New York State Department of Health
SPARCS Training

Improving and Expanding Race and Ethnicity Data Collection

Albany, NY
October 10, 2013
# Agenda

<table>
<thead>
<tr>
<th>Topic</th>
<th>Presenter</th>
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</table>
| Welcome and Introductions                | Eric Niehaus  
Vice President  
Healthcare Association of New York State |
| Health and Health Care Disparities       | Barbara A. Dennison, MD  
Director, Policy and Research Translation Unit  
Division of Chronic Disease Prevention  
Office of Public Health  
New York State Department of Health    |
| Race and Ethnicity                       |                                                                          |
| SPARCS Data Collection                   | John M. Skerritt  
Technical Specialist  
SPARCS Operations  
Office of Quality and Patient Safety  
New York State Department of Health |
| Questions & Answers                      | Dr. Dennison and John Skerritt                                           |
Objectives

• Describe why improved race and ethnicity data will help in identifying disparities in health care quality.

• Identify national legislative/regulatory attention to race and ethnicity data.

• Describe steps to improve quality of data collection and expand race and ethnicity categories.

• Describe how to code the expanded race and ethnicity data categories.
Definitions

• **Health Disparities**: *Differences in the incidence, prevalence, mortality, burden of disease and other adverse health conditions that exist among specific population groups.*

*Source: National Institute of Health*

• **Health Care Disparities**: Includes differences in treatment provided to members of different racial or ethnic groups that is not justified by the underlying health conditions or treatment preferences of patients.

*Source: Institute of Medicine*
What are Disparities in Health Care Quality?

- *Racial and ethnic minorities tend to receive a lower quality of health care than non-minorities*

- Less likely to receive:
  - Cancer screening
  - Cardiovascular therapy
  - Kidney dialysis
  - Transplants
  - Curative surgery for lung cancer
  - Hip and knee replacement
  - Pain medicines in the ER
Unequal Health Care

• The health care system contributes to disparities in care:

  • Increased medical errors
  • Prolonged length of stays
  • Avoidable admissions and readmissions
  • Over and under-utilization of procedures

Growing U.S. Minority Population

Population Projections, 2010 to 2050

Minorsity Groups Will Be Majority

U.S. Population 2000, %
- White, Non-Hispanic: 69.0
- Black: 13.0
- Hispanic: 13.0
- Asian: 3.8
- Other: 2.5

U.S. Population 2050, %
- White, Non-Hispanic: 50.0
- Black: 8.0
- Hispanic: 24.0
- Asian: 15.0
- Other: 5.3

Source: Eliminating Disparities: Why It’s Essential and How to Get It Done, American Hospital Association.

NY Race, %
- White: 71.2%
- Black: 17.5%
- AI/AN: 1.0%
- Asian: 8.0%
- Haw/Pac Islander: 1.0%
- 2 or More Races: 2.2%

NY Ethnicity, %
- Hispanic/Latino: 57.6%
- Not Hispanic/Latino: 18.2%

Source: U.S. Census Bureau
Increasing Legislative and Regulatory Attention to Race and Ethnicity Data

  - To be eligible for “meaningful use” incentive payments

- Patient Protection and Affordable Care Act of 2010
  - If receiving federal money

- Revised Joint Commission Standards - 2012
  - New requirement

- NYS SPARCS – All discharges effective January 1, 2014
  - Expanded race and ethnicity categories (CDC Race and Ethnicity Code Set - Version 1.0)
  - Increased attention to data quality
“Although the collection of race, ethnicity and language* data does not necessarily result in actions that will reduce disparities and improve care, the absence of the data guarantees that none of that will occur.”


*Note: The language reference is part of a direct quotation. SPARCS collects race and ethnicity data, but not language data.
Three Steps to Address Health Disparities

1. Standardize collection of self-reported race and ethnicity data

2. Stratify and analyze performance measures by race and ethnicity

3. Identify and develop quality improvement interventions targeted to specific patient populations
82% of hospitals collect race and ethnicity data, but...

