

Striving for Equity:

Improving Race and Ethnicity Data Collection in a Multiracial Population

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**THE QUEEN'S
MEDICAL CENTER**

Background

How is race and ethnicity data collected now?

- Minimum standards for race and ethnicity data collection remain unchanged since **1997**
- **5 race categories:** American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, or White
- **2 ethnicity categories:** Hispanic or Latino, not Hispanic or Latino
- ***No other standardized method of race and ethnicity data collection exists federally in the U.S.***

Are you Hispanic or Latino?

Yes

No

Regardless of your answer to the prior question, please indicate how you identify yourself. (Select one or more)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

White

Why change how we collect data?

- **Healthcare inequities are hidden when race, ethnicity, and language (REAL) data is not properly disaggregated**
 - High prevalence of fair or poor health status among Filipino Americans in California (Adia et al., 2020)
 - Severe maternal morbidity among American non-Hispanic Black women (Leonard et al., 2019)
 - Disproportionate rate of COVID-19 infection among Pacific Islanders in Hawai'i (Miller et al., 2021)
- **No standardized protocol** at most healthcare organizations for how, when, and who collects REAL data, which leads to incorrect/incomplete data

Other problems?

- **Non-inclusive race/ethnicity surveys** lead to incorrect/incomplete data
 - Patients who do not identify with any of the offered racial categories often forego providing racial data (Bhalla et al., 2012)
 - One NYC healthcare system found missing REAL data in 57.9% of its electronic health records (Polubriaginof et al., 2019)
- Over half of hospitals surveyed **relied on the visual observations of admitting staff** to determine a patient's race (Hasnain-Wynia, Pittman, and Pierce, 2004)

Our Goals

- Improve race and ethnicity data collection at Queen's Medical Center
- Pilot and refine a comprehensive, patient-facing data collection system
- Compare results to information already recorded in patients' electronic health records
- **What is the current state of race and ethnicity data collection at Queen's Medical Center? Can we improve it?**

Methods

Development of Pilot Survey

- *Race, Ethnicity, Language, and Disability (REALD): Implementation Guide* (Oregon Health Authority, 2020)
 - Open-ended questions
 - Verbally conveying language questions
 - Inclusively constructed race and ethnicity categories
- **50 race and ethnicity categories**, instead of just 5
 - 14 questions
- Administered on tablet device using Qualtrics software

Black or African American

African American

African (Black)

Caribbean (Black)

Other Black (please specify)

Hispanic and Latino/a

Hispanic or Latino/a Central American

Hispanic or Latino/a Mexican

Hispanic or Latino/a South American

Puerto Rican

Other Hispanic or Latino/a (please specify)

