

Race, Ethnicity and Language Data: Stakeholder Engagement

Julia E. Iyasere, MD, MBA

Executive Director, Dalio Center for Health Justice;
Senior Vice President, Health Justice and Equity, New York-Presbyterian;
Assistant Professor of Medicine, Columbia University Irving Medical Center

We Ask Because We Care is a component of HANY'S *Advancing Healthcare Excellence and Inclusion* learning collaborative, launched with generous support from the [Mother Cabrini Health Foundation](#). The goal is to improve the accuracy and completion of patient demographic data while cultivating community understanding of how hospitals use this data to inform patient care and improve health outcomes.



Agenda

- **Introductions**
 - HANYS AHEI team
 - AHEI faculty
- **Our partners**
- **Session 1:**
 - Race, ethnicity and language data:
Stakeholder engagement
- **Upcoming sessions**

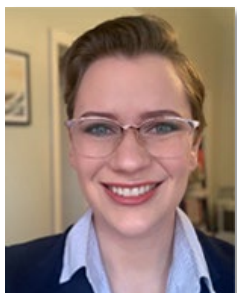
HANYS AHEI team



Kathleen Rauch, RN, MSHQS, BSN, CPHQ
Vice President, Quality Advocacy, Research and Innovation and Post-acute and Continuing Care



Christina Miller-Foster, MPA
Senior Director, Quality Advocacy, Research and Innovation



Morgan Black, MPA
Director,
Advancing Healthcare Excellence and Inclusion



Maria Baum, MS, RN, CPHQ
Project Manager,
Mohawk Valley



Rachael Brust, MBA
Project Manager,
North Country



Kira Cramer, MBA
Project Manager,
Downstate

HANYS faculty



Julia E. Iyasere, MD, MBA

Executive Director, Dalio Center for Health Justice; Senior Vice President, Health Justice and Equity, New York-Presbyterian; and Assistant Professor of Medicine, Columbia University Irving Medical Center



Theresa Green, PhD, MBA

Director, Community Health Policy and Education, URMC Center for Community Health



Pamela Y. Abner, MPA, CPXP

Vice President and Chief Diversity Operations Officer, Mount Sinai Health System



Barbara Warren, PsyD, CPXP

Senior Director, LGBT Programs and Policies, Mount Sinai Office for Diversity and Inclusion



Shana Dacon-Pereira, MPH, MBA

Assistant Vice President, Corporate Health System Affairs
Mount Sinai Office for Diversity and Inclusion

Presenter



Julia E. Iyasere, MD, MBA

Executive Director, Dalio Center for Health Justice;
Senior Vice President, Health Justice and Equity, New York-Presbyterian
Assistant Professor of Medicine, Columbia University Irving Medical
Center

[Bio](#)

Our funder and partner



OUR FUNDER

Funding from the [Mother Cabrini Health Foundation](#) allows HANY to expand its capacity to provide education, direct support, tools and data to our members in a strategic way. With this learning collaborative, we strive to effect lasting change in health equity at the local level by engaging providers and community stakeholders to address health disparities.



OUR PARTNER

Through a partnership with Socially Determined, provider of Social Risk Intelligence™ solutions, [DataGen](#) will develop custom analytics for participants to help them understand how and where communities are affected by social risk so they can develop tailored intervention strategies.

Session objectives

After this session, participants will be able to:

- 1) address common concerns on asking patients questions about their race, ethnicity and language;
- 2) implement proven strategies for staff training;
- 3) explain the importance of patient registration and access staff; and
- 4) promote a culture of open communication.

