

Attachment 9 - Consultations for the 2019 Questionnaire Redesign

Formal consultations with experts outside of the agency for the 2019 NHIS questionnaire redesign began in 2014 as discussions with CDC partners and Healthy People federal interagency working groups. In 2015, the first presentations on the NHIS redesign were given at government ([National Conference on Health Statistics](#)) and professional association ([Population Association of America](#)) conferences, and audience feedback was obtained. These groups expressed support for the overarching goal of the redesign to streamline the survey and increase the relevance of the data collected, and provided valuable suggestions on ways to collect the breadth of content in a streamlined survey, including matrix sampling, use of administrative or alternative data sources, other modes of data collection, and rotating content modules. NHIS redesign staff examined multiple possibilities and elected to pursue rotating content modules.

Following this initial outreach and preliminary decision-making about questionnaire content structure, three more formal, structured, and in-depth forms of consultation were pursued in the form of Technical Expert Panels and calls for public feedback (each described in detail below). In addition, meetings were held throughout the questionnaire development process between survey design staff at NCHS, stakeholders, and subject matter experts across health care, health economics and demography. These included experts from within the federal government (CDC, NIH, HHS, Census, and BLS) as well as academic and professional associations. Further briefings were held throughout the redesign process, including at the National Academy of Sciences, the Federal Interagency Forum on Child and Family Statistics, the American Economic Association, and the Council of Professional Associations on Federal Statistics, with audience feedback obtained at each. Information obtained through these consultation efforts led to changes, improvements, and fine-tuning in both the structure and content of the 2018 NHIS questionnaire.

a. Technical Expert Panels (TEPs)*

Technical Expert Panels (TEPs) were convened on four topics: child health, income, pain, and injury. These informal panels were an efficient and effective means for NCHS to collect feedback on specific topics from a broad range of NHIS data users and stakeholders. These meetings involved multiple conference calls lasting approximately 2 hours and typically involved discussing content areas, but not specific questions.

i. Child Health Technical Expert Panel

There were two TEPs for child health. The first TEP, consisting of twelve members, met three times between February and March in 2016, while the second TEP, consisting of five members met two times in April. Members of the first TEP were affiliated with a range of academic, government, non-profit, and private organization, including the University of Illinois College of Medicine at Chicago, Maternal and Child Health Bureau, Children's Hospital of Pittsburgh, Duke University School of Medicine, University of San Francisco College of Public Health, Harvard Medical School, UC Berkeley School of Public Health, RTI International, The Lucile Packard Foundation for Children's Health, Boston Public Health Commission, Abt Associates, and the University of North Carolina Gillings School of Global Public Health. Members from the second Child TEP were affiliated with Population Reference Bureau, Johns Hopkins Bloomberg, School of Public Health, DHHS Office of Minority Health, and the American Academy of Pediatrics. The members of the second TEP reviewed feedback from members of the first TEP, and offered their own ideas for reducing the number of topics covered.

The primary feedback received from members of the child TEPs included increased emphasis on social determinants of health, expanded focus on children's mental health, and use of functioning as the framework for measuring child disability. Additionally, members noted that a redesigned NHIS could decrease focus on rare health conditions and increase focus on key measures for which benchmarks and long-term trends are needed. Toward this end, the members of the TEPs identified priority populations who are at elevated risk of poorer

* The complete roster for each TEP is appended at the end of this document.

health or receiving poorer health care. Some TEP members were also interested in the possibility of pairing parent and child interviews into dyads that could be analyzed as a set.

ii. Income Technical Expert Panel.

NCHS held two meetings in April 2016 with the income TEP, a panel consisting of eight members from federal agencies and research organizations. These affiliations included: the Agency for Healthcare Research and Quality, National Center for Health Statistics' Division of Research and Methodology, HHS' Office of the Assistant Secretary for Planning and Evaluation, University of Michigan's Survey Research Center, and the U.S. Census Bureau.

In the 1997-2017 NHIS, the family respondent is asked about various sources of income received by family members. For the redesign, members of the TEP noted the importance of continuing to ask the questions on some of the various sources of income. Other ideas included rethinking the income reference period, and establishing a clear definition for who is included in the definition of a family.

iii. Pain Technical Expert Panel.

The Pain TEP, consisting of seven members representing governmental agencies, non-profits, and academics, met twice in May 2016. The panel included members affiliated with the CDC/National Center for Chronic Disease Prevention and Health Promotion, Group Health Research Institute, National Institute of Neurological Disorders and Stroke, and Stanford University. The members of the TEP focused on the impact of chronic pain rather than the area of the body in which the pain occurs, and used the recently published National Pain Strategy as a framework for their discussions.

iv. Injury Technical Expert Panel.

The Injury TEP consisted of a panel of 30 members from federal agencies, research and academic institutions. This group met monthly from June 2015 through February 2016. The Injury TEP included individuals affiliated with the Agency for Healthcare Research and Quality, CDC/National Center for Chronic Disease Prevention and Health Promotion, CDC/National Center for Injury Prevention and Control, CDC/National Institute for Occupational Safety and Health, Center for Injury Research and Policy, the Research Institute at Nationwide Children's Hospital, Colorado School of Public Health, Colorado State University, Johns Hopkins Center for Injury Research and Policy, Liberty Mutual, National Safety Council, Pacific Institute for Research and Evaluation, the Children's Hospital of Philadelphia, University of Iowa College of Public Health, and the University of Maryland School of Medicine. Members of this panel reviewed the utility of the poisoning data and noted that while sample sizes were small, the NHIS would continue to be an important data source for injury epidemiology and surveillance.