Native Hawaiian or Pacific Islander

Native Hawaiian or Pacific Islander

Native Hawaiian

Guamanian, Chamorro, Chamoru, Chamoru

Chuukese

Kosraean

Pohnpeian

Yapese

Palauan/Blauan

Nauruan

Kiribati

Marshallese

Samoan

Tongan

Maori

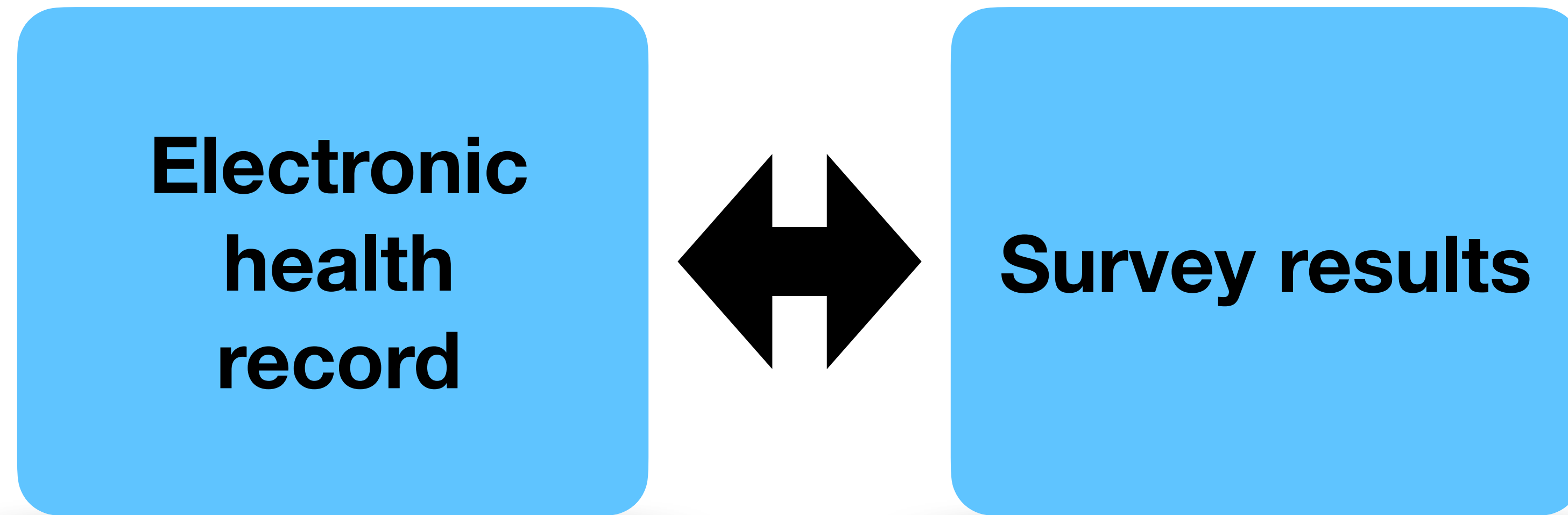
Fijian

Tahitian

Carolinian

Other Pacific Islander (please specify)

Data Comparison



- Data gathered from electronic health record (EHR): race and ethnicity, age, and insurance status
- Allowed estimation of the percentage of potential missing, incomplete, or incorrect REAL data in Queen's Medical Center EHRs

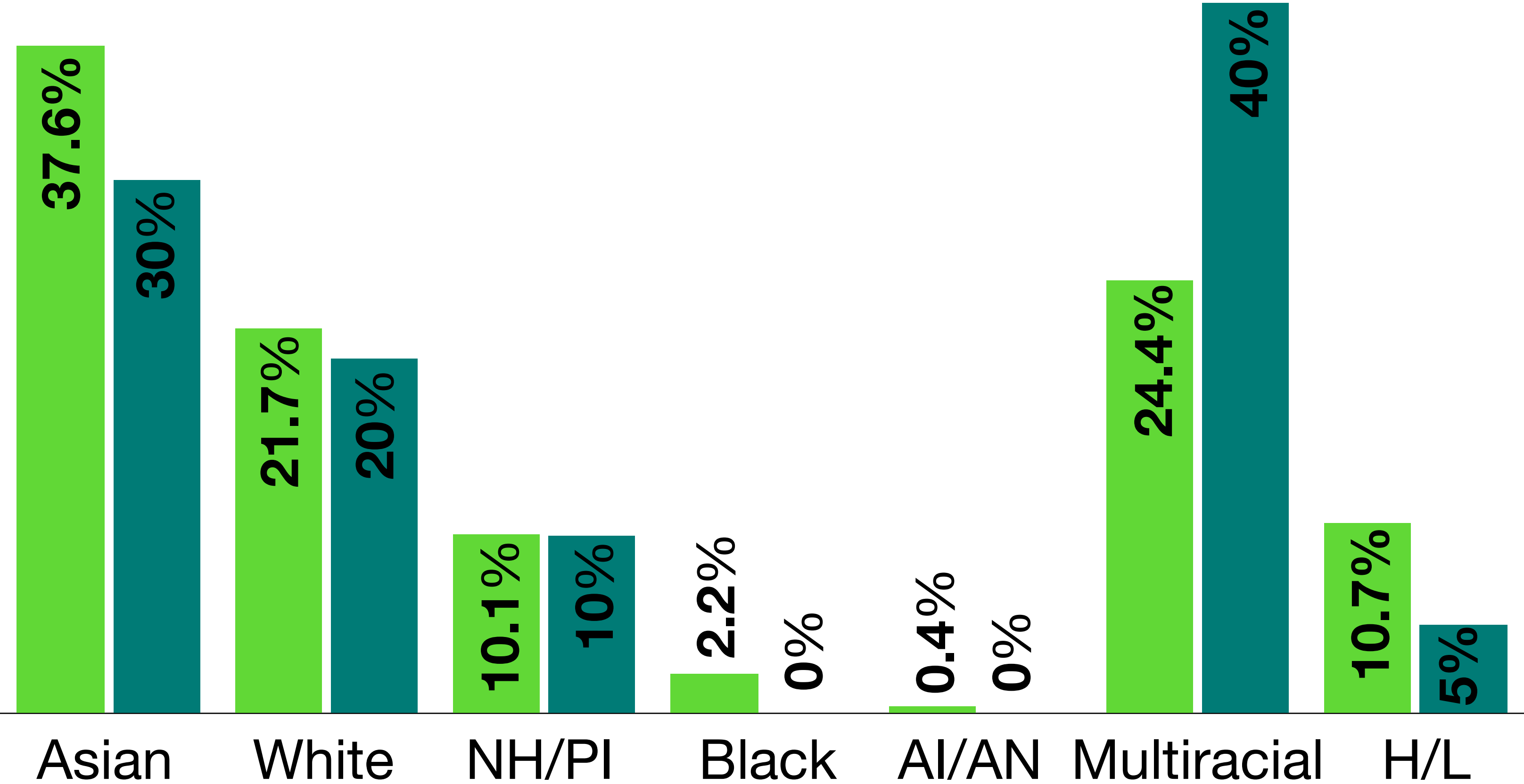
Surveyed Population

- 20 adult women
- OB/GYN in-patients at QMC Punchbowl
- Laboring or postpartum
- English-speaking