We Ask Because We Care: Race and Ethnicity Data Collection

A Case Study at NewYork-Presbyterian

Julia Iyasere, MD

STAY
AMAZING

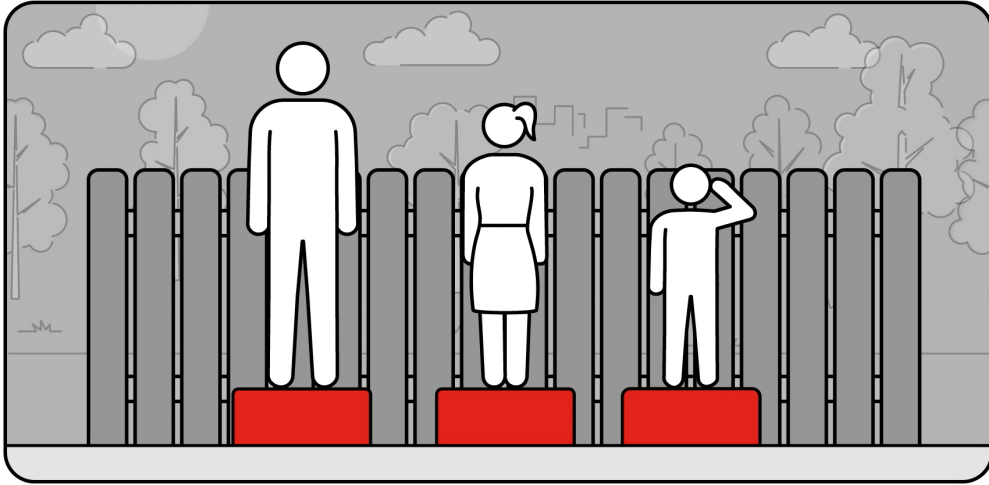
NewYork-
Presbyterian

Session 1: Key Stakeholder Engagement

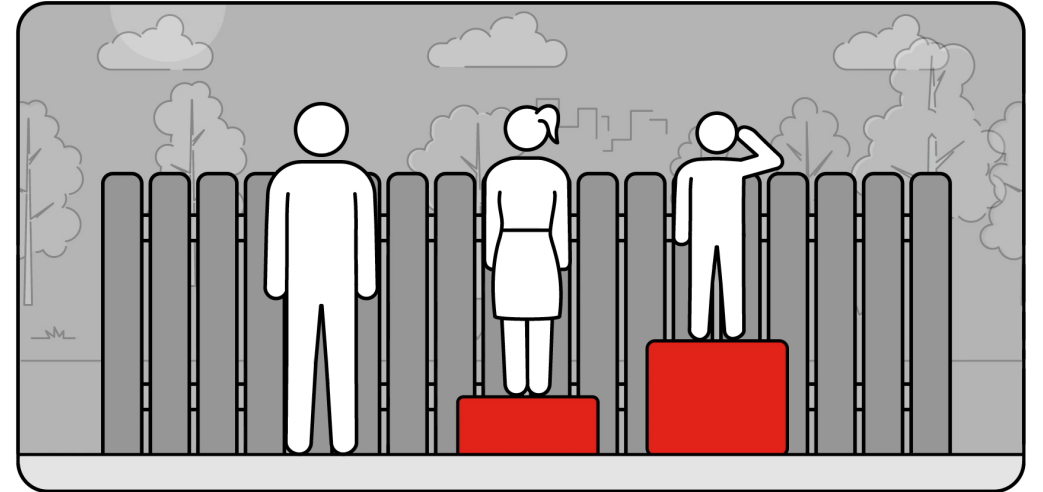
The Dalio Center for Health Justice at NewYork-Presbyterian

Our mission is to be a leader in understanding and improving health equity with a focus on the structural factors that lead to the conditions of poor health

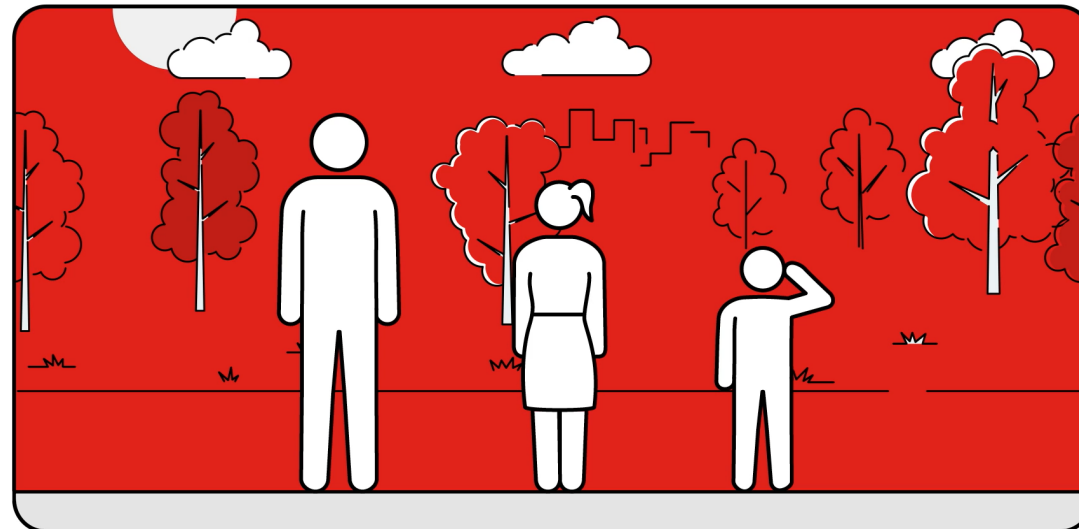
EQUALITY



EQUITY



JUSTICE



“Although the collection of race, ethnicity and language data does not necessarily result in actions that will reduce disparities and improve care, the absence of the data guarantees that none of that will occur.”

