

# We Ask Because We Care: Improving Demographic Data Collection to Advance Health Equity

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# Introduction

- St. John's Episcopal Hospital is a 257 bed teaching facility located in Far Rockaway, Queens in New York City.
- We are the only hospital providing emergency, acute and ambulatory care to the densely populated, culturally and economically diverse, and medically underserved populations of the Rockaways and Five Towns in southern Queens County and southwestern Nassau County.
- The SJEH Service Area consists of approximately 134,000 year-round residents who reside in the service area's six zip codes. Each zip code is diverse in many ways – race/ethnicity, income, religion, and education, among other factors.

# Problem statement

The communities that we serve represent the second hardest hit areas by COVID in NYC hospitalization and death rates during the first wave. In the midst of the crisis, the organization began providing demographic data for all COVID patients. This revealed significant discrepancies. After a deeper dive into pre-COVID data, we realized we had a long history of not collecting meaningful, accurate demographic information. We recognized **in order to understand, align and provide care for our community, first we need to know who they are.**

A review of 2018 demographic data revealed that:

- 35% of our patients are missing either their race or ethnicity in their record; and
- 17% of our patients have neither race nor ethnicity in their record.

The organization also took this opportunity to expand our efforts around data collection regarding gender and sexual orientation.

# Where we started

- Buy-in from senior executive leadership, including CEO, COO and CMO.
- Formed a multidisciplinary team, including:
  - senior leaders from various divisions;
  - middle managers;
  - front line team members;
  - Informatics; and
  - experts on organizational learning.
- We were not using race, ethnicity or language to stratify data and outcomes.



# What we did this year

- Developed a diverse, engaged task force
- Held multiple focus groups with registration teams. Some takeaways:
  - Key to our success
  - Despite technology, registration teams and patients preferred to answer these questions on paper.
- Redesigned the inpatient EMR
- Second round of focus groups with multidisciplinary teams post EMR changes
- Branded *We Ask Because We Care* educational materials for team members and patients and families.

# What we did this year



**We ask**  
because we care.

**Preguntamos porque nos importa**

As a patient, you will be asked detailed information about your race, ethnic background and preferred language.

Como paciente, le pediremos información detallada sobre su raza, origen étnico y el idioma que prefiere.

You are helping us better care for our diverse community.

Usted nos está ayudando a atender mejor a nuestra comunidad diversa.

What is your race?  
¿Cuál es su raza?

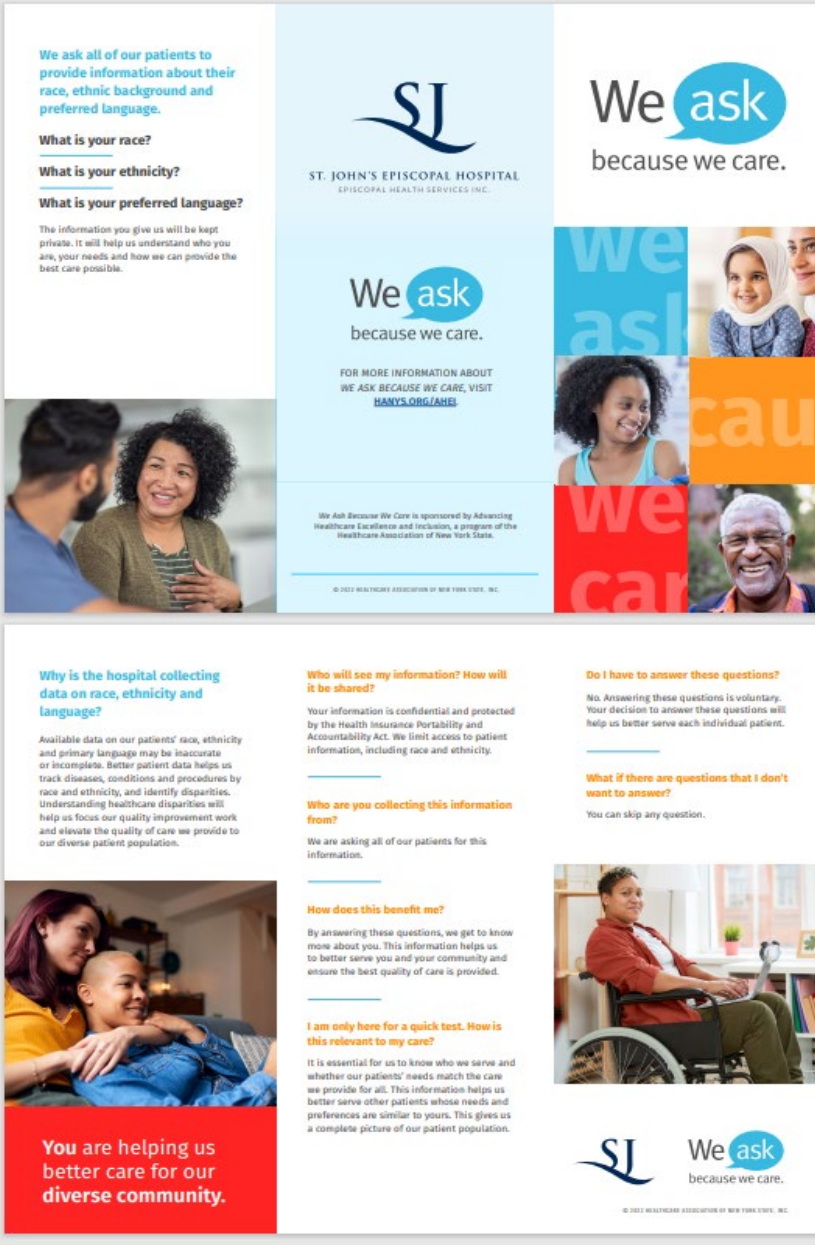
What is your ethnicity?  
¿Cuál es su origen étnico?