Results

Demographics

■ State of Hawai'i (U.S. Census July 2019) ■ Survey Population



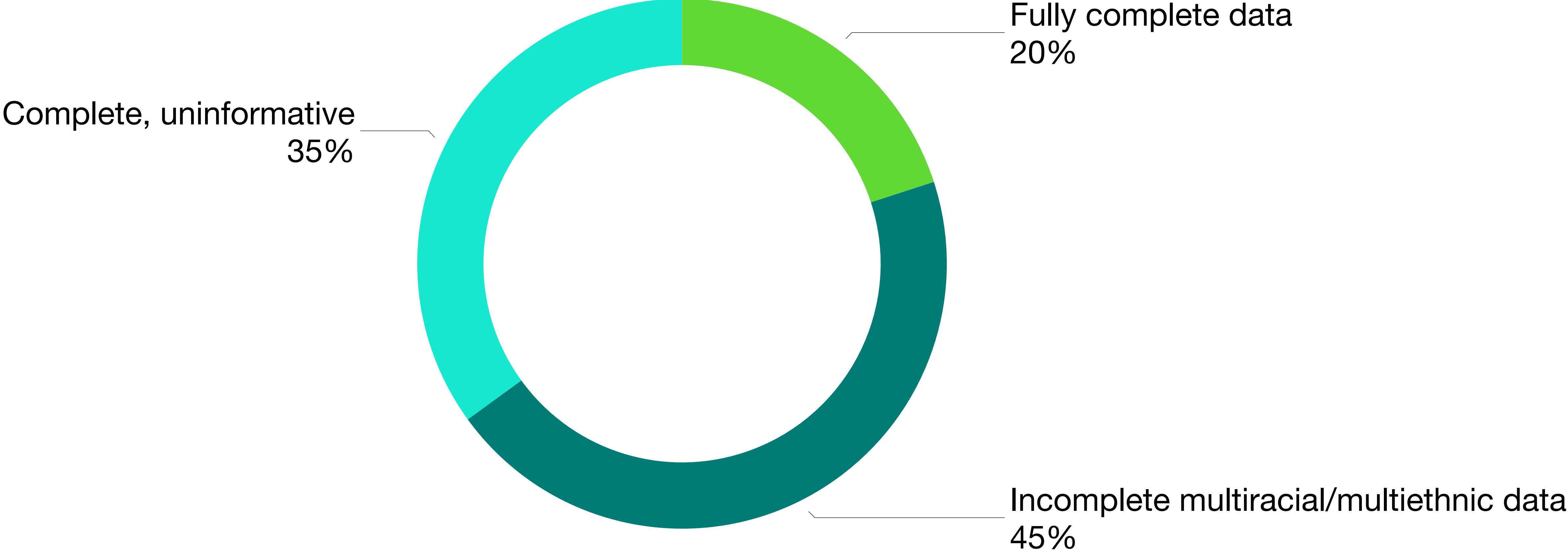
Survey Overview

- **80% of patients provided more informative data using our piloted survey** in comparison to what was recorded in their EHR
- **72.7% of multiracial or multiethnic patients had incomplete data**, with only one race or ethnicity recorded in their EHR
- **0% of patients had missing or incorrect data** recorded in the medical record