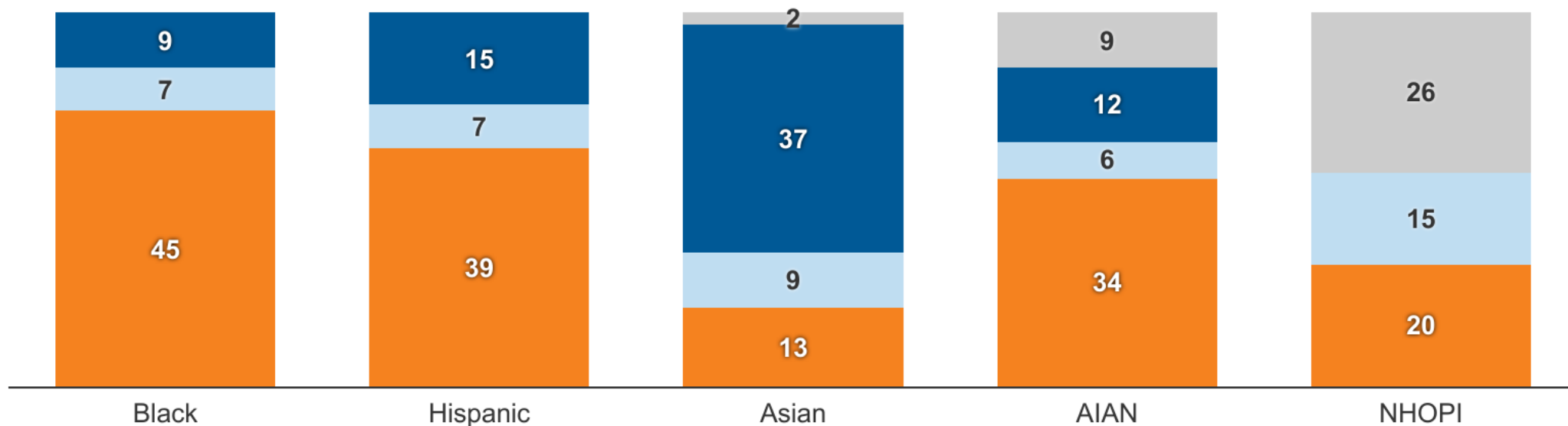
We Ask Because We Care

Figure 1

Health and Health Care among People of Color Compared to White People

NUMBER OF MEASURES FOR WHICH GROUP FARED BETTER, THE SAME, OR WORSE COMPARED TO WHITE PEOPLE:

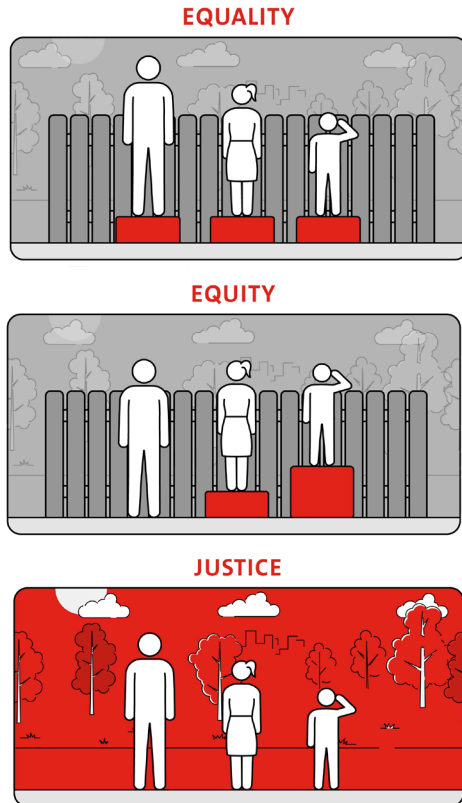
Worse No difference Better No data



NOTE: Measures are for the most recent year for which data are available. "Better" or "Worse" indicates a statistically significant difference from White people at the $p < 0.05$ level. No difference indicates no statistically significant difference. "Data limitation" indicates no separate data for a racial/ethnic group, insufficient data for a reliable estimate, or comparisons not possible due to overlapping samples. AIAN refers to American Indian or Alaska Native. NHOPI refers to Native Hawaiian or Other Pacific Islander. Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic.

Why should we invest resources in this activity?

1. To advance the hospital's **equity goals**



2. To meet **regulatory requirements**



3. To respond to external **measurement organizations**



Core Elements of the Program



REaL Data Improvement – Key Stakeholder Engagement



**Enterprise
Commitment**

- + Enterprise Goals**
- + Leadership Support & Participation**

REaL Workgroup Members



- ✓ Chief Information Officer
- ✓ Chief Transformation Officer
- ✓ Executive Director, Dalio Center for Health Justice
- ✓ VP Finance Revenue Cycle, Access
- ✓ Physician leaders, including Chief of OB, Associate CMIO, Director of Community Pediatrics
- ✓ Representatives from Epic, Data Analytics, Social Work, Dalio Center, & Division of Community and Population Health

REaL Data Improvement – Leveraging Information Technology





Technical Support

- + Reordering questions
- + Interface simplification
- + Welcome workflow

Race:  

Search:

Title
AMERICAN INDIAN OR ALASKA NATION
ASIAN
BLACK OR AFRICAN AMERICAN
DECLINED
NAT.HAWAIIAN/OTH.PACIFIC ISLAND
OTHER COMBINATIONS NOT DESCRIBED
WHITE

Ethnicity:  

Search:

Title
DECLINED
HISPANIC OR LATINO OR SPANISH ORIGIN
NOT HISPANIC OR LATINO OR SPANISH ORIGIN

REaL Data Improvement – Supporting Your Staff



Staff Education

- + Training Sessions
- + FAQs
- + Epic Tip Sheets
- + E-blast

Understanding Our Patients

At NewYork-Presbyterian, we are committed to celebrating the diversity of our patients, and we are dedicated to ensuring that every patient receives the best care possible regardless of race, ethnicity, gender identity, sexual orientation, cultural background, or language proficiency.

In order to support this mission, we ask that you provide additional information about themselves, their background, and their needs.

