



Project Overview

Equitable Engagement and Consent in Clinical Research

Overarching Goal: Advance health equity by increasing participation of underrepresented subpopulations in clinical research

Justification: Marginalized racial, ethnic, gender, age, and geographical subpopulations are underrepresented in clinical research. Consequently, medical diagnostics, treatments, and devices may not be equally safe or effective for all potential patients.

Project: Create and curate an online collection of resources that conveys the importance of authentically engaging diverse communities as partners in clinical research and provides best practices for stakeholders to increase participation by underrepresented subpopulations. We will individually customize content for sponsors, CBOs, healthcare providers, researchers and research staff, and participants.

Background

The [California Precision Medicine Advisory Council](#) is comprised of stakeholders including academics, industry researchers, clinicians, patient advocates, and venture capitalists. The council guides the activities of the [California Initiative to Advance Precision Medicine](#). Council members have formed a working group to developing a more equitable framework for engagement and consent of research participants, based on recommendations from [Precision Medicine: An Action Plan for California](#).

Phase One: Informal outreach and scoping

Meet with individuals from across sectors; present to committees and councils.

Phase Two: Content generation and formal outreach

Build out content and website infrastructure; conduct listening sessions and/or focus groups to ensure content coverage.

Phase Three: Content review

Engage stakeholders from across the research spectrum to review the content for style, digestibility, etc.

Phase Four: Dissemination

Work with academic institutions, trade associations, patient advocacy groups, professional societies, and others to bring awareness to the website; ongoing presentations to relevant organizations

To provide feedback about the content or help disseminate the final product, email Shannon.muir@opr.ca.gov