California Initiative to Advance
Precision Medicine

Equitable Consent Working Group
Draft Meeting Summary, April 2021

Prior to the meeting, Working Group members were asked to rank problems related to equitable consent that had been mentioned at the prior meetings, in the order in which they think the problems should be addressed:

	Problem	Proposed Solution
A	A normal consent process doesn't include much compelling information that would encourage people to be involved.	Include stories, specific to certain communities, in the consent process; inserts that address concerns within communities.
B	Staff at community health clinics don't have a solid foundation of the ethics, history, and principals of informed consent to fully understand the consent process.	Develop guidelines or materials to help train clinic staff to understand the consent process in a meaningful way; create checklists; Help sites to evaluate if they are compliant; Synthesize existing recommendations.
C	Data from study subjects can't move across studies or institutions, so data can't be analyzed on a large scale.	Create (recommendations for) standardized language to include in consent forms that will allow for wider sharing of data among researchers. What if we focused specifically on genomic data?
D	URM haven't been given the tools/opportunity to understand what research is, how it impacts them, and why they would want to engage, which limits study enrollment.	Create (recommendations for) training materials that CHWs and CBOs could use to educate potential URM research subjects.
E	Consent forms are long and complicated, and the information is not presented in a way that makes it easy for participants to make an informed decision about whether to participate.	Create recommendations or guidelines for the process of obtaining consent so that it is more accessible.

The eventual rankings were:

	Problem	Proposed Solution	1	2	3	4	5	6	Avg.
E	Consent forms don't adequately address the issues important to various URM.	Create recommendations for making the process more accessible.	3	1	4	1	1	3	2.167
C	Data is siloed.	Create recommendations for standardized language that will allow for wider sharing of data among researchers.	5	5	1	3	2	1	2.83
D	URM haven't been given the tools/opportunity to understand their role in research.	Create (recommendations for) training materials for CHWs and CBOs.	2	2	5	2	3	4	3
B	Staff at community health clinics need consent training.	Develop guidelines/materials to help clinic staff understand the consent process.	4	3	3	4	4	2	3.33
A	Consent process isn't compelling.	Include stories in the consent process that address community concerns.	1	4	2	5	5	5	3.67

Working Group members were reticent to address one problem at a time, expressing concern one problem could not be tackled without considering others. They suggested that a possible project could be to facilitate

focus groups to get feedback from different underrepresented communities specifically about UCLA's video on universal consent for leftover biological samples; that feedback could then be incorporated into future iterations/versions of the film.

Staff indicated that

1. At the present moment, there is no money to outsource that work.
2. Getting that work off the ground would require a significant time investment to find resources and gain knowledge related to the consent process and possible reasons why different communities might not want to participate.
3. A "quick win" might be to organize and synthesize all the resources and learnings that staff would have to collect and review anyway for the focus group project, and publish those on a webpage that is integrated with the existing CIAPM webpage's Precision Medicine Primer (also see the Educational Resources page).
4. While the webpage is be developed, staff could investigate and pursue mechanisms to fund the focus groups.

The webpage has several advantages over a stand-alone document in that it can

- Present information in digestible sections, instead of having to be comprehensive.
- Allow readers to navigate to topics of interest more easily.
- Link to external resources in a simple way.
- More easily have content dedicated to different stakeholder groups (researchers, research staff, existing and potential research participants from different communities).
- Be published in parts over time, instead of waiting for a final, all-inclusive product.
- Be updated easily to incorporate new resources.

The envisioned webpage would be more than a collection of resources; it would also summarize current thinking and provide toolkits, lists, and diagrams to convey information clearly so that it can be easily incorporated into workflows, customized for different circumstances, and utilized to improve the consent process, facilitate data sharing, and increase participation by underrepresented minorities in biomedical research.

The next step is for staff to draft an outline of the information to be contained on the website and send it to the working group members for review prior to the next working group meeting.

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