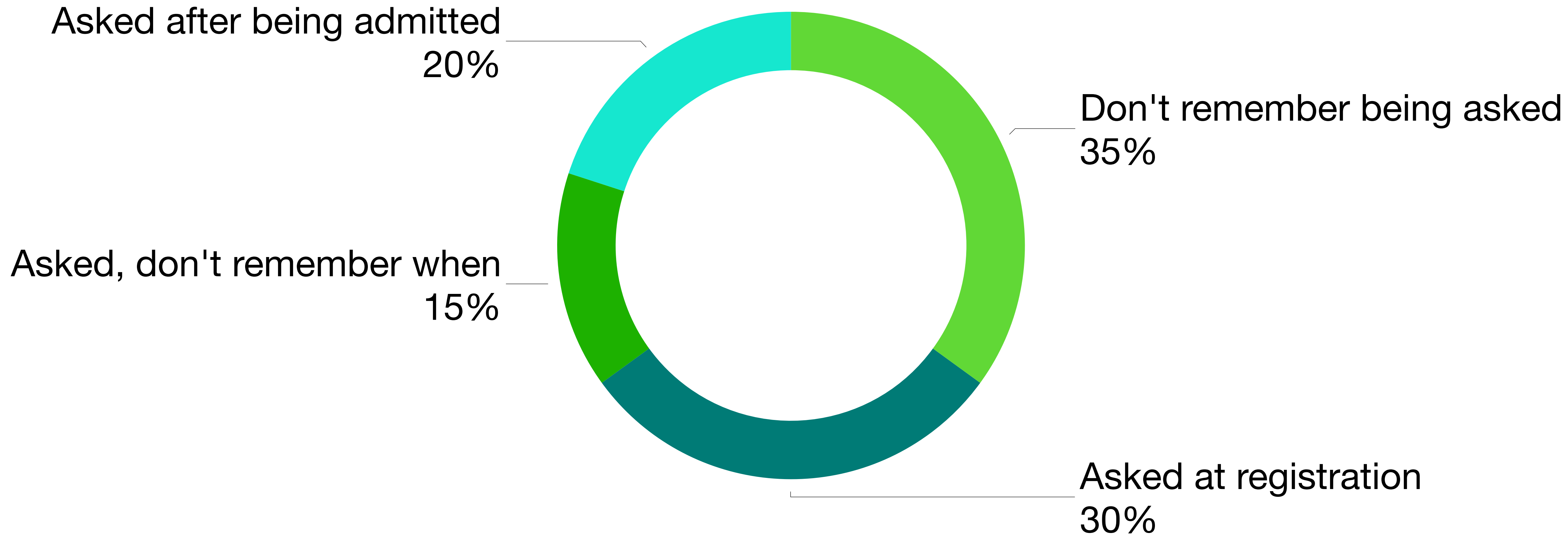
EHR	Survey
White, not Hispanic	Portuguese
Asian, not Hispanic	Japanese
Chinese, not Hispanic	Chinese/Filipino
Caucasian, not Hispanic	Western European
Japanese, not Hispanic	Japanese
Part Hawaiian, not Hispanic	Hawaiian/Filipino/ Eastern European
Asian, not Hispanic	Chinese/Japanese/ Caucasian
Caucasian, not Hispanic	Eastern European
Caucasian, not Hispanic	Western European
NH/PI, Tahitian, not Hispanic	Tahitian/Chinese/ German/Irish

EHR	Survey
Japanese, not Hispanic	Japanese
Part Hawaiian, not Hispanic	Hawaiian/Okinawan/ French
Asian, Other Asian, not Hispanic	Korean/Japanese
Part-Hawaiian, not Hispanic	Native Hawaiian/ Chinese/Filipino/
NH/PI, not Hispanic	Chinese/Filipino/ Samoan/Eastern
NH/PI, not Hispanic	Native Hawaiian/Filipino
White, Part Hawaiian, not Hispanic	Swedish/Irish/Scottish/ Native Hawaiian
Asian, Thai, not Hispanic	Thai
Part Hawaiian, Hispanic	Native Hawaiian/ Chinese/Mexican
NH/PI, Samoan, not Hispanic	Samoan

EHR Comparison



How was REAL data gathered at QMC?



Discussion/Conclusions

Limitations

- Only English-speaking participants
- No data from Black/African American or American Indian/Alaska Native patients
- Small sample population

So what?

1. **Development of a more inclusive, patient-facing survey** may allow healthcare institutions to collect more informative data from patients
2. A **standardized protocol needs to be established** that clarifies exactly how, when, and who collects race and ethnicity data from patients
3. Particular focus should be placed on **gathering more complete data from multiracial and multiethnic patients**, especially in a community as diverse as ours

Now what?

- **Comparison of survey responses to parental data on newborn birth certificates** (a previously established form of patient-recorded REAL data collection)
- **Comprehensive staff training** is just as necessary as establishing a new method of data collection
 - Cultural insensitivity, anxiety about current political climate, and misunderstandings about why REAL data is collected and how it will be used all contribute to **discomfort of healthcare staff** when collecting data (Cruz & Smith, 2021)
 - Negative patient reactions to data collection can be mitigated by providing staff with scripts, establishing training programs, and creating a standardized protocol for REAL data collection (Hasnain-Wynia et al, 2006)
- Budgets often prevent hospitals from rolling out new forms of REAL data collection and training, so **collaboration and sharing of resources among healthcare systems** is critical (Lee et al., 2016)

"Recent advances in health I.T. allow for the ***quantification of health disparities in real time*** ... Healthcare organizations are thus expected to collect race and ethnicity data ***as a part of care itself...***"

- "Health Equity Beyond Data," Cruz & Smith, 2021

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Citations

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