

BUILDING AN ORGANIZATIONAL RESPONSE TO HEALTH DISPARITIES



COMPENDIUM OF RESOURCES FOR STANDARDIZED DEMOGRAPHIC AND LANGUAGE DATA COLLECTION

Collecting standardized patient demographic and language data across health care systems is an important first step towards improving population health. Comprehensive patient data on race, ethnicity, language, and disability status is key to identifying disparities in quality of care and targeting quality improvement interventions to achieve equity. Here, you will find an overview of:

- Minimum standards for data collection as outlined by the U.S. Department of Health and Human Services;
- Best practices and guidelines for health care organizations in implementing standardized data collection, including information to address key challenges in collecting this data;
- Training tools and webinars to help health care organizations educate their staff on the importance of standardized data collection and best practices for data collection; and
- Sentinel articles and books that provide in-depth discussion of issues, challenges, recommendations, and best practices in standardized data collection.

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RACE, ETHNICITY, & LANGUAGE DATA COLLECTION RESOURCES

A robust body of guidance and tools has been developed for the collection of Race, Ethnicity, & Language (REaL) data in health care settings. Organizations are increasingly collecting these data to meet regulatory requirements and build a foundation for monitoring racial and ethnic disparities, as well as disparities in quality of care due to language barriers. Variation in the methods used to collect REaL data, and the accuracy and reliability of the data collected, call for increased awareness and implementation of best practices and guidelines for standardized collection of REaL data. The following resources and tools offer guidance to hospitals, health plans, and other health-related organizations interested in implementing or improving REaL data collection.

MINIMUM STANDARDS FOR REAL DATA COLLECTION

The [Office of Management and Budget](#) (OMB) has developed standardized questions on race and ethnicity required for reporting by federal agencies and recipients of federal funds.^{1,2} To ensure data quality, OMB advises collecting race and ethnicity data using two questions, with ethnicity being collected first.

The OMB racial categories are:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

The OMB categories for ethnicity are:

- Hispanic or Latino
- Not Hispanic or Latino

Respondents may select from one or more racial categories. These categories represent the minimum standard, and OMB encourages the collection of more granular data using categories that can be aggregated back to the minimum categories.^{2,3}

Additionally, [Section 4302](#) of the [Affordable Care Act](#) requires any data standards published by the U.S. Department of Health and Human Services (HHS) to comply with the OMB standards. HHS developed [data standards](#) that provide additional granularity within the OMB standard categories of Asian and Native Hawaiian or Other Pacific Islander, as well as for respondents who are of Hispanic, Latino/a, or Spanish origin.

In addition to race and ethnicity, the data collection standards include a question for capturing English language proficiency and optional questions for language spoken at home:

Data Standard for Primary Language:

- How well do you speak English?
 - Very well
 - Well
 - Not well
 - Not at all

Language Spoken Standard (optional):

- Do you speak a language other than English at home?
 - Yes
 - No
- For persons speaking a language other than English (answering yes to the question above):
What is this language?
 - Spanish
 - Other language (Identify)

To accompany the standards, HHS has developed an [explanation of the data standards](#), as well as [guidance for implementation](#).

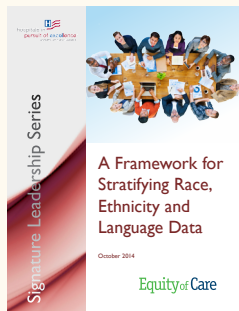
While the collection of more precise REaL data may be needed to identify disparities in care for specific groups, data collection efforts should, at a minimum, conform to the standards outlined by the OMB and required by Section 4302 of the Affordable Care Act.

REFERENCES

1. Office of Management and Budget. DIRECTIVE NO. 15 – Race and Ethnic Standards for Federal Statistics and Administrative Reporting. 1977; ftp://ftp.fcc.gov/pub/Bureaus/OSEC/library/legislative_histories/1195.pdf. Accessed December 1, 2015.
2. Office of Management and Budget. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. 1997; https://www.whitehouse.gov/omb/fedreg_1997standards. Accessed December 1, 2015.
3. Weissman JS, et al. *Commissioned Paper: Healthcare Disparities Report*; 2012.

