INVENTORY 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 toward improving population health. Comprehensive patient data on race, ethnicity, language, and disability status are 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 these 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.

The resources in this document are grouped by REaL and Disability categories as well as by the type of resource it is. Please click on the desired topic area or type of resource on the table of contents below.

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

TABLE OF CONTENTS

TABLE OF CONTENTS

Race, Ethnicity, and Language Data Collection Resources

A robust body of guidance and tools has been developed for the collection of Race, Ethnicity, and 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, calls 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

In 1997, the **Office of Management and Budget (OMB)** 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 categories for ethnicity are:

- Hispanic or Latino
- Not Hispanic or Latino

The OMB racial categories are:

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

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; https://transition.fcc.gov/Bureaus/OSEC/library/legislative_histories/1195.pdf. Accessed March 28, 2022.
2. Office of Management and Budget. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. 1997; https://obamawhitehouse.archives.gov/omb/fedreg_1997standards Accessed March 28, 2022.
3. Weissman JS, et al. *Commissioned Paper: Healthcare Disparities.* Disparities Solutions Center; 2012.

2021 COMPENDIUM OF DISABILITY DATA COLLECTION METHODS
Mathematica Policy Research
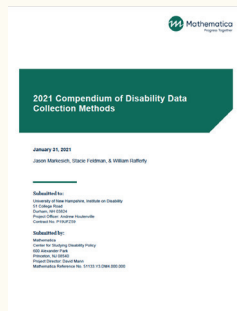
Entities involved in quantitative and qualitative data collection—such as federal agencies, university survey centers, and private polling firms—should (and sometimes by law must) consider the extent to which their methods create barriers to participation for people with disabilities. Yet few resources are available to address this problem. To fill this knowledge gap, we created the Compendium of Disability Data Collection Methods, an easily accessible source of research on the methodological issues associated with collecting data from or about people with disabilities. The 2021 version of the compendium, an indexed reference list, contains 441 references on the following subjects: disability/impairment type; aging and later-life disability; developmental, intellectual, and cognitive impairments, including dementia, traumatic brain injury, and learning disabilities; sensory and communication impairments, including blindness and low vision, hearing loss and deafness, autism spectrum disorder, and speech impairments; physical impairments, including musculoskeletal conditions, epilepsy, muscular dystrophy, multiple sclerosis, and other disabilities; psychiatric impairments and mental health, including anxiety disorders, post-traumatic stress disorder, psychotic disorders, and mood disorders.

A FRAMEWORK FOR STRATIFYING RACE, ETHNICITY AND LANGUAGE DATA
American Hospital Association, Equity of Care
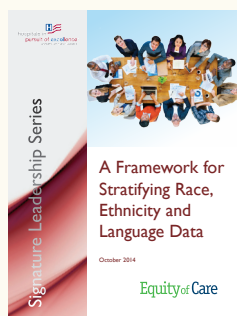
Collecting and stratifying patient REaL data are crucial for hospitals and health systems to understand the populations they serve and to implement the appropriate interventions for improving quality of care. While each health care system will stratify data in different ways to meet its own institutional 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
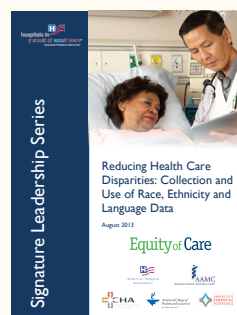
This guide addresses both the collection and implementation of REaL data. The guide provides a four-step approach to obtaining accurate data: determine appropriate data categories; develop methodology for data collection; train staff members on methodology; and assign accountability and monitor progress 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.

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

Institute of Medicine
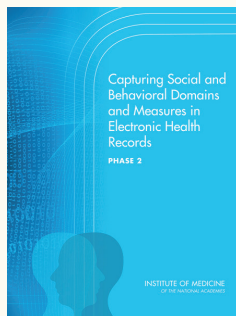
This report explores and provides rationale for including social determinants in the electronic health record and shares examples of how physicians can utilize this technology to improve the health of their patients. The domains outlined in the report include sociodemographic domains, psychological domains, 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 IN AMBULATORY SETTINGS: A WHITE PAPER WITH RECOMMENDATIONS FROM THE COMMISSION TO END HEALTH CARE DISPARITIES

