTEPs

A Program of the Association of Public Health Laboratories™

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Introduction

NewSTEPs, a program of the Association of Public Health Laboratories, presents its 2020 Annual Report with the goal of sharing the state of newborn screening laboratory and follow-up programs in the US with our members and stakeholders. Thank you to all of the newborn screening programs contributing data to support data driven continuous quality improvement and information sharing efforts. Please direct any questions regarding this report to newsteps@aphl.org.

Note: State profile level and case data is represented as of April 2021; quality indicator data and new disorder implementation data is represented as of August 2021. While NewSTEPs utilizes numerous data collection methods and solutions for data entry, there was a decrease in 2020 quality indicator and case data entered, partially due to competing COVID-19 related response priorities.

Director's Note:

2020 was a year filled with challenges, with every newborn screening program navigating unprecedented challenges resulting from the global pandemic. Many newborn screening staff had to navigate staggered work shifts and adherence to modified, distanced workflows in the laboratory. Others left their workplace to create makeshift offices at home. Others juggled children and aging parents while establishing a new normal for hybrid work environments. Yet one thing remained constant- all newborn screening staff continued to fulfill the essential role of ensuring the health and well-being of the most vulnerable among us. To date there have been over 40 million COVID-19 cases in the United States alone, with a staggering >650,000 deaths. We honor the lives of each loved one, co-worker, friend, spouse, acquaintance and family member who left this world too soon. Now more than ever, APHL thanks our public health members, our funders, and our newborn screening community for their resilience through these trying times and for their dedication to advancing newborn screening year round.

The State of Newborn Screening in the COVID-19 Pandemic

On March 11, 2020 the World Health Organization (WHO) declared the COVID-19 outbreak a global pandemic. Prior to that, on January 22, 2020, APHL established its Incident Command System (ICS) and activated its Emergency Operations Center (EOC). The ICS approach enabled APHL to effectively coordinate with the Centers for Disease Control and Prevention (CDC) and other partners to respond to COVID-19. APHL continues to monitor the response, providing assistance to member public health laboratories and advocate on their behalf.

The pandemic has had numerous impacts on newborn screening (NBS) systems, including but not limited to program operations and timeliness of newborn screens, continuity of operations, new disorder implementation, policies on second or repeat screens, health information technology (HIT) implications, and education and outreach efforts. Despite these unprecedented challenges, NBS programs have ensured that essential operations continue, and newborns are screened and treated. For 2020, NewSTEPs wanted to highlight the state of NBS during the global COVID-19 pandemic. This report will provide a snapshot of data collected in the NewSTEPs data repository, demonstrating how NBS programs have adapted quickly to changing operations and collaborated with stakeholders to continue their life saving work. For the purpose of this report, NBS programs refers to the state and territorial entities (or their designees) that test and report out for newborn screening, including laboratory and follow-up.

1. NBS programs continue to operate despite staffing shortages, rotating shifts, adjustments to remote work for follow-up and enforcement of physical distancing within laboratories.

2. Continuity of Operations Plans have proven essential although not all events could be included in a preemptive plan due to unprecedented and unforeseeable circumstances, such as clinic closures and the increase in implementation and utility of telehealth solutions.

3. New disorders have been implemented although there have been delays in the implementation of new disorders due to competing priorities, delays in stakeholder meetings, modifications in scheduling (reduced laboratory operating hours) and delays with vendor resources and services.

4. NBS programs adapted to changes in screening policies. The pandemic caused mothers and newborns to be discharged prior to the 24-48 hours recommended timeframe forspecimen collection, and caused uncertainty around the availability of specimen recollection options for families. These challenges are reflected in the increase in median percent of infants with no recorded final resolution in 2020.

5. NBS programs utilized HIT infrastructure (including telehealth and web portals), however the cost of technology and implementation services, along with the limitation of in-house tools and technologies are barriers to reducing paper access to electronicinformation.

NewSTEPs and NBS programs continue to work collaboratively, and have compiled COVID-19 NBS response related challenges, practices and resources according to topic area on the NewSTEPs website. Ad-hoc just-in-time webinars pertinent to the NBS pandemic response are also archived on the site. These webinars bring together expert advisors and leaders within NBS to address questions from the community and highlight member experiences.

State Profile Data
Newborn Screening Programs Overview

3,626,470
babies born in 2020

3.8%
decrease from 2019

There are 53 NBS programs represented in the NewSTEPs Data Repository, including five regional NBS laboratories receiving dried blood spot (DBS) specimens their own state hospitals and birthing centers as well as from other states. Seven states outsource screening of DBS specimens to PerkinElmer Genetics (a private laboratory). There are a number of NBS programs that outsource screening for specific disorders (e.g., Kentucky outsources screening for lysosomal storage disorders and Montana outsources screening for disorders detected using tandem mass spectrometry). For some NBS programs, outsourcing with external laboratories to test dried blood spot (DBS) specimens may be more cost effective than performing screening in house, depending on infrastructure and birth rate.[1] Number of births from 2020, type of laboratory used per state and territory and number of required screens by state and territory are outlined in **Table 1.** Newborns are born every day and, despite the global COVID-19 pandemic, NBS programs remain operational in performing their essential public health services.

Table 1: Newborn screening program overview, April 2021 (N=53)

NBS Program	2020 Annual Births[2]	Laboratory Type	Number of Required Screens
Alabama	57,634	State Public Health Laboratory	Two Screens
Alaska	9,447	Regional Laboratory	One Screen
Arizona	76,923	State Public Health Laboratory	Two Screens
Arkansas	35,210	State Public Health Laboratory	One Screen
California	419,612	State Public Health Laboratory	One Screen
Colorado°	61,493	State Public Health Laboratory	Two Screens
Connecticut	33,448	State Public Health Laboratory	One Screen
Delaware	10,336	Private Laboratory	One Screen
District of Columbia	8,858	Private Laboratory	One Screen
Florida	209,612	State Public Health Laboratory	One Screen
Georgia	122,266	State Public Health Laboratory	One Screen
Guam	3,041*	Regional Laboratory	One Screen
Hawaii	15,730	Regional Laboratory	One Screen
Idaho	21,520	Regional Laboratory	Two Screens
Illinois	133,207	State Public Health Laboratory	One Screen
Indiana	78,087	Private Laboratory	One Screen
Iowa°	36,080	State Public Health Laboratory	One Screen
Kansas	34,360	State Public Health Laboratory	One Screen

[1] Indiana Department of Health Request for Applications - Newborn Screening (NBS) Care Coordination. February 2021 https://www.in.gov/health/mch/funding-opportunities/

[2] Hamilton BE, Martin JA, Osterman MJK. Births: Provisional data for 2020. Vital Statistics Rapid Release; no 12. Hyattsville, MD: National Center for Health Statistics. May 2021. DOI: https://doi.org/10.15620/cdc:104993

NBS Program	2020 Annual Births[2]	Laboratory Type	Number of Required Screens
Kentucky	51,581	State Public Health Laboratory**	One Screen
Louisiana	57,070	State Public Health Laboratory***	One Screen
Maine	11,532	Regional Laboratory	One Screen
Maryland	68,523	State Public Health Laboratory	Two Screens
Massachusetts°	66,429	State Public Health Laboratory	One Screen
Michigan	103,846	State Public Health Laboratory	One Screen
Minnesota	63,387	State Public Health Laboratory	One Screen
Mississippi	35,457	Private Laboratory	One Screen
Missouri	69,238	State Public Health Laboratory	One Screen
Montana	10,785	State Public Health Laboratory****	One Screen
Nebraska	24,235	Private Laboratory	One Screen
Nevada	33,632	State Public Health Laboratory	Two Screens
New Hampshire	11,773	Regional Laboratory	One Screen
New Jersey	96,543	State Public Health Laboratory	One Screen
New Mexico	21,316	Regional Laboratory	Two Screens
New York	209,172	State Public Health Laboratory	One Screen
North Carolina	116,674	State Public Health Laboratory	One Screen
North Dakota	10,059	Regional Laboratory	One Screen
Ohio	129,071	State Public Health Laboratory	One Screen
Oklahoma	47,393	Private Laboratory	One Screen
Oregon°	39,792	State Public Health Laboratory	Two Screens
Pennsylvania	130,562	Private Laboratory	One Screen
Puerto Rico	18,228	State Public Health Laboratory	One Screen
Rhode Island	10,102	Regional Laboratory	One Screen
South Carolina	55,693	State Public Health Laboratory	One Screen
South Dakota	10,952	Regional Laboratory	One Screen
Tennessee	78,659	State Public Health Laboratory	One Screen
Texas	365,857	State Public Health Laboratory	Two Screens
Utah	45,702	State Public Health Laboratory*****	Two Screens
Vermont	5,117	Regional Laboratory	One Screen
Virginia	94,391	State Public Health Laboratory	One Screen
Washington°	83,067	State Public Health Laboratory	Two Screens
West Virginia	17,159	State Public Health Laboratory	One Screen
Wisconsin	60,491	State Public Health Laboratory	One Screen
Wyoming	6,118	Regional Laboratory	Two Screens
°Regional Laboratories		* Guam 2020 annual birth data is unavailable; data used is from 2019 **Kentucky outsources Lysosomal Storage Disorders to Mayo Clinic Laboratory ***Louisiana utilizes a hybrid screening model and outsources some DBS screening to PerkinElmer Genetics ****Montana outsources MS/MS to Wisconsin State Laboratory of Hygiene ***** Utah outsources MS/MS to ARUP Laboratories	

Newborn Screening Program Operations

Newborn screening programs range in hours and days of operation, but all continue to operate even with changing workflows, resource shortages and staffing limitations due to the pandemic. Because some NBS staff were pulled for COVID-19 response and because of the concern of close contact between staff in facilitating virus transmission, NBS laboratories often performed operations with skeleton teams or implemented staggered or rotating shifts to reduce risk. For example, the Michigan NBS laboratory switched to four, ten-hour shifts to minimize people in the laboratory. Amongst all NBS programs, temperatures were taken daily prior to laboratory entry, and all in person meetings were canceled. Laboratories also had to take additional measures for social distancing and to ensure sanitization of equipment.

