



Race and Ethnicity Data Collection

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Greater Northwest Healthcare Access Management Association

Agenda

- Purpose of this training
- Value of collecting race & ethnicity data
- State of the data
- Persistent problem areas
- Making it happen
- Additional resources
- Contacts

Purpose

- Understand key decision points in implementing standardized race and ethnicity (R/E) data collection within your organization
- To provide you with the knowledge and tools to train staff on the standardized collection of R/E data

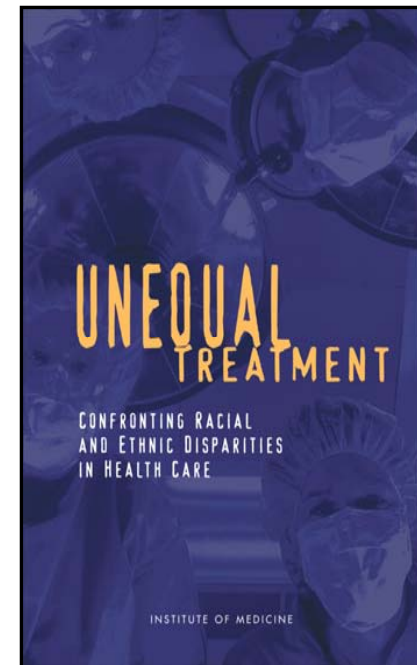
Goals

After this training session you should be able to:

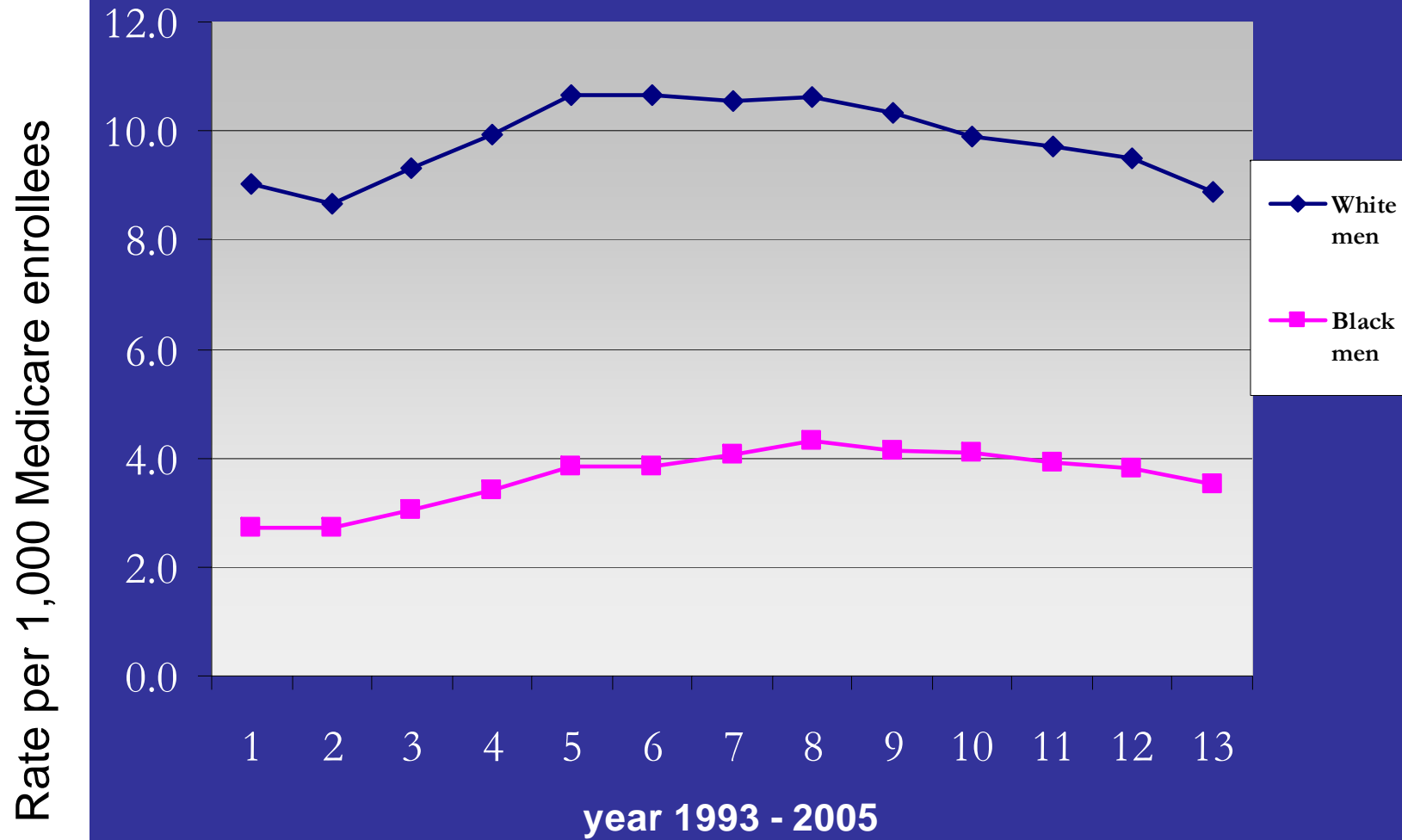
- Describe the reasons for standardizing the collection of patient R/E data
- Collect and report patient R/E data in a way that is consistent and directly comparable with data from other Oregon hospitals
- Use scripts to ask each patient to self-identify his or her R/E
- Address patient questions and concerns