A FRAMEWORK FOR STRATIFYING RACE, ETHNICITY, AND LANGUAGE DATA

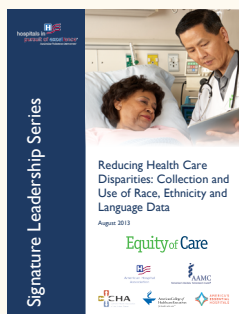
American Hospital Association, Equity of Care



Collecting and stratifying patient REaL data is crucial for hospitals and health systems to understand the populations they serve and implement the appropriate interventions to improve quality of care. While each health care system will stratify data in different ways to meet its own institutional needs, using the five-step framework recommended by this report will help systems to stratify REaL data to more effectively identify health care disparities. This report summarizes the framework and provides dashboard templates.

REDUCING HEALTH CARE DISPARITIES: COLLECTION AND USE OF RACE, ETHNICITY AND LANGUAGE DATA

American Hospital Association, Equity of Care



This guide addresses both the collection and implementation of REaL data collection. The guide provides a four-step approach to obtaining accurate data: determine appropriate data categories, develop methodology for data collection, train staff members on methodology, and assign accountability and monitor progress of data collection efforts. The guide also provides recommendations on the benefits of implementing REaL data collection within healthcare organizations.

RACE, ETHNICITY, AND LANGUAGE DATA: STANDARDIZATION FOR HEALTH CARE QUALITY IMPROVEMENT

Institute of Medicine



In this report the Institute of Medicine goes beyond standard OMB categories and provides guidance and examples of granular categories for REaL data collection.

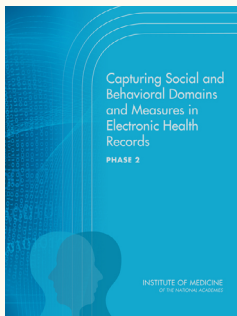
Key recommendations include:

- Expanding the six OMB race categories to include a “some other race” option.
- Including granular ethnicity categories that reflect the population of interest.
- At minimum, collecting data on a patient’s spoken English language proficiency.

REPORTS CONT.

CAPTURING SOCIAL AND BEHAVIORAL DOMAINS AND MEASURES IN ELECTRONIC HEALTH RECORDS: PHASE 2

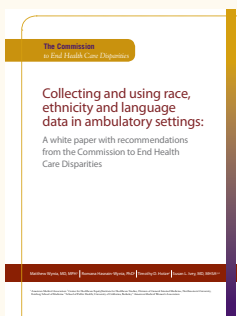
Institute of Medicine



This report explores and provides rationale for including social determinants in the electronic health record and shares examples of how physicians can utilize this technology to improve the health of their patients. The domains outlined in the report include sociodemographic domains, psychological domains, behavioral domains, individual level social relationships and living conditions, and neighborhoods/community domains. The report also outlines various organizational challenges to including these measures in electronic health records.

COLLECTING AND USING RACE, ETHNICITY, AND LANGUAGE DATA: A WHITE PAPER WITH RECOMMENDATIONS FROM THE COMMISSION TO END HEALTH CARE DISPARITIES

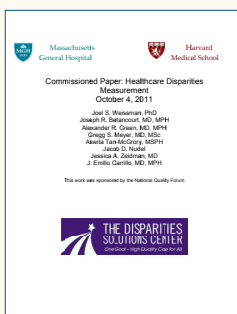
American Medical Association



Collecting valid and reliable demographic data on patients served in ambulatory practices is the first step in identifying and eliminating health care disparities. This report details the importance of collecting demographic data as well as recommendations on how to do so. This report aims to guide providers, Electronic Health Record (EHR) systems, policymakers, purchasers, hospitals, and health plans in data collection by discussing the value of these efforts in directly improving ambulatory practices.

HEALTH DISPARITIES MEASUREMENT

The Disparities Solutions Center, Massachusetts General Hospital



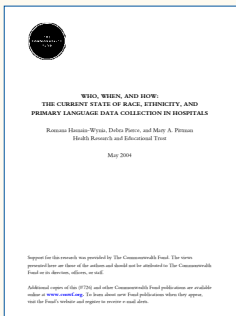
This report provides practical recommendations for healthcare organizations to increase their portfolio of race, ethnicity, and language data collection strategies and use that data to develop disparities-sensitive measures. This report is intended to guide organizations in disparities and quality measurement through the following:

- Building the foundation for data collection
- Determining measures and indicators to measure
- Methodological approaches to measuring and monitoring disparities
- Public reporting of healthcare disparities and priorities and options for quality improvement

REPORTS CONT.

