

California Precision Medicine Advisory Council

Fall Meeting Minutes, Part 2

November 20, 2020

Agenda Item #1: Introductions of Council Members and CIAPM Staff

Council Members present

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

Governor's Office of Planning and Research staff present

Shannon Muir; Julianne McCall; Megan Varvais; April Booth

Agenda Item #2 Update from the Newsom Administration

Delivered by Richard Figueroa, Deputy Cabinet Secretary. The rate of COVID infection is increasing and the State is looking at alternative care sites for hospital overflow. Counties have been moved into more restrictive categories to reduce mixing and the spread of the virus.

COVID-19 vaccine distribution will be rolling out soon. The Governor has set up three distinct advisory groups:

- COVID-19 Scientific Safety Review Workgroup to independently review the safety and efficacy of any vaccine approved by the FDA for distribution
- Vaccine Drafting Guidelines Workgroup to advise the state on COVID-19 vaccine prioritization and allocation
- Community Vaccine Advisory Committee will be launched soon to provide input and feedback for the ongoing planning and engagement efforts to ensure equitable vaccine distribution and allocation

Action Item: Fig to send list of members of the Community Vaccine Advisory Committee

[Update: <https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Community-Vaccine-Advisory-Committee.aspx> (also see Appendix A)]

For California's next budget cycle, the revenue picture is much brighter than expected in the short term, which will give us flexibility to work through ongoing challenges.

California voters approved Proposition 14, providing an additional \$5.5 billion for stem-cell and medical research through the California Institute for Regenerative Medicine (CIRM). Under the new leadership structure, the Governor has one additional appointee to the CIRM Board of Directors.

The Alzheimer's Prevention and Preparedness Taskforce has given their recommendations to the Governor, including to continue state funding for Alzheimer's research. Some of those recommendations may be pulled into the State's Master Plan for Aging which will probably be released in December. [Update: [release now scheduled for January 2021](#)]

Action Item: Send 1-3 paragraphs to Fig on what CIAPM would do with Alzheimer's funding (in light of all of the funding from the federal level).

Action Item: Send around report from California Alzheimer's Task Force

Link to report (also provided by Dr. Burke Harris during the meeting): http://caalztaskforce.org/wp-content/uploads/2020/11/2020-Alzheimers-Report_201118.pdf

The change of administrations at the federal level may effect our budget and our COVID-19-related work.

Agenda Item #3 Review discussion and action items from meeting Part 1

All of Us RFP update, provided by Julianne McCall

Funding Purpose:

- Improve enrollment and retention among groups underrepresented in biomedical research (UBR)
- Encourage diverse researchers to utilize All of Us data resources
- Contribute to the science of engaging UBR communities

Project Partners

- California Department of Aging
- California Department of Developmental Services
- California Department of Public Health
- California Department of Rehabilitation
- California Institute for Regenerative Medicine (CIRM)
- California Mental Health Services Oversight & Accountability Commission
- California State University Office of the Chancellor
- Office of the California Surgeon General
- University of California Office of the President
- California Council of Community Behavioral Health Agencies
- California Primary Care Association (CPCA)
- California Pan-Ethnic Health Network (CPEHN)
- Hollywood, Health & Society (University of Southern CA)
- A consortium of all CA-based Schools and Programs of Public Health
- American Nurses Association, California Chapter
- Association of California Nurse Leaders
- California Association of Colleges of Nursing

Proposal: Leverage expertise and expansive networks of state agencies and statewide health care provider associations to adapt All of Us promotional materials to better resonate with UBR communities and incorporate messaging into existing information streams.

