

Health Equity Train-the-Trainer Session: Collecting Data to Understand Health Disparities

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Mursal Khaliif
Izabel Arocha
Cambridge Health Alliance

Susan Choi
Ryann Bresnahan
Institute for Community Health



Elmer Freeman
Beverley Russell
Kerone Anderson
*Center for Community
Health Education,
Research and Service*



Training Team

- **Cambridge Health Alliance's (CHA)**
Department of Community Affairs and
Department of Multilingual Interpreting
- **Institute for Community Health**
- **The Center for Community Health,
Education and Research (CCHERS)**

Train-the-Trainer Model

Evaluation

For office use only: Date: 29 October 2004
Presentation: Race and Ethnicity Data Collection
Presenter(s): Brent Cas (ICD), Eric Ross/And (CCHERS)

Workshop Evaluation
Circle the number that describes whether you agree or disagree with each statement below.

	Strongly agree	Agree	Disagree	Strongly disagree
This topic is important for me to learn about.	1	2	3	4
The workshop helped me learn things I needed to know about this topic.	1	2	3	4
The presenters made me feel comfortable about asking questions.	1	2	3	4
The objectives for the workshop were outlined in a clear way.	1	2	3	4
The objectives for the workshop were met.	1	2	3	4
The workshop increased my skills on this topic.	1	2	3	4

What challenges do you anticipate with collecting race and ethnicity data within your program?

What types of additional resources and support would you like for collecting race and ethnicity data within your program?

Please complete **BOTH** sides of this evaluation. Your feedback is **greatly appreciated!!!**

Your Feedback is Anticipated!

Agenda

- **Welcome from MDPH**
- **Introduction Activity**
- **Best Practices for Collecting Race, Ethnicity and Language Data**
- **Training Tool: Videos**
- **Training Tool: Role Plays**
- **Training Tool: Resources**
- **Evaluation and Concluding Remarks**

Introduction Activity

Introduction Cards

Hello, my name is

_____.

My race is _____.
(You may list more than one.)

My ethnicity is _____.
(You may list more than one.)

My primary language spoken at
home is _____.

Before we begin...

The Golden Rule for Training Staff to Collect Race and Ethnicity Information:

**You only have to collect it once,
if you collect it correctly.**

What are health disparities?

Health disparities are differences between populations in:

- Presence of disease
- Access to health care
- Use of health care services
- Health outcomes

