



Measuring the Gaps

Collecting Data to Drive Improvements in Health Care Disparities

Lesley Russell December 2010

Center for American Progress



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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

ACA requirements for the collection of data on racial and ethnic disparities

Section 4302 (Understanding health disparities; data collection and analysis) of ACA amends the Public Health Service Act to expand the current requirements for the collection and analysis of health disparities data. All federally funded health programs and population surveys will be required by 2013 to collect and report data on race, ethnicity, primary language, and other indicators of disparity the secretary of health and human services identifies as appropriate. This provision also strengthens data collecting and reporting mechanisms in Medicaid and the Children's Health Insurance Program, bringing them up to the same standards as for Medicare.

The secretary is required to ensure that these data are analyzed to detect and monitor trends in health disparities and disseminate this information to the relevant federal agencies and to the public. The Office of Management and Budget categories of race and ethnicity will be the minimum standard (see Appendix), and the use of oversampling is authorized to produce statistically reliable estimates.

Issues around collecting the data

Improvements in data collection and reporting have the potential to raise public awareness about racial and ethnic health care disparities and drive new evidence-based initiatives that are effectively targeted. There are some barriers, however, that will hinder implementation efforts and limit the usefulness of the data collected unless addressed.

Let's examine each of these barriers.

Appropriate categories for race and ethnicity

The OMB race and ethnicity categories the federal government uses and endorses are large and relatively vague. There is considerable heterogeneity within each of the defined groups and this often presents problems when people are asked to self-identify or are identified by others.

People of Middle Eastern or Arab ancestry, for example, are often categorized as “white” or “Caucasian” although this may not be how they view themselves.⁴ The “Asian American,” “Native Hawaiian and Other Pacific Islander,” and “Latino” or “Hispanic” categories homogenize immense heterogeneity among various racial and ethnic groups.

Ethnicity in the case of Hispanics refers to the array of values, cultural norms, and behaviors that the different subgroups share, but people of this ethnicity may belong to a variety of racial groups. People from the Philippines, Japan, Vietnam, Laos, and China have significant differences in key health indicators, access to health care services, health beliefs, and behaviors, but are grouped together under the “Asian” category. Native Hawaiian and Other Pacific Islander data is included in the “Asian” category in many cases, thus compounding the heterogeneity.⁵ An increasing number of Americans identify as multiracial.⁶

While analyses based on the OMB categories can reveal important disparities in care, these categories are often not sufficiently descriptive to effectively target interventions. Using a very granular set of categories, however, also poses difficulties in terms of the statistical significance of a population analysis. In large part the level of granularity of the data collected should be a function of what the data will be used for, and it is possible to aggregate smaller categories in larger ones when required for analytical purposes.

Self-identification is generally considered the gold standard for categorizing people by race and ethnicity.⁷ Thus, the key issue is to ensure that participation and usability are factored into the design, development, and testing of questions so that patients (and providers where necessary) can understand and respond accurately and without resistance.

The Institute of Medicine has outlined requirements for standardization of race, ethnicity, and language data for health care quality improvement.⁸ A paper published several years ago on this topic suggested that a standard method is needed to allow patients to self-identify their race, ethnicity, and language using their own words rather than a pre-established list of categories.⁹ The researchers also recommend a standard approach for rolling up granular responses to the OMB categories for analytical and reporting purposes.

Language data to improve services

More than 46 million people in the United States do not speak English as their primary language. More than 21 million speak English less than “very well” and the proportion of the population that speaks a language other than English at home is increasing.¹⁰ Language barriers have a major impact on both the quality and the costs of health care. Patients with limited English-language proficiency encounter significant disparities in access to health care and are at increased risk of experiencing medical errors.¹¹

All federal programs and those receiving assistance from the federal government must take reasonable steps to ensure that persons who have limited English proficiency have meaningful access to the programs, services, and information that those entities provide. The DHHS Office of Minority Health issues standards on culturally and linguistically appropriate services in health care, referred to as CLAS.¹² These standards are designed to contribute to the elimination of health disparities by addressing the linguistic and cultural needs of patients in an appropriate manner. Clearly the language needs (and therefore the services such as translators that are required) will vary from region to region, in some cases from provider to provider.

