Collecting Patient Race and Ethnicity Data
A Voluntary Standard for Oregon

INTRODUCTION

The Institute of Medicine roused the health care world when its 2001 report on racial and ethnic disparities in health care stated that the "U.S. health care delivery system does not provide consistent, high-quality medical care to all people."[i] Numerous studies in the following years have supported that conclusion by identifying concrete differences in health processes and outcomes among racial and ethnic groups in the U.S.[ii]

Local examples of health care disparities have been demonstrated in Oregon. Birth and death certificate records for 2003–2007 show the teen birth rate for non-white Hispanics in Multnomah County to be nearly seven times the birth rate for white teens, and diabetes deaths among African Americans greatly outnumber diabetes deaths among the other racial and ethnic groups.[iii] Unfortunately, few data sources exist that link race and ethnicity to a patient's health information. This lack of information reduces the opportunity to identify and work to reduce further disparities in health care.

> " *All Oregonians deserve the same opportunities to achieve optimal health – but all Oregonians do not enjoy equal access to the factors that make us healthy. This is not only inherently unfair, but our whole community suffers as a result. Data offers one way to better understand and track our efforts to improve this issue here in Oregon. Providers can help by collecting patient race and ethnicity information accurately, respectfully, and consistently. Adopting the Oregon Voluntary Standard is a great way to get started.* "
>
> – Tricia Tillman, MPH, Administrator
> Oregon Office of Multicultural Health and Services

PURPOSE OF THIS REPORT

The Oregon Governor's 2000 Racial and Ethnic Health Task Force declared that race and ethnicity data collection is deficient in Oregon, and State-mandated data collection by Oregon hospitals and ambulatory surgery centers (ASCs) began eight years later (2008). Although the Task Force turned attention toward this important and often overlooked issue and progress has been made in some areas, there is much work yet to be done.

Collecting race and ethnicity data in ambulatory care settings is the next logical step. The Oregon Health Care Quality Corporation (Quality Corp) offers this report to establish a standardized data collection methodology to ensure data is directly comparable and can be aggregated for region-wide analysis. This report also provides a list of race and ethnicity categories appropriate for use in Oregon for organizations with the interest and ability to collect data at a more granular level. As part of this work, Quality Corp launched an extensive community outreach effort to ensure that Oregon's communities of color had a role in influencing the Oregon granular list and shaping the way this data is collected.

This report includes the following:

- Case for collecting patient race and ethnicity data
- Voluntary standard for Oregon
- Granular race/ethnicity list appropriate for Oregon
- Clarification of OHPR data standards
- Voices from the community
- Additional resources

CASE FOR COLLECTING PATIENT RACE AND ETHNICITY DATA

There are many reasons to collect information on a patient's race and ethnicity, including:

- To reduce ethnic and racial disparities in health care by identifying where disparities exist and gaining an understanding about the health and cultural needs of different populations
- To assist with the appropriate allocation of resources in order to address and improve health outcomes by targeting resources where they are needed
- To make health care more efficient by adjusting physician panels for interpreters and other needs based on the racial/ethnic breakdown of patient populations
- To enable providers to deliver culturally sensitive care by helping with staff education about the cultural differences between health care providers and members of the community
- To inform policy decisions for health organizations and the State by providing the data that is necessary for establishing best practices and analyzing health and social indicators

Even when health systems are not sure how best to use the data, it is worth collecting because it raises awareness and creates a more complete picture of a given organization's patient population. When collected, organizations are more likely to find a way to use the data.[iv]

OREGON VOLUNTARY STANDARD

Currently, Oregon hospitals and ASCs are required by the Oregon Office for Health Policy and Research (OHPR) to collect patient race and ethnicity data and to report it using standardized categories.[1] Collecting race and ethnicity data in ambulatory care settings (especially those with electronic health records) is essential to allow for the broader identification of ethnic and racial disparities in health care across care settings.

Quality Corp's proposed Oregon Voluntary Standard consists of two parts:

1. Ambulatory care settings should join their hospital and ASC counterparts by engaging in the collection of patient race and ethnicity information using OHPR's reporting categories at a minimum;

2. Organizations with the interest and ability to collect data at a more granular level should adopt the community-developed granular race and ethnicity list for Oregon (Tables 1 and 2) so data can be compared and aggregated across sites (this detailed list rolls up into the OHPR reporting categories).

