

Office of the President

TO MEMBERS OF THE HEALTH SERVICES COMMITTEE:

DISCUSSION ITEM¹

For Meeting of June 12, 2024

PROMOTING STRONG DATA GOVERNANCE AT UC HEALTH

EXECUTIVE SUMMARY

As a leading healthcare delivery and public research institution, the University of California has a duty to utilize its health data assets and do so in a safe and responsible way. UC has been on the forefront of health data governance for many years and on May 1, 2024, President Drake issued a report (attached), prepared by a systemwide task force. The report sets forth recommendations for managing and sharing health data responsibly, including recommendations aimed at ensuring that patients from diverse communities served by UC have a voice in the data governance practices UC uses for health research, clinical research, and policy-making.

BACKGROUND

Data-intensive projects are transforming health and medicine. For example, tools based on artificial intelligence have enhanced disease detection and prevention. Extracting insights from large data sets involves collaboration and data sharing amongst clinicians, technologists, bioethicists, and others both within and outside UC. Replicable and transparent processes for managing and sharing health data responsibly are critical to successful collaborations. Building upon the work of an earlier Presidential Task Force, President Drake launched the UC Health Data Governance Implementation Task Force in October 2021 to develop recommendations for safe and responsible use and sharing of health data. Task Force members include scientists, clinicians, ethicists, privacy and regulatory experts, and IT specialists from across University of California Health (UCH), as well as the UC Office of the President. Together, these experts developed a set of recommendations that will enable UC to be a strong data steward of its patients' data, a role that is ongoing and will evolve in the face of technological and regulatory changes.

The Task Force set forth five overarching principles for health data governance at UC: Attention to the University's Unique Responsibility and Mission; Sharing Data Outside UC for Public Benefit; Justice; Transparency and Patient Engagement; and Responsible Stewardship. Building off these principles, the Task Force developed three sets of recommendations:

¹ Of interest to the Compliance and Audit Committee and the Public Engagement and Development Committee

June 12, 2024

- Develop a justice-based model of health data use, which requires increasing transparency regarding how UC uses patient data, education to raise awareness of data sources and uses, and patient and community input to shape scientific and health goals.
- Develop a pilot system to capture key elements of data sharing agreements and resources regarding executing data sharing agreements.
- Implement updated data sharing guidelines across UC Health to provide a consistent, streamlined, transparent, and replicable framework that protects patient privacy, ensures data security, promotes responsible partnerships with third parties, and effectively balances the risks and benefits of data sharing before engaging in such efforts. These guidelines cover transactions involving the sharing of health data with third parties outside the UC system, including industry, nonprofit, governmental, and academic organizations.

In early May, President Drake distributed the report to the UC community and encouraged UC Health and its campuses to implement these recommendations into their local processes.

Developing a Patient-informed Model of Health Data Use

One area of particular focus for the Task Force was developing recommendations for incorporating the patient voice meaningfully and sustainably into decisions around data use. Engaging affected/potentially affected communities is a pillar of a justice-based model and UC patients in prior studies recognized the importance of bidirectional engagement around data use. The Task Force recommended direct community representation in health data governance processes and, ideally, a “participatory design” model that has patients actively participating in the creation of policies, systems, and processes, rather than simply providing feedback. The specific form of community engagement must be specific to the needs of each UC location and its network. To be successful, participants must represent the diverse communities of California, including both UC patients and non-patients. UC must create ways for community participation to be accessible and affordable, which would include reimbursement of expenses/time/expertise, transportation assistance, ensuring language concordance and respectful use of participants’ time.

The Task Force recommended that governance processes include people without prior knowledge of health data collection/use. In order to enable community members to be properly prepared to contribute meaningfully to deliberations, they should be provided adequate background information in clear and understandable language, including audio options. Finally, to be authentic and transparent, UC must clearly communicate with community members about how their input will be used – is the group advisory only, or is there a decision-making element?

Community partnerships are essential in ensuring that the perspectives of the average Californian are incorporated into decisions regarding Health Data use. This creates trust in UC, a belief that individuals are being treated respectfully and with dignity, as well as a willingness to collaborate with UC on health concerns for their specific community and society at large.

ATTACHMENTS

Attachment 1: [Letter from President Drake to UC Health System Leaders and UC Health Data Governance Task Force Report 2024](#)