Health care service providers need to know two pieces of information to best serve the language needs of their patients: how well the patient speaks English, and the patient's preferred language for talking about his or her health. The Institute of Medicine proposes assessing the matter with two questions: one asking whether a person rates his or her ability to speak English as less than "very well," and a second one to determine the language the patient prefers to use during health care encounters. The IOM also recommends that where possible and applicable, health care providers should collect information on the language the patient speaks at home and the language in which the patient prefers to receive written materials.¹³

It will also be important that there are methodologies developed for evaluating the effectiveness of addressing language and cultural needs in improving health outcomes and the quality of care. These methodologies should also consider the costs involved in providing language services and the cost-savings that such services can achieve.

Scope of data collection

ACA expands the scope of data collection and reporting requirements to all federally funded programs, and makes the Medicaid and CHIP programs subject to the same reporting requirements as Medicare.

Regardless of whether they receive federal funding or not, however, hospitals, community health centers, physician practices, health plans, and health care researchers all have a role to play in working with government to gather and analyze data.

Incentives are particularly needed to encourage health insurance plans to collect data on racial and ethnic disparities and to do this to agreed standards and methodologies so that the data can be used to address disparities and, ideally, shared with government and researchers. The development of these standards and methodologies should involve the relevant community stakeholders.

Health plans currently serving Medicare and Medicaid enrollees commonly obtain information on the race and ethnicity of beneficiary members from federal and state governments. This data has been described as containing only limited distinctions, however, and the quality and completeness of Medicaid data vary by state.¹⁴

Racial and ethnic data on commercially insured enrollees are not typically available from purchasers such as employers, so health plans must collect their own data.

A recent national survey indicates that only half of health plans attempt to collect this data.¹⁵ Sometimes this is inferred from postcodes and surnames, although this method is neither desirable nor particularly accurate. Even those plans with the most success in using direct methods have race and ethnicity data on only about 30 percent of their members.¹⁶

There are generally no legal barriers against collecting racial and ethnic data, despite often-voiced concerns from health plans.¹⁷ There is no federal prohibition and while six states have some restrictions about collecting data, these are limited, and apply only to the collection of such data as part of an application process. Data can, for example, be collected voluntarily or as part of a disease management program.

Most of the work that is done in this area by insurance funds is driven by the National Health Plan Collaborative. This was established in December 2004 and brings together 11 major health insurance companies, in partnership with organizations from the public and private sectors, including the Agency for Healthcare Research and Quality, to identify ways to improve the quality of health care for racially and ethnically diverse populations.¹⁸

Most physicians do not collect data on their patients' race and ethnic group. Collection is uncommon even in large group practices.¹⁹ Practices that do collect such data almost never use them to identify and address disparities or, for that matter, for any other clinically relevant purposes.²⁰

When queried, physicians variously thought that the collection of data on race and ethnic group would be expensive or time-consuming. Some voiced concerns about privacy, perceived legal barriers, or the discomfort of patients and staff in talking about race. But the most common and strongest objection to the routine collection of these data was that physicians saw no reason to do so, and indeed thought that knowing a patient's race and ethnic group is, or should be, clinically irrelevant.²¹

It is to be hoped that this attitude will change with increased education and awareness, along with expanded requirements for such data collection and utilization. For example, within-practice interventions targeting areas of disparities can have an overall positive effect on quality and thus contribute to increased reimbursement rates under pay-for-performance programs.²²

Standardization and coordination of DHHS data collection efforts

The key focus of this paper is around the provisions in ACA that increase the current requirements on HHS to collect racial and ethnic health care disparities data from the programs, activities, and surveys that it administers and funds. Some of this is currently reported back to HHS from health providers through initiatives that include the Medical Expenditure Survey, Hospital Compare, the Physician Quality Reporting Initiative, and Uniform Data System Reporting from Federally Qualified Health Centers.