Process for Making Decisions about Collecting Race and Ethnicity Data

To facilitate the achievement of the Oregon Health Fund Board's vision, in March 2009 the Oregon Safety Net Advisory Council, OHPR, Oregon Association of Hospitals and Health Systems (OAHHS) and Quality Corp convened a meeting to develop a voluntary state standard for collecting race, ethnicity and primary language data. Participants included consumer groups, health plans, providers and state agency representatives. The participants agreed on the following goal statement:

> *Collecting patient information about race, ethnicity and language through self-report from the patient by a well-trained staff in a practical, standardized, valid, reliable and culturally appropriate and sensitive format is critical to eliminate disparities and achieve high quality health care for all.*

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[1] For more information, see "Required Race and Ethnicity Categories and Definitions" on page 5.

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Participants discussed how to implement this goal. Due to time limitations and the complexity of the issue, participants focused on race and ethnicity data collection, leaving language data collection for future discussions. They noted that collecting data using a granular race and ethnicity list that rolls up to OHPR's reporting categories is preferable. Collecting detailed data increases the opportunity for consistency and accuracy and fosters dialogue. However, it is also important that organizations be capable of aggregating granular data into the OHPR categories to facilitate community-wide data aggregation and national comparison, and complete state and/or federal regulation reporting requirements.

There is no single set of nationally recommended granular data for this purpose, as locally relevant populations vary by region. Quality Corp drafted a granular list for race and ethnicity that comprises the OHPR reporting categories. The draft standard needed further review and input from community organizations, health plans and providers. Quality Corp hired a consultant specializing in minority advocacy to seek input on the draft voluntary standard from key racial, ethnic and cultural minority groups and individuals. Through this outreach process, these groups reached consensus on what the voluntary statewide standard categories should be for their constituency and recommended a methodology for collecting race and ethnicity data in Oregon.

OREGON GRANULAR LIST AND ROLL-UPS TO OHPR REPORTING CATEGORIES

Tables 1 and 2 below demonstrate the granular list for race and ethnicity developed through input received from the community. For information on additional recommendations received pertaining to data collection standards, see "Voices from the Community" in the attached Appendix.

Table 1: Oregon Community-Developed Granular Ethnicity List + OHPR Mappings

OMB + Additional Categories

	1	2	8	9
	Hispanic/ Latino	**Non Hispanic/Latino**	**Patient Refused**	**Unknown**
Cuban				
Guatemalan				
Honduran				
Kanjobal				
Mexican, Mexican-American or Chicano/a				
Mixtec				
Puerto Rican				
Purepecha				
Salvadoran				
Triqui				
Zapotec				
Other				

(Detailed List)

Table 2: Oregon Community-Developed Granular Race List + OHPR Mappings

OMB + Additional Categories

	1		2	3		4	5			7	8	9
	American Indian/Alaska Native		Asian	Black/African American		Native Hawaiian/Other Pacific Islander	White (includes Middle Eastern and North African)			Patient Refused	Unknown	Other
	American Indian	Alaska Native	Asian	Black	African	Pacific Islander	White/ Eastern European	Middle Eastern / North African	White/ Western European			
Detailed List	Burns Paiute Tribe	List Tribe(s) below	Asian Indian	African American	Central African Republic	Fijian	Belorussian	Afghanistani	English			
	Confederated Tribes of Coos, Lower Umpqua & Siuslaw Indians		Burmese	Cuban	Brundi	Guamanian or Chamorro	Bosnian	Algerian	French			
	Confederated Tribe of the Grand Ronde		Burmese-Karen	Haitian	Congolese	Native Hawaiian	Croatian	Armenian	German			
	Confederated Tribes of the Siletz Indians		Cambodian	Other Country	Ethiopian	Samoan	Czech	Egyptian	Irish			
	Confederated Tribes of the Umatilla		Chinese		Nigerian	Other Country	Georgian	Iranian	Italian			
	Confederated Tribes of the Warm Springs		Filipino		Somalian		Kosovar	Iraqi	Scottish			
	Coquille Indian Tribe		Hmong		Somalian-Bantu		Moldovan	Israeli	Other Country			
	Cow Creek Band of Umpqua Indians		Japanese		Sudanese		Polish	Jordanian				
	Cowlitz		Korean		Other Country		Romanian	Kurdish				
	Smith River		Laotian				Russian	Kuwaiti				
	Other Tribes		Mien				Ukrainian	Lebanese				
			Pakistani				Other Country	Libyan				
			Thai					Palestinian				
			Tibetan					Saudi Arabian				
			Vietnamese					Syrian				
			Other Country					Tunisian				
								Other Country				

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DATA COLLECTION STANDARDS FOR OHPR REPORTING

OHPR requires all Oregon hospitals and free-standing ASCs to collect and report data on patient race and ethnicity. A review of the first three years of data (2008 through 2010) shows a clear trend of improvement over time and reveals areas where data standards need further clarification.

