

# GETTING DATA RIGHT TO IMPROVE HISPANIC/LATINO HEALTH

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Hispanic Heritage Month

October 3, 2017



# OUTLINE

- Who is Hispanic or Latino?
  - US Hispanics: growth and diversity
  - National data systems and Hispanic diversity
  - What can be done and what are the potential benefits?
  - Conclusions
- 

# ACKNOWLEDGMENTS

- Mariana McDonald, DrPH, MPH, MA, Office of Health Disparities, National Center for Emerging and Zoonotic Infectious Diseases, CDC
- Ana Penman-Aguilar, PhD, MPH, Office of Minority Health & Health Equity, CDC
- Drue H. Barrett, PhD, Office of the Associate Director for Science, Office of the Director, CDC
- Jeffrey E. Hall PhD, MA, MSPH, CPH, Office of Minority Health & Health Equity, CDC

Presentation based on: Rodriguez Lainz A, et al. 2016. Getting Data Right—and Righteous to Improve Hispanic or Latino Health. *Journal of Healthcare, Science and the Humanities*, VI(2):60–83.

# WHO IS HISPANIC OR LATINO IN THE UNITED STATES?

- A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race

(US Office of Management and Budget [OMB],1997)



*Note: In this presentation, “Hispanic” will be used for simplicity*

# ETHNICITY DATA COLLECTION BY US FEDERAL AGENCIES

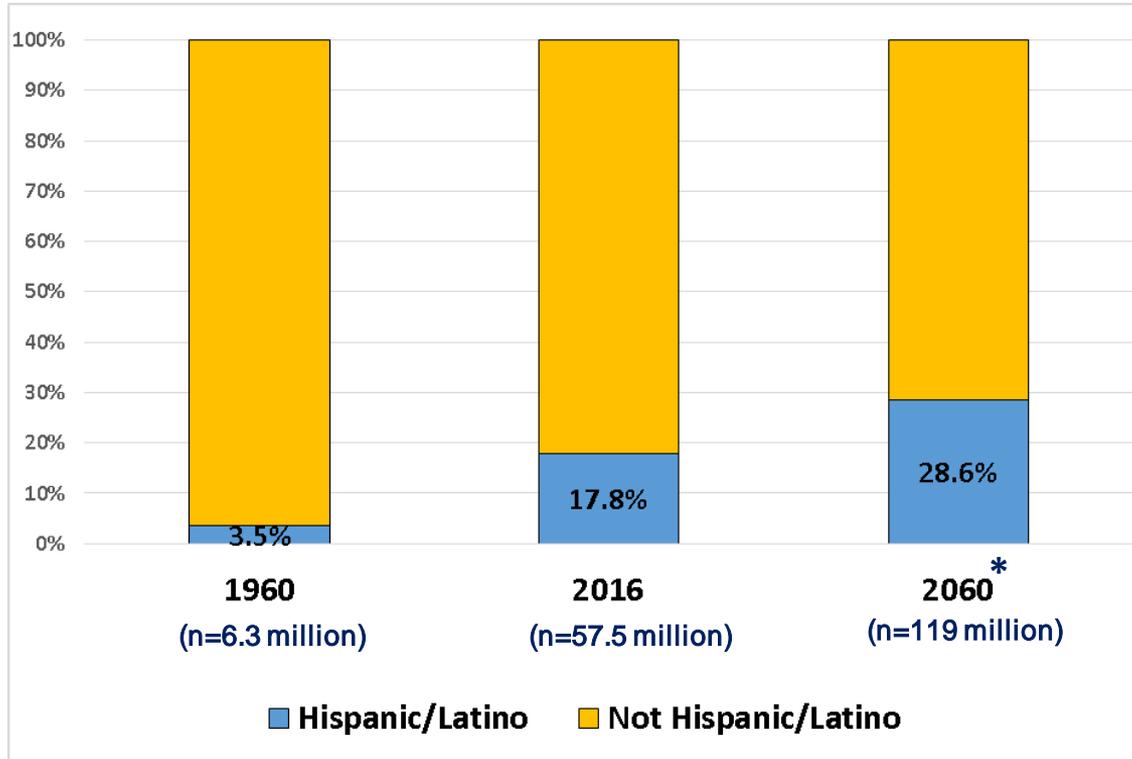
- Data requirements and methods of collection vary across federal agencies
- For federal agencies collecting and reporting ethnicity data, OMB requires two **minimum standard ethnic categories**:
  - *“Hispanic or Latino”* and *“Not Hispanic or Latino”*

Note: Additional (detailed) categories (e.g., Mexican, Puerto Rican, Salvadoran) are permitted provided they can be aggregated to the standard categories

