
Special Section

Race and Ethnicity

Health Care Organizations' Use of Data on Race/Ethnicity to Address Disparities in Health Care

David R. Nerenz, Kelly A. Hunt and José J. Escarce

Publication of the Institute of Medicine report *Unequal Treatment* (Smedley, Stith, and Nelson 2003) represented a key transition point in the field of disparities research. Up to that point, the vast majority of studies had been descriptive in nature, documenting racial/ethnic and socioeconomic disparities in specific domains of clinical care. Researchers, funding agencies, and health care policy-makers agree, however, that studies of racial/ethnic disparities should move beyond documenting disparities to focus on either understanding the causes of disparities or the development and testing of interventions designed to reduce or eliminate disparities. Such a movement is already occurring, as several recent papers provide sophisticated analyses of either underlying mechanisms or approaches to eliminating disparities (Earle et al. 2002; Tammemagi et al. 2004)

Understanding these underlying mechanisms, though, is only a step toward actually reducing or eliminating disparities. Given the range of potential causes of disparities, elimination of disparities will require action at several levels: federal policy; state and local policy; public and private purchasers of health care; health plans; large organizational providers like hospitals and medical groups; individual providers; patients and family members; and community groups.

The potential actions of federal, state, and local policy-makers have been described elsewhere (Lurie, Jung, and Lavizzo-Mourey 2005). Governmental action by itself is unlikely to eliminate disparities in health care, however, as many of the proximal causes of disparities are based in policies and behaviors of the health care delivery system that are beyond the reach of government. Reduction of racial and ethnic disparities in the quality of health care will

require action by health care organizations—health plans, hospitals, medical groups, and individual health care providers—as well. Many initiatives addressing health care disparities will involve engaging health care organizations that have an existing infrastructure for quality measurement and quality improvement in the effort to reduce disparities (Nerenz 2005).

In order to design and test interventions whose purpose is reducing disparities in care, these organizations need accurate racial and ethnic data on the populations they serve. In addition to a quality measurement and quality improvement infrastructure, many health care organizations have, or can obtain, data on the race/ethnicity of the members or patients they serve. Experts have raised legitimate concerns about the accuracy and completeness of racial and ethnic data in many settings, though the data that do exist have been adequate for a wide range of projects to date (Bierman et al. 2002).

A general “template” for projects to address disparities at the local organizational level has emerged from projects set in the context of managed care plans (Nerenz and Darling 2004). Obtaining data on race/ethnicity of plan members or patients is an essential part of that template, as subsequent steps in the process (e.g., creating quality of care measures stratified by race/ethnicity, creating culturally appropriate patient education materials) depend on having that information at the individual patient or member level.

THE PAPER SERIES

In February of 2004, the Robert Wood Johnson Foundation (RWJF) commissioned the preparation of five papers on the general theme of health care organizations' use of data on race/ethnicity for purposes of eliminating racial/ethnic disparities in care. This project was part of a larger Foundation strategy toward understanding the racial/ethnic data collection practices of providers as well as the barriers providers faced in gathering this information. Through these papers, RWJF hoped to inform the field about the adequacy of current racial and ethnic categories, whether geocoding and surname recognition are adequate alternatives for collecting self-reported race/ethnicity, how plans

Address correspondence to David R. Nerenz, Ph.D., Acting Director, Center for Health Services Research, Henry Ford Health System, 1 Ford Place (3A), Detroit, MI 48202. Kelly A. Hunt, M.P.P., Research Officer, is with The Robert Wood Johnson Foundation, Princeton, NJ. José J. Escarce, M.D., Professor of Medicine, is with the David Geffen School of Medicine, University of California, Los Angeles, Westwood, CA.

and providers could use racial and ethnic data to address disparities, and what key issues face the future of racial and ethnic data collection.

Four of the papers now appear in this issue of *Health Services Research*. (One of the papers was published in the special disparities issue of *Health Affairs* in March of 2005.) While these papers were going through the peer review process, another paper was prepared independently that was very closely related to the others, and is included in this special section as well.

