



California Initiative to Advance
Precision Medicine

California Precision Medicine Advisory Council Draft Meeting Summary, March 13, 2023

Welcoming New CIAPM Staff

- Saga Barberis, Program Administrator
- Maxwell Wayne, Undergraduate Student Intern
- Priscilla Hung, USC Master's Student
- Emily Graham, USC Master's Student
- Kayleigh Lloyd, USC Master's Student

Updates from the Newsom Administration

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

- In Governor Newsom's second term, he is looking to see the impact of projects and programs that have been launched since he took office.
- In addition to the new Office of Community Partnerships and Strategic Communications, OPR will soon launch the Racial Equity Commission and the Youth Empowerment Commission.
- OPR has tripled in size over the last few years and is still growing. This has increased our ability to provide CIAPM staff with additional administrative support.

Accepted November 2022 meeting summary

- California Surgeon General Dr. Diana Ramos joined for the first time as a member of the Council.
- Introductions to the Depression RFP and the Representative Research Collaborative
- CIAPM impact assessment efforts
- Reports back from working groups

Update: Representative Research Collaborative

Priority Populations

1. Central Valley residents
2. Migrant workers

3. Residents north of I-80 (Sacramento and above, particularly the far northern regions of California)

Project Aims: Diversify participation in biomedical research

1. Work with the All of Us consortium to develop assets and conduct multiple engagement, enrollment, and retention campaigns
2. Engage researchers from diverse backgrounds to utilize All of Us data resources
3. Contribute to the science of engaging, enrolling, and retaining underrepresented communities in research

Updated Timeline

March – August 2023

- Gather guidance; explore and initiate interagency agreements
- Finalize MOU with NIH
- Create a new position, Health Equity Specialist, and conduct recruitment
- Launch an RFI, design technical assistance

Sept 2023 – Feb 2024

- Recruit candidates for new Public Health Graduate Student Fellowships
- Launch RFP and select external partners

March 2024 - June 2028

- Launch annual conferences
- Project implementation

New and Anticipated Staff

Saga Barberis, JD

- Project Administrator
- Started mid-January

Equity Officer, expected to start June 20

Updates

State Government Landscape Analysis

- Reviewed all 236 state agencies
- Identified agencies who specialize in our target populations

- Opportunities especially in the Department of Health Care Services, CDPH, and the Labor and Workforce Development Agency (LWDA)

Expert Guidance

- LWDA Deputy Secretary Sebastian Sanchez
- Madera County Public Health Officer Dr. Simon Paul
- Madera County Public Health Director Dr. Sarah Bosse
- Dr. Fatima Muñoz, San Ysidro Health

Steering Committee & Advisory Group Development

- Conducted a public call for nominations

Next steps

New position proposed: Health Equity Specialist

- Originally designed for CDPH, now jointly managed by CIAPM and OPR's newest office, the Office of Community Partnerships & Strategic Communication

Expert Guidance

- Ysabel Duron, Founder and President of the Latino Cancer Institute
 - We could tap into the National Community Advisory Board and the Hispanic Representation session, the Hispanic Medical Association, and the Hispanic Health Alliance to ask them how they brought migrant workers to the program?
 - Community messaging: Highlight the stories of success that exist as a result of the data from Latinos inside the ORGANS research program on liver disease/cancer. The program involved 60,000 Latinos, half of whom are immigrants, the other half US born. And they've looked at some very fascinating data around liver disease (liver cancer).
- Ana Padilla, Exec. Director of the UC Merced Community and Labor Center
 - Success meant being at the table of the inner edge, educating community partners and members on what it means to implement a project of this scale, and how we can get our community represented by ~20,000 patients who are able to participate and willing to engage.
 - You can start collecting data about barriers, i.e., why some people were not motivated to participate, and for those who did participate, what was the motivation?