The input from these TEPs and other subject matter experts was iteratively integrated into draft versions of the redesigned questionnaire. The first draft of the proposed overall questionnaire structure and sample adult questionnaire topic areas was presented to NCHS leadership, the HHS Assistant Secretary for Planning and Evaluation, and released to the public in late 2015. A first draft of the sample child topic areas was released soon after (April 2016) and both questionnaire sections were presented to the [NCHS Board of Scientific Counselors in May 2016](#).

b. Calls for Public Feedback

In addition to convening subject matter experts throughout the TEP process, the general public was also consulted at multiple key decision points. Specifically, three calls for feedback were put out in which members of the public were asked to provide their thoughts more informally, directly to NCHS via email. In addition, a formal 30-day notice for public comment was placed in the Federal Register.

i. First call for feedback

In October 2015, the first call for public feedback was posted on the NCHS website and disseminated via the NHIS email listserv. The announcement informed the public that the NHIS would be redesigned in 2018 with the goals of improving the measurement of health topics, reducing respondent burden by shortening the questionnaire, harmonizing NHIS data with that on other federal surveys, establishing a long-term structure of ongoing and periodic topics, and incorporating best practices in survey methodology and measurements. In this announcement, the proposed plan was presented to keep some content on the survey annually while other content would rotate on and off with a fixed and pre-established periodicity. Additionally, it was announced that supplements would be limited to 5 minutes per sponsor, per year.

Commenters were requested to consider the uses and types of products for which they use NHIS data, the potential consequences on their work of losing NHIS as a data source, content areas no longer relevant or with limited utility to them, the minimum periodicity and number of consecutive years of survey data they require for their work, and the number and types of covariates needed to allow for meaningful use of NHIS content areas. Commenters were asked to support their ideas with evidence-based information when available.

This call for feedback resulted in 60 emails from CDC, agency partners, academia, non-profits, small businesses, and the general public. These comments echoed several reoccurring themes. Many stressed the importance of collecting broad measures of disability. Another key theme was the recommendation to maintain health insurance and utilization measures in the NHIS.

Information obtained through this first call for feedback was combined with information gleaned from the TEPs and meetings with key stakeholders to create a tentative content draft of topics to be covered in the sample adult NHIS redesign, and identify content areas under development.

ii. Second call for feedback

In February 2016, public feedback was invited on this tentative content draft, again via announcement on the NCHS website and dissemination to the email listserv. At this time, commenters were invited to weigh in on the benefits and drawbacks of eliminating the design element of having a separate family respondent to answer questions about all members of the family, relying instead on collection of a more limited scope of information as part of the remaining sample adult and sample child modules. Commenters were also asked to suggest validated questions that could be asked in the areas under development.

This call for feedback generated 319 emails. Most of these comments (264) were form letters or variations of form letters based on templates circulated by groups opposed to the elimination of the family questionnaire. Commenters emphasized the importance of having data on the health insurance status and type of all family members, requested that additional demographic information be collected about each family member, and called for improved measurement of same-sex and multiracial couples. Other comments emphasized the need to improve measurement of mental health, with some commenters advocating for a particular measure of mental health distress, depression, and/or anxiety.

In reaction to the concerns expressed by commenters about the loss of content from discontinuation of the family section, NCHS released a public statement to allay these concerns and clarify the content areas that

would remain on the survey, albeit integrated into the adult and child sections. Also, NCHS reconsidered and ultimately retained questions on the education and employment of all adults in the household.

iii. Third call for feedback

In June 2016, the third call for public feedback was announced on the NCHS website and through the NHIS listserv to solicit reactions on content drafts of both the sample adult and child questionnaires. Prior commenters were explicitly invited to review the new content drafts and provide additional comments.

This third call resulted in approximately 70 comments from the public, academics, state and federal government, and nonprofit/advocacy groups, and many repeat commenters. Most comments addressed the changes to the family section, disability, injury, and mental health.

iv. Federal Register Notice

A formal call for public comments was undertaken via a non-Paperwork Reduction Act (PRA) 30-day Federal Register Notice (FRN), which was published on October 7, 2016. Attached to this FRN were the draft questionnaires for the sample adult and sample child annual and rotating core, which included the proposed wording of each question, skip patterns, universe of people of whom the question would be asked, and proposed answer categories.

There were 60 comments received in response to this FRN. Two thirds of these comments had to do with four topics. These included the measurement of disability, and request for new or additional questions on oral health and tooth pain, specific food and other types of allergies, and the developmental status and behaviors of young children aged 0-4 years.

v. Response to the calls for feedback

Each individual comment received as part of the three calls for feedback and the non-PRA 30-day FRN was recorded in a database, noting the topic, affiliation of commenter, survey section to which the comment applied (i.e. family, sample adult, sample child, etc.) and whether the comment was suggesting an addition, deletion, or change.

Each comment received was read and considered; in some cases, changes were made to the questionnaire. Commenters responding to the three calls for public feedback disseminated via the NCHS website and listserv were sent tailored responses or, in cases where the comments came in the form of form letters, were sent a form letter. Commenters responding to the 30-day FRN were sent the standard CDC response.

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