What are disparities in health care quality?

- “Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities”
- Less likely to receive:
 - Cancer screening
 - Cardiovascular therapy
 - Kidney dialysis
 - Transplants
 - Curative surgery for lung cancer
 - Hip and knee replacement
 - Pain medicines in the ER



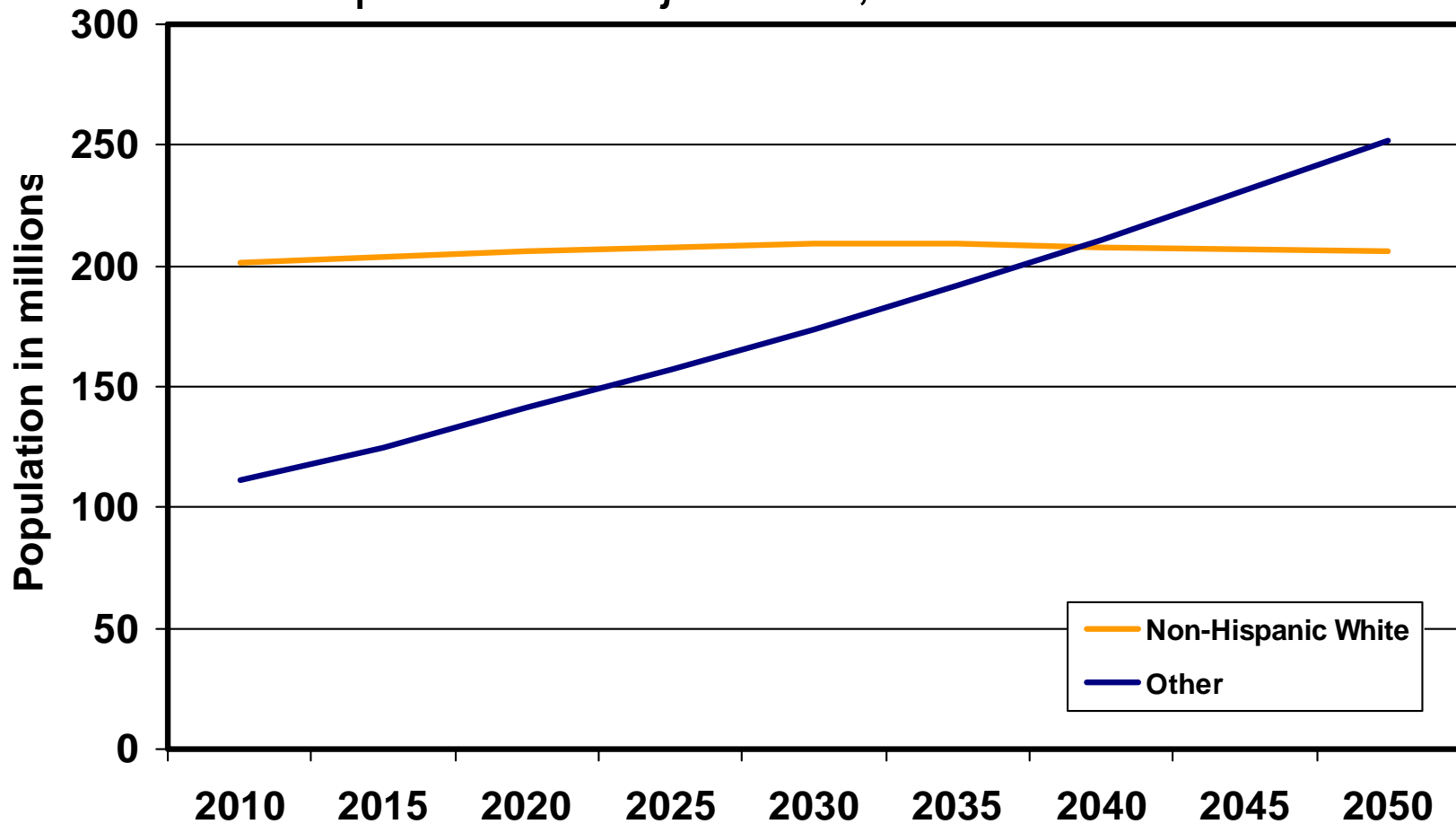
National CABG Rates



Source: Jha, NEJM, 2005

Growing U.S. Minority Population

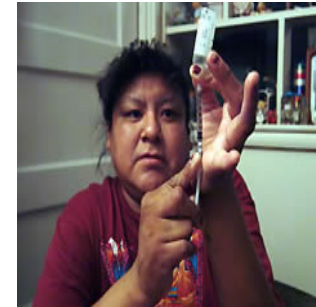
Population Projections, 2010 to 2050



Source: U.S. Census Bureau, 2009 National Population Projections (Supplemental) 4. Projections of the Population by Sex, Race, and Hispanic Origin for the United States: 2010 to 2050

Do disparities exist at your organization?

- We don't know until we look at the data
- We can't look at the data until we ask patients about their race and ethnicity



Why collect standardized R/E data?

- Evidence clearly shows disparities among quality of care exist across race and ethnicity.
- Linking patient race and ethnicity with clinical information allows us to examine any health care disparities.
- Once disparities are identified, we can develop resources to help providers and patients address disparities in their own communities.
