

Supporting Statement B

The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children's Public Health System Assessment Surveys

OMB Control No. 0915-0014

B. Collection of Information Employing Statistical Methods

Statistical methods will not be used to select respondents. All 59 states/territories will be asked to fill out the initial survey. States that are already screening for the nominated condition as part of the state's routine newborn screening (NBS) panel, are doing research and/or examining pre-live reporting results for the condition, or have received a mandate to screen for the nominated condition are excluded from the initial survey. Question 1 on the initial survey serves as an eligibility question. If a state checks any of the first three responses they are not eligible for the initial survey. Those states (up to 30) that were excluded from the initial survey will be contacted to participate in the follow-up survey. Due to the range of birth rates and populations across the U.S. and the variability of state newborn screening programs, it is preferable to collect information from as many states as possible. The Advisory Committee on Heritable Disorders in Newborns and Children (Committee) is interested in the public health impact assessment for all states so that they make a well informed recommendation to the Secretary of Health and Human Services.

2. Procedures for the Collection of Information

The initial survey questions will be programmed into Qualtrics, an online survey platform. All responses will be collected electronically. For the follow-up survey, respondents will have the option to electronically submit via email their responses or be interviewed via phone. The follow-up survey contains open ended questions so an option was added to conduct interviews over the phone as a way to help ease any burden States may face in reporting their information.

3. Methods to Maximize Response Rates and Deal with Nonresponse

Email notification will be sent out to all 59 states/territories inviting them to a webinar on the public health impact assessment for a nominated condition. A webinar will describe the purpose of the surveys and how the Committee will use the information to assist in their decision making process. The webinar will also explain the survey instruments and provide background information on the nominated condition. Within a week of the live webinar, the webinar will be archived on a public website so that states can view the webinar at a later time. On the day of the webinar, a unique survey link to the initial survey will be sent out to all state/territories. The unique survey link will ensure that only one response per state/territory is submitted. The survey email will emphasize that the individual completing the survey should collaborate with necessary stakeholders (e.g., laboratory experts, follow-up staff, medical specialists, Title V directors, advocates, public health commissioners) prior to completing the survey link. States that already screen for the nominated condition as part of the state's routine newborn screening (NBS) panel, are doing research and/or examining pre-live reporting results for the condition, or have received a mandate to screen for the nominated condition are excluded from the online initial survey. Those states (up to 30) will be contacted to participate in a follow up survey administered by phone interview or in writing via email.

The online survey will remain open for a minimum of 5 weeks to ensure the highest response rate possible. To improve response rates, after the third week of the survey launch, any non-responder will be contacted via email followed by a phone call during the fourth week if still no response.

The contractor anticipates a response rate of between 70 - 80%. This calculation is based on the expertise of the contractor, the contractor's close partnership with all newborn screening programs across the U.S. and the contractor's previous survey work that included similar methodology.

4. Tests of Procedures or Methods to be Undertaken

HRSA received input from Committee members, the contractor implementing the surveys, and five state newborn screening programs. Based on pilot testing of both surveys, respondents indicated a median time of 10 hours is needed to complete the initial survey and 2 hours to complete the follow-up survey.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

1) Designed the data collection

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2) Collect the data

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3) Analyze the data

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