In addition HHS does much original data collection through the National Center for Health Statistics and the surveillance functions of the Centers for Disease Control and Prevention. While there is some reporting on Medicaid and the Children's Health Insurance Program, ACA requires that data collecting and reporting mechanisms from the states for these programs are brought up to the same standards as for Medicare.

With a variety of data collection systems operating through several different HHS agencies, it will be critical to ensure that there are sufficient common standards and uniformity in how the data is collected to enable the sharing of data across agencies, as appropriate. There is clearly a leadership role here for the Office of Minority Health, which is reauthorized and expanded in ACA.²³

The report of a Study Panel on Medicare and Disparities convened by the National Academy of Social Insurance concluded that Medicare is obligated to take the lead in reducing disparities—both for its beneficiaries and throughout the health system.²⁴ However, the study panel also found that Medicare's efforts in this regard needed strengthening and made 17 recommendations to do this. To the extent that these recommendations have not yet been fully implemented, doing this should now become an urgent priority.

A recent report from the IoM provides guidance for standardization of Medicaid and CHIP data.²⁵ Efforts are underway in the Center for Medicaid and State Operations to enhance states' reporting of Medicaid and CHIP data. The CMSO has established an intra-agency, private, and public sector collaboration with states, various community-based organizations, stakeholders, and underserved communities interested in addressing health disparities. Information about best practices in health care disparities in Medicaid and CHIP is disseminated to the

forum and external organizations.²⁶ This work will need to be extended, and some states may require technical assistance to help them get these efforts up to the required standards.

Time and cost constraints

The implementation of any new data collection process will require effort. Addressing practical issues such as how and when to ask, what categories to use, how to code the data, and how to address common concerns, however, need not entail great expense. Free training tools are available to help providers implement new practices, such as that provided by the Health Research and Educational Trust, an affiliate of the American Hospital Association.²⁷

A major barrier to implementing improved data collection for some providers will be the need to reprogram their IT systems. The American Recovery and Reinvestment Act provides \$19 billion for health information systems and the “use of electronic systems to ensure the comprehensive collection of patient demographic data.” The “meaningful use” guidelines for e-health systems, which will determine whether providers, including physicians and hospitals, qualify for federal incentive payments, include the use of tools to collect patient demographic data.

The IOM has recommended that when awarding incentive payments, the CMS and others sponsoring payment incentive programs should take into account collection of the recommended data on race, ethnicity, granular ethnicity, and language need so these data can be used to identify and address disparities in care.²⁸ A variety of such systems are currently in place; some provide incentives for specific structural features such as e-health records and others for the collection and reporting of quality data. As these systems evolve and respond to the implementation of the provisions of ACA, they can incorporate the collection and use of data on race, ethnicity, and language for incentive payments linked to quality improvement or the achievement of specific goals for reducing disparities.

Alignment with national health priorities

Healthy People 2020, just released, establishes a set of Leading Health Indicators—goals and objectives with 10-year targets—to measure the health of the nation.²⁹ These indicators reflect the major health concerns in the United

States at the beginning of the 21st century. They were selected on the basis of their ability to motivate action, the availability of data to measure progress, and their importance as public health issues.³⁰

Each indicator has a number of objectives and sub-objectives. In Healthy People 2010 there were 498 population-based objectives and sub-objectives for which disparities among populations could be measured. But data are not available for all populations for each objective and sub-objective and tracking data is not always available to assess changes over time; only 195 objectives and sub-objectives have trend data for racial and ethnic groups.³¹

| Racial or ethnic group | Number of Healthy People 2010 objectives and sub-objectives for which data are collected |
|---|--|
| Hispanic | 330 |
| Black, non-Hispanic | 356 |
| White, non-Hispanic | 355 |
| American Indian/Alaska Native | 155 |
| Asian | 107 |
| Native Hawaiian and other Pacific Islanders | 43 |
| Combined Asian/Pacific Islander | 76 |
| Two or more races | 82 |

The Healthy People 2010 objectives encompass the Initiative to Eliminate Racial and Ethnic Disparities in Health, introduced by President Bill Clinton in 1998. The initiative focused on closing the gaps in health outcomes, particularly racial and ethnic disparities in diabetes, AIDS, heart disease, infant mortality, cancer screening and management, and immunizations. We can only assess progress against these goals, now more than a decade old, if the data are collected and evaluated regularly.