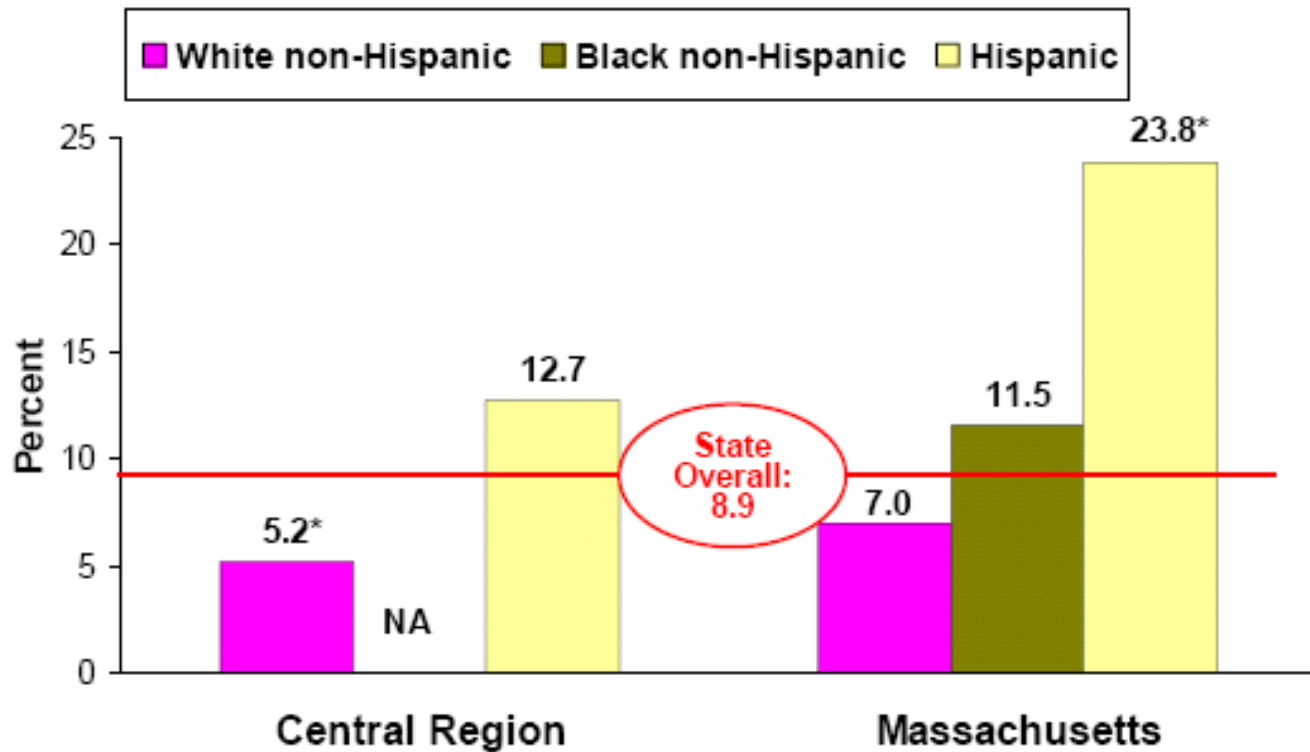


What causes health disparities?



- **Social, economic, and environmental factors**
- **Barriers to getting health care**
- **Differences in quality of health care**

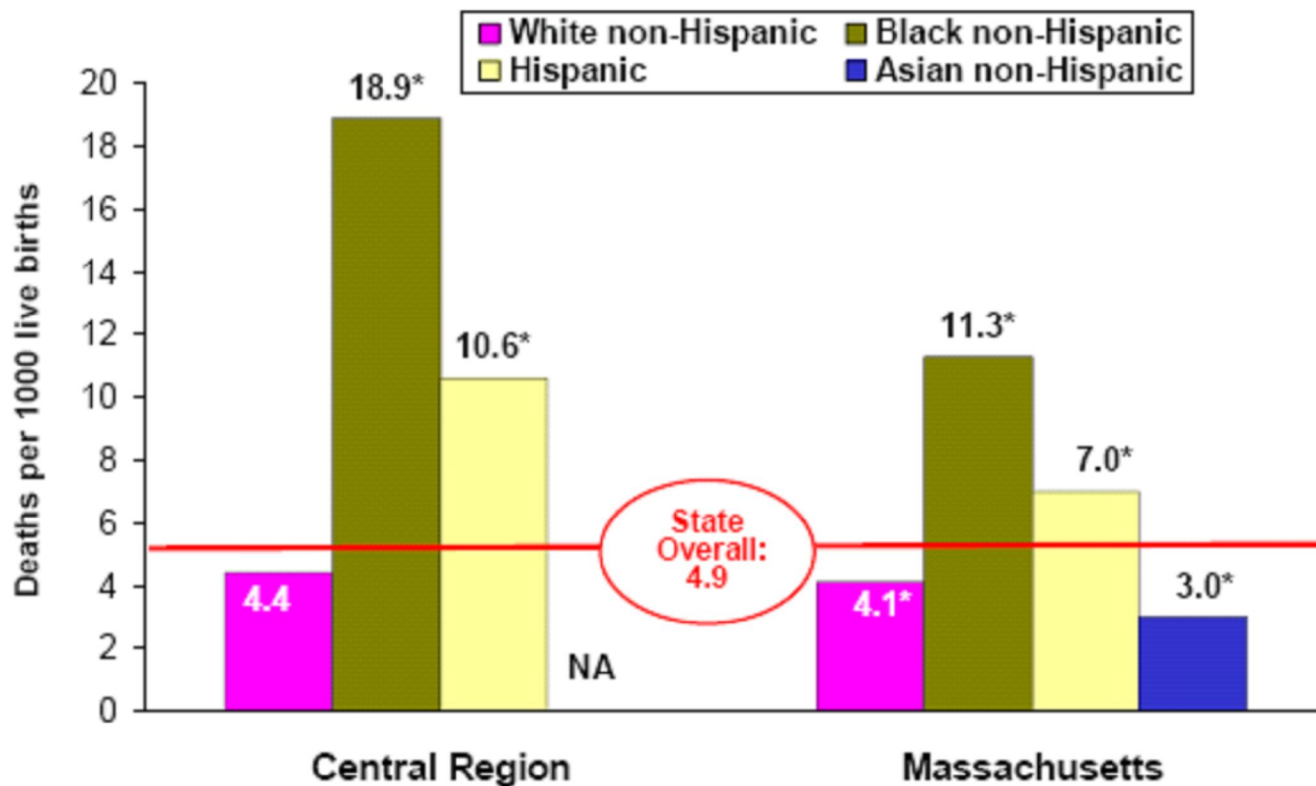
Adults who Have No Health Insurance by Race and Ethnicity Central Region and Massachusetts: 2005