In particular, confusion appears to exist in the following areas:

- Differentiating between *Unknown*, *Patient Refused* and *Other*
- The method for recording data on patients who identify as Hispanic for the ethnicity question but do not identify with any of the race categories
- The method for rolling granular race and ethnicity categories into OHPR's required reporting categories
- The method for recording data on patients that identify with more than one race

Quality Corp partnered with OHPR and OAHHS to set a clear standard for data collection so that all organizations may collect race and ethnicity data in a consistent, well-defined format. Such standardization is crucial to the accurate identification and analysis of health care disparities in Oregon.

Difference between Race and Ethnicity

The terms *race* and *ethnicity* are often used interchangeably. In fact, race and ethnicity represent different components of a person's background. Race can be best understood as the sharing of certain physical characteristics, while ethnicity refers to a shared culture and way of life. A person's ethnicity may reflect language, religion and cultural background.

A useful anecdote for remembering this distinction is to consider that an infant born in China and adopted by Cuban parents would likely identify as Asian for race and Hispanic for ethnicity.

Required Race and Ethnicity Categories and Definitions

OHPR uses the national Office of Management and Budget (OMB) categories as a foundation for the collection of race and ethnicity data. The OMB categories are supplemented with additional categories to permit greater flexibility in responses and to foster a more comfortable and accurate setting for data collection in Oregon. Such enhancements are fundamental to the subsequent data quality.[v] OHPR's required race and ethnicity categories are defined as follows:

Ethnicity

OHPR Code	Category
1	*Hispanic / Latino*—A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.
2	*Non Hispanic / Latino*—A person not of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin.
8	*Patient Refused*—This category is an indication that 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.
9	*Unknown*—This category should be used when data is missing or when 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.

Race

OHPR 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 Middle East, or North Africa.
7	*Patient Refused*—This category is an indication that 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*—This category should be used when data is missing or when 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.

Question Format and Order

Intake staff should not attempt to guess the patient's race and ethnicity. Studies have shown substantial differences between results based on intake staff guesses versus patient responses.[vi] Posing the questions to patients and allowing them to self-identify is the preferred method for collecting this information. The list of available responses may be shared with the patient upon request. Per OMB guidelines, this information should be solicited in the form of two questions, with the ethnicity question being posed first.

Missing Data

If a patient does not provide a response for either the race or ethnicity question (leaves the question blank), and staff is unable to elicit a response from the patient, the response should be categorized as *Unknown*.

Differentiating Between *Unknown*, *Patient Refused* and *Other* Categories

The *Unknown* category should be reserved for data that is truly missing. If a patient is unconscious when they arrive or if a patient leaves this response blank on a form and a response cannot be solicited, the response should be categorized as *Unknown*.

The *Patient Refused* category should be used only when a patient is explicitly unwilling to respond to the question. If a patient is amenable to the question but does not relate to any of the categories offered, this does not constitute refusal.

The *Other* category is an available response to the race question and provides an option for patients who either do not identify with any of the five available OMB race categories, or who identify with multiple categories. For more information on this response option, see "Race and Hispanic Ethnicity" and "Recording and Reporting Data on Multiple Races" below.

Race and Hispanic Ethnicity

People of Hispanic ethnic origin may be of any race and should be offered the opportunity to select from race categories including *White*, *Black* or *African American*, *American Indian or Alaska Native*, *Asian*, etc. Hispanic respondents who do not relate to any of the race categories should be encouraged to select *Other*.

Recording and Reporting Data on Multiple Races

Whenever possible, organizations should make it possible to record multiple responses for the race question. Per OMB guidelines, the method for respondents to report more than one race should take the form of multiple responses to a single question and not a *Multiracial* category. Two recommended forms for instruction accompanying the multiple response question are "Mark one or more…" and "Select one or more…"

When data are rolled up to the OHPR categories for reporting, individuals with multiple races recorded should be categorized in the *Other* category. Similarly, if a system does not allow the user to specify more than one race, and the patient does not indicate a primary race, *Other* should be recorded.

