
Creating Good Data Governance

The Evolving Role of the University as Gate Keeper and Cheerleader for Data Sharing

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University of California Report on Health Data Governance

6 core principles for strong data governance

- Attention to the University's responsibility and mission
- Justice
- Active stewardship
- Trustworthiness and patient engagement
- Sharing data outside UC for public benefit
- Promoting alignment and collaboration

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Recommendations

- Pioneer a patient-informed, justice-based model of health data use, and demonstrate the need for and benefits of more active data use
- Establish a System-level Health Data Office to identify and accelerate projects and partnerships to realize the public benefits of collaborations to analyze health data
 - Each campus takes a similar approach to provide oversight of projects that involve sharing local health data
- Develop criteria and processes for evaluating projects and transactions involving access to UC Health Data by outside parties

Tools to Build Trust

- Context
- Transparency
- Data security
- Data stewardship

Context

- How is the data being used?
- With whom is it being shared?
- Is the data de-identified?
- Is there patient involvement?

Transparency

- Innovate how you communicate
- Meaningfully incorporate the patient voice
- Consider the role of consent

Data Security

- Large databases make attractive targets
- Security by design
 - Network controls
 - Access controls
 - Choose and monitor vendors carefully

Use of De-identified Data

- De-identification does not eliminate privacy risks - consider context (who will have access? for what purpose? do you anticipate adding additional data elements?)
- Encourage reidentification prohibitions on users and downstream recipients
- “Bring code to the data”

University of California COVID Research Data Set (UC CORDS)

- Access open to all UC Health research faculty, staff, students
- Access through secure research environment
- HIPAA Limited Data Set (deidentified but with dates)
- All users must sign UC CORDS Data Use Agreement
 - Cannot download the dataset or remove from the environment
- UC Health IRB Directors are in agreement
 - Not human subjects research

Data Stewardship

- In addition to the above:
 - Accountability
 - Data quality and integrity
 - Equity considerations



Take-Aways

- Context will inform decisions and may evolve
- Data security is critical
- Be an active data steward – trust encourages use

Thank you!
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