

Community Outreach, Community of Color Accrual: CS-Link Registration and OnCore Enhancements to Capture Ethnic Subgroups, Gender, and Sexual Orientation

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1. Background

Collection of patient demographics for frontline operations and research patients has been standardized at Cedars-Sinai through use of CS-Link (Cedars-Sinai's patient management system) and OnCore (clinical research management system), but there has been a gap in capturing granular demographic data for research participants. This data has been defined as inclusive demographics for research (IDR) and consists of ethnic and racial categories, gender, and sexual orientation (SOGI) and preferred language. Collecting demographics in a comprehensive and inclusive manner provides important insights into populations participating in research at Cedars-Sinai and supports goals of inclusion and equity in research. Historically, the collection of demographics was not inclusive of many populations; this project seeks to correct this deficiency.

2. Goals

By expanding demographic standards, the goal is that historically under-represented populations will be equitably included and better understood in research. The metrics assessed represent an increased focus on the catchment area, targeting the largest communities of color: Latinx, Korean, Filipino, and Black, as well as data on sexual orientation and gender identity (SOGI).

3. Solutions and Methods

An assessment was conducted to review the ability in OnCore to support the collection of the IDR and compare it to CS-Link to determine the opportunity to pull existing IDR data from CS-Link to OnCore. We determined that CS-Link was missing the IDR (which meant information was not being collected at registration or patients were not disclosing the data), and OnCore did not have a location to contain the IDR. The issue was presented to our IRB, which resulted in Cedars-Sinai's IRB reviewing and approving the proposal to allow collection of IDR through a patient questionnaire. OnCore was enhanced to add additional fields to support the addition of the IDR. Through collaboration between Cedars-Sinai's IRB, cancer clinical trials office (CCTO), and health equity and marketing staff, resources were developed. These include an IDR work paper to explain the purpose from a policy perspective, a guidance document which introduces the subject and is a step-by-step guide of the IDR collection process, print versions of the questionnaire, verbal scripts, patient instructions to update their IDR on the patient portal, digital templates for including the questionnaire in research, and recorded presentations explaining resources to staff. Training was conducted for staff in collaboration with the National LGBT Cancer Network to enhance awareness of terminology and to obtain resources for potential challenges when collecting IDR.

4. Outcomes

Data collection for IDR within the CCTO began on February 23, 2022. During the period of February 23-28, there were a total of 12 questionnaires completed. While the numbers are less than 11 at this time, we are unable to share data tables in order to protect patient confidentiality. However, we are seeing positive granular data entries for origin and race, and SOGI.

5. Lessons Learned and Future Directions

Data collection to include historically under- or mis-represented groups requires multiple stakeholders and both electronic medical record and clinical trials software changes. Future work will center on obtaining IDR data directly into the CS-Link data stream which can be shared seamlessly with OnCore.