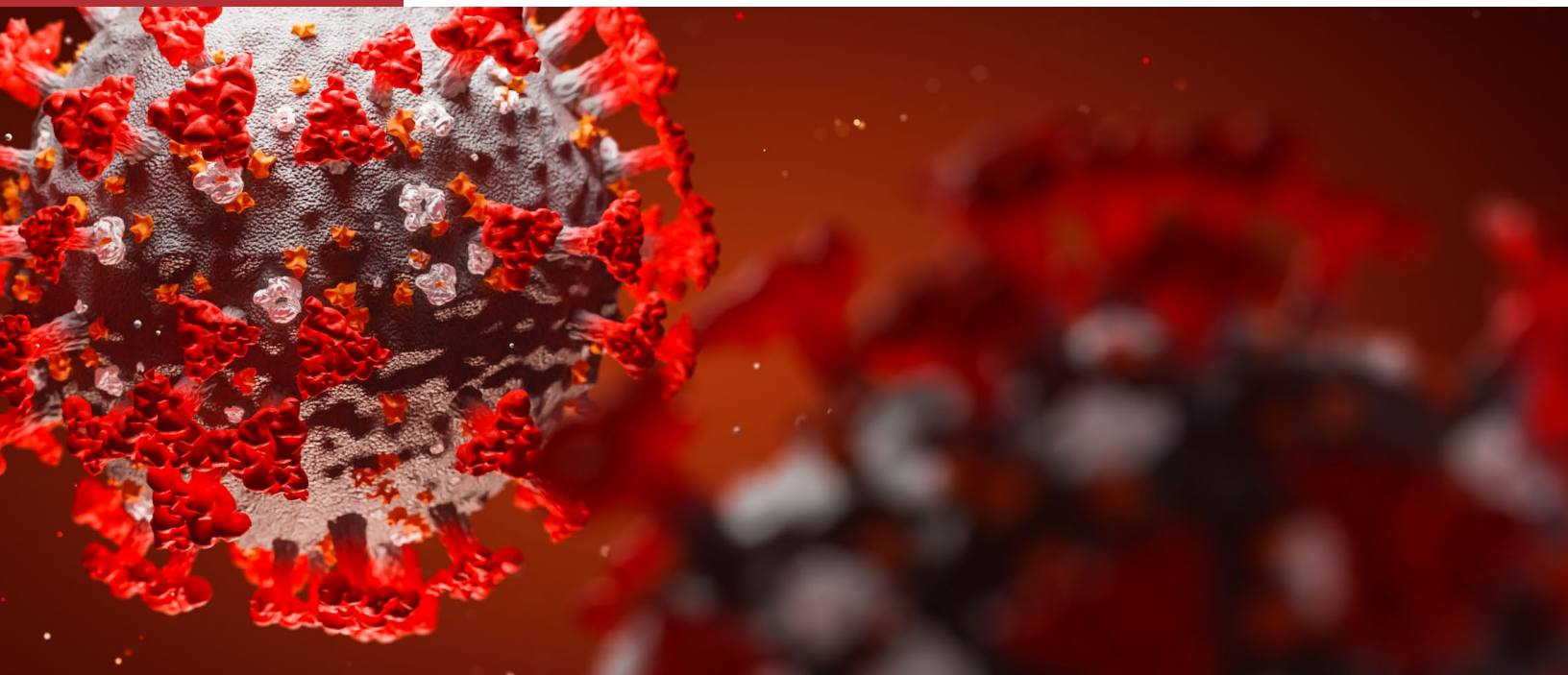


# Impacts to State Newborn Screening Programs from SARS-CoV-2 Pandemic

A summary of survey results and next steps



FEBRUARY 2021

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## BACKGROUND

On February 3, 2020, the United States declared a public health emergency in response to the coronavirus outbreak. In the weeks and months that followed, newborn screening (NBS) programs began seeing the impacts of the pandemic on various aspects of the NBS system. Messages posted to the Association of Public Health Laboratories' (APHL's) NBS listservs described staff reassignments to assist with COVID response, shortages of supplies, delays in specimen transport and receipt, and still countless other ways that NBS programs were being affected by the pandemic. APHL's Newborn Screening and Genetics (NBSG) program initiated a new series of national webinars—these “Hot Topics” webinars would take place monthly and provide an avenue for NBS programs to address one aspect or area of impact from the pandemic (e.g., staffing and telework, biosafety of specimens, best practices for remote follow-up work, etc.). In addition, all NBS committee, subcommittee and workgroup calls began to include updates on reagent and supply shortages resulting from the pandemic as a standing agenda item. These discussions highlighted the need for a measurable approach to collecting this information, to facilitate addressing supply shortages and other state needs in an organized and coordinated effort rather than state-by-state.

## THE SURVEY

Committee discussions revealed that the pandemic was affecting NBS laboratories and follow-up programs differently—even within the same NBS program—highlighting the need to allow multiple survey responses per program. Survey questions were developed with input and guidance from APHL's NBS committee membership. The survey was distributed to all state and territorial NBS programs including Washington, DC, Puerto Rico and Guam (53 programs total) using the Survey Monkey platform, and was open for three weeks in November 2020. Forty-five survey responses were received in total, representing 34 NBS programs: 11 states submitted responses from both their NBS laboratory and follow-up program, and 23 states submitted one response from either their NBS laboratory or follow-up program. Although the original intent of the survey was to gather information on specific reagent and supply shortages, the scope of the survey was expanded to include questions on the pandemic's effect (if any) on staff, information technology (IT) resources and support, specimen transport and support from vendors.



