Health Data Stewardship at UCSF

Toward Transparency, Community Engagement, and Shared Governance

Project Report

UCSF Clinical & Translational Science Institute
Regulatory Knowledge and Support

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EXECUTIVE SUMMARY

Responding to the exponential growth of digital health data and its increasingly vital role in medical research and clinical care, the University of California Office of the President (UCOP) issued reports in 2018 and 2024* articulating the need to move beyond the current regulatory and legal framework governing the use of patient data outside of clinical care. The traditional approach to oversight allows the health system to use and share patients' health data only under certain circumstances and without explicit patient consent, which hinders potential public benefit from large-scale data use and undermines patient trust. The reports' authors urged the UC system to move its data governance and stewardship approach beyond a narrow focus on privacy and security by adopting a patient-informed model of health data sharing. The new model would be informed by the principles of justice, transparency, responsible stewardship, patient engagement, and sharing data outside of UC for public benefit.

Understanding data sharing at UCSF

To create a roadmap that guides UCSF's adoption of UCOP's proposed model, the Clinical and Translational Science Institute's Regulatory Knowledge and Support (RKS) Program conducted a multi-staged investigation of:

a) Current policies and guidelines governing data use and sharing at UCSF.
b) Perspectives and experiences of stakeholders directly involved in and impacted by the internal and external use of aggregated health data for research, artificial intelligence (AI) development, and quality improvement (QI).

WHAT IS HEALTH DATA?

Health data is broadly conceived as information pertaining to patients' health, care, and treatment. Research data is generated through Institutional Review Board (IRB)-approved studies and is not typically considered health data unless it is also contained in the participant's medical record. Health data and research-generated data, and the policies and regulations that govern their use, often overlap. ***This report focuses primarily on health data used for research, AI, and QI***, although one of our recommendations also applies to health data and research-generated data.

* After the finalization of this report in 2024, UCOP's Ad Hoc Task Force on Health Data Governance issued its second Health Data Governance Task Force Report. The RKS team contributed to the development of UCOP's report as co-chairs and members of Work Group A, which was charged with developing a justice-based model of health data use. The task force's recommendations align well with the UCSF-focused recommendations presented in this report.

Our Approach

The RKS team conducted 24 hours of observation at UCSF outpatient clinics and 75 in-depth interviews with patients, community advisors, and UCSF faculty and staff involved in the management and oversight of health data and research-generated data. Questions specific to AI were not included in interviews because the use of AI in clinical care and research was limited at the time. We also reviewed UCSF websites with information about data use and sharing policies. This report outlines our findings and concludes with two actionable recommendations for putting UCOP's principles into practice at UCSF.

RECOMMENDATIONS

1. Expand and enhance how UCSF communicates with patients and the public about data sharing policies and practices.

2. Design and implement changes across three key domains of data governance at UCSF: Community Engagement, Investigator Support, and Accountability.

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INTRODUCTION

> *The root of the word governance derives from an ancient Greek nautical term. It meant "to steer the ship." That is a meaning worth recovering. In reflecting upon modes of governance, we must look beyond systems of codified rules and mechanisms of oversight to ask more fundamental questions: what course are we travelling, charted by whom, navigating with what instruments, who is at the helm, and what winds and currents are bearing us along—or driving us off course?*
>
> – J. Benjamin Hurlbut*, Imperatives of Governance*

RKS, a core program of UCSF's Clinical and Translational Science Institute (CTSI), provides guidance to faculty, staff, students, and institutional leaders on the policies, regulations, and ethical norms that guide health-related research. Data sharing and governance has become a pressing issue for RKS. The expanding use of health data (patient information derived from clinical services) for research, artificial intelligence (AI) development, and quality improvement (QI), has brought to light the limitations of existing governance mechanisms. Specifically, current regulations allow the sharing of de-identified health data for research without explicit patient authorization or consent, a practice that can create mistrust from a public that is increasingly suspicious about the tracking of every aspect of our digital lives. Moreover, data sharing policies and procedures are complex, evolving, and often unclear to the research community.

Positioning UCSF as an ethical data steward requires that greater attention be devoted to two important goals:

- Ensuring that researchers understand and are able to comply with data sharing policies and procedures.
- Moving beyond compliance to consider whether health data uses align with community values and benefits are equitably distributed.

Meaningful engagement with patients, communities, and UCSF stakeholders is essential for achieving these goals. This report shares perspectives from each of these groups and aims to guide UCSF toward a more open and participatory approach to data governance.

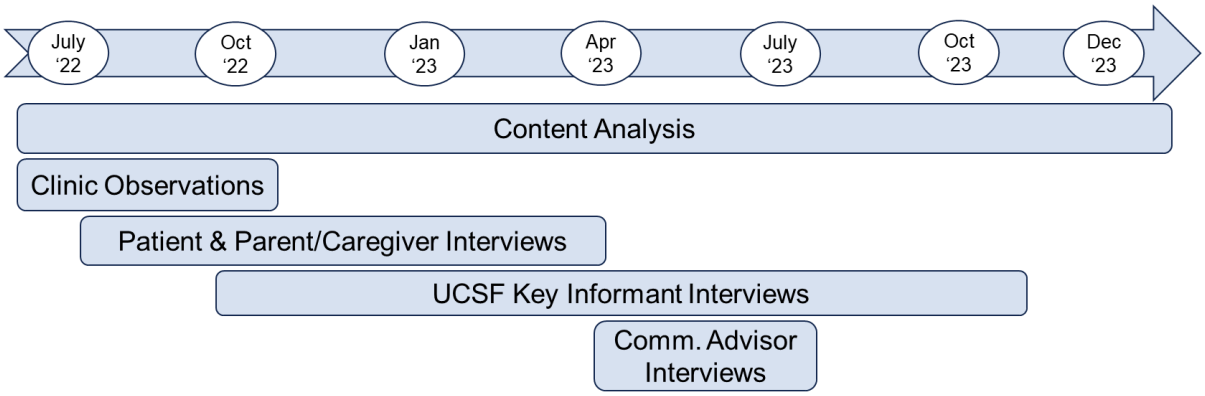
Our intended audience includes UCSF leaders responsible for creating and carrying out health data policies, as well as faculty, staff, students, and patients who are subject to these policies.

