The United States is in the midst of a profound demographic transition. By 2050, non-Hispanic whites will account for less than half the U.S. population and members of racial and ethnic minority groups will be in the majority. This shift is also reflected in the fact that the United States is now home to at least 20 million people who have low proficiency in the English language. Although there are differences among minority groups, all these populations face special challenges. Members of minority groups have higher rates of disease, poorer health, and more limited access to care than their white counterparts. They account for half of the uninsured population\(^1\) and 58% of the low-income uninsured population.\(^2\) Even when they have coverage, minority patients are at risk for receiving lower-quality medical and surgical care than white patients.\(^3\) The factors underlying these inequities are complex and go far beyond the health care system, but any meaningful reform must, at a minimum, confront disparities in care.

The major reform proposals aim to dramatically increase coverage. The result might be a lessening of racial and ethnic disparities, given that lack of insurance has tangible effects on health and health care. But it is not the entire solution. For instance, although Medicare has been instrumental in improving equity, marked ethnic and racial disparities in care persist within the program.\(^3\) We could be faced with an influx of millions of newly insured members of minority groups into a health care system that is unable or unwilling to provide them with high-quality care. Without an explicit focus on equity, reform will leave millions of Americans behind.

To begin with, the health care system must be given the tools to measure and improve the quality of care that minorities receive. Today, most doctors, hospitals, and health plans do not analyze the quality of care delivered according to patients’ race, ethnic group, or primary language. This lack of data makes it impossible to identify harmful variation or to develop strategies to reduce disparities. But models now exist for such action, and reform can build on these efforts.

The National Health Plan Collaborative, a partnership of public and private organizations including nine major health plans, ob-
### Key Elements of Recent Laws Affecting Data on Patients’ Race, Ethnic Group, and Language.

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<tr>
<th>Law</th>
<th>Requirement</th>
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<td>Medicare Improvements for Patients and Providers Act of 2008 (MIPPA)</td>
<td>Requires the secretary of health and human services to evaluate methods for ongoing data collection and the measurement and evaluation of disparities, as well as the assessment of performance according to patients’ race, ethnic background, and sex. The secretary is directed to implement the best measurement approaches. The Office of Inspector General at the Department of Health and Human Services must report within 2 years on Medicare providers’ compliance with standards for culturally and linguistically appropriate services. The secretary is mandated to address deficiencies in this area.</td>
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<td>American Recovery and Reinvestment Act of 2009</td>
<td>Creates the Health Information Technology for Economic and Clinical Health Act to support the development of health information technology (IT) and the Health IT Policy Committee, which will make recommendations on the development of electronic data-collection methods that provide for the collection of data on patients’ race, ethnic background, primary language, and sex.</td>
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<tr>
<td>House Leadership Bill, Affordable Health Care for America Act (H.R. 3962)</td>
<td>Would require the development of quality measures to assess health disparities, including those associated with race, ethnic group, and language. Would require data collection standards for assessing health disparities, the use of Office of Management and Budget standards for data on race and ethnic group, and the development of standards for collecting data on primary language. Would require a report on the populations that make use of trauma care centers; the report must include patient data on income, race, and ethnic group. Would require a study to examine the use and extent of language services for Medicare beneficiaries who have limited proficiency in English, and analysis of possible Medicare payment systems for language services. Would provide Medicare demonstration grants to reimburse culturally and linguistically appropriate services.</td>
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<td>Senate Bill, Patient Protection and Affordable Care Act (amendment to House bill H.R. 3590)</td>
<td>Would require federally conducted or supported health care or public health programs, activities, or surveys, to collect and report data on race, ethnic group, sex, and primary language, within 2 years of enactment. Would require a study of the effect of the hospital value-based purchasing program, including its effect on diverse Medicare populations, with the use of data on race and ethnic group. Would require the use of Office of Management and Budget standards for race and ethnic group and the development of standards to measure primary language. Would require Medicaid and the Children’s Health Insurance Program to collect data on disparities in health care services and performance on the basis of race, ethnic group, sex, primary language, and disability status. Also would require the identification of best approaches to collecting and evaluating such data.</td>
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Lawmakers have begun to recognize the importance of addressing equity and are building on these models. Both the Medicare Improvements for Patients and Providers Act of 2008 and the American Recovery and Reinvestment Act of 2009 contain provisions that require the collection and evaluation of data on patients’ race and ethnic group (see table). These laws have set the stage for pending efforts. Congress is currently considering health care reform proposals that have implications for ensuring equity for minority patients. Both the House bill, the Affordable Health Care for America Act, and the Senate bill, the Patient Protection and Affordable Care Act, propose the development and implementation of improved quality measures and the collection and analysis of data on race, ethnic group, and language as part of efforts to reduce disparities. However, these proposals apply only to federally funded programs (Medicare, Medicaid, and the Children’s Health Insurance Program, as well as any new public insurance plan) and the health plans that contract with them. In addition, other elements of these proposals could have unintended consequences that would make it harder for minority patients to obtain the best health care. The bills would accelerate pay-for-performance and transparency programs that are designed to promote quality improvement, but without thoughtful design, such programs could boomerang: doctors, hospitals, or health plans could discover that it is in their interest to avoid high-risk patients (who are often members of minority groups) whose outcomes could adversely affect their performance ratings. If decreased rates of re-
hospitalization were a performance goal, for instance, providers might wish to avoid poor, sick minority patients who are likely to lack access to good primary care. Public hospitals and clinics, which already have inadequate resources, could also face funding cuts if the quality of their care did not reach certain thresholds; such cuts would further undermine quality. Reform should include incentives for improvement, not just penalties for poor performance.

