

California Precision Medicine Advisory Council

Meeting Part 2

May 15, 2020

Minutes

Members present

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

Members not present

Mark Ghaly

Governor's Office of Planning & Research staff in attendance

Shannon Muir; Julianne McCall; Megan Varvais; Ken McCullough; April Booth; Chris Wang

10:03 am Meeting called to order by Dr. Lajonchere

Introductions

Shannon Muir invited the council members present and CIAPM staff to introduce themselves.

Draft Council Guidelines, revisited

Dr. Lajonchere introduced proposed changes to Article 3 of the Draft Advisory Council Guidelines that were initially proposed and/or suggested during meeting part 1 (italicized) or were newly suggested by CIAPM staff (in brackets):

1. Expected term of service of Council members may be as follows:
 - a. In the first year
 - i. Three members may be invited by OPR to serve a three-year term.
 - ii. One member may be invited by OPR to serve a two-year term.
 - iii. Three members may be invited by OPR to serve a one-year term.
 - b. Both members recommended by the Legislature may be invited to serve a two-year term.
 - c. Following the first year, all new terms may be three years.
 - d. Members should serve no more than six years total on the Council.
 - e. Members invited to fill vacancies should serve out the remainder of the position's term.
 - f. Vacancies that occur should be filled within 90 days after the occurrence of the vacancy, and should be filled in the same manner in which the vacating member was invited.

2. *The Council will elect a Chair and a Vice Chair for a one-year term.*
 - a. *Nominations*
 - i. *Nominations do not need to be seconded.*
 - ii. *A person can nominate himself or herself.*
 - iii. *Nominations for Vice Chair will follow election of Chair.*
 - b. *Nominee Statements*
 - i. *Each nominee will have two minutes to make a statement to the Council prior to the first round of voting.*
 - c. *Elections*
 - i. *Every Council Member, including ex officio members, get one vote.*
 - ii. *Ballots will be counted in secret.*
 - iii. *In the event of a tie, the Council will have a new round of voting [that includes all candidates. The new round will not be a runoff].*
 - d. *The Vice Chair will be responsible for fulfilling the Chair's duties when the chair is unavailable.*
3. *Quorum is achieved with seven Council members.*
4. *Six affirmative votes are needed for procedural motions to pass.*
5. *Ex officio members may vote and are counted toward quorum.*
6. *All motions that do not receive at least six affirmative votes during a meeting part are held open for 48 hours after that meeting part adjourns.*
7. *Council members who were not present at the time a motion was made may submit their votes for open motions up to 48 hours after that meeting part adjourns. Council members who voted for a motion during a meeting may not change their vote via email.*
8. *Votes for or against a motion may be submitted via email prior to a meeting. Votes submitted prior to a meeting will only be counted if the motion presented during the meeting matches, verbatim, the motion for which a vote was submitted via email.*
9. *Votes submitted via email prior to a meeting may be changed by the voter during the meeting when that motion is being considered and up to 48 hours after the meeting part has ended.*
10. *Non-election votes submitted by email are subject to public posting policies.*
11. *Council members will be reimbursed for travel consistent with OPR's travel policies.*
12. *Any member of the Precision Medicine Advisory Council should be ineligible to apply for [or receive] funding as a Principal Investigator from project grants during his or her*

term of service on the Council, and for one year immediately following his or her term of service on the Council.

13. The Council should meet at least four times annually in person and the meetings should be held in locations that allow stakeholders in different regions of the state to participate.

After discussion, Advisors suggested passing all suggested language except Article 2.8 and Article 2.9. The Draft Guidelines were ratified by a unanimous roll call vote.

Overview of CIAPM Budget and Changes Following the May Revision

Dr. Muir gave an overview of California state budget projections and how the budget has been impacted by the COVID-19 pandemic. Muir gave a summary of the CIAPM budget, planned projects, and the impacts of changes in state budget projections. In the Governor's May Revision of the 2020-2021 proposed budget, the Department of Finance recommended sweeping back \$18.2 million of CIAPM's unspent funds into the General Fund. CIAPM had intended to use the \$18.2 million to fund future demonstration projects (topics were to be determined). The funding that CIAPM had internally allocated for Adverse Childhood Experiences (ACEs) demonstration projects was left intact. CIAPM operating funds are projected to last through the end of the ACEs projects and formal project evaluations.