Although this report focuses primarily on health data used for research, AI development, and QI rather than research-generated data, we acknowledge that the distinction between health data and research data is increasingly blurred as we move toward a learning health system and AI-enabled health care. Moreover, institutional, state, and federal policies often apply to the use of both health data and research-generated data. This means that the need for clear policies and effective communication with patients, research participants, and investigators is more pressing than ever, particularly given the recent acceleration of AI applications in health research and clinical care. Accordingly, one of our two recommendations for fostering robust and responsible data governance at UCSF applies to the use of health data for research, AI, and QI, as well as for research-generated data.

Our work builds on the 2018 and 2024 reports released by UCOP's Ad Hoc Task Force on Health Data Governance, which highlighted the limitations of focusing exclusively on legal and regulatory compliance and risk disclosure. Both reports called for data oversight mechanisms that simultaneously optimize the use of health data to advance science, safeguard data privacy and security, engage patients and communities, and assess how benefits are distributed. RKS's goal in issuing this report is to guide UCSF toward implementing UCOP's recommendations and becoming a leader in participatory and transparent data governance. In supporting the responsible use of our diverse patient population's data, this report's findings and recommendations directly align with UCSF's mission to improve clinical care for all patients and advance health worldwide.

APPROACH

Figure 1. Project Timeline



We used an ethnographic approach to investigate health data sharing policies and practices at UCSF and explore multiple stakeholder groups' perspectives about data governance (Figure 1). We were particularly interested in understanding how data sharing is explained to patients, and what patients and community members know and think about how patient data may be used other than for clinical care. The use of health data for AI development was not explicitly discussed in the interviews; rather, the internal and external uses of health data were framed broadly in terms of research and learning. We also explored faculty, staff, patient, and community member perspectives about the potential involvement of patients and communities in data governance. Figure 2 provides a summary of each of our data collection activities (see Appendix A for more detail about methods, demographics, and representation:

Figure 2. Data Collection Activities

Clinic Observations	• Observation of check-in procedures at UCSF outpatient clinics. ▪ 24 hours at 7 Mission Bay, Parnassus, and Mt. Zion clinics.
Patient & Parent/Caregiver Interviews	• In-depth interviews: patients & caregivers of pediatric patients. ▪ 27 patients (22 English-speaking; 5 Spanish-speaking) ▪ 5 parents/caregivers
Community Advisor Interviews	• In-depth interviews: community members serving on UCSF patient and family advisory councils and research advisory boards. ▪ 13 community advisors
UCSF Key Informant Interviews	• Key informant interviews: UCSF faculty and staff involved in data management and oversight. ▪ 30 faculty and staff
Document Review	• Review and analysis of institutional documents and policies pertaining to data sharing and use.

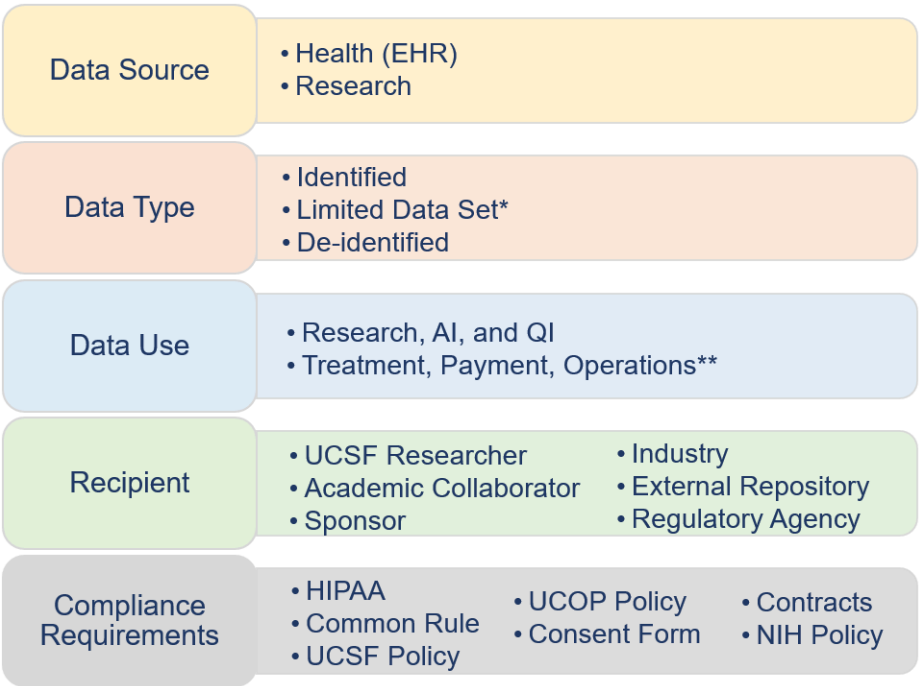
UCSF DATA LANDSCAPE

The UCSF health data landscape is complex, with multiple data access pathways, regulatory requirements, and governance mechanisms.

UCSF's health data landscape is a complex and dynamic network of administrative units, governing entities, data sets, researchers, technology platforms, policies, and regulations governing how health and research data can be used inside and outside the institution. Drawing on interviews with key informants and review of UCSF websites, this section provides an overview of UCSF's current data sharing policies and procedures. Our analysis is not focused on data security and does not encompass all data governance activities across the institution.

The landscape can be broadly conceptualized through a framework with five elements: data source (health or research), data type (identified, limited data set, or de-identified), data use (research/AI/QI or treatment/payment/operations), recipient, and compliance requirements. Depending on the multiple possible configurations of the first four elements, different compliance requirements apply (Figure 3).

Figure 3. Data Landscape and Sharing Overview



* Data set in which most protected health information has been removed. Limited data sets are not discussed in this report because of their infrequent use.

** Not the focus of this report.

Data types and the rules governing their use

The research use of **identified health data** is governed by both the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Policy for the Protection of Human Subjects (or, the Common Rule), as applied by IRBs. The IRB can waive the requirements of patient consent and HIPAA authorization for minimal risk research provided specific conditions are met, including privacy protection measures. Approximately 300 waivers are granted annually at UCSF for internal use of Protected Health Information (PHI) – most often for large-scale studies using electronic health records. Disclosing identifiable data to commercial entities is generally prohibited.