  - Self-reported (preferred) or by observer



# HISPANICS ARE A RISING SHARE OF THE US POPULATION

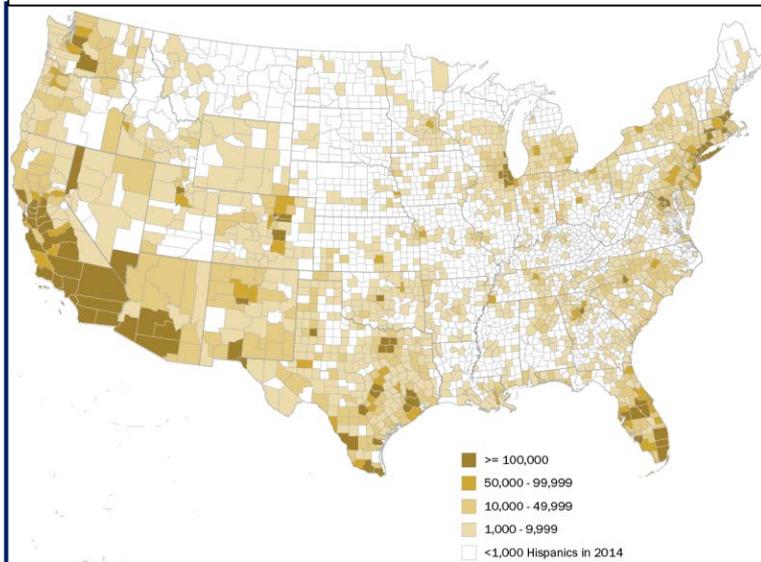


\* Projected

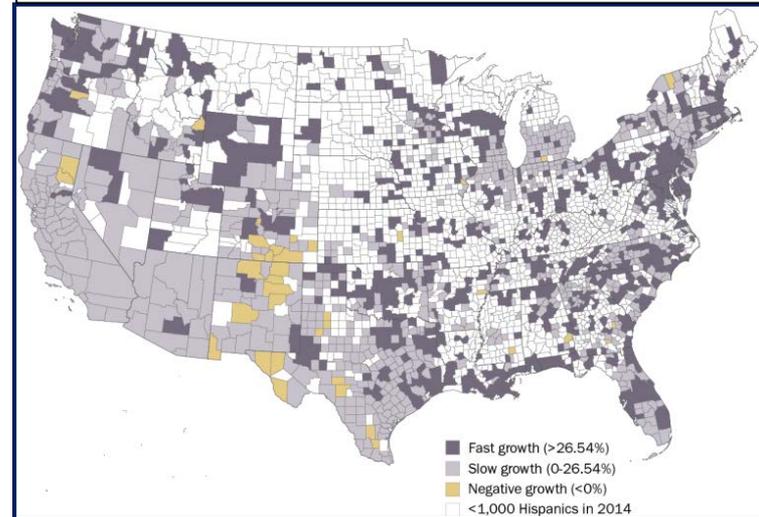
Source: Stepler Rand Brown A, 2016; U.S Census Bureau., 2017

# TOTAL HISPANIC POPULATION AND POPULATION GROWTH BY COUNTY, UNITED STATES, 2014

**Size of the Hispanic population by county, 2014**



**Counties with fast-growing, and declining Hispanic populations, 2007-2014**

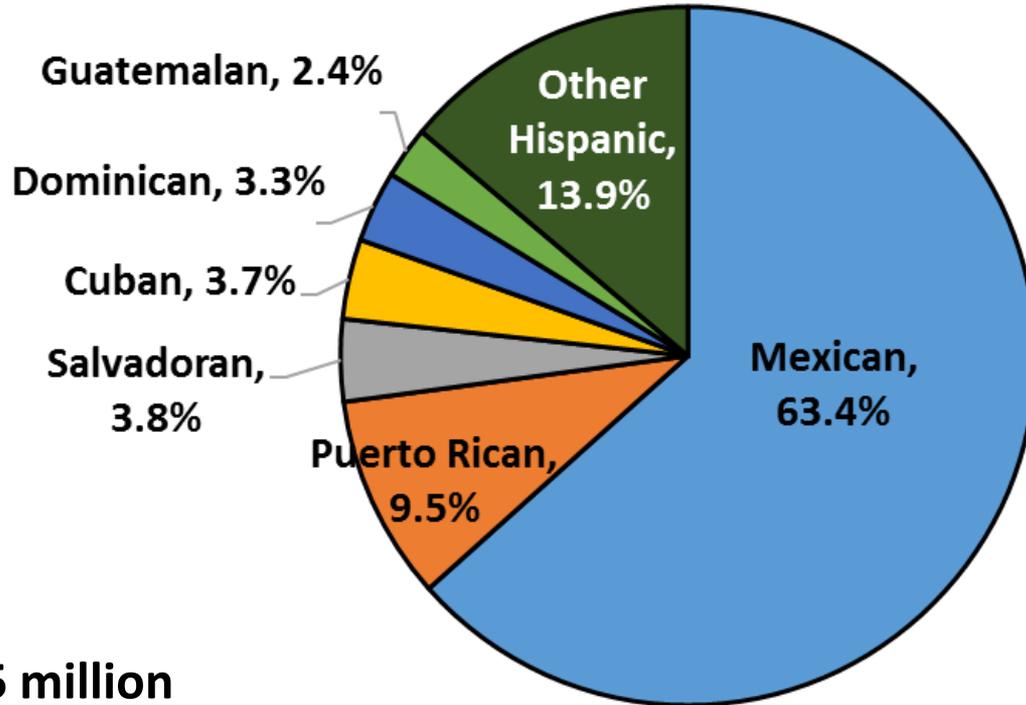


# INCREASING DIVERSITY OF HISPANICS IN THE UNITED STATES

- Country of origin
- Place/country of birth
- Citizenship
- Language
- Race
- Culture
- Others

