

9.27 EnRICH Questions and Comments

1. Do you have examples of data publications or products that states have developed using their NSCH data?
 - Examples of state-focused analyses and publications are available at www.childhealthdata.org.
2. Are there costs associated with accessing data via the Research Data Centers (RDCs)?
 - Yes, but costs may vary. Please visit [Federal Statistical Research Data Centers \(census.gov\)](https://www.census.gov) to learn more and find the RDC closest to you for more specific information.
3. How can I get involved in the study? I want to be able to help gather data.
 - HRSA MCHB partners with the US Census Bureau to field the NSCH, as such it is not a process that individuals, groups, or organizations can support through data collection. The best way to get involved with the NSCH is to use the data. Please visit www.childhealthdata.org for easy access to a user-defined query system or download the microdata file [here](#). For more information on how households are sampled please see our [FAQ](#) or [Methodology Report](#).
4. Can you repeat what year the supplemental file for metropolitan Atlanta will be available?
 - The metro Atlanta supplemental file will be available October 2022.
5. Is there data on the racial or ethnic background of the children and families participating?
 - Yes, respondents provide information on the racial and ethnic background of up to four children in the household; one of these children is randomly selected to serve as the subject for the more detailed questionnaire. Please see our questionnaires [here](#).
6. Is there a question that might determine the impact of the Public Health Emergency (PHE) that states have utilized for their Medicaid and children's health program?
 - Unfortunately, no. Respondents to the NSCH are parents/caregivers and the data are designed to be representative of children. This precludes us from including questions that focus on topics such as state-level policies which cannot necessarily be accurately reported through this type of survey.
7. I think an early slide said the (web) survey (invite) goes to 70% of households. How are those households selected?
 - This information is available under the discussion of Mixed Mode (High Paper) vs. Web-Push (High Web) in the [Methodology Report](#).
8. CYSHCN is still a large and diverse population of children. Have you considered being even more targeted to children with medical complexity, a sub-population that is getting considerable attention currently?
 - While children with medical complexity are an important population, the NSCH is designed to provide information on a wide variety of topics for the entire pediatric population. As a result, it is not always possible to include the breadth or depth of

questions for special populations, like those with medical complexity. Having said that, there are a number of questions throughout the survey that can be used to assess the experiences and needs of this population. You might want to see the following [paper](#): *Identifying Children With Medical Complexity From the National Survey of Children's Health Combined 2016–17 Data Set*.

9. Is the Longitudinal Cohort going to be continued after the current planned cycle?
 - Although dependent on the availability of funding, it is our intention to conduct an additional wave of data collection approximately three years after the 2023 (wave 2) data collection. The logistics and materials related to another wave of data collection are currently in the planning phase.

10. How important do you think to incorporate the Mental Health Screening Tool in the school? How can county health departments provide support when it comes to mental health and other lingering factors of COVID-19?
 - We cannot provide a recommendation on the relative importance of including mental health screenings in the school setting. However, it may be possible for data users to assess the scope and nature of the burden of mental health conditions within their community using sub-state data which is available through the Census Bureau's Research Data Center (RDC). See question 2 for more information on RDC access.

11. Will the Longitudinal Cohort survey take any measures to ensure that responses are obtained families who were likely to be most affected in the areas of priority content (e.g, economic hardship) during the pandemic? I see that the NSCH Datasets include STATA data files. Is it considered a positive or negative to include STATA multivariate regression models on Grant Applications? Especially applications involving Maternal and Child Health, to look at trends to illustrate the relationship between variables.
 - The base sample of the NSCH-LC is nationally and state-representative and it is a priority to ensure that the retained follow-up sample is similarly representative. However, there is overlap between the characteristics of households who were most affected by the health, social, and economic stressors related to the COVID-19 pandemic and those characteristics associated with low response rates. To support response rates among these and other hard-to-reach households, the Census Bureau is investing resources into locating households who have experienced residential moves prior to the fielding period and will conduct multiple attempts to reach households who have not responded. Additionally, pending the availability of funding, we are planning a field-based follow-up strategy to reach households whom we could not reach using traditional mail-based methods.

Unfortunately, we are not able to provide guidance on what statistics to include in a grant application. Please contact the funding agency to inquire about any recommended strategies.

