

Improving the Collection of Accurate Racial/Ethnic Data

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Our Presenters

■ Presenters

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Region X Infertility Prevention Project

Co-Providers

- Region X Infertility Prevention Project
- Office of Family Planning, Region X

Learning Objectives

- Describe why it is important to collect accurate racial/ethnic data
- Identify elements of a uniform framework for collecting racial/ethnic data
- Describe how to ask questions about race/ethnicity in standard ways that empower clients/patients to self-identify

Why Collect Racial/Ethnic Data?

- Identify racial/ethnic differences and disparities
- Improve quality of care
- Track quality indicators and health outcomes
- Target resources appropriately

Identify Racial/Ethnic Differences and Disparities

**The health of America depends on
the health of all Americans.
Despite enormous investment,
America is not achieving its full
health potential.**

—Robert Wood Johnson Foundation,
Commission to Build a Healthier America

Identify Differences/Disparities

- Higher rates of STDs among some racial/ethnic groups compared with rates among whites
 - Higher rates of CT & GC among African Americans, American Indians/Alaska Natives and Hispanics
 - Higher rates of P&S syphilis among African Americans and Hispanics
 - African Americans and Hispanics disproportionately affected by HIV

Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2008*. Atlanta, GA: U.S. Department of Health and Human Services; November 2009.

Identify Differences/Disparities

- Completeness of race/ethnicity data
 - 26.4% missing among CT cases
 - 20.3% missing among GC cases
 - 3.2% missing among P&S syphilis cases

Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2008*. Atlanta, GA: U.S. Department of Health and Human Services; November 2009.

Contributors—Racial Misreporting

- Racial misclassification causes inaccuracies in characterizing the burden of infectious disease in minorities.¹
- Previous studies have documented misreporting of American Indian/Alaska Native race resulting in under-estimates when characterizing burden of STDs.²

¹Thoroughman et al. Racial misclassification of American Indians in Oklahoma State Surveillance Data for Sexually Transmitted Diseases. *Am J Epidemiol* 2002;155:1137-1141.

²Centers for Disease Control and Prevention and Indian Health Service *Indian Health Surveillance Report—Sexually Transmitted Diseases 2007*, Atlanta, GA: U.S. Department of Health and Human Services, September 2009.

Contributors—Racial Misreporting

- Disaggregation of data is important.^{3,4}


³Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices, Ruth T. Perot and Mara Youdelman, The Commonwealth Fund, September 2001

⁴Bertolli et al. Racial misidentification of American Indians/Alaska Natives in the HIV/AIDS Reporting Systems of Five States and One Urban Health Jurisdiction, U.S., 1984-2002. Public Health Rep 2007;122:382-392

Contributors—Racial Misreporting

- All races and ethnicities
 - Provider collection of race based on physical appearance
 - Interpretation of mixed race heritage
- American Indian/Alaska Native specific
 - Urban residence
 - Degree of American Indian/Alaska Native heritage

AZ's Efforts to Improve the Collection of Racial/Ethnic Data



Arizona Department of Health Services

*Division of Public Health Services
Public Health Preparedness Services*
150 N. 18th Avenue, Suite 140
Phoenix, Arizona 85007-3237
Telephone: (602) 566-6666
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JANICE K. BRIDNER, GOVERNOR
WILL HARREL, INTERIM DIRECTOR

April 14, 2010

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R/V DETENT DURANGO
111 W BIRKLAND
PHOENIX, AZ 85009


Dear Provider:

Thank you for submitting the Communicable Disease Report (CDR) on the patients listed on the attached form. This form has been received by the county and entered into the state STD database.

According to Arizona Administrative Code (AAC R-9-202), it is a required component of communicable disease reporting to include race/ethnicity information for patients diagnosed with sexually transmitted diseases (STD). The attached form includes the name, date of birth, disease type and date of specimen collection for patients that were recently diagnosed with an STD at your clinic.