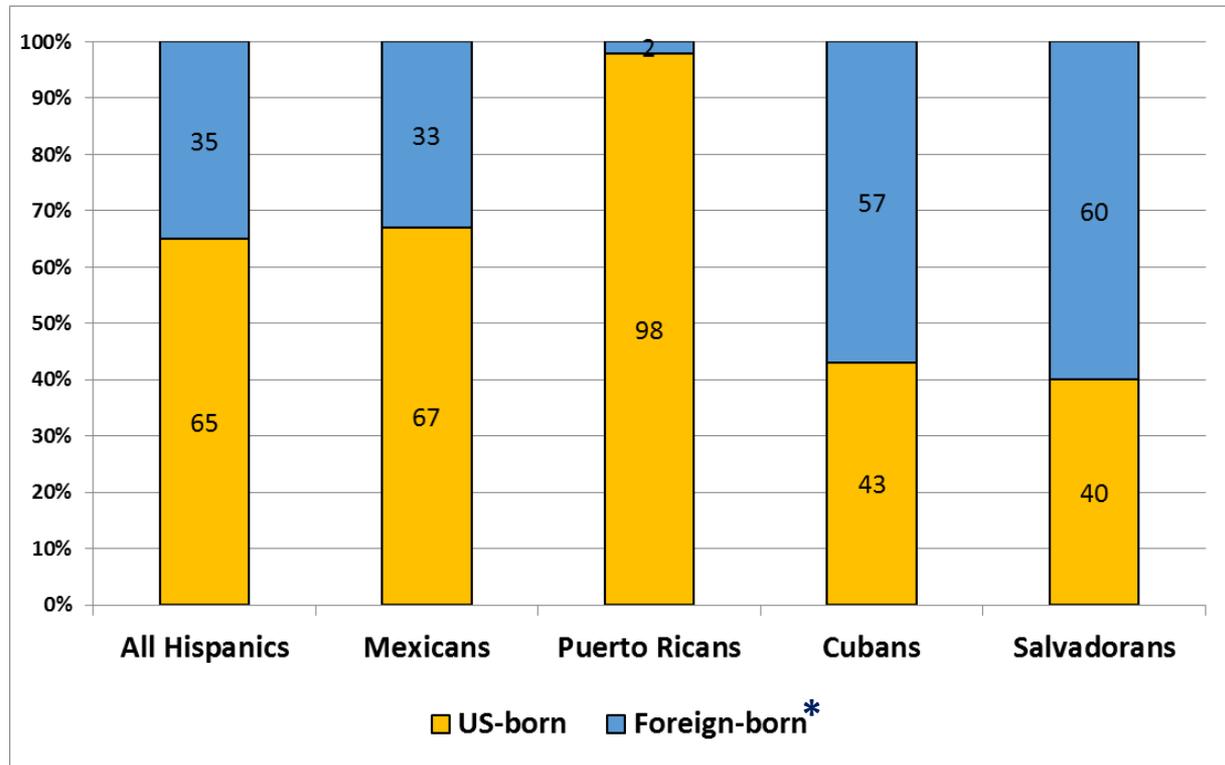


# LARGEST US HISPANIC SUBGROUPS BY COUNTRY OF ORIGIN, 2015



**N = 57.5 million**

# PLACE OF BIRTH OF HISPANICS BY SELECTED COUNTRY OF ORIGIN, 2013



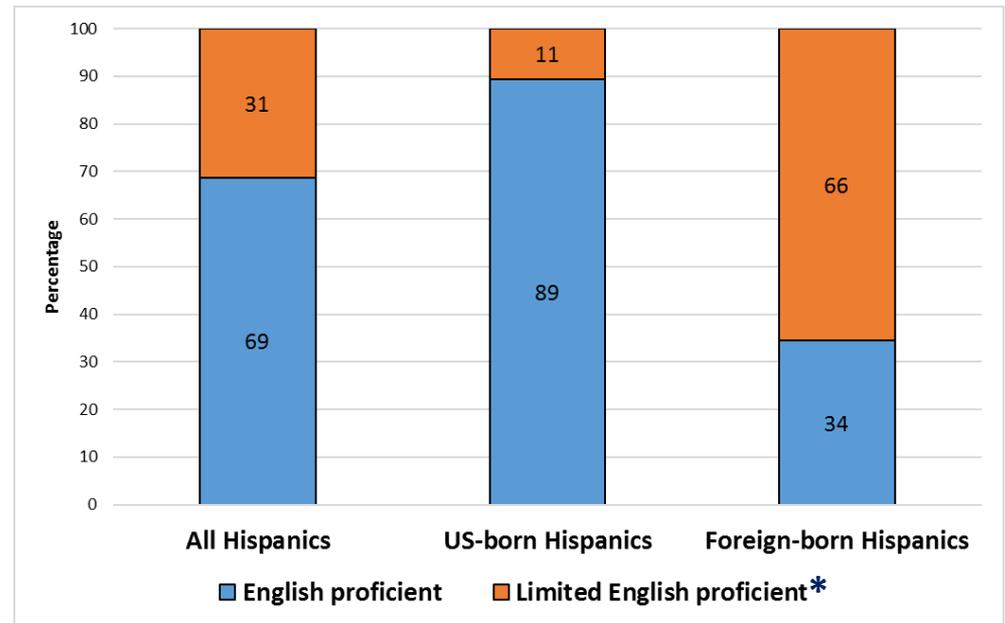
\*Foreign born: persons born outside the United States, Puerto Rico, or other US territories to parents who were not US citizens

# LANGUAGE USE AND ENGLISH PROFICIENCY AMONG HISPANICS

- 73% of Hispanics 5 years and older speak Spanish at home
- 69% are English proficient
- 26% of Hispanics speak only English