- Categories vary within and across hospitals
- Staff collect data mostly by observation
- Staff at some hospitals trained to “not ask”
- Most hospitals do not use data for quality improvement
  - Only 17% use data to assess and compare health outcomes among different patients

Source: Hospitals, Language, and Culture: a Snapshot of the Nation, 2010  N = 60 U.S. Hospitals
Some Anticipate Obstacles to Modifying Registration IT System

- Information technology
- Training/educating staff
- Time
- Costs

45% do not anticipate any obstacles
Registration Staff Face Challenges/Barriers to Race and Ethnicity Data Collection

• Patient reluctance to provide the data
• Staff reluctance to ask the questions
• Inability of staff to communicate in patient’s preferred language
• Lack of staff training on data collection
Barriers/Challenges to Using Race and Ethnicity Data

- Accuracy of the data
- Lack of consistent data collection process
- Lack of standardized data categories
- Data systems and integration with QI practices

41% reported no barriers or challenges
NYS Assessment of Hospitals and Ambulatory Surgery Facilities

• Policy or Procedure for collecting patient race and ethnicity information (74%)

• Provide staff training on R/E data collection (78%)
  • Registration/Admissions Supervisors (13%)
  • Outpatient Registration Staff (27%)
  • Ambulatory Surgery Admissions Staff (24%)
  • ER Registration Staff (21%)
  • Admissions Clerks (32%)
  • Registration Clerks (35%)

• Training offered only once to new employees (65%)
NYS Assessment of Hospitals and Ambulatory Surgery Facilities

• Frequency of collecting patient race and ethnicity information:
  • Initial Visit (34-40%)
  • Every Visit (42-53%)
  • Don’t Know (5-25%)

• Method of collecting patient race and ethnicity information:
  • Verbally asking the patient questions (87%)
  • Getting patient information from existing records (53%)
  • Having the patient fill out a form (40%)
  • Observing the patient’s physical characteristics (34%)
NYS Assessment of Hospitals and Ambulatory Surgery Facilities

• Reported barriers to collecting patient race and ethnicity information:
  • Patient declines to respond (64%)
  • Staff have not been trained (15%)
  • Question too sensitive (53%)
  • Language or communication barriers (39%)
  • There is not a good opportunity to collect (16%)
  • Not enough time to collect (17%)
  • No method to collect this information (2%)
Components of Standardized Race and Ethnicity Data Collection

- Use standardized categories across the organization
- Ask patient to self-report ethnicity, then race
  - No more “eyeballing” the patient
  - Data are collected from all patients
- Tell the patient why we are collecting his/her race and ethnicity and how the information will be used
Article 28 SPARCS Timeline

- July 1, 2013: Health care facilities may begin submitting files in the expanded format.
- All discharges effective January 1, 2014
  - Facilities must be fully transitioned to collect and report the expanded race and ethnicity categories.
Key Decision Points

• Who needs to be engaged?
• What system modifications need to be made?
• How will the registration process change?
• How will staff be trained on the new collection procedures?
• How will you monitor the data to ensure completeness and accuracy?
Quality Improvement

• Requires high-quality data.
• First Step: Helping hospitals gather data on patient race and ethnicity to obtain a more accurate and complete picture of their patients.
• Second Step: Use data to critically examine care delivered to learn whether they are providing equitable care.
• Third Step: Design Quality Improvement efforts to improve quality of care and reduce disparities.

Source: Robert Wood Foundation, Expecting Success: Excellence in Cardiac Care Program
# SPARCS Ethnicity Standards

Are you Hispanic, Latino/a, or Spanish origin? (One or more categories may be selected)

<table>
<thead>
<tr>
<th>Current Data Standard</th>
<th>Expanded Data Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>X12 Value</td>
<td>Ethnicity</td>
</tr>
<tr>
<td>E1</td>
<td>Spanish/Hispanic Origin</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>See: SPARCS Appendix RR for list of codes (CDC Code Set)</td>
</tr>
<tr>
<td></td>
<td>E2</td>
</tr>
<tr>
<td>E9</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
# SPARCS Race Standards