WHO, WHEN, AND HOW: THE CURRENT STATE OF RACE, ETHNICITY, AND PRIMARY LANGUAGE DATA COLLECTION IN HOSPITALS

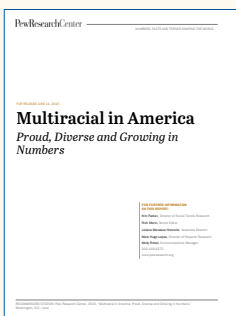
The Commonwealth Fund, Health Research and Educational Trust



This report summarizes the results of the nationwide American Hospital Association Annual Survey. The survey aimed to identify the number of hospitals that collect race and ethnicity data, how and why this data is collected, which categories are used, and barriers and concerns related to race and ethnicity data collection. One thousand hospitals were also interviewed to provide a summary of recent developments and a current view from the field of data collection.

MULTIRACIAL IN AMERICA: CHAPTER 1: RACE AND MULTIRACIAL AMERICANS IN THE U.S. CENSUS

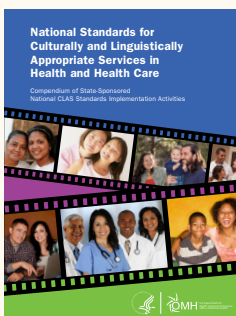
Pew Research Center



Collecting and stratifying patient REaL data is crucial for hospitals and health systems to understand the populations they serve and implement the appropriate interventions to improve quality of care. Using the five-step framework recommended by this report will help systems to stratify REaL data to more effectively identify health care disparities. This report summarizes the framework and provides dashboard templates.

COMPENDIUM OF STATE-SPONSORED NATIONAL CLAS STANDARDS IMPLEMENTATION ACTIVITIES TRACKING CLAS TOOL

U.S. Department of Health and Human Services, Office of Minority Health



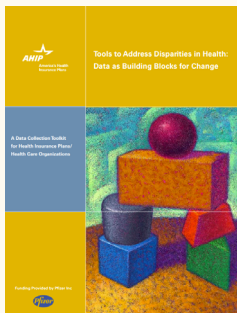
The U.S. Department of Health and Human Services recently released the first compendium of activities undertaken by states to implement the National Culturally and Linguistically Appropriate Services (CLAS) Standards, which include the collection of patient race, ethnicity, and language data. The report includes an overview of the National CLAS Standards, recommendations for improving state-sponsored implementation, and detailed findings from each state's activities.

The [Tracking CLAS Tool](#), is an interactive map that identifies state efforts to implement CLAS standards, including legislation related to cultural competency training for health professionals and state-sponsored implementation activities as of 2015.

REPORTS CONT.

TOOLS TO ADDRESS DISPARITIES IN HEALTH: DATA AS BUILDING BLOCKS FOR CHANGE

America's Health Insurance Plans



This report provides rationale for collecting and analyzing REaL data and provides detailed guidelines on how to collect this data. The report also summarizes federal and state regulations, policies, and stakeholder perspectives on data collection. Examples of strategies from insurance plans are also provided as well as other resources for organizations seeking to implement REaL data collection.

RACE AND ETHNICITY DATA COLLECTION: BEYOND STANDARDIZATION

Joint Center for Political and Economic Studies



This brief provides information on the history of race and ethnicity definitions, outlines the U.S. Department of Health and Human Services and the Office of Management and Budget REaL data collection standards, and reconciles this information with the Institute of Medicine recommendations. The brief also provides recommendations on how HHS can aid in mitigating issues with REaL data collection and clarifying the data collection standards for different organizations.

HEALTH EQUITY AND RACE AND ETHNICITY DATA: HOW RACE AND ETHNICITY DATA IS COLLECTED AND USED

The Colorado Trust

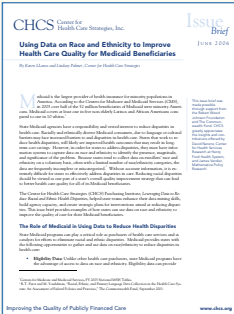


This report outlines the importance of collecting race and ethnicity data and provides guidance for addressing barriers to implementing this data collection. Case studies from organizations participating in the Colorado Trust's Equality in Health initiative are highlighted to provide insight on how these organizations have adapted to collect REaL data. In addition to data collection, the report discusses laws and regulations, staff training, data analysis, data reporting, and factors contributing to successful data collection.