(*) Statistically different from State ($p \leq .05$)

Source: MDPH, Bureau of Health Information, Statistics, Research, & Evaluation, Health Survey Program

Infant Mortality Rates by Race/Ethnicity Central Region and Massachusetts: 2002-2005



NA= Calculations based on less than 5 events are excluded

(*) Statistically different from State ($p \leq .05$)

Source: MDPH, Bureau of Health Information, Statistics, Research, & Evaluation, Division of Research & Epidemiology

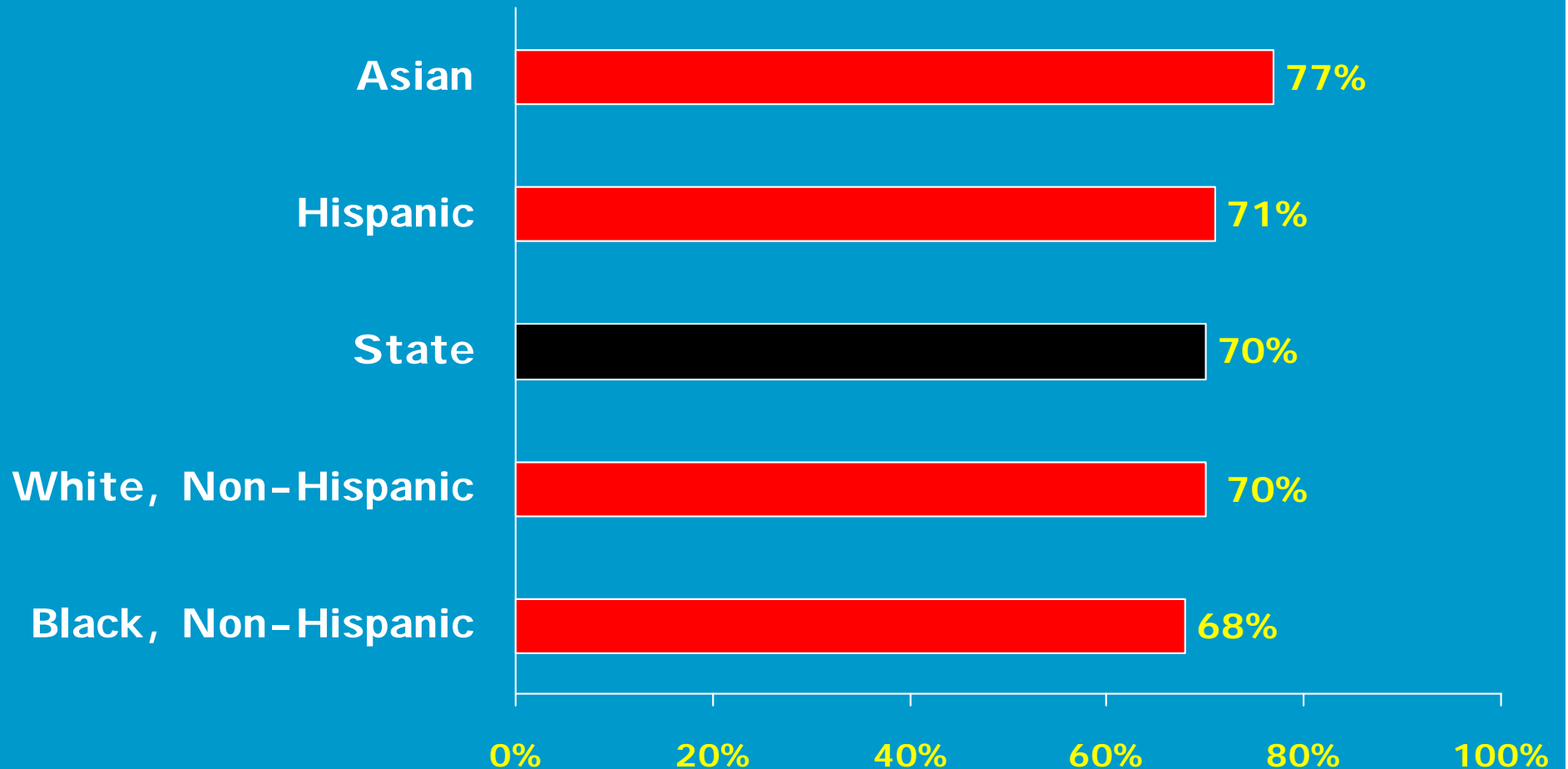
Disparities Exist and Persist

- Need to better understand populations
- More variation within groups than among them

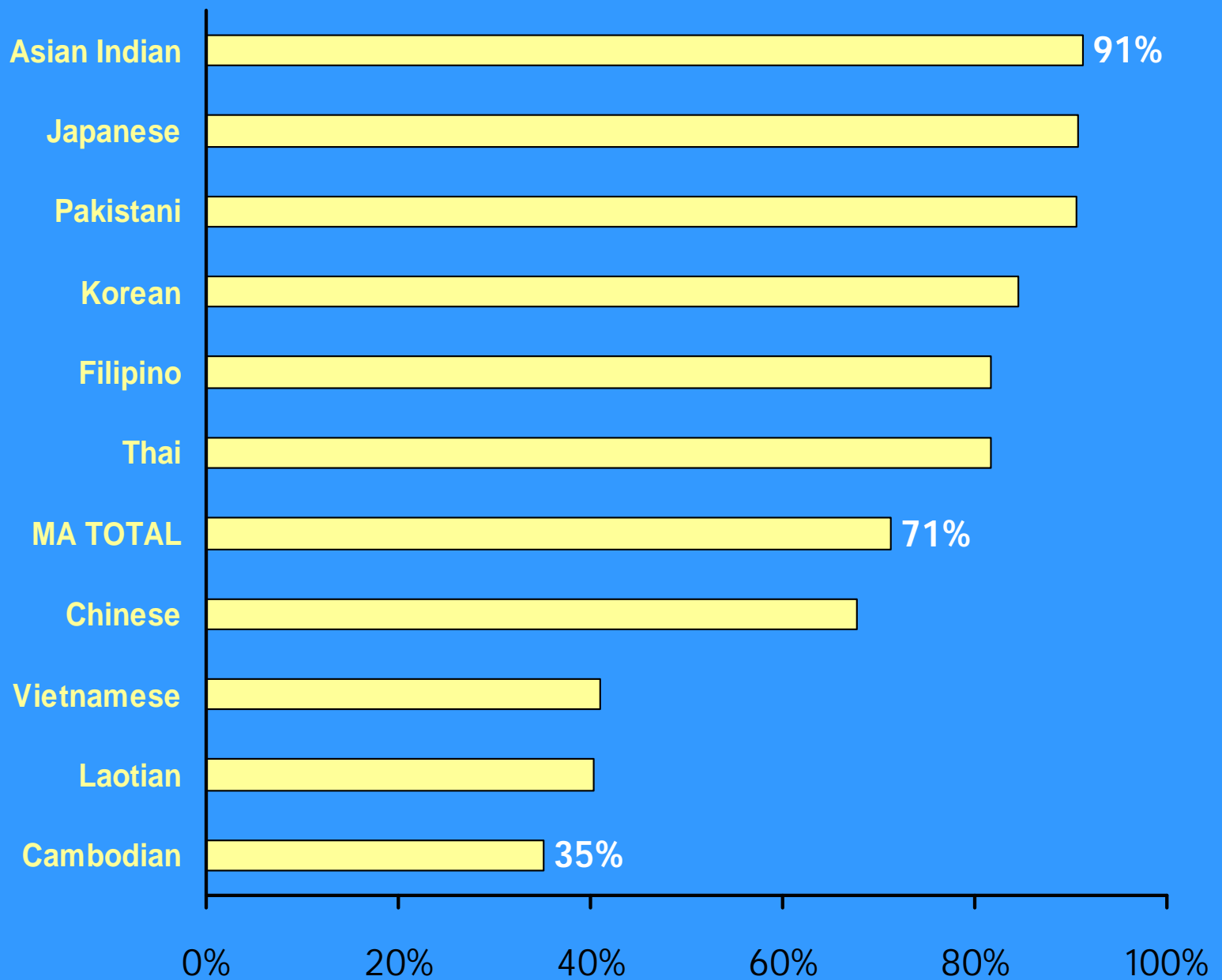
To Eliminate Disparities, We Need to Collect Better Data



