

November 7, 2016

Ms. Marcie Cynamon
Director
Division of Health Interview Statistics
National Center for Health Statistics
3311 Toledo Road, MS-P08
Hyattsville, MD 20782-2064

Re: Comment on 2018 National Health Interview Survey Questionnaire Redesign

Dear Ms. Cynamon:

The Partnership to Improve Patient Care (PIPC) appreciates the opportunity to comment on the review of the proposed changes to the National Health Interview Survey (NHIS). Since its founding, PIPC has been at the forefront of applying principles of patient-centeredness to the nation's health care system – from the generation of comparative clinical effectiveness research at the Patient-Centered Outcomes Research Institute (PCORI), to the translation of evidence into patient care in a manner that achieves value to the patient. Having driven the concepts of patient-centeredness and patient engagement in the conduct of research, PIPC is pleased to bring forward the voices of people with disabilities to support data collection that supports policies to address health disparities.

As a primary author of the Americans with Disabilities Act (ADA), I understand that the current set of disability questions in the NHIS is critically important for people with disabilities. As noted by the Consortium of Citizens with Disabilities (CCD), the current NHIS disability data provide critical data to policymakers, researchers and others to represent the complete population of people with disabilities as a demographic, and to inform policymakers and those of us who work to decrease disability health disparities. Especially as the population ages and the number of people with disabilities increases, this data will be even more vital to policymakers and advocates. The goal of Section 4302 of the Affordable Care Act is to increase data collection and decrease health disparities. It would be inconsistent to instead decrease the data currently collected.

PIPC supports the recommendations of the CCD Health Task Force urging the National Center for Health Statistics (NCHS) to include age of onset questions to help identify the adult population with developmental disabilities, especially considering the NCHS decision to stop asking the questions about specific conditions. As we understand, without the specific conditions or the age of onset questions, there will be insufficient questions to identify the population of adults with developmental disabilities. Therefore, we urge the NCHS to develop and test questions to identify adults with developmental disabilities. Otherwise, we urge you to

reconsider asking about the specific conditions (intellectual disability, autism, cerebral palsy, epilepsy and others) and the age of onset so that the data continues to identify individuals with developmental disabilities.

PIPC also shares the concerns of the CCD Health Task Force that the NHIS will include a variation of the six disability questions that are included in the American Community Survey (ACS). It is our understanding that HHS has adopted, at a minimum, the use of the six ACS questions to meet the ACA's data collection responsibilities. We are concerned that varying the questions may affect the reliability and comparability of the data. We urge the NCHS to continue to include the six ACS disability questions and to specify how often they will be included in the survey.

We appreciate the opportunity to provide comments. If you have any questions please contact Sara van Geertruyden (sara@pipcpatients.org).

Sincerely,



Tony Coelho
Chairman, Partnership to Improve Patient Care