The Process of Standardizing Race and Ethnicity Data Collection in a Hospital Setting: The New Mexico Experience

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October 23, 2012
NAHDO
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Funder: Agency for Healthcare Research and Quality (AHRQ)

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Purpose

• To improve the collection of Race/Ethnicity/Tribal Identification data collected by hospitals
New Mexico Population

- 2,059,179 people resided in New Mexico during 2010
  - 41% of the population lives in the metropolitan areas of Albuquerque, Santa Fe, Farmington and Las Cruces
  - 22 American Indian Tribes have land within borders of New Mexico

New Mexico Race Demographics from 2010 Census

- White: 68%
- American Indian/Alaskan Native: 15%
- Black: 10%
- Asian/Pacific Islander: 2%
- Other: 1%
- Multiple Race: 4%

New Mexico Ethnicity Demographics from 2010 Census

- Hispanic: 54%
- Non-Hispanic White: 46%
Hospital Inpatient Discharge Database (HIDD)

• Pursuant of the Health Information Systems Act (HIS) created by the Health Policy Commission (HPC)

• Goal: Collect, disseminate and analyze health data for public and private use to influence planning and policy development.

• Information including utilization, reasons for hospitalization, surgical procedures, diagnoses, patient demographics including race, ethnicity and tribal affiliation and payer.
Examples of Race/Ethnicity used within NMDOH

- Behavioral Risk Factor Surveillance System (BRFSS)*
- Youth Risk and Resiliency Survey (YRSS)
- Vital Statistics-Birth and Death Certificates*
- Childhood Immunizations
- NM’s Indicator Based Information system (IBIS)
- NM Race/Ethnicity Health Disparities Report Card
- Tobacco Surveillance
- HIV/AIDS Surveillance
- Diabetes
- Infectious Disease Surveillance
- Lead Screening Data
- Illicit Drug Abuse Morbidity and Mortality
- Sexually Transmitted Disease
- Pregnancy Risk Assessment Monitoring System (PRAMS)*
- Alcohol Related Morbidity and Mortality
- NM Violent Death Reporting System*

* denotes that tribal identification is also collected
Outline

• What are the guidelines for data collection?

• How can we improve the collection of race/ethnicity/tribal affiliation data?

• What are the common issues found in collecting, analyzing and reporting this data?
What are the guidelines for data collection?
Gold Standard for Data Collection by OMB 1997 Guidelines

- Self-identification/Self-Report
- Allowing for multiple race/tribe
- Asking for this information orally
### Data Reporting Requirements

- Statutory requirement for state to collect data (NMSA 1978 24-14a Health Information System Act (HIS Act))
- Based on OMB Standards of 1997

#### Q1: Ethnicity
- Hispanic /Latino
- Not Hispanic/Latino
- Declined*
- Unknown*

#### Q2: Race
- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian/Pacific Islander
- White
- Declined*
- Unknown*
- Other Race*
22 NM Tribes

- Acoma Pueblo
- Cochiti Pueblo
- Isleta Pueblo
- Jemez Pueblo
- Jicarilla Apache Nation
- Kewa/Santo Domingo Pueblo
- Laguna Pueblo
- Mescalero Apache Nation
- Nambe Pueblo
- Navajo Nation
- Ohkay Owingeh Pueblo
- Picuris Pueblo
- Pojoaque Pueblo

- San Felipe Pueblo
- San Ildefonso Pueblo
- Sandia Pueblo
- Santa Ana Pueblo
- Santa Clara Pueblo
- Taos Pueblo
- Tesuque Pueblo
- Zia Pueblo
- Zuni Pueblo
- Other Tribal Affiliation
- Declined
- Unknown
How can we improve the collection of race/ethnicity/tribal affiliation data?
Levels of Influence

**OPERATIONAL**
- Data Managers
- IT System
- Registration Personnel
- Patients

**LEGISLATION**
- Federal
- State

**INSTITUTION**
- Policy
- Administration

- Hospital Training
- Key Informant Interviews
- Focus Groups
- Site Visits to Hospitals
- Patient Telephone Survey

- Health Information Systems Act Change
- Regulation Change (NMAC 7.1.4)
Path of Patient Data