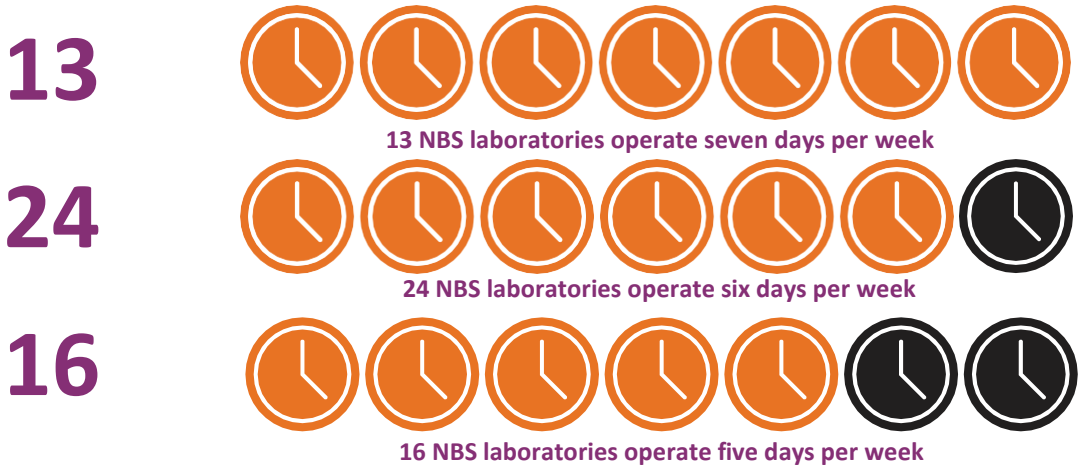
Unintended issues arose due to limited staff, including how to perform time critical testing with limited staff, or how to triage follow-up repeat requests in the event that staff become ill. Furthermore, follow-up personnel had to navigate working from home while still accessing necessary work electronically (which is often still done by mail or fax). While no NBS program expanded operating hours in 2020, they were able to adapt to unprecedented issues and maintain operations.

Newborn screening programs have undertaken various, creative methods to improve timeliness during the pandemic (e.g., virtual site visits) in addition to other quality improvement initiatives (e.g., implementing new disorders, moving toward electronic results reporting), in order to better identify and treat affected infants as early as possible.

Laboratory Operations

According to the NewSTEPs data repository, 30.2% (n=16) newborn screening programs have laboratories open five days a week; 45.3% (n=24) have laboratories open six days a week; and, 24.5% (n=13) have laboratories open seven days a week **(Figure 1a).**

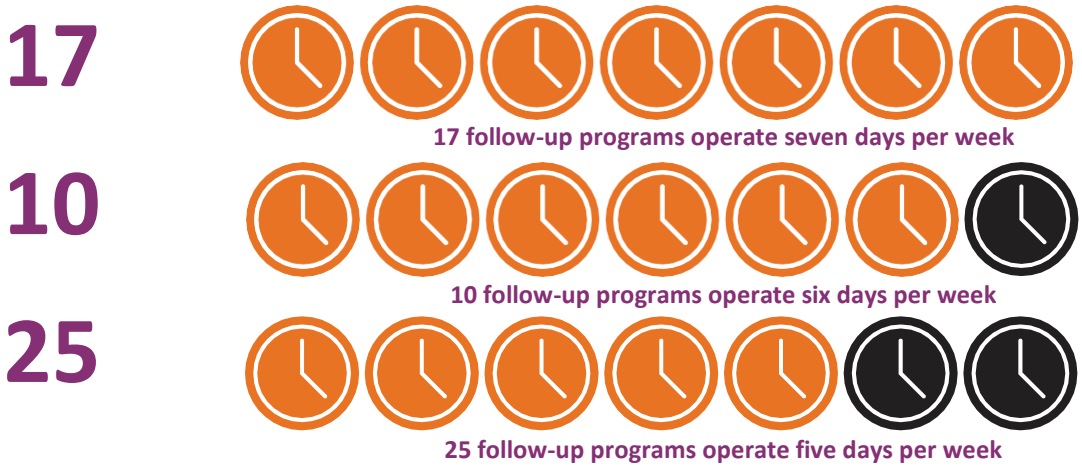
Figure 1a: NBS laboratory days of operation, April 2021 (N=53)



Follow-Up Operations

Similarly, 48.1% (n=25) of NBS programs reporting data have follow-up programs open five days a week; 19.2% (n=10) have follow-up open six days a week; and, 32.7% (n=17) have follow-up open seven days a week **(Figure 1b).**

Figure 1b: NBS follow-up days of operation, April 2021 (N=52*)



*Guam – missing data

Specimen Transport

Newborn screening programs use couriers as a method for transporting dried blood spot specimens from birthing centers to the NBS laboratory for testing.

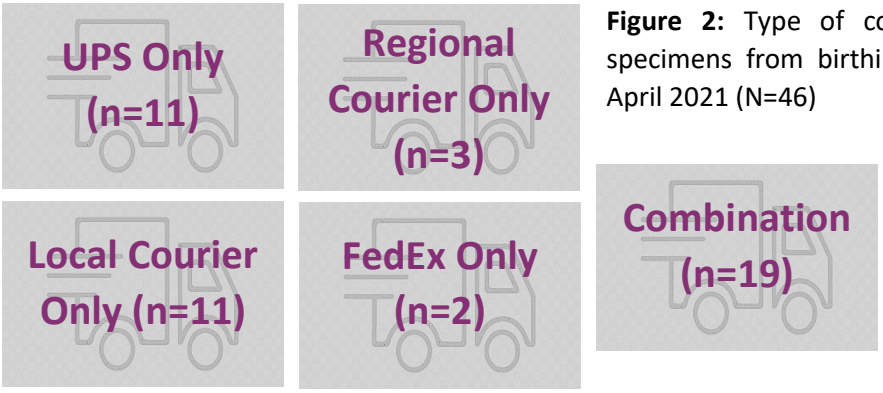


Figure 2: Type of courier services used to transport specimens from birthing centers to the NBS laboratory, April 2021 (N=46)

Out of the 46 NBS programs reporting data in 2020, 23.9% (n=11) use only UPS; 4.3% (n=2) use only FedEx; 23.9% (n=11) use only local couriers; 6.5% (n=3) use only regional couriers; and, 41.3% (n=19) use a combination of the aforementioned couriers. Local couriers are those particular to specific states or counties, including hospital specific couriers, whereas regional couriers may be shared amongst different states, and may operate across state lines.

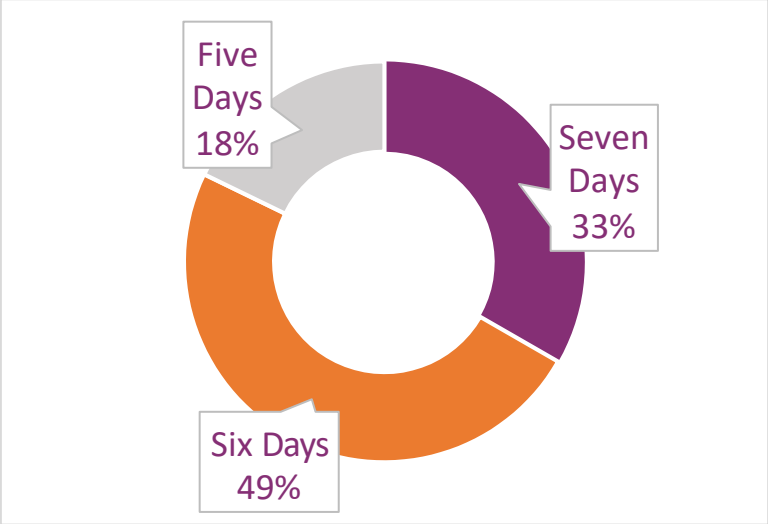


Figure 3: Courier days of pickup and delivery, April 2021 (N=45)

Courier pickup and delivery services vary by day of the week. Out of the 45 NBS programs contributing data, 17.8% (n=8) have couriers that pickup and deliver specimens five days a week; 48.9% (n=22) six days a week; and, 33.3% (n=15) seven days a week (Figure 3). One caveat of this data is that it does not capture the percentage of birthing centers that benefit from a courier open more than five days a week. For example, one NBS program provides a weekend courier to 48 of their birthing facilities, and the remaining ten receive a courier Monday through Friday due to a small number of births at the birthing facilities. NewSTEPs collects this data at the state-level and these specific details are not apparent in aggregate data.

Continuity of Operations Plans

The Association of Public Health Laboratories recommends that all state NBS systems maintain and update a Continuity of Operations Plan (COOP) with the intent of limiting interruption of services should a disruptive event occur. The continuity of NBS services is critical for public health, and a comprehensive plan is necessary to ensure newborns continue to be screened during a natural or man-made disaster, such as the COVID-19 pandemic, as well as during any event that interrupts services. Lessons learned from the COVID-19 pandemic must be incorporated into a state's COOP. The utility of telehealth particularly has been highlighted by the pandemic experience and should be explored for further incorporation throughout the NBS system. As such, APHL in collaboration with the Association of Maternal & Child Health Programs (AMCHP), developed a document highlighting the use of telehealth in NBS continuity of operations in a pandemic.

Out of the 48 NBS programs contributing data, 79.2% (n=38) have a NBS specific COOP. Out of the 38 NBS programs that do have a COOP and contributed data, 65.8% (n=25) test or exercise their COOP.

Newborn Screening Continuity of Operations Planning Funding

In light of the COVID-19 pandemic, in November 2020, the APHL NewSTEPs Quality Improvement Project collaborative issued a Request for Proposals to NBS programs interested in using a continuous quality improvement framework to improve or enhance their NBS COOP.

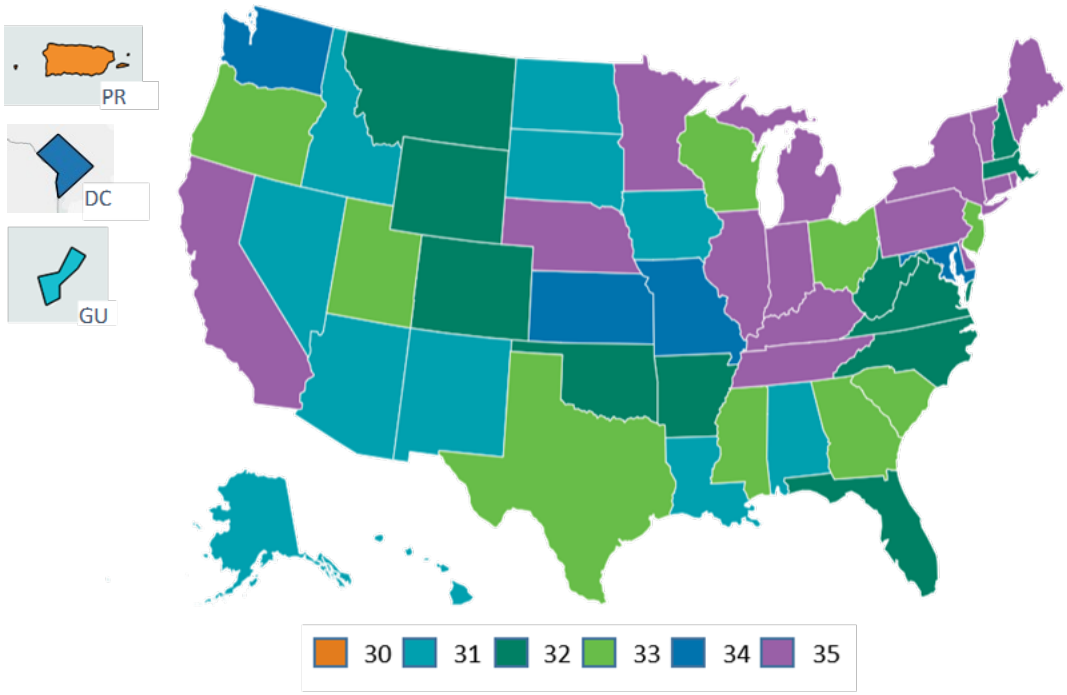
Through this award, NewSTEPs aimed to help strengthen NBS systems with the science of improvement that provides a structured approach to developing, testing and sustaining NBS continuity of operation plans. In March 2021, two NBS programs, Virginia and Iowa, were awarded the funding. Over the course of the next year from 2021-2022, awarded NBS programs will conduct the following activities:

- Review current COOP and identify areas for improvement.
- Convene key NBS stakeholders to address and discuss limitations to current COOP and areas for improvement including strategies for continuing NBS activities if unable to perform activities at the state level due to disruptions.
- Evaluate COOP through testing, training, and exercises.
- Develop final draft of revised COOP and any additional tools or resources.
- Upon completion of the of these activities, awarded NBS programs will disseminate any tools, resources and best practices developed to the larger newborn screening community.