Research using **de-identified health data** is not considered human subjects research under HIPAA or the Common Rule, therefore IRB review is not required. However, de-identified health data is subject to institutional policies governing access, use, and sharing for research purposes. For example, UCSF has drawn from UC Health's data classification rubric to create internal data classification types and related policies (see Figure 4).

Figure 4. UCSF Data Classification

Access to and sharing of health data for research and QI*

Understanding data access policies and procedures can be challenging because there are numerous websites with partially overlapping information. The following explanation is based on our understanding of written guidelines provided at multiple data access points.

Investigators with IRB approval to use **identified health data** are expected to consult with Academic Research Services (ARS) via a CTSI data extraction consultation. ARS provides guidance on the Enterprise Data Request (EDR) process and promotes compliance with university privacy and security policies by requesting information about plans to share identifying data with external parties. All data sharing proposals are then directed to a contracting unit to determine whether a formal data sharing agreement is required. EDR also prompts IT Security to decide whether a risk

* Because our landscape analysis predated the launch of many of UCSF's AI platforms and guidelines, this section does not explicitly address the use and sharing of health data for AI development and implementation.

assessment of a third party's data system is needed. Rare exceptions allow direct access to identified data by trained investigators without EDR routing. We were unable to determine what criteria are used to grant exceptions.

De-identified data can be accessed using the Data Access for Research form, or through consultation with ARS. The Data Access for Research process enables self-service access to de-identified health data. Unlike the EDR process, those using this pathway to access health data are not asked about external data sharing plans nor are they automatically routed to a contracting unit. This means that investigators accessing de-identified data are expected to understand and comply with UCSF data sharing policies without explicit guidance or additional oversight.

Institutional oversight of data sharing

The IT Governance Committee on Enterprise Information and Analytics (EIA) is the primary governing board for external data sharing at UCSF. Its mandate includes developing and implementing UCSF's data sharing and management policies and communicating with researchers about data-related resources, services, and policies. The committee meets monthly to review data-sharing agreements deemed high risk by the Industry Contracts Division (ICD) or another UCSF contracting unit. Cases usually involve a proposal to either use identifiable information outside of an IRB-approved study or share restricted or sensitive data with commercial entities or other external collaborators.

In addition to EIA, there are multiple programs involved in creating and implementing data policies and procedures at UCSF (Figure 5). A detailed explanation of each program's role in data governance is beyond the scope of this report.

The UCSF Campus Policy (650-20): "External Sharing of Personally Identifiable Information (PII) and PII-Derived Data" outlines UCSF's rules and procedures for sharing identified and de-identified data with external entities. The new policy states that all external sharing of UCSF-owned identified and de-identified health data must be reviewed in advance by a contracting unit unless certain exceptions apply. At the time this report was being prepared, public comments about the policy were under review by EIA.

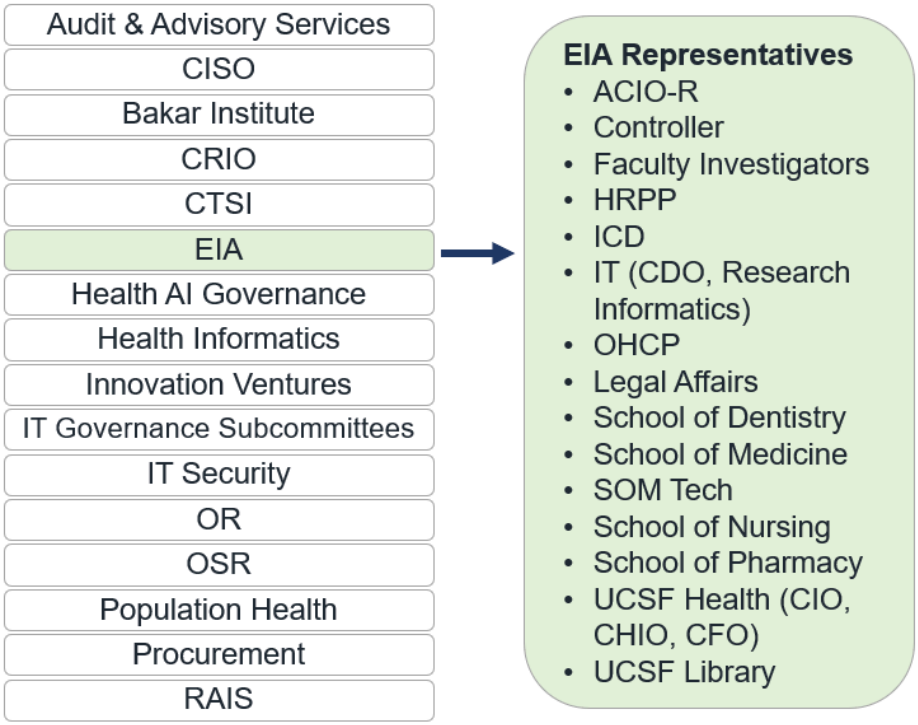
Data sharing activities in the absence of a formal agreement, e.g. directly sending or making data available to an external repository or collaborator, are not visible to UCSF's contracting units and thereby elude potential review by EIA. This oversight gap is concerning given the possibility that third parties could be given access to restricted or sensitive data by UCSF employees who are unfamiliar with data sharing policies.

After this report was completed, EIA convened a Data Sharing Education & Training working group with representatives from EIA, RKS, the Library, and ICD. The working group is developing guidance and training materials to improve data sharing policy implementation and compliance.

Data sharing resources and guidance for researchers

Guidance on data sharing policies and procedures is distributed across multiple websites (see Appendix B). UCSF Data Resources is a primary source of information, with sections on accessing health data for research and data sharing policies. The ARS website provides descriptions of research data assets and instructions for requesting a consultation on the use of health data for research.

Figure 5. Data Governance Stakeholders



Administrative units, such as School of Medicine Technology Services (SOM Tech), Human Resources Protection Program (HRPP), ICD, and Supply Chain Management (SCM), also offer guidance about compliance, security, ethics, and operational aspects of data sharing. Diffuse sources of information, and variations in terminology, present significant challenges for researchers attempting to comply with policies and could increase data security risks.