Please complete the race/ethnicity section of the form according to the enclosed guidelines. Please fax the completed form that includes the completed race/ethnicity section to 602-364-2119 or mail to the AIDS/STD Control Program at the above address. On final Communicable Disease Report (CDR) submissions please complete the race/ethnicity section for all patients to avoid receipt of this notice.

We appreciate your timely and complete submission of communicable disease reports.

Sincerely,

Melinda Taylor, MD, MPH
Medical Director
Office of HIV, STD and Hepatitis C Services
Arizona Department of Health Services
Phone: (602) 564-4565

Note: Please return the completed form to the address or fax as listed above.

AZ's Efforts to Improve the Collection of Racial/Ethnic Data



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R/V DETENT DURANGO
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PHOENIX, AZ 85009

Patient Name	Date of Birth	Type of Test	Date of Test	Etiology (Check one)	Race (Check all that apply)
[REDACTED]	[REDACTED]	GILAMYDIA	09/12/09	<input type="checkbox"/> Hepatic <input type="checkbox"/> Non-Hepatic <input type="checkbox"/> Unknown	<input type="checkbox"/> Black <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Other <input type="checkbox"/> Unknown
[REDACTED]	[REDACTED]	GONGPHERA	01/12/09	<input type="checkbox"/> Hepatic <input type="checkbox"/> Non-Hepatic <input type="checkbox"/> Unknown	<input type="checkbox"/> Black <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Other <input type="checkbox"/> Unknown
[REDACTED]	[REDACTED]	CHILAMPYRA	02/18/2010	<input type="checkbox"/> Hepatic <input type="checkbox"/> Non-Hepatic <input type="checkbox"/> Unknown	<input type="checkbox"/> Black <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Other <input type="checkbox"/> Unknown

Note: Please return the completed form to the address or fax as listed above.

**Improve Quality of Care and
Track Quality Indicators/Outcomes**

**Of all the forms of inequality,
injustice in health care is the most
shocking and inhumane.**

—Martin Luther King, Jr.

Improve Quality of Care and Track Quality Indicators/Outcomes

- Racial/ethnic minorities receive lower quality care across many core measures of quality and access.
 - Health indicators and outcomes
 - Timeliness of care
 - Patient centeredness
 - Health insurance coverage
 - Usual source of care
 - Patient perceptions of need

Agency for Healthcare Research and Quality. *2009 National Healthcare Disparities Report*. Rockville, MD: U.S. Department of Health and Human Services; March 2010.

Target Resources Appropriately

Unaddressed disparities in health care are a continuing source of unnecessary health spending in this country.

—Lee Partridge,
National Partnership for Women & Families

Questions?

Standardizing Data Collection

- Always collect data from clients or their caregivers
- Collect data at registration/upon admission
- Use Census and OMB categories
- Address client concerns up front and clearly
- Store data in a standard electronic format
- Provide ongoing staff training and evaluation

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Is a Uniform Framework Important?

Yes!

Elements of a Uniform Framework

- Rationale for asking the client/patient to provide race/ethnicity
- Assurances that data will be kept confidential
- Script to support staff in asking the questions in a uniform manner
- Method for allowing clients/patients to self-identify race and ethnicity
- Standardized approach for analyzing and reporting data

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Rationale

Explain why you're collecting these data and how they will be used...

We want to make sure that all of our clients get the best care. We would like you to tell us your racial/ethnic background, so that we can review the services that all clients receive and make sure that everyone gets the highest quality care.

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Assurance of Confidentiality

Assure the client that data will be kept confidential...

The only people who see this information are registration staff, administrators and managers, and people involved in quality improvement and oversight, and the confidentiality of what you say is protected by law.

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Script/Method for Client to Self-ID

Ask about ethnicity first...

Do you consider yourself Hispanic or Latino?

Options = Yes, No, Declined, Unavailable/Unknown

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Script/Method for Client to Self-ID

Then, ask about race...

Which (category/of the following) best describes your race?