American Medical Association
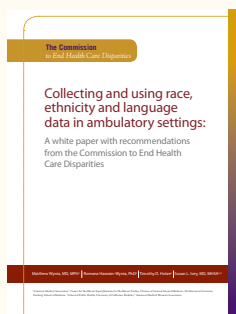
Collecting valid and reliable demographic data on patients served in ambulatory practices is the first step in identifying and eliminating heath care disparities. This report details the importance of collecting demographic data as well as recommendations on how to do so. This report aims to guide providers, electronic health record 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
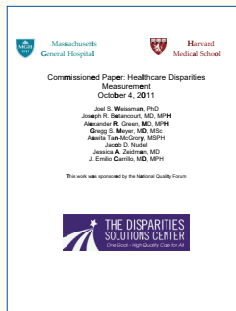
This report provides practical recommendations for health care organizations to increase their portfolio of race, ethnicity, and language data collection strategies and use those data to develop disparity-sensitive measures. This report is intended to guide organizations in disparities and quality measurement 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 health care disparities and priorities and options for quality improvement.

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

Pew Research Center
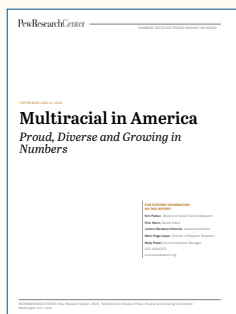
Collecting and stratifying patient REaL data are crucial for hospitals and health systems to understand the populations they serve and implement the appropriate interventions to improve quality of care. This report recommends a five-step framework that will help systems to stratify REaL data to more effectively identify health care disparities. This report summarizes the framework and provides dashboard templates.

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

U.S. Department of Health and Human Services, Office of Minority Health
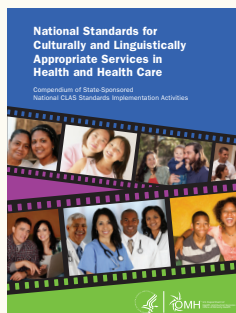
The U.S. Department of Health and Human Services recently released the first compendium of activities undertaken by states to implement the National Culturally and Linguistically Appropriate Services (CLAS) Standards, which includes the collection of patient race, ethnicity, and language data. The report 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.

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

America's Health Insurance Plans
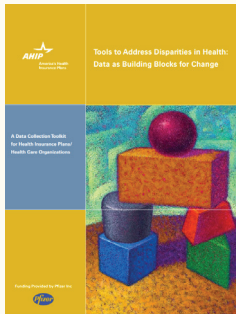
This report provides rationale for collecting and analyzing REaL data and provides detailed guidelines on how to collect these data. The report also summarizes federal and state regulations, policies, and stakeholder perspectives on data collection. Examples of strategies from insurance plans are also provided as well as other resources for organizations seeking to implement REaL data collection. The data collection toolkit is geared for health professionals at health insurance plans and health care 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 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.

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

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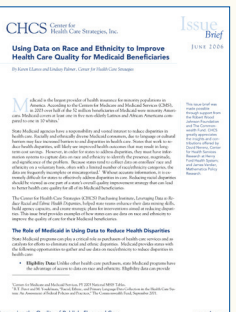
This issue brief emphasizes the importance of reliable data and provides examples of how state programs can utilize race and ethnicity data to improve health care for Medicaid beneficiaries. The brief describes how state agencies, managed care organizations, and providers can aid Medicaid agencies in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

IMPROVED RACE AND ETHNICITY MEASURES REVEAL U.S. POPULATION IS MUCH MORE MULTIRACIAL

United States Census Bureau

POPULATION

2020 U.S. Population More Racially and Ethnically Diverse Than Measured in 2010

2020 Census results released today allow us to measure the nation's racial and ethnic diversity and how it varies at different geographic levels.

This webpage provides updated information on racial and ethnic composition of the country as a result of improvements in the design of the race and ethnicity questions, processing, and coding.

COUNTING A DIVERSE NATION: DISAGGREGATING DATA ON RACE AND ETHNICITY TO ADVANCE A CULTURE OF HEALTH

PolicyLink

Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health

PolicyLink
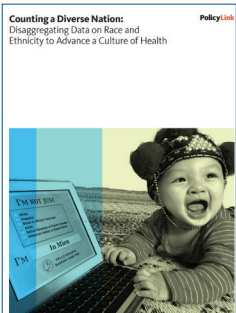
A report outlining how the research community and governmental policy can take on reforms to better collect data that is more extensive and specific to the multidimensional diversity across America.

