

Analyzing Patterns in NewSTEPs Site Review Recommendations: The Big Picture for Newborn Screening Programs

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⁴Retired ☺



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Objectives

- Share the outcome of the site review analysis (i.e., top needs identified).
 - Identify actions states can take to strengthen their newborn screening programs
- Be proactive - Get ahead of the media by highlighting common issues programs are experiencing



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Overview of Methods

- Reviewed the 7 site review reports
- Interviewed 3 experts who had been on more than 1 site visit
 - Lab
 - Follow-Up
 - Physician



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How to Strengthen Your Newborn Screening Program



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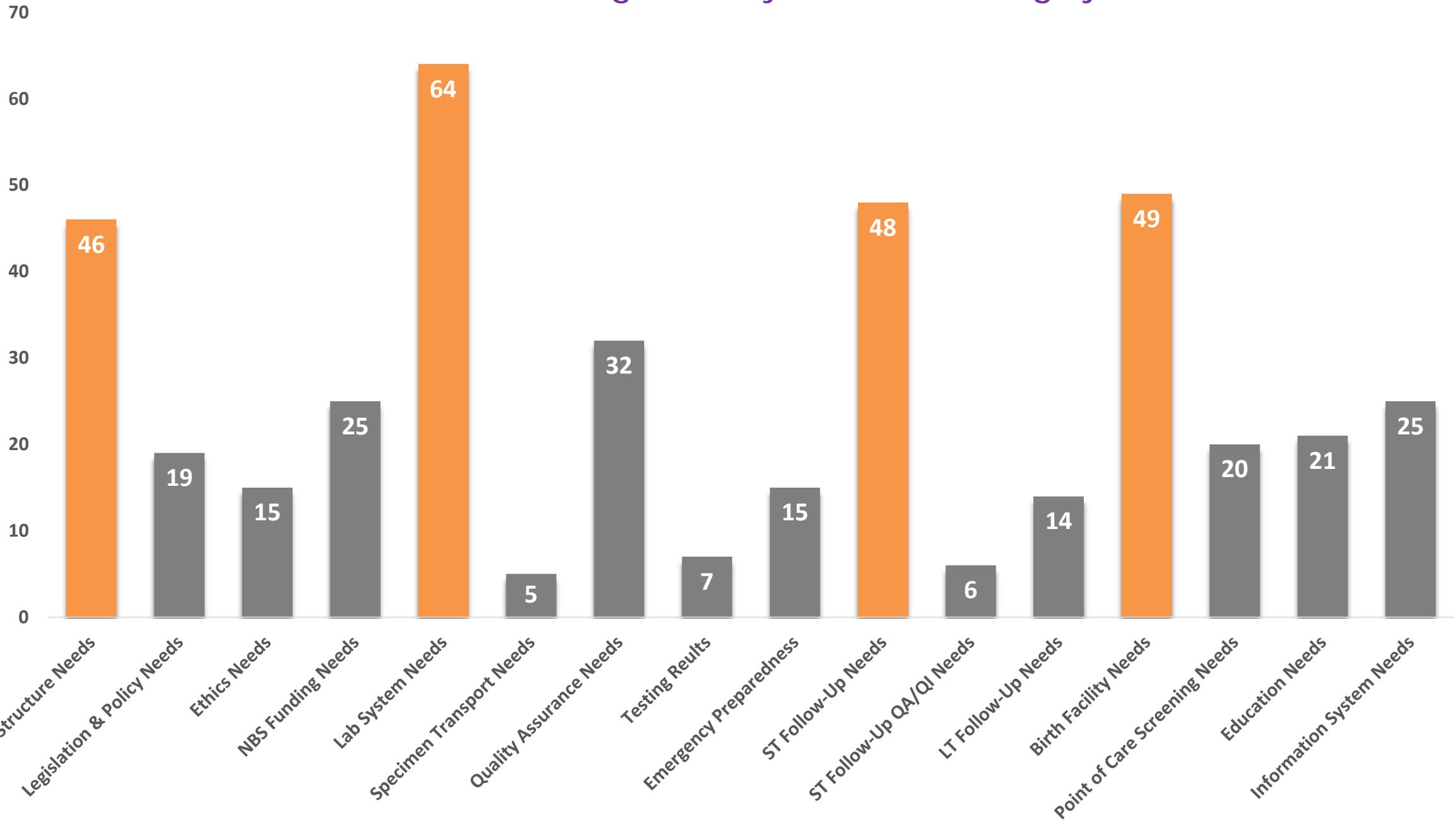
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Total Count of Newborn Screening Needs by Site Review Category