- We can develop appropriate cultural competency training for staff.
- By collecting this information, we can ensure that all patients receive high-quality care.

Why collect standardized R/E data?

Increasing legislative and regulatory attention to R/E data:

- Health care reform
 - American Recovery and Reinvestment Act of 2009
 - Patient Protection and Affordable Care Act of 2010
- State mandate (Oregon)
 - Under Oregon Revised Statute 442.120 and detailed in Oregon Administrative Rule 409-022-0100 through 409-022-0080, the Office for Oregon Health Policy and Research (OHPR) requires that all hospitals and licensed free-standing Ambulatory Surgery Centers in Oregon collect patient race and ethnicity data.

Why collect standardized R/E data?

“....But we already collect this information!”

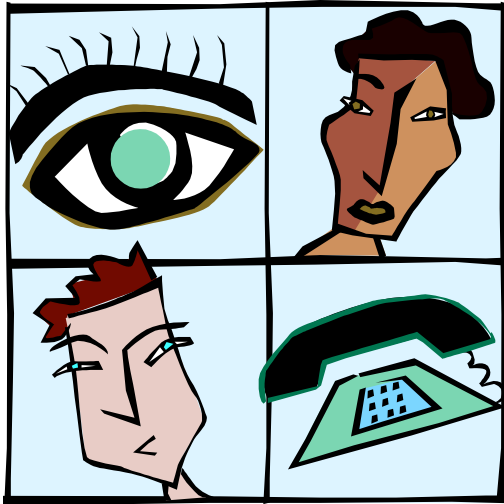
That may be true, but a review of the R/E data collected so far in Oregon hospitals and ASCs has shown:

- Organizations are not using the same set of definitions and guidelines for R/E data collection.
- Many registrars collect the information by observing the patient and guessing.
- In many organizations that currently collect R/E data, the data is of too poor quality for use.

