Utilization of Tableau to Visualize Research Demographic Data Pulled From OnCore and Epic

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1. Background

Equitable participation in clinical trials, including a diverse and representative population, is key to ethical and broad-reaching research. Without diversity, there is a risk of biased or incomplete results, limiting generalizability of findings and effectiveness of interventions in real-world settings. Researchers face hurdles in identifying inclusion gaps due to limited: 1) demographic data in the electronic medical record (EMR); 2) institutional resources to support standardization and inclusiveness; and 3) infrastructure flexibility in the clinical trials management system (CTMS) to incorporate EMR data.

Our project utilizes a data visualization software, Tableau, to merge Epic (EMR) and OnCore (CTMS) data to help researchers identify a subject population reflective of the larger population impacted by the condition under study. This tool fosters outcomes generalizability, and the burdens and benefits of research are fairly distributed.

2. Goals

- Support equitable selection of subjects by understanding the current population and identifying changes over time to evaluate inclusion efforts
- Implement a granular demographics tool for researchers to design studie
- Facilitate understanding of diverse cultural factors for improved recruitment and retention.
- Identify population-based disparities
- Visualize enhanced demographics from Epic and OnCore
- Honor "respect for persons" by asking research subjects to self-identify with more inclusive selections, while collecting required data
- Support Cedars-Sinai's mission of valuing diversity, equity, and inclusion

3. Solutions and Methods

The Cedars-Sinai Cancer Center (CSCC) clinical trials office developed an inclusive demographics questionnaire (IDQ) with stakeholders, including the Institutional Review Board (IRB), Health Equity Office, and the research community.

The institution conducted benchmarking of demographics and demographic collection categorizations from national, state, and city sources, LGBTQIA+ organization guidance, and institutional demographics to determine demographic categories requiring expansion. An IDQ template and support materials (subject information sheet, guidance, staff instructions, REDCap template, and OnCore updates) were created. The categories included race, Latinx ethnicity, ethnic or family origin, sexual orientation, gender identity, and preferred language.

The IDQ and associated resources, including training by the IRB, was deployed in the cancer center. A Tableau dashboard was developed to visualize demographics collected from all clinical trials. This dashboard will allow leadership and researchers to measure the success of implementation of the IDQ and shifting demographics over time.

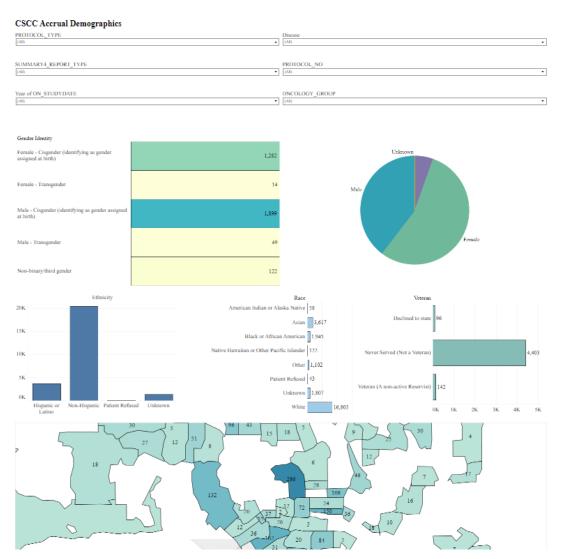
4. Outcomes

The project was implemented in February 2022. The IDQ was translated and is available in the most common seven languages. IDQ data entered in OnCore represent over 170 participants. When merging the demographic data between OnCore and Epic, we can visualize in Tableau the enhanced demographics for over 14,000 research participants between 2001-2024. Our dashboard filters subject demographic data in real time by protocol type, disease type, Data Table 4, on study year, and disease research group.

5. Lessons Learned and Future Directions

We plan to: 1) develop best practices for implementing demographic collection from children with Pediatrics leadership; 2) provide the Tableau dashboard to all researchers and study team members to enhance recruitment methods; and 3) support the requirements under AB 1204, newly passed legislation which requires all California Health Systems/Hospitals to submit an Annual Health Equity Report starting in 2025.

Figure



Category: Community Outreach and Engagement & Diversity, Equity, and Inclusion - Completed project