BUILDING AN ORGANIZATIONAL RESPONSE TO HEALTH DISPARITIES

Centers for 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. This document includes resources and concepts key to addressing disparities and improving health care quality.

#123FOREQUITY: A TOOLKIT FOR ACHIEVING SUCCESS AND SHARING YOUR STORY

American Hospital Association, Equity of Care

A user-friendly "how-to" guide to help accelerate the elimination of health care disparities. This guide contains resources to assist all hospitals in their work to achieve the Equity of Care goals.

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

Health Research and Educational Trust
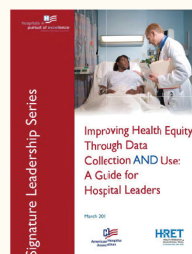
This guide uses exploratory interviews with four hospitals as well as an extensive literature review to provide recommendations for health care organizations to streamline their data collection process. Strategies are provided for utilizing these patient data in a meaningful way, such as developing interventions and increasing access for underserved populations.

IMPROVING QUALITY AND ACHIEVING EQUITY: A GUIDE FOR HOSPITAL LEADERS

The Disparities Solutions Center, Massachusetts General Hospital
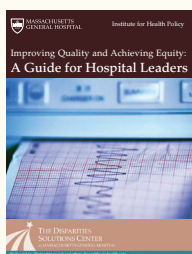
This report outlines the importance of using existing systems within health care organizations to identify medical errors for patients with limited English proficiency. Recommendations are provided to improve these systems to accurately capture root causes and risk factors for patients, including:

- 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

IMPLEMENTING MULTICULTURAL HEALTH CARE STANDARDS: IDEAS AND EXAMPLES
National Committee for Quality Assurance
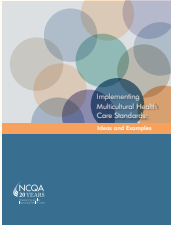
This guide provides standards for REaL data collection for health care organizations to implement the National Committee for Quality Assurance standards for distinction in Multicultural Health. The guide also provides information on access and availability of language services, practitioner network cultural responsiveness, culturally and linguistically appropriate services, and reducing health care disparities.

MULTICULTURAL HEALTH CARE: A QUALITY IMPROVEMENT GUIDE
National Committee for Quality Assurance
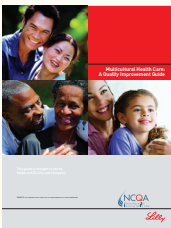
This guide provides a framework for health care organizations to incorporate culturally and linguistically appropriate care, improve access for patients with limited English proficiency, and reduce health care disparities. The guide can be used by managed care organizations, public health organizations, community clinics, hospitals, and other organizations centered on health care 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
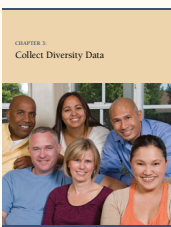
This publication provides guidance and practical approaches for how to provide culturally and linguistically appropriate services within public health settings. Each chapter includes tools, lists of resources, and case studies from the public health and social services sectors within Massachusetts. Chapter 3 provides tools to assist in the process of collecting race, ethnicity, and language data.

HRET HIIN HEALTH EQUITY ORGANIZATIONAL ASSESSMENT
Health Research and Educational Trust

A guide to classifying the extent to which hospitals are reducing disparities through 7 categories: data collection, data collection training, data validation, data stratification, communication of findings, addressing and resolving gaps in care, and organizational infrastructure and culture. This a general tool for understanding how hospitals can reduce disparities seems less relevant to data collection and more relevant to disparities solutions in general.

TOOLKITS

A PRACTICAL GUIDE TO IMPLEMENTING THE NATIONAL CLAS STANDARDS: FOR RACIAL, ETHNIC AND LINGUISTIC MINORITIES, PEOPLE WITH DISABILITIES AND SEXUAL AND GENDER MINORITIES

Centers for Medicare and Medicaid Services, Office of Minority Health
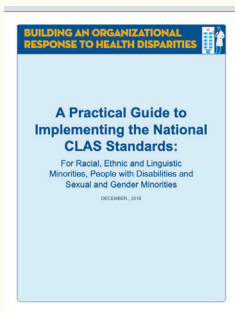
The purpose of this toolkit is to enable organizations to implement the National CLAS Standards and improve health equity. It is organized according to the enhanced National CLAS Standards and provides practical tools and examples of CLAS, in addition to efforts to implement the National CLAS Standards that can be adapted for use by health care organizations. It is intended for organizations that have already decided to pursue CLAS to improve equity and eliminate health care disparities.