Why Improve the Data?



Percent of Mothers Breastfeeding by Race/Ethnicity, MA



Source: Asian Births in Massachusetts: 1996-1999; Hispanic Births in Massachusetts: 1996-1999; and Black Births in Massachusetts: 1997-2000

Why Collect the Data?

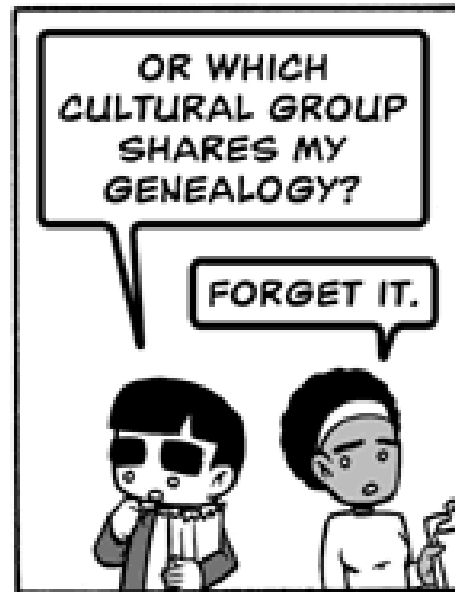
- **Identify Disparities or Differences**
- **Target Interventions to Address Gaps**
- **Improve Quality of Care and/or Services for All**

How to Collect Race and Ethnicity Data?

- **What is your RACE?**
- **What is your ETHNICITY?**



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Asking about Language

- **What is the primary language spoken in your home?**
- **What language do you prefer to speak with us about health?**
- **What language do you prefer to read health-related materials?**

How to Collect Race, Ethnicity and Language Data?

- In Person?
- On a Form?
- Over the Phone?
- Other Methods?

How to Collect Race, Ethnicity and Language Data?

- **Explain why it is being collected**
- **Be prepared for questions**
- **Give people the tools they need to identify**

MDPH Data Collection Tool

MDPH Race-Ethnicity and Language Preference Data Collection Instrument

Introduction: In order to guarantee that all patients receive the highest quality of care and to ensure the best services possible, we are collecting data on race and ethnicity. Could you please select the category or categories that best describes your background?