PATIENT → REGISTRATION → ELECTRONIC HEALTH RECORD

- IT/DATA MANAGER
- BILLING
- DOH
Policy Change

- New Mexico Administrative Code (NMAC 7.1.4) changed as of January 2011
  - Submit HIDD quarterly instead of annually
  - Race and Ethnicity as separate variables
  - Tribal Affiliation collected
  - Allow for multiple race and tribe

- As of 2012, HIDD now resides at NMDOH

- In the midst of changing the NMAC for 2013
  - Additional data elements such as revenue codes
Hospital Training

• Health Insight NM- contracted to educate and train registration staff to better collect race/ethnicity/tribal affiliation data

• Nine pilot hospitals received education and training in Summer 2011

• Last 43 hospitals have been trained as of September 30, 2012

• Goal: Reduce barriers of race/ethnicity/tribal affiliation data collection to increase completeness and quality of this data
Training Evaluation

- Key Informant Survey

- Pre and Post Tests
  - Day of the training and three months after training
How do we evaluate hospitals?

- Feedback to hospitals:
  - Hospital Specific Progress Reports describing:
    - Patient demographics compared county population
    - Status of submitted data
    - Possible issues with data collection
New Mexico Race and Ethnicity Data Quarter One Report

DATES: January 1, 2011 – March 31, 2011

FACILITY NAME: SAMPLE
FILES RECEIVED: Yes
NUMBER OF RECORDS: 3119

QUARTER 1 RACE AND ETHNICITY VARIABLE EVALUATION:

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COMMENTS:

- Patients were categorized as American Indian, however there are no tribal identifiers. Those that are American Indian should have a tribal affiliation. All other races should not have a tribal affiliation.

QUESTIONS:

- Were race/ethnicity/tribal affiliation fields based on self-report?
*COMPARISON OF INPATIENT HOSPITAL RACE AND ETHNICITY DEMOGRAPHICS TO COUNTY LEVEL:

**Sample Hospital Inpatient Race Demographics for Q1**
- American Indian or Alaska Native: 5%
- Asian: 10%
- African American/Black: 20%
- Native Hawaiians or Pacific Islander: 20%
- White: 30%
- Other: 10%
- Two or more races: 10%

**xxx County Race Demographics from 2010 Census**
- American Indian or Alaska Native: 2%
- Asian: 3%
- African American/Black: 11%
- Native Hawaiians or Pacific Islander: 0%
- White: 84%
- Other: 2%
- Two or more races: 0%

**Sample Hospital Inpatient Ethnicity Demographics for Q1**
- Hispanic: 10%
- Non-Hispanic: 40%
- Missing: 50%

**xxx County Ethnicity Demographics from 2010 Census**
- Hispanic: 26%
- Non-Hispanic: 74%

*Disclaimer: Hospital demographics may not align with county demographics*
Patient Follow-Up Survey

• Telephone Survey to a random sample of patients admitted to the hospital in the last year

• Questions on their race/ethnicity/tribal identification which will be compared to the hospital data
Focus Groups

• Native American populations served in non-Indian Health Service (IHS) facilities

• Discuss issues and barriers of the collection of tribal identification data
  – How should we collect this data?
  – How do the communities think this question should be asked?
Proposed Data Linkages

• Indian Health Service (IHS) to affirm tribal affiliations and determine misclassification

• Vital Records – Birth and Death Certificate Data

• Emergency Department (E.D.)

• Emergency Management Services (EMS)
What are the common issues found in collecting this data?
Electronic Health Records

• Unable to collect this information in the hospital’s EHR
  • Unavailable fields/Not enough fields especially for multiple races
  • Incorrect categories for race/ethnicity/tribal affiliation
  • Can result in many missing, other or unknown race/ethnicity/tribal affiliation

• Hospitals have to negotiate with the vendors to change their system to be able to collect these new fields
Hospital Personnel

- Staff can be uncomfortable asking this information from patients
- Staff lack expertise for data extraction
- Turnover in registration staff and upper level management
- Departments of hospital are not communicating with one another
- R/E/T data collection not a priority
Help Us Know Our Patients Better

We are now collecting race, ethnicity and tribal affiliation information from all of our patients to help us know them better. We can better meet the needs of all our patients if we know more about race, ethnicity, and tribal affiliation.