## TARGET AUDIENCE

NBS laboratory directors and follow-up supervisors in all 53 NBS programs.



## RESPONSES

Multiple surveys allowed per state to capture all relevant perspectives.

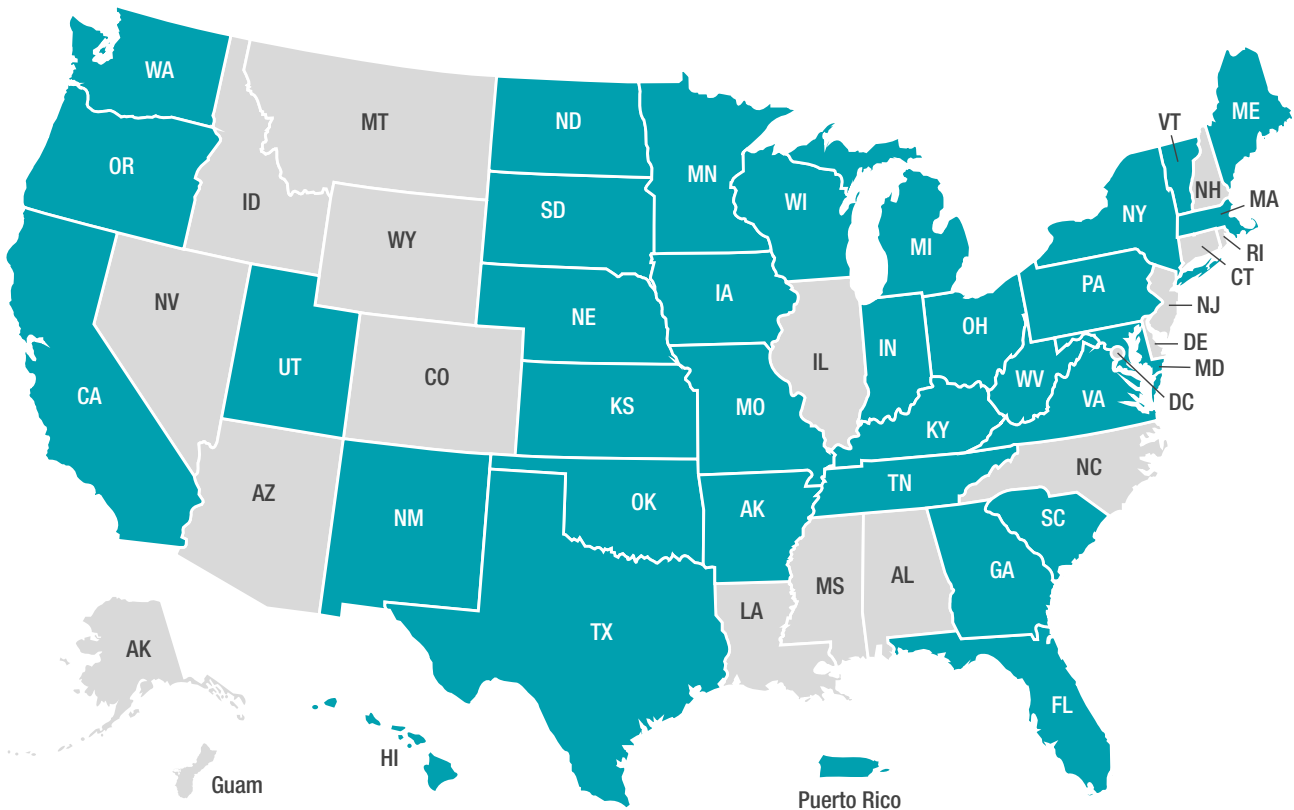


## RESPONSE RATE

34 NBS programs responded.  
45 survey responses received.

## PARTICIPATING STATES

States shaded in teal represent those that completed the survey. To protect the anonymity of the data, states that submitted multiple responses and those that submitted only one response are not differentiated.