1. Are you Hispanic/Latino/Spanish?

- Yes
- No

2. What is your ethnicity? (You can specify one or more)

- | | |
|------------------------------------|------------------------------------|
| African (specify _____) | Haitian |
| African American | Honduran |
| American | Japanese |
| Asian Indian | Korean |
| Brazilian | Laotian |
| Cambodian | Mexican, Mexican American, Chicano |
| Cape Verdean | Middle Eastern (specify _____) |
| Caribbean Islander (specify _____) | Portuguese |
| Chinese | Puerto Rican |
| Colombian | Russian |
| Cuban | Salvadoran |
| Dominican | Vietnamese |
| European | Other (specify _____) |
| Filipino | Unknown/not specified |
| Guatemalan | |

3. What is your race? (You can specify one or more)

- American Indian/Alaska Native (specify tribal nation _____)
- Asian
- Black
- Native Hawaiian or other Pacific Islander (specify _____)
- White
- Other (specify _____)
- Unknown/not specified

4. In what language do you prefer to discuss health-related concerns?

- | | |
|---------------------|---------------------------------|
| English | Somali |
| Spanish | Arabic |
| Portuguese | Albanian |
| Cape Verdean Creole | Chinese (specify dialect _____) |
| Haitian Creole | Russian |
| Khmer | Other (specify _____) |
| Vietnamese | |

August 2008 version

DPH Race-Ethnicity and Language Preference Data Collection Instrument

Introduction: In order to guarantee that all patients receive the highest quality of care and to ensure the best services possible, we are collecting data on race and ethnicity. Could you please select the category or categories that best describes your background?

1. What is your ethnicity? (You can specify one or more)

- | | |
|---|---|
| <input type="checkbox"/> African (specify _____) | <input type="checkbox"/> Haitian |
| <input type="checkbox"/> African American | <input type="checkbox"/> Honduran |
| <input type="checkbox"/> American | <input type="checkbox"/> Japanese |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Brazilian | <input type="checkbox"/> Laotian |
| <input type="checkbox"/> Cambodian | <input type="checkbox"/> Mexican, Mexican American, Chicano |
| <input type="checkbox"/> Cape Verdean | <input type="checkbox"/> Middle Eastern (specify _____) |
| <input type="checkbox"/> Caribbean Islander (specify _____) | <input type="checkbox"/> Portuguese |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Colombian | <input type="checkbox"/> Russian |
| <input type="checkbox"/> Cuban | <input type="checkbox"/> Salvadoran |
| <input type="checkbox"/> Dominican | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> European | <input type="checkbox"/> Other (specify _____) |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Unknown/not specified |
| <input type="checkbox"/> Guatemalan | |

2. What is your race? (You can specify one or more)

- American Indian/Alaska Native (specify tribal nation _____)
- Asian
- Black
- Hispanic/Latino/Black
- Hispanic/Latino/White
- Hispanic/Latino/other
- Native Hawaiian or other Pacific Islander (specify _____)
- White
- Other (specify _____)
- Unknown/not specified

3. What language do you prefer to speak with us about health?

- | | |
|--|--|
| <input type="checkbox"/> English | <input type="checkbox"/> Somali |
| <input type="checkbox"/> Spanish | <input type="checkbox"/> Arabic |
| <input type="checkbox"/> Portuguese | <input type="checkbox"/> Albanian |
| <input type="checkbox"/> Cape Verdean Creole | <input type="checkbox"/> Chinese (specify dialect _____) |
| <input type="checkbox"/> Haitian Creole | <input type="checkbox"/> Russian |
| <input type="checkbox"/> Khmer | <input type="checkbox"/> Other (specify _____) |
| <input type="checkbox"/> Vietnamese | |

March 2009 version

How to Collect Race, Ethnicity and Language Data?

- The MDPH Data Collection Tool is a suggested instrument to collect these data.
- However, it is only one example of how to collect race, ethnicity and language data.
- Ensure that whichever form/method your organization chooses that when reporting data, you are able to meet state and other reporting requirements.