Communication

Information
Technology



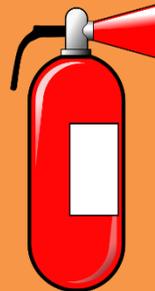
Education



Organizational
Structure



COOP



Funding &
Policy



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Communication Within State NBS Program



- Need to improve communication between laboratory and follow-up
 - Lack of regular meetings between the two parts
 - One part of NBS program was not aware of actions taken by other part
 - Lab and Follow-up are not aware of other's workflow

“There are not, however, regular in-person meetings between laboratory and follow-up personnel which could be valuable to discuss updates, programmatic issues, etc.”

“Seems to be there is some lack of communication from Lab to LTFU, specifically they stopped testing for [condition] which had an impact on the LTFU team, but [the lab] did not notify them of this change.”



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Communication Around Quality Assurance



- Need better communication to aid quality assurance
 - Difficulty with follow-up reporting out-of-range results back to the lab
 - No communication around out-of-range results to lab
 - Specialists wanted to be part of the Quality Assurance process

“[Follow Up] are careful and notice patterns when they occur and provide that feedback to the lab. Though there is some confusion on who they should be working with when these patterns are noticed.”

“Specialists noted that some important decisions impacting their care provision were made unilaterally by the program without appropriate input from the specialists.”



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Communication with Partners Outside the State Newborn Screening Program



State NBS program needs to communicate better with:

- Specialists
 - Specialists wanted to understand how programs were screening for conditions
 - Specialist wanted to provide input to ACT/FACT sheets
- Hospitals
 - Hospitals in more than half the sites said they did not receive out of range results communications or when a baby was identified with a condition
 - Hospitals felt communication was lost because the NBS Program communicates with part of the hospital system but not the whole system

“Specimens are collected by the nurses in the NICU but they do not receive copies of the report card which is only sent to the hospital lab”

“Hospital staff want to know how many newborns were identified with a condition through NBS”



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Information Technology (IT)

- Lab and Follow-Up IT systems needs to talk to each other
- LIMS system is often under-utilized or the full features are not being utilized

“The lab does not have access to the [data] site that is used by follow-up staff and hospitals for reporting outcomes of out-of-range results as well as false negatives. The lab hears about the final ascertainment as true positives only during the monthly meeting with the specialist group for that month.”

“. . . although it takes less than three days to complete all testing, there are four to five days of delays to report out results after all testing are completed. These delays, caused by limitations on staff and lack of a centralized LIMS system. . .”

“The [vendor] Laboratory Information Management System (LIMS) is not being utilized to its capacity”



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Education



- There is a need to provide education to newborn screening partners
 - Provide more training to hospitals
 - Provide consistent training to hospitals
 - Ensure up-to-date and accurate education materials for hospitals and specialists
 - Make it easy for them to get
 - Do not assume they can find them on your website
 - Do not assume they know materials were updated

“Staff is very interested in receiving educational interventions to learn more about NBS and in quality improvement projects around specimen quality, timeliness, and outcomes”

“was noted that the [state] NBS program websites are difficult to navigate and that [hospital] staff would like easier access to educational materials. . .”