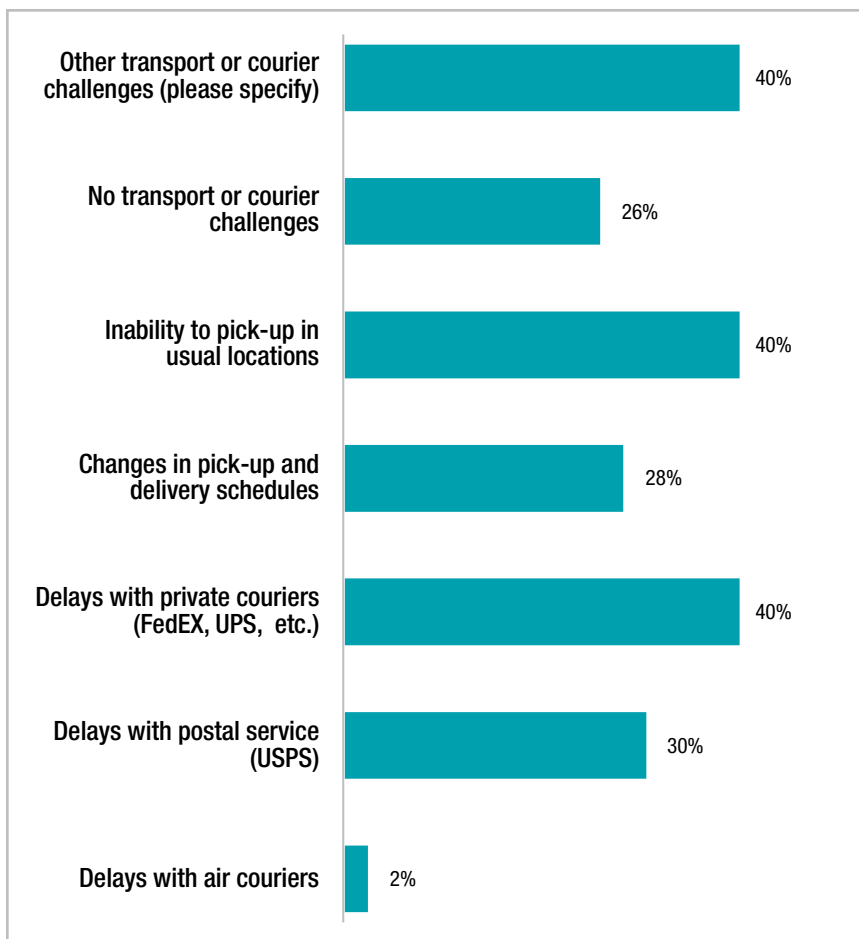


# RESULTS

Responses described a broad spectrum of effects across NBS programs on staff, IT resources and support, specimen transport, reagent and/or supply shortages, and support from vendors. For all multiple choice questions, respondents could select more than one answer. Text responses and/or “other” responses have been summarized into common themes as applicable for each question. Any identifying information included in text responses has been removed for the purposes of this summary report.

## 1. What transport and/or courier challenges have you encountered in your newborn screening (NBS) program during the COVID-19 pandemic? (n = 43)

The bar chart below shows the breadth and frequency of staffing challenges that NBS programs are reporting. The majority of programs are reporting delays with private couriers and issues with picking up specimens in the usual locations. Notably, 11 NBS programs reported no transport or courier challenges at the time of this survey. Two responses in the “other” category were omitted as respondents deferred to their counterpart in the lab.



### “Other” Common Themes:

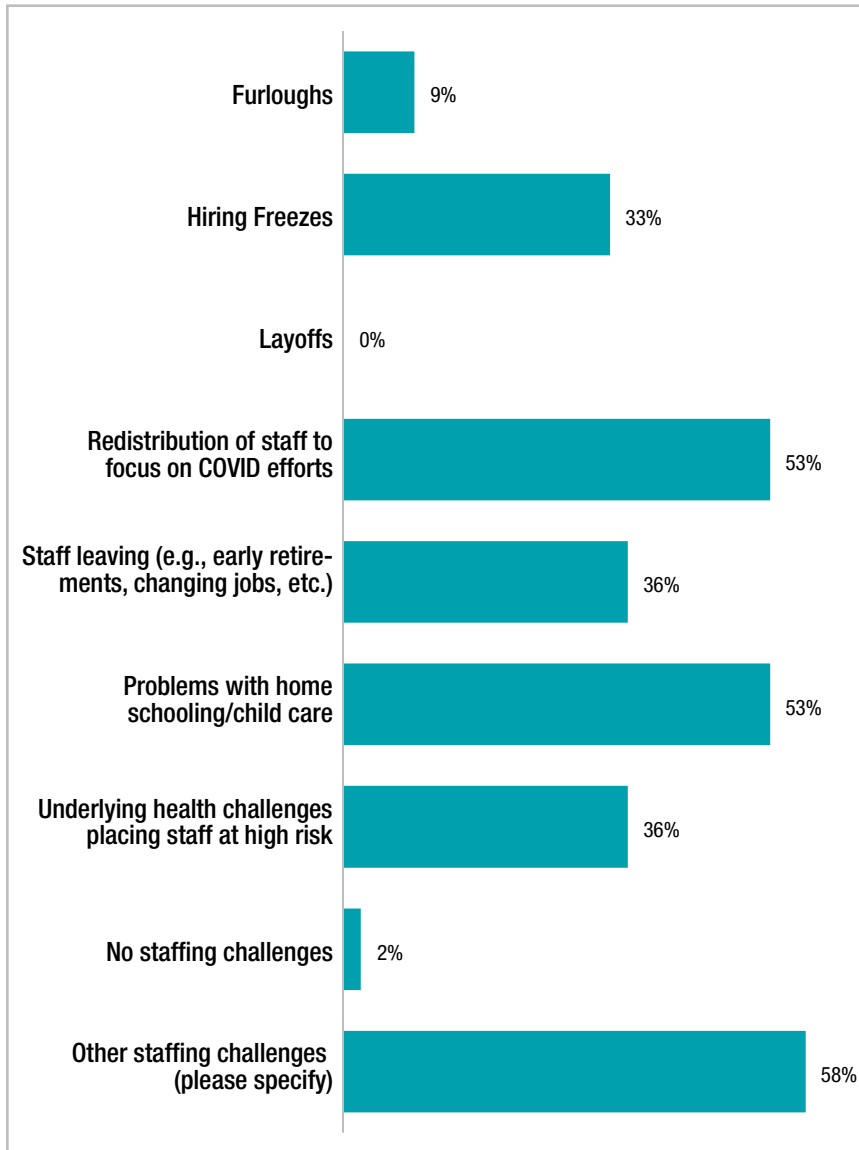
- Delays in picking up specimens due to screening checkpoints at hospitals/ facilities (3 or 7.3%)
- Lost or damaged specimens (2 or 4.9%)
- Inability to pick up due to hospital or facility closure (2 or 4.9%)



*We've had many challenges with FedEx due to the COVID-19 pandemic. During phone calls with our regional and local FedEx managers they have expressed to us that they're not able to maintain the high number of packages that are being sent. They've said that they've been at "peak" shipping since COVID-19 began in March, 2020. This has had a very obvious effect on newborn screening here in [state]. Specimens have been delayed, lost, damaged, repackaged and returned. It has been an ongoing issue that we continue to work through.*

## 2. What staffing challenges have you encountered as a result of the COVID-19 pandemic? (n = 45)

The bar chart below shows the breadth and frequency of staffing challenges that NBS programs are reporting. A majority of programs have had their staff reassigned to COVID response and many others are experiencing difficulties with home schooling and child care. Notably, one program reported experiencing no staffing challenges, and no programs reported having to lay off staff. Three responses in the “other” category were omitted from the analysis as irrelevant.