Information for **NYP Staff** about **Race, Ethnicity, and Language**:

- Letter to Staff about Race, Ethnicity, and Language
- Tip Sheet for Staff
- Training Video for Staff

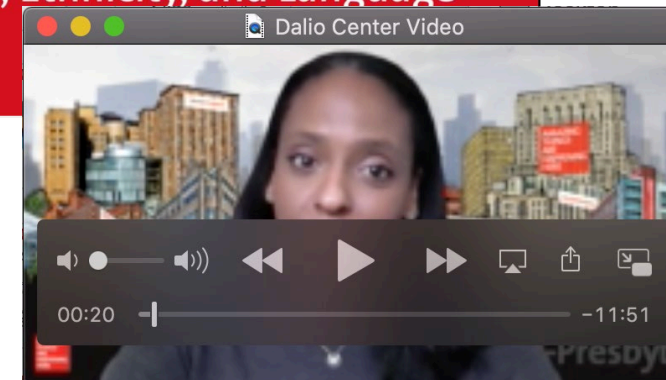
Information for **Patients** about **Race, Ethnicity, and Language**:

- Letter to Patients about Race & Ethnicity
- Letter to Patients (Arabic)
- Letter to Patients (Chinese)
- Letter to Patients (French)
- Letter to Patients (Korean)
- Letter to Patients (Russian)
- Letter to Patients (Spanish)
- 'We Ask Because We Care' flyers
- FAQs for Patients

Information for **NYP Staff** about **Sexual Orientation & Gender Identity (SOGI)** data collection:

- Updates and Best Practices for Enhancing Patient Experience: Names and Pronouns

Understanding our Patients
Race, Ethnicity, and Language



REaL Data Improvement – Patient Engagement



**Patient
Communication**

- + REaL Materials
- + Website
- + Poster, signage
- + Emails & Newsletters

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.

NewYork-Presbyterian
Dalio Center for Health Justice

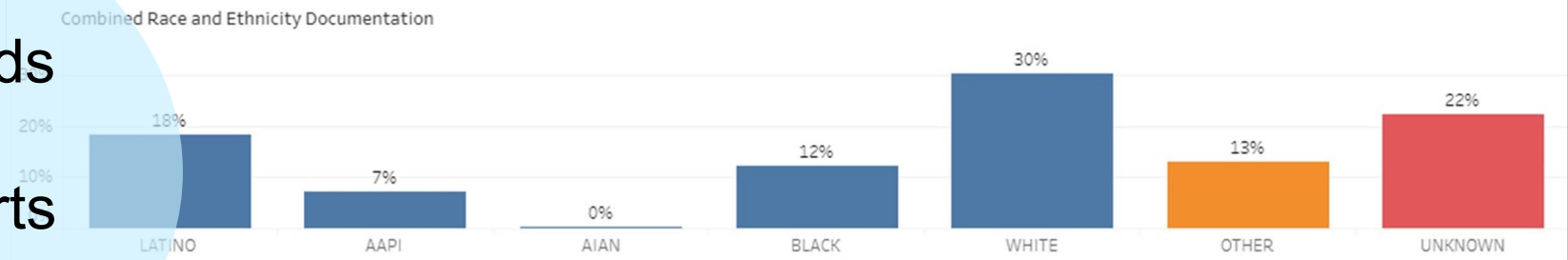
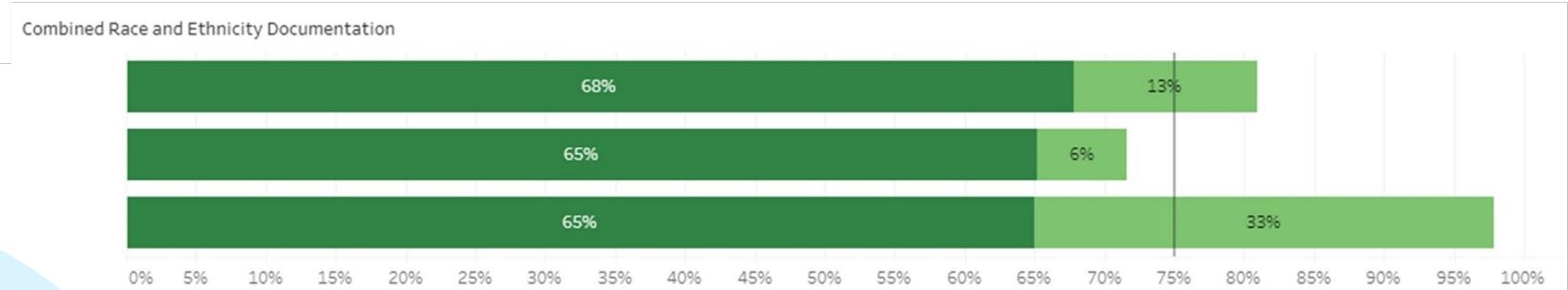
© Well Cornell Medicine | NewYork-Presbyterian | COLUMBIA

REaL Data Improvement – Continuous Monitoring



**Monitoring
& Targeted
Intervention**

- + Enterprise dashboards
- + Focused 'push' reports
- + Newborn focus area



Should a health care organization be collecting race and ethnicity data at all, given that race is a *social construct* and not a clinically valuable identifier?

**Should we call the electronic medical record field
“race” or “*background*” or something else?**

Should we purchase data to augment our existing race and ethnicity data?

**Should we use algorithms to *infer*
patient race and ethnicity?**

Should we leverage *natural language processing* to pull race and ethnicity from clinical notes?

“We acknowledge that race is artificial and that differentiating by race is not a valid way to understand human difference.

