

REaL Data Collection Toolbox



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This Learning Toolbox focuses on healthcare facilities collecting data on race, ethnicity, and language preference (REaL) as an important component of the provision of equity in the healthcare setting. It includes a quick primer on data collection, and provides links to articles, tools, and resources to educate providers on the importance of knowing the diverse patient population for which they provide care.

QUICK PRIMER

What is Race, Ethnicity, and Language (REaL) data collection?

At its core, REaL data collection means obtaining patient information regarding his or her race, ethnicity, and primary language. The importance of collecting patients' race and ethnicity is the ability to measure any disparities in care that may exist within an organization or community. The Institute for Healthcare Improvement (IHI) defines this practice as the collection and stratification of REaL data to identify inequities, help set priorities, and drive improvement activities.

Why is it important to collect and document REaL data?

Information that a provider or organization collects about patients helps the healthcare team to communicate effectively based on the patients' unique needs by understanding their culture and language preference. This information becomes part of patients' medical records and can be used to prepare for each clinical encounter. For example, if it is noted in a patient's medical record that he or she is limited English proficient, a professional language interpreter can be ordered in advance of an appointment. It is important to establish a systematic process for collecting patients' REaL data. Consequences of not collecting and acting upon REaL data can be detrimental, particularly in the event where health disparities exist and are not addressed. Not only can it result in unnecessary and unintended adverse clinical outcomes, but it is also taxing and costly for the healthcare system.

What is the benefit of collecting REaL data and how can it be used?

Having access to accurate REaL data can improve the ability and accountability of providers to identify and address health disparities, empower development of effective programs to eliminate health disparities, and evaluate effectiveness of care and programs targeting reduction in health disparities. Collecting REaL data can help hospitals improve quality of care by looking for variations in clinical outcomes, resource utilization, length of stay (LOS), readmissions, and patient satisfaction scores among diverse groups so appropriate action can be taken, as necessary. Hospitals can also use REaL data for strategic outreach and planning. Accurate REaL data represents actual patients being served by the facility, and therefore is actionable at the local community level.

“Collecting standardized patient demographic and language data across health care systems is an important first step toward improving population health.”

– CMS Office of Minority Health

For the steps for standardizing the process for REaL data collection, use this Health Equity Organizational Assessment (HEOA) as your guide.

The HEOA was originally developed by the Centers for Medicare & Medicaid Services Partnership for Patients Hospital Improvement Innovation Network Health Equity Affinity Group to better understand hospitals: (1) preparedness to address health disparities through the consistent collection of accurate demographic data; (2) use of demographic data to identify and resolve disparities; and (3) implementation of organizational and cultural structures needed to sustain the delivery of equitable care.

Health Equity Organizational Assessment (HEOA)*

I. Data Collection: Hospital collects demographic data from the patient and/or caregiver through a self-reporting methodology.

The hospital... (please select all that apply)

Uses self-reporting methodology to collect patient Race, Ethnicity, and Language (REaL) data.

Collects REaL data for at least 95 percent of its patients.

Has REaL data roll up to the [Office of Management and Budget \(OMB\) categories](#).¹

Has opportunities for REaL data verification that exist at multiple points of care (beyond patient registration) to ensure accuracy and [completeness](#).²

Uses self-reporting methodology to collect additional patient demographic data (beyond REaL) such as disability status, sexual orientation/gender identity (SO/GI), veteran status, geography, and/or other social determinants of health (SDOH) risk factors such as housing, income, education, employment, food security, and [others](#).³

Utilizes ICD-10 Z Codes to document identified social determinants of health (SDOH) in the patient medical record.

- All race and ethnicity categories collected should, at a minimum, roll up to the OMB categories and should be collected in separate fields.
- Using a self-reporting methodology to collect patient demographic data removes “guess-work” and ensures accurate data is being collected.

II. Training on Data Collection: Hospital provides workforce training to ensure patient self-reported demographic data are collected accurately and consistently.

Workforce training (please select all that apply)

Is provided regarding the collection of patient self-reported REaL data.

Is evaluated for effectiveness on at least an annual basis to ensure staff competency in collecting patient demographic data. Such evaluation can include methods such as tests, role plays, and observations.