### “Other” Common Themes:

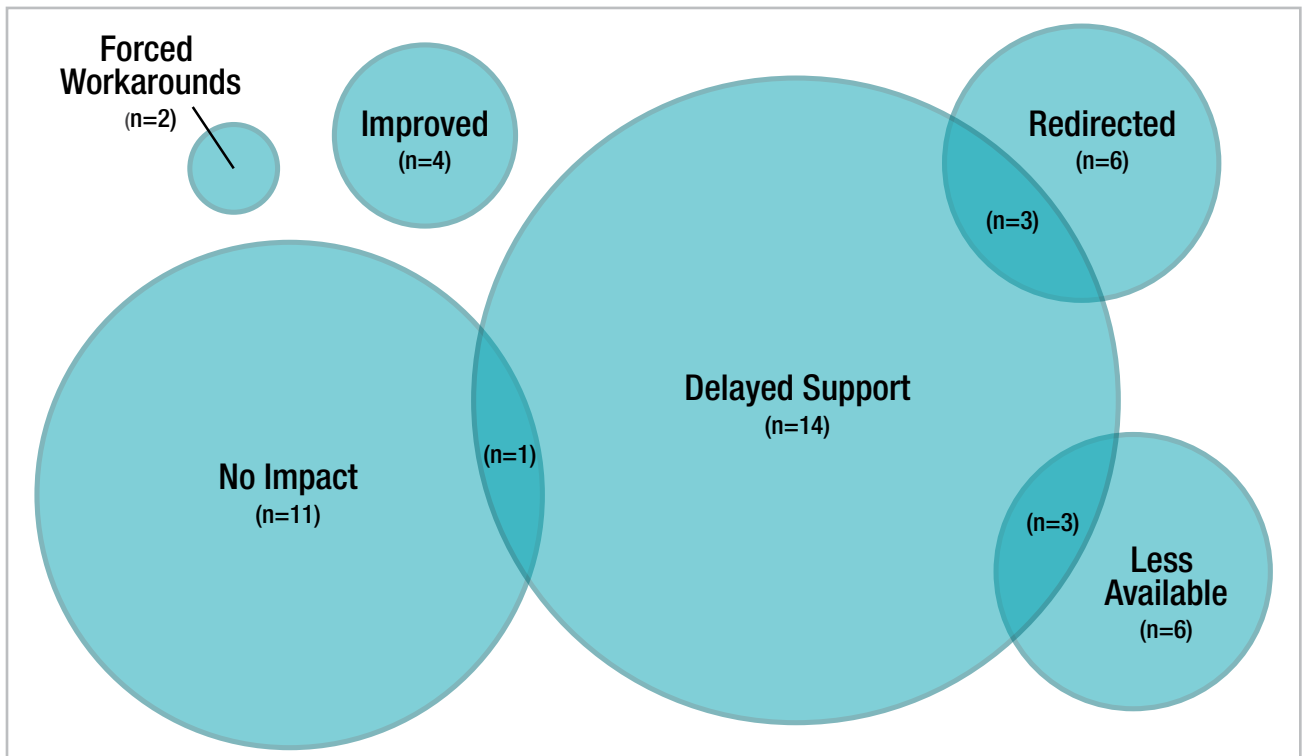
- Staff or their family members testing positive or exposed to COVID (8 or 19%)
- Morale/general anxiety (4 or 9.5%)
- Difficulties training new staff remotely (4 or 9.5%)
- Issues working from home (3 or 7.1%)
- Staggered shifts and/or social distancing resulting in slower/longer workflows (3 or 7.1%)
- Difficulty of staff getting to work due to cancellations or changes in public transportation (2 or 4.8%)



*Split staff into two isolated teams to better protect team members and prevent shut-down of unit [with] several staff members [having] to be quarantined at once. It's been a challenge to maintain functions while working with 50% of the unit in the laboratory at any given time. We were hoping to bring all staff back in January [2021] to have more available staff to begin validations for x-ALD and a new HPLC system, but that is looking less likely right now.*

