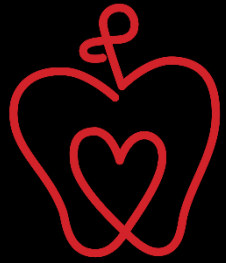




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Race, Ethnicity and Language Data Collection

This video outlines the importance of accurate and standardized collection of data on race, ethnicity and language (REaL).

Practical steps required to routinize REaL data workflows are discussed.

Strategies enabling patients to self-identify REaL characteristics are highlighted for their usefulness in assessing internal areas for improvement, enhancing patient services and clinical outcomes.

This event was supported in part by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).

June 2021



The REaL Data

Tekisha Dwan
Everette, PhD



A training developed for CHCANYS

Objectives

1. Overview definitions related to race, ethnicity, and language data collection
2. Share practical steps to improve and standardize REaL data collection

FD



Race & Ethnicity

Race:

- A social construct that classifies people into distinct groups based on defined criteria, e.g. skin color
- Socially significant not biologically
- Changes throughout time

Ethnicity:

- Shared culture that defines or shapes a group
 - *language*
 - *ancestry*
 - *practices*
 - *beliefs*

It's Racism, Not Race

- Complex social system deeming access to power, privilege, & resources (i.e. health care) based on race
- Multiple forms
 - *Structural/Institutional*
 - *Individual/Internalized*
- Produces inequities based on race
- Rooted in history, social structures, & culture

RACE IS THE CHILD OF RACISM NOT THE FATHER

TA-NEHISI COATES
BETWEEN THE WORLD & ME

It's Racism, Not Race

- Complex social system deeming access to power, privilege, & resources (i.e. health care) based on race
- Multiple forms
 - *Structural/Institutional*
 - *Individual/Internalized*
- Produces inequities based on race
- Rooted in history, social structures, & culture

Recommended Reading:

[Levels of Racism: A Theoretic Framework and a Gardener's Tale](#)

Camara Phyllis Jones, MD, MPH, PhD

American Journal of Public Health
August 2000, Vol. 90, No. 8

Sex and Gender

Sex:

- Biological differences between males & females
- Linked to genitalia & genetic differences

Gender:

- Socially constructed roles, expressions, & identities
- Power & privilege linked to gender
- Cultural variation



REaL DATA COLLECTION STANDARDS



Current Recommendations & Guidance

- OMB 1997: Standard OMB-5; only ethnicity: Hispanic/Latino
- IOM 2002: highlighted the importance of collecting race, ethnicity, and language as a strategy to address health disparities
- IOM 2009: standardization; called for the collection of granular ethnicity and language need data in addition to the standard OMB-5
- ACA 2010: Section 4302 – self-reported and sets the floor at the OMB standards

Other Federal Policies

- Health Insurance Portability and Accountability Act of 1996
- Initiative to Eliminate Racial and Ethnic Disparities in Health (1998)
- Consumer Bill of Rights and Responsibilities (1997)
- Benefits Improvement and Protection Act (2000)
- Report of U.S. Commission on Civil Rights, The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equity (1999)
- Executive Orders 13166 "Improving Access to Services for Persons with Limited English Proficiency" and 13125 "Improving the Quality of Life of Asian Americans and Pacific Islanders" (2000)
- Minority and Health Disparities Research and Education Act of 2000
- Department of Health and Human Services Title VI Regulations (1964)
- Department of Health and Human Services Inclusion Policy (1997)
- Healthy People 2010 (2000)
- Culturally and Linguistically Appropriate Services (2000)
- HHS Data Council Activities (ongoing)
- National Committee on Vital Health Statistics (ongoing)

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MAKING THE CASE FOR REaL DATA

Concerns & Questions

■ Basic 5 W's + H

- *Why ...collect REaL data?*
- *Who ... should collect it?*
- *Where/When ...should it be collected?*
- *What ... should we collect?*
- *How?*



REaL related disparities
persist in health care

Accurate, standard, &
complete REaL data can:

- Understanding patients/community
- Identify health & health care disparities
- Improve quality
- Improve culturally competent and appropriate care
- Improve evaluation

Federal reporting/State
mandates

Why Collect REaL Data?