REPORTS CONT.

USING DATA ON RACE AND ETHNICITY TO IMPROVE HEALTH CARE QUALITY FOR MEDICAID BENEFICIARIES

Center for Health Care Strategies



This issue brief emphasizes the importance of reliable data and provides examples of how state programs can utilize race and ethnicity data to improve healthcare for Medicaid beneficiaries. The brief describes how state agencies, managed care organizations, and providers can aid Medicaid agencies in: obtaining information on the race and ethnicity of their enrollees, using data to create reports stratified by race and ethnicity, incorporating disparities reduction goals into quality improvement projects, and developing new quality improvement projects designed to reduce disparities in healthcare.

THE TWO OR MORE RACES POPULATION: 2010 CENSUS BRIEFS

United States Census Bureau



This report indicates that people who reported multiple races grew by a larger percentage than those reporting a single race between 2000 and 2010. The report also summarizes the race and ethnicity definitions and concepts used in the 2010 census.

BUILDING AN ORGANIZATIONAL RESPONSE TO HEALTH DISPARITIES

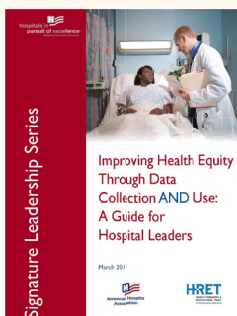
Centers of Medicare and Medicaid Services, Office of Minority Health



Disparities in the quality of care that minority populations receive, even when they have the same insurance, socioeconomic status, and comorbidities as their non-minority counterparts are well documented. Evidence based interventions are an effective tool for reducing health disparities and lowering cost. Therefore, focused quality improvement efforts should be targeted to populations at risk for disparities. Following are resources and concepts key to addressing disparities and improving health care quality.

IMPROVING HEALTH EQUITY THROUGH DATA COLLECTION AND USE: A GUIDE FOR HOSPITAL LEADERS

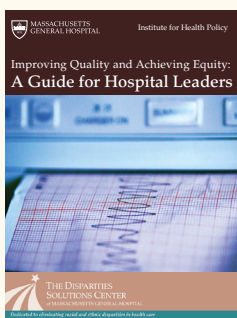
Health Research and Educational Trust



This guide provides recommendations for healthcare organizations to streamline their data collection process from exploratory interviews with four hospitals as well as an extensive literature review. Strategies are provided for utilizing this patient data in a meaningful way, such as developing interventions and increasing access for underserved populations.

IMPROVING QUALITY AND ACHIEVING EQUITY: A GUIDE FOR HOSPITAL LEADERS

The Disparities Solutions Center, Massachusetts General Hospital



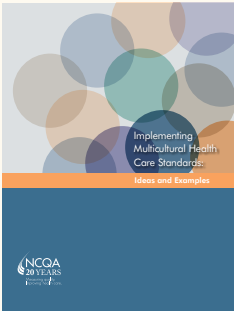
This report outlines the importance of using existing systems within healthcare organizations to identify medical errors for patients with limited English proficiency. Recommendations are provided to improve these systems to accurately capture root causes and risk factors for patients, including:

- Collecting REaL data systematically at registration
- Ensuring that patients can indicate language preference and whether an interpreter is needed
- Creating prompts for frontline staff to ask patients about language preferences to determine need for interpreter

GUIDES CONT.

IMPLEMENTING MULTICULTURAL HEALTH CARE STANDARDS: IDEAS AND EXAMPLES

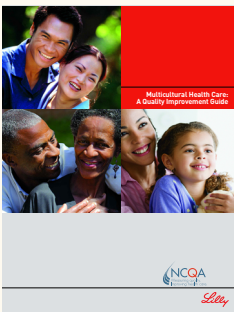
National Committee for Quality Assurance



Implementing Multicultural Health Care Standards provides standards for REaL data collection for healthcare organizations to implement the National Committee for Quality Assurance standards for distinction in Multicultural Health. The guide also provides information on access and availability of language services, practitioner network cultural responsiveness, culturally and linguistically appropriate services, and reducing health care disparities.