Disorders Screened

At the recommendation of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), the US Health and Human Services (HHS) Secretary has recommended 35 NBS disorders for inclusion on the Recommended Uniform Screening Panel (RUSP). All NBS programs screen for at least 30 disorders on the RUSP and 15 NBS programs screen for all 35 disorders (**Figure 4**).

Figure 4: Number of RUSP core disorders universally screened by state, August 2021 (N=53)



After the initial 29 disorders were added to the RUSP in 2005, Severe Combined Immunodeficiency (SCID) was added in 2010, followed by Critical Congenital Heart Disease (CCHD) in 2011, Pompe disease in 2015, and X-linked Adrenoleukodystrophy (X-ALD) and Mucopolysaccharidosis type I (MPS I) in 2016. Spinal muscular atrophy (SMA) is the most recent disorder added to the RUSP in 2018. As of August 2021, 52.8% (n=28) of NBS programs screen for screen for Pompe, 41.5% (n=22) screen for X-ALD, 49.1% (n=26) screen for MPS I and 64.2% (n=34) screen for SMA. **Table 2 and figures 5a, 5b, 5c, and 5d** below provide more detail regarding newborns with access to universal screening and screening implementation timelines for most recently added RUSP disorders. In 2020, some NBS programs delayed implementation of new disorders due to competing pandemic response priorities, delays in stakeholder meetings, modifications in operating hours and delays with vendor resources and services.

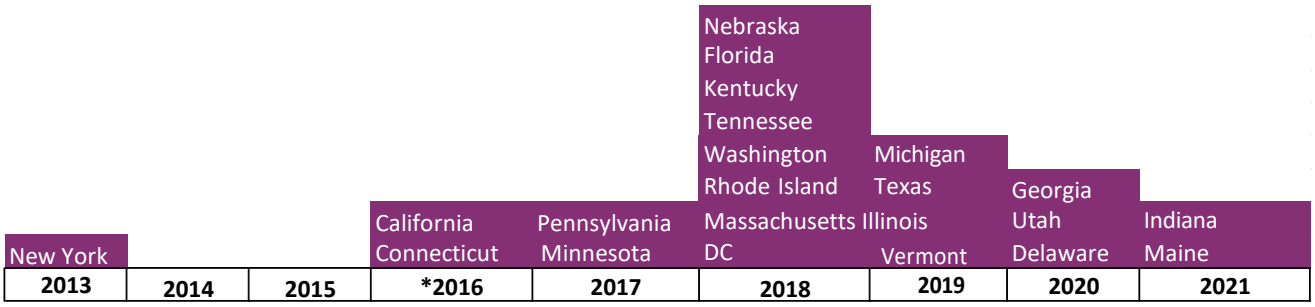
Table 2: Number and percentage of newborn screening programs universally screening for most recently added RUSP disorders, August 2021 (N=53)

Disorder	Year added to the RUSP	NBS programs offering universal screening	Newborns with access to universal screening
Pompe	2015	28	61%
X-ALD	2016	22	62%
MPS I	2016	26	58%
SMA	2018	34	78%

Figure 5a: Pompe screening implementation timeline, August 2021 (N=28)

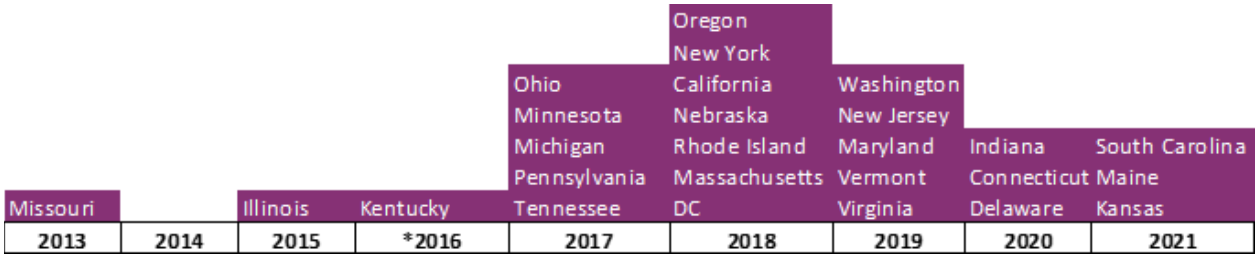
*Pompe added to the RUSP

Figure 5b: X-ALD screening implementation timeline, August 2021 (N=22)



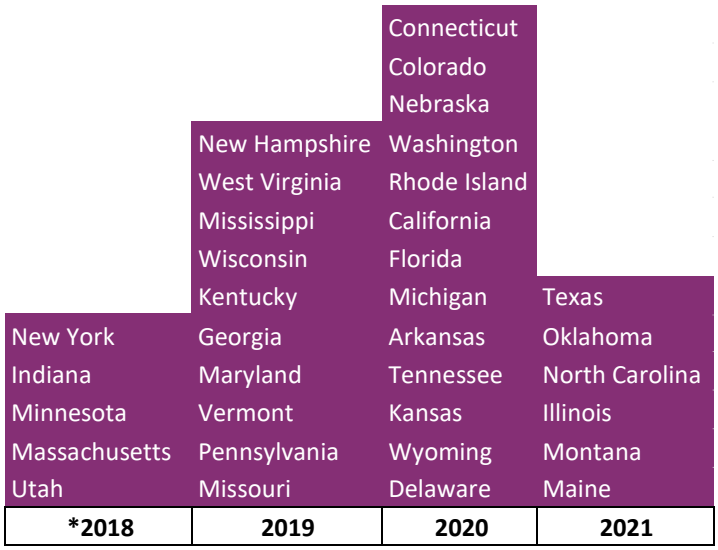
*X-ALD added to the RUSP

Figure 5c: MPS I screening implementation timeline, August 2021 (N=26)



*MPS I added to the RUSP

Figure 5d: SMA screening implementation timeline, August 2021 (N=34)



*SMA added to the RUSP

Case Study:

Kansas Newborn Screening New Disorder Implementation

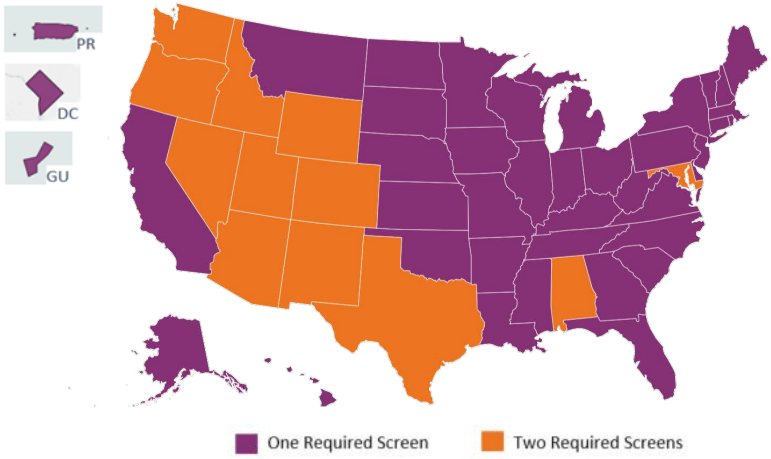
As national NBS priorities shifted to focus on pandemic response, the Kansas NBS team persevered and continued to focus on implementation of both Pompe and Mucopolysaccharidosis type I (MPS) I during the COVID-19 pandemic. With the overwhelming nature of a global pandemic, it would be expected to see a reduction in family, provider, and key stakeholder engagement. The Kansas experience was different. Moving collaborative activities to virtual platforms (e.g., Microsoft Teams, Zoom) allowed for greater opportunity for engagement and helped move implementation forward.

Through the pandemic, the Kansas NBS team learned the importance of "nuts and bolts" planning, ensuring steps were clearly defined and the expectations were collaborative to assure implementation of new disorder screening was effective. Another critical aspect was to have all stakeholders involved in the implementation process from the beginning, some of which included: providers, families, subject matter experts, and several public health entities. While contingency plans were in place for operations at the onset of the pandemic, they were fortunate enough that their NBS laboratory did not have to utilize them. Cross training laboratory staff enabled the NBS laboratory to maintain normal operations while also assisting in a huge way to the COVID-19 response efforts of the overall laboratory, in addition to the pandemic response efforts of the follow-up team. Implementing new disorders in the midst of a pandemic response, as well as other NBS activities, speaks to the resiliency and dedication of the Kansas NBS program.

Newborn Screening Policies

Each state/territory has mandates to screen newborns, and these mandates specify if newborns will receive one or two screens. Twelve states (Alabama, Arizona, Colorado, Idaho, Maryland, Nevada, New Mexico, Oregon, Texas, Utah, Washington, and Wyoming) are two-screen states that require that a second dried blood spot newborn screening specimen be routinely collected on all newborns regardless of the results of the first newborn screen **(Figure 6)**. The purpose of the second screen is to improve the specificity and minimize delayed diagnoses (false-negatives) of disorders that are not detectable on the initial screen.[3] Newborns in the other 41 states and territories typically undergo a single newborn screen.

Figure 6: Number of required screens by state, August 2021 (N=53)



[3] Shapira, S. K., Hinton, C. F., Held, P. K., Jones, E., Harry Hannon, W., & Ojodu, J. (2015). Single newborn screen or routine second screening for primary congenital hypothyroidism. Molecular genetics and metabolism, 116(3), 125–132. doi:10.1016/j.ymgme.2015.08.003

There are certain circumstances that may prompt an additional screen in one-screen states, such as when a specimen is collected too early or if there is an unsatisfactory specimen due to collection or transportation errors. Out of the 12 two-screen states, 58.3% (n=7) have a policy that mandates a second screen on all infants for a partial panel of disorders; 16.7% (n=2) have a policy that mandates a second screen on all infants for the full panel of disorders; 16.7% (n=2) have a policy that recommends, but does not mandate, a second screen on all infants for a partial panel of disorders; and, 8.3% (n=1) has a policy that recommends, but does not mandate, a second screen on all infants for the full panel of disorders.

