FINDING MEANING IN MEANINGFUL USE: UPDATING PATIENT DEMOGRAPHICS FROM ELECTRONIC HEALTH RECORDS

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INTRODUCTION

- Patient identifiers and demographic information are collected by cancer registries for use in consolidating records for the same patient from multiple sources and for analyzing disparities in cancer burden by race, ethnicity, age, geographic area, insurance status and other characteristics.
- NJSCR and other registries have experienced increasing challenges to obtaining three of these key variables: race, ethnicity, and Social Security number (SSN).
- Table 1 shows the percent of 2017 case reports received by the NJSCR with an unknown race, ethnicity and SSN by reporting facility type.

TABLE 1.

	Unk Race	Unk Ethnicity	Unk SSN
Hospitals	27%	57%	27%
Labs	88%	99%	72%
Outpatient/MD Offices	8%	10%	8%
Other	2%	1%	3%

The NJSCR conducted an analysis of electronic health records (EHR) submitted by private physician offices through the Meaningful Use (MU) component of the Centers for Medicare and Medicaid's Merit-Based Incentive Payment System to determine the feasibility of obtaining more complete race, ethnicity and SSN data.

METHODS

- MU Clinical Data Architecture messages (CDA-m) are transmitted to NJSCR via secure file transfer protocol. Production CDA-m data are imported into the SEER*DMS registry database via an autoloader.
- Auto-linking routines within SEER*DMS link CDA-m data to existing patients and tumors using patient identifiers and SEER multiple primary and histology rules.
- Structured Query Language was used to identify existing patients with unknown SSN, race, or ethnicity in SEER*DMS with a linked CDA-m.
- Existing cases from diagnosis years 2016 and 2017 with a linked CDA-m were manually reviewed to update SSN, race, and/or ethnicity in the existing patient record.

RESULTS

- To date, the NJSCR has received over 330,000 CDA-m from 17 physician practices, including 9 hematology/oncology practices, 7 dermatology groups, and 1 multi-specialty practice and matching more than 28,000 unique patients in the NJSCR registry database and over 14,000 primary tumors.
- 638 patients with a missing or unknown race (175), ethnicity (249) or SSN (276), encompassing 887 primary cancers, had at least one linked CDA-m.
- After manual review, 130 (74.3%), 158 (61.0%), and 179 (64.9%) patients were updated with a known race, ethnicity or SSN, respectively, from the CDA-m (Figure 1).
- The greatest number of cases with an unknown race, ethnicity or SSN and a linked CDA-m were hematopoietic malignancies, followed by skin, prostate and breast (Figure 2).
- The greatest proportion of updates were made to race among breast cancer cases, (n = 10), followed by SSN for hematopoietic cases (n = 118) and skin (n = 37) (Figure 3).
- The review required approximate 8 hours of staff time to complete.

FIGURE 1.
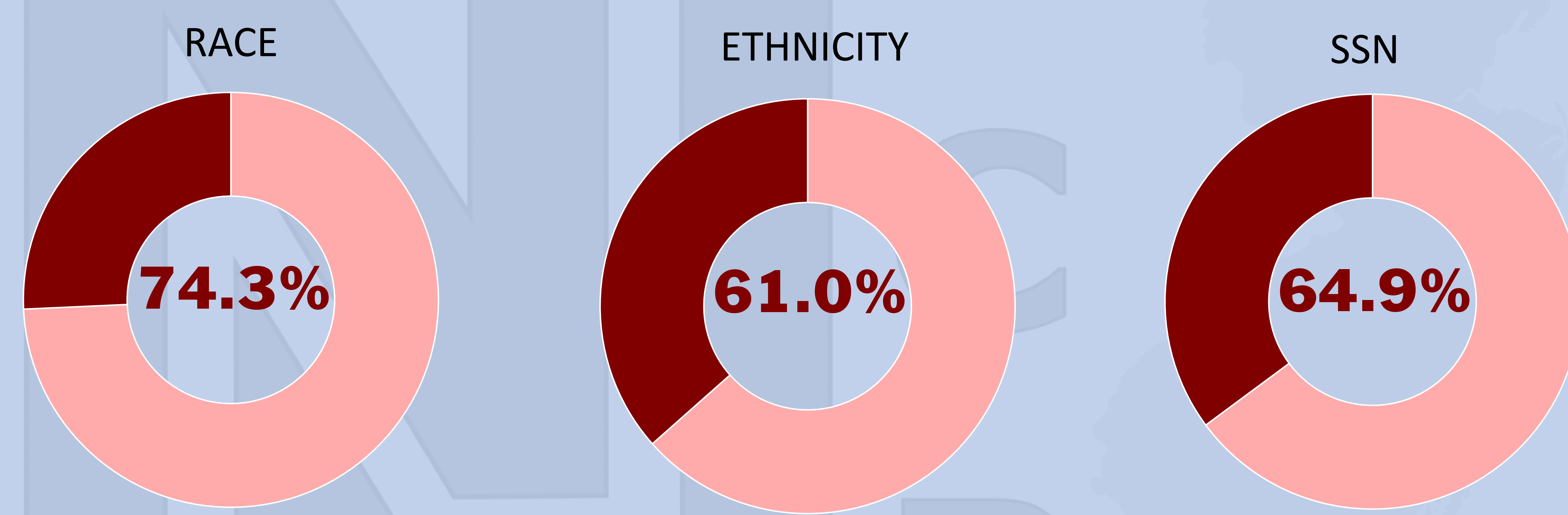**Percent of Patients with Updated Race, Ethnicity or Social Security Number**

