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>
<thead>
<tr>
<th>Facility Type</th>
<th>Unk Race</th>
<th>Unk Ethnicity</th>
<th>Unk SSN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals</td>
<td>27.0%</td>
<td>57.0%</td>
<td>27.0%</td>
</tr>
<tr>
<td>Labs</td>
<td>88.0%</td>
<td>99.0%</td>
<td>72.0%</td>
</tr>
<tr>
<td>Outpatient/MD Offices</td>
<td>8.0%</td>
<td>10.0%</td>
<td>8.0%</td>
</tr>
<tr>
<td>Other</td>
<td>2.0%</td>
<td>1.0%</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

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 history 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 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.

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 interest, 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.

AKNOWLEDGEMENTS

The authors would like to thank Information Management Services, Inc. (IMS) and the SEER*DMS Workgroup for their contributions to incorporating MU data into the registry workflow. Cancer Epidemiology Services, including the New Jersey State Cancer Registry, receives support from the National Program of Cancer Registries, Centers for Disease Control and Prevention under cooperative agreement 6NU58DP006279-02-02, the State of New Jersey, and the Rutgers Cancer Institute of New Jersey. Collection of data used in this project was also supported by the Surveillance, Epidemiology, and End Results Program of the National Cancer Institute under contract HHSN 261201300021I and control No. N01PC-2013-000221.