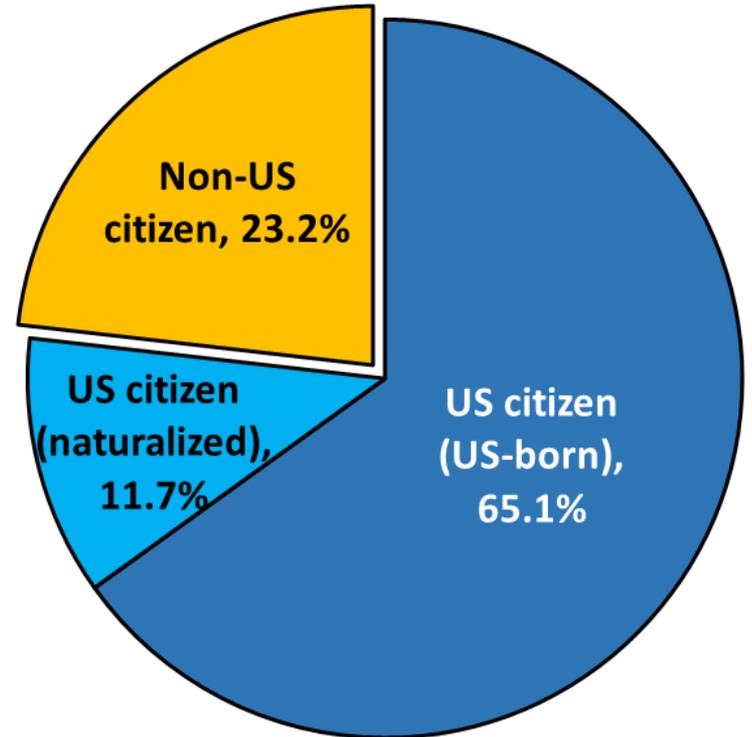
\*Those who report speaking English “less than very well”

English proficiency among Hispanics by place of birth, United States, 2013

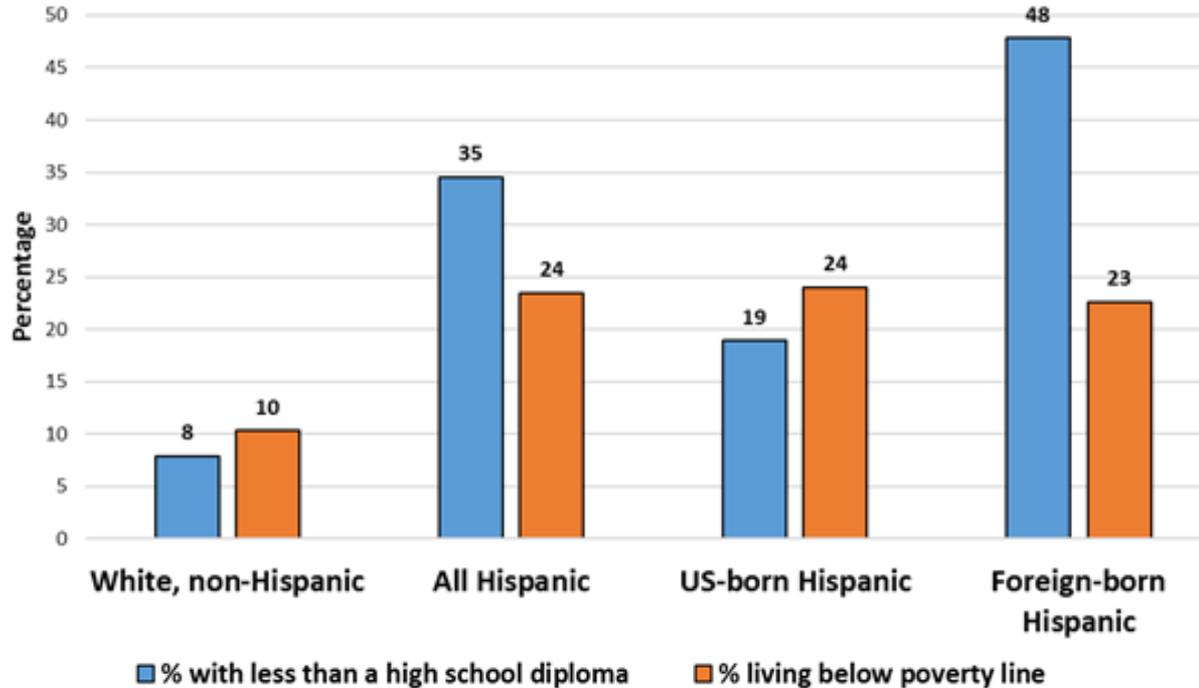


# HISPANICS BY CITIZENSHIP, 2014

- 77% of Hispanics are US citizens
  - Range: 99% of Puerto Ricans to 58% of Salvadorans
- Citizenship status affects access to healthcare and public services