Is provided regarding the collection of additional patient self-reported demographic data (beyond REaL) such as disability status, SO/GI, veteran status, geography, and/or other SDOH risk factors such as housing, income, education, employment, food security, and others.³

Is provided in documenting ICD-10 Z Codes completely and correctly.

- Standardized procedures are important for training staff to use patient self-reporting methodologies to collect demographic data, and ensuring this data is accurately and consistently collected. Examples of training may include: role playing, scripts, didactic, manuals, on-line modules, or other tools/job aids.
- Patient/Family Advisors should be included in the development and delivery of workforce training to collect REaL data.

III. Data Validation: Hospital has a standardized process in place to verify the accuracy and completeness of patient self-reported demographic data.

The hospital (please select all that apply)

Has a standardized process in place to evaluate the accuracy and completeness (percent of fields completed) of REaL data.

Has a standardized process in place to evaluate and compare hospital-collected REaL data to local community demographic data.

Addresses system-level issues to improve the collection of self-reported REaL data (e.g., changes in patient registration screens/fields, data flow, workforce training).

Has a standardized process in place to evaluate accuracy and completeness of additional demographic data (beyond REaL) such as disability status, SO/GI, veteran status, geography, and/or other SDOH risk factors such as housing, income, education, employment, food security, and [others](#).³

Has a standardized process in place to compare hospital-collected additional demographic data (beyond REaL) to local community demographic data.

REaL Data Collection Toolbox

- *Data Validation includes determining percent of “unknown,” “unavailable,” or “declined” for missing data fields, with a cumulative goal of less than 5 percent missing data for REaL data.*
- *Hospital evaluates and addresses system-level issues throughout evaluation processes to continually improve the collection of self-reported patient demographic data.*

IV. Data Stratification: Hospital stratifies patient safety, quality, and/or outcome measures using patient demographic data.

The hospital (please select all that apply)

Stratifies at least one patient safety, quality, and or outcome measure by REaL.

Stratifies more than one patient safety, quality, and or outcome measure by REaL.

Stratifies more than one patient safety, quality, and/or outcome measure by additional demographic data (beyond REaL) such as disability status, SO/GI, veteran status, geography, and/or other SDOH risk factors such as housing, income, education, employment, food security, and others.³

Stratifies at least one patient safety, quality, and/or outcome measure by documented ICD-10 Z codes.

V. Communicating Patient Demographic Findings: Hospital uses a reporting mechanism (e.g., equity dashboard, scorecard, report, etc.) to communicate the results of stratified measures for various patient populations.

The hospital (please select all that apply):

Uses a reporting mechanism (e.g., equity dashboard) to routinely communicate patient population outcomes to hospital executive leadership (including medical staff leadership) and the board.

Uses a reporting mechanism (e.g., equity dashboard) to routinely communicate patient population outcomes within the organization (e.g., to front-line staff, quality staff, managers, directors, providers, committees, departments, service lines, etc.).

Uses a reporting mechanism (e.g., equity dashboard) to routinely communicate patient population outcomes to patients and families (e.g., to Patient and Family Advisory Council [PFAC] members) and/or to other community partners or stakeholders.

- *Hospital communicates identified gaps in disparities with the intent to create organization- and community-wide awareness of potential differences in patient outcomes and promotes understanding of patient population needs.*
- *A regular reporting mechanism (e.g. quarterly, semi-annually, etc.) is in place that leadership can visually assess for potential differences in patient outcomes. This may include equity dashboards, scorecards or reports.*

VI. Addressing and Resolving Gaps in Care: Hospital implements interventions to resolve differences in quality, safety, and/or outcomes among identified patient population groups.

The hospital (please select all that apply):

Develops and pilot tests interventions to address identified healthcare disparities.

Implements interventions to resolve identified disparities, continuously informing and involving staff/workforce in support of the process.

Has a process in place for ongoing review, monitoring, and recalibrating interventions to ensure changes are sustainable.

- *Ensure proper provision of resources to resolve differences in patient outcomes.*
- *Tailor interventions to resolve differences in patient outcomes and educate staff about gaps in care.*
- *To every extent possible, existing teams should be utilized to address gaps in care*

VII. Organizational Infrastructure and Culture: Hospital has an organizational culture and infrastructure that supports equitable delivery of healthcare.