DISABILITY DATA ADVOCACY TOOLKIT

Washington Group
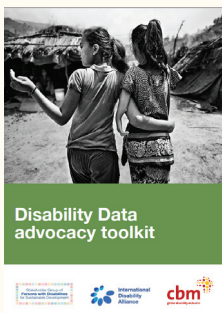
This toolkit was created in response to increasing interest and requests from persons with disabilities and their representative organizations from all over the world. The aim of this toolkit is to contribute to the growing global dialogue on the importance of data on persons with disabilities, specifically to provide some basic knowledge on data collection, analysis, and use of data for evidenced based advocacy to influence policy and decision makers. The toolkit discusses the use of the WG questions as best practices to be employed in data collections and disaggregating data by disability.

EQUITY OF CARE: A TOOLKIT FOR ELIMINATING HEALTH CARE DISPARITIES

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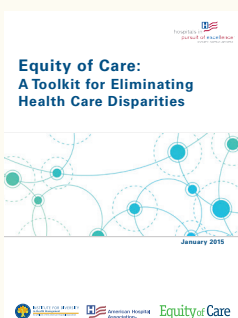
The American Hospital Association toolkit provides best practices for improving the quality of REaL data, stratifying REaL data, and identifying disparities within health care organizations. This resource is appropriate for organizations at all stages of the REaL data collection process. In addition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

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

Health Research and Educational Trust
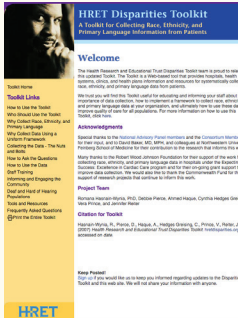
This toolkit provides guidance for health care organizations on how to collect REaL data from patients. It contains federal guidelines and recommendations for collecting data; modules and scripts for frontline staff; evaluative tools; and guidance on how to use REaL data for quality-improvement initiatives. Health care 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
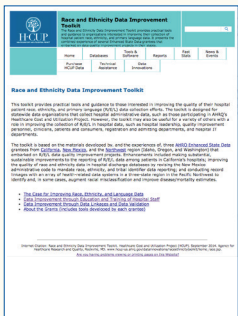
This toolkit provides guidance for organizations aiming to improve the collection of REaL data from patients. The toolkit incorporates experience from Enhanced State data grantees that have made significant efforts in improving data collection within their states. The toolkit provides resources for ensuring adequate IT infrastructure, collecting REaL data from patients, and measuring the effectiveness of education and training efforts.

TRAINING TOOLS & WEBINARS

IDENTIFYING AND MEETING THE LANGUAGE PREFERENCES OF HEALTH PLAN MEMBERS

Resources for Integrated Care
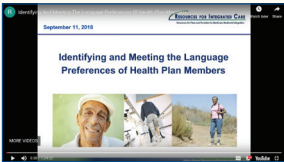
A webinar discussing the strategies that health plans can use to meet and assess diverse language preferences. The webinar has multiple speakers who talk about strategies for collecting language data and then using this data to inform operations.

COLLECTING PATIENT DATA: IMPROVING HEALTH EQUITY IN YOUR PRACTICE

American Medical Association

This online module discusses the importance of collecting patient race and ethnicity data, explains the minimum standards for collecting these data, and elucidates how race and ethnicity data can be used to improve quality outcomes. Participants will learn about establishing standards for race and ethnicity data collection in their practice and how to train staff to collect these data.

DATA ON RACE, ETHNICITY, AND LANGUAGE LARGELY INCOMPLETE FOR MANAGED CARE PLAN MEMBERS

Citation: Ng JH, Ye F, Ward LM, Haffer, SC. Health Aff. (2017).