Discussion Prompts

- Do models exist for state government-NIH partnership?
- RFP Process & Technical Assistance
 - Gold standards to emulate
 - Duration of RFP dissemination
- Selection Committee for External Partners
 - Out-of-State vs Within-State vs OPR staff

Update: Depression Research Program

Background

- \$10 million: \$9 million in grants + \$1 million for admin over ~5 years
- Competitive grant program to support precision medicine-based approaches to preventing, diagnosing, and treating depression
- 3-5 projects
- Up to \$3 million per project, 36-month project period

Process

Completed

- Advisors discuss major points, suggest emphases, etc.

Ongoing

- RFP: Background research and drafting
- Procure an application management system

Upcoming

- Set RFP Timeline
- RFP review with state entities (OSG, HHS, OHE, etc.)
- RFP released
- Recruit out-of-state selection committee
- Select finalists
- Select awardees

RFP Review

Cancer Disparities Proposals Reviewers

- Elizabeth Gross Cohn, RN, PhD, Columbia University
- Meg Gaines, JD, LLM, University of Wisconsin

Office of Health Equity

- Silvia Rodriguez, Behavioral Health Equity Branch, CA Health and Human Services (CHHS)
- Stephanie Welch, Deputy Secretary of Behavioral Health, CHHS
- Melissa Stafford-Jones, Child and Youth Behavioral Health Initiative (CYBHI)
- Jennifer Harrison, CYBHI

Next Steps

Engagement:

- Partnering with other state organizations to maximize impact
- With \$9M, is there an opportunity for other agencies to come [indiscernible]?
- Notice of intent (NOI) dissemination
- RFP dissemination
- Recommendations for out-of-state reviewers
- Sharing RFP examples

Update: Impact Assessment

Background

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

Science Policy Fellowship & Internship Program

Goals:

- Strengthen workforce development in precision medicine
 - Since 2019, CIAPM has trained & supported 15 graduate & undergraduate student interns/fellows
- Advance equity through workforce development
 - Nearly all interns surveyed represent populations that are underserved in California, such as first-generation, living with a disability, non-white, or members of the LGBTQ+ community

Product

A dynamic webpage with information linked across projects

- Compile, visualize, and analyze outcomes of California's investments in CIAPM
- In parallel to our other reports, CIAPM needs a dynamic, whole-program overview
- Quantitative analysis:
 - Number of Californians engaged, diagnosed, supported, and/or treated
 - Amount of matching funds or leveraged resources
 - Number of patents or patent extensions

- New or improved data sharing and analytical platforms, tools, or software
- New validated technologies and approaches
- Novel curricula for training programs
- New or improved toolkits for healthcare providers
- Number of press coverage or activity focused on the project
- Number of publications in peer-reviewed journals and books
- Number of presentations about the project, both to expert and public audiences
- 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.)
- Number, size, and sustainability of collaborative networks, such as between researchers, communities, industry, universities, and philanthropy

Amplify perspectives and experiences

Whose lives are changed by CIAPM?

- 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

Legislative Outreach

- Goal: inform our state representatives, one district at a time
- More than half of all state legislators will receive information about CIAPM-funded projects specific to their district, offered alongside the opportunity for a tailored briefing for more information.
- Tailored impact reporting: What are the impacts for a given region? Sector? Health condition? Method? Network?

Discussion Prompts

- What outcomes would you like to see included?
- Are you aware of compelling narratives we can collect?

Next Steps

- A virtual briefing will be provided in early April
- Please expect an invitation to be interviewed for the assessment

Working Group report-back: Equitable Consent

Staff have been able to put together a lot of the content for the equitable consent website, and now we have the opportunity to maximize the impact of the website by combining it with the larger effort of the Representative Research Collaborative.