# EDUCATIONAL ATTAINMENT AND POVERTY BY SELECTED RACE/ETHNICITY AND PLACE OF BIRTH, UNITED STATES, 2013



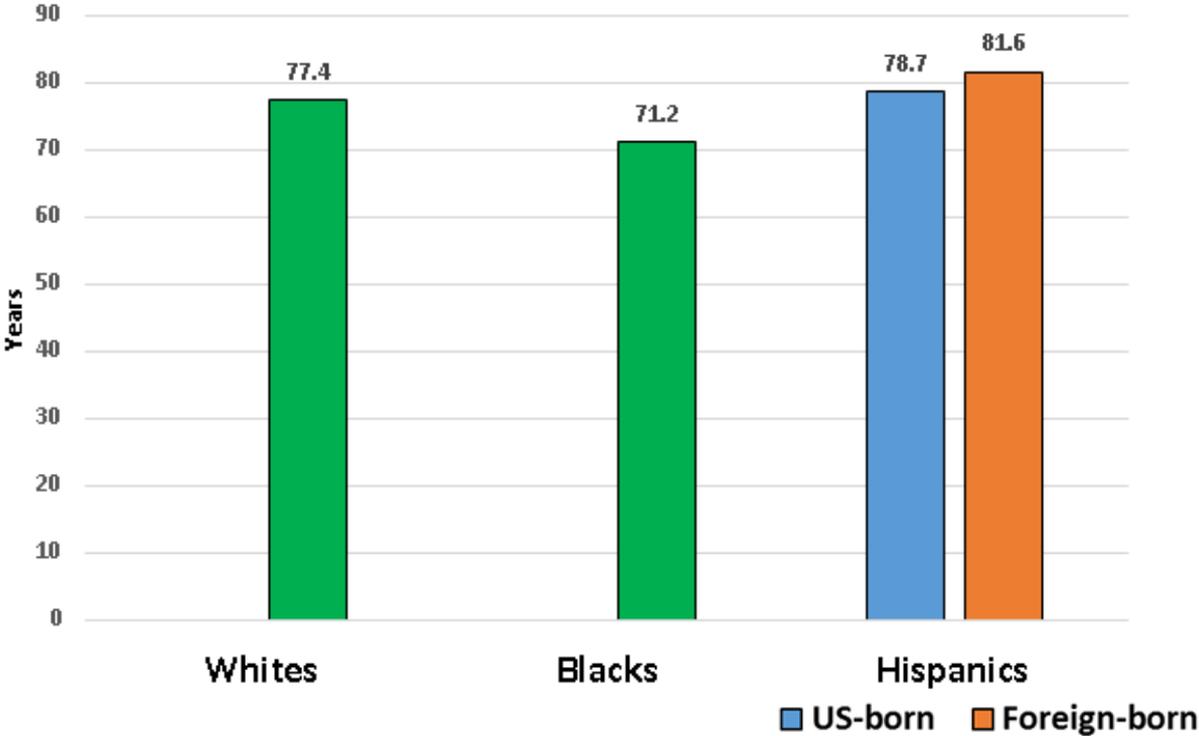
# HISPANIC (IMMIGRANT) HEALTH PARADOX

- In general, and spite of socioeconomic disadvantages ...
  - Hispanics have better health profile for several health indicators compared to non-Hispanic whites and also to other minority groups
  - Hispanics also experience severe disparities for other health issues
  - Differences exist by Hispanic subgroups

# GREAT DIVERSITY IN HEALTH OUTCOMES BY HISPANIC SUBGROUPS

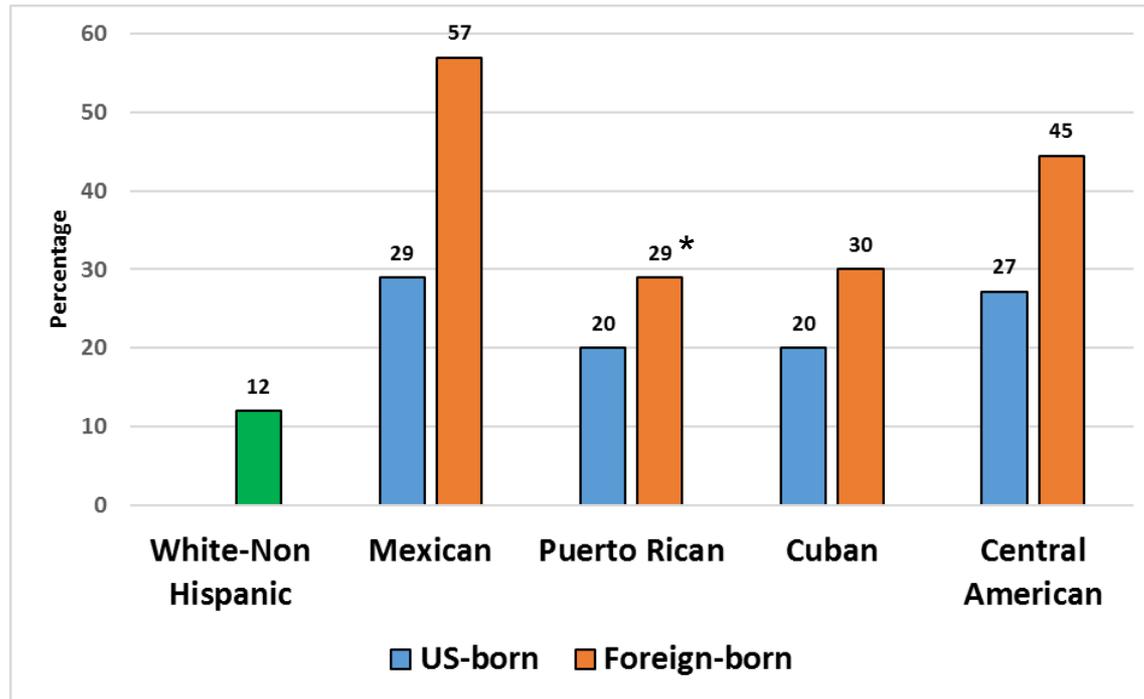
- Defined by:
  - Country of origin
  - Place/country of birth
  - Citizenship
  - Language
  - Race
  - Years in the United States
  - Others