Who, Where & When?

Hospital/Clinics/Group Practices

Registration staff

Asked once at registration &
validated on a periodic basis

- IDFHE recommends every 2 yrs

Directly from patient/caregiver

Standard format that links to
clinical data

Provide rationale

- Staff & clients must understand why these data are being collected

Asked once at registration & validated on a periodic basis

- IDFHE recommends every 2 yrs

Self-identified by patient/caregiver

- Provide options to decline/refuse to answer as well as don't know

How?

What Should I Collect?


- Decide broad or granular
 - *Focus on granularity but be mindful of capacity*
- OMB: 5 racial categories; 1 ethnicity
 - *Not detailed enough*
 - *Is the floor, not the ceiling*
- CDC: Detailed Race Codes=900+;
Detailed Ethnicity Codes=43
 - *Most detailed and informative*
 - *Challenging to ask in “check the box” paper format*


What Should I Collect?

- Maintain self-reported standard
- Granular racial/ethnic groups should roll up to federal OMB reporting categories
- Base expanded R/E and language data on current service area population

IDFHE Toolkit Options

<https://ifdhe.aha.org/hretdisparities/toolkit>





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AHA Disparities Toolkit

About the Toolkit

The AHA Disparities Toolkit team is proud to release this updated Toolkit. The Toolkit is a Web-based tool that provides hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients.

We trust you will find this Toolkit useful for educating and informing your 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.

Acknowledgments

Special thanks to the [National Advisory Panel members](#) and the [Consortium Members](#) for their input, and to David Baker, MD, MPH, and colleagues at Northwestern University Feinberg School of Medicine for their contribution to the research that informs this work.

Many thanks to the Robert Wood Johnson Foundation for their support of the work for collecting race, ethnicity, and primary language data in hospitals under the Expecting Success: Excellence in Cardiac Care program and for their ongoing grant support to improve data collection. We would also like to thank the Commonwealth Fund for their support of research projects that continue to inform this work.

Project Team

Romana Hasnain-Wynia, PhD, Debbie Pierce, Ahmed Haque, Cynthia Hedges Greising, Vera Prince, and Jennifer Reiter

Citation for Toolkit

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and*

DISPARITIES TOOLKIT

- [How to Use the Toolkit](#)
- [Who Should Use the Toolkit](#)
- [Why Collect Race, Ethnicity, and Primary Language](#)
- [Why Collect Data Using a Uniform Framework](#)
- [Collecting the Data - The Nuts and Bolts](#)
- [How to Ask the Questions](#)
- [How to Use the Data](#)
- [Staff Training](#)
- [Informing and Engaging the Community](#)
- [Deaf and Hard of Hearing Populations](#)
- [Visually Impaired Populations](#)
- [Tools and Resources](#)
- [Frequently Asked Questions](#)

IDFHE Toolkit Options

PPACA 2011 Standards

■ PPACA Standards

Ask broad ethnicity question first

- *Hispanic or Latino or Spanish: person of Chicano, Cuban, Mexican, Mexican American, Puerto Rican, or another Hispanic, Latino, or Spanish culture or origin*
- *Not Hispanic, Latino, or Spanish*

IDFHE Toolkit Options

PPACA 2011 Standards

At minimum ask race according to this standard

- *American Indian/Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.*
- *Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.*

IDFHE Toolkit Options

PPACA 2011 Standards

At minimum ask race according to this standard

- *Black/African American: A person having origins in any of the black racial groups of Africa. Terms such as "Haitian," "Dominican," or "Somali" can be used in addition to "Black or African American."*
- *Native Hawaiian/Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.*
- *White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.*