Patient notification

UCSF Health uses two documents to notify patients that their health data could be used for purposes other than clinical care: Terms and Conditions of Service (TACOS) and Notice of Privacy Practices (NOPP). Provided annually, TACOS covers various aspects of hospital admissions, medical services, and financial agreements, but does not explicitly mention the use of health data for research. NOPP is provided once – typically during a patient's first clinical visit – and states that patient authorization is not required for health data research undergoing "a special review process." TACOS and NOPP both require a high level of reading comprehension.

KEY FINDINGS 1

AWARENESS OF HEALTH DATA POLICIES AND PRACTICES

KEY INSIGHT
Strengthening institutional communication about data use policies and activities, and providing guidelines to help researchers comply with policies, will increase awareness and understanding among patients, the public, and researchers and will improve UCSF's trustworthiness and credibility as a data steward.

Patients are largely unaware of data policies

When asked whether they received information about UCSF's data use policies, most patients recalled being given the TACOS and NOPP forms but few had read them. Many patients explained that they were unsure of the forms' purpose, pointing to their length and inscrutable language. Compounding these access challenges, the forms were not always available in a patient's preferred language. Additionally, most patients had not received a clear explanation about what constitutes identifiable and de-identified health data.

Patients and community advisors want to learn about health data research

Both patients and community advisors wanted to know more about how health data is used, what type of research it supports, who the sponsors are, what is learned, and who will benefit. There was also consensus about the need for data sharing explanations in multiple languages and in terminology that is accessible to adults of all ages and literacy levels.

There is strong support for transparency about health data use

For the most part, UCSF key informants agreed with patients and community advisors that UCSF should be more transparent about how health data is used. The current approach, they explained, emphasizes compliance with laws and regulations rather than effective communication with patients and communities about who has access to health data and for what purposes it can be used.

Health data policies and procedures are not well understood by UCSF investigators

Key informants reported that there is an overall lack of understanding among UCSF investigators and research teams about data sharing policies and procedures.

> ***"There's a ton of researchers that have no clue about the services and offerings that exist that could help them. And … anytime we … do education … probably half the room is like, 'I had no idea this existed at UCSF.'" (Key informant 14)***

For example, they indicated that there is confusion about how to establish data sharing agreements with external collaborators, uncertainty about the circumstances in which such agreements are required, and little understanding of the criteria used to determine whether institutional review of a data sharing plan is needed.

> ***"… different investigators are doing different things. Not everyone is aware of a single unified pathway to do this. There's still a lot of uncertainty. Some people will go digging and will ask questions to try to get answers, and other people might not even recognize that these are things that need to be looked into." (Key informant 12)***

POTENTIAL BENEFITS AND RISKS OF DATA USE AND SHARING

KEY INSIGHT
Most patients reported a high degree of trust in UCSF's ability to protect health data and patient privacy, and expected benefits of health data sharing include scientific and clinical breakthroughs. Patient and community concerns include the possibility of privacy breaches resulting from sharing data outside UCSF, profiteering, and inequitably distributed benefits from health data research.

Health data is crucial for advancing medical research and clinical care

Patients and community advisors expected that data sharing would lead to advances in medical knowledge and, in turn, to better health care for themselves, their communities, and society more broadly. Among key informants, data sharing was framed as an important activity in the university's effort to achieve its goals of excellence in research, education, and patient care. The term "public benefit" was mentioned often by key informants and appears to have an implicit, shared meaning that is contrasted with purely commercial interests and tied to expectations of advancement in scientific knowledge and clinical care. However, we also learned that the institution's ability to assess whether benefits have accrued, and for whom, remains woefully underdeveloped.

A high level of trust in UCSF is accompanied by concerns about data sharing activities

Patients' perspectives about health data research were informed by the extent to which they felt trust in and and satisfaction with UCSF as a health care provider. For internal data sharing, in particular, there was consensus among both patients and community advisors that UCSF takes data security seriously and can be entrusted to safeguard health data while minimizing risks to patients.

However, well-reasoned doubts about the trustworthiness of sharing data for research also surfaced, including concerns that researchers might be more motivated by career advancement opportunities than public benefit. Most patients and community advisors also voiced unease about the lack of information about how and by whom health data is used. Community advisors voiced that this can be particularly harmful for communities experiencing health disparities.

Many patients and community advisors believe that for-profit data users are not trustworthy

Most patients and community advisors also expressed discomfort with the idea of health data (whether identified or de-identified) being used by external institutions. A particularly strong moral line was drawn between academic medical institutions and for-profit entities, with many interviewees expressing the conviction that industry motives – particularly those of pharmaceutical companies – are based more in profit-seeking than a commitment to the public good. On the other hand, some interviewees said unequivocally that sharing data with any research partner was acceptable in the interest of scientific advancement. Others were of the opinion that academic-industry partnerships could lead to important innovations provided that all partners were responsible data stewards.

> ***"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)***

We frequently heard that the solution to distrust is the intentional and consistent building of trust. Trust-building takes place, in part, through clear communication with patients about the purposes of data sharing and what is being learned. ***"I would like to know that my information is being used" (Patient 3),*** one interviewee put it plainly.

Patients and community advisors are concerned about threats to privacy

Most interviewees said they had confidence in UCSF's commitment to safeguarding patients' privacy. Some patients, however, were afraid that UCSF may be unable to consistently protect their or their family members' privacy. In cases of de-identified data sharing, concerns about re-identification were particularly acute among parents with transgender children who worried that their child could be identified and targeted. Similar anxieties were highlighted in discussions about genomic information. The idea that genomic data can be de-identified is a fiction, at least one patient told us.

> ***"…I don't think anyone can ever be a hundred percent sure of security breaches and things like that. Whether it's UCSF or Stanford or even a tech company that literally does it as their job, it's impossible to really fully know and be comfortable with it, I think." (Patient 21)***

The possibility that health data would be perennially re-shared also contributed to privacy concerns. One patient asked, ***"…who do they share with and where does it go from there? Does it stop with them or no?" (Patient 20).***

Finally, while data security and privacy protections are strongly prioritized at UCSF, and are the primary concern of federal policies and regulations such as HIPAA, at least one key informant made the case for shifting the conventional data sharing discourse from its primary focus on privacy and individual rights toward a consideration of health data as a collective resource that should be used for public benefit.

