

Family Voices

Data collection Race/Ethnicity and language

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Health Disparities

- Differences between groups of people that affect
 - how frequently a disease affects a group
 - how many people get sick
 - how often the disease causes death.
- Many populations are affected by disparities.
 - Racial and ethnic minorities
 - Residents of rural areas
 - Women, children, the elderly
 - Persons with disabilities
 - Gender and sexual orientation



NIH: National Cancer Institute

Race/Ethnicity Categories

- Categories are not static
- Categories used as proxies for cultural, social, economic and environmental influences.
 - 1850 (assumed White unless other indicated)
 - American Indian added 1860
 - 1960 self selection
 - 2000 126 racial and ethnic categories

Winker, M (2004). Measuring race and ethnicity: Why and how? *JAMA*, 292(13), 1612-1614.

Research and Evaluation

- Measurement and outcomes important for demonstrating the effectiveness of programs.
- Data is needed to track disparities and develop effective programs.
- Resolve the political and social context in which need persists.
- Benefit of research is not guaranteed for those in silence.
- Accurate reporting in necessary



Data collection

- Asking about race/ethnicity can be uncomfortable
 - Surveyor
 - How do you feel when you ask about race/ethnicity and language?
 - Participant
 - History of abuses in communities of color.
- Its necessary to obtain accurate data.
- Develop a plan to handle missing data.

Mitigate the discomfort

- Explanation
 - How do you explain why you are asking about race/ethnicity and language?
 - Participation is voluntary
 - Note if the choice is *not* to disclose
- Patience
 - One explanation may not be enough
 - Different experiences and perspectives
 - May not understand why you, your organization or the government needs this information

Children with Special Health Care needs (CSHCN)

- Children who have or are at risk for chronic physical, developmental, behavioral, or emotions conditions and who also require health and related services of a type or amount beyond that required by children generally



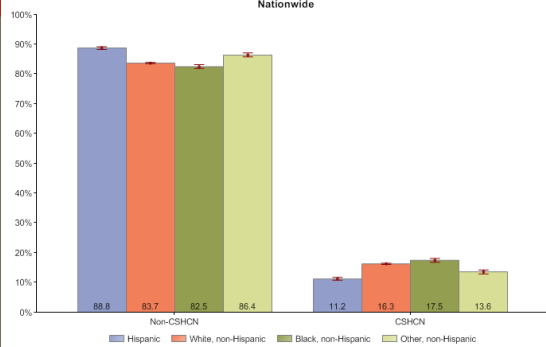
Maternal and Child Health Bureau

Data Resource center for child and adolescent health

- Telephone survey conducted by the National Center of Health Statistics at the Centers for Disease Control
 - Sponsored by the federal Maternal and Child Health Bureau
 - Households with children 0-17 years of age enrolled
- In 2007, 91,642 child-level NSCH interviews were completed nationally
- Approximately 1,800 interviews collected per state
 - range from 1,725 to 1,932
- NSCH results are weighted to represent the U.S. population and population of each state

<http://childhealthdata.org/learn/methods/sampling>

How many children/youth have special health care needs?
Children ages 0-17 years
Nationwide



Data collection

- Why collect race/ethnicity and language data?
 - Gather accurate data to track health disparities.
 - National reporting requirements
 - Contribute to health literacy for all populations



National Reporting Requirements

- Health and Human Services data policy
 - All HHS sponsored projects required
 - Race, ethnicity, sex, primary language and disability status
- In 2011, the Section 4302 Standards Workgroup (ACA) was created to develop a standard of data collection.
 - Reviewed current policy and federal data collection standards (OMB), adequacy of prior testing, and quality of the data.
 - Consulted with statistical agencies and programs and reviewed the Institute of Medicine Report *Race, Ethnicity, and Language Data Collection: Standardization for Health Care Quality Improvement*.
 - Built on members' experience with collecting and analyzing demographic data

<http://aspe.hhs.gov/>

Race/Ethnicity data collection Standards

- Self-identification** is the preferred way of obtaining race and ethnicity information.
- To ensure data quality, separate questions for race and ethnicity should be used wherever feasible.
 - Ethnicity is asked first, and then race.
 - Categories for ethnicity are: Hispanic/Latino & Not Hispanic/Latino.
 - Categories for race are: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White.
- Respondents who wish to identify their multi-racial heritage may choose more than one race.

Self-Identification

- Self identification is key to collecting accurate data
 - Data collectors can not rely on own assessment
 - U.S is experiencing a demographic shift due to immigration and intermarriage
 - One in seven marriages is between spouses of different races or ethnicities. (2008- 2009 Pew Research Center)
- If we identify incorrectly:
 - False inflation of results
 - Underreporting of results
 - Contribute to health inequities



Exercise



Ethnicity data standards

Are you Hispanic, Latino/a, or Spanish Origin?

Category	Notes
No, not of Hispanic, Latino/a, or Spanish Origin	No
Yes, Mexican, Mexican American, Chicano/a	These categories equal "yes"
Yes, Puerto Rican	
Yes, Cuban	
Yes, another Hispanic, Latino/a, or Spanish Origin	

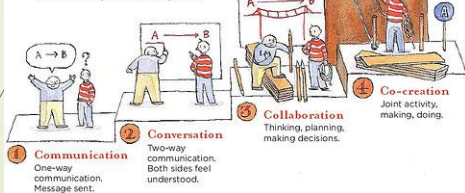
Race Data Standard

What is your race?

Category	Notes
White	Current OMB standards
Black or African American	
American Indian/Alaska Native	These categories sum to equal the Asian race category.
Asian Indian	
Chinese	
Filipino	
Japanese	
Korean	
Other Asian	

What is language?

Language is more than just communication, it is the primary method by which we do things together.
 Language is the accumulation of shared meaning - of common ground.



<http://www.lzwrightnow.com/5-tips-to-overcoming-language-barriers/>

Language

- Disparities have been associated with English language proficiency rather than specific language spoken.
- Standards for primary language is a measure of English proficiency.
 - How well do you speak English? (<=5 years old)
 - Very well
 - Well
 - Not well
 - Not at all



Language

- Assist with developing health literacy:
 - The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan and Parker, 2000).
- HL skills are mediated by education, culture and language.
 - Race is often used as a proxy measure of culture
- Think about the services you offer as part of your job, can you link low/high health literacy to outcomes such as illness management or decision-making?

In sum...

- Collection of race, ethnicity and language data are important to:
 1. Gather accurate data to track health disparities.
 2. National reporting requirements
 3. Contribute to health literacy for all populations
- In short, contribute to health equity.



Questions, Comments, or Concerns?

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