VOICES FROM THE COMMUNITY

Individual meetings with 11 leaders from the Hispanic/Latino, Asian Pacific Islander, African, African American, Russian and Native American communities sought input and reactions to collecting this data. Conversations focused on why health care organizations will be collecting data and its potential uses. Community leaders were asked about strategies to help patients feel comfortable responding to data collection questions and ways that health care organizations could implement workflow changes and policies to successfully address the diversity of patients being served. These meetings with community leaders assisted with developing relationships, opened communications and helped address barriers in their communities regarding health education and awareness.

Recommendations for Data Collection Methodology and Tools

Below are recommendations from the community for promoting accurate data collection:

- Allow the patient to self-identify. Do not have the health care office determine a patient's race and ethnicity by observation.

- Collect data as part of basic intake (registration). Avoid asking for race and ethnicity data after a patient is in the exam room unless it is presented in a way that ties into their medical needs. Ask for information when the medical assistant is taking vitals.

- Have someone at the clinical level (not administration or billing) collect race and ethnicity data during the registration process. Patients may not trust the front office staff because this is also the level that handles payments and financial issues. There is more trust at the care level.

- Explain that answers to the questions will not affect a patient's care. Offer the option not to answer.

- Develop a script and train staff. Find a community partner to assist with vetting the script and process. Statements such as "We are asking you this question so we can provide you with the best care for you; it won't be shared with the government" or "We are starting to collect this information from all patients, would you be willing to provide this information in private?" can be helpful.

- Make the granular list available in other languages.

- Use a form, but also allow patient to provide information in person.

- Use open-ended questions.

- Do not inquire about immigration status. Ask only about relevant information.

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- Strengthen the patient-provider relationship by asking if there are any customs, traditions and beliefs the patient wants to share. Respect what is shared.

- Vet communication messages with appropriate community contacts. Provide incentives for community organizations to assist with designing communication messaging (i.e., postcards and/or training to message information to community).

- Focus on collecting language with race and ethnicity information to remove language barriers.

- Focus on workforce diversity so that staff understand and reflect the patient population.

- Have more than one approach for collecting data.

Commentary on Oregon's Granular List

Community leaders articulated their views and suggestions on the standard categories and recommended a methodology for collection of race and ethnicity data in Oregon. While the questions asked by the interviewer focused specifically on collecting race and ethnicity data, participants also provided rich information about why it is important to recognize different ethnic groups within a race category and the specific needs of each population. Their comments provide insight about the host of health implications for dealing with minority populations and underscore the need to collect detailed race and ethnicity data in order to provide culturally sensitive care. Much research has been done on providing culturally competent care, but was not within the scope of this project.

The information below comes from conversations with minority communities in response to these questions:

1. Is the list satisfactory for an initial start to collecting race and ethnicity information for your community?
2. Does it reflect the race and ethnic demographics for Oregon?
3. What are your concerns with the list?

African

- Because language and ethnicity define the African community, language should be captured at the same time as race and ethnicity. Asking the African community to list "other" as an option for race/ethnicity would be confusing.

- The category should ask for "Country of Origin" and should allow for patients to list additional ethnic information. Learning an African's ethnicity is important; for example, Africans who migrated from the Middle East would not identify themselves as Middle Easterners.

- The African community will not feel comfortable providing race and ethnicity information – they would need some culturally appropriate community outreach and education. They would also feel more comfortable if the health care organization had diverse front desk staff.

- In the African community, knowing ethnicity is more important than race. It is also important for a provider to know if a patient is an immigrant or refugee.

Asian

- Language is a big barrier to receiving quality care for the Asian community. It is also important to address the need to collect data that reflects the different languages in the Asian community.

- Knowing a patient is Asian may not provide enough information that would successfully describe an accurate problem list (for example, hepatitis is an issue with Cambodians, so it's good to know if the patient is from Cambodia to possibly test for hepatitis based on any symptoms present).

- It is not enough to have a category called Asian; it is important to know what area of Asia a patient is from (i.e., North Central, Southwest, South, East and Southeast). This is important to know because of specific health indicators that providers should be aware of based on a patient's race and ethnicity. It is also important to know if a patient is a refugee or immigrant.

- The issue with the Asian community is getting them into the doctor's office – most will not seek health care until it is an acute care status. Refugees have issues with trusting the health care system because some of them come from a system where the government is corrupt, resulting in some concern about how the data will be used.