Newborn screening programs may differ in which specimens are deemed unsatisfactory for screening. NewSTEPs follows the definition for unsatisfactory specimens found in the Clinical and Laboratory Standards Institute (CLSI) –Dried Blood Spot Specimen Collection for Newborn Screening; Approved Standard— 7th Edition. [4] Examples of unsatisfactory specimens include, but are not limited to, if specimens have insufficient quantity of blood, clotting, smearing or contamination, inadequately filled circles, oversaturation of blood, blood layering due to improper collection or incomplete drying; or, if the specimen was collected too early, or if the specimen is too old.

Similarly, NBS programs may differ in screening policies after a specimen has been deemed unsatisfactory. Some NBS programs have had to adapt to changes in screening policies with the COVID-19 pandemic as they continue to strive for reporting out results as quickly as possible, despite challenges with obtaining second or repeat screens (e.g., families discharged early from birthing facilities).

[4] Clinical and Laboratory Standards Institute (CLSI). Dried Blood Spot Specimen Collection for Newborn Screening. 7th ed. CLSI standard NBS01. Clinical and Laboratory Standards Institute; 2021. https://clsi.org/standards/products/newborn-screening/documents/nbs01/

Hot Topic Webinar: Unsatisfactory Specimens

APHL hosted a Hot Topic webinar on the screening of unsatisfactory specimens: APHL Hot Topic Webinar Series: Screening of Unsatisfactory Specimens as second or repeat specimens have proven difficult to obtain in the pandemic because of early discharge of families in birthing facilities, and limitations in the availability of recollection options for families.

The Maryland NBS program screens every specimen that comes to the laboratory, regardless if it is unsatisfactory, and presumptive positive results are reported to the follow-up program with a note saying the specimen is unsatisfactory and for what reason. Similarly, the Tennessee NBS program has the ability to report results even if the DBS card has missing information, as opposed to saying it is a "global unsat," which is the term used for unsatisfactory specimens that are clotted or oversaturated. There are challenges to testing unsatisfactory specimens, including the inability to flag an infant as abnormal with an unsatisfactory specimen in the laboratory information management system (LIMS), or the lax response of providers if a result is reported abnormal, but the specimen is deemed unsatisfactory. However, both NBS programs have detected newborns at risk for NBS disorders on unsatisfactory specimens, and thus hold firm to the belief that they only have one chance to catch these cases.

Though not discussed on this webinar, during the COVID-19 pandemic some two screen states have had difficulty obtaining a second screen, and have found that the second screen recommendation for all infants was putting families at risk and had the potential to tax the medical system. Thus, the Washington NBS program provided documents including justification for relaxing the recommendation that all infants have their second screens for the duration of the pandemic, and temporary second screening recommendations.

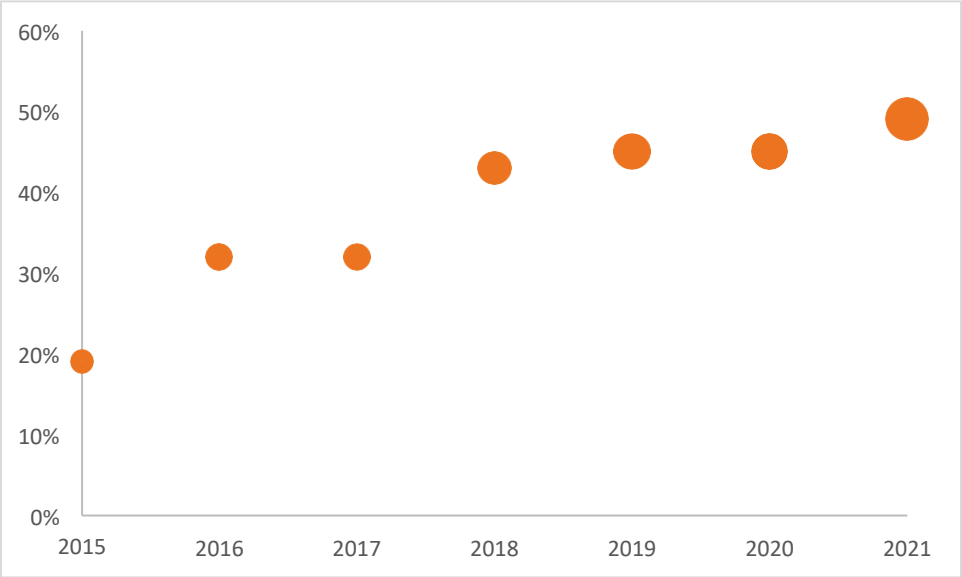
Additional challenges and strategies regarding second or repeat screens can be found on the NewSTEPs COVID-19 webpage: https://www.newsteps.org/resources/covid-19-nbs-response- second-or-repeat-screens.

According to the NewSTEPs data repository, 52.8% (n=28) of NBS programs test all specimens and report results when possible; 20.8% (n=11) do not test unsatisfactory specimens, instead requesting repeat samples; and, 26.4% (n=14) have an "other" unsatisfactory screening policy. Other policies include testing unsatisfactory specimens for the most time sensitive disorders and reporting results; not testing unsatisfactory specimens if they are on expired kits and/ or if collection date and time are missing; testing unsatisfactory specimens but reporting out results to follow-up rather than on a formal laboratory report; testing unsatisfactory specimens and still requiring a repeat screen; testing for hemoglobinopathy and molecular disorders only; and testing dependent on the quality of the specimen.

Health Information Technology

Due to the COVID-19 pandemic, NBS programs had to adjust workflows, including how to share critical results from the laboratory to follow-up and other clients electronically. NBS programs use web portals as an avenue for clients (e.g., birthing hospitals, clinicians) to access these data. Web portals may be used in different capacities depending on programmatic needs and infrastructure. Out of the 47 NBS programs that provided data, 55.3% (n=26) use a web portal for sharing data related to the newborn screen, and 44.7% (n=21) do not. A timeline of the percent of NBS programs with a data sharing portal from 2015 to 2021 is outlined in **Figure 7**.

Figure 7: Percent of NBS Programs with a Data Sharing Portal, April 2021 (N=47)



Hot Topic Webinar: Electronic Reporting

APHL hosted a Hot Topic webinar on electronic reporting and other efforts to reduce paper reporting/ messaging in NBS: APHL Hot Topic Webinar Series: Electronic Reporting

While there are still improvements to be made and challenges with electronic reporting, including the cost of technology and limitation of in-house tools, the Nevada, Louisiana and Texas NBS programs have made great strides in reducing paper access to electronic information in order to better streamline and automate their processes. The Nevada NBS program moved from printing 200-800 physical mailers daily, which took three days to get to submitters, to auto faxing reports through PerkinElmer's Screening Center, which includes military base IT security features. They are also implementing eReport results through an online portal to accommodate for lost fax reports. Louisiana NBS also utilizes electronic faxing and case reports. Preliminary reports for satisfactory and unsatisfactory abnormal results are sent via Natus (LIMS). Report results are sent as they are generated, and reports are also sent to follow-up. Texas NBS utilizes a mix of manual reporting, faxing, HL7 and use of a web application. The web application has the ability to enter specimen demographics, access result reports, and allows providers to have access to monthly report cards for quality purposes.

As a result of the webinar, NewSTEPs has developed a Guide to NBS Results Portals to assist newborn screening programs with implementing and maintaining result report portals. The document outlines recommendations and potential solutions, covering activities around information technology (IT) to access administration to privacy and authentication practices.

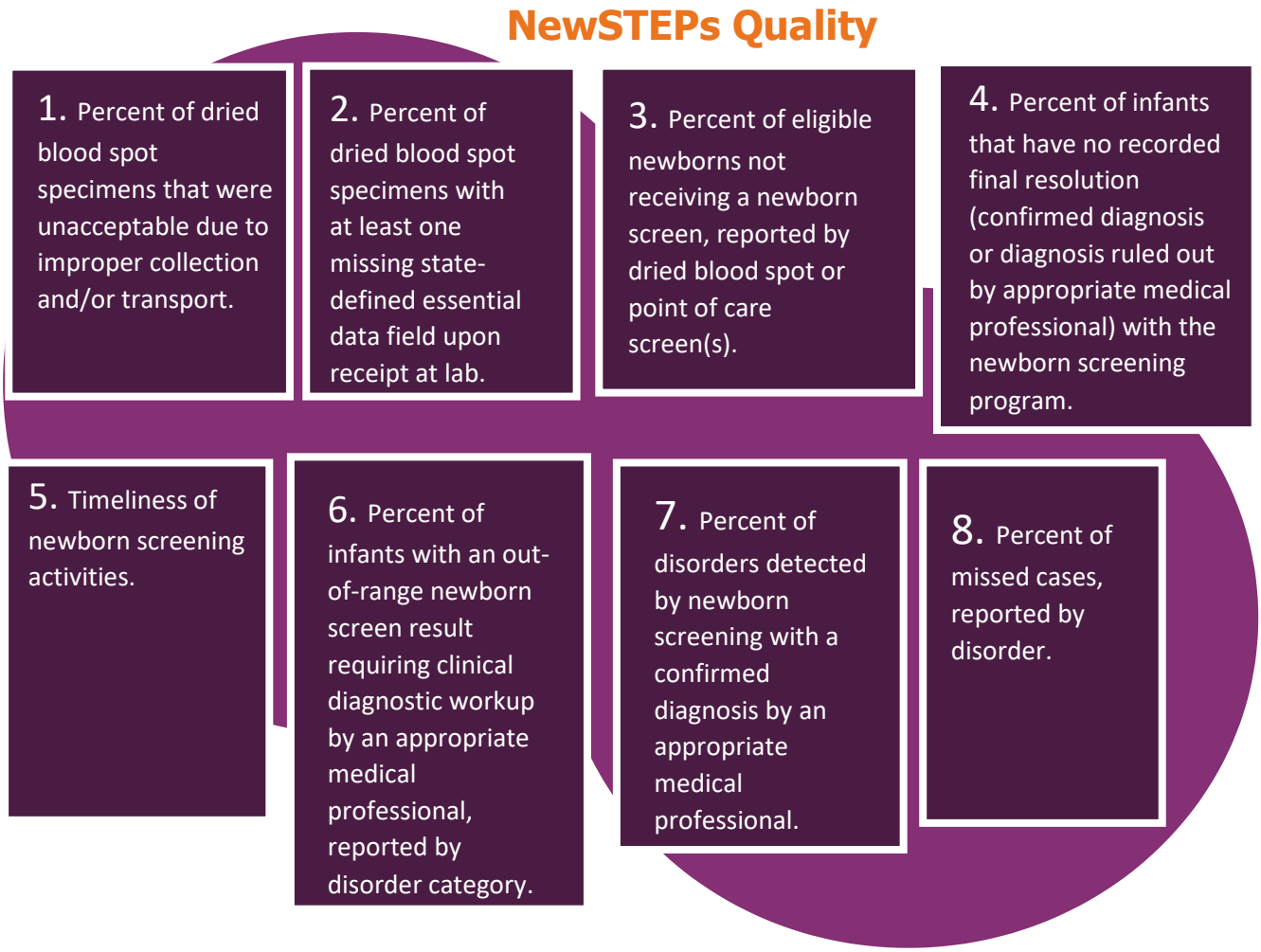
Additional challenges and strategies regarding health information technology during the pandemic can be found on the NewSTEPs COVID-19 webpage: https://www.newsteps.org/resources/covid-19- nbs-response-education-and-outreach

The pandemic has also highlighted the need for frequent NBS data back up to plan for emergent situations. For example, as more employees work remotely during the pandemic, proper data back up plans can mitigate risk as errors may build up from going undetected or unreported for longer periods of time. Furthermore, data backups can be used to restore data and make it accessible from remote locations if there are any interruptions or outages. Out of the 47 NBS programs that provided data, 85.1% (n=40) back up data every day; 6.4% (n=3) back up data every hour; 4.3% (n=2) back up transaction logs every hour, but back up the whole data base every day; and, 4.3% (n=2) back up data every 15 minutes.

