PXPF Comments on Closing the Equity Gap in CMS Hospital Quality Programs
Federal Register, Volume 86, Number 88, pages 25557-25561
Re: Federal Register File Code CMS-1752-P

The Patient Experience Policy Forum (PXPF), supported by The Beryl Institute, is a broad-based and diverse coalition of patients, family members, caregivers, and health care professionals uniquely led by a balanced board of patient/family partners and senior patient experience leaders. Our purpose and commitment are to advocate for and help shape policy at the national and local levels on issues that directly affect patient and family experience and elevate the human experience in healthcare. We do so through convening policy forums, educating policy makers, sponsoring advocacy events, providing communication updates, and publishing calls to action.

We appreciate the opportunity to provide the following comments in response to the CMS Solicitation of Public Comment regarding Closing the Equity Gap in CMS Hospital Quality Programs, included in the proposed Fiscal Year 2022 updates to the Quality Data Reporting Requirements for Specific Providers and Suppliers, as posted in the Federal Register, Volume 86, Number 88, published on May 10, 2021. Specifically, our comments pertain to the subsection titled, Potential Expansion of the CMS Disparity Methods, pages 25557-25561.

Recommendations for other types of feasibly collected data elements for measuring disadvantage and discrimination: We recommend the collection of a minimum set of demographic data elements for all healthcare patients, inclusive of all payers, as follows: race, ethnicity, sex, sexual orientation and gender identity, primary language, tribal membership and disability status. Furthermore, this minimum data set should be standardized across provider types and care settings—inclusive of hospitals, LTCHs, Rehab Facilities, Skilled Nursing Facilities, Hospices, Medical Groups, etc. Recognizing the importance of language and words, we support ongoing research on the language used to describe categories of race, ethnicity, sex, gender identity and other demographic variables within questions asking for demographic information. This should help to ensure that the questions asking for this information remain relevant to, and consistent with the way that people describe their own identities, facilitating increased question response rates.

Regarding race and ethnicity, we support the use of a nationally standardized (i.e., universally employed) minimum set of race and ethnicity categorizations, as listed below:

1. Race
   a. American Indian or Alaska Native
   b. Asian
   c. Black or African American
   d. Middle Eastern or North African
   e. Native Hawaiian or Other Pacific Islander
   f. White
   g. Other Race, Ethnicity or Origin

2. Ethnicity
   a. Hispanic, Latino or Spanish Origin
   b. Non-Hispanic, Non-Latino or Non-Spanish Origin

We support any organization's ability to use more detailed race and ethnicity categorizations, e.g., the CDC's code system, as long as such expanded categories can be "rolled up" to this minimum set, also in a standardized manner. Importantly, in any scenario in which patients are asked for their race and ethnicity, they should be given the opportunity to self-report multiple races.

We recognize that the use of our recommended minimum set of racial categories will require that the OMB Standards for Race and Ethnicity (1997) be modified to add the category of "Middle Eastern or North African." However, we believe that the benefits of using this additional category, including the potential for more accurately identifying racial disparities, warrant the effort.

As a final comment on this topic, we suggest that in the longer term, after race and ethnicity data are being routinely, accurately and completely collected by healthcare providers "upstream" and included in the dataset provided to vendors to conduct surveys on providers' behalf, CMS consider removing race and ethnicity questions from the demographic section of CMS patient experience surveys in order to reduce survey length and minimize duplication of data collection.

Recommendations for other types of quality measures or measurement domains, in addition to readmission measures, to prioritize for stratified reporting: We strongly recommend that, in addition to readmission measures, patient experience of care measures be prioritized by CMS for stratified reporting by dual eligibility, race and ethnicity, and disability. CMS's own analyses (e.g., "Racial, Ethnic, and Gender Disparities in Health Care in Medicare Advantage." CMS Office of Minority Health in Collaboration with the RAND Corporation. April 2020) reveal the existence of racial and ethnic disparities within aggregated patient experience data. Reinforcing these findings, a recent survey (*The Beryl Institute – Ipsos PX Pulse: Consumer Perspectives on Patient Experience in the US, July 2020)* found that US consumers reported very different perceptions of the quality of care they receive based on their racial/ethnic backgrounds. While a total of 4 percent of White people report that they "often" or "sometimes" feel discrimination in health care, 35 percent of Black people and 24 percent of Hispanic/Latino people report this experience. These findings provide a strong rationale for stratified measurement and reporting of patient experience at the organizational level. An even more compelling argument for stratified reporting of patient experience may be that patient experience is not only a significant measure of performance in its own right but also highly correlates with clinical quality and other important outcomes of care.

Possible collection of a minimum set of demographic data elements by hospitals at the time of admission, **using electronic data definitions which permit nationwide, interoperable health information exchange, for the purposes of incorporating into measure specifications and other data collection efforts relating to quality:** Recognizing that there will be substantial challenges surrounding implementation, we support collection of a standardized minimum set of demographic data elements (race, ethnicity, sex, sexual orientation and gender identity, primary language, tribal membership and disability status) by healthcare provider organizations and clinicians at the time and point of admission or initial service to an individual. (Although this CMS solicitation of comments pertains only to hospitals, we support collection of these demographic data set across provider types and care settings.)

Due to the work by the ONC in recent years to require that certified health IT products be able to collect race and ethnicity data via the Common Clinical Data Set, and in the future the United States Core Data

for Interoperability, the technical functionality exists to collect and transmit race and ethnicity data in a standardized manner. However, the ability and willingness of hospital staff and others to effectively utilize this functionality to collect self-reported race, ethnicity and potentially other demographic data are far less developed.

Therefore, we strongly commend CMS for its recognition within this Proposed Rule that the collection of self-reported race, ethnicity and other demographic data will require additional resources, including staff training, to ensure that "the conditions are created whereby all patients are comfortable answering all demographic questions…" Earlier efforts aimed at collection of self-reported race/ethnicity/primary language data from all patients at admission (e.g., Robert Wood Johnson Foundation Aligning Forces for Quality Initiative) revealed some of the challenges associated with this seemingly straightforward task, such as staff discomfort in asking questions about patients' race and ethnicity, the need for staff training in how to respond appropriately to questions around "why are you asking me these questions," etc. In order to address these challenges to collecting self-reported race and ethnicity data, we urge CMS to assemble and make available relevant resources (funding, training materials, trained patient and family advisors, best practices, etc.) to healthcare provider organizations.

Correspondingly, there is an equally important need to educate and raise awareness on the part of patients and the general public as to why it is critically important to answer these race, ethnicity and other demographic questions when they are asked during the admission/registration process. We urge CMS, HHS and other entities with an interest in this issue to financially support widespread educational campaigns in this regard.

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on behalf of the Patient Experience Policy Forum Board

Additional reference:

Listening To The Voice Of All Patients To Help Heal Health Disparities In A Post-COVID-19 World
https://www.healthaffairs.org/do/10.1377/hblog20210430.456198/