Background

- Established after funding for future RFPs was pulled back to the general fund
- Selected as a topic area by the council to address a group of recommendations from the Precision Medicine Action Plan and other sources

Website: Equitable Engagement and Consent in Clinical Research

Provide resources and best practices for clinical research partners to increase participation by underrepresented subpopulations:

- Sponsors
- Researchers
- Research staff
- Potential and current research participants
- Health care providers/Clinics

EC Website: Status

- Generated: Content for community members and content for researchers
- Website construction is ongoing
- Incorporation into Representative Research Collaborative:
 - Coordinated launch/communications
 - Coordinated branding
 - Review, input, and dissemination through RRC partners
- Working group on hiatus until further notice

Working Group report-back: Data Integration

The most recent meeting featured a guest expert, Dr. Peter Oh, who leads the Health Equity Research and Statistics Section of the California Department of Public Health.

Data dis-aggregation

- Data disaggregation: the collection, provision and reporting of information on subgroups, not just a group as a whole.
- From an equity perspective, data disaggregation refers specifically to breaking down aggregate data to reflect subgroups that have been excluded or marginalized.
- Data can be disaggregated by race and ethnicity, sexual orientation and gender identity, age groups, and/or other characteristics.

Intersections between CPDH work and Precision Medicine?

- University of California & CDPH research collaborations on long COVID and long-term economic and social impacts of the pandemic Assessing the Impact of COVID-19 in California
 - California Collaborative for Pandemic Recovery and Readiness Research (CPR³)
 - <https://cpr3.ucsf.edu/>
- Pilot efforts to link electronic health records – including SDH data – via a health information exchange, for public health purposes
 - Biomonitoring applications <https://biomonitoring.ca.gov/>

Next Steps

For the next meeting of the working group, Advisors will learn more about CHHS's partnership with the Coleridge Initiative to establish a California-based Administrative Data Research Facility.

Cancer Disparities Research Program: Progress Reports

Background

- 2017/2018 Budget
- \$9 million
- 3 projects

Addressing Disparities in Breast Cancer in Latinas: A Multi-Tiered Approach

- Project Lead: Dr. Elad Ziv
- Primary Institution: UCSF
- Collaborating Institutions: City of Hope, Promoters for better health, and more
- Aims
 - Understand which genetic variants cause Latinas to develop breast cancer

- Increase community awareness of hereditary cancer and genetic testing
- Progress
 - Recruited hundreds of new patients; analyzing existing samples. Look at germ line vs. tumor DNA to classify VUS; calculate polygenic risk scores. Found genes with potential differential risk in Latinas than in other populations
 - Trained 24 promotoras, presented to 1300 community members; 1100 family histories. 7% referred to genetic counselors, genetic testing for BRCA. 6 positives so far.
- Committee comments:
 - Virtual meetings were more successful because you were able to have a greater reach

Machine-Learning Platform to Inform Precision Therapy in Breast Cancer Patients

- Project Leads: Dr. William Kim, Dr. Pablo Tamayo
- Primary Institution: UCSD
- Collaborating Institutions: Cancer Resource Center of the Desert, El Centro Regional Medical Center, San Diego State University, Tri-City Medical Center and others
- Aims
 - Study triple-negative breast tumors in Latinas to better align subtypes with specific treatments
 - Identify barriers to cancer care in Latina patients with triple-negative breast cancer
- Progress
 - Set up new collaborations with 7 different orgs, including 2 CBOs, and 2 community clinics
 - Collected before/after treatment tumor samples for WES, rna-seq, organoid development; single-cell sequencing; test effectiveness of drugs

Cancer Disparities Through Innovative Community-Academic Partnerships

- Project Lead: Dr. Manali Patel
- Primary Institution: Stanford University
- Collaborating Institutions: Cancer Patients Alliance, Clinica de Salud del Valle de Salinas, Latino Cancer Institute, Pacific Cancer Care
- Aims
 - ALCANCE (Addressing Latinx CANcer Care Equity) Project: Partner with communities to design and apply interventions that optimize cancer care in underserved populations, from screening through end-of-life planning
- Progress:
 - 150 participants enrolled in cancer screening and prevention study
 - 1000 Community Health Worker outreach contacts

- 150 patients with cancer enrolled in study to assess knowledge of precision cancer care
- Committee comments:
 - Important to link-in and provide primary care to participants

Public Comment

None