Measuring NBS Program Performance

NewSTEPs utilizes quality indicators (QIs) to provide longitudinal comparisons within an NBS program as well as comparisons to aggregate data across NBS programs. Eight QIs track quality practices and performance within NBS in order to support data-driven outcome assessments, and ultimately, improve the quality of the NBS system.[5]

The QIs below span the NBS process from collection of a DBS, DBS specimen receipt at the NBS laboratory, testing and reporting out screen results, time of medical intervention and confirmation for a screened disorder.



[5] Yusuf, C., Sontag, M. K., Miller, J., Kellar-Guenther, Y., McKasson, S., Shone, S., Singh, S., & Ojodu, J. (2019). Development of National Newborn Screening Quality Indicators in the United States. *International journal of neonatal screening*, *5*(3), 34. https://doi.org/10.3390/ijns5030034

Specimen Collection: Time from birth to specimen collection (QI 5a)

The timeliness related Quality Indicator (QI 5) quantifies time components of the NBS system that may be shortened in order to decrease the time to identification of infants at risk for NBS disorders, thereby lowering the risk of potential harm to infants who may be identified with a disorder on the NBS panel. The ACHDNC recommends that initial NBS specimens should be collected in the appropriate time frame for the newborn, but no later than 48 hours of life. The majority of NBS programs that submit data to the NewSTEPs data repository collect DBS specimens within this timeframe, with a gradual improvement each year (**Table 3**). In 2020, among the 18 NBS programs submitting data to the NewSTEPs data repository, the median percent of first dried blood spot specimens collected within 48 hours from birth (QI 5ai) was 97.63%. Fourteen NBS programs reported that over 95% of first dried blood spot specimens were collected within 48 hours after birth.

Table 3: Median of percent of first DBS specimens collected within hour timeframes from birth, by year (QI 5a)

Year (N)	<12 hours	12-24 hours	>24-48 hours	>48-72 hours	>72 hours	Unknown
2017 (N=34)	1.38%	2.01%	85.82%	2.44%	0.98%	0.07%
2018 (N=34)	1.25%	2.65%	85.07%	2.86%	0.93%	0.07%
2019 (N=28)	1.12%	2.07%	89.18%	2.27%	0.98%	0.04%
2020 (N=18)	0.98%	1.18%	90.74%	1.07%	0.77%	0.02%

Specimen Receipt by Laboratory: Time from specimen collection to receipt at NBS laboratory (QI 5b)

Most NBS programs are still working to achieve the ACHDNC specimen delivery recommendation of 95% of specimens received by the laboratory within 24 hours of collection (Table 4). In 2020, among the 17 NBS programs submitting data to the NewSTEPs data repository, the median percent of first dried blood spot specimens received within 24 hours of collection (QI 5bi) was 45.86%. Of the 17 state submitting data to the NewSTEPs Data Repository in 2020 on this metric, one NBS program achieved this benchmark.

Table 4: Median of the percent of first DBS specimens received within day timeframes after specimen collection, by year

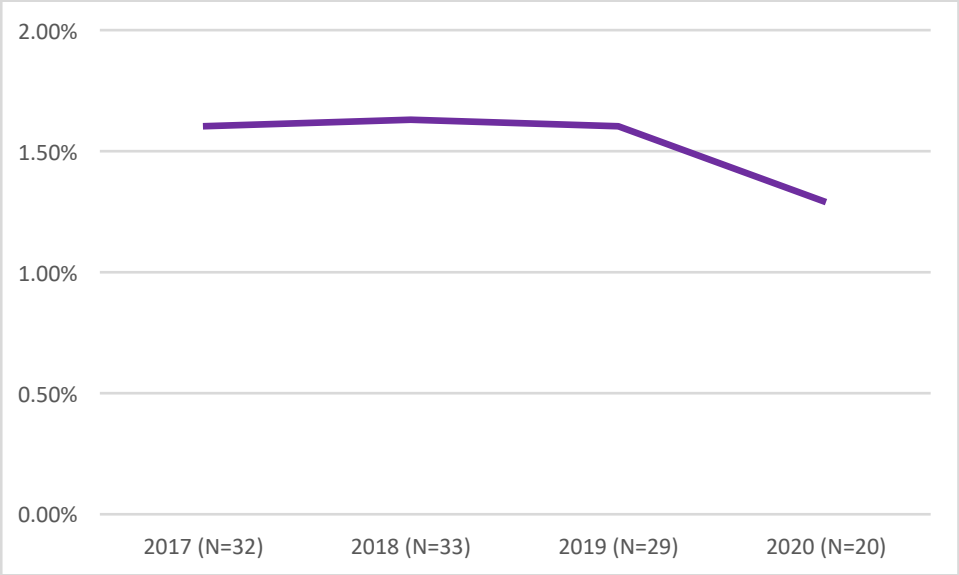
Year (N)	Same day as collection	Day 1 after collection	Day 2 after collection	Day 3 after collection	Day 4 after collection	Day 5 after collection	Day 6 after collection	≥Day 7 after collection	Unknown
2017 (N=34)	3.14%	33.71%	29.94%	15.48%	4.42%	1.28%	0.31%	0.17%	0.03%
2018 (N=34)	0.7%	35.38%	30.07%	14.88%	4.21%	1.35%	0.34%	0.25%	0.06%
2019 (N=28)	4.33%	39%	27.86%	14.23%	4.27%	1.15%	0.37%	0.24%	0.01%
2020 (N=17)	4.47%	34.31%	35.95%	14.43%	3.49%	1.04%	0.46%	0.22%	0.03%

Unacceptable Specimens: Percent of DBS specimens that were unacceptable due to improper collection and/ or transport (QI 1)

As stated in the NBS Policies section, specimens may be deemed unsatisfactory for a variety of reasons once they arrive at the NBS laboratory. As NBS laboratories flag unsatisfactory specimens for analysis and request a new specimen prior to testing, these activities can contribute to delays.

Because of the COVID-19 pandemic, NBS programs faced a number of challenges with getting a repeat specimen. For example, families did not want to return to the hospital/birthing centers to get specimens collected; hospitals/birthing centers/ commercial laboratories limited access to only "essential" patients and some facilities modified their operating hours making it challenging to schedule families for specimen collection. In response, NBS programs adjusted their processes to accommodate collection of specimens outside of the recommended timeframes, and closely monitored the return of these repeat specimens to ensure no delays occurred. Additional information is available on the COVID-19 Second or Repeat Screen Challenges Practices and Resources webpage. Data shows that the median percent of unsatisfactory specimens has remained under 2% for those NBS programs submitting data. In 2020, for the 20 NBS programs that submitted data, the median was 1.29% **(Figure 8).** The variation in range was fairly wide, between 0.25% and 5.96%.

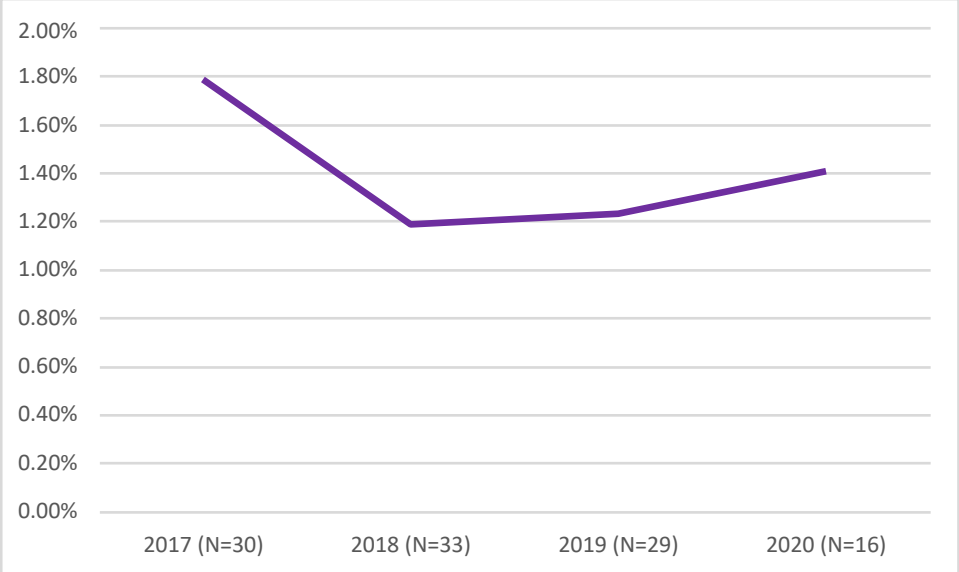
Figure 8: Median of the percent of unsatisfactory specimens, by year



Specimens with Missing Information: Percent of DBS specimens with at least one missing state-defined essential data field upon receipt at the laboratory (QI 2)

In addition to checking for the quality of DBS specimens, NBS laboratories also check to see there are any missing state-defined essential information on the DBS card. Missing essential information may also delay testing and reporting of results, causing potential harm to the newborn and requiring additional work for laboratory personnel to acquire the missing information. The national median for QI 2 has remained below 2% across the years **(Figure 9).** In 2020, among the 16 NBS programs that submitted data to the NewSTEPs data repository, the range of specimens missing state-defined essential information was from 0% to 17.3%. Challenges to data submission of this QI includes that some NBS programs cannot separate first and subsequent samples, creating potential bias in reporting.