Why collect standardized R/E data?

Only through quality, uniform data collection can effective strategies be developed and evaluated to improve the quality of care for all Oregonians.

What is standardized data collection?



- Standardized categories across organizations
- Patient self-reports race and ethnicity
 - No more “eyeballing” the patient
 - Data are collected from **all** patients
- Telling the patient why we are collecting his/her race and ethnicity

OHPR Race and Ethnicity Categories and Corresponding Code System

Race

1. American Indian/
Alaska Native
2. Asian
3. Black/African
American
4. Native Hawaiian
/Other Pacific
Islander
5. White
7. Patient Refused
8. Unknown
9. Other

Ethnicity

1. Hispanic/Latino
2. Non-Hispanic/
Latino
8. Patient Refused
9. Unknown

Challenging Assumptions – Race



Race Definitions

American Indian / Alaska Native: A person having origins in any of the original peoples of North and South America.

Asian: A person having origins in any peoples of the Far East, Southeast Asia, or the Indian Islands, Thailand and Vietnam.

Black or African American: A person having origins in any of the black racial groups of Africa.

Native Hawaiian/Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

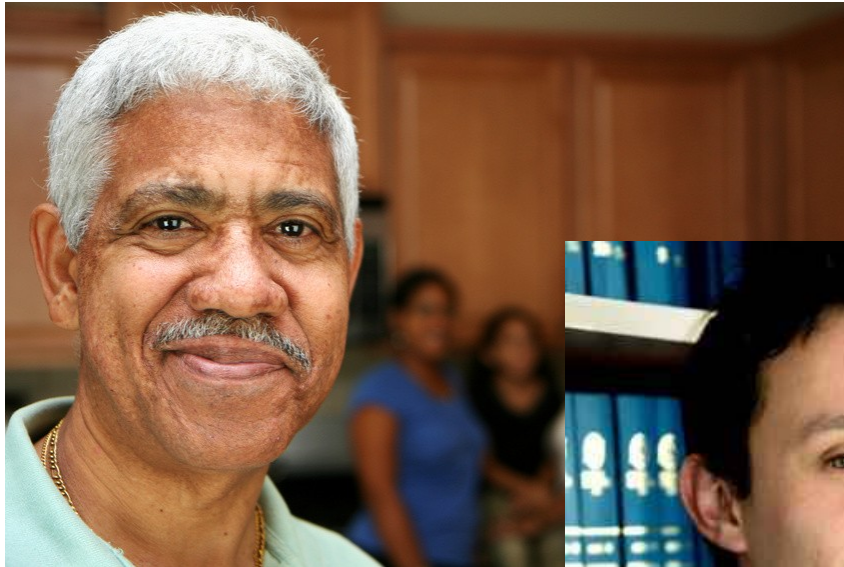
White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Patient Refused: The person did not want to respond to the question and should not be asked again during the same visit or during a subsequent visit.

Unknown: Data is missing or the patient or caregiver is unable to provide an answer. The patient may be asked again during the same visit or during a subsequent visit.

Other: Those who do not identify with a specific race category or respondents who identify with more than one race.

Challenging Assumptions – Ethnicity



Ethnicity Definitions

Hispanic / Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

Non-Hispanic or Latino: Person not of Hispanic or Latino ethnicity.

Patient Refused: The person did not want to respond to the question and should not be asked again during the same visit or during a subsequent visit.

Unknown: Data is missing or the patient or caregiver is unable to provide an answer. The patient may be asked again during the same visit or during a subsequent visit.

State of Data– Hospitals

Face Validity Assessment Criteria

A hospital's data was flagged as “suspicious” if any of the following were true:

AHRQ/HCUP

1. “Other” race is >30%
2. “Unknown” race is >50%
3. All discharges are “White,” “Other” or “Unknown”
4. All discharges are “White” and hospital has >50 beds

Additional

1. “American Indian” >30%

State of Data– Hospitals Face Validity Assessment

Time Period	Data Quality	
	Good	Suspicious
2008	62% 36/58	38% 22/58
2009	74% 43/58	26% 15/58
2010	76% 45/59	24% 14/59

The data appear to be improving!