The hospital (*please select all that apply*):

Has a standardized process to train its workforce in cultural and linguistic competence, according to National Culturally and Linguistically Appropriate Services (CLAS) Standards.⁴

Has named individual(s) with leadership responsibility and accountability for health equity efforts.

Has a leader—who may or may not be a member of the C-suite—and engages clinical champions, patients, and families and/or community partners in strategic and action-planning activities to reduce disparities.

Demonstrates leadership and board commitment to equitable healthcare through written policies, protocols, pledges, and/or strategic planning documents (e.g., mission/vision/values, organizational goals, and objectives).

- *Training should routinely involve patient and family input (e.g., PFACs and can include cultural competency/intelligence regarding racial and ethnic minorities, patients with physical and mental disabilities, veterans, limited English proficient patients, lesbian, gay, bisexual and transgender (LGBT) patients, elderly patients, etc.*
- *Responsible individual may “wear more than one hat,” be full-time or dedicate a portion of their time to equity efforts.*
- *Hospital actively involves key stakeholders including patients and families and/or community partners in the planning, development and implementation of health equity efforts.*
- *Hospital explicitly prioritizes equity in organization mission and goals.*

*The Health Equity Organizational Assessment (HEOA) was originally developed by the Centers for Medicare & Medicaid Services Partnership for Patients Hospital Improvement Innovation Network Health Equity Affinity Group.

1. Office of Management and Budget (OMB). [HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status | ASPE](#).
2. Greater Cincinnati Health Council. REaL Data Collection Best Practices. http://forces4quality.org/af4q/download-document/6011/Resource-validated_final_rel_data_collection_best_practice_guidelines_updated_11-28.pdf.
3. Office of Disease Prevention and Health Promotion. Healthy People. Social Determinants of Health. <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>
4. U.S. Department of Health and Human Services. National Culturally and Linguistically Appropriate Services (CLAS) Standards. <https://thinkculturalhealth.hhs.gov/clas/standards>

Data Collection Basics – Importance of REaL Data Collection				
Title	Resource Type	Source	Date	Description
AHA Disparities Toolkit	Web-based toolkit	American Hospital Association (AHA) Institute for Diversity and Health Equity	Updated 2021	Comprehensive toolkit that provides hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients. Informs staff about the importance of data collection, how to implement a framework to collect race, ethnicity, and primary language data at your organization, and ultimately how to use these data to improve quality of care for all populations.
Addressing Health Care Disparities through Race, Ethnicity, and Language Data (REaL)	Resource	AHA Institute for Diversity and Health Equity	2020	The AHA's Institute for Diversity and Health Equity has developed new REaL data resource brief with explanations, web links, answers to frequently asked questions and case study examples of how hospitals are using REaL data to their advantage.
An Equity Agenda for the Field of Health Care Quality Improvement	Discussion Paper	National Academy of Medicine	2021	On the occasion of the 20th anniversary of the publication of To Err Is Human: Building a Safer Health System (IOM, 2000) and Crossing the Quality Chasm: A New Health System for the 21st Century (IOM, 2001), the National Academy of Medicine convened the leaders of seven prominent U.S. health care quality organizations to discuss and author a paper identifying the most important priorities for the health care quality movement in the next 20 years. The authors identified equity as the area of most urgent and cross-cutting concern for the field. This paper summarizes the authors' conclusions about key barriers and strategies to advancing equity in health care quality.
Improving Quality and Achieving Equity: A Guide for Hospital Leaders	Guide	Disparities Solution Center, Massachusetts General Hospital	2015	Guide designed to help health care leaders address disparities through change management. It also highlights model practices and recommends activities and resources that can help hospital leaders initiate an agenda for action.
Building an Organizational Response to Health Disparities	Guide	CMS	2016	Simple, step-by-step guide that includes comprehensive resources and covers topics such as data collection and analysis, leadership, cultural competence, and quality improvement within a health equity framework. The documents also highlight interventions designed to reduce disparities that providers and health plans are implementing.

