

## **General Comment**

I have read this proposed data collections carefully and find several problems with this. It doesn't really define whether the data collected contains information on individuals or only at an aggregate level. It does not address who has access to this data or much information on how the data will be used. Mental health data is particularly sensitive area and individuals and families need to have a better sense that this information will be protected.

We have a lot of discussion of Medicare / Medicaid reform as well as "remove and replace" of the ACA (Affordable Care Act). Some in Congress (Paul Ryan, Speaker of the House) have discussed publicly the possibility of privatizing the VA, Social Security, and Medicare. I believe our seniors deserve to know that their information is safe from private, for profit, corporations. Rightly or wrongly in the aftermath of the 2016 elections, some American's are deeply concerned about the database that the Federal Government currently has, being used by an Executive Branch that has very strong opinions that the data that they have given to the Federal Government can no longer be trusted to be used fairly and accurately. Specifically, I believe we need to reference DACA (Deferred Action for Childhood Arrivals) to understand the issues related to Federal Government's data vis-à-vis a partisan change in the Executive or Legislative branches. Rightly or wrongly the feeling of the American public has changed in regard to the peaceful transition of power and that the contracts with the American people regarding their data, and the institutions that we rely upon to be used responsibly.

## **CMS Response**

CMS appreciates this thoughtful comment. The Home Health CAHPS data that are submitted by survey vendors on behalf of home health agencies to the Centers for Medicare & Medicaid Services (CMS) are deidentified. Survey vendors submit to CMS patient-level survey responses; however, they strip off any information that would identify an individual. It was set up this way to protect the privacy of individuals completing the survey.

The survey data are analyzed to produce agency-specific scores (aggregate data). These data are publicly reported to help Medicare beneficiaries and their loved ones make decisions about which home health agency to use. The aggregate data are also used for agencies to identify opportunities for quality improvement. Finally, the data will be used in value-based purchasing models paying providers on the quality of care provided to Medicare beneficiaries.

The survey includes one question about the respondent's self-reported view of their own mental health status. These data are never publicly reported. These data, along with some other "About You" demographic data questions, are used in patient mix adjustment to adjust the agency-level measures of performance for characteristics that may impact how a patient responds to the survey. Again, these data are not associated with the name or identifying information of a patient.

The HHCAHPS data are completely safe from compromised and inappropriate use. Also note that the data do not pertain to home health patients who are: (1) under the age of 18, (2) who have claimed a "no publicity" status for survey exclusion, (3) who qualify for survey exclusion

due to state regulations, (4) who are institutionalized, and (5) who are in the criminal justice system.

All HHCAHPS survey vendors (who implement the survey) are independent non-government entities who have no affiliation with home health care agencies. All of the HHCAHPS survey vendors must implement the survey according to very strict guidelines that can be found in our [HHCAHPS Protocols and Guidelines Manual](#) (which is updated annually) on <https://homehealthcahps.org>. CMS posts information about HHCAHPS on that website and this includes the information about the extensive requirements for our HHCAHPS survey vendors, including an annual submission of the vendors' Quality Assurance Plan outlining all steps of the data collection process, the annual update training, and participation in CMS oversight activities to ensure proper administration of the survey.