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.
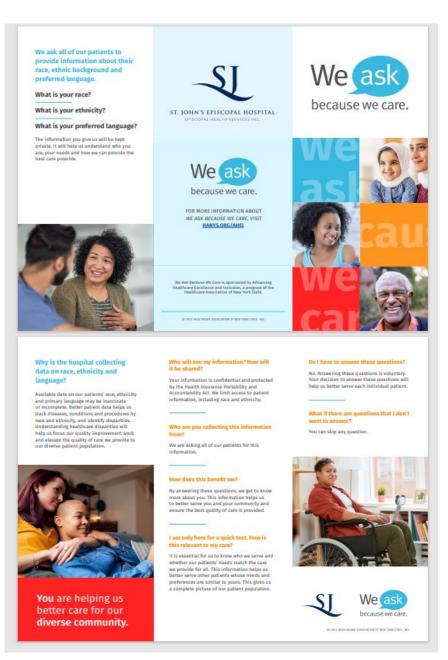
What we did this year

- 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.
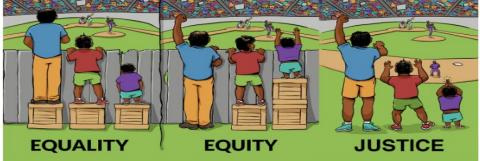
What we did this year

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.

EQUALITY   EQUITY   JUSTICE

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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Questions?

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