State of Data - **Moving Forward**

- Improvement noted as systems have made adjustments for data collection and worked out initial “kinks”
- Remaining trouble spots need attention

Persistent Problem Areas

1. Miscoding: “White” and “American Indian”
2. Differentiating between “Patient Refused,” “Unknown” and “Other”
3. Hispanic ethnicity → race confusion
4. Recording data for patients who identify with more than one race

Persistent Problem Areas

1. Miscoding -“White” and “American Indian”

Code	Category
1	American Indian / Alaska Native —A person having origins in any of the original peoples of North and South America.
2	Asian—A person having origins in any peoples of the Far East, Southeast Asia, or the Indian Islands, Thailand and Vietnam.
3	Black / African American—A person having origins in any of the black racial groups of Africa.
4	Native Hawaiian / Other Pacific Islander—A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
5	White —A person having origins in any of the original peoples of Europe, the <u>Middle East</u> , or <u>North Africa</u> .
7	Patient Refused—The person did not want to respond to the question and should not be asked again during the same visit or during a subsequent visit.
8	Unknown—Data is missing or the patient or caregiver is unable to provide an answer. The patient may be asked again during the same visit or during a subsequent visit.
9	Other—This category provides a response for those who do not identify with a specific race category or respondents who identify with more than one race.

Persistent Problem Areas

2. “Patient Refused,” “Unknown” and “Other”

Patient Refused

- Patient did not want to respond to question
- Should not be asked again

Unknown

- Patient/caregiver unable to respond
- Data is missing
- Should ask again

Other

- Patient does not identify with a specific race category
- Patient identifies with more than one race

Persistent Problem Areas

3. Hispanic Ethnicity and Race

- People of Hispanic ethnicity may be of any race.
- Offer patients the opportunity to select from the race categories: White, Black or African American, American Indian or Alaska Native, etc.
- Hispanic respondents who do not relate to any of the race categories should be encouraged to select “Other,” just like any other person who does not relate to the race categories. *[Note: This differs from “refusing.”]*

Persistent Problem Areas

4. More Than One Race

- If your system can handle multiple responses to the race category, all the better!
- Per OMB guidelines, the method to report multiple races should take the form of multiple responses to the same question, not a “Multiracial” category.
- For reporting to OHPR, individuals of multiple races should be categorized as “Other.”

Making It Happen

1. Tell patients why you are asking

“I have two questions I’d like to ask you about your race and ethnic background. The information you share helps us understand our patient population to provide the highest quality of care for everyone.”

Wall Posters

Preguntamos porque nos importa.

Al preguntar sobre su raza, descendencia étnica e idioma, nosotros estamos mejor capacitados para proveer cuidado médico a todos los pacientes por igual.

¿Cuál es su raza?
¿Cuál es su descendencia étnica?
¿Cuál es su idioma preferido?



Respetando cada diferencia, tratando cada uno por igual.

Aligning Purposes for Quality | Improving Health & Health Care in Communities Across America

GET REAL
Race, Ethnicity, and Language

Hospital
Logo

Can be displayed in:

- Registration areas
- Waiting rooms

We Ask Because We Care.

By asking about your race, ethnicity and language, we are better able to deliver health care equally to all patients.

What is your race?
What is your ethnicity?
What is your preferred language?



Respecting every difference, treating each equally.

Aligning Purposes for Quality | Improving Health & Health Care in Communities Across America

GET REAL
Race, Ethnicity, and Language

Hospital
Logo

Making It Happen

2. Recommended script for patient's ethnicity

*“My first question is about your ethnic background.
Do you consider yourself Hispanic or Latino?”*

- Hispanic/Latino
- Non-Hispanic/Latino
- Patient Refused
- Unknown

Making It Happen

3. Recommended script for patient's race

*“My second question is about race.
Which category best describes your race?”*

- American Indian/Alaska Native
- Asian
- Black/African American
- Native Hawaiian/Other Pacific Islander
- White
- Patient Refused
- Unknown
- Other

Making It Happen

4. Encouraged but not mandated: patient's preferred language

“What language do you feel most comfortable speaking with your doctor or nurse?”

