

California Precision Medicine Advisory Council Summer 2020 Meeting, Part 2 August 27, 2020 Meeting Minutes

Call to Order

Meeting called to order by Chair Clara Lajonchere at 10:00 am.

Introductions of Council Members and Staff

Council members present

Nadine Burke Harris; Ysabel Duron; Oliver Keown; Kenneth Kim; Clara Lajonchere; Bonnie Maldonado; Fatima Munoz; Hakan Sakul; Mary Ann Schultz; Keith Yamamoto

Governor's Office of Planning and Research staff present

Megan Varvais; Shannon Muir; Julianne McCall; Ken McCullough; Aiyana Emigh; Hyunsoo Gloria Kim; April Booth

World Economic Forum presentation

Dr. Lajonchere introduced Genya Dana, PhD, Head of Precision Medicine at the World Economic Forum.

Dr. Dana discussed the background of the World Economic Forum, its precision medicine program, and presented the *Precision Medicine Vision Statement: A Product of the World Economic Forum Global Precision Medicine Council*. The Vision Statement involved over 40 experts from 18 countries, and focuses on the governance gaps that impede widespread implementation of precision medicine practices and principles. The Vision Statement analyzes the following five governance gaps: data sharing and interoperability; trust and public engagement; ethical technology use; access and pricing; and regulatory systems.

Several of the governance gaps in the *Vision Statement* align with the policy recommendations brought forth in the 2018 report *Precision Medicine: An Action Plan for California* (PMAC).

Following the presentation, Dr. Dana answered questions from several Council members.

Discussion of potential CIAPM projects

Prior to the meeting, a survey was sent to Council members asking them to rank ten possible projects for the CIAPM to undertake, in order of their perceived importance. The options were:

Social Determinants of Health Standards (SDOH)
Model Framework for Informed Consent (MFFIC)
Data-sharing guidance

Educational Programs for Research Participants
Improve Laboratory Developed Tests- Lessons learned from key COVID indicators (LDTs)
APIs for EHRs
Genetic Information Nondiscrimination Act (GINA)
Hollywood, Health, and Society Program
Patient-centered study design
Economic model of precision health care

Shannon provided background on the source of the ten projects, and several others that were presented for discussion but not included for ranking. The proposals were sourced from the PMAC (with special consideration for those that overlapped WEF *Vision Statement* governance gaps), and Council member discussions and public comments from the May meeting. The top three ranked projects were Social Determinants of Health (SDOH) Standards; Data-sharing guidance; and APIs for EHRs.

Dr. Lajonchere laid out the timeline for projects, which is through 2025.

Dr. Keown suggested data-sharing guidance and SDOH could be bundled together as a single project, since they overlap.

Dr. Yamamoto commented that the MFFIC proposal could help assure patients their data was safe, while also liberating the information for more research. He felt it was a large step forward for precision medicine with little investment of staff time.

Dr. Munoz thought Educational Programs for Research Participants, Patient-centered study design, and MFFIC could be bundled together as complementary ideas.

Ms. Duron stressed the importance of a universal informed consent framework. She has investigated different ways consent is offered and each provider uses their own protocol, which is confusing and unhelpful for patients. She would like to see patients give meaningful consent, instead of simply signing a form because someone in their provider's office asked them to. Dr. Lajonchere agreed, and said the UC system is working on a universal consent framework using videos, which are easier for patients to understand.

Dr. Sakul commented that he would like to spend more time considering the project options, and asked if the top 10 could be expanded at this point. Dr. Lajonchere explained the top 10 were highlighted because they aligned with the Governor's priorities, already considered in the PMAC report, and possible with CIAPM's current resources. Dr. Lajonchere said she wanted to form a committee for fundraising, even though it wasn't listed among the project options.

Dr. Muir explained the process by which the top 10 project options were screened. She mentioned that although LDTs were included in these options and discussed in the PMAC, it is a very difficult area to make an impact. The PMAC recommendations were drafted pre-COVID, so perhaps a brainstorm of new ideas is warranted.

Dr. Kim asked if there was any interest in COVID-specific precision medicine projects. Dr. Muir said the Council could formulate COVID-related outcomes for any of the existing options. Dr. Kim said the impact of COVID research on minorities is at the forefront of many stakeholders' thinking. Dr. Muir agreed this is a pressing issue, with a crowded playing field. CIAPM should be strategic with its resources, and consider how the Governor's Office of Planning and Research can be an *exceptional* addition to any existing work.

Dr. Burke Harris suggested CIAPM should create guidance for the enormous amount of research that is already occurring in SDOH, or COVID. Dr. Muir said providing guidance to researchers is a good fit for CIAPM, instead of attempting primary research.

Public Comment

No public comment was received.

Wrap up and next steps

There was further discussion about the project proposals. Dr. Yamamoto thought the top ten projects could be seen as responses to what COVID has taught researchers about process.

Dr. Sakul suggested grouping the ideas together into topical buckets, instead of considering each one individually.

Dr. Lajonchere said Council members could even consider ideas not listed today, with staff input on feasibility.

Ms. Duron said that GINA should be paired with MFFIC, because achieving buy-in from patients must include the assurances provided by GINA.

Dr. Sakul suggested the scope of LDT project options be narrowed, perhaps in a way that complements MFFIC.

CIAPM staff will consider the suggestions offered from the Council and follow up at a later time.

Adjourn

Dr. Lajonchere adjourned the meeting at 12:01.