Community Leaders Role in Educating Community Members about Sharing Information for Better Health
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Introduction and Overview

The Patient Protection and Affordable Care Act (PPACA), commonly called the Affordable Care Act (ACA) or “Obamacare” is requiring better collection of information on race and ethnicity. This will help healthcare providers to identify disparities in health and healthcare, to create greater accountability for reducing these disparities and ensure that all patients get the best care possible.

To provide better health services and improve health outcomes, some basic information is needed from patients; such as address, age, gender, race and ethnicity. Improved collection of this information will allow hospitals and facilities to develop an understanding of the patients and communities they serve and to identify and address any differences in health outcomes they may face.

Often, cultural, linguistic, communication, immigration-related, socio-economic and institutional factors serve as barriers for both providers and consumers regarding the collection of essential race and ethnicity data necessary for the provision of the highest quality of care.

Community leaders and organizations can help reduce barriers to collecting race and ethnicity data by improving their understanding of barriers that impact collection of data, having discussions with community members about why these data are being collected, why it is important for hospitals to collect this information and what community members can expect when they go to the hospital.

The goal of this section is to provide community leaders with the tools and information needed to familiarize themselves with the communities they serve and inform their clientele about the new expanded information required of all patients accessing care in hospitals across NYS; including why it is important, what patients can expect and how the information is to be used.
Key Terms

Health Disparities

Health disparities are differences in health among groups of people. These differences can include: how frequently a disease affects a group; how many people get sick; or how often the disease causes death.

Some people experience poor health due to life circumstances, discrimination or exclusion. Among them:

- Certain Racial and Ethnic Populations
- Rural Residents
- Women, Children and Senior Citizens
- People with Disabilities
- Lower Socioeconomic Classes (low-income/poor)
- People of Various Religious Groups
- Lesbian, Gay, Bisexual and Transgender Individuals; and
- Individuals and Families Experiencing Mental Illness

Health Equity

Health Equity is achieved when every person has the opportunity to "attain his or her full health potential" and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances."

Social Determinants of Health

Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics.

Self-Identification

Self-identification is when an individual provides information about how they personally see themselves.
Data Collection in Hospitals across NYS

Collecting Race and Ethnicity to Fix Health Disparity

In order to improve the quality of healthcare services, information is needed to identify any differences in health and health care among different populations and to provide better services. This helps to identify and address each patient’s needs and ensure that all patients get the best care possible.

Race and Ethnicity Impact on Health

Although we share similarities, our racial and ethnic backgrounds may place us at differing risks for some diseases. We can work to reduce these risks by ensuring that everyone gets appropriate and high quality health care.

The Affordable Care Act (Obamacare) and Health Disparity

Patient Protection and Affordable Care Act (PPACA), commonly called the Affordable Care Act (ACA) or Obamacare is requiring better collection of information on Race and Ethnicity. This helps healthcare providers to know their patients better, and get a better idea of health risks to better meet their health needs.

The Way the Information will be Collected

Starting January of 2014, all NYS hospitals and ambulatory surgery centers are required to collect more detailed race and ethnicity information from each patient. Hospital staff will ask patients to self-identify their race(s) and ethnicity (ies) either verbally or by having the patient fill out a form. This may happen at registration or admission depending upon the hospital system.

*Self-identification is when an individual provides information about how they personally see them self in regards to demographic information such as: gender, race and ethnicity.
Guidance for Community Leaders

The Role of the Community Leader

Community leaders and organizations can help reduce barriers to collecting race and ethnicity data by having discussions with community members about why this data is being collected, why it is important for hospitals to collect this information and what to community members can expect when they go to the hospital.

Tools for Educating Communities

In the tools/resources section of this document you will find answers to frequently asked questions about the collection of race and ethnicity data in NYS hospitals, example of patient demographics form and other resources for educating your community.

You can also visit [http://improvepatientdatanys.org/](http://improvepatientdatanys.org/) to view training resources and archived webinars for hospital staff.
Community Leaders

Tools/Resources Section
Frequently Asked Questions for Community Leaders on Data Collection in Hospitals across New York State

When will this requirement go into effect?
As of January 1 2014, in efforts to meet the federal standards of the Patient Protection and Affordable Care Act (PPACA), commonly called the Affordable Care Act (ACA), NYS is requiring all NYS hospitals and ambulatory surgery centers to collect expanded race and ethnicity data from each patient.

Why are these questions being asked?
To provide better health services and outcomes, hospitals need some basic information from patients; this includes address, age, gender, race and ethnicity. Improved/expanded collection of this information will allow hospitals and facilities to gain a better understanding of the patients and communities they serve and provide tailored health services to meet the individual needs of patients. This approach will help to address the differences in health outcomes they may face and ultimately improve health outcomes.