- English
- Spanish
- Other _____
- Declined
- Unavailable

“What language do you feel most comfortable reading medical or health care instructions?”

- English
- Spanish
- Other _____
- Declined
- Unavailable

Making It Happen

“I Speak” Poster Interpreter Services

You have the right to an interpreter at no cost to you. Please point to your language. An interpreter will be called. Please wait.

Albanian

Shqip

Kerit t's drejtën për përkthyes falas gjatë vizitës mjekësore. Ju lutem tregoni më gjuhën që flisni. Ju lutem pritni, do t'ju çojmë një përkthyes për vizitën mjekësore.

Amharic

አማርኛ

ያለገንጾ ወል አስተርጓሚ የግግንት ጭብት አለግት። የሚናገሩትን የሚረዱበትን ቋንቋ በመጠቀም ያመልክቱ። አስተርጓሚ እስኪጠሩ ድረስ እስኪያገኙ።

Arabic

عربي

بحق لك الحصول على خدمات ترجمة فورية دون أي مقابل. يُرجى منك أن تشير بإصبعك إلى لُغتك كي نستدعي المترجم المعني. يُرجى منك الانتظار لحين استدعاء المترجم.

Armenian

Հայերեն

Դուք անվճար քարոզչություն ստանալու իրազեակոց անստիճ արևի ցնորը: Հնչյունի ենք ձեր ասումը: Ձեր լեզուն է քարոզչությունը: Լսանա՞նք: Հնչյունի ենք սպասելը:

Bengali

বাংলা

আপনার অধিকার রয়েছে বিনামূল্যে একজন লোভাঙ্গী পাঠ্যকার। অনুগ্রহ করে আপনার ভাষা কেলটি আ দেখিয়ে দিন। একজন লোভাঙ্গীকে ডাকা হবে। অনুগ্রহ করে অপেক্ষা করুন।

Cape Verdean Creole

Criolu di Cabu Verdi

Nhós tem direito a um intérprete gratuito di nhós língua. Mostra qual qui nhós língua pa nó podi tchoma intérprete. Nhós aguarda um momento, por favor.

Chinese

Haitian Creole

Kreyòl Ayisyen

Ou gen dwa a yon entèprèt gratis. Tanpri montre nou lang pa w la. N ap rele yon entèprèt pou ou. Tanpri ret tann.

Hebrew

עברית

יש לך זכות להשתמש בשרותיו של מתורגמן ללא תשלום. אנא הצבע על השפה שלך. מיד ניצור קשר עם מתורגמן. אנא המתן.

Hindi

हिन्दी

आपके नि:शुल्क ट्रांसलेशन (संवादक) का अधिकार है। कृपया अपने भाषा की ओर इशारा करें। एक ट्रांसलेशन (अनुवादक) को बुलाना हमारा काम है। कृपया प्रतीक्षा करें।

Hmong

Hmoob

Koj muaj cai txais kev pab txhais lus dawb tsis them nryaj. Thov tau tes rau koj hom lus nov. Mam hu tus txhais lus. Thov nyob tos.

Italian

Italiano

Avete diritto ad un interprete. Il servizio è gratuito. Indicate la vostra lingua e attendete; un interprete sarà chiamato al più presto.

Japanese

日本語

通訳を無料でご利用になれます。該当する言語を指示して下さい。通訳を手配いたしますのでお待ち下さい。

Khmer

ខ្មែរ

Russian

Русский

Вы имеете право на услуги бесплатного переводчика. Назовите, пожалуйста, свой язык. Медицинский переводчик будет вызван. Пожалуйста, подождите.

Serbo-Croatian

Srpsko-Hrvatski jezik

Vi imate pravo na besplatnog prevodilaca. Molimo vas da pokazete na vas govorni jezik. Lagalan prevodilac ce biti pozvan. Hvala i molimo vas da sačekate.

Somali

Soomaali

Waxaad xaq u leedahay in tarjumaan lacag la'aan ah laguugu yeero. Fadlan farta ku riiq luqaddaada. Tarjumaan ayaa laguugu wacayaa. Ee fadlan sug!

