



Equitable Consent Working Group Meeting Summary, June 2021

The draft outline for the Equitable Consent website includes:

- A definition
- History, including case studies
- Existing laws and policies
- Best practices and toolkits for researchers, research staff, and potential and existing research participants

During the meeting, the following points were made to update the outline:

- Page Description: Equitable Engagement and Consent in Clinical Research
- Write a more robust introduction, delineating between different types of consent (consent to be treated, research consent, etc.)
- Include an overview of research engagement, and where the consent process fits in the life cycle
- A more detailed definition of equitable consent, including cultural competency and proportional representation
- Inclusion of data on the current state of URM participation in research
- Addition of content specifically for research funders, including best practices for developing RFPs, like CABs and proportional representation
- Inclusion of stories and quotes from community members, along with consent to participate
- Address payment/compensation for research participants
- Develop one-pagers that research staff can print and distribute to community members
- Include the Belmont report
- Include the Guatemalan prison study
- Include history of research with Havasupi
- Use the term “research participants” instead of “subjects”
- Link to CIAPM’s existing community engagement guidance

Advisors also added the following organizations and contacts to a list of entities that might be resources:

- Patients Like Me
- California Pan-ethnic health network
- NORDD- national organization for rare diseases
- All of Us
 - Hispanic Health Networks
 - AAPI groups
- Scripps and Rady Children's
- Charles Drew faculty

Next Steps:

- Develop content of case studies
- Build test site
- Contact outside organizations and people who may be of assistance