> ***"…framing everything as privacy already tilts the balance towards individual rights. And I think health data, as we've seen in the pandemic, is a public good… we need to balance the public good against the right to privacy." (Key informant 23)***

There is broad agreement that ensuring equitable benefit from health data use is an essential goal

Everyone we spoke with was adamant that the downstream benefits of data sharing can and should ultimately reach patients and the public. Community advisors, in particular, emphasized that benefits should be distributed equitably across all patient populations. Achieving this goal, they asserted, is only possible through ongoing and meaningful engagement with communities about their values and priorities, particularly those who have historically been excluded from or exploited by medical research. Regularly disseminating research findings to communities, and to the institutions that serve them, is also important for ensuring broad benefit.

> ***"…who are you sharing your findings with? Not just with each other in silos but are you going into public health care systems and saying, 'we have this documentation of data on these health outcomes for this Latino group. And we thought we'd share these with you because from the population and from the data we've seen, you probably have a larger population of these Latinos that you are serving in public health.'" (Community Advisor 4)***

IMPROVING THE DATA SHARING ECOSYSTEM AT UCSF

KEY INSIGHT
UCSF's efforts to ensure that health data is shared safely and with maximum public benefit can be bolstered by centralized data governance and improved communication with investigators and research staff about data policies and procedures. Specific areas of growth include support for data de-identification, communication of external data sharing rules, prevention of data leakage, and accountability following execution of data sharing agreements.

Guidance and support for researchers

Key informants reported that there are multiple administrative units providing data sharing guidance, leading to a lack of clarity about rules and procedures among investigators.

The solution, interviewees proposed, would be to communicate data sharing policies and services by way of a single source of information or A-to-Z roadmap. More coordinated guidance would help researchers determine if a risk assessment or data sharing agreement is needed, understand how to set up a data-sharing agreement, and access available data de-identification services.

> ***"…I think a lot of people's frustrations are just in the variability of experience and navigation and trying to figure out…who do you go to for what." (Key Informant 12)***

Reducing the risk of re-identification of de-identified data sets

UCSF interviewees reported that the institution is limited in its capacity to assist investigators with the process of de-identifying data, particularly research data, and to ensure that de-identification has been performed correctly.

The implication is that research teams are expected to either de-identify data independently, following guidelines provided by ARS, or pay for an external de-identification service. Additionally, certification of data de-identification is neither available nor required at UCSF. A related issue is the ongoing cost of data storage and management, which presents a considerable financial burden that – in the case of research-generated data – usually falls on investigators.

> ***"…bring folks together so that we're not issuing very specific guidance over here that doesn't apply to people over here."***
> ***(Key Informant 7)***

Preventing data leakage

Concerns about "data leakage" were also mentioned. Interviewees explained that data leakage occurs when health or research data is moved outside UCSF servers, or a third party gains access to UCSF data, without institutional oversight or review. Leakage is not usually intentional, we were told, but is likely a result of investigators' lack of awareness of UCSF's external sharing rules. For example, investigators who are forming an industry-academic partnership are likely to understand that a data sharing agreement approved by ICD is required. Investigators sending data directly to an external collaborator or repository, by contrast, may not know when consultation and approval from ICD or another contracting unit is required. This suggests that institutional oversight is more robust along some data sharing pathways than others. Moreover, there does not appear to be a mechanism in place to assess the extent of data leakage at UCSF.

> ***"I think we have a very leaky system. …we tend to ask for forgiveness rather than permission so it's not unusual for somebody to stumble across a relationship that seems to have been cemented without any institutional oversight and it happens all the time…"***
> ***(Key informant 16)***

Contract clauses related to downstream data use

Contracts often stipulate that data must be returned or destroyed after being used for a designated purpose and can also prohibit commercialization and further sharing of the data. However, these stipulations are difficult to enforce.

> ***"We put lots of legal requirements in place about not resharing the data, but we enforce absolutely nothing. We have no mechanism to enforce any of the guardrails we put around data sharing."***
> ***(Key informant 4)***

Distributed data governance

UCSF does not have a unified data governance process or explicit data sharing guidelines for investigators. The creation of the IT Governance Committee on EIA was an important step forward, key informants explained. But they noted that there are multiple groups making data use decisions and that criteria may not be standardized across those groups.

Moreover, EIA is a high-resource committee in terms of time, cost, and "brain power," a key informant told us. This suggests that individual case review should be supplemented by policies and procedures that can be clearly communicated and broadly applied and enforced. The result would be a reduction in the number of cases needing individual review and increased compliance with data use policies.

Considering UCSF's ongoing efforts to address health disparities, several key informants also noted that EIA review would benefit from adding new members representing bioethics as well as community and patient perspectives.

> ***"[Ethics]comes up, particularly the justice and equitable benefit part comes up. Is it always one of the principles that's in the conversation? Probably not in the way that it ought to be."***
> ***(Key informant 20)***

> ***"I feel like patients are not included in the way those problems are defined, or the needs or concerns of patients are not taken into account yet, in how we design those processes."***
> ***(Key informant 21)***

TOWARD SHARED GOVERNANCE

KEY INSIGHT
Patients and community advisors support a shared governance approach that includes meaningful public involvement. UCSF key informants were more equivocal about multi-stakeholder governance. All groups expressed concern about inequitable representation and training requirements given the technical aspects of data sharing.

Patients and community advisors support the inclusion of patient/public representatives in data oversight

Patients expressed strong support for the formation of a governance group in which their perspectives on health data sharing would be heard. Several emphasized the importance of diverse representation. The committee could help increase transparency about the purpose of health data research and urge UCSF to clearly define and communicate what it means to "improve patient health." Proposed topics for a health data committee to discuss include data sharing guidelines and consent form language. A small minority of patient interviewees did not trust other patients to represent their perspectives.

> ***"I feel like I'm okay with digital information being shared as long as it's to better people's health, but then I think they need to define what that means." (Patient 17)***

Community advisors agreed that including patients in governance is essential. Some recommended that patients help evaluate which forms of data sharing would ultimately benefit patients. Several community advisors emphasized that the committee must have the power to influence decisions made about health data sharing rather than acting solely in an advisory capacity.