# LIFE EXPECTANCY AT BIRTH BY SELECTED RACE AND ETHNIC CATEGORIES, 1999–2001



Source: Singh GK et al., 2013b

# LACK OF HEALTH INSURANCE COVERAGE (%) FOR ADULT RACIAL AND ETHNIC SUBGROUPS BY PLACE OF BIRTH, NHIS, 2008–2010



\*Born in the Island of Puerto Rico

Source: Singh GK, et al., 2013a

**How have national population health monitoring data systems adapted to the increasing Hispanic diversity?**

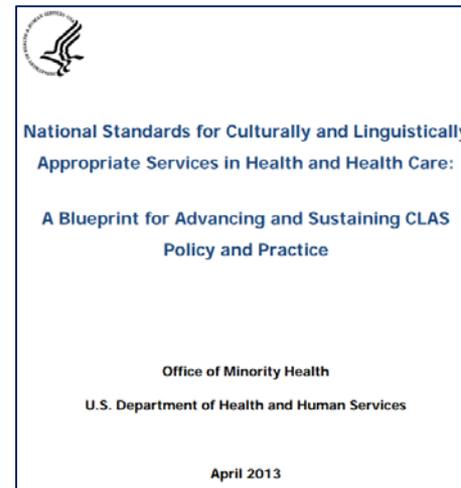
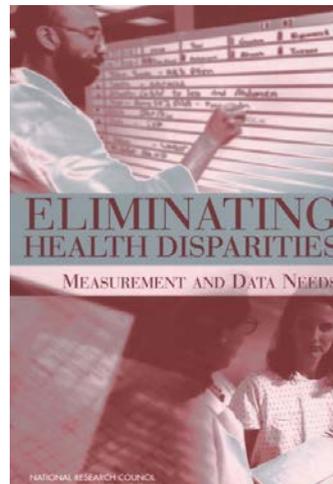
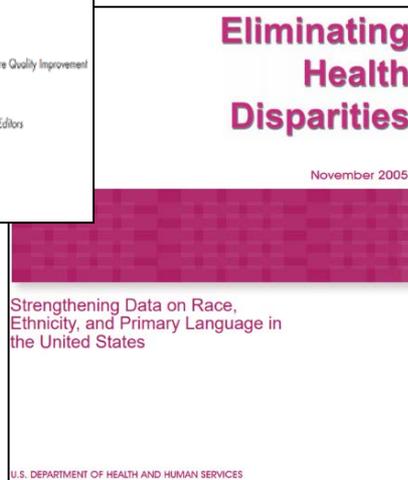
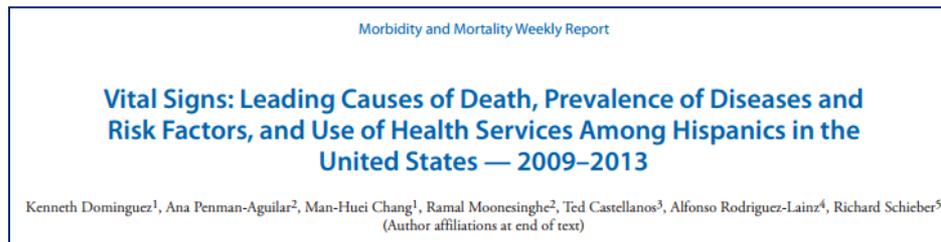
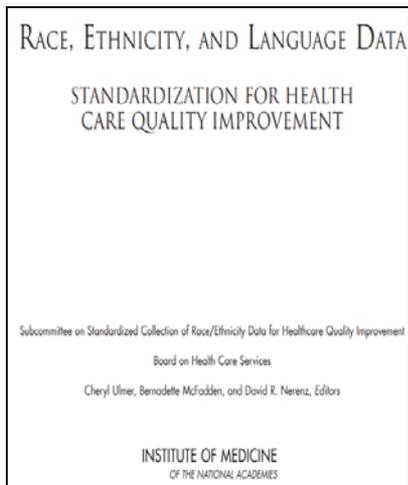
# NATIONAL HEALTH MONITORING DATA SYSTEMS AND HISPANIC DIVERSITY

- Some initiatives and successes
- Important gaps in availability, quality, and comparability of data in national data systems used to monitor Hispanics' and other minorities' health
  - Limitations in the collection and reporting of Hispanic diversity data elements (e.g., detailed ethnic categories, language, place of birth)
  - Barriers to participation by individuals with limited English proficiency

References: Department of Health and Human Services [DHHS], 1968; DHHS, 2005; Li, 2001; Dorsey, 2011; DHHS, 2011; National Research Council, 2004; Institute of Medicine, 2009; DHHSACF, 2014; Dominguez et al., 2015; Richardson, 2016

**What can be done?**

# SIMILAR RECOMMENDATIONS FROM MULTIPLE ORGANIZATIONS, ADVISORY GROUPS, AND RESEARCHERS



# WHAT CAN BE DONE?

## 1. Enhance collection, analysis and reporting of standardized Hispanic diversity data elements

- Detailed racial and ethnic categories (e.g., Mexican, Puerto Rican)
- Language spoken at home and English-speaking proficiency
- Detailed place/country of birth (including US Territories)
- Citizenship
- Years in the United States (for the foreign-born)
- All the above variables about parents for systems that collect data on children

# WHAT CAN BE DONE?

## 1. Enhance collection, analysis and reporting of standardized Hispanic diversity variables

- Detailed race and ethnicity
- Detailed country of birth (including US Territories)
- Language spoken at home and English- speaking ability
- Citizenship
- Years in the United States (for the foreign-born)
- All the above variables about parents for systems that collect data on children

# EXAMPLES OF FEDERAL DATA STANDARDS

- **DHHS data standards for race, ethnicity and language (2011)**
  - Available at:  
<https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=23>
- **US Census Bureau standards for place of birth, citizenship and years in the United States**
  - Available at:  
[http://www.census.gov/acs/www/methodology/questionnaire\\_archive](http://www.census.gov/acs/www/methodology/questionnaire_archive)

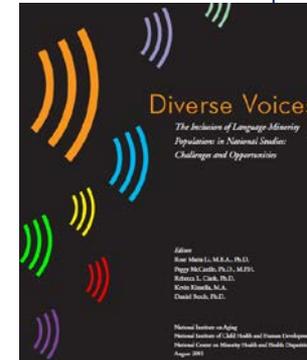
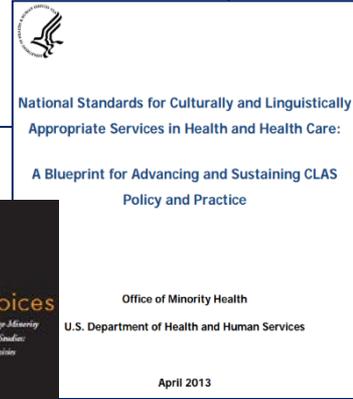
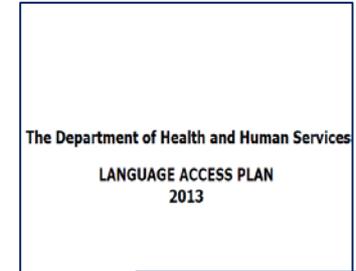
# WHAT CAN BE DONE?