- The Asian community is a very private culture. Education and income level may not play a part in their decision to seek medical care. Data should be collected in the exam room by a clinician (RN, MA); the physician should not be the person asking for the information. A script should be developed to assist staff with knowing how to ask for the information.

American Indian & Alaska Native

- All of Oregon's Tribes should be listed because this is their homeland. However, this only represents about 10 percent of the American Indian population in Oregon. Because there are 565 American tribes and 338 Alaska tribes, patients should be allowed to list their own tribe(s).

- Because there are so many tribes and patients may belong to multiple tribes, it is best to allow people to self identify their tribe(s). They will normally list more than one. A lot of Native Americans and Native Alaskans belong to more than one tribe and it is disrespectful to not allow them to identify all the tribes that they are part of. It is recommended that sub-categories of tribes should be listed.

- Ninety percent of American Indians and Alaska Natives are not identified as such by health providers; they are often mistaken for Hispanic, Asian, Caucasian or something else. This is why it is important to allow people to self identify.

- Cowlitz and Smith River could be added to the list to capture tribes on the California and Washington borders. Rather than rolling the data up into OMB categories, it would be helpful to the tribes if health care systems could capture specific tribal information.

- American Indians may want to provide information in person or talk with staff prior to providing change information. Health care providers should also be aware of American Indian traditions. If an American Indian is in the hospital, lots of friends and family may visit. Cultural practices may include a healer to come sing and pray; this may be disruptive to other patients, care processes and workflows.

Black

- There should be a biracial category that allows patients to list two races.

- The granular list is appropriate for the Black community; however, trust is an issue with the African American community and health care providers. Creating an environment where patients feel comfortable providing this information is very important. Patients may not feel confident they will receive

the same level of care as Whites if they provide this information. Patients need to be educated as to why the information is being requested and what is going to happen to the information.

- It is important that African Americans feel they have a relationship with their provider prior to providing information regarding race. They do not trust that they will get the same quality of care as others when this information is provided; staff diversity makes African Americans feel more comfortable.

Hispanic/Latino

- Language is a large barrier for the Hispanic community in receiving quality care; it is important to have interpreters to be able to communicate medical information for patients.

- It may be important to know if a patient is from North America, Central American or South America, as there are some cultural differences.

- The Hispanic community would feel comfortable providing race and ethnicity information as long as questions do not focus on immigration status or U.S. residency.

- The community has to trust the person or organization that is providing and requesting the information. Patients will not ask why the information is being requested. They will just be leery and may not return to a provider's office – the Hispanic community is not the best at self-advocacy.

White/Eastern European

- Eastern European and Middle Eastern will not really identify themselves as white. New immigrants do not identify with race but would understand ethnicity.

- The patient-provider relationship is important. There are many cultural rituals that providers should have knowledge of that may assist in accurate diagnoses.

ADDITIONAL RESOURCES

HRET Toolkit

For more information and training materials for systematically collecting patient race, ethnicity and primary language data, consult the *Health Research and Educational Trust Disparities Toolkit*. You can view or download a copy of the web-based toolkit at www.hretdisparities.org.

Office for Oregon Health Research and Policy (OHPR)

For questions about reporting race and ethnicity data to OHPR, contact Elyssa Tran, Health System Research & Data Manager: elyssa.tran@state.or.us

Oregon Association of Hospitals and Health Services (OAHHS)

Hospitals that need special assistance may contact Diane Waldo, Director of Quality: diane.waldo@oahhs.org

Oregon Health Care Quality Corporation (Quality Corp)

Quality Corp is very interested in receiving feedback from organizations about this report. We are also interested in knowing what other organizations are doing to collect race and ethnicity data, and how Quality Corp can help. Learning from the experiences of other organizations will add to the body of knowledge and guide future work. Please contact Stephanie Renfro, Health Information Specialist: stephanie.renfro@q-corp.org

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[i] Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century*, March 2001.

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[iii] Multnomah County Health Department, *Report Card on Racial and Ethnic Health Disparities*, April 2011.

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[v] IOM (Institute of Medicine). *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, 2009. Washington, DC: The National Academies Press.

[vi] Robert Wood Johnson Foundation, *Collecting Data on Patient Race, Ethnicity and Primary Language is Helping Hospitals Improve the Quality of Care*, September 2007.