> ***"[Members of the committee] should be involved in all the data decisions that come up…the ethics of the use of the data in all its forms." (Community Advisor 1)***

UCSF key informants are equivocal about patient/public involvement in governance

One key informant emphasized that including patients in governance could increase accountability and equity in health data research and recommended that a representative from UCSF Health's Patient and Family Advisory Committees (PFACs) be included in a health data governance group.

> ***"I would love to see something come out of the PFAC task force that really radically restructures those groups, and then those groups could send a representative to another body that forms that integrated ethics and equity deliberative conversation. […] What an amazing group that would be. And then have that group really have some power and influence when it comes to just systems of accountability." (Key Informant 21)***

On the other hand, several key informants highlighted the potential challenges of assembling a committee to represent diverse patient viewpoints, and ensuring that all committee members receive adequate training and information. Including patients in health data sharing decision making could also slow the process of research approval, they surmised.

Suggested alternatives to direct community involvement in data governance included incorporating patient/public input in the IRB, which governs the use of identified health data for research and currently has community representatives. Another recommendation was to invite patient and community representatives to collaborate on the development of data sharing principles or other forms of guidance for researchers.

> ***"Half of me says absolutely that would be great because we are governing, in a way, patient data. And so, I think it would be a good thing. I think the other half of me says, how do you get there and make it meaningful, timely, and have an educated population that can really think through the pieces?" (Key Informant 14)***

RECOMMENDATIONS

Responding to the findings detailed in this report, and moving UCSF toward leadership in principled and transparent data stewardship, require dedicated resources and an institutional commitment to structural change. Such an investment will align with UCSF's commitment to serving the public and will position our institution as a groundbreaking leader among its peers. RKS will be an active partner in this process, providing dedicated staff time and material support to help realize the following detailed recommendations. Note that Recommendation 1 is specific to health data while Recommendation 2 pertains to both health data and research-generated data. Both recommendations concern the use of health data for research, clinical AI development, and QI. We anticipate that implementation of the recommendations can take place concurrently and immediately.

RECOMMENDATION 1. Expand and enhance how UCSF communicates with patients and the public about data sharing policies and practices.

Strategies could include:

- Implementing a more interactive patient notification process, including revised TACOS and NOPP forms and plain language multimedia aids to supplement the forms.
- Offering training and scripts for clinic staff on the purpose and meaning of TACOS and NOPP and how to respond to commonly asked questions from patients.
- Conveying regular updates about the use of health data for research, AI development, and QI to patients and the public.
- Providing FAQs to inform internal and external audiences about UCSF's efforts to protect, use and optimize the benefits of health data.

RECOMMENDATION 2. Design and implement changes across three key domains of health data and research-generated data governance at UCSF: Community Engagement, Investigator Support, and Accountability.

We recommend that the goals outlined below be pursued in consultation with representatives from the following groups, among others: HRPP, the Center for Community Engagement (CCE), UCSF Bioethics, UCSF Health, EIA, RKS, Legal Affairs, IT Security, and the Office of the Associate Vice Chancellor for Research - Inclusion, Diversity, Equity, and Anti-Racism (AVCR-IDEA).

A. Community Engagement: Establish meaningful patient/public involvement in data governance, including:

- Providing financial support for and convening a health data oversight committee that will interact with other governing bodies including EIA. Members would include patient and community representatives.
- Revisiting the membership of existing governing committees, such as EIA, to include patient/community representatives, bioethicists, and UCSF community engagement experts (see Appendix C for interviewees' recommendations for addressing shared governance challenges).

B. Investigator Support: Provide coordinated support and guidance to ensure that faculty, staff, and students are aware of, understand, and are able to comply with UCSF data use policies and procedures, including:

- Conducting a comprehensive review of UCSF's data policies and guidelines to a) assess their consistency, accessibility, and comprehensibility; and b) ensure that all types of data are addressed, including health data, research-generated data, qualitative data, and quantitative data.
- Ensuring that data policies are communicated in plain language and with consistent terminology to all clinicians, investigators, research staff, and trainees.
- Supporting the creation of ethics guidance and training for UCSF investigators who develop, implement, and/or oversee AI projects.
- Developing an institutional strategy to assist investigators with data de-identification.

C. Accountability: Determine how UCSF should hold itself and its external collaborators accountable for institutional commitments to transparency, equity, and public benefit, including:

- Creating a participatory, community-engaged design process to define and operationalize "accountability" in the use of health data and research data, including:
  - Co-designing rules and procedures for follow up after data use, e.g. strategies to ensure that study results are communicated to research participants.
  - Developing methods for assessing the impact of health data research.

ACKNOWLEDGEMENTS

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APPENDICES

APPENDIX A

Approach in Detail

To assess how UCSF's health data sharing is understood, introduced to patients, governed, and carried out, we conducted an ethnographic investigation of institutional policies and practices as well as the perspectives of multiple stakeholder groups at UCSF. Data collection methods included (a) content analysis of institutional documents and policies pertaining to data use and sharing at UCSF, (b) clinic observations at UCSF outpatient clinics, and (c) in-depth interviews with patients, caregivers, community members serving on UCSF advisory committees, and UCSF faculty and staff. The project was submitted to IRB and designated as exempt research.

Content analysis of UCSF data sharing documents and websites

We reviewed information from the following sources:

- Patient-facing documents explaining individual rights and the potential uses of personal health information
- Public-facing materials and communications pertaining to data stewardship
- Documents and websites pertaining to the policies and practices of UCSF entities involved in data use and sharing
- Internal reports about data governance and sharing

Materials were identified through searches of publicly accessible websites and in consultation with CTSI and other institutional collaborators. We created detailed field notes to document data sharing language and policies as well as our concerns about the clarity, consistency, and accessibility of these documents and websites. Although we attempted as broad a search as possible, data sharing at UCSF is constituted by a large and complex network of policies and practices and there are likely health data-related rules and activities that our review does not include, such as those at the department and division level.

Clinic Observation

We conducted 24 hours of observation at seven UCSF outpatient clinics. Clinics were purposefully chosen to represent a range of locations and specialties. We spent a minimum of two hours in the waiting room at each clinic, observing how patients interacted with front desk staff during check-in. When possible, we conducted brief, informal interviews with patients to assess their understanding of the TACOS and NOPP forms and how their health information might be used for research. We also spoke with front desk staff and clinic managers about how TACOS and NOPP forms were distributed to patients. Our observations and conversations with patients and staff were documented in detailed field notes.