This article presents findings from assessing REaL data availability in commercial, Medicaid, and Medicare managed care plans using the Healthcare Effectiveness Data and Information Set (HEDIS). The authors looked at 2012–2015 HEDIS data and found that in 2015 the largest gaps in race data occurred in commercial and Medicaid plans, while all plan types reported incomplete data on ethnicity and language. Between 2012 and 2015, completeness of data generally did not improve. The authors conclude that the ability to identify disparities through improved documentation of race, ethnicity, and language is necessary in order to reduce disparities.

IMPROVING THE COLLECTION OF RACE, ETHNICITY, AND LANGUAGE DATA TO REDUCE HEALTHCARE DISPARITIES: A CASE STUDY FROM AN ACADEMIC MEDICAL CENTER

Citation: Lee WC, Veeranki SP, Serag H, Eschbach K, Smith KD. Perspect Health Inf Manag. (2016).

Well-designed electronic health records (EHRs) must integrate a variety of accurate information to support efforts to improve quality of care, particularly equity-in-care initiatives. This case study provides insight into the challenges those initiatives may face in collecting accurate REaL information in the EHR. The authors present the experience of an academic medical center strengthening its EHR for better collection of REaL data with funding from the EHR Incentive Programs for meaningful use of health information technology and the Texas Medicaid 1115 Waiver program. They also present a plan to address some of the challenges that arose during the course of the project. These experiences at an academic medical center can provide guidance about the likely challenges similar institutions may expect when they implement new initiatives to collect REaL data, particularly challenges regarding scope, personnel, and other resource needs.

A ROADMAP AND BEST PRACTICES FOR ORGANIZATIONS TO REDUCE RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE
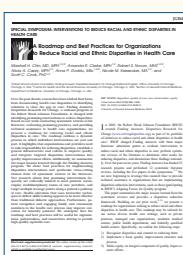
Citation: Chin MH, et al. J Gen Intern Med. (2012).

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 health care organizations to address disparities within diverse populations.

A Plan for Action: Key Perspectives from the Racial/Ethnic Disparities Strategy Forum

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. The recommendations are: collect race and ethnicity data on patients or enrollees in a routine and standardized fashion; implement tools to measure and monitor for disparities in care; develop quality improvement strategies to address disparities; secure the support of leadership; use incentives to address disparities; and create a message and communication strategy for these efforts.

The National Health Plan Collaborative to Reduce Disparities and Improve Quality
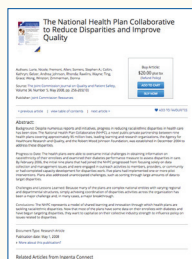
Citation: Lurie N, et al. Jt Comm J Qual Patient Saf. (2008).

The National Health Plan Collaborative 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 should collect race, ethnicity, and language data, reviews current practices, discusses the rationale for collecting this information directly from patients, and describes 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.

CHALLENGES WITH QUALITY OF RACE AND ETHNICITY DATA IN OBSERVATIONAL DATABASES

Citation: Polubriaginof FCG, Ryan P, Salmasian H, et al. Challenges with quality of race and ethnicity data in observational databases. J Am Med Informatics Assoc. 2019. doi:10.1093/jamia/ocz113

This study assesses the quality of race and ethnicity information in observational health databases, including electronic health records (EHRs). The authors assessed completeness of race and ethnicity information in large observational health databases in the United States (Healthcare Cost and Utilization Project and Optum Labs), and at a single healthcare system in New York City serving a racially and ethnically diverse population. They compared race and ethnicity data collected via administrative processes with data recorded directly by respondents via paper surveys (National Health and Nutrition Examination Survey and Hospital Consumer Assessment of Healthcare Providers and Systems). The article discusses findings on the quality of race and ethnicity data and proposes opportunities for improvement, including patient self-recording

EXAMINING RACE AND ETHNICITY INFORMATION IN MEDICARE ADMINISTRATIVE DATA

Citation: Filice, Clara E. MD, MPH, MHS; Joynt, Karen E. MD, MPH. Examining Race and Ethnicity Information in Medicare Administrative Data. Medical Care. 55(12):e170-e176, December 2017.