Options = American Indian or Alaska Native,
Asian, Black or African American,
Native Hawaiian or Other Pacific Islander, White, Some other race,
More than one race/Multiracial, Declined, Unavailable/Unknown

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Script/Method for Client to Self-ID

Then, ask about specific racial/ethnic background...

Please describe your race or ethnic background.

Sample responses =
Cuban, Mexican, Puerto Rican
Nez Perce, Yakama, Haida, Inupiat
Cambodian, Chinese, Japanese, Korean, Vietnamese
Ethiopian, Eritrean, Somali
Guamanian, Hawaiian, Samoan

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Questions?

Handling Client Responses

- Use common sense
- Allow clients to respond and use as much of their own description of race and ethnicity
- Respect their descriptions and choices
- Avoid language that might cause client discomfort

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Handling Client Responses

If the client says...

I'm American.

You might say...

*Would you like to use another option,
or would you like me to just put American?*

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Handling Client Responses

If the client says...

Can't you tell by looking at me?

You might say...

*Sometimes I can. But, sometimes I'm wrong,
so we think it's better to let our clients tell us.
I don't want to put in the wrong answer.
I'm trained not to make assumptions.*

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Handling Client Responses

If the client says...

*I was born in Ethiopia, but I've lived here all my life.
What should I say?*

You might say...

*That's up to you. You can identify in any way that you like.
It's fine to say that you are Ethiopian.*

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Handling Client Responses

If the client says...

*I'm human.
or
It's none of your business.*

You might say...

*If you prefer not to answer the question, I can just say that.
That's fine.*

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Handling Client Responses

If the client says...

Are you trying to find out if I'm a U.S. citizen?

You might say...

No. The confidentiality of what you say is protected by law, and we do not share information with anyone.

Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on June 1, 2010.

Data Analysis and Reporting

- Linking to clinical quality measures
- Linking to client satisfaction measures
- Making appropriate decisions in targeting resources
- Complying with civil rights laws

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Questions?

Resources

- Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, November 2002, http://www.nap.edu/catalog.php?record_id=12875#orgs
- Centers for Disease Control and Prevention, *Sexually Transmitted Disease Surveillance, 2008*, November 2009, <http://www.cdc.gov/std/stats08/toc.htm>
- Centers for Disease Control and Prevention and Indian Health Service, *Indian Health Service Surveillance Report—Sexually Transmitted Diseases 2007*, September 2009, http://www.cdc.gov/std/stats/IHS/IHS-SurvRpt_Web508Nov2009.pdf

Resources

- Agency for Healthcare Research and Quality, *2009 National Healthcare Disparities Report*, March 2010, <http://www.ahrq.gov/qual/qdr09.htm>
- Health Research and Educational Trust, *HRET Disparities Toolkit: A Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients*, 2007, <http://www.hretdisparities.org/>
- Office of Management and Budget, *Standards for Maintaining, Collecting and Presenting Federal Data on Race and Ethnicity*, 2000, http://www.whitehouse.gov/omb/inforeg/re_app-a-update.pdf

Resources

Cultural Competency

- Office of Minority Health, Think Cultural Health, <https://www.thinkculturalhealth.org/>
 - CE credit—A Physician's Practical Guide to Culturally Competent Care, <https://cccm.thinkculturalhealth.org/>
 - CE credit—Culturally Competent Nursing Care: A Cornerstone of Caring, <https://ccnm.thinkculturalhealth.org/>
- Management Sciences for Health, The Provider's Guide to Quality and Culture, <http://erc.msh.org/mainpage.cfm?file=1.0.htm&module=provider&language=English>

Resources

Language Access

- Robert Wood Johnson Foundation, Speaking Together Toolkit, 2008, <http://www.rwjf.org/qualityequality/product.jsp?id=29653>
- National Health Law Program, *Language Services Resource Guide for Health Care Providers*, 2006, <http://www.healthlaw.org/images/stories/issues/ResourceGuideFinal.pdf>
- Office of Minority Health, *A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations*, 2005, <http://minorityhealth.hhs.gov/Assets/pdf/Checked/HC-LSIG.pdf>

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For More Information...

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