**What is your race? (One or more categories may be selected)**

<table>
<thead>
<tr>
<th>Current Data Standard</th>
<th>Expanded Data Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>X12 Value</strong></td>
<td><strong>Race</strong></td>
</tr>
<tr>
<td>R1 American Indian or</td>
<td>R1 American Indian or</td>
</tr>
<tr>
<td>Alaska Native</td>
<td>Alaska Native</td>
</tr>
<tr>
<td>R2 Asian</td>
<td>R2.01 Asian Indian</td>
</tr>
<tr>
<td></td>
<td>R2.06 Chinese</td>
</tr>
<tr>
<td></td>
<td>R2.08 Filipino</td>
</tr>
<tr>
<td></td>
<td>R2.11 Japanese</td>
</tr>
<tr>
<td></td>
<td>R2.12 Korean</td>
</tr>
<tr>
<td></td>
<td>R2.19 Vietnamese</td>
</tr>
<tr>
<td></td>
<td>See: SPARCS Appendix RR for list of codes (CDC Code Set)</td>
</tr>
</tbody>
</table>

See: SPARCS Appendix RR for list of codes (CDC Code Set)
# SPARCS Race Standards

## Race Standards

### What is your race? (One or more categories may be selected)

<table>
<thead>
<tr>
<th>X12 Value</th>
<th>Current Data Standard</th>
<th>Expanded Data Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>R3 Black or African American</td>
<td>R3 Black or African American</td>
</tr>
<tr>
<td>R4</td>
<td>Native Hawaiian or Pacific Islander</td>
<td>R4.01.001 Native Hawaiian</td>
</tr>
<tr>
<td></td>
<td></td>
<td>R4.02.001 Guamanian or Chamorro</td>
</tr>
<tr>
<td></td>
<td></td>
<td>R4.01.002 Samoan</td>
</tr>
<tr>
<td></td>
<td></td>
<td>See: SPARCS Appendix RR for list of codes (CDC Code Set) Additional Pacific Islander categories</td>
</tr>
<tr>
<td>R5</td>
<td>White</td>
<td>R5 White</td>
</tr>
<tr>
<td>R9</td>
<td>Other Race</td>
<td>R9 Other Race</td>
</tr>
</tbody>
</table>

See: SPARCS Appendix RR for list of codes (CDC Code Set) Additional Pacific Islander categories
How Will SPARCS Collect Data?

• X12-837, Version 5010 format
• Repetition separator in ISA
• DMG segment format
• Edit reports
• Data dictionary
• SPARCS Appendix RR (CDC Race and Ethnicity Code Set - Version 1.0)

SPARCS Data Collection

The X12-837 file:
• Using Version 5010R: this is the only format supported.
• The race and ethnicity data elements are collected in the DMG segment and make use of the repetition separator.
• ISA 11 segment must contain the same character as DMG 05 separating multiple race values.
• ISA*00* *00*..... *^* <- ISA 11
SPARCS Data Collection

• The DMG segment contains the race and ethnicity information.
• The race and ethnicity can repeat; up to 10 total in the segment.
• The repetition separator is used to identify each unique value.
• DMG*D8*20130115*F**RET:R2.02^:RET:E2* <- DMG 05
SPARCS Data Collection

• SPARCS edit reports have an error code for race and ethnicity:
  • 2010DMG5000 RACE and ETHNICITY CODE
  • Most errors to date have been missing the repetition separator or missing the values completely
Data Element Name: Subscriber Race

Format-Length: AN - 9

Effective Date: January 1, 1994

National Standard Mapping:
Electronic - 837I Version: X12 Loop 2010BA
Ref. Des. DMG05 - 3
Data Element 1271
Code SEE BELOW
X-12 Data Element Name Subscriber Race

Definition:
The code which best describes the race of the subscriber. The DMG05 is a composite data element. Each composite section refers to a specific data element. The first element is the Component Element Separator. This is the second element for race. There can be up to 10 race/ethnicity codes reported.

Codes and Values:

1. Equals a valid Race Code in accordance with the Race Codes in Appendix RR.
2. Up to ten selections of race and/or ethnicity may be reported.