Why every patient needs to be asked

- **ALL patients should be asked about their race, ethnicity and language!**
- Self-reporting is the most accurate source of information
- Self-reporting will increase consistent reporting within a health care institution
 - Patients are more likely to select the same categories to describe themselves over time than staff who are assuming or guessing

Why every patient needs to be asked



Why every patient needs to be asked



Why every patient needs to be asked



Helpful Hints

Several studies have shown that a brief introduction before asking the questions makes patients more comfortable.

This will make your job easier and will make the data collected better!



Introduction: Key Points

The Introduction should tell people:

- **“We are collecting race, ethnicity and language data from all participants to learn more about the communities we serve**
- **This information will only be used to give all patients the best care possible”**

****A sample introduction to the questions can be found in your folders.**

Frequently Asked Questions

If a participant asks “Why are you collecting this information?”

“We are asking all patients about their race, ethnicity, and language to learn more about the communities we serve.”

“This data helps us ensure that everyone receives the highest quality of care.”

“Collecting these data also helps improve the quality of services provided overall.”

If a participant asks “How is my information kept private/confidential?”

- “Your name and other information that could identify you will not be used when data are reported.”
- “Your privacy is protected” (mention HIPAA when appropriate).
- “The users of the data have very strict rules about how data are reported.”

We will not share this information with immigration

If a participant asks about Privacy

**** We encourage you to share your Individual Hospital/Health Center/Program Privacy Statement****

If a participant asks “Can I still receive services if I don’t tell you my race/ethnicity?”

“You can still receive our services even if you choose not to answer these questions.”

**“Answering these questions is voluntary.
However, the more data we collect, the better we are able to serve our client population.”**

If a patient asks “What is Ethnicity?”

“Your ethnicity refers to your background, heritage, culture, ancestry or sometimes the country where you were born.

You can tell me more than one.”

For example, please let us know if you are Haitian, Vietnamese, Brazilian, etc.

If the participant responds “I’m Multiethnic”

“We can record as many categories as you need to describe yourself. Please tell me all of your ethnicities.”

If the patient cannot describe their ethnicity

Give examples!

“For ethnicity, please let us know if you are Haitian, Vietnamese, Brazilian, etc. You can tell me in your own words and I will record your response.”

- Record Participant’s Response
- If category not found, write it in!

If a participant asks “What is meant by Hispanic, Latino or Spanish?”

“A person is Hispanic, Latino or Spanish if they or their family come from a country in Latin America or another Spanish-speaking country.”

- Record Participant’s Yes or No Response**
- If the response is some, partly, half, or a little, please enter Yes.**
- If a participant declines, enter No.**

If a participant asks “What is Race?”

“Your race is the group or groups that you identify with as having similar physical characteristics or similar social and geographic origins. You can tell me more than one.”

For example, please let us know if you are Asian, Black, White, etc.

If the participant responds “I’m Multiracial”

“We can record as many categories as you need to describe yourself.

Please tell me all of your races.”

If the participant cannot describe their race

Give examples!

“For race, please let us know if you are Asian, Black, White, etc.

You can tell me in your own words and I will record your response.”

If the participant thinks the answers are obvious

“I understand that you may think that the answers are obvious. I have to ask every patient. It is really important that we record your response.”

If the participant refuses

“I understand that these questions may be a little sensitive. We are required to ask all patients. This information will be kept private and will only be used to improve the care we provide to everyone.”

If the participant still refuses

“That is okay. You have the right to not answer these questions.”

If the participant gets upset

“Let’s move on to the next question.”

OR

If appropriate: “I will call my manager.”

What are some other options that you could use in your work environment?

Don't Forget!

**The Golden Rule for Training Staff to
Collect Race and Ethnicity
Information:**

**You only have to collect it once,
if you collect it correctly.**

Best Practices



Help Us Know Our Patients Better

When we know your race and ethnicity, we learn more about your culture and language. This helps us to know you better and to improve the care that we give to all patients. Beginning in January 2007, we will ask for race and ethnicity information from all patients.

• What is Your Ethnicity?

Your ethnicity refers to your background, heritage, culture, ancestry or sometimes the country where you were born. Please let us know if you are Haitian, Vietnamese, Brazilian, etc.



