

# **Issues, challenges, and lessons learned from HHS national monitoring and reporting efforts**

UNECE Workshop on Statistical Data Collection: Riding the Wave of the Data Deluge  
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**Centers for Disease Control and Prevention**  
**National Center for Health Statistics**

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# Overview

## **Selected national monitoring and reporting initiatives**

*Health, United States* (HUS, NCHS)

National Healthcare Quality and Disparities Report (NHQR/DR, AHRQ)

Healthy People (Healthy People, NCHS)

Health Indicators Warehouse (HIW, NCHS)

## **Issues and approaches**

Factors influencing selection of measures

Criteria for selecting data sources

Standards for data collection and reporting (race and ethnicity)

Factors affecting decisions about data display

- Data availability

- Data quality standards

- Summarizing across measures

Procedures for adding, retiring measures

# Factors influencing selection of measures

- **Legislative mandates**
  - HUS
  - NHQR/DR
- **Conceptual frameworks, Overarching goals**
  - NHQR/DR
  - Healthy People
  - HIW
- **Federal interagency advisory groups**
  - NHQR/DR
  - Healthy People
  - HIW
- **Availability of data for trend analysis**
  - HUS
  - NHQR/DR
  - Healthy People
  - HIW

# Criteria for selecting data sources

- Nationally representative
- Data collected consistently over time to permit examination of trends
- Provide technical notes to assess quality
- Permit state-level estimates where possible
- Contain sufficient sample size to support sub-analyses by standard socio-demographic measures
- Publicly available, to the extent possible

# A variety of data sources

- Population-based sample surveys: provide self reported data about persons, households; health examination data
- Encounter/establishment-based sample surveys: provide data about the health care system, clinical practice, and health care utilization
- Administrative data: provide vital statistics (births, deaths), enrollment, utilization (Medicare, Medicaid)
- Surveillance systems, registries: provide data on selected events (case reporting), health care conditions, populations

## **A variety of data sources (continued)**

- The goal is nationally representative, publicly available data
- Sources can be national, state, county, private and global in scope
  - Health, United States – 40 data sources
  - National Quality and Disparities Reports – 36 data sources
  - Healthy People - 180 data sources
  - Health Indicators Warehouse – approximately 200 data sources
- Sources and measures are coordinated across these initiatives to the extent possible, chiefly through federal work/advisory groups

# Standards for data collection and reporting

## Race and ethnicity

- Federal standards affect what data on race/ethnicity are collected, but ...
  - Federal reporting standards do not affect non-federal systems
  - Not all data systems are able to report reliably on race/ethnicity groups due to sample size limitations
  - The quality of race and ethnicity data varies by data source

# OMB standard categories for race

[https://www.whitehouse.gov/omb/fedreg\\_1997standards/](https://www.whitehouse.gov/omb/fedreg_1997standards/)

- **Directive 15 (1977)**

“Select one...”

- American Indian or Alaska Native
- Asian or Pacific Islander
- Black
- White

- **Revised Standard (1997)**

“Select one or more...”

- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White

# HHS Data Collection Standards for Race and Ethnicity, October 2011

<http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.shtml>

## Ethnicity Data Standard

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

- a.  *No, not of Hispanic, Latino/a, or Spanish origin*
- b.  *Yes, Mexican, Mexican American, Chicano/a*
- c.  *Yes, Puerto Rican*
- d.  *Yes, Cuban*
- e.  *Yes, another Hispanic, Latino, or Spanish origin*

## Race Data Standard

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

- a.  *White*
- b.  *Black or African American*
- c.  *American Indian or Alaska Native*
  
- d.  *Asian Indian*
- e.  *Chinese*
- f.  *Filipino*
- g.  *Japanese*
- h.  *Korean*
- i.  *Vietnamese*
- j.  *Other Asian*
  
- k.  *Native Hawaiian*
- l.  *Guamanian or Chamorro*
- m.  *Samoan*
- n.  *Other Pacific Islander*

# Factors affecting decisions about data display

- **Data availability**

- Collapse race/ethnicity categories to show data (HUS)
- Show all categories with a notation that data are suppressed, or that data are not available in order to highlight data gaps (NHDR, Healthy People)
- Show race/ethnicity stratified by socioeconomic status since these disparities are often related (NHDR)

- **Data quality**

- Note potential problems with misclassification of race/ethnicity
- Develop data standards for reporting to reflect stability of estimates

# Data sources differ in who reports race and ethnicity

- Population-based surveys → Self Report (gold standard)
- Encounter-based surveys → Proxy/Observation
- Vital records-deaths → Funeral Director or relative
- Vital records-births → Mother

