

# Agenda VI: Discussion on Demographic Data Collection Resources

Ignatius Bau, Health Equity Subject Matter Expert, Consultant

# Race and Ethnicity Data

hospitals in pursuit of excellence  
Accelerating Performance Improvement

Signature Leadership Series

Improving Health Equity Through Data Collection AND Use: A Guide for Hospital Leaders

March 2011

American Hospital Association

HRET  
HEALTH RESEARCH & EDUCATIONAL TRUST  
In Partnership with AHA

The cover features a photograph of a male doctor in a white lab coat standing by a hospital bed, looking at a clipboard while a female patient looks up at him. The background is a hospital room with medical equipment.

hospitals in pursuit of excellence  
Accelerating Performance Improvement

Signature Leadership Series

Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data

August 2013

Equity of Care

American Hospital Association

AAMC  
Tomorrow's Doctors, Tomorrow's Cures®

CHA  
Community Health Association of the United States

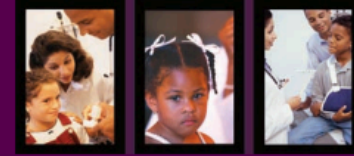
American College of Healthcare Executives  
For Leaders who care®

AMERICA'S ESSENTIAL HOSPITALS

The cover features a photograph of a male doctor in a white lab coat looking at a tablet computer while a female patient lies in a hospital bed. The background is a hospital room.