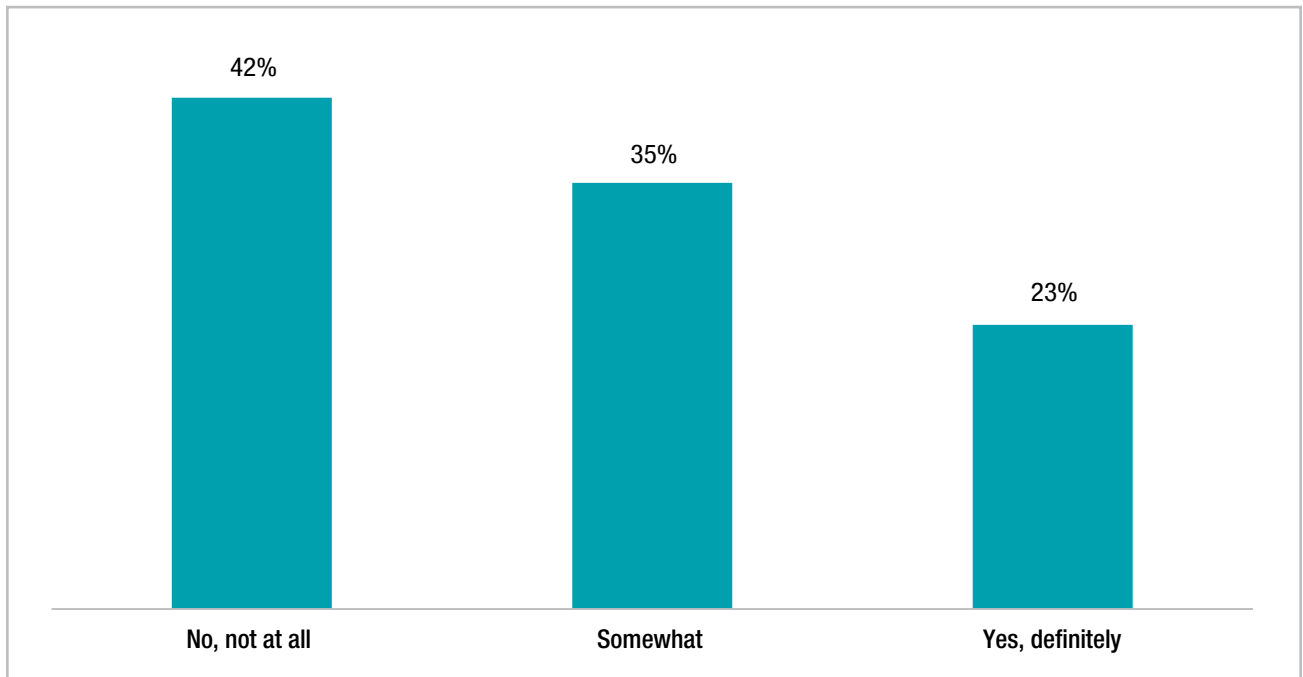
### 3. How have information technology (IT) resources and support for NBS been impacted as a result of the COVID-19 pandemic? (n = 39)

The Venn diagram below depicts common themes pulled from the text responses for this question. The majority of respondents (n= 14 or 38.9%) mentioned that requests for IT support have been delayed. Eleven programs (30.6%) noted that there has been no change to their IT resources or support for NBS, with one of those programs noting initial delays felt in the first months of the pandemic and a resumption of normal service since then. This is represented in the overlap between “no impact” and “delayed support.” Six programs (16.7%) mentioned a decrease in availability of IT resources and support, with three of the six also noting that requests for support have been delayed (see overlap). Another six programs cited that IT staff have been redirected or reassigned to focus on COVID response, with three of the six again noting that this has resulted in delayed support (see overlap). Four programs (11.1%) reported an improvement in IT services and two programs (5.6%) noted that either the program or the staff have had to implement other solutions to circumvent IT issues. Specifically, one program reported that staff are using their own personal equipment for work to overcome a lack of state-issued equipment despite telework requirements, and another noted that the program had to implement paperless processes and reporting sooner than planned, also due to telework requirements. Three of the 39 responses were omitted from the analysis as irrelevant.