The papers are all related to the general theme of health care organizations' use of data on race/ethnicity to address disparities. Four of the papers in this special section focus on specific ways to obtain data on race/ethnicity of patients or health plan members; the other paper focuses on some of the legal, technical, and ethical issues that arise when data on race/ethnicity are used to identify disparities and/or to organize projects to reduce or eliminate disparities. The sequence of topics includes:

Paper 1—U.S. Census Data and Other Federal Data Sources

The paper by Drs. Sequist and Schneider discusses race/ethnicity data in the U.S. Census, in CMS, and in a number of large national health and health care surveys. The paper describes the completeness and accuracy of data in the various federal sources, and discusses how health care organizations can obtain and use this information to gain insight on disparities issues, either in their own organizations or in their local service areas.

Paper 2—Use of Surname Recognition Methods to Enhance Identification of Hispanic Patients in Claims Data Sets

Dr. Wei's paper describes some of the problems with under-identification of Hispanic/Latino patients in administrative data sets, specifically Medicare, and then goes on to show how this identification can be improved through the use of software that infers Hispanic ethnicity on the basis of distinctive characteristics of Hispanic surnames. This technology is readily available to health plans and hospitals, so local organizations should be able to replicate the increased accuracy of identification illustrated in Dr. Wei's study.

Paper 3—Indirect Methods of Obtaining Race/Ethnicity Data

The paper by Drs. Fiscella and Fremont describes in more general terms some "indirect" methods for obtaining (or inferring) race/ethnicity information on defined groups of individuals like members of a health plan or patients in a medical group. The emphasis of the paper is on geocoding and surname

recognition systems that support inferences about race/ethnicity based on name and address information that health care organizations already have.

Paper 4—Asking Patients About Race/Ethnicity

Dr. Hasnain-Wynia and colleagues review what is known about obtaining race/ethnicity information directly from patients or health plan members. The paper summarizes the findings of recent surveys of health care organizations' current policies and practices, reviews recent work on ways to ask patients for this information, and describes examples from specific hospitals and health plans.

Paper 5—Looking Forward—Legal, Technical, and Ethical Issues

The paper from Drs. Lurie and Fremont reviews many of the legal and ethical issues involved in health care organizations' collection and use of race/ethnicity data (e.g., HIPAA). It also identifies potential solutions to some of the technical barriers to use of race/ethnicity data at the individual organization level (e.g., small sample sizes in analyses, missing or inaccurate race/ethnicity data, use of multiracial or "other" categories). This paper draws extensively on material from the other papers in the set, and serves as an excellent summary of next steps as health care organizations embark on the task of eliminating disparities.

WHAT'S NEXT IN RESEARCH ON RACIAL/ETHNIC DISPARITIES IN HEALTH CARE?

Better Data on Race/Ethnicity and Other Demographic Characteristics of Patients or Plan Members

The papers describe ways in which available demographic data can be used effectively, but they also point out problems with the completeness, accuracy, or level of detail of those data. The processes through which data are collected, the location, time, and context of data collection, the categories or metrics used, and the extent to which individuals can use their own terms to describe themselves are all potential topics for research.

Is It Race/Ethnicity or Is It Something Else?

Others have pointed out the importance of understanding the relative contributions of race/ethnicity and SES to disparities in care. Isaacs and Schroeder (2004) argue that class has been seriously "understudied" as a contributing factor to health and health care disparities (relative to race/ethnicity), in part because data on class (and the specific components thereof) are not as readily

available in large survey or administrative data sets. Kawachi, Daniels, and Robinson (2005) make a similar argument, but emphasize the potential independent contributions of both race and class to disparities. They point out how, in some circumstances, race can be a proxy for class, but that race and class can affect health care through different causal pathways, so that they should be studied as separate concepts, even if they are closely correlated in some study settings. Similar questions can be raised about the roles of primary language, acculturation, geographic variation, or specific elements of SES (e.g., formal education or literacy) as the “real” reasons for observed racial/ethnic disparities.

What Works?