# Language Data

## I SPEAK ...

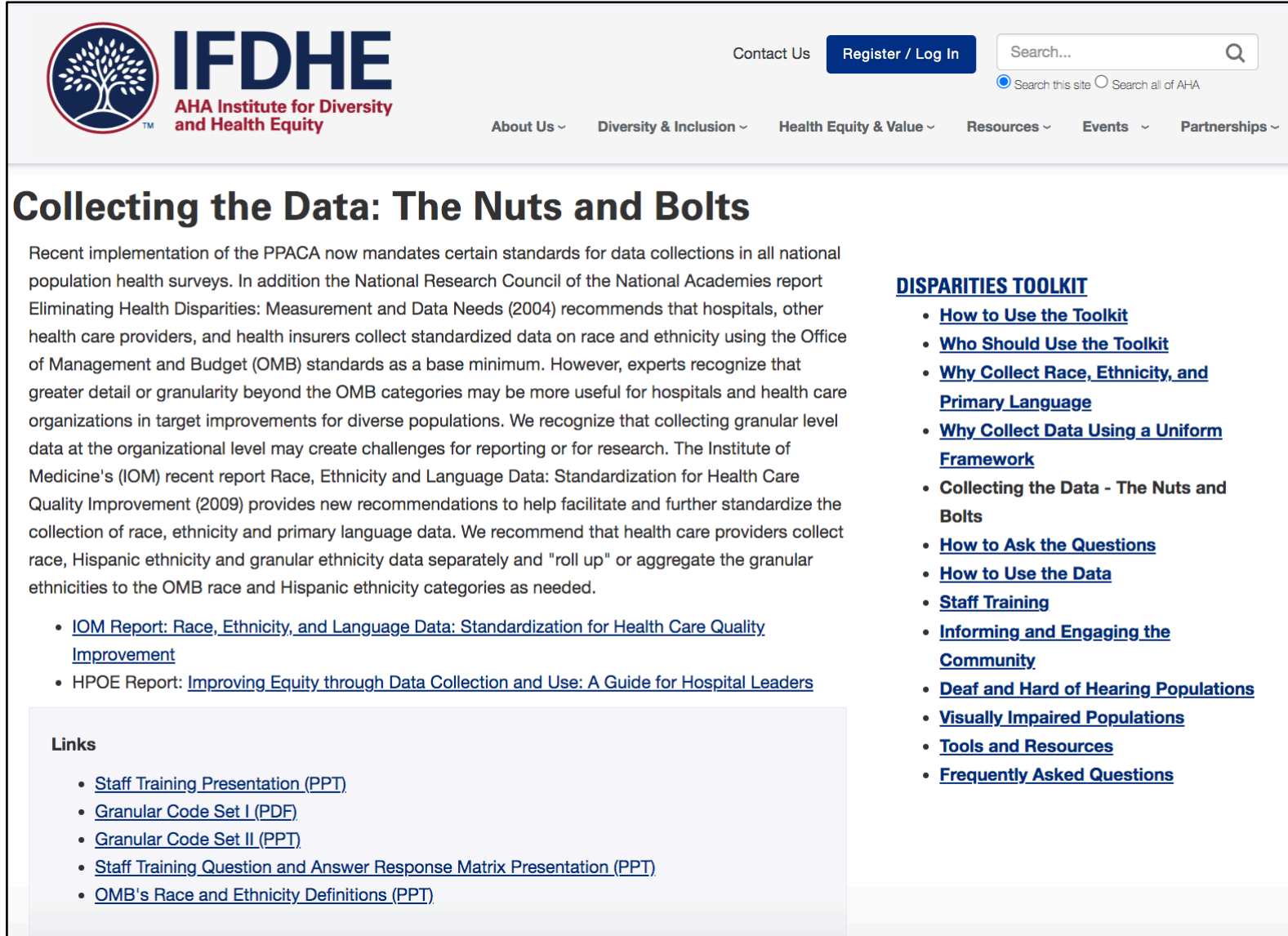


<b>ARABIC</b>	أنا أتحدث اللغة العربية	<b>FRENCH</b>	Je parle français	<b>LAOTIAN</b>	ຂ້ອຍປາກພາສາລາວ	<b>SPANISH</b>	Yo hablo español
<b>ARMENIAN</b>	Ես խոսում եմ հայերեն	<b>FRENCH CREOLE (HAITIAN CREOLE)</b>	M pale kreyòl ayisyen	<b>LITHUANIAN</b>	Aš kalbu lietuviškai	<b>SWAHILI</b>	Ninaongea Kiswahili
<b>BENGALI</b>	আমী বাংলা কথা বলেতে পারী	<b>GERMAN</b>	Ich spreche Deutsch	<b>MANDARIN (CHINESE)</b>	我講國語 我讲国语/普通话	<b>SWEDISH</b>	Jag talar svenska
<b>BOSNIAN</b>	Ja govorim bosanski	<b>GREEK</b>	Μιλώ τα ελληνικά	<b>NORWEGIAN</b>	Jeg snakker norsk	<b>TAGALOG</b>	Marunong akong mag-Tagalog
<b>BULGARIAN</b>	Аз говоря български	<b>GUJARATI</b>	હું ગુજરાતી બોલુ છું	<b>POLISH</b>	Mówi' po polsku	<b>THAI</b>	พูดภาษาไทย
<b>BURMESE</b>	ကျွန်တော်/ကျွန်မ မြန်မာ ဝို ခြံတော် မိဘဝဟ်	<b>HEBREW</b>	אני מדבר עברית	<b>PORTUGUESE</b>	Eu falo português do Brasil (Brasil) Eu falo português de Portugal (Portugal)	<b>TURKISH</b>	Türkçe konuşurum
<b>CAMBODIAN</b>	ខ្ញុំនិយាយភាសាខ្មែរ	<b>HINDI</b>	मैं हिंदी बोलता हूँ ।	<b>PUNJABI</b>	ਮੈਂ ਪੰਜਾਬੀ ਬੋਲਦਾ/ਬੋਲਦੀ ਹਾਂ।	<b>UKRAINIAN</b>	Я розмовляю українською мовою
<b>CANTONESE (CHINESE)</b>	我講廣東話 我讲广东话	<b>HMONG</b>	Kuv has lug Moob	<b>ROMANIAN</b>	Vorbesc românește	<b>URDU</b>	میں اردو بولتا ہوں
<b>CROATIAN</b>	Govorim hrvatski	<b>HUNGARIAN</b>	Beszélek magyarul	<b>RUSSIAN</b>	Я говорю по-русски	<b>VIETNAMESE</b>	Tôi nói tiếng Việt
<b>CZECH</b>	Mluvím česky	<b>ITALIAN</b>	Parlo italiano	<b>SERBIAN</b>	Ja говорим српски	<b>YORUBA</b>	Mo nso Yooba
<b>DUTCH</b>	Ik spreek het Nederlands	<b>JAPANESE</b>	私は日本語を話す	<b>SLOVAK</b>	Hovorím po slovensky		
<b>FARSI (PERSIAN)</b>	من فارسی صحبت می کنم	<b>KOREAN</b>	한국어 합니다				

\* Registrars should use this tool to guide patients in identifying their spoken language when they do not speak English at all.