Racial and ethnic disparities are observed in the health status and health outcomes of Medicare beneficiaries. Reducing these disparities is a national priority, and having high-quality data on individuals' race and ethnicity is critical for researchers working to do so. However, using Medicare data to identify race and ethnicity is not straightforward. Currently, Medicare largely relies on Social Security Administration data for information about Medicare beneficiary race and ethnicity. Directly self-reported race and ethnicity information is collected for subsets of Medicare beneficiaries but is not explicitly collected for the purpose of populating race/ ethnicity information in the Medicare administrative record. As a consequence of historical data collection practices, the quality of Medicare's administrative data on race and ethnicity varies substantially by racial/ethnic group; the data are generally much more accurate for whites and blacks than for other racial/ethnic groups. Identification of Hispanic and Asian/Pacific Islander beneficiaries has improved through use of an imputation algorithm recently applied to the Medicare administrative database. To improve the accuracy of race/ethnicity data for Medicare beneficiaries, researchers have developed techniques such as geocoding and surname analysis that indirectly assign Medicare beneficiary race and ethnicity. However, these techniques are relatively new and data may not be widely available. Understanding the strengths and limitations of different approaches to identifying race and ethnicity will help researchers choose the best method for their particular purpose, and help policymakers interpret studies using these measures.

A PATIENT AND FAMILY DATA DOMAIN COLLECTION FRAMEWORK FOR IDENTIFYING DISPARITIES IN PEDIATRICS: RESULTS FROM THE PEDIATRIC HEALTH EQUITY COLLABORATIVE

Citation: Tan-McGrory A, Bennett-AbuAyyash C, Gee S, Dabney K, Cowden JD, Williams L, et al. A patient and family data domain collection framework for identifying disparities in pediatrics: results from the pediatric health equity collaborative. BMC Pediatrics. 2018;18(1):18.

By 2020, the child population is projected to have more racial and ethnic minorities make up the majority of the populations and health care organizations will need to have a system in place that collects accurate and reliable demographic data in order to monitor disparities. The goals of this group were to establish sample practices, approaches and lessons learned with regard to race, ethnicity, language, and other demographic data collection in pediatric care setting. A panel of 16 research and clinical professional experts working in 10 pediatric care delivery systems in the US and Canada convened twice in person for 3-day consensus development meetings and met multiple times via conference calls over a two year period. Current evidence on adult demographic data collection was systematically reviewed and unique aspects of data collection in the pediatric setting were outlined. Human centered design methods were utilized to facilitate theme development, facilitate constructive and innovative discussion, and generate consensus. Group consensus determined six final data collection domains: 1) caregivers, 2) race and ethnicity, 3) language, 4) sexual orientation and gender identity, 5) disability, and 6) social determinants of health. For each domain, the group defined the domain, established a rational for collection, identified the unique challenges for data collection in a pediatric setting, and developed sample practices which are based on the experience of the members as a starting point to allow for customization unique to each health care organization. Several unique challenges in the pediatric setting across all domains include: data collection on caregivers, determining an age at which it is appropriate to collect data from the patient, collecting and updating data at multiple points across the lifespan, the limits of the electronic health record, and determining the purpose of the data collection before implementation. There is no single approach that will work for all organizations when collecting race, ethnicity, language and other social determinants of health data. Each organization will need to tailor their data collection based on the population they serve, the financial resources available, and the capacity of the electronic health record.

DISABILITY DATA COLLECTION RESOURCES

Disability covers a wide range of impairments that may be physical, sensory, or cognitive. 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 subpopulations. 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

Minimum Standards

The **six-item set of questions** developed for the **American Community Survey**, 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.

THE FUTURE OF DISABILITY IN AMERICA
Institute of Medicine

Disability affects between 40 million and 50 million people in the United States 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 and the World Bank

This report provides policy-makers, practitioners, researchers, academics, development agencies, and civil society with a description of what is a 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
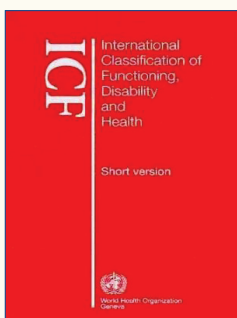
The World Health Organization uses the International Classification of Functioning, Disability, and Health (ICF) to classify different types of functioning and disabilities. The ICF provides classifications for body function, including mental and physiological functions; activities and participations, including learning, daily tasks, and relationships; and environmental factors, including the physical and social environment.