The data that are made publicly available through the annual National Healthcare Disparities Report do not allow data for key indicators such as immunizations (by vaccine) and cancer screening (by cancer) to be tracked by racial and ethnic group across the years. This means that tracking the success of initiatives to improve uptake of services and health outcomes over time is made more difficult.

Provider and patient concerns and perceptions

Concerns, real and imagined, from providers and patients can hinder the collection of racial and ethnic data. Providers, especially clinicians, are concerned about undermining the quality of patient-provider relationships. Many health plans are concerned that their ability to serve minority patients could be hampered if these population groups were to consider data collection efforts as an attempt to ration care or somehow tailor care in ways that are detrimental.³²

It is clearly critical that systems are in place to ensure that data are handled sensitively and properly to maintain patients' privacy and community trust.

While patients may have some perceptions about intrusion and concerns about the protection of privacy, most patients think health care providers should collect information about race and ethnicity. Many feel uncomfortable giving this information, however, especially those from minority groups. There is evidence that health care providers can increase patients' comfort levels by telling them this will be used to monitor quality of care. Much of patients' discomfort arises from fears that this information could be used to discriminate against patients, with African Americans most concerned about this.³³

Some of these fears may be well-founded, given that racial discrimination has figured prominently in the history of American medicine.³⁴ Evidence suggests that bias, prejudice, and stereotyping on the part of providers may contribute to health care disparities.³⁵

Efforts to improve the racial diversity and cultural sensitivity training of the health care workforce will help address patients' perceptions and concerns in this area.

Education and awareness about the need to address disparities

The IOM report makes the point that patients, administration staff, and health professionals need greater understanding about how the collection of race, ethnicity, and language data can help improve the quality of care delivered to patients.³⁶

Efforts to raise the public's awareness of racial and ethnic health care disparities have achieved only modest success. Nearly 60 percent of people surveyed in 2006 believed African Americans received the same quality of care as whites, and 50 percent believed Latinos received the same quality care as whites—similar to findings in a 1999 survey.³⁷

In contrast to the general public's continued lack of awareness, the level of awareness among physicians has risen sharply in recent years, presumably because of education efforts by government, medical colleges, and professional bodies. The majority—69 percent—of physicians said in 2002 that the health care system “rarely or never” treated people from minority groups unfairly. Less than a quarter—24 percent—of physicians in 2005 disagreed with the statement “minority patients generally receive lower quality care than white patients.”³⁸

What else is needed

There are several areas where additional data could contribute both to a better understanding of the causes of racial and ethnic health care disparities and to more effective interventions.

These include:

- Measures of patients' socioeconomic status such as income or education attained are useful to understand mediators of racial and ethnic disparities.³⁹ While it is possible to use geographic locators such as zip code to estimate socioeconomic status through geocoding, these methods are less precise than individual-level data.⁴⁰
- Patients' assessments of aspects of their care, including patient-provider communications, perceived biases and discrimination, and shared decision-making. A report from the Commonwealth Fund in 2006 made a number of recommendations for research in these areas that remain valid.⁴¹
- Improved measures of referral practices and timeliness of access to care, especially in those aspects of care where these issues are crucial, such as antenatal care, HIV infection, and a suspected diagnosis of cancer.
- A more widespread adoption of community-based participatory research approaches to improving health and reducing health disparities.⁴² While community participation in data collection is increasingly seen, less common is community participation in data analysis, the interpretation of findings, and the development and implementation of programs.