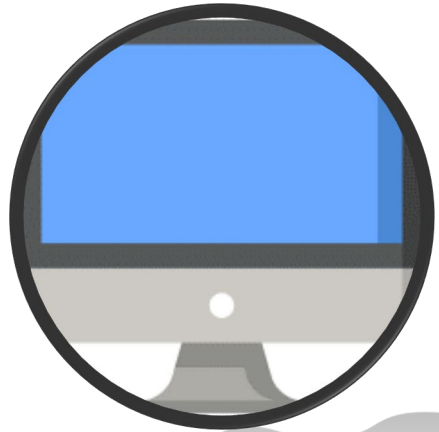
We also acknowledge that racism continues to shape the lives, opportunities, and health of many. So, even though race is merely a social construct, race and ethnicity data are critical to inform retrospective research and analysis on health equity.

We believe that self-identified race and ethnicity are the gold standard; thus, we did not purchase data or use inferred race and ethnicity to augment self-identified race and ethnicity in the electronic medical record.”

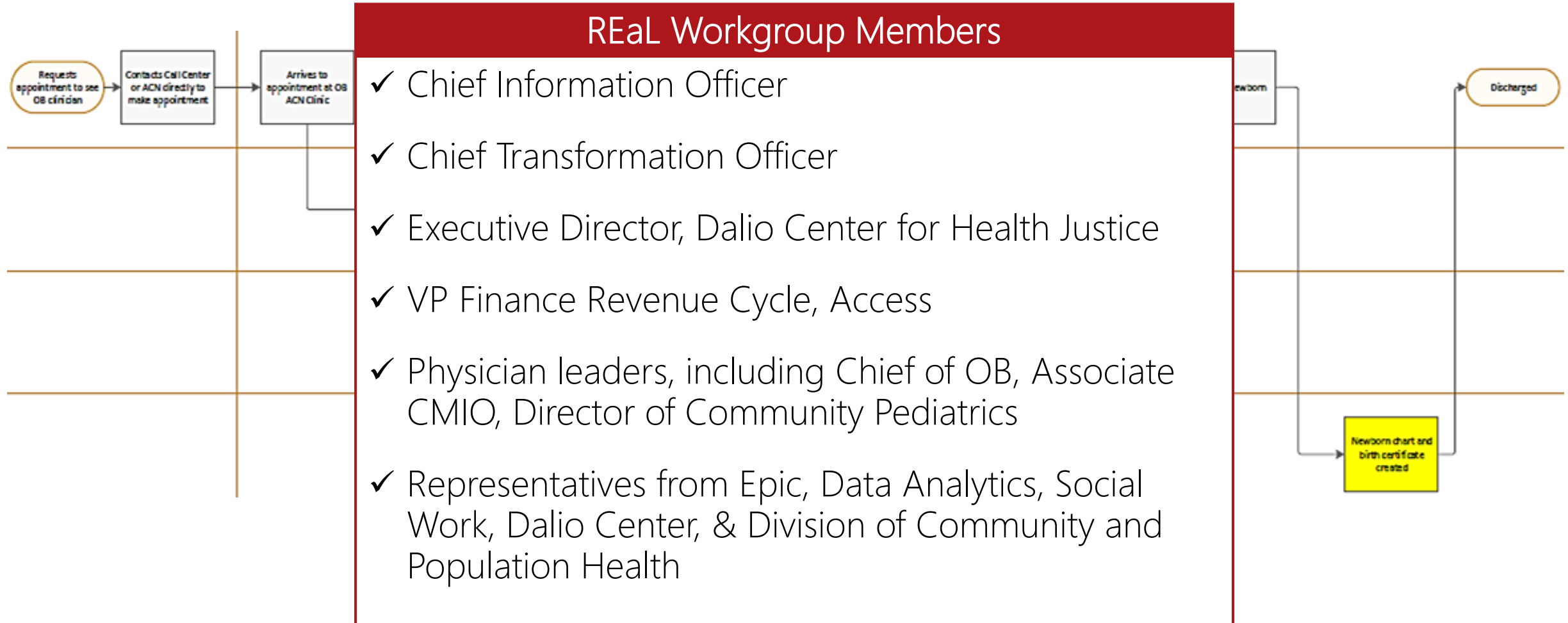
Who do you need in the room to advance this work?

- Map out your patient's journey from the point of first contact and identify the key process owners

REaL Data Improvement – Patient Journey Mapping



REaL Data Improvement – Workgroup Members at NYP



STAY
AMAZING

NewYork-
Presbyterian

Standardizing Staff Education

REaL Data Improvement – Patient Journey Mapping



Introductory Letter

- Emailed to all staff before formal training launched

NewYork-Presbyterian Dalio Center for Health Justice

We Ask Because We Care!

At NewYork-Presbyterian, we are committed to celebrating the diversity of the patients and communities that we serve, and we are dedicated to ensuring that every patient receives the best care possible regardless of race, ethnicity, age, gender identity or expression, sexual orientation, cultural background, or language proficiency.

In order to support this mission, we will ask our patients to provide additional information about themselves, about their background and their preferred language. This helps us to better personalize their care and allows us to review the treatment that all our patients receive to make sure that everyone gets the highest quality of care. Patients can update their personal information at <https://www.myconnectnyc.org/MyChart/PersonalInformation>.

Our patients' information is confidential and answering these questions is voluntary. But **we ask because we care** about the health and well-being of all our patients.