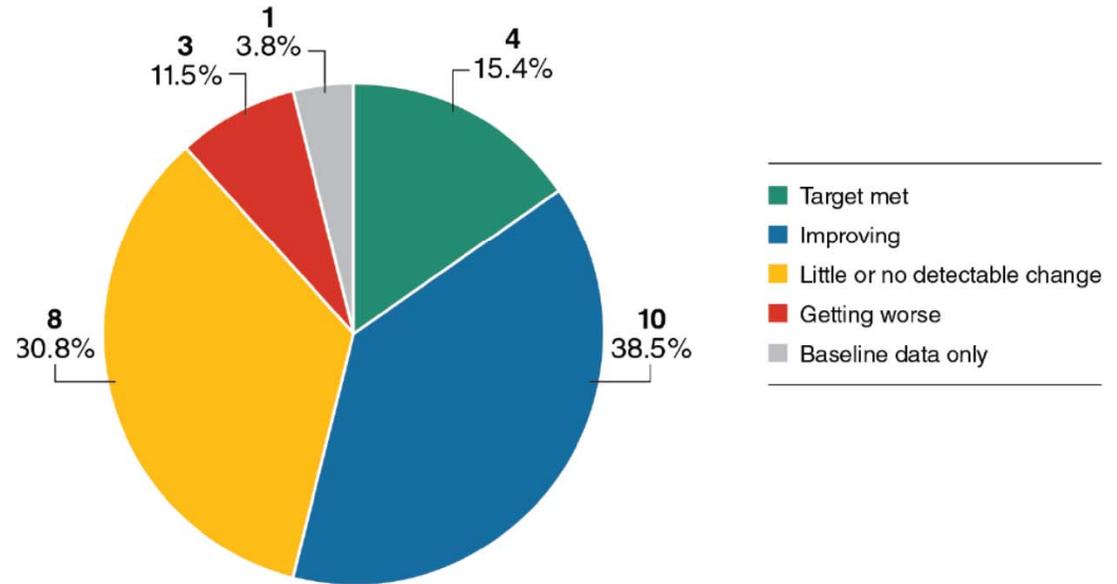
# Developing data quality standards

- Goal is consistency in reporting while maintaining data system's usual suppression criteria
- In practice, criteria vary and are related to the sample design and sample size
- Suppression criteria for unreliable estimates are based on cell size and relative standard error (RSE)
  - HUS: 20-30% RSE and cell size criteria for each data source
  - NHQR/DR: 30% RSE or cell size less than 30
  - Healthy People: uses data source's criteria; 30% RSE or cell size less than 50 where criteria absent
  - HIW: uses data source's criteria

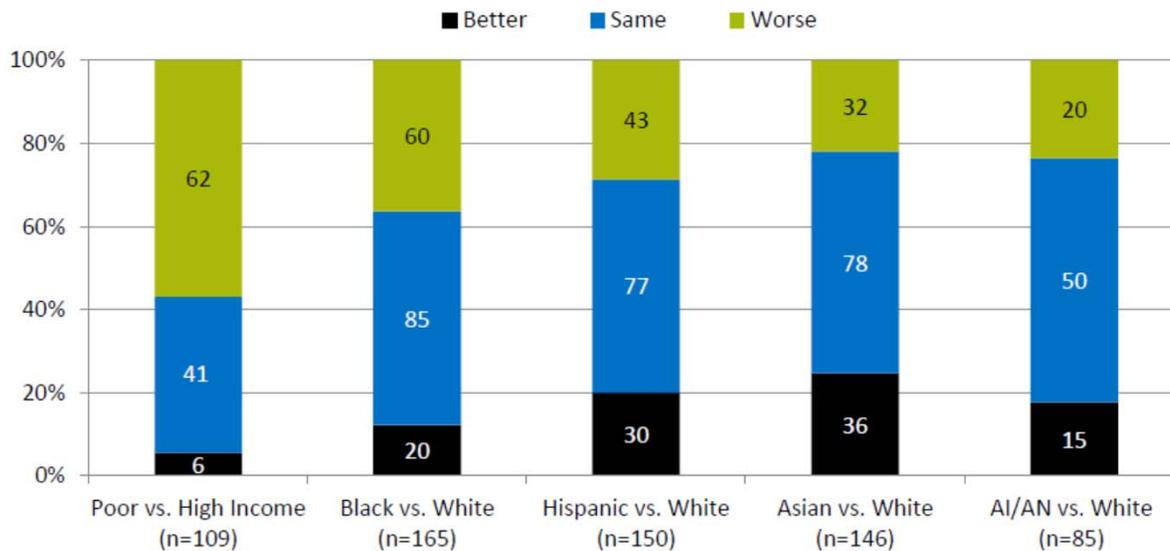
# Summarizing across Measures

Counting measures by  
change over time  
Source: Healthy People  
2020 Leading Health  
Indicators: Progress Update

Status of the 26 HP2020 Leading Health Indicators  
March 2014



Disparities: Number and percentage of quality measures for which members of selected groups experienced better, same, or worse quality of care compared with reference group



Counting measures by  
presence of disparities  
Source: 2014 National  
Healthcare Quality and  
Disparities Report

Key: AI/AN = American Indian or Alaska Native; n = number of measures.

# Procedures for adding or retiring measures

- **Informed by**

- Recommendations of advisory groups (NHQR/DR, Healthy People, HIW)
- Success in meeting target levels (NHQR/DR, Healthy People)
- Changes in data sources, availability, appropriateness for trend analysis (All initiatives)

- **Timing for decision-making**

- HUS: Annual
- NHQR/DR: Ongoing
- Healthy People: Monthly until mid-decade; major revisions every 10 years
- HIW: Ongoing

# For more information

Health, United States

[cdc.gov/nchs/hus.htm](https://www.cdc.gov/nchs/hus.htm)

National Healthcare Quality and Disparities Reports

[ahrq.gov/research/findings/nhqrdr](https://www.ahrq.gov/research/findings/nhqrdr)

Healthy People

[healthypeople.gov/](https://www.healthypeople.gov/)

Health Indicators Warehouse

[healthindicators.gov/](https://www.healthindicators.gov/)