IDFHE Toolkit Options

HRET Modifications

- Some Other Race
 - *replaces the "Multiracial" category; provides a response option for those Hispanics and others who do not relate to the current OMB race categories*
- Declined
 - *Indicates the person did NOT want to respond to the question and should not be asked again during the same visit or during a subsequent visit*
- Unavailable
 - *Indicates that the person could not respond to the question and can be asked again during the same visit or during a subsequent visit.*

IDFHE Toolkit Options

Granular Data Collection

- Granular ethnicity options should be **based on the population you serve**
- Categories should be selected from CDC/HL7 Code Set
- Always include an open-ended “Other, please specify:” option
- IF only an ethnicity is selected, then a process for rolling up to the PPACA should be used
- Ethnicities written in that do not align with a single PPACA race, should be coded as “no determinate” OMB classification

American
Indian/Alaska
Native

Alaska Indian

Alaska Native

American Indian

Lenni Lenape

Mohegan

Montauk

Oneida

Asian

Asian Indian

Bangladeshi

Burmese

Cambodian

Chinese

Filipino

Hmong

Indonesian

Japanese

Korean

Laotian

Malaysian

Nepalese

Pakistani

Sri Lankan

Taiwanese

Thai

Vietnamese

Black or
African
American

African

African American

Barbadian/Bajan

Black

Haitian

Ibo/Igbo

Jamaican

Nigerian

West Indian

Hispanic, Latino/a, or Spanish

Puerto Rican

Argentinian

Mexican, Mexican American, Chicano/a

Cuban

Ecuadorian

Dominican

Peruvian

Chilean

Venezuelan

Uruguayan

Columbian

Costa Rican

Salvadorian

Honduran

Guatemalan

Nicaraguan

Panamanian

Spanish

Spaniard

Native
Hawaiian
or Other
Pacific
Islander

Native Hawaiian

Guamanian or
Chamorro

Samoan

White

Anglo

Arab/Arabic

British

European

Italian

Israeli

Middle Eastern or North African

Portuguese

IDFHE Toolkit Options

Granular Data Collection Tools

- [CDC/HL7 List](#)
- [IOM Subcmte
Proposed Template](#)
 - *Crosswalks various ethnicity/ancestry standards*

IDFHE Toolkit Options

Language Data Collection

*means facilitator recommends

- Start with common languages used by those you serve
- Include an open-ended question “Other, please specify”
 - *Monitor this data and set a threshold to add to list & set an update schedule**
- Base categories on [Census list](#) or [ARHQ list](#)
- Include:
 - *Do not know*
 - *Unavailable/Unknown*
 - *Declined*

Primary
Language
Used at
Home

American Sign Language

Arabic

Chinese

English


French Creole

Hindi

Italian

Portuguese

Spanish

A thick black L-shaped frame surrounds the text. The vertical bar is on the left, and the horizontal bar is at the bottom, meeting at a corner on the right side.

SEXUAL ORIENTATION & GENDER IDENTITY (SOGI) DATA STANDARDS

Sexual Orientation & Gender Identity (SOGI) Data

- Provide rationale for collecting
- Avoid common pitfalls by:
 - *Separating gender identity from sexual orientation*
 - *Ask 2-tier question*
 - Assigned sex at birth
 - Current legal sex
 - *Ask gender identity in 2-tiers*
 - Gender
 - Gender modality (cisgender vs transgender)



**HOW DO I ASK?
WHAT DO I ASK?**



Start with your why...

Sample Staff Script Options

We want to make sure that [everyone we serve] gets the best care possible. We would like you to tell us your racial/ethnic background so we can review the treatment everyone receives and make sure that everyone get the highest quality of care.

OR

We want to make sure that [everyone we serve] gets the best care possible. We are asking some questions regarding your race, ethnicity, sexual orientation, and gender identity so we can give the best treatment to everyone and make sure that everyone get the highest quality of care. We'll keep your information confidential, and it will be updated in your medical record.