- 5 years, beginning May 2021
- Up to \$1.5 million / year
- PIs: Julianne McCall, Shannon Muir

- Deadline: Nov. 23, 2020
- NIH Other Transaction Authority Funds

[Update: Application submitted to NIH on 11/23/2020]

Agenda Item #4: Integrating social, behavioral, biological, and discovery data to improve health

Chair: Hakan Sakul

Members: Nadine Burke Harris (would like to stay engaged but may not be able to fully participate); Oliver Keown; Clara Lajonchere; Bonnie Maldonado; Samar Muzaffar; Mary Anne Schultz; Keith Yamamoto

A (ultimate goal): Acute and accurate prevention of disease to improve health outcomes

To accomplish A, we need to (B) Understand relationships (both associations *and* mechanisms) between data and data types, e.g., *how* social factors affect epigenome, metabolic, etc., functions.

One way to accomplish B is to (C) Integrate social, behavioral, biological, and discovery data;

One way to accomplish C is to (D) Integrate SDOH into the medical/health record; link SDOH with “objective” (e.g. genomics) determinants.

In order to accomplish D we need to (E) Set/define standards for SDOH in a way that is computationally useful

In order to accomplish E we need to (F) Encourage stakeholder engagement and get commitments from stakeholders to join a coalition

One way to accomplish F is to (G) convene stakeholders (tactic)

Outstanding Questions

- What data already exist? What fraction of it is accessible? What are barriers to data accessibility?
- What SDOH data need to be collected? How should we collect it? Do recommendations already exist?
- How do we design tools that don't exacerbate existing health disparities?
- How do we incentivize SDOH data collection, storage, and sharing in a way that is most useful?
- What health data-sharing platforms already exist?
- What security measures are needed in a platform?
- What are *our* metrics for success?
- Centralization vs. Federation?
- What has become of the effort link Biobanks across the state?
- Population level vs. Patient level tracking?
- What levers are available to the Council (convening power, communication, financial)?
- What other expertise do we need on the team?

How much is our mandate to look inwardly at opportunities for State Government and the administration to institute new practices/ policies or standards vs. influence the broader ecosystem outside of the State apparatus? For example, is there an opportunity to audit state government data repositories that align or incorporate SDoH to best position the State to accelerate broader use of SDoH?

Challenges

- Companies may not want to share data.
- There are no current requirements to collect data on race/ethnicity.

Stakeholders

- Patients
- Academia
- Health Systems
- Biotech and Pharma

Examples/Possible Partners/Ongoing Efforts

- [UC Health Data Warehouse](#) that combines data from across UC medical centers
- [Blood PAC](#) (offshoot from Biden Cancer Moonshot): Development of a collaborative infrastructure that enables sharing of information about liquid biopsies between stakeholders in the public, industry, academia, and regulatory agencies to better inform clinical decisions and improve patient outcomes.
- Federal efforts by payers and health systems to define metrics, or find metrics that are most supported by evidence (CMS, CDC, and state Medicaid programs)
- PMAC report recommendations
- CPCA, NACHC have been working with CHC/FQHCs
- San Ysidro Health has integrated a system in EHRs to collect more robust information about SDoH

Agenda Item #5: Education for research participants, informed consent, and patient-centered study design

Chair: Kenneth Kim

Members: Ysabel Duron; Clara Lajonchere; Hakan Sakul; Keith Yamamoto

A (ultimate goal): URM are informed partners in biomedical research and clinical care

In order to accomplish A we need to (B) create an equitable consent framework

In order to accomplish B we need to (C) define equitable consent, and develop a consent process that is linguistically and culturally appropriate, doesn't unintentionally deepen disparities, has built in accommodations for different groups, and clearly defines what consent means

In order to accomplish C we need to (D) identify sensitivities and barriers to participation

In order to accomplish D we need to (E) engage URM communities broadly

One step in accomplishing E is to (F) perform a landscape analysis of current effort

In order to accomplish A we need to (G) get community buy-in

In order to accomplish G we need to (H) educate community members on the science, the trustworthiness of the science, the research process, why they should care, and the impact of their participation on themselves and their communities. “We have to establish trustworthiness to build trust.”

In order to accomplish H we need to (I) create opportunities to teach, or provide information to CBOs so that they can teach

One way to accomplish I is to (J) identify organizations that are already involved in the work.

