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

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

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.
  - It is 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 emotional 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/team/methods/sampling

Data collection
- Why collect race/ethnicity and language data?
  1. Gather accurate data to track health disparities.
  2. National reporting requirements
  3. 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.

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 Alaskan 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.

http://aspe.hhs.gov/
Self-Identification

- Self identification is key to collecting accurate data
- Data collectors cannot 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

Ethnicity data standards

<table>
<thead>
<tr>
<th>Category</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, not of Hispanic, Latino/a, or Spanish</td>
<td>No</td>
</tr>
<tr>
<td>Origin</td>
<td></td>
</tr>
<tr>
<td>Yes, Mexican, Mexican American, Chicana/a</td>
<td>These categories equal “yes”</td>
</tr>
<tr>
<td>Yes, Puerto Rican</td>
<td></td>
</tr>
<tr>
<td>Yes, Cuban</td>
<td></td>
</tr>
<tr>
<td>Yes, another Hispanic, Latino/a, or Spanish</td>
<td></td>
</tr>
<tr>
<td>Origin</td>
<td></td>
</tr>
</tbody>
</table>

Race Data Standard

<table>
<thead>
<tr>
<th>What is your race?</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Current OMB standards</td>
</tr>
<tr>
<td>Black or African American</td>
<td></td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>These categories sum to equal the Asian race category.</td>
</tr>
<tr>
<td>Asian Indian</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Filipino</td>
<td></td>
</tr>
<tr>
<td>Japanese</td>
<td></td>
</tr>
<tr>
<td>Korean</td>
<td></td>
</tr>
<tr>
<td>Vietnamese</td>
<td></td>
</tr>
<tr>
<td>Other Asian</td>
<td></td>
</tr>
</tbody>
</table>

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)
    a. Very well
    b. Well
    c. Not well
    d. Not at all

http://www.lizwrightnow.com/5-tips-to-overcoming-language-barriers/
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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