At NewYork-Presbyterian, we put patients first.



Julia Iyasere, MD
Vice President, Dalio Center for Health Justice at NewYork-Presbyterian



 Well Cornell Medicine |  NewYork-Presbyterian |  COLUMBIA

Training Video

- **Assigned to every staff member with an access role and to SW/CC staff**



1-page Job Aid

- Scripted language available for all registration/access staff as a guide

Why we ask this important question

- We want to make sure that all of our patients get the best care possible. We collect racial/ethnic background information so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care.
- Collecting this data helps to evaluate population trends and ensure nondiscrimination on the basis of race and national origin. It can also help identify disease trends across different populations
- Covid 19 has highlighted the importance of knowing what population of people are affected by a particular disease
- City, state and federal agencies require hospitals to collect this data so we know the characteristics of the population we serve
- Race and Ethnicity data is sometimes used in research studies to help improve medical care we have available to our patients
- The confidentiality of what you say is protected by law. The only people who see this information are registration staff, administrators for the hospital, and the people involved in quality improvement and oversight. **NYP takes patient privacy very seriously**, and therefore this information is also protected by our policies and practices.

Key Concepts

What is the difference between race and ethnicity?

- **Race** is a population considered distinct based on physical characteristics and self-identification but is not considered primarily biological or genetic in nature
- **Ethnicity** represents a social group with a shared sense of identity, geography, and cultural roots, which may occur despite racial differences. Example: Puerto Ricans are of many different races, but they have a shared sense of Hispanic culture and customs

What Staff Need to Know and Do:

- Staff must inquire about patients' race and ethnicity and should not make assumptions.
- Suggested script during the patient interview:
 - *In order to guarantee that all patients receive the highest quality of care and to provide the best services possible, we are asking all patients about their race, ethnicity, and language*
 - *How would you like your race and ethnicity recorded in our system?*
 - *Are you of Hispanic or Spanish background?*
 - **Hispanic** (person of Cuban, Mexican, Puerto Rican, Central or South America or other Spanish origin regardless of race)
 - **Non-Hispanic**
 - **Declined.** A person who is unwilling to choose/provide a race category or cannot identify him/herself with of the races listed.
 - **Unknown.** Select this category if the patient is unable to 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.
 - *What Race do you associate with?*
 - **White** – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.
 - **Black or African American** – A person having origins in any of the Black racial groups of Africa.
 - **American Indian or Alaska Native** – 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.
 - **Asian** – 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.
 - **Native Hawaiian or Other Pacific Islander** – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands

4-page FAQ and Tip Sheet

- **Best practices, references, and sample answers to potential questions**

Equity Matters to NYP

Tip Sheet for Staff Collecting Race & Ethnicity Data



In 2020, NewYork-Presbyterian launched the Dalio Center for Health Justice. The overarching goals of the Center are to be a leader in understanding and improving health equity, and drive action that results in measurable improvements in health outcomes for all. We formed the Center to address longstanding health disparities due to race, socio-economic differences, limited access to care, and other complex factors that impact the wellbeing of our communities disproportionately.

To support these aims, NewYork-Presbyterian is supporting enterprise-wide efforts to improve collection of data on race and ethnicity. We collect racial/ethnic background information so that we can review the treatment that all patients receive and make sure that everyone gets the **highest quality of care**.

This *Tip Sheet* provides sample answers to potential patient questions and details about how to interpret the race and ethnicity options.

Sample Questions from Patients

Why do we ask about race, ethnicity, and language?

We want to make sure that all of our patients get the best care possible. We collect racial/ethnic background information so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care. We use race, ethnicity, and language data:

- To better understand the community we serve
- To be culturally sensitive to the workforce and our patients
- To understand need for interpreter services
- For grant applications and potential donors
- To help appropriately target quality initiatives
- To fulfill our compliance obligations

What do race and ethnicity have to do with health?

Race continues to be mistakenly used as a marker of biological, genetic, and social differences in humans. While both scientists and human rights activists have been successful in discrediting the validity of race as a concept to understanding human difference – racial discrimination continue to shape the lives, opportunities, and health of many.

Who will see the information? How will it be shared?

NYP limits access to patient information, including into patients' race and ethnicity, to instances where the information is necessary for providing care, hospital operations, and billing. NYP has dedicated teams in place to help safeguard your information including the Office of Corporate Compliance and the Information Security Department. For more information, please see the Notice of Privacy Practice (NOPP).

Who are you collecting this information from?

We are asking all our patients for this information.

Small Group Presentations

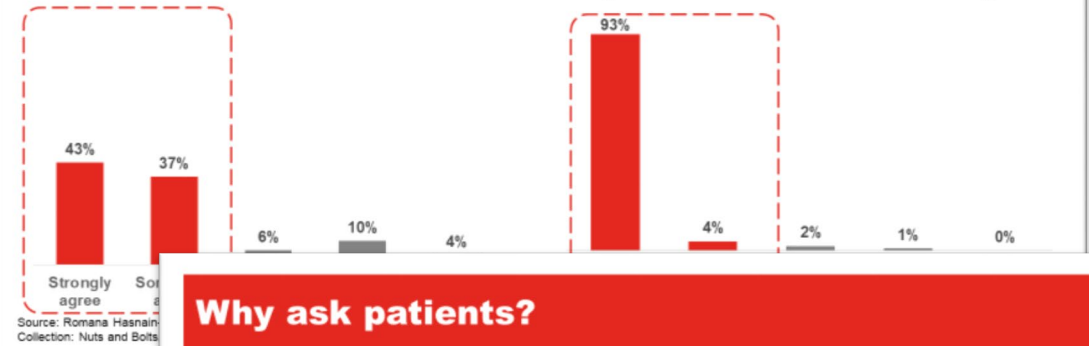
- In person sessions with open Q&A

How Do Patients Feel?