In-depth Interviews

We conducted 75 in-depth interviews with three groups:

1. **Patients and parents/caregivers of pediatric patients***

Recruitment strategies included direct invitation during clinic observations, referrals from clinic staff, and outreach by mail and phone using a list generated by the UCSF Health Patient Experience office that included patients and parents/caregivers who had consented to be contacted for QI activities. We aimed for diversity across multiple demographic characteristics, including age, gender, self-identified race/ethnicity, and insurance status (see Table 1). In order to foreground perspectives from populations that have been historically underserved by health care systems, we purposefully oversampled for patients who identify as Black and/or Latinx, and those whose preferred language is Spanish.

* Funding provided by UC Health Center for Data-Driven Insights and Innovation (CDI2)

Table 1. Patients and Parents/Caregivers of Pediatric Patients Demographics

Age (years)	**N**
18 – 34	3 (9%)
35 – 50	12 (38%)
51 – 67	15 (47%)
68 +	2 (6%)
Self-Identified Race/Ethnicity	
Black or African American	9 (28%)
American Indian or Alaska Native	1 (3%)
Asian	7 (22%)
White	9 (28%)
Hispanic or Latinx	6 (19%)
Native Hawaiian, Other Pacific	0
Preferred Language	
English	27 (84%)
Spanish	5 (16%)
Gender	
Female	20 (63%)
Male	12 (38%)
Education	
Elementary School	2 (6%)
Less than High School	2 (6%)
High School	6 (19%)
Some College / Associates Degree	8 (25%)
Bachelors Degree	9 (28%)
Some Graduate School	1 (3%)
Master's / JD / PhD	4 (13%)
Health Insurance	
Medi-Cal	16 (50%)
Medicare	2 (6%)
Worker's Compensation	1 (3%)
Private / Employer Paid	13 (41%)
Total Participants	**N = 32**

2. Community Advisors*

We recruited current or past members of groups including UCSF Health Patient and Family Advisory Councils (PFACs), community advisory boards whose members collaborate with UCSF researchers, and a UCOP advisory board. We aimed for diversity across gender, self-identified race/ethnicity, type of advisory group served on, and disability status (see Table 2). Prospective participants were identified through institutional contacts at CTSI's Community Engagement Program and UCSF Health's Patient Experience office. Our participants include a higher proportion of women than people of other genders, primarily because women are overrepresented on UCSF community advisory boards and PFACs.

* Funding provided by an NIH administrative supplement.

Table 2. Community Advisors Demographics and Groups Represented

Years as a UCSF Community Adivsor	N
0 - 3	7 (54%)
4 - 7	5 (38%)
8 - 11	1 (8%)
Self-Identified Race/Ethnicity	
Black or African American	1 (8%)
Asian	3 (23%)
White	6 (46%)
Hispanic or Latinx	3 (23%)
American Indian or Alaska Native	0
Native Hawaiian or Other Pacific Islander	0
Gender	
Female	10 (77%)
Male	3 (23%)
Self-Described Special Needs/Disability	
Yes	4 (31%)
No	9 (69%)
Education	
Some College / Associates Degree	1 (8%)
Bachelors Degree	3 (23%)
Graduate Degree	9 (69%)
Advisory Groups Represented	
BCH Cross-Bay Youth Advisory Council	1 (8%)
COVID Research PCAB	6 (46%)
Hospital Medicine PFAC	2 (8%)
Patients with Disabilities Advisory Council	2 (15%)
Research IDEA Advisory Board	1 (7%)
UCOP CD12 Oversight Board	2 (15%)
Total Participants	**N = 13**

3. Key informants

This cohort included UCSF faculty and staff with knowledge of and/or direct involvement in data governance, data policy, and operational decisions about data management, data de-identification, data sharing, and data use in research (see Table 3). A combination of purposeful and snowball sampling was used, and potential participants were recruited by email.

Table 3. Key Informants Representation

Department or Administrative Unit	N
Academic Research Services (ARS)	2
Associate Chief Information Officer for Research (ACIOR)	1
Bakar Computational Health Sciences Institute (BCHSI)	1
Bioethics Program	1
Center for Community Engagement	1
Center for Real World Evidence	1
Chief Research Informatics Officer (CRIO)	1
Clinical Informatics and Digital Transformation	1
CTSI Community Engagement	1
CTSI Informatics and Research Innovation	1
CTSI Research Technology	1
Human Research Protection Program (HRPP)	1
Indutry Contracts Division (ICD)	2
Institutional Review Board (IRB)	2
IT Enterprise Information & Analytics Committee (EIA)	2
IT EIA Compliance	2
IT Governance	3
Library Data Science	1
Office of Healthcare Compliance and Privacy (OHCP)	1
UC BRAID	1
UCSF Health Chief Data Officer	1
UCSF Health Chief Medical Information Officer	1
UCSF Health Patient Experience	2
Total Participants	**N = 30**

Data Management and Analysis

All interviews were conducted in person, by phone, or by video conference, lasted between 45-60 minutes, and were audio-recorded and professionally transcribed.

Field notes and interview transcripts were uploaded to the qualitative data management application Dedoose. Five members of the RKS team then participated in a rigorous and iterative process of coding and thematic analysis to develop the findings detailed in this report.