12. Has there been a study regarding postpartum depression and self-harm?
 - The NSCH does not address these topics.

13. You stated that you will measure family resiliency factors. Do you include anything about social support or informal safety nets?

- Yes, the NSCH includes questions on the presence and sources of day-to-day emotional support in raising children. See our interactive [codebook](#) to search for more information.
14. You mentioned that a question about suicidality will be added for the young adults. Is there any additional data collected on mental health (anxiety or depression) and COVID from the 3 age groups?
- The NSCH-LC will include a caregiver-reported question about suicidality only for the young adult sample. In addition to that, multiple mental health measures are included in all instruments, including depression and anxiety diagnoses and the severity of these diagnoses at the baseline wave (2018 or 2019) and the second wave (2023), caregiver-reported concerns about the child's or young adult's mental health during the pandemic, and a validated measure of internalizing and externalizing behavior problems in 2023 that is predictive of mental health problems.
15. I work with an organization that focuses on kids with neurological conditions (Child Neurology Foundation). I would be curious to know if the CYSHCN is connected to sociodemographic data to identify health disparities, and whether any information about experiences with prior authorization or other utilization management techniques is gathered as well as participation in clinical trials. These are some priority areas for CNF so would be awesome to know if there is any data collected that would support their work.
- The NSCH collects information on both CSHCN status and sociodemographic characteristics concurrently, and associations have been explored by researchers previously. One recent citation of interest may include:
- Reem M. Ghandour, Ashley H. Hirai, Mary Kay Kenney; Children and Youth With Special Health Care Needs: A Profile. *Pediatrics* June 2022; 149 (Supplement 7): e2021056150D. 10.1542/peds.2021-056150D
- The NSCH does not collect information on participation in clinical trials.
16. Is the minimum number of completed surveys per state the same for CYSHCN?
- We've been debating the pros and cons of different sampling strategies.
17. Are there incentives for participation?
- Yes, we use incentives: 90% of the sample received a small denomination bill as an incentive to complete the survey, 30% receiving a \$2 bill and 60% a \$5 bill. The other 10% of the sample do not receive an incentive and represented the control group for monitoring the effectiveness of the incentive treatments.
18. Can you explain again how the data is being collected. If it's household data, who in the household responds and who completes the follow-up survey you mentioned?
- Data are collected via web and paper. The NSCH utilizes a two-phase data collection approach:
 - ✓ An initial household screener to assess the presence, basic demographic characteristics, and special health care needs status of any children in the home; and

- ✓ A substantive topical questionnaire to be completed by a parent or caregiver of the selected child.

19. Are the oversampling results publicly available or are they only available to the states that pay for it?

- Oversample data can be released with the Public Use File. However, the Census Bureau has fairly strict policies to protect respondents' confidentiality, so not all data, e.g., more granular data on geography, would not be released without additional approvals.

20. Great to see HRTL included. Any attempt to align or harmonize with any states who are considering so-called Kindergarten Readiness measures (e.g., Oregon)?

- Yes, absolutely. We've always seen HRTL to be complementary to what states are doing individually. We can provide a high level, population level picture that is comparable to other states and the nation while state level efforts with the EDI other tools will provide a deeper picture.

21. Will be there be inclusion of questions for (1) Experiencing violence in environments, (2) Feeling the need to display violence in environments for self-protection?

- Not yet. We've been discussing this with CDC's Division of Injury Prevention, but there are significant challenges.

22. Are the new questions about diet and physical activity for young children are supposed to include what they eat/do at their childcare settings?

- We do not specify where the child's behaviors might take place. Parents/caregivers are asked whether the child engaged in any of a number of behaviors during the past 12 months.

23. Can you say when the 5-year combined dataset will be available on the Census website?

- If you need/want to do some quick work with the 5-year combined file, it is available at: www.childhealthdata.org; <https://www.childhealthdata.org/browse/survey?s=2&y=41&r=1>

24. Is the survey fielded in multiple languages?

- Yes, the survey is fielded in English and Spanish. Telephone support is available for other languages.

25. Can you highlight some more of the information gathered on CYSHCN?

- We collect lots of info on Children and Youth with Special Health Care Needs beyond the presence and general impact, including all 6 core quality outcomes which combine to create the overall NOM on System of Care.

26. I think the 5-year data is still restricted to NPM and NOM indicators on childhealthdata.org.

- This is true right now - it will be updated.