

### **Attachment 3f - NHIS Questionnaire Redesign Consultations**

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.

## NHIS REDESIGN TECHNICAL EXPERT PANEL ROSTERS

### **CHILD**

#### First Child Technical Expert Panel (met on 2/2/16, 2/25/16, 3/8/16)

Rachel Caskey, MD, MAPP  
Division Chief  
Academic Internal Medicine and Geriatrics  
University of Illinois College of Medicine at Chicago  
rcaskey@uic.edu  
312.413.1595

Reem Ghandour, DrPH, MPA  
Director  
Division of Epidemiology  
Office of Epidemiology and Research  
Maternal and Child Health Bureau  
rghandour@hrsa.gov  
301.443.3786

Amy Houtrow, MD, PhD, MPH  
Chief  
Division of Pediatric Rehabilitation Medicine  
Children's Hospital of Pittsburgh  
houtrow@upmc.edu  
412.692.5097

Alex Kemper, MD, MPH, MS  
Professor of Pediatrics  
Duke University School of Medicine  
alex.kemper@duke.edu  
919.668.8038

Russell Kirby, PhD, MS  
Chair and Professor  
Department of Community and Family Health  
USF College of Public Health  
rkirby@health.usf.edu  
813.396.2347

Michael Kogan, PhD  
Director  
Office of Epidemiology and Research  
Maternal and Child Health Bureau  
mkogan@hrsa.gov  
301.443.3145

Milton Kotelchuck, PhD, MPH  
Professor of Pediatrics  
Harvard Medical School  
mkotelchuck@mgh.harvard.edu  
617.724.3594

Cheri Pies, MSW, DrPH  
Clinical Professor  
School of Public Health  
University of California, Berkeley  
cpies@berkeley.edu  
510.643.1250

Heather Ringeisen, PhD, MS  
Director  
Children and Families Research Program  
RTI International  
hringeisen@rti.org  
919.541.6000

Edward Schor, MD  
Senior Vice President  
The Lucile Packard Foundation for  
Children's Health  
Edward.Schor@LPFCH.org  
650.736.2663

Snehal Shah, MD, MPH  
Director  
Research and Evaluation Office  
Boston Public Health Commission  
sshah@bphc.org  
617.414.5946

Deborah Klein Walker, EdD  
Vice President  
Public Health and Epidemiology Practice  
Abt Associates  
Deborah\_Walker@abtassociates.com  
617.492.7100

Bharathi Zvara, PhD  
Research Assistant Professor  
Maternal and Child Health  
UNC Gillings School of Global Public Health  
zvara@email.unc.edu  
919.966.1370

Second Child Technical Expert Panel (met on 4/21/16, 4/28/16)

Wendy Baldwin, PhD  
Former President and CEO  
Population Reference Bureau  
wendybburg@gmail.com  
202.939.5409

Christy Bethell, PhD  
Director  
Child & Adolescent Health Measurement Initiative  
Johns Hopkins Bloomberg School of Public Health  
cbethell@jhu.edu  
443.287.5092

J. Nadine Gracia, MD, MSCE  
Deputy Assistant Secretary  
Office of Minority Health  
Nadine.Gracia@hhs.gov  
202.960.7694

Lynn Olson, PhD  
Director  
Department of Research  
American Academy of Pediatrics  
lolson@aap.org  
847.434.7631

Minh Wendt, PhD  
Public Health Advisor  
Office of Minority Health  
Minh.Wendt@hhs.gov  
202.960.7694

## **CHRONIC PAIN**

Charles Helmick, MD  
Medical Officer, IV  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
CHelmick@cdc.gov  
770.488.5456

Sean Mackey, MD, PhD  
Chief, Division of Pain Medicine  
Director of the Systems Neuroscience and Pain Laboratory (SNAPL) and Redlich Professor of Anesthesiology,  
Perioperative and Pain Medicine, Neurosciences and Neurology  
Stanford University  
(Past President of American Academy of Pain Medicine)  
smackey@stanford.edu  
650.498.6477

Linda Porter, PhD  
Director  
Office of Pain Policy  
National Institute of Neurological Disorders and Strokes  
National Institutes of Health  
porterl@ninds.nih.gov  
301.451.4460

Michael Von Korff, ScD  
Senior Investigator  
Kaiser Permanente Washington Health Research Institute  
vonkorff.m@ghc.org  
206.287.2874



## **INCOME**

Jason Fields, PhD  
Survey Director  
Survey of Income and Program participation & National Children's Health Survey  
U.S. Census Bureau  
Jason.M.Fields@census.gov  
301.763.2465

Steven Hill, PhD  
Senior Economist  
Center for Financing, Access, and Cost Trends  
Agency for Healthcare Research and Quality  
Steven.Hill@ahrq.hhs.gov  
301.427.1672

David Johnson, PhD  
Research Professor & Deputy Director (Panel Study of Income Dynamics)  
Survey Research Center  
University of Michigan  
johnsods@umich.edu  
734.647.4076