• Are You Hispanic, Latino or Spanish?

You may be Hispanic, Latino or Spanish if you or your family come from a country in Latin America or another Spanish-speaking country. Please let us know if you think of yourself as Hispanic, Latino or Spanish.

• What is Your Race?

Your race is the group or groups that you identify with as having similar physical characteristics or similar social and geographic origins. Please let us know if you are Asian, Black, White, etc.

• Examples:

My name is John. My race is Asian and my ethnicity is Bangladeshi.
My name is Claudia. My race is Black and my ethnicity is Haitian and Jamaican.
My name is Rosendo. My race is White and Black and my ethnicity is Brazilian.
My name is Pat. My race is Black and my ethnicity is African American.
My name is Chris. My race is White and my ethnicity is Italian and American.



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

Our goal is to meet the needs of all of the patients that we serve. Studies have shown that there are differences in health among racial and ethnic groups. We don't know what causes these differences and we need to learn more about them. We can better meet the needs of the communities that we serve if we know more about our patients' race, ethnicity, culture and language. This information will only be used to make sure that all patients are receiving appropriate care of the best quality.



Improving the health of ALL



Signs about the data collection

Help Us Know Our Patients Better

Questions about the Collection of Patient Race and Ethnicity Information



Why are these questions being asked?

We are now collecting race and ethnicity information from all of our patients to help us learn more about them. We can better meet the needs of the communities that we serve if we know more about our patients, their cultures and their language. This information will only be used to make sure that all patients are receiving appropriate care of the best quality.

Why am I being asked these questions?

We are collecting this information from all patients. This will help us to see differences in health among different populations. We can reduce these differences by making sure that all patients receive the same quality of care.

Are these questions being asked at other hospitals?

There are state-wide regulations requiring all hospitals in Massachusetts to collect this information. We are collecting this information as part of a statewide effort to improve the health of all.



Cambridge Health Alliance
A COMMITMENT TO EXCELLENCE

How are my race and ethnicity related to my health?

Doctors have shown that there are differences in health among racial and ethnic groups. We don't know what causes these differences and we need to know more about them. We can work to eliminate these differences by making sure that all people receive the same quality of care.



How will this information be used?

We will use the race and ethnicity information that we collect from all patients to see if there are any differences in health among different groups of people. This will help us make sure that we give the same quality of care to all people. We will also use this information to understand the needs of the populations we serve and to make sure that people have care that is culturally appropriate.

Our goal is to provide the best care for all of the patients that we serve.

We can meet this goal by providing language services, offering patient information translated into different languages, and making sure that we can provide culturally appropriate care.

What if I don't want to share this information?

It is your decision if you want to share this information. This information is only being collected to help us know the patients that we serve better and it will not affect the care or services that you receive.



Improving the
health of **ALL**

Develop a Quality Assurance System

- **Observation**
- **Phone Recordings**
- **Data Validation**

Training Tool: Videos

Training Tool: Role Plays

Some Final Questions for the Audience:

- Do you think these guidelines will work well in your job setting?
- What will help you facilitate collecting these data?
- What might be a hindering factor in collecting these data?

Training Tool: Resources

- Role Plays
- Health Equity Library
- Critical Mass Toolkit
- MDPH Data Collection Tool
- Massachusetts Hospital Association Website:
<http://www.mhalink.org/public/news/2006/2006-11-09.cfm>
**Information specific to hospitals, but resources may be adapted to fit your organization's needs.

Your Feedback is Welcome



Sharing Materials

- The training materials have been developed in partnership with the Massachusetts Department of Public Health; the Center for Community Health Education, Research, and Service; the Institute for Community Health; and, the Department of Community Affairs and Multilingual Interpreting at the Cambridge Health Alliance.
- The information provided in the training materials is intended for non-commercial or educational use. It may be used without further permission from the developers provided that users 1) exercise due diligence in ensuring that the material is accurately reproduced and 2) identify the developers as the source of the materials.

Many Thanks!

For more information, please contact

Ryann Bresnahan

rbresnahan@challiance.org

617.499.6675