Health care reform offers an opportunity to address disparities productively, but four things will need to happen. First, it is essential that newly covered populations be enrolled in health plans that meet rigorous, nationally set quality benchmarks. Because so many uninsured people are members of minority groups, expanding coverage will mean reducing disparities in coverage. But it will also require substantial subsidies, given the low incomes of so many of those who are uninsured. Denying insurance subsidies to certain groups, such as undocumented immigrants, will serve only to maintain disparities. And since millions of minority patients may be brought into the health care system, it is important to ensure that health plans are prepared to meet their needs. Disparities in health status and outcomes will probably be even more apparent in newly covered populations, and these populations deserve equitable, effective, and timely care.

Second, we need to understand who our patients are and the quality of care they receive. All health plans and providers that are regulated by the federal government or are direct or indirect beneficiaries of public subsidies should be required to collect data on patients’ race, ethnic group, and language in a uniform fashion, as recently recommended by the Institute of Medicine.8 There is a precedent for such a requirement: since 1990, almost all entities that give home loans in the United States have had to report applicants’ race.

Third, meaningful incentives should be implemented to encourage providers and plans to address disparities. For example, physicians and hospitals could be paid to report information on quality that is stratified according to patients’ race or ethnic group. This approach would be a logical extension of that used in existing federal programs such as the Reporting Hospital Quality Data for Annual Payment Update program and the Physician Quality Reporting Initiative, which include “pay-for-reporting” incentives. Eventually, the collected data could be made publicly available — although such a move would encounter some opposition. Pay-for-performance programs will have to reward improvement rather than absolute performance, so as not to erode the funding needed for improving care in settings with fewer resources. The Premier Hospital Quality Incentive Demonstration of the Centers for Medicare and Medicaid Services has shown the promise of such an approach.

Fourth, substantial investment should be made in the safety net. If we want to improve the care of minority patients, we need to go where they are — federally qualified health centers, public and inner-city hospitals, and a certain segment of physician practices. Providers who treat a disproportionate number of minority patients often do not achieve maximal performance.9 The American Recovery and Reinvestment Act of 2009 provided funding to health centers and other Medicaid providers to improve health information technology, but a transformation of the safety net must go beyond technology and ensure that these providers implement rigorous interventions such as adherence to clinical guidelines and coordination of care for the chronically ill.

Health care reform provides a unique opportunity to reverse a legacy of inequality in health and health care. This chance should not be squandered.

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From the Center for Health Care Quality, George Washington University School of Public Health and Health Services, Washington, DC. The opinions expressed here are solely those of the authors.

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