PERSONS WITH DISABILITIES AS AN UNRECOGNIZED HEALTH DISPARITY POPULATION
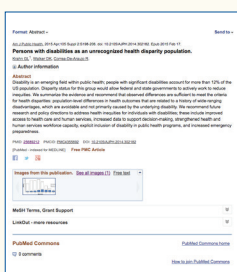
Citation: Krahn GL, Walker DK, Correa-de-Araujo R. Am J Public Health. (2015).

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

COLLECTION OF PATIENTS' DISABILITY STATUS BY HEALTHCARE ORGANIZATIONS: PATIENTS' PERCEPTIONS AND ATTITUDES

Citation: Morris MA, Schliep M, Liesinger J, Cameron KA. Collection of Patients' Disability Status by Healthcare Organizations: Patients' Perceptions and Attitudes. J Healthc Qual. 2017. doi:10.1097/JHQ.0000000000000036

Recent policies call for healthcare organizations to consistently document patients' disability status for the purpose of tracking the quality of care experienced by patients with disabilities. The purpose of the study was to explore patients' attitudes toward healthcare organizations collecting disability status. We surveyed a convenience sample of patients in three outpatient clinics, including primary care and rehabilitation clinics. A total of 303 patients participated; 49% self-identified as disabled, 59% were female and the mean age was 52 years. The majority of participants (88%) either agreed or strongly agreed that it is important for healthcare organizations to collect information about disabilities; 77% stated that they were comfortable or very comfortable with healthcare organizations collecting this information. By contrast, we found that almost a quarter of participants had concerns with front desk staff collecting disability status information. When we presented disability questions endorsed by the Health and Human Services Department, over a quarter of participants (28%) felt that the questions were not inclusive of all disability categories. Although patients are supportive of healthcare organizations collecting disability status information, concerns exist regarding how the information is collected and which categories are included, suggesting the need for continued development of evidence-based, patient-centered methods and questions.

## THE DISABILITY DATA REPORT, 2021

Citation: Mitra, S. and Yap, J. (2021). The Disability Data Report. Disability Data Initiative. Fordham Research Consortium on Disability: New York

This report provides a systematic analysis of the availability and quality of questions on disability between 2009 and 2018 in national censuses and surveys. This report also presents disaggregation results for 41 countries with censuses or national surveys with functional difficulty questions in at least four domains (seeing, hearing, walking, cognition). For some countries, data is also available for the self-care and/or communication domains and the Washington Group Short Set of questions. This report has not been peer reviewed.
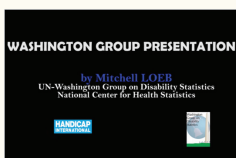
VIDEOS

THE WASHINGTON GROUP ON DISABILITY STATISTICS AND THE SHORT SET OF QUESTIONS, 2016 ONLINE TRAINING

Handicap International Innovation and Knowledge Management Unit & the Washington Group on Disability Statistics
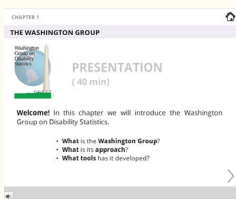
This e-learning module aims to help organizations and investigators to understand the approach behind the short set of questions and to gain a deeper knowledge about disability data collection and analysis.

WASHINGTON GROUP 2015 VIDEO SERIES

This video series, presented by Mitchell Loeb from the National Center for Health Statistics, provides background on the six-item short set of questions designed by the Washington group. The series presents the short set of questions and provides recommendations for data collection and analysis of disability data.

- Video 1 – Introduction to the Washington Group

- Video 2 – The Approach Developed by the Washington Group

- Video 3 – Short Set of Questions: Tool Presentation

- Video 4 – Short Set of Questions: Data Collection

- Video 5 – Short Set of Questions: Data Analysis

- Video 6 – Presentation of the Methodology to Implement WG Tools

WASHINGTON GROUP TRAINING FOR NON – GOVERNMENTAL ORGANIZATIONS, MARCH 16, 2017

The Washington Group presented a 1 day training event on Disability Measurement using the Washington Group methodology specifically for an NGO audience.

- Video 1 – Introduction to the Washington Group and Disability Measurement

- Video 2 – Collecting Disability Data

- Video 3 – The Importance & Feasibility of Disaggregation by Disability Status

- Video 4 – The WG/UNICEF Module on Child Functioning