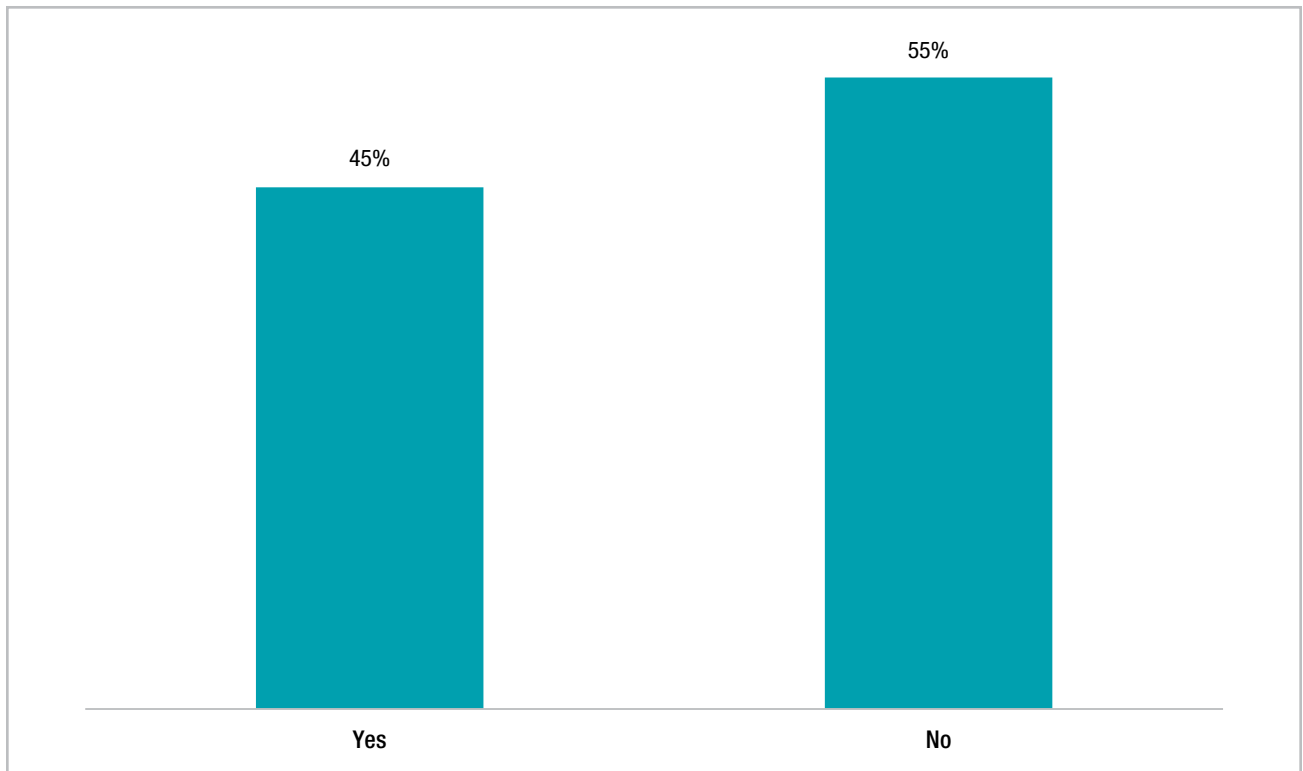


*IT resources and support (including staff) are focused on the COVID-19 response efforts. We have not been able to move forward with planned IT projects, and staff who are re-deployed to COVID roles will not likely be available at regular capacity until June 2021.*

4. Has your NBS program experienced challenges with accessing clinical providers, specialists or NBS coordinators during the COVID-19 pandemic? (n = 43)

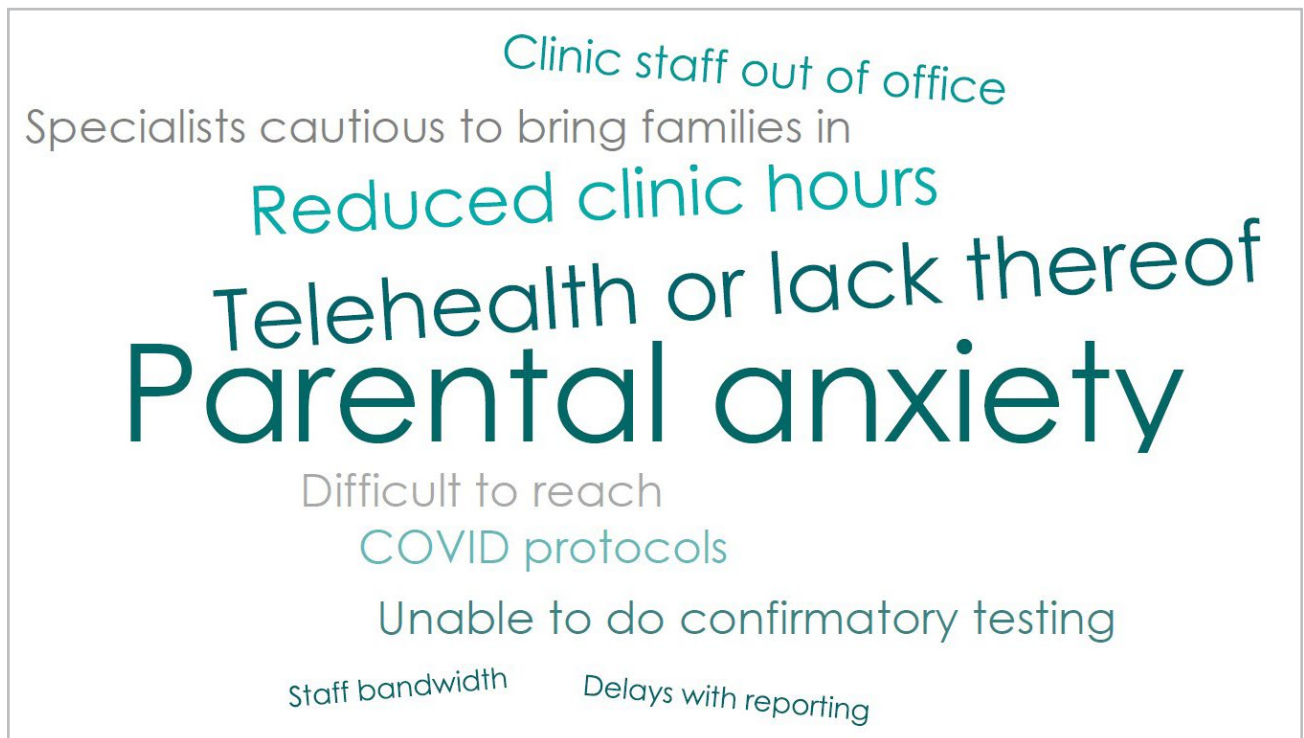


5. Has your program heard from clinical providers that they have difficulties completing evaluations in a timely manner? (n = 42)



**6. If yes to 5, list reasons you have been given. (n = 22)**

The word cloud below depicts themes and individual responses submitted for this question, with font size weighted according to frequency of response. Of the 22 responses, two were omitted from the analysis as irrelevant or not applicable. Parental anxiety was the most frequent reason for delayed evaluations; 15 programs (75% of responses) cited parental concerns or anxiety around bringing an infant in for an office visit during the pandemic. Reduced clinic hours appeared in five (25%) responses. Lack of telehealth services, as well as requirements around telehealth visits were both cited as reasons for delayed evaluations and appeared in four (20%) responses. Difficulty in reaching either providers or families were reported by four programs (20%), with three of those programs citing that providers were more difficult to reach and one program citing that clinics were having a hard time reaching families. Four programs (20%) mentioned that specialists were being cautious to bring families in. Inability to do confirmatory testing (see illustrative quotes below) was mentioned by three programs (15%). Delays with reporting and staff bandwidth each appeared in one (5%) response.