It is important for hospitals and clinics to...

...collect information from patients about their race or ethnic background

...conduct studies to make sure that all patients get the same high-quality care regardless of their race or ethnic background



Why ask patients?

- **Self-reporting** is the most accurate and consistent source of information
 - We do *not* make any assumptions based on how a person looks
 - Patients are more likely to select the same categories to describe themselves over time than staff who are assuming or guessing
- **All** patients should be asked about their race/ethnicity, and language



STAY
AMAZING

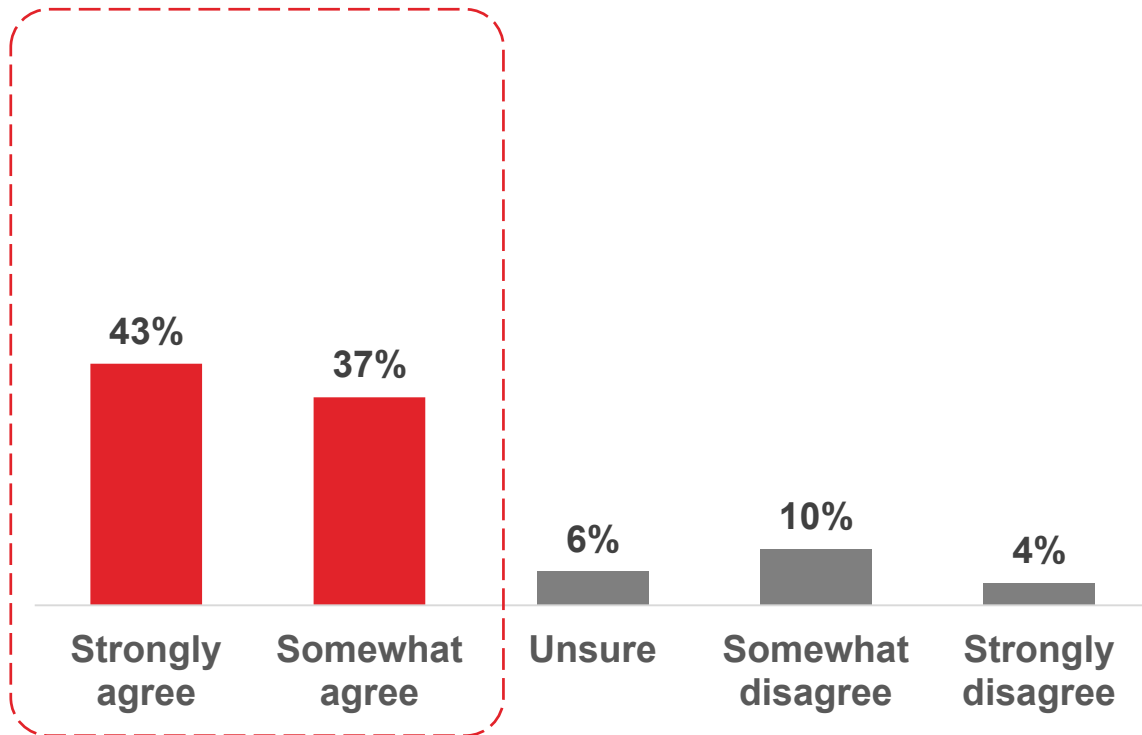
NewYork-
Presbyterian

Direct Patient Communication

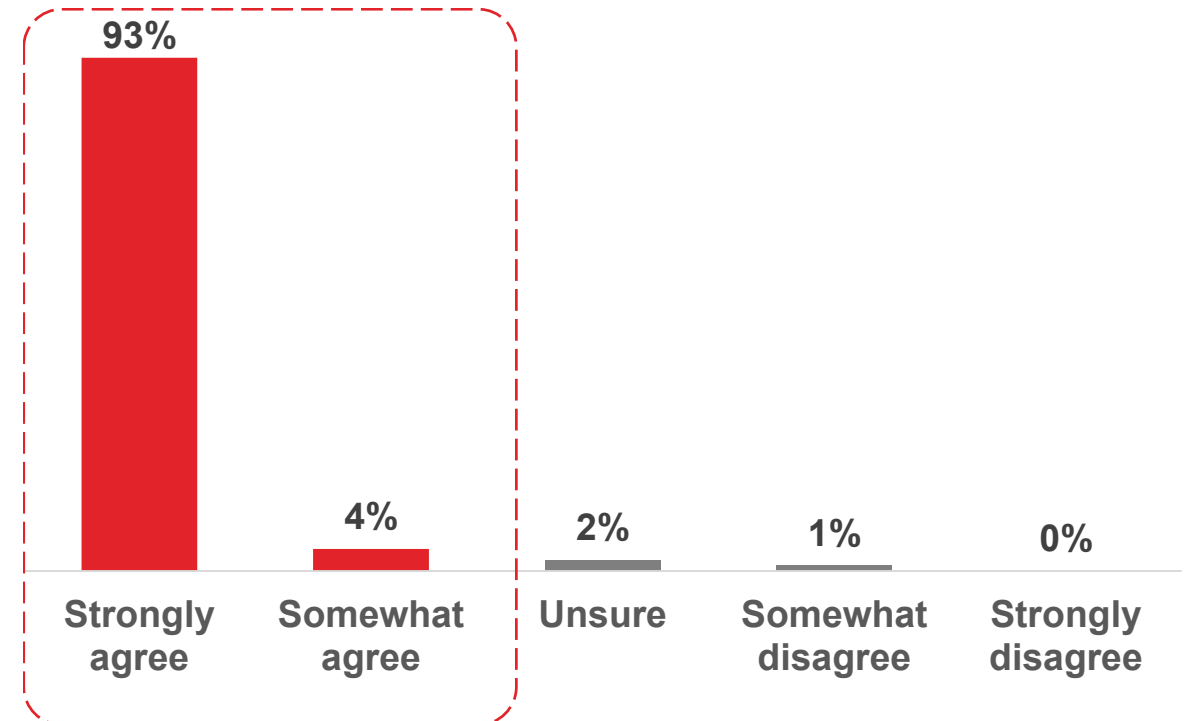
How Do Patients Feel?