In order to accomplish A we need to (K) identify those communities that are underrepresented

One way to accomplish K is to (L) look at clinical trials data from Pharma companies

Outstanding Questions

- What is feasible for this group to accomplish?
- Should we focus on population health, or individual health?
- How do we ensure that participants have the necessary level of understanding to consent? (e.g., having someone there in real time to answer questions, which cannot be done with some new consenting modalities)
- What lessons can we learn from vaccine uptake campaigns?

Examples/Possible Partners/Ongoing Efforts

- All of Us
- UCLA and other UCs
- Geisinger Health System
- Janssen

Schedule working group meetings to refine project goals.

Agenda Item #6: Wrap up and next steps

Next Council meeting February 2021.

Appendix A:

List of members of the Community Vaccine Advisory Committee

- AARP
- American Civil Liberties Union (ACLU)
- American College of Emergency Physicians (ACEP)
- American Federation of State, County and Municipal Employees (AFSCME)
- Alzheimer's Association
- Asian Americans Advancing Justice – Los Angeles
- Asian and Pacific Islander American Health Forum (APIAHF)
- Association of California School Administrators (ACSA)
- California Academy of Family Physicians (CAFP)
- California Advocates for Nursing Home Reform (CANHR)
- California Area Indian Health Service
- California Assisted Living Association (CALA)
- California Association of Area Agencies on Aging (C4A)
- California Association of Health Facilities (CAHF)
- California Association of Health Plans (CAHP)
- California Association for Health Services at Home (CAHSAH)
- California Association of Long-Term Care Medicine (CALTCM)
- California Association of Public Hospitals and Health Systems (CAPH)
- California Association of Rural Health Clinics (CARHC)
- California Association of Veteran Service Agencies
- California Behavioral Health Directors Association (CBHDA)
- California Black Health Network
- California Chamber of Commerce
- California Conference of Local Health Officers (CCLHO)
- California Consortium for Urban Indian Health, Inc. (CCUIH)
- California Dental Association (CDA)
- California Foundation for Independent Living Centers (CFILC)
- California Hospital Association (CHA)
- California Immigrant Policy Center (CIPC)
- California Immunization Coalition
- California Labor Federation
- California LGBTQ Health and Human Services Network
- California Long-Term Care Ombudsman Association (CLTCOA)
- California Manufacturers & Technology Association (CMTA)
- California Medical Association (CMA)
- California Nurses Association (CNA)
- California Pan-Ethnic Health Network (CPEHN)
- California Pharmacists Association (CPHA)
- California Primary Care Association (CPCA)
- California Rural Indian Health Board (CRIHB)
- California Rural Legal Assistance, Inc. (CRLA)

- California School Boards Association (CSBA)
- California School Nurses Organization (CSNO)
- California Society of Health-System Pharmacists (CSHP)
- California State Parent Teachers Association (CAPTA)
- California Superintendent of Public Instruction
- California Teachers Association (CTA)
- Catholic Charities of California
- Comite Civico del Valle
- County Health Executives Association of California (CHEAC)
- Disability Rights California (DRC)
- Disability Rights Education and Defense Fund (DREDF)
- Emergency Medical Services Administrators of California (EMSAC)
- Faith in the Valley
- First African Methodist Episcopal Church
- First Five Association
- Health Access
- Housing California
- Jakara Movement
- Justice in Aging
- Latino Coalition for a Healthy California (LCHC)
- Local Health Plans of California (LHPC)
- Mixteco Indigena Community Organizing Project (MICOP) (Central Coast/Indigenous Farmworker population)
- Planned Parenthood Affiliates of California (PPAC)
- Service Employees International Union (SEIU) California State Council
- Service Employees International Union Local 1000 (SEIU 1000) (Unit 17-Nurses)
- State Council on Development Disabilities
- The California Endowment
- The Children's Partnership
- UFW Foundation
- United Domestic Workers (UDW/AFSCME)
- United Food and Commercial Workers (UFCW) California
- Vision y Compromiso
- Western Center on Law and Poverty