MULTICULTURAL HEALTH CARE: A QUALITY IMPROVEMENT GUIDE

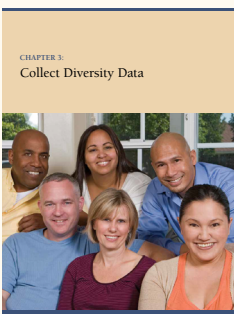
National Committee for Quality Assurance



Multicultural Health Care: A Quality Improvement Guide provides a framework for healthcare organizations to incorporate culturally and linguistically appropriate care, improve access for patients with limited English proficiency, and reduce healthcare disparities. The guide can be used by managed care organizations, public health organizations, community clinics, hospitals, and other organizations centered on healthcare delivery. Each of the four sections (assessment, planning, implementation, and evaluation) includes a summary, specific examples from varied settings, and relevant resources.

MAKING CLAS HAPPEN: CHAPTER 3 - COLLECT DIVERSITY DATA

Massachusetts Department of Public Health, Office of Health Equity



Making CLAS Happen provides guidance and practical approaches for how to provide culturally and linguistically appropriate services within public health settings. Each chapter includes tools, lists of resources, and case studies from the public health and social services sectors within Massachusetts. Chapter 3 provides tools to assist in the process of collecting race, ethnicity, and language data.

TOOLKITS

EQUITY OF CARE: A TOOLKIT FOR ELIMINATING HEALTHCARE DISPARITIES

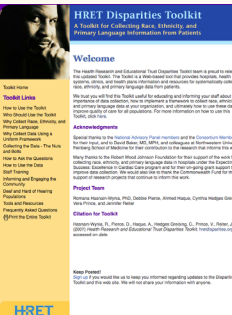
American Hospital Association, Equity of Care



The American Hospital Association (AHA) toolkit provides best practices for improving the quality of REaL data, stratifying REaL data, and identifying disparities within healthcare organizations. This resource is appropriate for organizations at all stages of the REaL data collection process. In addition to data collection, the toolkit includes resources for cultural competency training and increasing diversity in governance and leadership.

HRET DISPARITIES TOOLKIT: A TOOLKIT FOR COLLECTING RACE, ETHNICITY, AND PRIMARY LANGUAGE INFORMATION FROM PATIENTS

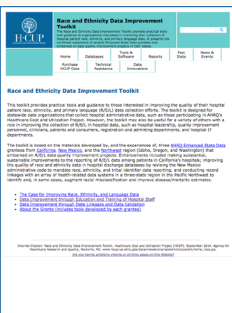
Health Research and Educational Trust



This toolkit provides guidance for healthcare organizations on how to collect REaL data from patients. It contains federal guidelines and recommendations for collecting data, modules and scripts for frontline staff, evaluative tools, and guidance on how to use REaL data for quality improvement initiatives. Healthcare organizations and providers can use this toolkit to implement a data collection framework.

RACE AND ETHNICITY DATA IMPROVEMENT TOOLKIT

Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services

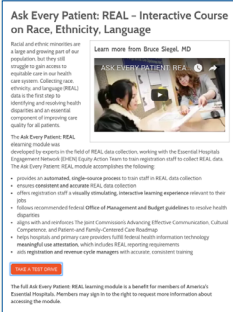


This toolkit provides guidance for organizations aiming to improve the collection of REaL data from patients. The toolkit incorporates experience from Enhanced State data grantees that have made significant efforts in improving data collection within their states. The toolkit provides resources for ensuring adequate IT infrastructure, collecting REaL data from patients, and measuring the effectiveness of education and training efforts.

TRAINING TOOLS & WEBINARS

ASK EVERY PATIENT: REaL - INTERACTIVE COURSE ON RACE, ETHNICITY, AND LANGUAGE

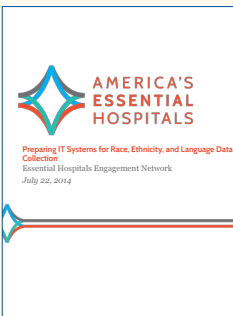
America's Essential Hospitals



This online course trains hospital registration staff how to collect REaL data from patients. It includes an e-learning module and downloadable materials, including a three-part webinar series with guidance on the importance of REaL data collection. The course is available to member organizations of America's Essential Hospitals.

PREPARING IT SYSTEMS FOR RACE, ETHNICITY, AND LANGUAGE DATA COLLECTION

America's Essential Hospitals



This webinar discusses how hospitals can adapt their electronic health records to comply with local and national standards for collecting REaL data. The presenters also discuss meaningful use requirements, Joint Commission recommendations, reporting data for multiple races, and the usage and adaptation of granular categories for local populations.