It is important for hospitals and clinics to...

...collect information from patients about their race or ethnic background



...conduct studies to make sure that all patients get the same high-quality care regardless of their race or ethnic background



Reassure patients that:

- ✓ The data will serve a positive and **valuable purpose**
- ✓ Their **care will not be affected** by their answer
- ✓ They are **not required** to provide the information
- ✓ Their **privacy and patient rights** are being respected
- ✓ Data collection **does not take too much time** and won't cause them to be late for an appointment

Patient Letter

- Emailed to patients with a direct link to update demographics

 **NewYork-Presbyterian**
Dalio Center for Health Justice

We Ask Because We Care!

NewYork-Presbyterian, Columbia, and Weill Cornell Medicine celebrate the diverse people and communities we serve. We pledge to give **every** patient the best care possible regardless of race, ethnicity, gender identity, sexual orientation, cultural background, or language.

We will strive to make sure all patients have **equal access** to the highest quality of care. To support this mission, we will ask you questions about your background and preferred language. You can update your information today at www.myconnectnyc.org.

Your information is confidential. Sharing it is your choice. But **we ask because we care** about you and the health and wellbeing of all our patients.

At NewYork-Presbyterian, Columbia, and Weill Cornell Medicine, we put patients first.



External Website

Overview

A Letter from Ray and Barbara Dalio

Focus Areas & Key Initiatives

We Ask Because We Care Campaign

Social Determinants of Health

Education & Leadership

External Advisory Board

Meet the Team

We Ask Because We Care

NewYork-Presbyterian, Columbia, and Weill Cornell Medicine celebrate the diverse people and communities we serve. We pledge to give **every** patient the best care possible regardless of race, ethnicity, gender identity, sexual orientation, cultural background, or language.

We will strive to make sure all patients have **equal access** to the highest quality of care. To support this mission, we will ask you questions about your background and preferred language. You can update your information today at www.myconnectnyc.org.

Your information is confidential. Sharing it is your choice. But **we ask because we care** about you and the health and wellbeing of all our patients.



External Website

Responses to Frequently Asked Questions

+ Why do we ask about race, ethnicity, and language?

+ Who will see the information? How will it be shared?

+ Who are you collecting this information from?

+ Is it mandatory for patients to provide race and ethnicity?

Poster/Tent Cards

- In entryways, waiting rooms, lobbies



“By educating staff about disparities, we were able to reframe race and ethnicity collection, moving away from concerns about stereotyping and toward understanding the equity goals.”

*“By educating staff **and patients** about disparities, we were able to reframe race and ethnicity collection, moving away from concerns about stereotyping and toward understanding the equity goals.”*

A woman with long, dark braids is wearing a dark blue suit jacket over a white collared shirt. She is standing in front of a chain-link fence with green foliage in the background. The text "Thank you!" is centered in the image.

Thank you!

Next session

Monday, Apr. 10 | Noon - 1 p.m.

Race, Ethnicity and Language Data: Measurement and Monitoring

To ensure successful quality improvement, it is crucial to measure and monitor progress. This session will discuss strategies for standardizing health system data, creating meaningful reports and visualizing data for internal and external stakeholders. The session will also cover methods for stratifying patient outcomes, such as mortality, readmissions and HCAHPS, based on patient demographic data.

Remaining sessions in the *We Ask Because We Care* series will be held on the following dates at noon:

- Monday, Apr. 17 (90-minute session)
- Monday, Apr. 24



ADVANCING HEALTHCARE
EXCELLENCE AND INCLUSION

Questions?

Julia E. Iyasere, MD, MBA

Executive Director, Dalio Center for Health Justice;
Senior Vice President, Health Justice and Equity,
New York-Presbyterian
Assistant Professor of Medicine, Columbia
University Irving Medical Center
jiyasere@nyp.org

Morgan Black, MPA

Director, AHEI
HANYS
mblack@hanys.org

AHEI Team

ahei@hanys.org