*One major specialty referral facility implemented a blanket policy that no labs would be drawn that required send-out to a referral lab (purpose was to decrease on-site visits that could theoretically be handled by primary pediatricians).*



*For babies deemed to be at lower risk, perhaps because of their particular result or the disorder they were positive for, their evaluations were put off to a later time felt to be safer. Parents are reluctant to bring babies out in public at all, let alone into a healthcare setting where the risk of exposure is thought to be higher. Some parents rely on public transportation and didn't want to bring their babies out. Some labs were converted to only COVID testing making accessibility more of an issue.*

## 7. What new reagent, supply, or equipment shortages is your NBS program currently experiencing as a result of the COVID-19 pandemic? (n = 38)

The table below lists the responses provided in order of frequency for this question. Of the 38 responses, 14 “not applicable” responses from follow-up staff were omitted from the analysis. Responses varied greatly in level of detail, as seen below. Notably, five laboratories (20.8%) reported experiencing no supply shortages of any kind at the time of this survey. Pipette tips, liquid handling tips, and plates (unspecified manufacturers and product numbers) were among the most frequent responses. It should be noted that in January 2021, APHL NBSG program staff reached out to NBS programs to ascertain specific pipette tip shortages, including manufacturer and product number information in an attempt to pursue a centralized solution to procurement for essential testing services.

Product or Service	Frequency	Percentage
Pipette tips (unspecified)	6	25%
None	5	20.8%
Liquid handling tips (unspecified)	4	37.5%
Plates (unspecified)	4	37.5%
Gloves	3	12.5%
Reagents (unspecified)	3	12.5%
Instrument servicing	2	8.3%
Disinfecting reagents (e.g., bleach)	2	8.3%
Personal protective equipment (PPE) (unspecified)	2	8.3%
RT-PCR primers and probes	2	8.3%
96 well plates	1	4.2%
384 well plates	1	4.2%
300 µL filtered sterile clip tip pipette tips (Fischer)	1	4.2%
Chemical fume hood (needed to implement testing for Pompe and MPS I)	1	4.2%
Consumables (unspecified)	1	4.2%
Disposable lab coats	1	4.2%
Envelopes	1	4.2%
Plate covers for cystic fibrosis (CF) DNA testing	1	4.2%
Reagent grade sodium hypochlorite	1	4.2%
Spinal muscular atrophy (SMA) qPCR reagents	1	4.2%



*Tips! Tips! Tips! And plates.*

*We had to delay training for X-ALD screening by 14 weeks last spring, and then had to wait again for repairs to the equipment for X-ALD. This has delayed validation of the assay by about five months.*



**8. What additional resource shortages (e.g., funding cuts, budget freezes, vendor support, human resources, etc.) is your program facing as a result of the COVID-19 pandemic? (n = 36)**

The word cloud below depicts common themes pulled from the text responses for this question (font size again corresponds to frequency of response). Human resources (HR) were the most common resource shortage mentioned; 12 programs (33.3%) cited ongoing HR issues, including hiring freezes or delays in recruiting and filling vacancies. Notably, nine programs (25%) reported no additional resource shortages aside from those listed in the previous question (three of these programs also reported no supply shortages in the previous question). Budget cuts, and delayed approvals for contracts or purchasing supplies were each mentioned in approximately 20% of responses (n=7 for each). Six programs (17%) mentioned travel restrictions in place, the large majority of which impacted vendor support for preventive maintenance or equipment repairs. One response mentioning travel restrictions pointed to an impact on hospital and provider trainings for NBS specimen collection. Five programs reported staff reassignments to focus on COVID response (13.9%). One of those programs cited this as the reason for two of their staff being exposed to someone who tested positive for COVID. One program (2.8%) mentioned a delay in implementation of long-term projects as a result of diverted resources across the agency to focus on COVID, and another program (2.8%) mentioned a space shortage in the NBS program caused by conversion of space normally used by NBS follow-up, to COVID testing.



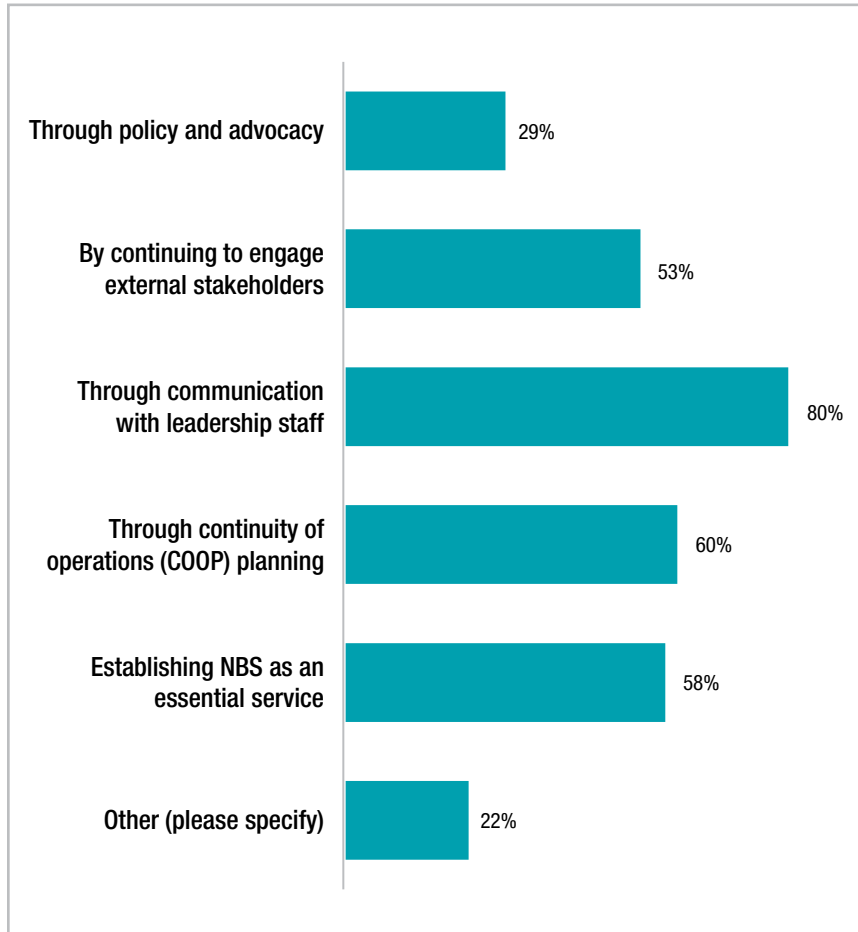
*It takes a long time to get orders processed and contracts if they are not COVID related. Special exception letters have to accompany orders/contracts for approval to be given to order. This adds weeks to months on an order.*