• What is your race?
  Your race refers to the group or groups that you identify with having similar physical characteristics or similar social and geographic origins. Please let us know which category or categories best describe your race.
  • American Indian or Alaska Native
  • Asian
  • Black or African American
  • Native Hawaiian or Other Pacific Islander
  • White
  • Other Race

• What is your ethnicity? Do you consider yourself Hispanic or Latino?
  Hispanic or Latino refers to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. Please let us know if you consider yourself Hispanic or Latino.

• If you describe your race as American Indian or Alaska Native, please let us know your tribe(s) or pueblo(s)
  • Acorn Pueblo
  • Cochiti Pueblo
  • Isleta Pueblo
  • Jemez Pueblo
  • Jicarilla Apache Nation
  • Kewa/Santo Domingo Pueblo
  • Laguna Pueblo
  • Mesilla Apache Nation
  • Nambe Pueblo
  • Nambú Nation
  • Ohkay Owingh Pueblo
  • Picuris Pueblo
  • Pojoaque Pueblo
  • San Felipe Pueblo
  • San Ildefonso Pueblo
  • Sandia Pueblo
  • Santa Ana Pueblo
  • Santa Clara Pueblo
  • Taos Pueblo
  • Tesuque Pueblo
  • Zia Pueblo
  • Zuni Pueblo
  • Other Tribal Affiliation

By knowing you better, we can provide better care to our patients.

Ayúdenos a conocer mejor a nuestros pacientes

Estamos juntando información sobre su raza, etnicidad y afiliación de tribu de todos nuestros pacientes para ayudarnos a conocerlos mejor. Podemos cumplir mejor con las necesidades de todos nuestros pacientes al tener más información sobre su raza, etnicidad y afiliación de tribu.

• ¿Qué es su raza?
  A decir raza se refiere al grupo o los grupos con el cual o los cuales usted se identifica al pensar en características físicas similares o al pensar en orígenes sociales o geográficos similares. Favor de hacernos saber cual categoría o cuales categorías mejor describen su raza.
  • Americano/a Nativo/a o Nativo/a de Alaska
  • Asiático/a
  • Negro o Afro-americano/a
  • Nativo/a de Hawaii o Otra Isla del Pacífico
  • Blaneco/a
  • Otros

• ¿Qué es su etnicidad? ¿Se considera hispánico/a o latino/a?
  A decir hispánico/a o latino/a se refiere a una persona de origen cubano, mexicano, puertorriqueño, de sur o centro América, u otra cultura hispana o origen, sin importar la raza. Favor de hacernos saber si usted se considera hispánico/a o latino/a

• Si usted describe su raza como Americano/a Nativo/a o Nativo/a de Alaska, favor de indicar su(s) tribu(s) o pueblo(s).
  • Pueblo de Acorn
  • Pueblo de Cochiti
  • Pueblo de Isleta
  • Pueblo de Jemez
  • Nación de Jicarilla Apache
  • Pueblo de Kewa/Santo Domingo
  • Pueblo de Laguna
  • Nación de Mesilla Apache
  • Pueblo de Nambe
  • Nación de Nambú
  • Pueblo de Ohkay Owingh
  • Pueblo de Picuris
  • Pueblo de San Felipe
  • Pueblo de San Ildefonso
  • Pueblo de Sandia
  • Pueblo de Santa Ana
  • Pueblo de Santa Clara
  • Pueblo de Taos
  • Pueblo de Tesuque
  • Pueblo de Zia
  • Pueblo de Zuni
  • Otros afiliación de tribu

Al conocerle mejor, podemos dar mejor servicio a nuestros pacientes.
Next Steps

- Create a toolkit for states
- Contribute to a joint-website between all states involved in state data enhancement grants
Useful References

• Agency for Healthcare Research: http://www.ahrq.gov/

• Aligning Forces For Quality: http://www.rwjf.org/qualityequality/af4q/about.jsp

• Robert Wood Johnson Foundation: http://www.rwjf.org/

• Health Cost Utilization Project: http://www.ahrq.gov/data/hcup/

• NMAC 7.4.1 – Data Reporting Requirements for Health Care Facilities: http://nmhealth.org/HPC/documents/Rules/7_1_4_NMAC_12-1-2010_Final.pdf
Comments or Questions?

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