BOOKS & SENTINEL ARTICLES

A ROADMAP AND BEST PRACTICES FOR ORGANIZATIONS TO REDUCE RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE

Finding Answers: Disparities Research for Change



Citation: Chin MH, et al. J Gen Intern Med. (2012).

This article summarizes the key findings of the literature reviews and funded research projects conducted through Finding Answers, a Robert Wood Johnson Foundation initiative. The authors use these findings to provide a roadmap for healthcare organizations to address disparities within diverse populations.

COLLECTION OF RACE AND ETHNICITY DATA BY HEALTH PLANS HAS GROWN SUBSTANTIALLY, BUT OPPORTUNITIES REMAIN TO EXPAND EFFORTS



Citation: Escarce JJ, et al. Health Aff. (2011).

In 2003, the Institute of Medicine called on health plans to collect data on their members' race and ethnicity as a foundation for improving the quality of care and reducing disparities. They describe the progress made toward collecting these data, the most commonly used data collection methods, and the challenges plans have encountered.

A PLAN FOR ACTION: KEY PERSPECTIVES FROM THE RACIAL/ETHNIC DISPARITIES STRATEGY FORUM

The Disparities Solutions Center, Massachusetts General Hospital



Citation: King RK, et al. Milbank Q. (2008).

This paper summarizes six key recommendations for organizations to address disparities in care, including standardized collection of race and ethnicity data.

BOOKS & SENTINEL ARTICLES CONT.

THE NATIONAL HEALTH PLAN COLLABORATIVE TO REDUCE DISPARITIES AND IMPROVE QUALITY

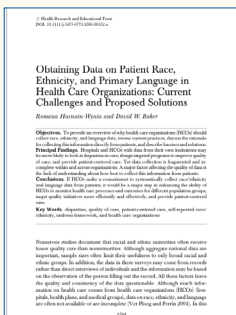
The Joint Commission



Citation: Lurie N, et al. Jt Comm J Qual Patient Saf. (2008).

The National Health Plan Collaborative (NHPC) represents a model of shared learning and innovation through which health plans are addressing racial/ethnic disparities. This paper describes the challenges and lessons learned by health plans in obtaining information on race/ethnicity of their enrollees and examining their diabetes performance measure to assess disparities in care.

OBTAINING DATA ON PATIENT RACE, ETHNICITY, AND PRIMARY LANGUAGE IN HEALTH CARE ORGANIZATIONS: CURRENT CHALLENGES AND PROPOSED SOLUTIONS



Citation: Hasnain-Wynia R & Baker DW. Health Serv Res. (2006).

This paper provides an overview of why health care organizations (HCOs) should collect race, ethnicity, and language data, review current practices, discuss the rationale for collecting this information directly from patients, and describe barriers and solutions.

TAKING ON RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE: THE EXPERIENCE AT AETNA



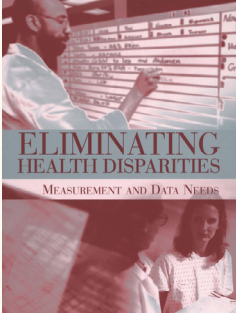
Citation: Hassett P. Health Aff. (2005).

This Perspective describes the work of a task force led by Aetna's chairman and CEO, charged with a number of strategic activities including cultural competency training and the identification of disparities occurring within the Aetna membership population. Aetna is putting the data to work in its chronic disease management, breast health, and African American Preterm Labor Prevention and Breastfeeding programs.

BOOKS & SENTINEL ARTICLES CONT.

ELIMINATING HEALTH DISPARITIES: MEASUREMENT AND DATA NEEDS

National Research Council of the National Academies

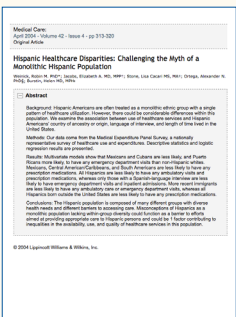


Citation: National Research Council. (2004).

Data collection on race, ethnicity, socioeconomic position, and acculturation and language are often limited or not standardized among both public and private data systems. To address this concern, the HHS Office of the Assistant Secretary for Planning and Evaluation requested the Committee on National Statistics of the National Academies to form a panel of experts to review the data collection and reporting systems of HHS activities, in addition to federal and private health care agencies. This book discusses the panel's recommendations based on its review of these data systems.

