

FOLLOW-UP Survey of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children's Public Health System Assessment

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IMPLEMENTATION PROCESS

1. The first few questions deal with the implementation process and some of the decisions your program had to make. In what capacity are you screening for Condition X? How long have you been screening?
2. *(States with mandate)* If you have not started screening, when do you plan to start?
3. *(States that are in the pilot stage)* How long do you anticipate to be in a pilot phase? Was this planned? Please explain.
4. Please tell us how you implemented/plan to implement Condition X.
5. *(For States that have started screening)* After having gone through this process, was there something you would have changed?
6. *(For States that have started screening)* Did you have any surprises with implementation? Please explain.
7. What has been/will be the most significant barrier to screening for Condition X?

8. Is there something specific to your program that has/will aid in implementing screening for Condition X?

METHODOLOGY

9. The next few questions deal with screening methodology. What methods are you using/do you plan to use to screen for Condition X?

10. Why did you choose x method?

11. Please explain what new equipment you needed to/will need to procure for this method?

12. (*If screening has begun*) Are you getting the outcomes you expected with this method? Please explain why or why not.

13. Have you had to adjust your cutoff? If so, why? Has this changed your outcomes?

14. Do you have concerns with the method you are using/planning to use? Please elaborate.

15. Will you continue using this method? Explain.

TIMEFRAME

16. In an attempt to better understand timeframe for a variety of implementation activities we would like to know how long it took/will take you to do the following (**answer options < 1yr., 1-2 yrs., 2-3 yrs. >3 years**):

- Obtain and procure equipment for screening
- Hire necessary laboratory and follow-up staff
- Consult with medical staff and specialists
- Select, develop, and validate the screening test within your laboratory
- Add the screening test to the existing outside laboratory contract
- Pilot test the screening process within your state, after validation has taken place
- Implement statewide screening for all newborns, including full reporting and follow-up of abnormal screens after validation and pilot testing
- Entire process from obtaining equipment to implementing statewide screening (assuming that some activities occurred simultaneously)

17. What advice do you have for other state NBS programs in order to ensure smooth and timely implementation?

PERSONNEL AND FOLLOW-UP

18. The next few questions are more specific and deal with personnel requirements and follow-up issues. Do you have staffing concerns with screening for Condition X? If so, what are they?

19. How many FTEs and what level (education/experience) do you have for screening for Condition X (technical only)?

20. This question pertains to follow-up. Do you have concerns with short-term and long-term follow up for Condition X? If so what are your concerns?

CONCLUSION

21. That concludes the formal part of the interview. Do you have anything else to add?

22. Name of respondent, title, how long in position.