Why am I being asked about my race and ethnicity?
Culture, language, socio-economic status, age, gender, race and ethnicity influence how an individual receives and/or utilizes healthcare. Providers’ knowledge of these identifiers will allow them to better close healthcare gaps and inform programs and policies to improve the health of all New Yorkers.

What does race and ethnicity have to do with health?
Although every individual shares similarities, our racial and ethnic backgrounds may place us at differing risks for some diseases. We can work to reduce these risks by ensuring that everyone gets appropriately tailored and high quality health care.

Is this legal?
Yes, collection of this information is a requirement of Section 4302 of the Affordable Care Act. The law requires that once these data collection standards are established; they be used to enhance the ability of the public health and healthcare systems to identify and track disparities in health and health care, and to create greater accountability for reducing these disparities.

What will the information be used for?
The information will be used to identify any differences in health and health care among different populations and to provide better services.
Frequently Asked Questions for Community Leaders on Data Collection in Hospitals across New York State

Who will see this information?

This information will be kept private and confidential and is protected by law. The only people who will see this information are members of the health care team and others who are authorized to see the medical record.

What if a person has a concern about their immigration status when being asked about race and ethnicity?

The race and ethnicity questions are not being asked to identify or determine immigration status; responses to the questions will not be reported to the authorities.

How will the hospitals collect this information?

Hospital staff will ask patients to self-identify either verbally or by having the patient fill out a form. This may happen at registration or admission depending upon the hospital system.

*Self-identification is when an individual provides information about how they personally see them self in regards to demographic information such as: gender, race and ethnicity.

What can I do as a Community Leader to help?

Community leaders and organizations can help reduce barriers to collecting race and ethnicity data by having discussions with community members about why these data are being collected, why it is important for hospitals to collect this information and what to community members can expect when they go to the hospital.
Frequently Asked Questions by Patients

Q: What do my race and ethnicity have to do with my health?
A: Although all people share similarities, our racial and ethnic backgrounds may place us at differing risks for some diseases. We can work to reduce these risks by making sure that everyone gets appropriate and high quality health care.

Q: Why am I being asked these questions?
A: To provide better health services and outcomes, hospitals need some basic information from patients; this includes address, age, gender, race and ethnicity. Improved collection of this information will allow hospitals and facilities to gain a better understanding of the patients and communities they serve and address the differences in health outcomes they may face.

Q: Why am I being asked my race and ethnicity?
A: Improving the quality and completeness of race and ethnicity data helps to better identify healthcare gaps and inform programs and policies to improve the health of all New Yorkers.

Q: What will my information be used for?
A: Information you give us will help us improve the health services and programs provided to our patients.

Q: Who will see my information?
A: Your information is kept private and confidential and is protected by law. The only people who will see your information are members of your care team and others who are authorized to see your medical record.

Q: Who are you collecting this information from?
A: We are collecting this information from all our patients.

Q: What if I don’t want to answer these questions?
A: It is perfectly alright if you do not want to answer some or all of the questions. However, this information does help our hospital provide better care. Regardless of whether you answer these questions, we will provide you care.

Q: What if I identify with more than one race?
A: You can check off all the races to which you identify.

Q: What if I identify with more than one ethnicity?
A: You can check off all ethnicities to which you identify.

Q: Who can I ask questions about this?
A: The hospital registration staff and their supervisors are happy to answer any questions that you may have about why you are being asked about your race and ethnicity.

Q: What if I don’t know my race or ethnicity?
A: If you don’t know your race or ethnicity, you can leave these questions blank.
Example Patient Race and Ethnicity Questionnaire

“We want to make sure that we identify and address each patient’s needs and ensure that all patients get the best care possible. We’re going to ask you some questions so that we can provide our patients with appropriate and high quality care.

We will keep this information confidential and will update it in your medical record. The information you share will not be used to identify or determine your immigration status, and will not be reported to the authorities. You may choose not to answer any question(s).

You have been provided a list of Frequently Asked Questions and Definitions to help answer questions that you may have about this form, but our registration staff members are also happy to answer your questions.

