Community Outreach, Accrual: Epic Registration and OnCore Enhancements to Capture Inclusive Demographics

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Background

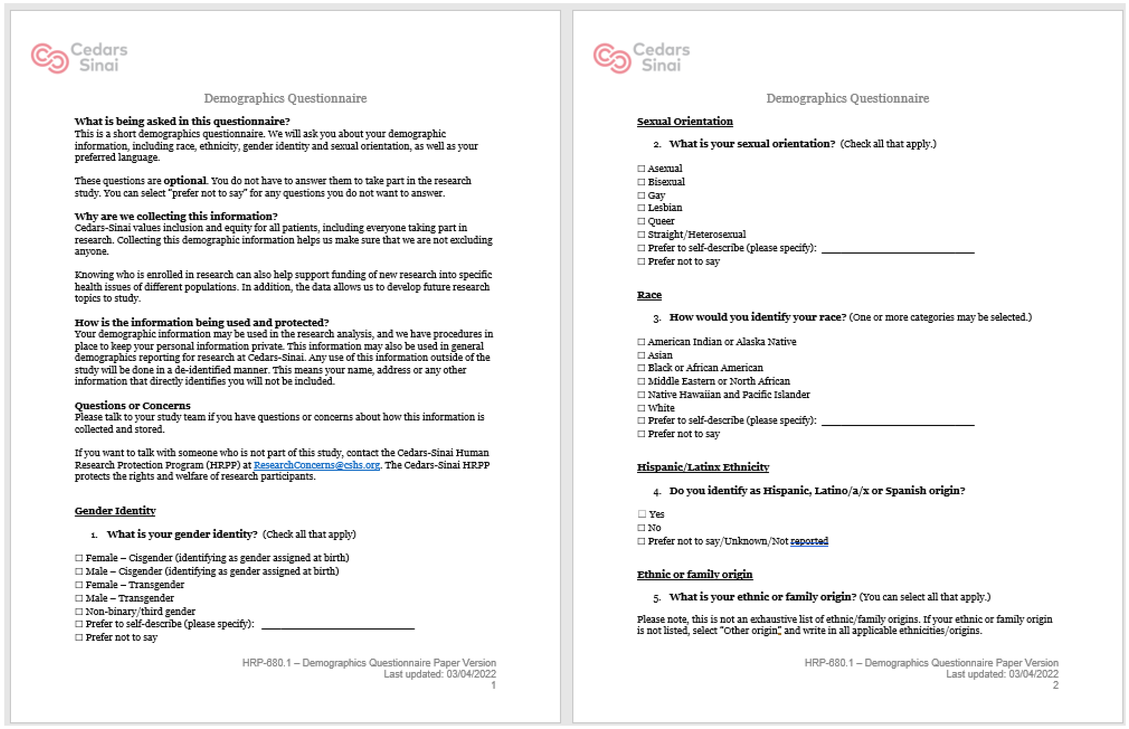
While collection of patient demographics for frontline operations and research patients has been standardized at Cedars-Sinai through use of CS-Link (Cedars-Sinai's electronic medical record and patient portal) and OnCore (clinical research management system), there has been a gap in capturing granular 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.

Metrics and 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, Black and data on sexual orientation and gender identity (SOGI).

Solutions and Methods Implemented

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: 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), Health Equity and Marketing staff, resources were developed: 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.



Demographics Questionnaire

What is being asked in this questionnaire?
This is a short demographics questionnaire. We will ask you about your demographic information, including race, ethnicity, gender identity and sexual orientation, as well as your preferred language.

These questions are **optional**. You do not have to answer them to take part in the research study. You can select "prefer not to say" for any questions you do not want to answer.

Why are we collecting this information?
Cedars-Sinai values inclusion and equity for all patients, including everyone taking part in research. Collecting this demographic information helps us make sure that we are not excluding anyone.

Knowing who is enrolled in research can also help support funding of new research into specific health issues of different populations. In addition, the data allows us to develop future research topics to study.

How is the information being used and protected?
Your demographic information may be used in the research analysis, and we have procedures in place to keep your personal information private. This information may also be used in general demographics reporting for research at Cedars-Sinai. Any use of this information outside of the study will be done in a de-identified manner. This means your name, address or any other information that directly identifies you will not be included.

Questions or Concerns
Please talk to your study team if you have questions or concerns about how this information is collected and stored.

If you want to talk with someone who is not part of this study, contact the Cedars-Sinai Human Research Protection Program (HRPP) at ResearchConcerns@cshs.org. The Cedars-Sinai HRPP protects the rights and welfare of research participants.

Gender Identity

1. **What is your gender identity?** (Check all that apply)

☐ Female – Cisgender (identifying as gender assigned at birth)
☐ Male – Cisgender (identifying as gender assigned at birth)
☐ Female – Transgender
☐ Male – Transgender
☐ Non-binary/third gender
☐ Prefer to self-describe (please specify): _____
☐ Prefer not to say

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1

Demographics Questionnaire

Sexual Orientation

2. **What is your sexual orientation?** (Check all that apply.)

☐ Asexual
☐ Bisexual
☐ Gay
☐ Lesbian
☐ Queer
☐ Straight/Heterosexual
☐ Prefer to self-describe (please specify): _____
☐ Prefer not to say

Race

3. **How would you identify your race?** (One or more categories may be selected.)

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Middle Eastern or North African
☐ Native Hawaiian and Pacific Islander
☐ White
☐ Prefer to self-describe (please specify): _____
☐ Prefer not to say

Hispanic/Latinx Ethnicity

4. **Do you identify as Hispanic, Latino/a/x or Spanish origin?**

☐ Yes
☐ No
☐ Prefer not to say/Unknown/Not reported

Ethnic or family origin

5. **What is your ethnic or family origin?** (You can select all that apply.)

Please note, this is not an exhaustive list of ethnic/family origins. If your ethnic or family origin is not listed, select "Other origin," and write in all applicable ethnicities/origins.

HRP-680.1 – Demographics Questionnaire Paper Version
Last updated: 03/04/2022
2

Figure 1 Paper Questionnaire

Outcomes and Data / Representing Change

Data collection for IDR within the CCTO began on February 23, 2022. Between the period of 2/23/22 – 4/30/22 there were a total of 18 questionnaires completed representing the following approximate participation in interventional therapeutic trials: 1% for LGBTQ+, 1% for Filipino, 1% for two or more races, 3% Chinese, 5% for Black, and 14% for Latinx communities.

Lessons Learned / Pointing Toward the Future

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 in addition to synthesizing the new data into possible research.