RACE 74.3%   ETHNICITY 61.0%   SSN 64.9%

FIGURE 2.
NUMBER OF PRIMARY CANCERS WITH UNKNOWN DEMOGRAPHICS WITH A LINKED CDA-m BY SITE
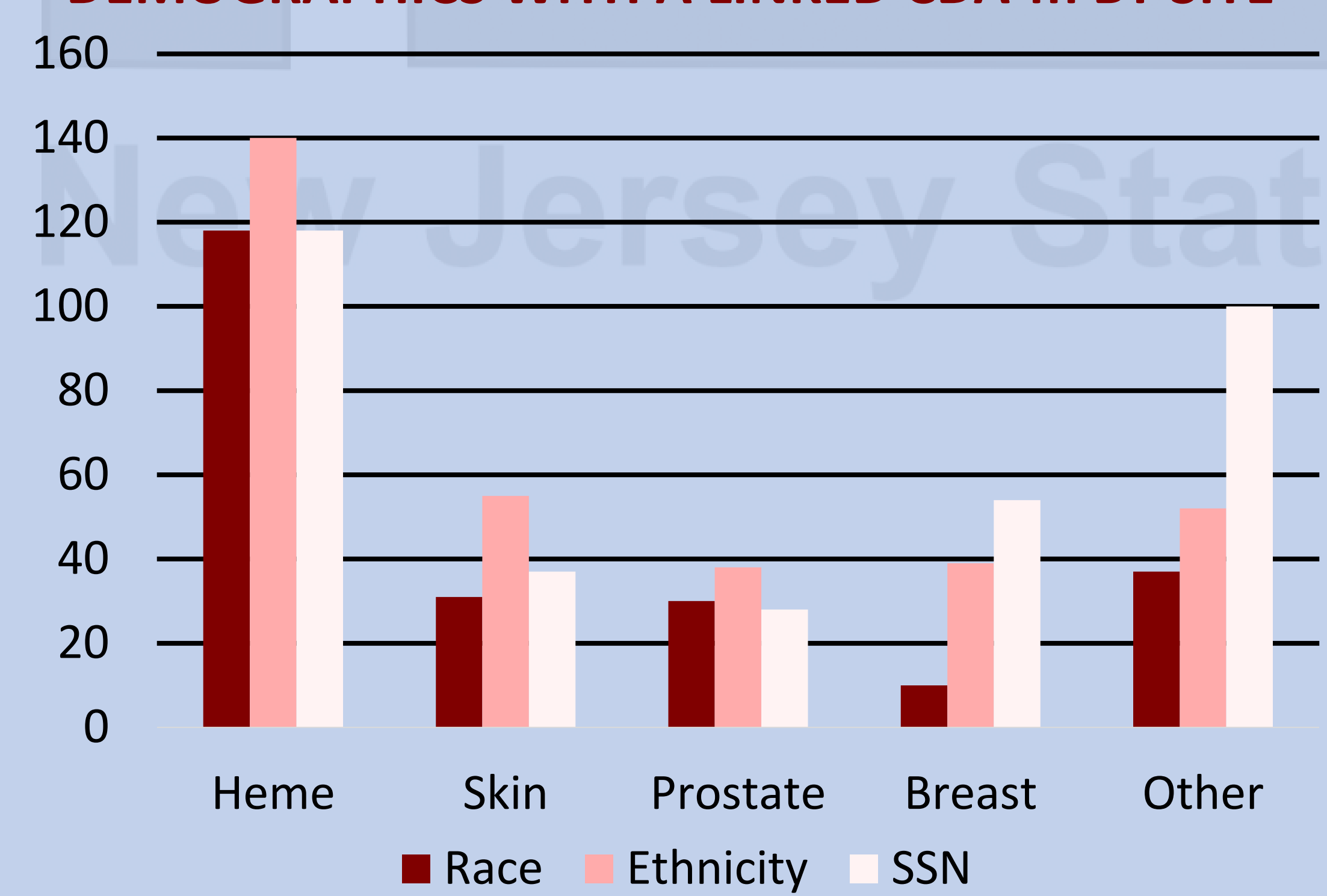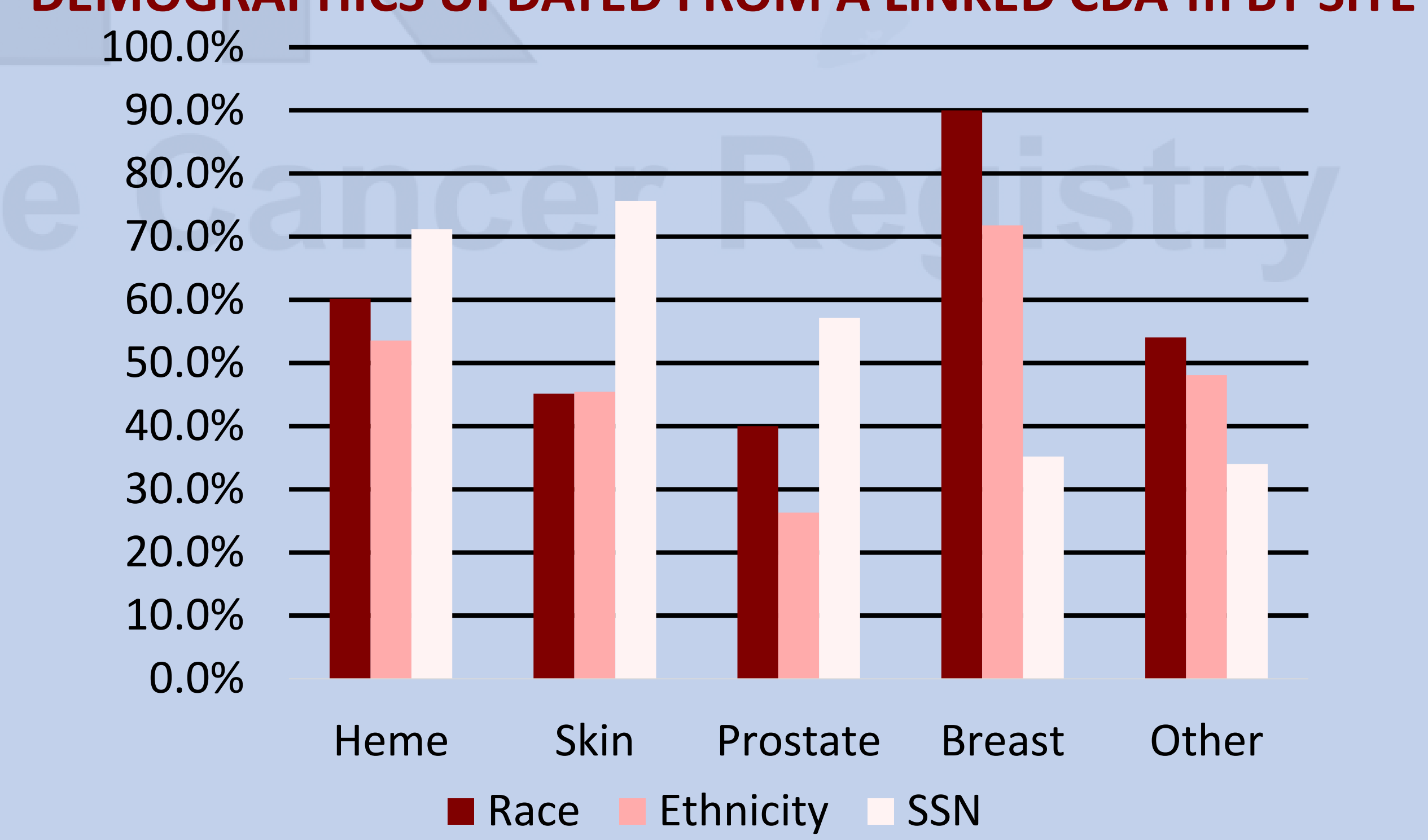

FIGURE 3.
PERCENT OF PRIMARY CANCERS WITH UNKNOWN DEMOGRAPHICS UPDATED FROM A LINKED CDA-m BY SITE

DISCUSSION

- A high proportion of CDA-m received from physician practices through the MU program contain valid race, ethnicity and SSN data.
- Although this analysis was limited to the 17 physician practices currently in production for MU in New Jersey, the expansion of MU reporting to a greater number of physician practices has the potential to significantly impact collection of key demographic variables by the central registry. Currently there are 146 practices that have registered intent, 116 of which was in testing for MU reporting.
- Because MU data is reported for all patients, regardless of address at diagnosis, the expansion of physician reporting of CDA-m has the potential to improve collection of demographic data for central registries outside of New Jersey through the NAACCR interstate data exchange agreement.

CONCLUSIONS

- NJSCR should continue efforts to expand MU reporting by physician practices in order to improve the collection of race, ethnicity and SSN.
- NJSCR should work with key partners to develop automated processes for incorporating race, ethnicity and SSN data from CDA-m into the central registry database.

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