California Precision Medicine Advisory Council
Meeting Summary, May 2021

Update from the Newsom Administration

- Richard Figueroa, Deputy Cabinet Secretary
  - The Governor's May Revise included $12.4M for CIAPM to fund three more ACEs demonstration projects, as part of a much larger package for children's behavioral health
  - The May Revise now goes to the Legislature for negotiations
- Kate Gordon, Senior Advisor on Climate, Director of Governor's Office of Planning and Research
  - The ACEs funding is expected to pass in June, even though much of the budget may be passed later in trailer bills

Council Elections

Council members voted to suspended Council Guidelines for the purpose of allowing ranked-choice voting for elections.

Clara Lajonchere was the only nominee for the Council Chair, so no vote was held as she was considered elected.

Keith Yamamoto and Hakan Sakul were nominated for Council Vice Chair; Keith accepted his nomination; no vote was held as Keith was considered elected.

Accepted February 2021 meeting summary

Accept as amended when ACEs RFP update information is added.

Update: CIAPM-sponsored projects in ACEs

RFP selection process finished; out-of-state expert selection committee recommended four proposals for funding, at 80% budgets:

- *Scalable Measurement and Clinical Deployment of Mitochondrial Biomarkers of Toxic Stress.* Pat Levitt, PhD, Children's Hospital Los Angeles
- *A Multi-Component Intervention to Strengthen Families and Build Youth Resilience.* Ariane Marie-Mitchell, MD, PhD, MPH, Loma Linda University
- *Using Precision Medicine to Tackle the Impact of ACEs (including a Novel Actionable ACE) on Children's Neurodevelopment.* Tallie Z Baram MD, PhD, UC Irvine
- *The Collaborative approach to examining Adversity and building Resilience (CARE) Program.* Neeta Thakur, MD, MPH, UCSF

If the Governor's budget is passed and ACEs project funding is expanded, these four projects will be funded at 100% and the following projects will also be funded:

- *Systems-based, Multidisciplinary Assessment of Adversity and Toxic Stress for Individualized Care (The SYSTEMAATIC Project).* Sayantani Sindher, MD, Stanford University
- *San Diego County, UC San Diego, & Community Partners Better Address ACEs with Precision Medicine & Organizational Change.* Gary Firestein, MD, MPH, UC San Diego
- *Identifying Social, Molecular, & Immunological Processes for Mitigating Toxic Stress & Enhancing Personalized Resilience.* George Slavich, PhD, UCLA

Certifications for health professionals: Julianne McCall will reach out to the California Board of Behavioral Sciences, within the Department of Consumer Affairs, to gather information.

Working Group report back: Data Integration ~1:45

- Working Group's SDOH Definition: The conditions in which people are born, live, learn, work, play, and age that affect a wide range of health outcomes, which are responsible for most health inequities, and the forces and systems that shape daily life, including economic policies and systems, development agendas, social norms, social policies, and political systems
- CalAIM: California Advancing and Innovating Medi-Cal
    - "….provide for non-clinical interventions focused on a whole-person care approach via Medi-Cal that targets social determinants of health and reduces health disparities and inequities."
    - Timeline: 2-5 years
    - More info: dhcs.ca.gov/provgovpart/Pages/CalAIM.aspx

The Gravity Project

- **A network across academia, government, nonprofit, community, and industry that seeks to identify coded data elements and associated value sets to represent social determinants of health data documented in EHRs across four clinical activities: screening, diagnosis, planning, and interventions.**
- **In mid-May, CIAPM joined as a member of the Gravity Project network, specifically committed to the Terminology Workstream**
- **More info: hl7.org/gravity/**

TASK	STATUS (as of May)
Engage with leaders of CalAIM as they ramp up their program	Ongoing
Consider drafting guidelines for the "Minimum viable product," or minimum common metrics for SDOH.	Not yet started
Connect with newly-launched CHHS Center for Data Insights and Innovation (and other state entities)	Done
Consider reaching out to other groups (NASEM)	Not yet started
Landscape analysis of SDOH data integration efforts	Ongoing
Define SDOH for Working Group	Done
Launch expert briefings	Not yet started

Hakan Sakul and Julianne McCall will connect with the Personalized Medicine Coalition about opportunities to advance data integration of SDOH.

Working Group report back: Equitable Consent
Ranking the Problem

	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: It's hard to tackle one problem without considering the others
- Suggested project: facilitate focus groups to get feedback about UCLA's video on universal consent for leftover biological samples
- No current funding to outsource that work.
- Requires a significant time to do it ourselves
- Quick win: organize and synthesize resources on a webpage that is integrated with the existing CIAPM webpage.
- In the meantime, pursue mechanisms to fund the focus groups.
- Equitable consent webpage:
  - Present information in digestible sections, instead of having to be comprehensive
  - Allow readers to navigate to topics of interest
  - Link to external resources
  - Content dedicated to different stakeholder groups
    - Researchers
    - Research staff
    - Research participants from different communities
  - Publish over time, instead of waiting for a final product

- Easily incorporate new resources

TASK	STATUS (as of August 2021)
Clarify the problem(s) that we are trying to solve.	The problems were ranked, but working group members felt it was hard to tackle one problem without another
Reach out to people and organizations that are doing similar work.	Creating org list and collecting potential contacts
Look into providing stipends to community members who participate in the project	Ongoing
Create high-level outline for website content	Done
Collect and organize resources related to consent and data sharing	Ongoing