Ethnicity

- Are you Hispanic, Latino, or Spanish origin
 - *Yes, Mexican, Mexican American, Chicano*
 - *Yes, Puerto Rican*
 - *Yes, Cuban*
 - *Yes, another Hispanic, Latino, or Spanish origin*
- No, not of Hispanic, Latino, or Spanish origin
- Unavailable/Unknown
- Declined to answer

**Which one or
more of the
following best
describes your
race?**

- Use the categories for race and ethnic from prior slides
- Allow for multiple selections for race and the ethnic subcategories
- Make sure these options are present
 - *Some other race*
 - *Unavailable/Unknown*
 - *Declined*

Sex Assigned at Birth

- Female
- Male
- Unspecified
- Unavailable/Unknown
- Declined

Current legal sex in your state

- Female
- Male
- Intersex
- Non-binary
- Unavailable/Unknown
- Declined

What is your gender?

- Woman/Girl
- Man/Boy
- Agender/No gender
- Non-binary
- Questioning
- Not listed. Please specify:
- Don't know
- Decline to answer

Are you transgender?

- Yes
- No
- Not listed. Please specify:
- Don't know
- Decline to answer

How do you describe your sexual orientation/sexual identity?

- Same-gender loving
- Same-sex loving
- Lesbian
- Gay
- Bisexual
- Straight (attracted mainly to or only other gender[s])
- Pansexual
- Asexual
- Queer
- Questioning
- Not listed. Please specify:
- Don't know
- Unavailable/Unknown
- Declined

What
pronoun(s) do
you use?

- She/Her
- He/Him
- They/Them
- Other, please specify:

Preferred Name

- This response should be flagged or color-coded in the system

Language

- How well do you speak English?
- Would you like an interpreter?
- Do you speak a language other than English?
- What is this language? (list top options)
- What language do you feel most comfortable speaking with your doctor or nurse?
- What language do you feel most comfortable reading medical or health instructions?

Important Notes

It may seem like a lot to learn but it is quite simple once adopted into the workflow

Follows federal guidance

Suggested categorization is based on current ACS/Census/CDC hierarchy

Options may not fully reflect an individual's identity & will change over time

Continuous learning/re-learning/unlearning needed (cultural humility/cultural competence; implicit/unconscious bias)

Before You Start...You Should Know

- Capabilities of your EHR system
- Engage IT, Chief Admin, and others
- Why you are collecting these data?
- How you will use these data
- Where the data will be stored
- Who will collect these data? What's the workflow?
- Paper version/electronic version
- Are there state specific requirements on data collection?
- Plan for on-going staff training
- How will inform the people you serve?

Sample Campaign

Connecticut State Medical Society

WE ASK BECAUSE WE CARE

**PREGUNTAMOS
PORQUE NOS IMPORTA**

¿Cuál es tu raza?

¿Cuáles tu origen étnico?

¿Cuál es tu idioma favorito?

¿Te identificas con la comunidad LGTBQI?

**CONTESTAR PREGUNTAS COMO
ESTAS NOS AYUDA A BRINDARTE
LA MEJOR ATENCIÓN POSIBLE**



Tools & Resources

- [AHA IFDHE Toolkit](#)
- [Connecticut State Medical Society Health Equity Toolkit](#)

We are not all starting at the same place...



Story Based Strategy

<https://www.storybasedstrategy.org/tools-and-resources>

start
where you
are.
use what
you have.
do what you
can.

- ARTHUR ASHE -

WE ALL START
SOMEWHERE

Sources & Resources

- American Hospital Association Institute for Diversity and Health Equity (AHA IFDHE)
 - *Disparities Toolkit*
- Agency for Healthcare Research & Quality
- American Journal of Public Health
- Centers for Disease Control & Prevention
- Health Equity Data Analytics research team
- Institute of Medicine
- Office of Management and Budget
- Various Academic Resources



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For further information regarding CHCANYS'
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