Trivellore Raghunathan, PhD  
Director  
Survey Research Center  
University of Michigan  
teraghu@umich.edu  
734.764.8365

Thomas Selden, PhD  
Director  
Center for Financing, Access, and Cost Trends  
Agency for Healthcare Research and Quality  
Thomas.Selden@ahrq.hhs.gov  
301.427.1677

Kathleen Short, PhD  
Research Economist  
Social, Economic & Housing Statistics Division  
U.S. Census Bureau  
Kathleen.S.Short@census.gov

Joan Turek, PhD  
Senior Economist  
Office of the Assistant Secretary for Planning and Evaluation  
Joan.Turek@hhs.gov  
202.690.5965

## **INJURY**

Abay Asfaw  
Economist  
National Institute for Occupational Safety and Health  
hqp0@cdc.gov  
202.245.0635

Anasua Bhattacharya  
Economist  
National Institute for Occupational Safety and Health  
fwa4@cdc.gov  
513.533.8331

Matt Breiding  
Research Scientist  
National Center for Injury Prevention and Control  
dvi8@cdc.gov  
770.488.1396

Tim Bushnell  
Economist  
National Institute for Occupational Safety and Health  
plb4@cdc.gov  
513.458.7108

Susan Carlson  
Health Scientist  
National Center for Chronic Disease Prevention and Health Promotion  
scarlson1@cdc.gov  
770.488.6091

Lily Chen  
Health Scientist  
National Center for Health Statistics  
eyx5@cdc.gov  
202.205.4908

Ann Dellinger  
Branch Chief  
National Center for Injury Prevention and Control  
amd1@cdc.gov  
770.488.4811

Carolyn DiGuseppi  
Associate Dean for Faculty, Professor, and Director of the Preventive Medicine Residency Program  
Colorado School of Public Health  
Carolyn.DiGuseppi@ucdenver.edu  
303.724.4415

Andrea Gielen  
Professor  
Johns Hopkins Center for Injury Research and Policy  
agielen1@jhu.edu  
410.955.2397

Christina Greene  
University of Maryland School of Medicine  
creagangreene@umaryland.edu

Siobhan Gruschow  
Clinical Research Coordinator  
The Children's Hospital of Philadelphia  
GRUSCHOWS@email.chop.edu

Holly Hedegaard  
Medical Officer  
National Center for Health Statistics  
hdh6@cdc.gov  
301.458.4460

Ken Kolosh  
Manager of Statistics  
National Safety Council  
Ken.Kolosh@nsc.org

Marcie-Jo Kresnow-Sedacca  
Mathematical Statistician  
National Center for Injury Prevention and Control  
mjk1@cdc.gov  
770.488.4753

Marie-Claude Lavoie  
Epidemiologist  
University of Maryland School of Medicine  
mclavoie@umaryland.edu

David Lombardi  
Principal Research Scientist  
Liberty Mutual Research Institute for Safety  
david.lombardi@libertymutual.com

Karen Mack  
Science Officer  
National Center for Injury Prevention and Control  
kim9@cdc.gov  
770.488.4389

Suzanne Marsh  
Health Statistician  
National Institute for Occupational Safety and Health  
SMMarsh@cdc.gov  
304.285.6009

Helen Marucci-Wellman  
Senior Research Scientist/Epidemiologist  
Center for Injury Epidemiology, Liberty Mutual Research Institute for Safety  
helen.wellman@libertymutual.com

Ted Miller  
Senior Research Scientist  
Pacific Institute for Research and Evaluation  
miller@PIRE.org  
301.593.7471

Ryan Mutter  
Lead Social Science Analyst  
Agency for Healthcare Research and Quality  
ryan.mutter@ahrq.hhs.gov  
240.276.2754

Corinne Peek-Asa  
Professor, Associate Dean for Research  
University of Iowa College of Public Health  
corinne-peek-asa@uiowa.edu  
319.335.4895

Keisha Pollack  
Professor  
Johns Hopkins Center for Injury Research and Policy  
kpollac1@jhu.edu  
410.502.6272

Rose Rudd  
Health Scientist  
National Center for Injury Prevention and Control  
rvr2@cdc.gov  
770.488.3712

Yahtyng Sheu  
Statistician  
National Center for Health Statistics  
ydq6@cdc.gov  
301.443.1426

Gordon Smith  
Adjunct Professor of Epidemiology & Public Health  
University of Maryland School of Medicine  
gssmith@som.umaryland.edu  
410.328.3847

Lorann Stallones  
Professor, Director of the Graduate Program in Public Health  
Colorado State University  
Lorann.Stallones@colostate.edu  
970.491.6156

Ray Tapas  
Senior Service Fellow  
National Institute for Occupational Safety and Health  
cvt1@cdc.gov

Margaret Warner  
Statistician  
National Center for Health Statistics  
mmw9@cdc.gov  
301.458.4556

Huiyun Xiang  
Director and Principal Investigator  
Center for Injury Research and Policy and Center for Pediatric Trauma Research, The Research Institute at  
Nationwide Children's Hospital  
huiyun.xiang@nationwidechildrens.org  
614.355.5850