Surgeon General Burke Harris provided some clarification on issues related to state-wide funding, stating that 50% of funding for training for ACEs screening had also been recommended for reappropriation by the Department of Finance. Several Council members (Dr. Kim, Ms. Duron, Dr. Yamamoto, and Surgeon General Burke Harris) highlighted that it is critical to address the current COVID-19 pandemic, and health disparities resulting from it.

Dr. Lajonchere noted that, absent of funding for demonstration projects, CIAPM is in a position to bring together leaders and experts in the study of precision medicine and Social Determinants of Health. One of the critical roles of CIAPM is to identify topic areas of special importance and value for the Governor.

Discussion of Current ACEs Request for Proposals

Dr. McCall delivered an update on the current status of the ACEs RFP. The window for required Letters of Intent closed in February. CIAPM received 39 letters from 17 institutions across the state. Concept proposals are due July 22nd. The Selection Committee will meet in August to identify finalists. Up to five awardees will be announced by December 8 and begin in February 2021.

Presentation of Precision Medicine Action Plan

Dr. Lajonchere presented selected recommendations from *Precision Medicine: An Action Plan for California*, that may act as guideposts for CIAPM's future activities. She highlighted recommendations that named OPR and/or the Governor's Office. The recommendations included, but were not limited to, convening working groups that establish standards or guidance for the following:

- Social Determinants of Health data collection
- Cross-institutional data sharing
- A California Patient Record
- A model consent framework
- Third-party review of Laboratory Developed Tests and direct-to-consumer tests.

The *Action Plan* also recommends that OPR and the Governor’s Office develop economic models that integrate precision medicine principles into healthcare.

Discussion of Future Directions and CIAPM Initiatives

Dr. Sakul noted that both during the current situation and more normal times the government may act as a key partner to promote new diagnostics and treatments by interfacing with regulatory agencies in the federal government.

Dr. Lajonchere stated that the current global health situation accentuates the importance of developing equitable healthcare cost models that allow access for all Californians, and that this may be a crucial area of interest for CIAPM. Surgeon General Burke Harris noted that the work of CIAPM remains critically important and that building precision medicine models will advance our understanding of health outcome disparities. She added that this is an opportunity for CIAPM to develop a strong agenda using its expertise and Council members to connect with foundations and funders. Ms. Duron seconded the need to build equitable care models based on prevention and value-based care. Dr. Muñoz stated that funding challenges provide opportunities to build partnerships between public and private institutions to promote common agendas. Dr. Keown pointed out that CIAPM is well placed to develop a health equity agenda and promote precision medicine for value-based care.

Dr. Yamamoto emphasized the need for precision medicine approaches in the current situation, adding that research needs to be completed quickly to optimize impacts on health outcomes. Dr. Maldonado agreed and state that there is a large outpouring of philanthropic interest in addressing health disparities related to COVID -19.

Public Comment

Angela Ramirez Holmes, Founder and President for the California Action Link for Rare Diseases, spoke about the opportunity to address rare diseases through principles of precision medicine.

Thomas Earnest, Founder and CEO of Savant Healthtech, submitted comments via chat, saying that two major obstacles that must be solved for precision medicine to achieve a high level of impact on public health are low and non-representative sampling, especially of the underserved, and lack of integration with other information, including medical, health, environmental, and others.

Wrap up and Next Steps

- Council Guidelines were ratified. Draft language for submitting comments (no more than half a page) prior to meetings will be circulated before the next Council meeting.
- The Department of Finance recommended that \$18.2 million of unspent CIAPM funding be swept back to the State General Fund. The budget must be passed by the Legislature by June 15th.
- Considerations for the future of CIAPM:
 - Develop focused agendas around which others can convene
 - Ground-up work
 - Developing critical relationships, and consider primary care
 - Develop economic framework: Precision medicine in value-based care (with SDOH and equity lens)
 - Capitalize on current public interest in mechanisms of disease for an information/education campaign
 - Craft messages of impact to foster philanthropic opportunities
- Next Council meeting is to take place in Summer 2020.

Election of Chair and Vice Chair

Clara Lajonchere was unanimously elected chair of the Council. Keith Yamamoto was elected Vice Chair.