SOURCE: Adapted from the State of Ohio's Office of Criminal Justice Services and recommended by the US Department of Health and Human Services - Office of Civil Rights for use by healthcare facilities

# Race and Ethnicity Data



The screenshot shows the IFDHE (AHA Institute for Diversity and Health Equity) website. The header includes the IFDHE logo, navigation links (Contact Us, Register / Log In), a search bar, and a menu with categories like About Us, Diversity & Inclusion, Health Equity & Value, Resources, Events, and Partnerships. The main content area features a title 'Collecting the Data: The Nuts and Bolts' and a detailed paragraph about data collection standards. A 'DISPARITIES TOOLKIT' section lists various resources. A 'Links' box at the bottom left contains additional presentation and code set links.

**IFDHE**  
AHA Institute for Diversity and Health Equity

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 Search this site  Search all of AHA

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## Collecting the Data: The Nuts and Bolts

Recent implementation of the PPACA now mandates certain standards for data collections in all national population health surveys. In addition the National Research Council of the National Academies report Eliminating Health Disparities: Measurement and Data Needs (2004) recommends that hospitals, other health care providers, and health insurers collect standardized data on race and ethnicity using the Office of Management and Budget (OMB) standards as a base minimum. However, experts recognize that greater detail or granularity beyond the OMB categories may be more useful for hospitals and health care organizations in target improvements for diverse populations. We recognize that collecting granular level data at the organizational level may create challenges for reporting or for research. The Institute of Medicine's (IOM) recent report Race, Ethnicity and Language Data: Standardization for Health Care Quality Improvement (2009) provides new recommendations to help facilitate and further standardize the collection of race, ethnicity and primary language data. We recommend that health care providers collect race, Hispanic ethnicity and granular ethnicity data separately and "roll up" or aggregate the granular ethnicities to the OMB race and Hispanic ethnicity categories as needed.

- [IOM Report: Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#)
- HPOE Report: [Improving Equity through Data Collection and Use: A Guide for Hospital Leaders](#)

**Links**

- [Staff Training Presentation \(PPT\)](#)
- [Granular Code Set I \(PDF\)](#)
- [Granular Code Set II \(PPT\)](#)
- [Staff Training Question and Answer Response Matrix Presentation \(PPT\)](#)
- [OMB's Race and Ethnicity Definitions \(PPT\)](#)

### 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](#)

# Sexual Orientation and Gender Identity Data

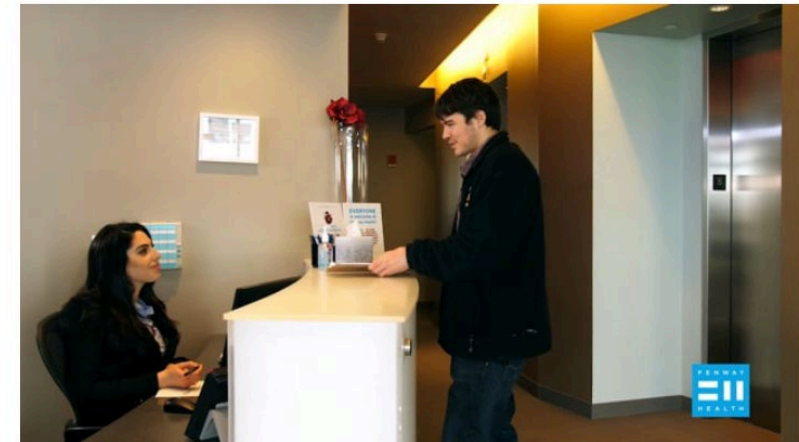


**EH** NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER  
A PROGRAM OF THE FENWAY INSTITUTE

Learning Resources ▾ What We Offer ▾

## SO/GI Data Collection Demonstration Videos

### Registration Staff



- Helping a patient who does not understand why he is being asked about his sexual orientation

