Gathering Data on Subpopulations Beyond OMB Categories

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National multicultural advocacy coalition, established in 2000, that is committed to achieve health parity for people of color.

OMO believes that the attainment of the highest level of health and quality of life is a basic human and civil right.
OMO Members

- ‘Ahahui o na Kauka
- APHA- Asian Pacific Islander Caucus
- APHA- Latino Caucus
- Asian and Pacific Islander American Health Forum
- Association of Asian Pacific Community Health Organizations
- California Pan-Ethnic Health Network
- Ke Ali`i Maka`ainana Hawaiian Civic Club
- Khmer Health Advocates, Inc.
- Latin American Health Institute
- National Black Nurses Association
- National Hispanic Medical Association
- National Indian Project Center
- National Organization of Black County Officials
- Papa Ola Lokahi
- Southeast Asia Resource Action Center
- Summit Health Institute for Research and Education, Inc.
OMO Health Data Taskforce
Activities

- Improving Medicare data on race, ethnicity and primary language
- Supporting legislation or commenting on regulations to improve data collection in CHIP, Medicare, and HIT.
- Providing information to GAO on research of CMS policies & language access services
- Engaging health data experts at the state/territory level (PR, GA, MA, CA) and bringing issues to the national stage
- Providing comments to NCHS & NCQA related to improving data collection in the context of health surveys and improving health care quality and addressing disparities
1997 OMB Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity

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

- **Ethnicity**
  - "Hispanic or Latino"
  - "Not Hispanic or Latino."
Cultural & Language Differences within Government Categories

- “American Indian or Alaska Native” encompasses 562 tribes and people from Alaska to Montana to Florida.
- “Asian” racial category encompasses ethnic groups from Pakistanis to Japanese to Hmong.
- “Black or African American” can include a 3rd generation individual from Alabama and a African Immigrant from Somalia.
- “Hispanic or Latino” encompasses people from Spain to Mexico to Puerto Rico to Argentina.
- “Native Hawaiian and Pacific Islander” category encompasses indigenous people from “Oceania” that is comprised of 20,000+ islands.
Importance of disaggregated data

- Achieve measurable improvements in health status and healthcare access and quality
- Identify needs, develop and monitor specific programs, inform policy, and identify potential discrimination
- Reflect the Heterogeneity of Communities
  - Cultural Diversity, Language, Geography, Variety of ethnic groups within each “category”
Examples of why disaggregated data is important

In the Hispanic community overall, asthma and infant mortality rates are both lower than for non-Hispanics. However, they are big problems in the Puerto Rican population (both on the mainland and the island).

- One in five Puerto Rican children have physician-diagnosed asthma (20%), compared to less than one in ten (9%) Hispanic children overall.

- The infant mortality rate for Puerto Ricans is nearly double (8.3 per 1,000), the rate for Cubans (4.42) and Central/South Americans (4.68), and is still higher than the rate for Mexicans (5.53).
AA & NHPI communities face high rates of uninsurance:
- 24% Native Hawaiians & Pacific Islanders uninsured
- 31% Korean Americans uninsured
Geographic Variations

- Concentrations of groups in specific areas/regions of the U.S.
- Heterogeneity of racial/ethnic groups
- Newly emerging communities in areas with limited infrastructure
OMO Recommendations

- Produce data that takes causal and contextual factors into account
- Prioritize research questions to focus on specific communities/Allocate funding towards data collection of statistically “smaller” populations
- Include community members on advisory committees and planning processes
- All government agencies (federal, state, local), institutions and organizations that serve minority communities should be enlisted in the effort to collect disaggregated data
OMO Recommendations to Improve Collection and Reporting of Data

DATA COLLECTION PROCEDURES
- Conduct interviews in multiple languages
- Translate research materials and data collection tools
- Use self-reported data on race, ethnicity and primary language
- Re-examine data collection systems for validity

RESEARCH DESIGN
- Develop and adopt innovative screening methods
- Encourage integrated design methods
- Focus on smaller geographic units, such as counties or MSAs
- Use geocoding

SAMPLING
- Pool Data
- Link data from different surveys
- Oversample for small populations
- Weight for disproportionate sampling
- Apply dual frame sampling

OTHER
- Require dissemination strategies that include the community
- Apply data standards to Health Information Technology efforts
- Federal Agencies should increase the availability of public-use data files
Suggested Data

- Age
- Gender
- Socioeconomic Status
- Race/Ethnicity
- Primary Language
- Housing
- Geography
- Any Chronic and infectious disease issue
- Health insurance status
- Military service, i.e. a veteran.
- Acculturation
- Cultural Context
- Marital Status
- Education
- Income
- Traditional Healing Practice
- *Length of residence in U.S.*
Promising Practices: National and State surveys

- National Latino and Asian American Study (NLAAS)
  - Example of data collection for native born versus generational status

- California Health Interview Survey
  - Includes local-level estimates and statewide estimates
  - Includes linguistically isolated communities, through English simplification, cultural adaptation and linguistic translation of its materials
Georgia Health Care Disparities Report 2008:


- Developed by the Georgia Department of Community Health’s Office of Health Improvement and the DCH Minority Health Advisory Council
- Inaugural report gives an account of the health status of Georgia’s minority populations by county
- Identifies inequality in health care and outcomes, and
- Encourages action towards health equality for all Georgians.
Promising practice: Community driven

Tribal Epidemiology Centers are American Indian and Alaska Native (AI/AN) programs working with Tribal entities and urban AI/AN communities by:

- Managing public health information systems
- Investigating diseases of concern
- Managing disease prevention and control programs
- Responding to public health emergencies
- Coordinating these activities with other public health authorities.
Tribal Epidemiology Centers (TEC) By State

- WA
- OR
- ID
- MT
- ND
- NE
- IA
- SD
- WI
- MI
- MN
- IA
- MO
- IL
- IN
- OH
- KY
- WV
- VA
- NC
- SC
- GA
- FL
- AL
- MS
- TN
- AR
- LA
- OK
- OK
- KS
- CO
- WY
- UT
- NV
- AZ
- CA
- AK
- HI
- NH
- ME
- VT
- MA
- RI
- CT
- NJ
- DE
- MD
- WV
- WV
- NC
- SC
- GA
- FL
- AL
- MS
- TN
- AR
- LA
- OK
- OK
- KS
- CO
- WY
- UT
- NV
- AZ
- CA
- AK
- HI

• SIHB
• Epi Center
• NPAIHB
• Epi Center
• ITCA
• Epi Center
• NPDOH
• Epi Center
• Albq Area IHB
• Epi Center
• OKCAITHB
• Epi Center
• ANTHC
• Epi Center

= HHS Division of Epi
= Tribal Epi Centers
= Not covered by a TEC
Papa Ola Lokahi
Native Hawaiian Epidemiology Center

- National support of the health and well being of Native Hawaiian communities through health information, scientific inquiry, and technology
- Assist in the development of workable strategies to address data issues for the Native Hawaiian people
- Native Hawaiian community based and controlled
- Partnerships with the private sector and federal, state, local governments
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