Data Collection Basics – Importance of REaL Data Collection				
Data Collection Standards				
Title	Resource Type	Source	Date	Description
<u>Inventory of Resources for Standardized Demographic and Language Data Collection</u>	Resource Guide	CMS OMH	2021	This guide contains an overview of multiple topics on the collection of race, ethnicity, and other data used in health equity initiatives. There is a section for standards for data collection as outlined by the U.S. Department of Health and Human services, best practices for healthcare organizations, and training tools for staff.
<u>Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity</u>	Official Communication	OMB	2011	The standards in this Directive have been updated from the ones used for almost two decades throughout the Federal government for recordkeeping, collection, and presentation of data on race and Hispanic origin. The updates are outline in the summary and the Supplementary Information provides background information on the standards development.
<u>Race, Ethnicity, and Language Data Standardization for Health Care Quality Improvement</u>	Resource Guide	National Academy of Medicine	2009	Foundational resource that contains important information on categorizing REAL data beyond standard OMB categories and provides guidance and examples of granular categories. Additionally, it emphasizes at minimum, collecting data on a patient’s spoken English language proficiency.
<u>A Blueprint for Advancing and Sustaining CLAS Policy and Practice</u>	Resource Guide	HHS	2013	The Blueprint is an implementation guide to help you advance and sustain culturally and linguistically appropriate services within your organization. It offers concise, practical information on how to use the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care at your organization.

Data Collection Basics – Importance of REaL Data Collection				
Data Collection Methodology				
Who will collect the data, when will the data be collected and how often, what format will be used to collect the data				
Title	Resource Type	Source	Date	Description
<u>A Practical Guide to Implementing the National CLAS Standards: For Racial and Linguistic Minorities, People with Disabilities and Sexual and Gender Minorities</u>	Toolkit	CMS	2016	Toolkit enables organizations to implement National CLAS Standards and improve health equity. It provides practical tools and examples of CLAS, in addition to efforts to implement National CLAS Standards that can be adapted for use by health care organizations.
<u>Addressing Health Care Disparities through Race, Ethnicity and Language (REaL) Data</u>	Report	AHA	2020	This report documents the request to the Department of Health and Human Services to collect and report demographic data and address disparities in the federal response to the pandemic and ensure access to equitable treatment and share timely, relevant and culturally appropriate public health information.
<u>Guide to Demographic Data Collection in Healthcare Settings</u>	Resource Guide	Ontario Toronto Central Local Health Integrated Network – Sinai Health Systems	2017	Poor understanding of data collection goals, challenges with IT solutions, staff discomfort with collecting demographic information, and patient/client reservations are all frequently cited as system-level and individual-level barriers to sustainable demographic data collection and use. This guide was developed to help healthcare organizations overcome these challenges and embrace the opportunities in standardized demographic data collection.
<u>Data Strategy Worksheet</u>	Worksheet	Center for Care Innovations	2016	This worksheet is a resource that can be used to document and review a healthcare facility's data strategy. It guides the respondent in aligning the organization's key performance metrics or a family of measures toward a specific improvement effort.

Data Collection Basics – Importance of REaL Data Collection				
Staff Training on Data Collection				
Teaches what to collect, how to ask the questions, ensures more accurate data collection, teaches patients to understand why data are being collected, addresses discomfort in asking the questions, sample talking points/scripts.				
Title	Resource Type	Source	Date	Description
Race and Ethnicity Data Improvement Toolkit	Toolkit	Healthcare Cost and Utilization Project	2014	Toolkit includes several tools that are easy to print out use including surveys and scripting.
AHA Disparities Toolkit - Staff Training	Resources	AHA	2020	To ensure that data are collected accurately and consistently, organizations need to invest in training staff. Staff should be partners in this process. The training should provide information about why it is important to collect these data, how to collect data, and how to answer questions or address concerns from patients. The resource provides tools and resources for staff training and scripts for how to ask the questions .
New York State Toolkit to Reduce Health Care Disparities: Improving Race and Ethnicity Data	Toolkit	New York State Department of Health	2014	Toolkit is designed to help hospitals, ambulatory care centers, community health centers and other users understand the importance of collecting accurate data on race and ethnicity. The toolkit includes sample tools, forms, training materials, resources for implementation, frequently asked questions, patient/ consumer materials, resources for hospital leaders and quality improvement resources.
Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals	Report	The Commonwealth Fund	2004	This report serves to assess the state of how race, ethnicity, and primary language information is collected in hospitals. The authors conducted site visits to each of the consortium hospitals to address questions about their data collection practices.
Henry Ford Best Practice: Why-We-Ask	Website	Henry Ford Health System	2021	Example of best practice from a health system of how they educate patients and train staff on the need to collect REaL data.
Improving the Collection of Race, Ethnicity, and Language Data to Reduce Healthcare Disparities: A Case Study from an Academic Medical Center	Report	AHIMA Foundation	2016	This case study provides insight into the challenges initiatives may face in collecting accurate race, ethnicity, and language (REaL) information in the EHR. The experience of an academic medical center adjusting its EHR for better collection of REAL data is presented.