Conclusion

Defining and measuring health care disparities is a prerequisite for addressing the problems. Defining and measuring these disparities, however, requires navigating the intersections of health and medicine with poverty, race, and geography. This is a task fraught with difficulty and one that inevitably strays beyond the boundaries of health care.

It requires consensus among governments, health insurers, health providers, and consumers about the need to collect data; how this will be done in ways that are consistent across jurisdictions and address the needs and concerns of all stakeholders; and how the data will be analyzed, publicized, and used to close the gap on health care disparities.

Efforts to address disparities must acknowledge the significant heterogeneity within each of the federally defined racial and ethnic groups, and balance requirements for sufficient granularity to highlight local needs with the need for sufficiently robust statistical significance to drive population-based policies and programs.

Data are only useful when they become information and information is only valuable when it is used.⁴³ Researchers at Johns Hopkins University have stressed the need to improve the science of evaluating interventions to reduce disparities.⁴⁴ The key question is what actually works for reducing racial and ethnic disparities in health care. The answers range from individual provider and patient interventions to improving the organization of health care and changing community behaviors. Despite an accumulating body of literature addressing racial and ethnic disparities in health care, there have been few published studies of interventions that have been successful in eliminating these disparities.

Some of these interventions will involve generic quality improvement approaches; others will be culturally tailored for targeted subpopulations. The relative effectiveness of the population-based general performance incentives in reducing disparities needs to be compared with that of more specific incentives.

It is imperative that implementation of the increased reporting requirements of ACA is accompanied by efforts to increase awareness of the importance and value of this data, by requirements that will protect patients' sensibilities around race and ethnicity, by strong confidentiality provisions, and by needed guidelines and resources, including health IT resources.

Strong leadership and coordination of the data collection and utilization efforts will be critical to the efforts to eliminate health care disparities. It is assumed that the Office of Minority Health, which is reauthorized and expanded in ACA, will play a key role in this regard.⁴⁵ The profile for minority health issues is also boosted by the transition of the National Center on Minority Health and Health Disparities to the National Institute on Minority Health and Health Disparities.⁴⁶

Appendix: OMB requirements for the collection of racial and ethnic data⁴⁷

In 1997, the Office of Management and Budget released the revised standards for the collection of race and ethnicity known as Statistical Directive 15 and required federal agencies to comply with these by January 2003. These new standards included self-identification as the preferred data collection method and the ability to report multiple races for an individual. These standards were further revised in 2003.

Development of these data standards stemmed in large measure from the enforcement of civil rights laws. Data were needed to monitor equal access in housing, education, employment, and other areas for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity. The categories thus represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in the United States.

The minimum race categories for the 1997 OMB standards for collecting data on race and ethnicity are: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; White. The minimum ethnicity categories are: Hispanic or Latino; not Hispanic or Latino. The OMB standards allow for additional race categories to be collected, although they must be additive (i.e., non-overlapping subcategories) within the minimum set of race categories. Finally, the respondent instructions specify “Mark (X) one or more races” to indicate what this person considers himself or herself to be, which allows for multiple-race responses.

The 2003 revision of the standards for vital certificates recommends the following race and ethnicity categories, which are in principle the same as those used for the 2000 and 2010 decennial censuses:

1. Hispanic Origin

- No, not Spanish/Hispanic/Latino
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino (with space to write in group)

2. Race

- White
- Black or African American
- American Indian or Alaska Native (with space to write in principal tribe)
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian (with space to write in race)
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander (write in race)
- Other (write in race)

The current format allows for multiple-race reporting for an individual, but not multiple ethnicities.

There is an issue of comparability between data based on the 1997 race and ethnicity categories and the more detailed 2003 categories. The National Center for Health Statistics, with the help of the Census Bureau, has made efforts to estimate the resulting respondent differences and mitigate the comparability issues.⁴⁸

Other data collection requirements

For birth certificates, currently the race of the newborn is not collected and, for reporting purposes, it is based on the race of the mother, which she is to self-report.

For death certificates, it is usually the responsibility of the funeral director to elicit race and ethnicity of the decedent from a family member or responsible party.

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