# Disability Data



## 2023 Compendium of Disability Data Collection Methods

August 25, 2023

Jason Markesich and Stacie Feldman

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**Submitted to:**

University of New Hampshire, Institute on Disability  
51 College Road  
Durham, NH 03824  
Project Officer: Andrew Houtenville  
Contract No. P19UFZ59

**Submitted by:**

Mathematica  
Center for Studying Disability Policy  
600 Alexander Park  
Princeton, NJ 08540  
Project Director: David Mann  
Mathematica Reference No. 51731.Y5.DM4.000.000



## Charting Equality

Why Demographic Disability Data is Good for Everyone

by Mary Lou Breslin and Silvia Yee  
January 2024





**CHPSO**

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and improving the quality of  
health care delivery*

**Collaborative Healthcare Patient Safety Organization**



A DIVISION OF THE HOSPITAL QUALITY INSTITUTE

# Leveraging Data to Promote Equity in Care

**Thursday, September 1, 2022**

*Developed by the Health Research and Educational Trust of New Jersey, a nonprofit affiliate of the New Jersey Hospital Association. Development of these resources were funded by a grant from the Robert Wood Johnson Foundation.*

## *Introducing a Series of Educational Tools and Resources for Improving Patient Race, Ethnicity and Primary Language Data Collection*

Now healthcare organizations, community agencies and other facilities collecting patient data can use these resources to:

- Establish a structure for training staff on the importance of collecting accurate patient data and ways to implement the recommended guidelines/strategies;
- Apply the recommended standardized guidelines across all registration encounters and ensure accuracy of patient data;
- Ask questions about race, ethnicity and primary language using a simple interview script;
- Guide and assist patients in selecting categories that accurately and appropriately identify them; and,
- Respond effectively to patient questions and concerns.



# Reducing Health Disparities in California's Public Health Care Systems

June 2019

## Data Collection

Over the past three years, public health care systems have made significant advancements in their ability to collect detailed REAL data (See Figure 1). PRIME helped advance data collection efforts so that public health care systems could better identify the diversity of their patients and provide more tailored care.

By the end of program year three, public health care systems collected detailed REAL data for more than 638,000 patients - an additional 345,000 patients since program year one.

Figure 1. REAL Data Collection (Years 1-3)\*



Figure 2. SOGI Data Collection (Years 2-3)\*

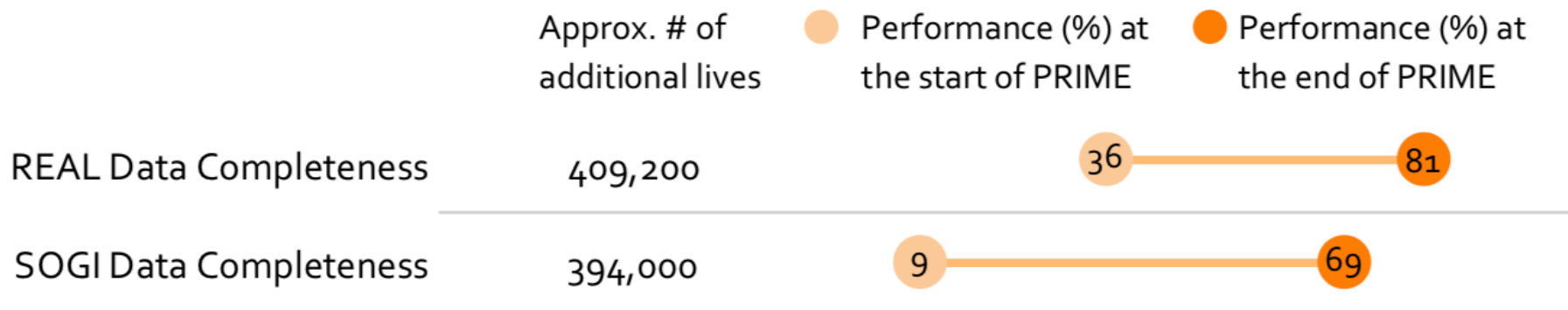


\*Data shows rates for public health care systems participating as individual PRIME entities (e.g. S1 = System 1).