*75-80% of our entire state health department staff are reassigned to COVID-19 response roles, which means nearly every department and function within our health department has less capacity (and in some cases no capacity) to perform normal functions, including human resources, legal (contracts and data agreements), purchasing, facilities, etc.*



## 9. How is your program ensuring that NBS remains a priority during the COVID-19 pandemic? (n = 45)

The bar chart below depicts the methods that NBS programs are using to ensure that NBS remains a priority. A majority of programs reported that NBS is already considered an essential service and/or have enacted their continuity of operations plan (COOP).



### “Other” Common Themes:

- Already considered essential service (5 or 11.1%)
- Communication with leadership, human resources (HR), and/or clinics and primary care providers (PCPs) (2 or 4.4%)



*Our DOH is steeped in COVID response and that is the priority; for NBS the struggle is real.*

*I am completing this survey on behalf of our NBS Long-Term Follow-Up program, which is not considered a priority program within NBS unlike the laboratory and short-term follow-up program. Nearly 90% of our long-term follow-up team has been reassigned to COVID duties. Currently, about half of our team is reassigned 90-100% of their FTE to COVID, the other half of our team is reassigned 40-50% of their FTE. We continue to advocate with leadership and be involved in COOP planning, but it is difficult to negotiate and change our priority level in the middle of the pandemic response.*



## NEXT STEPS

APHL has activated its Incident Command System to support member laboratories, and APHL's Newborn Screening and Genetics (NBSG) program continues to explore opportunities to work with the Emergency Operations Center (EOC) to meet the need for supplies and reagents in NBS laboratories.

APHL's NBSG program will also be working with the NBS Committee to prioritize the activities below that would be most impactful and helpful to NBS programs in preparing for the next emergency event.

Planning Activities	Testing Activities	Implementation Activities	Feedback Loop
<ul style="list-style-type: none"> <li>• Work with states to update existing COOPs and work with states who do not have a COOP to develop one.</li> <li>• APHL Hot Topic Webinar on COOP landscape: pre-pandemic, gaps revealed by pandemic, barriers in being agile to address those needs.</li> <li>• Develop a manuscript or host a national webinar to share barriers and solutions to effective COOP.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide direct funding to states to test and enhance their COOP.</li> <li>• Host national COOP test events comprised of small cohorts of states and develop case studies from findings and results.</li> <li>• Host national COOP workshop on plan development, modifications and testing. Include access to a simulation NBS laboratory.</li> <li>• Host unannounced national COOP drill days on a semi-annual basis.</li> </ul>	<p>Establish a COOP experts review (SWAT) team comprised of individuals who can assist states that request COOP-related technical support for developing and strengthening their respective contingency planning documents.</p>	<ul style="list-style-type: none"> <li>• Report gaps and needs as identified to the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC).</li> <li>• Work with the Association of Maternal and Child Health Programs (AMCHP) and other national stakeholders to develop pandemic-related appendices to the national NBS contingency plan.</li> <li>• Connect with vendors to discuss how they solve for supply chain or testing problems revealed during the pandemic.</li> <li>• Collaborate with APHL Public Health Preparedness and Response (PHPR) program to update public health laboratory COOP templates.</li> <li>• Routine outreach to APHL member programs to review needs and limitations.</li> </ul>

Newborn screening programs routinely find ways to be resourceful in the face of urgency. In the months since the pandemic, as supply shortages and hiring freezes have been felt acutely by NBS programs, we have heard a number of examples of this resourcefulness. One NBS program director crossed state lines to replenish her laboratory's supply of skirted plates, another laboratorian developed a wash solution to reuse pipette tips, and a number of programs enacted their COOP or were by other means able to maintain their staff and continue newborn screening operations. It is our goal for every state to have a newborn screening COOP in place once states are able to resume normal operations. Emergency preparedness is part of APHL's role in supporting member laboratories to perform at their best, so that programs can focus more on the work of newborn screening without needing to compete for resources.

## Association of Public Health Laboratories

The Association of Public Health Laboratories (APHL) works to strengthen laboratory systems serving the public's health in the US and globally. APHL's member laboratories protect the public's health by monitoring and detecting infectious and foodborne diseases, environmental contaminants, terrorist agents, genetic disorders in newborns and other diverse health threats.

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8515 Georgia Avenue, Suite 700  
Silver Spring, MD 20910

Phone: 240.485.2745

Fax: 240.485.2700

[www.aphl.org](http://www.aphl.org)