## 2. Promote culturally and linguistically appropriate data collection

- Translation and cultural validation of data collection instruments
- Provide interpreters for limited English proficient individuals

# EXAMPLES OF FEDERAL GUIDANCE

- **DHHS National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (2013)**
- **DHHS Language Access Plan (2013)**
- **Diverse Voices (National Institute on Aging and National Institute of Child Health and Human Development) (2001)**



<https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedCLASStandardsBlueprint.pdf>

<https://www.hhs.gov/sites/default/files/open/pres-actions/2013-hhs-language-access-plan.pdf>

[https://www.nichd.nih.gov/publications/pubs/documents/Diverse\\_Voices.pdf](https://www.nichd.nih.gov/publications/pubs/documents/Diverse_Voices.pdf)

# APPROACHES TO IMPLEMENTING SUGGESTED STRATEGIES

- National health monitoring data systems can review the available initiatives and assess feasibility based on :
  - Information needs
  - Area of public health focus
  - Affected population(s)
  - Who collects the data
  - If data is collected directly from individuals or not
  - Current and historic data collection practices
  - Logistic and technological barriers
  - Available resources

# EXAMPLES OF GOOD PRACTICES

- in 2014, the National Notifiable Diseases Surveillance System added country of birth as a core demographic variable
- CDC HIV Surveillance System collects detailed country of birth and extended race and ethnicity information
- CDC Listeria Initiative added detailed race and ethnicity, country of birth, and language, as well as made their questionnaire available in Spanish
- National Immunization Survey provides interpreters in multiple languages