## Celebrating the Advancement of Equitable Care in California Through PRIME

### IMPROVEMENTS IN QUALITY OF CARE

Public health care systems made significant gains across key outcome and process measures in PRIME. The graphic below illustrates a few of the improvements, including the number of additional lives impacted due to PRIME (through 2019). For example, public health care systems collected Race, Ethnicity and Language (REAL) data for 409,200 additional lives and Sexual Orientation and Gender Identity (SOGI) data for 394,000 additional lives over the last five years. For the first time, public health care systems took a standardized approach to identify disparities in health care, laying the foundation for health equity work for years to come.

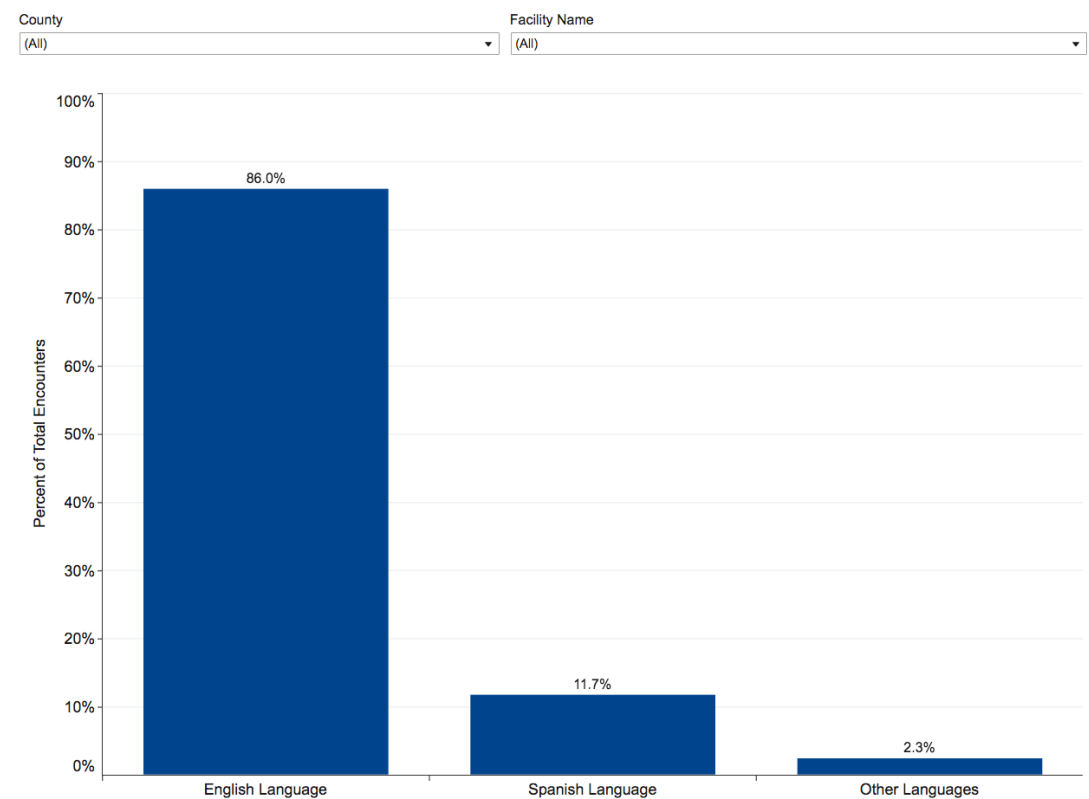


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# Preferred Languages Spoken in California Facilities

Out of the 16 million patient encounters statewide in 2021, patients in more than two million encounters preferred a language other than English.

All Preferred Languages Spoken by Facility and County, 2021



*Note: All reported percentages are calculated using de-identified and masked values. See section 6b: Applying Data De-Identification Guidelines.*

What other resources would be useful to California hospitals in collecting patient demographic data?