1. Ethnicity

Are you Hispanic, Latino/a, or Spanish origin? (One or more categories may be selected)

- Mexican
- Mexican American
- Chicano/a
- Puerto Rican
- Cuban
- Unknown

- Another Hispanic, Latino/a, or Spanish Origin (Please Choose from the list in Table One)

- Not of Hispanic, Latino/a, or Spanish origin

2. Race

What is your race? (One or more categories may be selected)

- American Indian or Alaska Native
- Black or African American
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian (Please Choose From the List In Table Two)

- Samoan
- Other Pacific Islander (Please Choose from the List In Table Three)

- White
- Other Race
- Native Hawaiian
- Guamanian or Chamorro
### Other Ethnicity Table

#### Table One: Other Hispanic, Latino/a, or Spanish Origin

<table>
<thead>
<tr>
<th>Spanish</th>
<th>La Raza</th>
<th>South American</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Argentinean</td>
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<td>Andalusian</td>
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<tr>
<td>Spanish Basque</td>
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### Other Race Tables

#### Table Two: Other Asian

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<td>Indonesian</td>
<td>Nepalese</td>
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<td>Loation</td>
<td>Singaporean</td>
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<td>Malaysian</td>
<td>Madagascar</td>
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</table>

#### Table Three: Other Pacific Islander

<table>
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<tr>
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<td>Tongan</td>
<td>Saipanese</td>
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<td>Tokelauan</td>
<td>Palauan</td>
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<td>Guamanian</td>
<td>Carolinian</td>
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<td>Kosraean</td>
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<td>Solomon Islander</td>
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<td></td>
<td>New Hebrides</td>
</tr>
<tr>
<td></td>
<td>Other Pacific Islander</td>
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</tbody>
</table>
Definitions of Race and Ethnicity

**Ethnicity**

**Hispanic or Latino:** refers to a person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin regardless of race.

**Unknown:** Select this category if the patient is unable to physically respond, there is no available family member or caregiver to respond for the patient, or if for any reason, the demographic portion of the medical record cannot be completed.

**Race**

**Black or African American** refers to a person having origins in any of the Black racial groups of Africa. It includes people who indicated their race(s) as “Black, African American, or Negro” or reported entries such as African American, Kenyan, Nigerian, or Haitian.

**White** refers to a person having origins in any of the original peoples of Europe, the Middle East, or North Africa. It includes people who indicated their race(s) as “White” or reported entries such as Irish, German, Italian, Lebanese, Arab, Moroccan, or Caucasian.

**Asian** refers to a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. It includes people who indicated their race(s) as “Asian” or reported entries such as “Asian Indian,” “Chinese,” “Filipino,” “Korean,” “Japanese,” “Vietnamese,” and “Other Asian” or provided other detailed Asian responses.

**American Indian/Alaska Native** refers to a person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment. This category includes people who indicated their race(s) as “American Indian or Alaska Native” or reported their enrolled or principal tribe, such as Navajo, Blackfeet, Inupiat, Yup’ik, or Central American Indian groups or South American Indian groups.

**Native Hawaiian/Other Pacific Islander** refers to a person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. It includes people who indicated their race(s) as “Pacific Islander” or reported entries such as “Native Hawaiian,” “Guamanian or Chamorro,” “Samoan,” and “Other Pacific Islander” or provided other detailed Pacific Islander responses.

**Other Race** includes all other responses not included in the White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander race categories described above or the lists provided.
Help Us Serve **YOU** Better

Sharing important information about yourself helps us provide better healthcare for all.

Treating all equally.

NEW YORK state department of HEALTH
Help Us Serve YOU Better

What information are we looking for?

Hospitals across New York will be asking questions about your age, gender, ethnicity, race, address, city, state and zip code to ensure that patients are receiving appropriate care of the best quality.

Why are the questions being asked?

We can better meet the needs of the communities that we serve if we know more about our patients, their cultures and their languages. This information will only be used to make sure that all patients are receiving the best care possible.

How will this information be used?

We will use the information that we collect from all patients to ensure that we understand the needs of the population we serve and to make sure that people have care that is culturally appropriate.

Our goal is to meet the needs of all of the patients we serve. We can achieve this goal by providing interpreter services, offering patient information translated into different languages, and making sure that our staff provide culturally appropriate care.

What if you don’t want to share this information?

It is your decision to share this information. This is only being collected to help us better serve you.

Are these questions being asked at other hospitals?

Yes. There are new state regulations requiring all hospitals in New York to collect this information. We are collecting this information as part of a statewide effort to improve the health of all.

Adapted by New York State Department of Health and the University at Albany School of Public Health from the Collaborative Effort of Massachusetts Hospital Association, the Boston Public Health Commission, the Massachusetts Department of Public Health, the Division of Health Care Finance and Policy, Robin Weinick of the Disparities Solutions Center at Massachusetts General Hospital and the Cambridge Health Alliance.