Figure 9: Median of the percent of specimens with missing state-defined essential information reported, by year



Birth to Reporting out Results: Time from birth to reporting out specimen results (QI 5d)

Once the DBS specimens are tested, screen results are shared with the follow-up program and appropriate medical providers (including hospitals/birthing centers). For reporting purposes, NewSTEPs separates reporting of results by time critical disorders (5di), non-time critical disorders (5dii) and all results (5diii), to be consistent with the ACHDNC timeliness recommendations. The ACHDNC recommends that time critical results be reported within five days of life; and, all results be reported within seven days of life. Data shows that it is difficult for NBS programs to reach the five day benchmark. In 2020, the median percent of time critical results that were reported within 5 days of life from 18 participating NBS programs was 48.25% **(Figure 10a)**. Of the 18 NBS programs, two NBS programs met the ACHDNC benchmark of 95% of time-critical results reported out within 5 days of birth. In 2020, the median percent of all results reported within seven days of life was 91.61% **(Figure 10b**). Of the 16 NBS programs submitting data to the NewSTEPs data repository, five NBS programs met the ACHDNC benchmark of 95% of all results should be reported out within seven days of life. NBS programs adapted to the COVID-19 pandemic by leveraging result report portals (see Health Information Technology section) and encouraged the use of telehealth in newborn screening.

Figure 10a: Median of the percent of specimens with time critical results reported <= 5 days from birth, by year

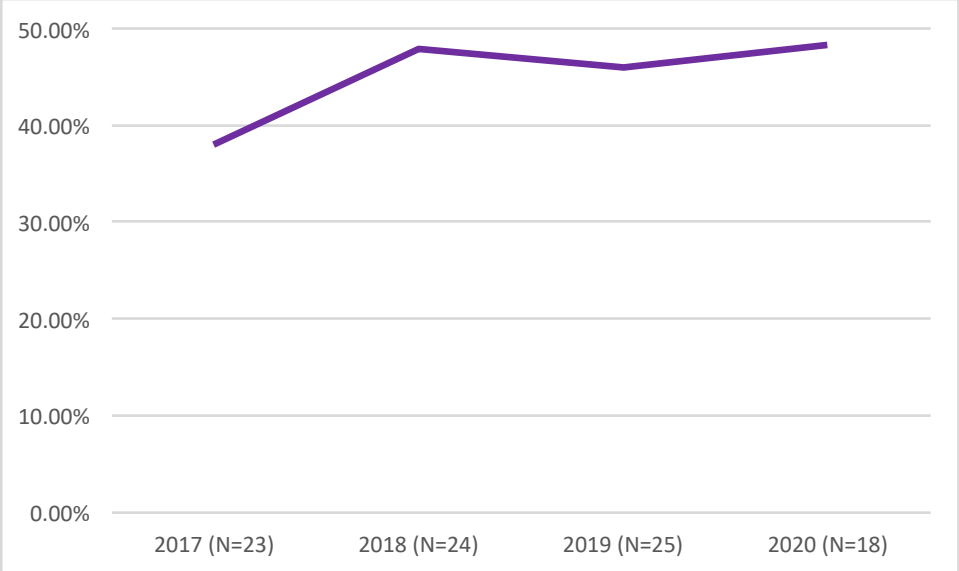
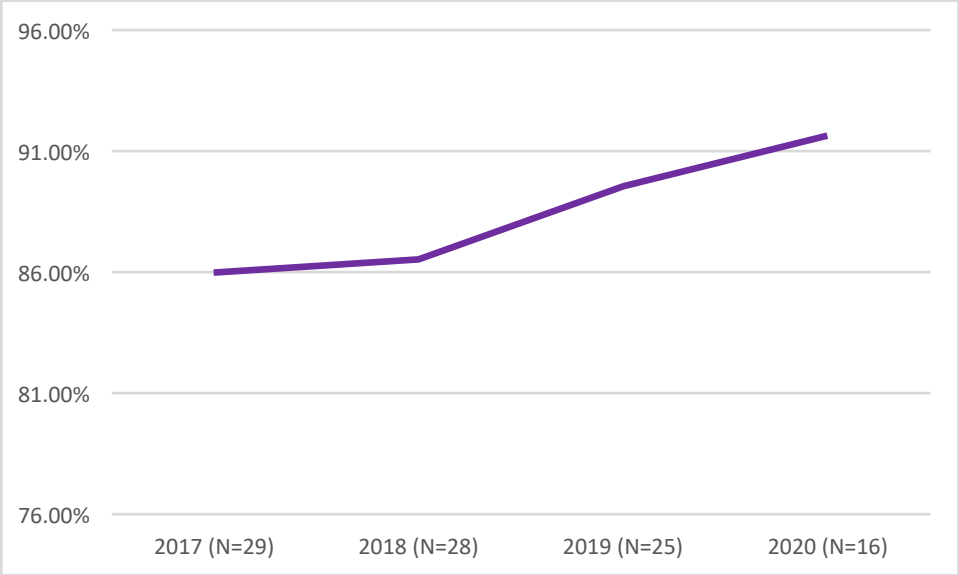


Figure 10b: Medians of the percent of specimens with any disorder results reported ≤ 7 days from birth, by year



Hot Topic Webinar: Telehealth

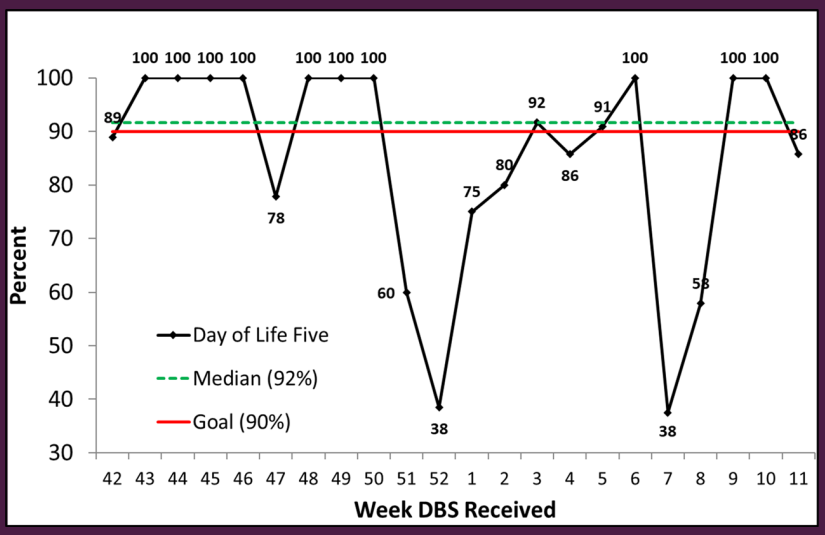
APHL hosted a Hot Topic webinar on Telehealth in Newborn Screening: APHL Hot Topic Webinar Series: Telehealth in Newborn Screening

Additional challenges and strategies on the use of Telehealth during the pandemic can be found on the NewSTEPs COVID-19 webpage: https://www.newsteps.org/resources/covid-19-nbs-response-telehealth

Tennessee Newborn Screening Timeliness Success

The Tennessee NBS program is one of the few NBS programs who were able to report out >95% of time critical results within five days of life in 2020 and continuing into 2021. Due to their dedication and tireless work, the NBS program has been able to sustain 100% of time critical results reported in this timeframe over several weeks, and >90% reported (their original goal) over several months, only slightly dropping with inclement weather events, challenges with implementing a new disorder screening, and bombing near the laboratory in Nashville **(Figure 11).** The team has implemented and sustained numerous timeliness related initiatives, including but not limited to, targeted reporting and assistance to birthing facilities, daily courier operation, educational site views (now virtual via WebEx due to the COVID-19 pandemic), and efforts to implement OZ specimen tracking software. Efforts are coupled with additional financial and technical assistance from the APHL Quality Improvement Projects collaborative. Despite all challenges, the NBS program continues to implement multi-faceted, creative approaches to improve NBS timeliness for the Tennessee babies and families. They are a remarkable representation of the resiliency and dedication of the NBS community.

Figure 11: Percent of specimens with time critical results reported ≤5 days from birth, Tennessee 2020-2021



Cases Identified Through Newborn Screening

NewSTEPs collects individual-level data for infants diagnosed with a disorder identified through NBS. These data include demographic information, time elapsed for different NBS services and the final diagnosis recorded for the infant. Confirmed case data is reported to the NewSTEPs Data Repository on a two year lag time (i.e., for an infant with a confirmed case who is born in 2018, their case data is submitted by 2020). This allows a full year for the NBS program to gather and record the final diagnosis of the infant.

Participating NBS programs reported 3,416 individual-level cases in 2016, they reported 4,298 individual-level cases in 2017 and they reported 4,886 individual-level cases in 2018 **(Table 7)**. These cases represent a confirmed diagnosis of disorder identified by NBS.[6] The median time to intervention for time critical cases between 2016 and 2018 did not change, however, there was an increase in median time to diagnosis for time critical cases in 2018 (19 days) as compared to 14 days in 2016. The reason for this change is unknown. Conversely, there was a decrease in the median time to intervention for non-time critical cases from 2018 (12 days) as compared to 18 days in 2016 and an increase in median time to diagnosis for non-time critical cases (29 days) in 2018 as compared to 27 days in 2016.

Medical intervention is defined as when care of the infant changed (i.e., the earliest point at which a clinical action was rendered based on follow-up on the newborn screening results and is inclusive of date therapy was initiated or a decision was made to defer therapy based on current presentation). Medical intervention may occur before a diagnosis is determined and is therefore a critical step in ensuring the newborn is under medical supervision as soon as possible.

[6] NewSTEPs collects individual level confirmed cases for disorders screened via dried blood spots and pulse oximetry (critical congenital heart disease). NewSTEPs does not collect individual level confirmed cases of hearing loss.

