

California Precision Medicine Advisory Council Draft Meeting Summary, May 2022

Introduction of new council member

Corrin Buchanan is the Deputy Secretary for Policy and Strategic Planning at the California Health and Human Services Agency. Corrin has spent most of her career in systems change work in state and local government. Prior to joining CalHHS, Corrin served at the Assistant Director of Housing and Homelessness for the California Department of Social Services. She worked for the Los Angeles County Department of Health Services as the Deputy Director for the Office of Diversion and Reentry where she oversaw countywide behavioral health diversion, reentry, and youth diversion and development efforts. Also, with Los Angeles County Department of Health Services, she launched and managed the Flexible Housing Subsidy Pool, a locally funded rental subsidy program with the Housing for Health division. Corrin was Health Program Planner for Housing and Urban Health at the San Francisco Department of Public Health and the Community Programs Director for the San Francisco Women's Building. Corrin holds a bachelor's degree and a master's degree in public policy from UC Berkeley.

Update from the Newsom Administration

Richard Figueroa, Deputy Cabinet Secretary

- I appreciate CIAPM's engagement with the legislature, to remind them that this program exists and that there are scientists working in the Governor's Office.
- The state in good fiscal health, and the governor has proposed substantial reserves because there is so much uncertainty. We are trying to be good stewards of resources, but we are also making one-time investments for drought, fire resiliency, climate change, and homelessness.
- New institute for immunology and immunotherapy at UCLA, \$500 million matched with \$500 million in private investment. The state doesn't generally do this; we usually rely on the UCs to get private investment or federal grants, but the governor feels strongly about this.

For the State Appropriations Limit, infrastructure investments don't count toward

Sam Assefa, Director of Governor's Office of Planning and Research

- CIAPM has two budget asks that are moving through the legislature: \$10 million for depression research, and the Underrepresented Minorities in Research item.
- The budget items have made it out of the Senate budget subcommittee and will be heard by the full Senate budget committee within the next few weeks. The items have been heard by the Assembly subcommittee but have yet to be voted upon. After being passed by the separate, full budget committees, they will be heard on the floors of both houses and voted upon by all members, then the items go to the governor's desk for signature.
- We are very proud to have released <u>CIAPM's 2021 Annual Report to the Legislature</u> last Tuesday. Thank you to those of you who were panel members during the briefings for the annual report, and to those of you who attended the briefings. I know that there wasn't time on the agenda today, but staff are planning to give an overview of the report during the summer council meeting.
- Megan Varvais, the Communication and Administrative Specialist for CIAPM recently stepped down from her position. I wanted to take the chance to publicly thank her for all her hard work over the last three transformative years at CIAPM. Julianne and Shannon are in the process of recruiting a new team member to fill that role.
- Discussed the Governor's proposed <u>Office of Community Partnerships and Strategic Communications</u>. During COVID the Administration engaged over 700 CBOs, and this office will continue the engagement and give them funding, not only with health issues, but also with drought, etc.

Accepted February 2021 meeting summary

- Amended the guidelines regarding eligible members of the council to include deputy secretaries, in addition to the already-included assistant secretaries, of Health and Human Services
- Amended the guidelines to clarify how amendments to the guidelines are made
- Updates about two CIAPM budget items in the 22-23 budget
- Discussed the CIAPM impact assessment
- Reports back from working groups

Chair and Vice Chair Elections

Clara Lajonchere was elected for another one-year term as chair of the California Precision Medicine Advisory Council. Dr. Keith Yamamoto as elected for another on-year term as vice chair.

22-23 Budget Item Update

- \$10M for a competitive grant program to support precision medicine-based approaches to preventing, diagnosing, and treating depression.
 - 3-5 projects
 - Up to \$3M per project, 36-month project period
 - Later in the agenda: craft major points, suggest out-of-state reviewers
- \$9.25M to increase participation in biomedical research
 - 5-year interagency collaborative
 - study/develop best practices, create materials, host events
 - Commitments from nine public agencies
- Status: Senate budget committee; Assembly budget subcommittee

We have proposed language that would allow us to spend more than 10% on administration of non-demonstration projects; it's moving through the system.

Discussion: 23/24 Budget Priorities

Clara: We should stick to research but lean into public-private partnerships. For research topics, we need to align with the priorities of the governor. Priorities can be included in the new strategic plan. We need to be able to show the governor and the state what we have done for California. We need to have a strategic plan that has short-term, medium-term, and long-term goals, and include measures of success.

Ken: Form a collaborative with the DEI officers from the pharma companies to discuss best practices for recruitment and data sharing. We can get the companies to pitch in to help fund it.

Keith: Removing barriers between academic/industry partnerships should be a goal. In early CIAPM RFPs, we mandated that the projects include an industry partner. We also brought together all applicants, even those who were not successful, for a discussion, which generated a lot of good ideas.

Ysabel: Big data is not used well, and it is not gathered on the right people. We need disaggregation and SDOH data included in all the work that we're doing, if we're going to get accurate, precision care.

Fatima: We need to align the priorities of all the shareholders so they each see the role that they have in the process.

Hakan: Accessing the resources in pharma companies that focus on communities and collaborations. We can ask for matching funding from industry. We can also work with professional societies such as the Personalized Medicine Coalition.