Single Race Example:
DMG*D8*19880208***RET:R5**:RET:E1.01******~

Multiple Race Example:
DMG*D8*19880208***RET:R5**:RET:R4.01.001**:RET:R2.19**:RET:R2.01**:RET:E1.01******~
# Appendix RR - Race and Ethnicity Codes

**Source:** CDC Race and Ethnicity Code Set - Version 1.0  
**Effective:** January 2014

<table>
<thead>
<tr>
<th>CODE</th>
<th>RACE DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>AMERICAN INDIAN OR ALASKA NATIVE</td>
</tr>
<tr>
<td>R2</td>
<td>ASIAN</td>
</tr>
<tr>
<td>R2.01</td>
<td>Asian Indian</td>
</tr>
<tr>
<td>R2.02</td>
<td>Bangladeshi</td>
</tr>
<tr>
<td>R2.03</td>
<td>Bhutanese</td>
</tr>
<tr>
<td>R2.04</td>
<td>Burmese</td>
</tr>
<tr>
<td>R2.05</td>
<td>Cambodian</td>
</tr>
<tr>
<td>R2.06</td>
<td>Chinese</td>
</tr>
<tr>
<td>R2.07</td>
<td>Taiwanese</td>
</tr>
<tr>
<td>R2.08</td>
<td>Filipino</td>
</tr>
<tr>
<td>R2.09</td>
<td>Hmong</td>
</tr>
<tr>
<td>R2.10</td>
<td>Indonesian</td>
</tr>
<tr>
<td>R2.11</td>
<td>Japanese</td>
</tr>
<tr>
<td>R2.12</td>
<td>Korean</td>
</tr>
<tr>
<td>R2.13</td>
<td>Laotian</td>
</tr>
<tr>
<td>R2.14</td>
<td>Malaysian</td>
</tr>
<tr>
<td>R2.15</td>
<td>Okinawan</td>
</tr>
</tbody>
</table>
New York State Department of Health Resources

Data Dictionary Race and Ethnicity Addendum Pages:

Appendix RR:

Frequently-Asked Questions:
Staff at the Facility

• Get everyone at the facility on board from the top down.

• Standardize the collection process:
  • Patient should self-identify/report
  • Report ethnicity(ies) first, then race(s)
  • Data are collected on all patients

• Review in-house security to protect data.

• Train all staff to collect data and answer the patient with the same response.
Patients at the Facility

- Tell patients you are collecting the information before you collect it and explain why.
- Create forms, so they can self-identify.
- Assure them the data will be protected.
- Engage the community.
Resources

• NYS Toolkit to Reduce Health Disparities: Improve Race and Ethnicity Data

• Health Research and Educational Trust (HRET) Toolkit:
  • On-line resource to help hospitals and facilities systemically collect race and ethnicity data from patients: http://www.hretdisparities.org
Next Steps

• Collecting the Data: First Steps in Achieving Health Equity
  • October 17, 2013, 9-10:30 a.m.
  • http://www.phlive.org

• Several Webinars for:
  • Physicians, Hospital Executives, Quality Improvement Advisors, and Medical Staff
  • Registration and Admission Supervisors and Staff
  • Community-Based Organizations and Community Leaders

• NYS Toolkit to Reduce Disparities: Improving Race and Ethnicity Data Collection
Our Goal...

- Improve the quality of race and ethnicity data collected.
- Expand the granularity (number of categories) of race and ethnicity data.

Questions?
SPARCS Operations

John Skerritt, Trainer

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<thead>
<tr>
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<tbody>
<tr>
<td>Website:</td>
<td><a href="http://www.health.ny.gov/statistics/sparcs/">http://www.health.ny.gov/statistics/sparcs/</a></td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:sparcs@health.state.ny.us">sparcs@health.state.ny.us</a></td>
</tr>
<tr>
<td>Phone:</td>
<td>(518) 473-8144</td>
</tr>
<tr>
<td>Fax:</td>
<td>(518) 486-3518</td>
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