Spanish

Español

Usted tiene derecho a un intérprete gratis. Por favor, señale su idioma y llamaremos a un intérprete. Por favor, espere.

Swahili

Swahili

Ni hakiki yako kuwa na mtafsiri bila malipo yoyote. Tafadhali chagua lugha yako kati ya hizi. Mtafsiri ataitwa. Tafadhali ngoja.

Tagalog

Tagalog

Kaw ay may karapatan na magkaroon ng tagapagsalin na walang bayad. Ituro ang iyong wika. Ang tagapagsalin ay tatawagin. Maghintay.

Thai

ไทย

Making It Happen

What do staff think?

“Patients will get angry if we ask these questions”

“It’s illegal to collect this information”

“I’m uncomfortable asking these questions”

“It will take too much time to ask these questions”

“We don’t need to collect this information, we already know who our patients are”

Making It Happen

What do patients think?

- Most patients (80%) think hospitals and clinics should be collecting data.
- Most patients (97%) also think it's important for hospitals and clinics to examine differences in quality.
- Some patients are concerned about how the data will be used.

Addressing Patient Concerns

Patient Response	Suggested Response	Code
"I'm American."	Would you like to use an additional term, or would you like me to just put American?	"Other"
"Can't you tell by looking at me?"	Well, usually I can. But sometimes I'm wrong, so we think it is better to let people tell us. I don't want to put in the wrong answer. I'm trained not to make any assumptions.	As specified
If using open-ended option: "I don't know. What are the responses?"	You can say White, Black or African American, Latino or Hispanic, Asian, American Indian or Alaska Native, Pacific Islander or Native Hawaiian, some other race, or any combination of these. You can also use more specific terms like Irish, Jamaican, Mexican.	As specified
"I was born in Nigeria, but I've really lived here all my life. What should I say?"	That is really up to you. You can use any term you like. It is fine to say that you are Nigerian.	As specified
"I'm part Asian and part White."	Great– and do you identify more strongly with one of those than the other?	The primary race specified, or "Other" if no primary race is indicated

Addressing Patient Concerns

Patient Response	Suggested Response	Code
"I'm human."	Is that your way of saying that you don't want to answer the question? If so, I can just say that you didn't want to answer.	"Patient Refused"
"It's none of your business."	I'll just put down that you didn't want to answer, which is fine.	"Patient Refused"
In response to the race question: "I already told you, I'm Hispanic. Why are you asking me again?"	In our system ethnic origin is considered to be a separate concept from race. A person may be of Hispanic ethnicity but still consider themselves to be White, or Black, or any other race. Is there a race you identify with?	As indicated or "Other" if no choice is given
Patient crossed out this question on the form.		"Patient Refused"
Patient left this part of the form blank.		"Unknown"
"Who looks at this?"	The only people who see this information are registration staff, administrators for the hospital, and the people involved in quality improvement.	
"Are you trying to find out if I'm a US citizen?"	No. Definitely not! Also, you should know that the confidentiality of what you say is protected by law, and we do not share this information with anyone.	

Key Points

We collect data on patient race and ethnicity in order to:

- Identify Disparities
- Target Interventions
- Improve Quality

Key Points, cont'd

Recommendations for standardization:

- Provide staff training
- Tell patients why you are asking
- Allow patients to self-identify
- Use the correct definitions for race and ethnicity categories
- Address patients' concerns

Additional Resources

- HRET Toolkit

www.hretdisparities.org

—*Why to collect the data*

—*How to collect the data (training materials)*

—*Additional tools and resources*

- Oregon Health Care Quality Corp

Stephanie Renfro: stephanie.renfro@q-corp.org

—*Granular race/ethnicity list for use in Oregon*

—*“We Ask Because We Care” posters for display in lobbies and exam rooms*



Oregon Contacts

- **Hospitals:**

Oregon Association of Hospitals and Health Services (OAHHS)

Diane Waldo, Director of Quality

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- **ASCs:**

Office for Oregon Health Policy and Research (OHPR)

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Next Steps

- Apply what you have learned today
- Continue to monitor your data
- Use your resources/ask for help as needed
- Future education will be offered as needed

Questions?