Understanding a problem is one thing; being able to actually do something about it is another. The large number of potential underlying reasons for disparities suggests that there will be no single or dominant solution to the disparities problem. It seems more likely that there will be a variety of legitimate approaches, whose specific features will have to be tailored to local circumstances. We are just beginning to learn about the actual or potential positive effects of a variety of types of interventions designed to address disparities. The RWJF, in its “Finding Answers” program, is seeking to identify and disseminate promising approaches to intervention (“Finding Answers” 2006). A similar effort at the Massachusetts General Hospital seeks to identify, test, and disseminate information about effective interventions (Robert Wood Johnson Foundation 2006). These efforts at collecting and disseminating information about successful interventions are particularly important to the extent that organizations adopt a quality improvement, as opposed to health services research, approach to addressing disparities. Successful QI projects will frequently not have all of the essential features for publication in peer-reviewed journals (Berwick 1996; Nerenz, Stoltz, and Jordan 2003), so alternative methods of information exchange will have to be developed to complement the peer review process and make information available to the entire range of individuals in health care organizations (health plan medical directors, QI leaders, clinic administrators) whose active participation in disparity-reduction efforts is crucial to success.

SUMMARY

The set of papers should provide a useful guide to those in health care organizations who wish to take the essential first steps toward identifying and

eliminating disparities in care. They should be equally useful to researchers who are evaluating these efforts, either in collaboration with local health care organizations using data at that level, or in the more aggregate sense of using state or local data sets to track trends in disparities. The papers will not be the final word on these topics, though, and we look forward to continued exploration, challenge, dialogue, and improved understanding about how disparities in care can be eliminated.

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REFERENCES

- Berwick, D. M. 1996. "Harvesting Knowledge from Quality Improvement." *Journal of the American Medical Association* 275 (11): 877-8.
- Bierman, A. S., N. Lurie, K. S. Colins, and J. M. Eisenberg. 2002. "Addressing Racial and Ethnic Barriers to Effective Health Care: The Need for Better Data." *Health Affairs* 21 (3): 91-102.
- Earle, C. C., P. J. Neumann, R. D. Gelber, et al. 2002. "Impact of Referral Patterns on the Use of Chemotherapy for Lung Cancer." *Journal of Clinical Oncology* 20 (7): 1786-92.
- Finding Answers: Disparities Research for Change. 2006. [accessed on April 10, 2006] available at <http://www.solvingdisparities.org>
- Isaacs, S.L., and S. A. Schroeder. 2004. "Class—The Ignored Determinant of the Nation's Health." *New England Journal of Medicine* 351 (11): 1137-42.
- Kawachi, I., N. Daniels, and D. E. Robinson. 2005. "Health Disparities by Race and Class: Why Both Matter." *Health Affairs* 24 (2): 343-52.
- Lurie, N., M. Jung, and R. Lavizzo-Mourey. 2005. "Disparities and Quality Improvement: Federal Policy Levers." *Health Affairs* 24 (2): 354-64.
- Nerenz, D. R. 2005. "Health Care Organizations' Use of Race/Ethnicity Data to Address Quality Disparities." *Health Affairs* 24 (2): 409-16.
- Nerenz, D. R., and D. Darling. 2004. "Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project." Final Report for Project 250-02-0010. Rockville, MD: Bureau of Primary Health Care, HRSA.
- Nerenz, D. R., P. K. Stolz, and J. Jordan. 2003. "Quality Improvement and the Need for IRB Review." *Quality Management in Health Care* 12 (3): 159-70.

- Robert Wood Johnson Foundation. 2006. "Disparities Learning Network: Tracking and Disseminating Proven Interventions to Decrease Disparities and Improve Quality of Care among Minorities." [accessed on April 10, 2006] available at <http://www.rwjf.org/portfolios/grant.jsp?id=53709&iaid=133>
- Smedley, B. D, A. Y Stith, and A. R. Nelson, (Eds.) 2003. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press.
- Tammemagi, C. M., C. Neslund-Dudas, M. Simoff, and P. Kvale. 2004. "Lung Carcinoma Symptoms—An Independent Predictor of Survival and an Important Mediator of African-American Disparity in Survival." *Cancer* 101 (7): 1655–63.