HISPANIC HEALTHCARE DISPARITIES: CHALLENGING THE MYTH OF A MONOLITHIC HISPANIC POPULATION

Citation: Weinick RM, et al. Med Care. (2004).



This paper examines the association between use of healthcare services and Hispanic Americans' country of ancestry or origin, language of interview, and length of time lived in the United States.

HEALTH DATA ISSUES FOR HISPANICS: IMPLICATIONS FOR PUBLIC HEALTH RESEARCH

Citation: Zambrana RE & Carter-Pokras O. J Health Care Poor Underserved. (2001).



This paper explores current issues in Hispanic health data collection, examines methodological concerns, and presents recommendations for future Hispanic public health data collection.

THE MULTIPLE-RACE POPULATION OF THE UNITED STATES: ISSUES AND ESTIMATES

Citation: Goldstein JR & Morning AJ. Proc Natl Acad Sci USA. (2000).



This paper presents national estimates of the population likely to identify with more than one race in the 2000 census as a result of a new federal policy allowing multiple racial identification.

DISABILITY DATA COLLECTION RESOURCES

Disability covers a wide range of impairments that may be physical, sensory, or cognitive, and the degree to which impairments and environmental factors impact individual functioning may vary. The reasons for collecting disability status data are also varied. Health care organizations may collect disability data in order to ensure compliance with the Americans with Disabilities Act and improve the accessibility of facilities, equipment, and services; to inform clinical practice and individual care plans for patients with functional limitations associated with physical, cognitive or other mental impairments; or to monitor for disparities in quality of care for sub-populations. While all of these are valid and important reasons for collecting data on disability status, how organizations plan to use the data will determine what questions to ask. The following resources offer recommendations and frameworks from several leading national and international organizations related to disability and disability data collection.

MINIMUM STANDARDS

The [six-item set of questions](#) developed for the [American Community Survey \(ACS\)](#), U.S. Census Bureau, represent the minimum data standard for disability data collection within federal agencies. The questions cover six types of disability: hearing, vision, cognitive, ambulatory, self-care, and independent living. Respondents who report difficulties in one or more of these categories are considered to have a disability. This six-item set cannot be altered and must be used as a set to assure a meaningful measure of disability.

The U.S. Department of Health and Human Services [Implementation Guidance](#) on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status was developed to promote standardized data collection in HHS-conducted or sponsored surveys.

The U.S. Census Bureau's [How Disability Data are Collected site](#) describes how disability information is collected in a number of existing federal surveys.

REPORTS & ARTICLES

THE FUTURE OF DISABILITY IN AMERICA

Institute of Medicine



Disability affects between 40 and 50 million people in the U.S. and will continue to affect a large number of Americans as the population ages. The report offers recommendations in the areas of disability monitoring, disability research, access to health care and other support services, and public and professional education.

WORLD REPORT ON DISABILITY

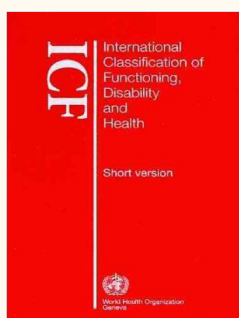
World Health Organization



This report provides policy-makers, practitioners, researchers, academics, development agencies, and civil society with a description of disability, an analysis of services for people with disabilities, and recommendations for national and international policy to address the needs of populations with disabilities.

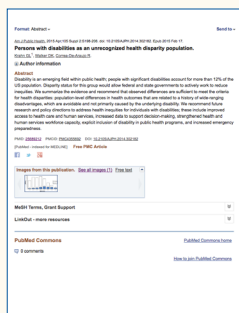
INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

World Health Organization



The World Health Organization (WHO) uses the International Classification of Functioning, Disability, and Health (ICF) to classify different types of functioning and disabilities. The ICF provides classifications for body function, including mental and physiological functions; activities and participations, including learning, daily tasks, and relationships; and environmental factors, including the physical and social environment.

PERSONS WITH DISABILITIES AS AN UNRECOGNIZED HEALTH DISPARITY POPULATION



Citation: Krahn GL, et al. Am J Public Health (2015).

This paper recommends that observed population-level differences in health outcomes among persons with a disability supports classification as a health disparity population.