Table 5: Timeliness metrics for newborns identified with a disorder on the newborn screening panel, by year, April 2021; Median (Interquartile Range)

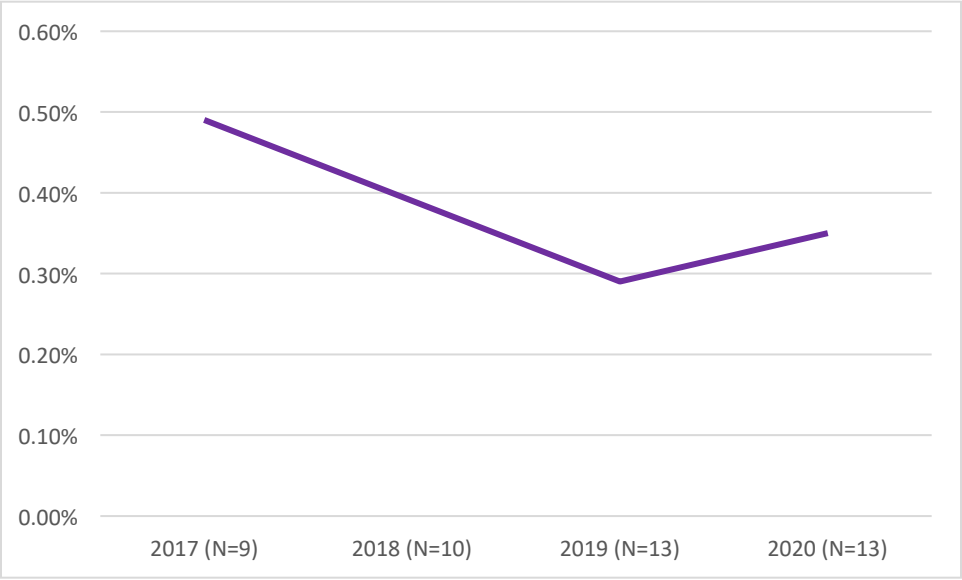
	2016 (N=40)			2017 (N=42)			2018 (N=43)		
	All	Time-critical	Non-time-critical	All	Time-critical	Non-time-critical	All	Time-critical	Non-time-critical
Total Number	3,461	504	2,957	4,298	557	3,741	4,886	648	4,238
Collection (hours)	28 (24-38)	29 (24-39)	28 (24-38)	28 (24-38)	27.5 (24-37)	28 (24-38)	26 (24-37)	26 (24-36)	26 (24-37)
Receipt at lab (days from birth)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)
Result release (days from birth)	6 (4-8)	5 (4-6)	6 (4-8)	6 (4-8)	5 (3-6)	6 (4-8)	6 (5-8)	5 (4-6.25)	6 (5-9)
Intervention (days from birth)	15 (7-32)	6 (4-9)	18 (8-35)	11 (6-27)	5 (4-8)	13 (7-29)	10.5 (6-26)	6 (4-10)	12 (7-28)
Diagnosis (days from birth)	25 (12-50)	14 (7-30)	27 (14-54)	24 (11-52)	13 (7-32)	26 (12-54)	28 (12-61)	19 (7-41)	29 (13-64)

Eligible Newborns Not Receiving a Screen: Percent of eligible newborns not receiving a newborn screen, reported by DBS or point-of-care screen(s) (QI 3)

Newborn screening is a critical part of the public health system and to ensure health equity, all newborns should have access to NBS. Once NBS programs have processed the DBS specimens they receive, they review their data and that from other health agencies (e.g., vital records) to identify those newborns who may not have received a newborn screen.

Quality indicator three was established to determine the proportion of eligible newborns that were not screened due to parental refusal, pre-analytic error and missing or unmatched screens. Eligibility for NBS is based on individual state protocol. This will typically be the number of live births minus those who are not eligible due to death, due to being transferred and screened out-of-state, and for whom screening was inappropriate. Newborn screening programs have reported that this QI is difficult to collect because they may not be able to differentiate between number of births and specimens received in a timely manner. Many NBS programs also do not have access to point of care screen information. Of the NBS programs that are able to report, the median percent of eligible newborns not receiving a dried blood spot newborn screen has remained below 0.5% (**Figure 12**).

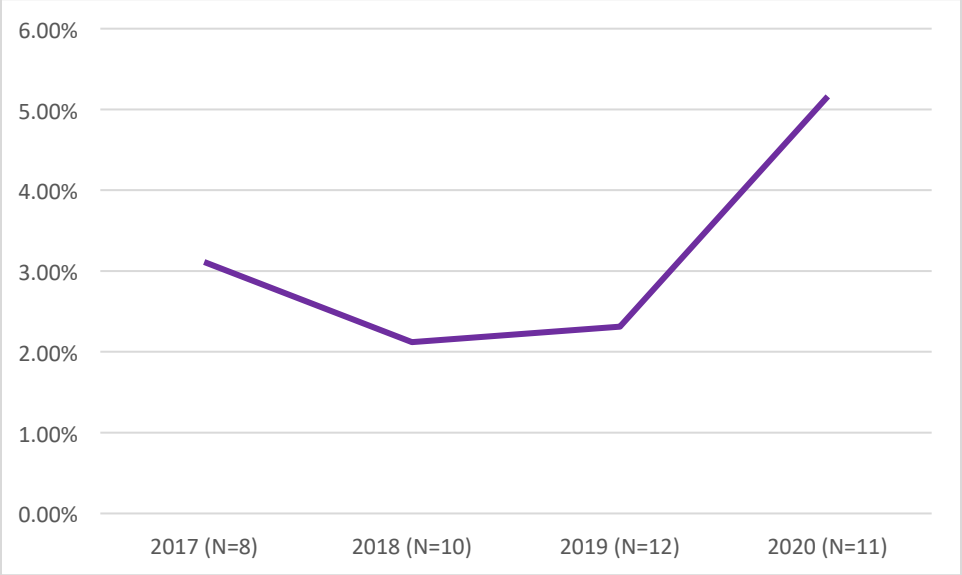
Figure 12: Median of the percent of eligible newborns not receiving a valid dried blood spot screen, by year



Infants with No Final Resolution: Percent of infants that have no recorded final resolution with the NBS program (QI 4a)

Another valuable metric for NBS programs is to ensure that the newborns who have a DBS specimen collected receive a valid NBS and as appropriate are diagnosed or that a diagnosis is ruled out. NBS programs can measure this using QI 4a - the purpose of this QI is to determine the percentage of infants that have no recorded final resolution by 12 months of age due to not receiving appropriate screening, evaluation, and/ or treatment, and therefore increasing the probability of harm to infants who are at-risk for a disorder on the NBS panel. Newborn screening programs have indicated that this QI is difficult to collect because they may not receive reliable information, or may not have a mechanism to collect this information. In 2020 for the 11 NBS programs that submitted data to the NewSTEPs data repository, the median percent of infants that had no recorded final resolution was 5.16%, with a range of 0% of infants with no recorded final resolution in two NBS programs to 31.54% of infants with no recorded final resolution in one NBS program **(Figure 13).** The marked increase in this median may correlate with the anecdotal data that fewer parents were returning for repeat or subsequent screens due to COVID-19 restrictions at hospitals or clinics. Having no recorded final resolution at the NBS program does not necessarily mean harm to the infant, but could be a function of other priorities across the surveillance and clinical system.

Figure 13: Median percent of infants that have no recorded final resolution with the NBS program, by year



Summary

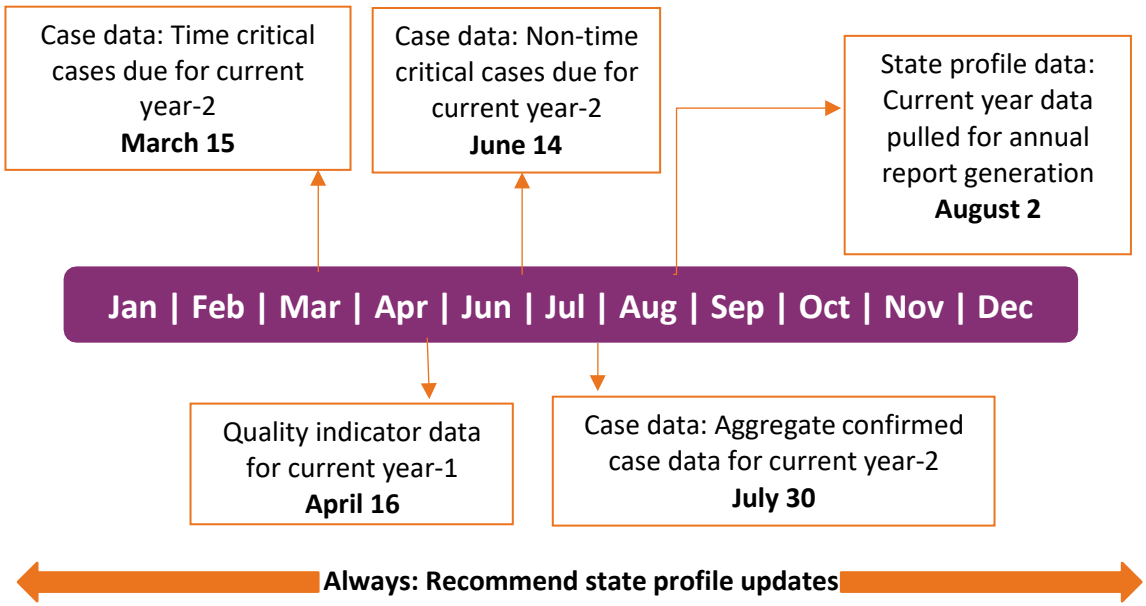
This report illustrates the continued efforts of NBS programs and their dedicated staff persevering despite the challenges throughout the year 2020, including a global pandemic. Despite all the challenges, NBS programs submitted data into the NewSTEPs data repository and this data highlights their commitment to making sure that all newborns have access to quality NBS services. NBS programs are continuously working on quality improvement by:

- **Implementation of new disorders to expand their state NBS panels**
- **Adjusting policies around unsatisfactory specimens and repeat specimens to accommodate challenges with obtaining additional specimens**
- **Utilizing remote standard electronic data exchange methods for timely medical intervention and diagnosis**
    - **Utilization of electronic data sharing tools for reporting out of screen results using web portals**
    - **Expanding the use of telehealth in newborn screening**
- **Maintaining the timeliness of reporting out screen results for time-critical disorders within 5 days of life**

NewSTEPs in collaboration with NBS programs will continue to collect, analyze, and report data with the purpose of facilitating data driven quality improvements. NewSTEPs will continue to cultivate collaborative relationships and facilitate information exchange within NBS systems.

Appendix A: Data Collection Timeline

All data is collected in accordance with the data entry timeline displayed in the figure below.



NBS programs are encouraged to provide:

- NBS programs are encouraged to update State Profile information for the current year by August 2 of the current year.
- Annual quality indicator data for the current year-1 by April 16 of the current year. For example, 2020 quality indicators were submitted by April 16, 2021.
- Time-critical case data for the current year-2 by March 15 of the current year and non-time-critical case data for the current year-2 by June 14, of the current year. For example, the 2019 time-critical and non-time-critical case data were submitted and will be submitted by March 15, 2021 and June 14, 2021 respectively.
- Aggregate confirmed case data for current year-2 by July 30 of the current year.

Appendix B: NBS Programs and Data Collection Methods

Data Collection

There are 53 NBS programs included in the data repository, consisting of all 50 states, the District of Columbia, Puerto Rico, and Guam. NewSTEPs collaborates with each NBS program to improve the quality of their NBS program through a variety of activities including reviewing each NBS program's data in the NewSTEPs Data Repository. The NewSTEPs Data Repository is a centralized and secure database that can be accessed by authorized users from anywhere. It allows each NBS program to explore data to meet local evaluation needs.

The data collected in the NewSTEPs Data Repository has been deemed Non-Human Subject Research. Each NBS program is required to enter into a Memorandum of Understanding (MOU) with APHL in order to submit quality indicator data and case data. The MOU includes information around data ownership, data reporting, and data security. It establishes the framework in which the NBS program will share elements of its NBS data with NewSTEPs and identifies each party's roles and responsibilities.

