Health Data Sharing at UCSF

Promoting Openness, Community Involvement, and Shared Decision Making

Clinical and Translational Science Institute
Regulatory Knowledge and Support Program

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You are receiving this report because you participated in an interview about health data sharing at the University of California San Francisco (UCSF) between July 2022 and April 2023. Thank you for your time and for sharing your perspectives. Without you, this report would not have been possible. Here you will find information about the purpose of our project, how we collected the information, what we learned, and some of our recommendations to UCSF.

The work for this report was done by the Regulatory Knowledge and Support Program (RKS) at UCSF's Clinical and Translational Science Institute.

Purpose

The University of California San Francisco is a public health care, education and research institution that is committed to protecting patient health data while using it to conduct research and improve medical care. Protecting patients' privacy is crucial, but it is also important to share health data responsibly with academic and commercial partners. Doing so enables new research that may benefit patients in the future. Engaging openly with patients and communities is necessary to ensure that data sharing rules take into account the preferences of the communities we serve. This is especially important for underserved communities facing greater challenges in accessing health care.

The purpose of this report is to share what we learned about the views and experiences of different groups who are affected by the use of health data for research. This report presents insights from patients and community advisors and aims to help UCSF adopt a more clear and community-focused approach to managing health data. UCSF is committed to ensuring that health data is used responsibly and benefits both patients and the larger public.

What is health data?

Health Data is information about a patient's health care and medical treatment. It includes the patient's medical history, the results of medical tests, what treatments they are getting, their lifestyle choices, demographic information, and their physical measurements. It can also include information about tissue and blood, saliva, or urine samples collected for medical testing.

Some of the ways we collected the information for our project:

- We looked at current written policies and guidelines that UCSF has about using and sharing health data for research.
- We interviewed 27 patients, 5 parents of pediatric patients, and 13 community members serving on UCSF advisory boards.
- We observed how patients checked in at 7 UCSF clinics to see how they interacted with staff and with written documents provided to them about the privacy and use of their data.

By looking at these different sources of information, we were able to get a good understanding of UCSF's data sharing rules and practices and how our communities want data sharing to be managed.

What We Learned (Key Findings)

1. Most patients are not aware their health data may be used for research. While many remember getting documents while checking in for appointments, they often didn't read them thoroughly due to their complex language and length. Additionally, these forms weren't always available in the patients' preferred languages. Most patients had not been clearly told the difference between "identified" and "de-identified" health data. Both patients and community advisors are eager to

understand more about health data research. They want to know how the data is used, the type of research it supports, who sponsors it, the findings, and who benefits from it. They also agree on the need for clear data sharing explanations that are easy for people of all ages, reading levels and languages to understand.

2. Patients and community advisors believe that using health data for research can lead to important discoveries in medicine and improved health care for them, their communities, and society at large. They trust UCSF and believe the institution handles internal data sharing securely. However, some also have concerns about sharing data for research purposes when it involves for-profit companies. These concerns come from a general distrust of the for-profit sector, fueled by data breaches reported in the news and the profit motives of drug companies.

   Although there were concerns, many patients were open to sharing data with any research partner if it helped advance scientific research. Others believed that partnerships between universities and industries could be beneficial, but only if every party involved managed the data responsibly. To address these concerns, it was suggested that trust needed to be built intentionally by clearly communicating the goals and results of data sharing. Everyone agreed that the benefits from using health data should be shared fairly, stressing the importance of ongoing and meaningful interaction with communities, especially with those that have been left out or taken advantage of in past medical research.

> One patient said:
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> *I think that the institution itself has the foundation and they know–they should know how to use the information. … I completely trust that the institution has their ethics code and knows how to use the information. (Patient 19)*

> Another patient had a different point of view:
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> *I don't agree about [data sharing with] private companies because those companies make a profit, right?…but if the hospital is going to use it, then that's fine, for research. (Patient 10)*

3. Patients supported the idea of forming a new decision making group that included patients and community members and would decide how health data can be used. Everyone we interviewed was concerned about the issue of fair representation and the need for new group members to receive special training on the technical aspects of how to protect and share data. Some patients worried about having other patients represent their views, but overall, there was a strong push for this group to have the power to make real decisions, not just give advice. One community advisor said:

> *I think while it could ultimately slow down certain vitally important research, I think having patients be in charge of deciding when certain information is shared or not ensures a really healthy and functional relationship and a power relationship between the institution and the people seeking care. (Community Advisor 10)*

Recommendations to UCSF Leadership

Along with patients and community advisors, we also interviewed 30 UCSF faculty members and staff who work with or help manage health data as part of their jobs. This group included researchers, medical doctors, privacy specialists, bioethicists, and data scientists. Putting together what we learned from all three groups, the Regulatory Knowledge and Support group came up with recommendations for UCSF leadership on how to improve decision making and communication about health data use. We've written a more detailed report for that audience and will be meeting with UCSF leaders to present what we learned and what we think the next steps should be to share health data in a way that benefits the most people while addressing patients' concerns.

Our Recommendations:

1. **UCSF should enhance communication with patients about health data sharing for research by making forms and materials clearer and more interactive**. This includes updating how patients are informed about how their health data is used and protected, training clinic staff to answer questions, and giving regular updates about changes in how data is used.

2. **UCSF should make changes in three key areas of how health and research data are handled:**
   - ***a) Community Engagement***: including patients and the public in decision-making about data sharing.
   - ***b) Investigator Support***: giving researchers (faculty, staff, and students) more support and guidance about how to use and share data safely.
   - ***c) Accountability***: working together with the community to make clear rules that ensure UCSF is open, fair, and helpful to the public when sharing health data. This could involve:
     - Creating ways to encourage sharing the results of studies with the people whose data is used.
     - Coming up with methods to check how the health data research affects all groups of people.

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