Data Collection Basics – Importance of REaL Data Collection				
Title	Resource Type	Source	Date	Description
Example Patient Race and Ethnicity Questionnaire	Questionnaire	University of Albany	2020	This sample questionnaire was designed to be administered by hospital or clinic personnel to ask patients to provide information on their race and ethnicity. A script is provided for staff to use to help introduce the questions that follow.
Improving Race and Ethnicity Data Collection	Training Tool	Rutgers Center for State Health Policy	2017	This training tool is designed to educate the front-line staff in the importance in collecting REaL data from patients. A worker self-assessment tool and as well as a Patient Information Sheet is included. It provides a mock script for workers who collect information at registration.
Data Analysis/Identifying Opportunities for Improvement				
Create the Data Infrastructure to Improve Health Equity	Toolkit	Institute for Healthcare Improvement (IHI)	2019	The guide includes examples for collecting and using REaL data to improve health equity, mostly focused on stratification by race and ethnicity data, with relatively little focus on language data.
Using Data to Address Health Inequities	Podcast	AHA	2021	Representatives from the fourteen organizations including Providence Health and Henry Ford Health Systems that have formed Truvena come together to discuss this new platform that they use to address healthcare disparities. The platform will de-identify the data and use Artificial Intelligence to mine datasets providing new insights into the unique needs of their patient populations.
Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data	Guide	AHA	2013	Resource that focuses on addressing both collection and use of REAL data through a four-step approach on how to obtain an accurate and usable REAL data set and discussing how hospitals and care systems can use REAL data to achieve clinical, operational, financial, and population health benefits.

Data Collection Basics – Importance of REaL Data Collection				
Title	Resource Type	Source	Date	Description
Health Equity, Diversity & Inclusion Measures for Hospitals and Health System Dashboards	Guide	AHA	2020	Provides guidance on the use of dashboards to equip health care leaders with the necessary information on their journey to advance health equity, diversity and inclusion. A basic level health equity, diversity and inclusion dashboard may include measures to include the following: race, ethnicity and language preference (REaL) data collection, stratification and use; cultural competency training; diversity and inclusion in governance and leadership; and community partnerships.
Mapping Medicare Disparities Tool	Website	CMS Office of Minority Health	2015	The Mapping Medicare Disparities Tool is an example of a tool that uses race/ethnicity in reporting quality measures. This tool contains health outcome measures for disease prevalence, costs, hospitalization for 60 specific chronic conditions, emergency department utilization, readmissions rates, mortality, preventable hospitalizations, and preventive services.
Data Stratification				
A Framework for Stratifying Race, Ethnicity and Language Data	Guide	AHA	2014	This resource provides a five-step framework for stratifying REaL data. The framework includes assembling a work group focused on disparities data, validate the REaL data, identify the highest priority metrics for stratification, determine if stratification is possible on the selected metrics and stratify the data.
Collecting Patient Data: Improving Health Equity in Your Practice	Training	American Medical Association	2018	During this learning opportunity, participants will learn how to develop a standardized process for the collection of patient demographic data and how to use that data for quality improvement initiatives related to population health.
Data-Driven Care Delivery: Data Collection, Stratification and Use	Resource Guide	American Hospital Association	2021	This guide focuses on approaches to promote data collection and stratification to improve patient outcomes. It offers compelling strategies to prioritize health equity at healthcare facilities.



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