

Laboratory Standards and Procedures Workgroup Members

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Laboratory Standards and Procedures Workgroup Discussion Questions

At the August 2021 ACHDNC meeting, APHL outlined challenges facing the NBS laboratory and follow-up workforce and resources that have been used to address those challenges.

1. Are there other resources that have been used at the state/national level to address laboratory workforce challenges?
2. How could those resources be expanded to further strengthen the NBS laboratory workforce?

- APHL Workforce Workgroup (started Sept 2019) trying to address the workforce issue
 - Goals include:
 - Examine each program
 - Identify critical components common to all programs
 - Develop APHL position statement that lays out critical components of NBS programs that every program needs to staff, at a minimum
- Fellowships – already expanded, could be expanded more
 - APHL
 - ACMG added a fellowship in laboratory genetics and genomics
- Grants – come with administrative burden

- Pay - Need increase across the board to compete with other industries/laboratories
- Incentives
 - Paid training where you owe X years of work after graduation/degree
 - Loan repayment programs, e.g., public servant repayment after 10 years
 - Pay for classes/degrees through the public university system
 - Telework
- In states that require clinical laboratory certification/licensure, extend exemptions for public health
 - Often employee earns certification and then leaves
- Mentoring help for programs that don't have people/time to help with development

- There could be a cooperative agreement between federal government and public health laboratories for NBS, similar to programs such as Public Health Emergency Preparedness (PHEP) and Epidemiology and Laboratory Capacity (ELC). Additional funding would be needed to support the following:
 - The cooperative funding could be provided to fund activities, that include funding FTEs, in exchange for meeting goals/recommendations around NBS (e.g., quality assurance, timeliness, follow-up), perhaps those that come from the ACHDNC
 - Could include a governance structure, similar to ELC/PHEP, that requires staff from across the program to come together. This plan could facilitate tackling program issues and perhaps longstanding issues with the newborn screening system
 - Helps to build infrastructure, may help tackle some of the disparities between states
 - Fold administrative piece into the agreement

Workgroup Discussion Questions

All Workgroups:

- Should the Committee consider the availability of follow-up experts (clinical, follow-up, public health, laboratory, etc.) when reviewing a new condition nominated to the RUSP? How could that information be collected? What role could the Committee play in calling attention to identified shortages of follow-up experts?

- For conditions in a new area, this information is more important to collect e.g., SMA (neurologists) vs. rare metabolic conditions
- Do we have a good test?
 - Robust pilot studies along with a test with very good PPV - know that babies that are being referred will need care, fewer false positives
- Inquire whether there are disparities in specialists – some states may have no specialists or they're located in one part of the state
- Could the survey ask if the state has the capacity for certain number of hours per child per specialist or genetic counselor?
- Per ACMG survey, 2x Geneticists are needed for current workload
- Bottom line - states just make it work. (Is there a condition that a state had difficulty screening for due to availability of specialists?)