

California Precision Medicine Advisory Council

Data Integration Working Group

Meeting Summary

11.30.21

Meeting purpose

- Discuss ongoing efforts in SDOH data integration in California
- Refine project scope and direction
- Brainstorm external experts to invite for briefings

Agenda

- Welcome and Introductions
- Opening Remarks
- Meeting Minutes, 2021.09.08
- Meetings Report-Back
- Project Discussion
- Public Comment
- Wrap up and next steps
- Adjourn until January

Accepted Sept. 8 Meeting Minutes

Meetings Report-Back

Expert Interviews and Meetings

- CA Health & Human Services (CHHS)
 - Undersecretary Marko Mijic
 - Data Officer John Ohanian
 - Dept. Director of the Center for Data Insights & Innovation Elaine Scordakis
- CA Department of Health Care Services
 - Chief Medical Information Officer Dr. Linette Scott
- CA Homeless Coordinating & Financing Council
 - Executive Officer Julie Lo
- CA Board of Behavioral Sciences
 - Executive Officer Steven Sondgren
- CA Cancer Registry
 - Co-Founder Dr. Hoda Anton-Culver
- CA Precision Medicine Consortium
 - Co-PI Dr. Lucila Ohno-Machado
- CA Institute for Regenerative Medicine
 - CEO Dr. Maria Millan

- Vice President of Scientific Programs Rosa Canet-Aviles
- University of CA, San Francisco
 - Professor Dr. Sergio Baranzini
- Loma Linda University
 - Professor Ariane Marie-Mitchell

Key Takeaways from Expert Interviews

- Concept of a unique data identifier number to pull data across databases
- How to collect “good” data
- Biggest issues won’t be the science but the data governance
- Resistance to “another registry”
- Legislative mandates - incentives and disincentives are helpful
- Researchers and government agencies are already taking steps to make data more available- we can identify and partner with the groups that are doing it best

Key Recommendations from Expert Interviews

- Connect with other key experts and change-makers
 - John Ohanian (CHHS), Joy Bonaguro (GovOps Agency), Linette Scott (DHCS), Sergio Baranzini (UCSF), Atul Butte (UC Health), Scott Cristman (HCAI)
- Landscape analyses
 - What are the current research and government databases that could be used, and what data do they specifically collect that relates to advancing our goals around ACEs and Toxic Stress?
 - Are there gold standard examples?
- Convenings
 - Researchers to develop study questions, data needs, and to discuss implementing pilot knowledge network with CIAPM grantees and CIRM
 - Multisector convening including researchers, data scientists, IT, government to:
 - Define the product
 - Review and identify current resources and gaps
 - Establish concrete next steps to build the product

Potential State Partners

- CA Institute for Regenerative Medicine
- Office of the CA Surgeon General
- CHHS Center for Data Insights & Innovation
- Coleridge Administrative Data Research Facility (via CHHS)
- CA Dept. Health Care Access & Information
- CA Dept. Health Care Services

Select Ongoing CA State Government-Based SDOH-Relevant Data Sharing Efforts

- California Health and Human Services Agency Data Exchange Framework
 - Advisory Committee to deliver recommendations by July 1, 2022 for standing up a Data Exchange Framework by 2024 requiring all healthcare systems to make EHR data accessible via a federated hybrid system
- CalAIM: California Advancing and Innovating Medi-Cal (Dept. Of Health Care Services)

- Provides 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.
- All-Payer Claims Database (CA Dept. of Health Care Access and Information, HCAI)
 - By July 2023, the database will serve as a collection of health care data from health care plans, health insurers, government agencies and others. With the database, HCAI intends to support greater health care cost transparency, inform policy decisions supporting quality health care, and to reduce health care costs and disparities. It is also intended for the information to be used to develop innovative approaches, services, and programs that may have the potential to deliver health care that is both cost effective and responsive to the needs of all Californians.
- CHHS - Coleridge Administrative Data Research Facility (ADRF) Partnership
 - California state agencies may access the facility's secure cloud-based computing platform designed to promote collaboration, facilitate documentation, and provide information about data use to the agencies that own the data. The ADRF was established by the Census Bureau with funding from the Office of Management and Budget to inform the decision-making of the Commission on Evidence-Based Policy. The platform is a FedRAMP-certified environment that currently hosts de-identified data and is operated as a secure remote access data facility within the Amazon Web Services GovCloud. It provides secure access to data sets that historically have not been available for analysis by authorized researchers allowing them to develop rich metadata and access search features to find and use government datasets. So far, California has used the system for social services data.

Project Discussion

Progress To-Date

- Completed: Landscape analysis of ongoing efforts to integrate SDOH data, within and external to California state government
- Completed: Identify areas of opportunity to advance the integration of SDOH data into healthcare decision-making
- Ongoing: Work with fellow public agencies to formulate a role for CIAPM to support ongoing efforts and explore ideas for improvement
- Ongoing: Meet regularly with fellow agencies and engage experts for guidance

Potential Goals

- Short term: Start with pilot knowledge network among CIAPM Adverse Childhood Experiences (ACEs) grantees, CIRM, and government agencies to advance data sharing and research on social determinants of health (SDOHs) and ACEs
- Long term: Advancement in the precision and efficacy in clinical and social care
 - Associate SDOHs with diagnostic criteria and biomarkers
 - Accelerate the development of individualized interventions

Opportunity to Partner with the CA Surgeon General and the CA Institute for Regenerative Medicine

CIAPM is continuing to explore a potential knowledge network project in close partnership with the Office of the California Surgeon General (OSG) and the California Institute for Regenerative Medicine (CIRM). The timeline is long: dedicated work is unlikely to begin before 2023. The ideal end product would grant researchers access to de-identified and secure state administrative data to:

- Advance outcomes research relative to SDOH and other data to serve as a knowledge base to inform clinical and social service decision-making
- Accelerate the discovery-to-clinical application pipeline

Discussion Questions

- What ideal, long-range outcomes are we developing a pilot project to help achieve?
- What do researchers need to improve SDOH-relevant studies?
- What short-term goals would be appropriate?
- Consider the feasibility, benefits, and challenges of engaging CIAPM-funded researchers.
- What nonstate partners would be helpful to engage?
- Which experts should we prioritize engaging? Staff interviews or working group briefings?

Members discussed and agreed that the opportunity to continue scoping a partnership with OSG and CIRM was aligned with the working group's goals. The group would also like to see flushed out additional opportunities to contribute to state efforts, like the Data Exchange Framework and the Coleridge Initiative Administrative Data Research Facility before selecting a project.