APPENDIX B

Data Sharing Policies, Resources, and Training

POLICIES

UCSF

200-28: HIPPA Business Associates view here

200-32: Workforce Sanctions for Patient Privacy Violations view here

650-16: Information Security and Confidentiality view here
Includes Addenda A-Roles and Responsibilities, B-Minimum Security Standards, F-Data Classification Standard

650-18: Authorized and Acceptable Use of Institutional Information and IT Resources view here

650-20: External Sharing of Personally Identifiable Information (PII) and PII-Derived Data view here

5.01.06: Control of Access to and Release of Information from UCSF Medical Center Information Systems view here (UCSF login required)

UCOP

Electronic Communications Policy view here

Research Data Policy view here

Guidance on Implementation of UC Research Data Policy view here (UCSF login required)

Electronic Information Security view here

RESOURCES (UCSF login required)

How to Obtain and Share Data Through External Registries

Guidelines for De-Identifying Data Sets to Meet NIH Requirements

Enterprise Data Request Process Steps for Sharing Data with Third Parties

General Data Sharing FAQs

Research Data Workflow

Sharing Research Data with Industry, External Researchers, and Data Repositories (Webinar, 9/2023)

Academic Research Services view here
Includes Research Data Assets and Services, Clinical Data Research Consultants and FAQs, Requesting EHR Data Wiki Page view here (UCSF login required)

Clinical and Translational Science Institute
Participant Recruitment: EHR Recruitment Consultation view here
Research Consultation view here
Includes Data Extraction, Data Management, APeX-Enabled Research

Data Resources
For Research view here
Includes Data Sharing, Data Management, Clinical Data, Counts, De-Identified Data, De-Identified Data with Dates and Zip Codes, Fully Identified Data, APeX-enabled Research
Data Sharing Toolkit view here
Research Data Series (slides and videos) view here

Enterprise Data Request Process for Research (UCSF login required) view here
Includes Process & Policies for Research, Research Compliance, Data De-Identification, Clinical Data Request Process: IRB Checklist, Guidance: De-Identifying UCSF Clinical Data sets to Meet NIH Data Sharing Requirements, Data Sharing Partnerships (Contracting Units, Review Process, Escalation Criteria, Resources and FAQs), Sharing De-Identified Data in Repositories

Human Research Protection Program view here
Use "Search" Box to find: Electronic Data Security, Medical Records Review, HIPAA Requirements and Forms, NIH Data Management and Sharing Policy, Device and Technology Guidance: Data Sharing

Industry Contracts Division view here
Material/Data Transfer Agreements, Industry Contracts & Grants MTA FAQs, De-Identified Data Policy

Information Commons view here
Includes Research Data Assets, Tools, Infrastructure, Getting Started

IT Governance view here
Includes Standing Committees on Research Technology (CRT), Enterprise Information and Analytics (EIA), Cybersecurity

IT Security view here
Use "Search" Box to find: Risk Assessment, Sharing Sensitive Data with Non-UCSF Collaborators, Your Role in Protecting UCSF Data, Outreach and Training

Library
Reproducible Data Management Plan view here
Make a Data Management Plan, Prepare your Research Data for Sharing, Select a Research Data Repository
NIH 2023 Data Management and Sharing Policy view here
Templates and Sample Plans, Presentations, FAQs
Data Science and Programming view here
What is the Vivli Clinical Data Repository, What is the Qualitative Data Repository, What is the Dryad Data Repository
Resources for Sharing Qualitative Data view here
De-Identifying Qualitative Data, Qualitative Data Repositories

Office of Healthcare Compliance and Privacy view here
Privacy & Confidentiality, Notice of Privacy Practices, Research Recruitment Opt-Out
My Compliance view here (UCSF login required)
Includes UCSF Privacy and Confidentiality Handbook, Research Compliance Guidance on: Research Use and Disclosure of PHI, HIPAA and Research

Research Cybersecurity view here
Includes Research Data Security Assessments, Onboarding Consultations, Approved Data Storage, Secure Research Guide, Data Security Training

Supply Chain Management
Data Privacy view here

TRAINING (UCSF login required)
Collaborative Learning Environment (CLE) view here
Use “Find Courses” field for webinars on NIH Data Management and Sharing Policy, and Introduction to Inclusive and Collaborative Open Science; Reproducibility Courses
HIPAA 101 Training view here
UC Ethics and Compliance Briefing for Researchers view here
Library: Data Science Education and Training Portal view here
Data Resources: Training view here

APPENDIX C

Recommendations Proposed by Interviewees for Shared Governance of Health Data

- Allocate resources for training patients and community advisors to address the complex topic of health data sharing.
- Decide in advance whether patients' roles would be merely advisory, or if they would participate in decision making.
- Create a new oversight group that could collaborate with the IRB or Communications office, leveraging existing structures and knowledge to maximize impact.
- Develop innovative recruitment strategies to promote equitable representation in the data governance committee.
- Form multiple committees to address a range of health issues and community priorities.
- Include "translators" or "ambassadors" in a multi-stakeholder governance group to promote understanding between specialists and communities.

APPENDIX D

Acronyms

APeX	Advanced Patient-Centered Excellence
AAS	Audit Advisory Services
AI	Artificial Intelligence
ACIOR	Associate Chief Information Officer for Research
ARS	Academic Research Services
AVCR-IDEA	Associate Vice Chancellor for Research-Inclusion, Diversity, Equity, Anti-Racism
BCH	Benioff Children's Oakland
BCHSI	Bakar Computational Health Services Institute
CAB	Community Advisory Board
CD12	Center for Data-driven Insights & Innovation
CDO	Chief Data Officer
CFO	Chief Financial Officer
CIO	Chief Information Officer
CISO	Chief Information Security Officer
CRIO	Chief Research Informatics Officer
CTSI	Clinical & Translational Science Institute
EDR	Enterprise Data Request
EHR	Electronic Health Record
EIA	Enterprise Information & Analytics
HIPAA	Health Insurance Portability & Accountability Act
HRPP	Human Research Protection Program
ICD	Industry Contracts Division
IRB	Institutional Review Board
NIH	National Institute of Health
NOPP	Notice of Privacy Practices
OHCP	Office of Healthcare Compliance & Privacy
PCAB	Patient & Community Advisory Board
PFAC	Patient & Family Advisory Board
PHI	Protected Health Information
QI	Quality Improvement
RAIS	Risk Advisory & Insurance Services
RKS	Regulatory Knowledge & Support
SCM	Supply Chain management
SOD	School of Dentistry
SOM	School of Medicine
SOMTech	School of Medicine Technology
SON	School of Nursing
SOP	School of Pharmacy
TACOS	Terms & Conditions of Services
UCOP	University of California Office of the President

APPENDIX E

Plain Language Version of Report for Patient, Caregiver, and Community Advisor Interviewees

(Follows on next 6 pages)

Health Data Sharing at UCSF

Promoting Openness, Community Involvement, and Shared Decision Making

Clinical and Translational Science Institute
Regulatory Knowledge and Support Program

October 2024

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:
>
> *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:
>
> *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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