**What are the potential benefits of implementing the suggested strategies?**

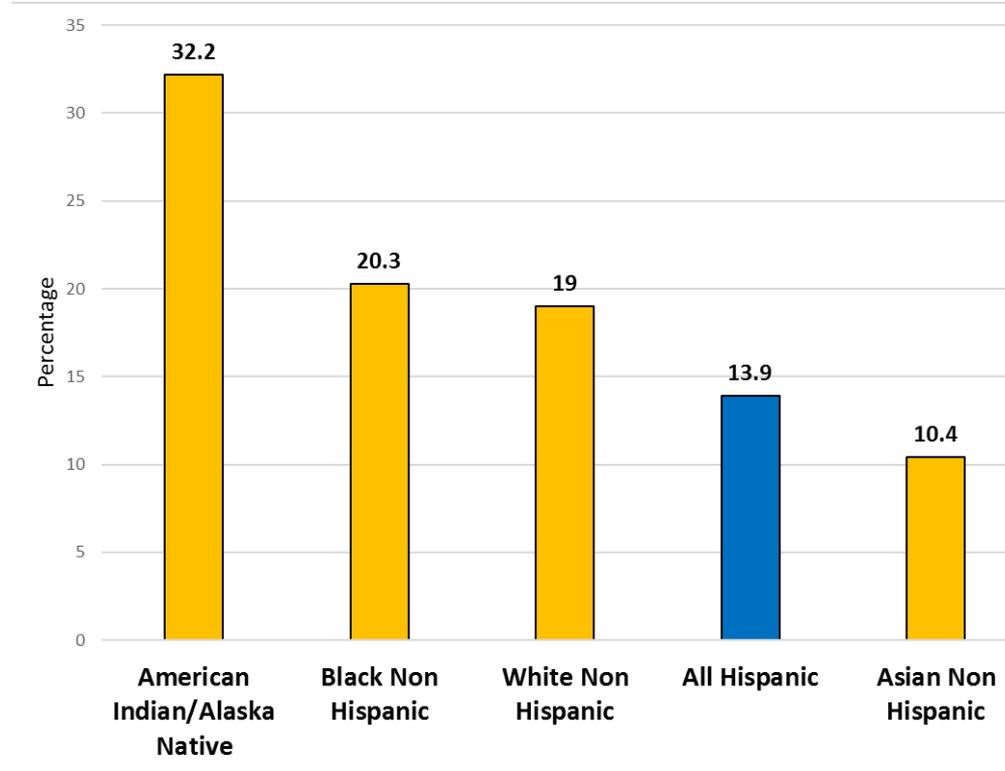
# POTENTIAL BENEFITS FOR DATA SYSTEMS AND PUBLIC HEALTH

- Three perspectives:
  1. Scientific
  2. Programmatic
  3. Ethical

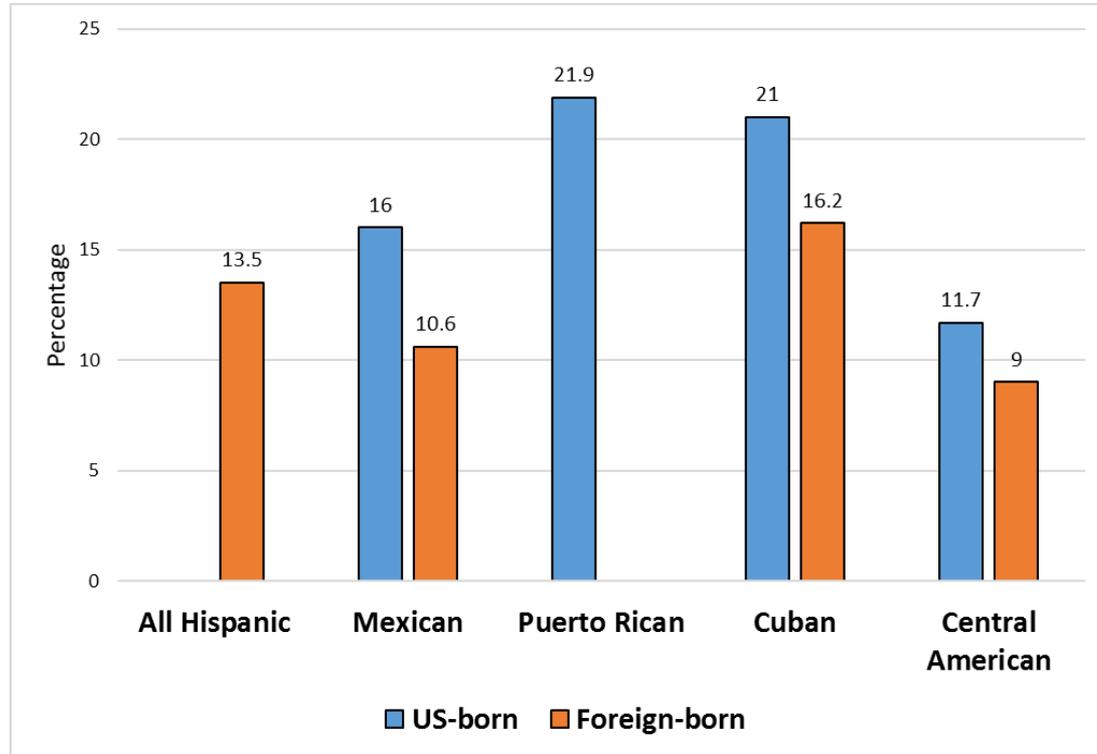
# POTENTIAL SCIENTIFIC BENEFITS

- Higher participation rate
- More representative data
- Higher quality and completeness of data
- Increased ability to identify varying health risks (especially emergent ones) and health disparities affecting Hispanic subpopulations

# CURRENT CIGARETTE SMOKING (%) BY SELECTED RACIAL/ETHNIC CATEGORIES, US, BRFSS\*, 2013



# CIGARETTE SMOKING (%) BY HISPANIC ORIGIN AND PLACE OF BIRTH, US, NHIS 2009–2013



# POTENTIAL PROGRAMMATIC BENEFITS

- Increased ability to design culturally and linguistically appropriate interventions
- More effective public health interventions (both universal and targeted) and use of resources

# DEMOGRAPHICS OF TRAVEL-ASSOCIATED ZIKA CASES COMPARED TO OVERALL COUNTY POPULATION, SAN DIEGO COUNTY, 2016–2017 (N=78)

	Zika case- patients	County population
Hispanic Majority Mexicans	54%*	33%
Foreign-born Majority born in Mexico	33%*	23%

Note: Similar national-level data have not been published

# POTENTIAL ETHICAL BENEFITS

- Ensuring **fair inclusion** of subpopulations in data collection and distribution of public health services and resources
- **Prioritizing** public health interventions to those with highest disease burden or fewer resources

# POTENTIAL ETHICAL BENEFITS

- **If data are collected only in English:**
  - How can we ensure all Hispanics have equitable opportunity to participate in data collection and that their needs will be identified, given the high percentage of Hispanics with limited English proficiency?



# PROTECTING DISADVANTAGED AND VULNERABLE POPULATIONS IN DATA COLLECTION EFFORTS

- Protecting data confidentiality and privacy
  - Respecting autonomy/informed consent
  - Data collection benefiting the community
  - Preventing stigmatization
- 

# CONCLUSIONS

- Hispanics are an increasing share of the US population and very heterogeneous in terms of sociodemographic and health characteristics
- Numerous rationales for collecting the recommended data elements and providing language access exist
- Good resources and examples of expanded data collection are available

# CONCLUSIONS

- Expanded data collection:
  - May improve the quality of data needed to monitor and address Hispanic (and other minority population) health;
  - Is critical for eliminating health disparities, promoting health equity, and improving the nation's health.

**Thank you!**  
**¡Muchas gracias!**



For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [www.cdc.gov](http://www.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



**Additional slides**

# 2011 DHHS DATA STANDARDS FOR ETHNICITY

- **Are you Hispanic, Latino/a, or Spanish origin (one or more categories may be selected)**
  - Not, not of Hispanic, Latino/a, or Spanish origin
  - Yes, Mexican, Mexican American, Chicano/a
  - Yes, Puerto Rican
  - Yes, Cuban
  - Yes, another Hispanic, Latino/a, or Spanish origin

# 2011 HHS DATA STANDARDS FOR LANGUAGE

- **How well do you speak English?** (5 years old or older)
  - Very well
  - Well
  - Not well
  - Not at all
  
- **Do you speak a language other than English at home?** (5 years old or older)
  - If yes ... What is this language?**
  - Spanish
  - Other language (Identify)

# US CENSUS BUREAU QUESTIONS

- **Where was this person born?**
  - In the United States
  - Outside the United States—*Print name of foreign country, or Puerto Rico, Guam, etc.*
  
- **When did this person come to live in the United States? (Year)**  
*Print number in box*

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