What is your preferred language?  
¿Cuál es el idioma que prefiere?

Learn more about We Ask Because We Care. Visit [hany.org/ahel](https://hany.org/ahel).

Obtenga más información sobre Preguntamos porque nos importa. Visite [hany.org/ahel](https://hany.org/ahel).

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**Why is the hospital collecting data on race, ethnicity and language?**

Available data on our patients' race, ethnicity and primary language may be inaccurate or incomplete. Better patient data helps us track diseases, conditions and procedures by race and ethnicity, and identify disparities. Understanding healthcare disparities will help us focus our quality improvement work and elevate the quality of care we provide to our diverse patient population.

**Who will see my information? How will it be shared?**

Your information is confidential and protected by the Health Insurance Portability and Accountability Act. We limit access to patient information, including race and ethnicity.

**Who are you collecting this information from?**

We are asking all of our patients for this information.

**How does this benefit me?**

By answering these questions, we get to know more about you. This information helps us to better serve you and your community and ensure the best quality of care is provided.

**I am only here for a quick test. How is this relevant to my care?**

It is essential for us to know who we serve and whether our patients' needs match the care we provide for all. This information helps us better serve other patients whose needs and preferences are similar to yours. This gives us a complete picture of our patient population.

**Do I have to answer these questions?**

No. Answering these questions is voluntary. Your decision to answer these questions will help us better serve each individual patient.

**What if there are questions that I don't want to answer?**

You can skip any question.

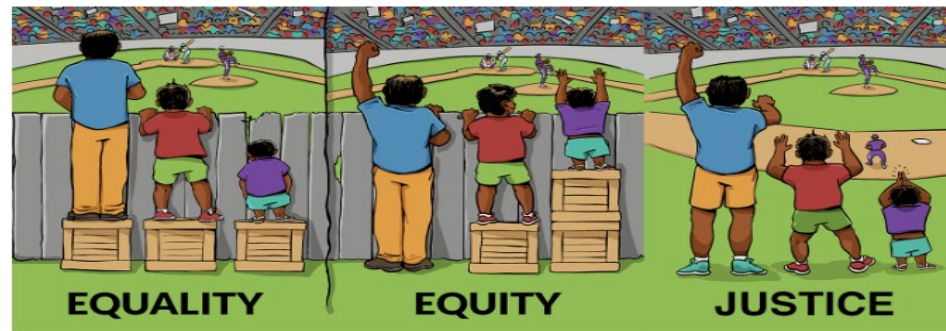
**You are helping us better care for our diverse community.**

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# What we did this year

- Trained all registration teams starting in ambulatory areas
- Updated the inpatient EMR to align with outpatient data collection capabilities; changes went live in November 2022
- Monitoring of demographic data in outpatient behavioral health clinics demonstrated meaningful improvements in data collection for ethnicity, gender and sexual orientation
- Ongoing monitoring of data reports will take place quarterly and report out to the multidisciplinary task force to identify successes and opportunities for further improvement in data collection
- Using ambulatory data to help the organization meet the new Joint Commission Health Equity Standards.



# Lessons learned

## What went well:

- Team cohesion, shared understanding of the problem, buy-in from executives and front line team members, multiple successful focus groups, patient and family participation
- New health equity regulations added a sense of urgency



## What did not go so well:

- Outcome after implementation: Othering of Latino/a/x without clear representation in demographic data as compared to CHNA data
- 2 EMRs need to interface, but one is more advanced than the other
- SPARCS data was confusing
- EMRs have ethnicities embedded as races
- Multi-ethnic, multiracial categories excluded



# What's next?

- Continue monitoring
- Build capacity in the organization and continue stratifying data to:
  - improve health outcomes;
  - build community partnerships;
  - inform performance improvement efforts;
  - guide human resources in recruitment efforts; and
  - provide a foundation for development of new clinical programming to meet the needs of the population.



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**EXCELLENCE AND INCLUSION**

# Questions?

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