Julianne: There is the opportunity to work with GoBiz.

Clara: We could bring on a graduate student to work specifically on public-private partnerships, but we must have a value proposition for the pharma companies.

Depression RFP

Keith: Private sector should need to be involved.

Ysabel: We need to define what we mean by CBOs, perhaps making them tiered.

Shannon: We can lean on the expertise of the new proposed Office of Community Partnerships and Strategic Communications.

Clara: Consider seed funding for technical assistance, to assist CBOs.

Shannon: We can contact our technical assistance professionals for consult.

Clara: We can consider having a specific percent of the funds that has to go to community partners.

Working Group report-back: Data Integration

Looking Ahead

The Data Integration Working Group will next meet in two days, on May 25, when the Chief Data Scientist of the California Health and Human Services Agency, John Ohanian, will join for a discussion about the California Health and Human Services Data Exchange Framework and the CHHS Center for Data Insights and Innovation.

Since our last meeting, CIAPM staff and several other members of the CIAPM network, including ACEs PIs, attended a two-day workshop on neurological diseases and data management practices, hosted by the California Institute for Regenerative Medicine (CIRM). CIAPM continues to discuss CIRM's interest in partnering to leverage shared foci on health equity and the application of data to make research more efficient and impactful.

Working Group report-back: Equitable Consent

Website: Equitable Engagement and Consent in Clinical Research

- Provide resources and best practices for clinical research stakeholders to increase participation by underrepresented subpopulations. Stakeholder groups include:
 - Sponsors
 - Researchers
 - Research staff
 - Potential and current research participants
 - Health care providers/Clinics

New Outreach Meetings

- David Higgins, PhD, CIRM Board of Directors, UCSD Parkinson's Patient Advocacy Group Leader
- Robb Layne, Senior Advocate, Policy and Legislative Affairs, CA Council of Community Behavioral Health Agencies
- Debra Cooper, PhD, California Black Health Network Board of Directors Member
- Dannie Ceseña, Office of Health Equity Advisory Committee, CA LGTBQ Health and Human Services Network
- Transgender Research Group Just Research? Trans Futures in Health and Scientific Knowledge
- Coalition for Demographic Data Equity (CODDE)

Phased rollout of website content: new schedule

PHASE 1- expected fall 2022

Introduction

Existing Laws and Policies

For existing and potential research participants, excluding stories

PHASE 2- expected winter 2022

For researchers, excluding population-specific guidance

For research staff

PHASE 3- expected spring 2023

History and case studies

Population-specific guidance

PHASE 4- expected summer 2023

For Sponsors

For Healthcare providers

Stories of participants

TASK	STATUS (as of August 2022)
Continue 1:1 and organization meetings	Ongoing

TASK	STATUS (as of August 2022)
Finalize first draft of content	In progress
Distribute content for internal review	September 2022
Continue content development and organization	Ongoing
Secure vendor for website content review	In progress

Impact Assessment

Need

Convey importance and impact of CIAPM

Purpose

Compile, visualize, and analyze outcomes of California's investments in CIAPM to:

- Improve communications
 - Cater to a general audience
 - Describe impacts in digestible and compelling formats
 - Amplify visibility
 - Create more opportunities to inform stakeholders
- Compare our mission against demonstrated impacts
 - Illuminate disconnects, gaps, or shortcomings
 - Adjust reporting to better capture informative data
 - Update RFP criteria to align with current priorities

Product: A dynamic webpage with information linked across projects **Content**

- 1. Number of Californians engaged, diagnosed, supported, and/or treated
- 2. Amount of matching funds or leveraged resources
- 3. Number of patents or patent extensions
- 4. New or improved data sharing and analytical platforms, tools, or software
- 5. New validated technologies and approaches
- 6. Novel curricula for training programs
- 7. New or improved toolkits for healthcare providers
- 8. Number of press coverage or activity focused on the project
- 9. Number of publications in peer-reviewed journals and books
- 10. Number of presentations about the project, both to expert and public audiences
- 11. Number of trainees engaged in the project (post-doctoral fellows, graduate students, community health workers, technicians, medical students, undergraduate students, interns, residents, fellows, physicians, educators, etc.)

12. Number, size, and sustainability of collaborative networks, such as between researchers, communities, industry, universities, and philanthropy

Tailored Reporting

Calculate and provide information about the impact for specific regions, sectors, health conditions, methods, and networks.

Amplifying Perspectives and Experiences

Include stories and narratives that capture:

- A patient's experience participating in a CIAPM study
- How a community organization detected a local challenge and partnered with researchers to address it together
- Why a researcher chose their line of work
- What's unique about a CIAPM-funded project
- Why a business chose to provide in-kind support to propel research
- How projects can sustain momentum following the conclusion of a CIAPM grant
- What steps are involved in creating a new cross-sector network
- Deliberate centering of health and social equity as the primary goal

Presentation/Discussion

Aiyana: Test webpage includes infographics related to matching and leveraged funds, funding breakdown by research area, number and types and locations of organizations involved in projects, and feature stories based on interviews with select projects

Ysabel: Would like to know more about demographics of populations engaged with projects

Aiyana: Wants to facilitate discussion at next meeting with advisory council on specific data they would like to collect from each project regarding populations of participants, training curricula and available toolkits, and additional project stories and narratives