Measuring the Gaps
Collecting Data to Drive Improvements in Health Care Disparities

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Introduction and summary

There are currently large and worrisome health disparities across the United States in access to quality health care between racial and ethnic minority groups and white Americans. In some cases these disparities have existed for a long time and are getting worse.¹

Collecting and analyzing valid and reliable data regarding these disparities provides the building blocks for identifying differences in care and developing targeted interventions to improve the quality of care delivered to specific population groups—regardless of whether those population groups are identified by geography, disability, socioeconomic status, race, or ethnicity.

The drive toward quality care for all Americans serves to highlight the areas where there is inequity not just in quality but in access and in more subtle measures such as cultural and linguistic concordance. However, while there is a growing consensus that integrating the reduction of disparities into the quality of care is a coherent and efficient approach to redesigning the health care system—an approach that focuses on the patient and is blind to their race or ethnicity—it cannot be assumed that this will necessarily result in the elimination in health care disparities.² Race-specific strategies may be necessary to address some types of disparities.

The Affordable Care Act expands the current requirements for the collection and analysis of health care disparities data. The new health reform law recognizes that greater efforts are needed to quantify racial and ethnic disparities in health care, to investigate their causes and impacts, and to implement and evaluate interventions to address them. There are a significant number of provisions in ACA that require the collection and analysis of data on racial and ethnic health care disparities. These data will be critical for guiding both government policy and the programs and practices of individual health care institutions and providers.

It is important that the collection of data on racial and ethnic health care disparities is not merely confined to sample sets but involves all health care providers as willing participants in the effort. The importance is twofold: first, the larger the data
sets, the more reliable the information; second, health care providers who have data from their own institutions and practices are more likely to look at disparities in care, design targeted programs to improve quality of care, and provide patient-centered care.

It is also critical to ensure that data collected by different agencies of the Department of Health and Human Services are collected with sufficient uniformity and to the same standards so that they can be utilized effectively across all sectors and by all stakeholders.

The Affordable Care Act will help drive efforts to understand and address the current racial and ethnic disparities in health care. To ensure that these new requirements are maximally effective, their implementation will need to address a number of issues:

- Design of questions that will allow patients to self-identify their race and ethnicity accurately and without resistance

- Provision of a standard approach for rolling up these individual responses into the Office of Management and Budget categories for analytical and reporting purposes

- Collection of information about spoken English-language proficiency, the preferred language for health-related encounters information, the language spoken by the patient at home, and the language in which the patient prefers to receive written materials

- Standardization of the way data on racial and ethnic disparities are collected across the various agencies of the Department of Health and Human Services and the development and promulgation of best practices in this regard

- Requirements and incentives to ensure that all health insurance plans and providers, regardless of whether they receive federal funding, collect, use, and share data on racial and ethnic disparities to agreed standards and methodologies

- The use of education and awareness materials to inform patients, providers, and health plans about the need for data collection on racial and ethnic disparities

- Training programs and resources, including health IT, to facilitate the collection of this data to the agreed standards
• More research to improve the science of evaluating interventions to reduce disparities, and the dissemination and uptake of best practice in this area

• Strong national leadership and coordination of efforts

A recent report from the Institute of Medicine concludes that although the annual National Health Disparities Report and the companion National Healthcare Quality Report have made valuable contributions in raising awareness and identifying gaps in quality and equity in the nation’s health care, the reports could be improved and could be more influential in promoting improvements in the health care system.³
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