Race, Ethnicity, and Language (REAL) Data

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The importance of Race, Ethnicity, and Language (REAL) Data is increasingly highlighted. With the predominance of the electronic health record and constant expansion of its uses, there is increasing potential to collect well-documented REAL data to inform work to mitigate health disparities as part of quality improvement efforts.

Efforts are ongoing to standardize the collection of REAL data. For example, the Institute of Medicine has created a standardized framework for demographic data collection. Additionally, the Centers for Medicare and Medicaid Services, the Institute of Medicine (IOM), and several accreditation organizations, such as the Joint Commission, include the expectation for REAL data collection in their refined standards for quality improvement measures aimed at disparity reduction. The Joint Commission goes further, specifically recommending automating and standardizing REAL data collection, and prioritizing use of this data to identify inequities.

Accurate REAL data requires use of clear, direct language when asking patients to self-report. Thereafter the responses can be coded, standardized and collated into actionable data.

How can REAL data be used to improve care quality? Stratifying outcomes based on REAL data can help identify inequities by highlighting differences in outcomes for a specific racial or ethnic group. This can provide a focus for further investigation to uncover potential systems issues contributing to a higher rate of adverse outcomes within specific patient populations and potential solutions.   Partaking in alliances with other entities (for example state or local ObGyn or multidisciplinary quality programs) can improve the breadth and quality of the data and help inform interventions.

Ultimately, a culture of transparency should be established to allow both patients and the workforce to be comfortable with giving, receiving, and using REAL data. This will require health system efforts, including initial and ongoing education and training to enhance the cultural competency of the workforce. Collecting REAL data elements is a necessary component of comprehensive patient-centered care.

Example:
One practical application of REAL data results from capturing patients' primary language. Language barriers can adversely affect patient outcomes by limiting patients' ability to access services, fully understand health information and advocate for themselves. Accurate data about a patient's English proficiency and preferred language enables all members of the care team to adapt care to better meet their needs, including providing ready access to medical interpretation services for each contact.

A healthcare system identified via REAL data collection that a significant number of patients in their system utilize American Sign Language (ASL) as their primary language and strongly prefer in-person interpretation over other means of communication. A workflow is developed that automatically requests an in-person ASL interpreter every time a patient with ASL designated as their primary language makes an outpatient appointment. In the hospital, the system is redesigned to ensure that patients who designate ASL as their primary language have in-person interpreters available for key times, including on admission and discharge and for in-hospital procedures   Follow up data showed that these interventions significantly improve patient satisfaction.   Readmission rates also decreased, with patients reporting better understanding of their discharge instructions and medications.

References:
[1]The Center for Medicare and Medicaid Services. "Inventory of Resources for Standardized Demographic and Language Data Collection."
https://www.cms.gov/about-cms/agency-information/omh/downloads/data-collection-resources.pdf. Accessed 9 October 2024.
[2]National Committee for Quality Assurance and Grantmakers in Health. "Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity." Grant Makers in Health.
https://collections.nlm.nih.gov/catalog/nlm:nlmuid-9918383081606676-pdf. Accessed 9 October 2024.

Additional Reading

Rodriguez-Lainz A, McDonald M, Fonseca-Ford M, et al. "Collection of Data on Race, Ethnicity, Language, and Nativity by US Public Health Surveillance and Monitoring Systems: Gaps and Opportunities." Public Health Rep. 2018 Jan/Feb;133(1):45-54. doi: 10.1177/0033354917745503. Epub 2017 Dec 20. PMID: 29262290; PMCID: PMC5805104.