Newborn screening programs that enter data into the NewSTEPs Data Repository have access to their own data as well as aggregate data from other participating NBS programs who have an MOU with APHL. As of April 2021, 48 states have an MOU with NewSTEPs. The NewSTEPs Data Repository collects three levels of data:

State Profiles: Publicly available data that describes the NBS program and its activities. State profile data encompasses the following: an overview of the NBS program, such as annual births, number of required screens and responsible laboratory; disorders screened, including method, method's target and equipment used; policies in place, such as opt out policies, consent policies and courier service usage; processes for adding to the NBS panel; fees, such as funding sources and fee use details; NBS program structure; contacts; advisory committee data; information technology (IT) support data; and HIT elements.

Quality Indicators: Eight performance metrics utilized to provide longitudinal comparisons within an NBS program, as well as comparisons to aggregate data across NBS programs. These quality indicators have undergone careful, iterative evaluation by stakeholders to assure agreement on definitions. The quality indicator source document outlines purpose, definitions and general considerations.[7] Quality indicator data is secure and only accessible to authorized users. Quality indicators are as follows:

1. Percent of DBS specimens that were unacceptable due to improper collection and/or transport
2. Percent of DBS specimens with at least one missing state-defined essential data field upon receipt at the laboratory
3. Percent of eligible newborns not receiving a newborn screen, reported by DBS or point of care screen(s)
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
5. Timeliness of newborn screening activities
6. Percent of infants with an out-of-range newborn screen result requiring clinical diagnostic workup by an appropriate medical professional, reported by disorder category
7. Percent of disorders detected by newborn screening with a confirmed diagnosis by an appropriate medical professional
8. Percent of missed cases, reported by disorder

[7] NewSTEPs Quality Indicator Source Document: https://www.newsteps.org/media/2/download?inline

Confirmed Cases: Infant level data, including demographics and diagnostic criteria to facilitate common classifications for diagnoses across NBS programs for all of the core newborn screening disorders. Case data is secure and only accessible to authorized users.

Data collection follows a data collection timeline each year as described in Appendix A.

Challenges and Solutions to Data Collection

Barriers to data entry that NewSTEPs staff have become aware of include competing priorities with COVID-19 related response efforts, inability to differentiate between specimen level and case level data, lack of dedicated personnel to enter data, lack of expertise to query information management systems, no incorporation of NewSTEPs data entry into general workflow and lack of prioritization of NewSTEPs data entry in comparison to other laboratory activities (i.e., onboarding screening of new disorders).

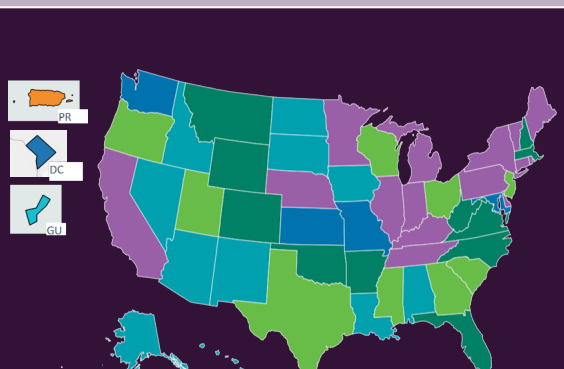
To address these barriers, NewSTEPs continues to engage with NBS programs and encourages data submission for all of the data categories collected. NewSTEPs has provided:

1. The continued iterative QI evaluation process, NewSTEPs convened a QI Workgroup over three consensus driven sessions in April 2021. This Workgroup is made up of diverse NBS stakeholders who advised NewSTEPs on QI clarifications, refinement and prioritization to get more NBS programs to submit more and more accurate data. Recommendations from this Workgroup will be circulated to the NBS community in 2021
2. Customized technical assistance to access, collate, upload, analyze and interpret data
3. A Quality Indicator Source Document is available online that defines each QI, provides a glossary of terms, quick tips, Laboratory Information Management Systems hints, calculation examples and scenarios
4. Extract, Transform, Load (ETL) pilot projects that facilitate automated data extraction and transformation (calculations as needed), and uploads into the NewSTEPs Data Repository
5. Data request page available on the NewSTEPs Website with form to request data (vetted through NewSTEPs' Data Review Workgroup) to further incentivize entry
6. Interactive data visualizations utilizing data pulled from the Data Repository via secure Tableau sign-ins
7. Regular reminders of data entry timeline; targeted and repeated outreach via phone and email coinciding with data entry timeline
8. Customized tutorials of the NewSTEPs Website and Data Repository elements with states who have signed an MOU, with new staff or upon request
9. Reports of frequently asked questions
10. Import templates (CSV files) to facilitate the automation of data submission
11. Engagement of Information Management Vendors (IMS) vendors
12. State Administrator and General User Guides available on the Data Repository that include detailed information about data entry timelines and user permissions
13. Bimonthly data repository and website office hours

Appendix C: NewSTEPs Data Repository Infographic

NewSTEPs Data Repository and Website: The Premier Newborn Screening Community

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



STATE PROFILE DATA

As the national newborn screening technical assistance center, NewSTEPs collects and shares publicly available information on characteristics of state newborn screening programs, ranging from program contacts, disorders screened, hours of operation, fees, and more.

This heat map, pulled from state profile data in the repository, represents number of core Recommended Uniform Screening Panel (RUSP) disorders screened nationally.

NEW DISORDERS IMPLEMENTATION

NewSTEPs supports state newborn screening programs in implementing the screening of new disorders as recommended by the Advisory Committee on Heritable Disorders in Newborns and Children. The NewSTEPs data repository captures these implementation timelines.

This timeline shows **SMA** screening implementation.

*2018	2019	2020	2021
New York	Georgia	Arkansas	Oklahoma
Indiana	Maryland	Tennessee	North Carolina
Minnesota	Vermont	Kansas	Illinois
Massachusetts	Pennsylvania	Wyoming	Montana
Utah	Missouri	Delaware	Maine
	New Hampshire	Connecticut	
	West Virginia	Colorado	
	Mississippi	Nebraska	
	Wisconsin	Washington	
	Kentucky	Rhode Island	
		California	
		Florida	
		Michigan	Texas

QUALITY INDICATOR DATA

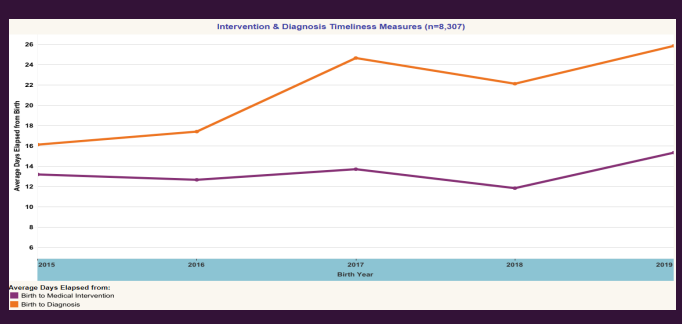
NewSTEPs facilitates data driven continuous quality improvement using community-developed Quality Indicators that serve as national, harmonized metrics to quantify and track quality practices within the newborn screening system from the pre-analytic, analytic and post-analytic stages.

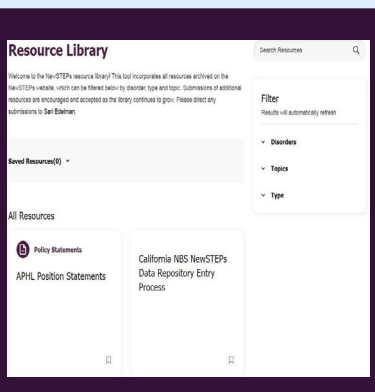
Quality Indicator data shows that programs are continuously improving the timeliness of reporting out newborn screening results to meet national recommendations.

CASE DEFINITIONS

NewSTEPs collects detailed, de-identified information using public health surveillance case definitions. Newborn screening programs identify over 12,000 newborns who are diagnosed with a congenital disorder on the core Recommended Uniform Screening Panel (RUSP) .

NewSTEPs captures the time from birth to medical intervention and diagnosis per disorder, as shown with Congenital Hypothyroidism, an endocrine disorder on the core RUSP.



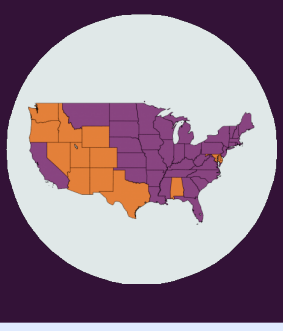


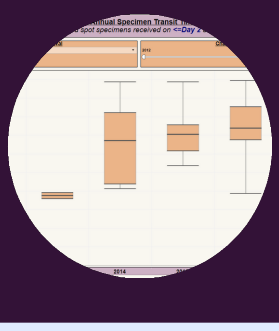
RESOURCE LIBRARY

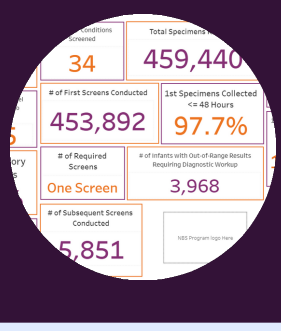
NewSTEPs curates and maintains a resource library of webinars, guidance documents, policy statements, and technical assistance resources on its public facing website. The nearly 400 resources within the resource library are intended to guide newborn screening laboratory and follow-up programs in their process improvement activities.

DATA VISUALIZATIONS

NewSTEPs makes available data visualizations that are updated in real-time reflecting various characteristics and quality metrics of US newborn screening programs.

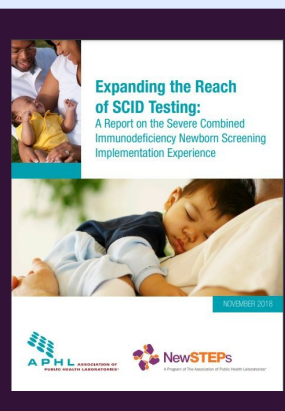






PUBLICATIONS AND REPORTS

NewSTEPs leads and contributes data in the development of reports and peer-reviewed publications around the state of newborn screening systems. NewSTEPs has completed 26 data requests from the newborn screening community.



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NewSTEPs
A Program of the Association of Public Health Laboratories™

Acronym Glossary

ACHDNC	Advisory Committee on Heritable Disorders in Newborns and Children
APHL	Association of Public Health Laboratories
CDC	Centers for Disease Control and Prevention
COOP	Continuity of Operations Plans
DBS	Dried Blood Spot
EOC	Emergency Operations Center
ETL	Extract, Transform, Load
HHS	Health and Human Services
HIT	Health Information Technology
HRSA	Health Resources and Services Administration
ICS	Incident Command System
IMS	Information Management System
IT	Information Technology
MOU	Memorandum of Understanding
MPS I	Mucopolysaccharidosis type I
NBS	Newborn Screening
NewSTEPs	Newborn Screening Technical assistance and Evaluation Program
QIs	Quality Indicators
RUSP	Recommended Uniform Screening Panel
SMA	Spinal Muscular Atrophy
WHO	World Health Organization
X-ALD	X-linked Adrenoleukodystrophy

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APHL also commends our members for their work in ensuring that essential operations continue, and newborns are screened and treated during these extraordinary times.

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