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Education



- Need To Remember To Educate Others Within The State NBS System
 - Cross training within a unit
 - Both parts of the newborn screening program educate each other on workflow and procedures
- Need to Provide Just-In-Time Education to Parents of Children with Out of Range Results.

“The Laboratory does not cross-train all staff to do all tasks (testing and reporting).”

“Consider sending out fact sheets for families and providers with each result”



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Continuity of Operations Plan

- Need To Ensure The Program Has A COOP
- Remember To Review The COOP At Least Annually
- Practice And Test Using The Emergency Plan On A Periodic Basis
 - The whole newborn screening program should do this
 - Lab and follow-up should practice together and share COOP activities

“data backup is housed on same campus which is problem in emergency”

“routinely perform tabletop and functional exercises to ensure all program staff can comply with the emergency procedures.”



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Standard Operating Procedures, Regulations, & Rules

- Need to Review SOPs, Rules, and Regulations at least annually
- Issues to consider for SOPs
 - Guidance to establish specimen age
 - A way to monitor/track specimen receipt

“Develop a policy for reporting out-of-range results to the NICU”

“The regulations were last updated in 2011 and, while currently under review for revisions are outdated with regard to terminology and NBS systems, and would benefit from a complete re-write by the Program leadership staff.”

“Currently, there are is no system in place, or policy manager role, to ensure compliance with current rules”



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Tools NewSTEPs Can Provide Right Now



- ✓ Site Reviewer Manual
 - Use for table top exercise
- ✓ Request Targeted Site Reviews
 - Cut-off Specific
 - Long Term Follow-Up
- ✓ Resource Page on the NewSTEPs Website
 - NewSTEPs, NewSTEPs 360, and Baby's First Test are working on a list of educational videos so states do not have to re-create educational resources
- ✓ NewSTEPs Technical Assistance Webinars



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Next Steps

- NewSTEPs will work to publish all the findings of the review
- NewSTEPs Steering Committee and program staff have had a presentation on the findings
 - We are working to identify what Technical Assistance can be done that is consistent with the lessons learned from this review.
- NewSTEPs will look at lessons learned from other programs that can help states
 - NewSTEPs 360
 - SCID
 - New Disorders



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Next Steps

Some TA NewSTEPS is already working on:

- ✓ NewSTEPS is currently working on a position statement around Long Term Follow Up which should be helpful for programs looking to establish a Long Term Follow Up program
- ✓ NewSTEPS can help states
 - Work on cost assessment with regards to adding a new disorder
 - Think through engaging policy for fee increases



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- State Programs Who Have Had Site Reviews
- Site Review Teams
- NewSTEPs Steering Committee
- NewSTEPs Team



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APPENDIX – In Case Questions Come Up



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Needs Programs Have Little to No Control Over



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Organizational structure

- Lab and follow-up have different reporting structures
- Lab and follow up are not co-located
- Attrition/ Staff retention is difficult
 - Lab
 - Follow-Up
 - Information Technology
 - Quality Assurance
 - Statistics

Quotes: **“ . . .both the lab and follow-up services are understaffed and have had a hard time retaining strong employees because of the inability of the units to reallocate staff to higher level positions and provide well-deserved raised”**



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Budgeting



- Programs asked for or were recommended to seek assistance calculating budget fee increase or procedure for fee calculation
 - Cost of covering new conditions is difficult
 - How many FTE
 - Engaging with policy group now to work on this for adding new disorders

Quotes: **“These unfunded additions [new disorders] have strained the system and increased NBS costs, making it more difficult to fulfill the core duties fundamental to a NBS program”**



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Other Issues

- Short-Term Follow Up needs a way to track loss/lost to follow up
 - Is there someone who can help? Can the Follow Up group have a training on this?
- Long Term Follow Up
 - A little less than half had no LTFU program or were not getting LTFU data
 - Only came up in 1 presite review but again they could only list 3



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Cross Cutting Themes

