

Placing Equity

at the Center of Health Care & Technology

Summary Brief

March 2022

CDT's report, *Placing Equity at the Center of Health Care & Technology*, identifies and suggests ways in which privacy protections around consumer health information can benefit everyone, including underrepresented and overlooked communities harmed by current health data practices. Modern consumer health technologies can collect and store troves of individualized health information. Data that may seem irrelevant to our health can be analyzed, combined with other data, and used in ways that are probative and revealing of health conditions.

When appropriately protected, data generated by our devices and other technologies has the potential to help us all be healthier and address a history of inequities, including inequities in the provision of health care. However, for these critical, life-changing benefits to be realized, we must change certain consumer health data practices and root those protections in fair and equitable principles.

Reforms are Necessary Because U.S.'s Health Data Legal Regime Fails to Protect Health-Related Data Equally

Uneven regulatory environments can cause inequities. Inadequate data protections result in a greater likelihood that consumers will be harmed when their health data is used in ways they don't anticipate, expect, understand, or even know about. Unregulated or inappropriate data use can produce biased data, compound historical discrimination, and yield incorrect assumptions that, all too often, disproportionately affect historically marginalized groups, including people of color, immigrants, Indigenous communities, women, disabled people, and LGBTQ+ communities.

There is no single U.S. standard or law protecting all health data. The Health Insurance Portability and Accountability Act (HIPAA), provides some protections only for health data in the hands of covered entities, which are limited to hospitals, doctor's offices, insurance companies, and their business partners. It covers no other entity, nor any health-related data they collect or use, including when data is transferred from a HIPAA-covered entity to a non-HIPAA-covered entity. Relatedly, health data from outside the traditional health system routinely finds its way to HIPAA-covered entities. This constant data exchange between differently regulated (or unregulated) regimes is relevant to the discussion of how health data should be protected. New technologies in the health care space will only continue to increase the amount and quality of health data that is shareable, and the frequency with which it's shared, across a very uneven and unfair regulatory environment.

The resulting harms can take a number of different forms:

- **Inaccurate and Biased Data** - Data can harm people if their data is not accurately or fully represented, and can result in negative health outcomes and lost or denied services and benefits.
- **Discriminatory Health Treatment** - Data use that relies on biased and non-representative foundations of medical practice and research will continue to disproportionately harm underrepresented and overlooked communities.
- **Exposure, Embarrassment, and Stigma** - Health data is extremely personal and sensitive, which can be embarrassing if it is disclosed to others, and can cause social stigma, discrimination, and emotional harm.
- **Lack of Trust in Technology and Health Services** - Some communities don't trust health care systems when those systems engage in long-standing deceptive and harmful practices, especially those with disproportionate impacts on underrepresented communities.
- **Lack of Autonomy** - People often lack knowledge, control, and agency over their data, and how it is collected and used, and they experience particularly acute harms when data is used for other, secondary, and potentially unknown purposes.

The COVID-19 pandemic highlighted and exacerbated many of these harms and disparities.

Ensuring Equitable Practices for Health Data

Consumer-facing health technologies can help and empower people, health care providers, and governments to achieve better health outcomes. However, the current regulatory regime fails to adequately address privacy harms and discriminatory uses of health data, particularly given the prevalence of data exchange between variously regulated entities.

We must take the following steps to curtail data practices whose associated harms can be especially acute for underrepresented and overlooked communities:

1. *Creating a Proper Health Data Definition*

The modern health data system is complex and opaque. As we consider solutions to level the playing field and ensure that all health data enjoys strong privacy protections, we should identify and define the universe of health data. “Health data” should include any data either directly about a person’s health or that is used to make inferences about a person’s health, even if the data is unrelated to health on its face. The time has long passed since it made sense to apply different protections for health data based solely on what entity held the data. Instead, the protections must be attached to the data itself. To ensure equitable protections, we must have a clear understanding and approach that consistently recognizes when data is health data, including Social Determinants of Health (SDOH) data.

2. *Helping Prevent Inequities Through Appropriate Collection and Use of Data About Race or Sexual Orientation*

Data about peoples’ sexual orientation or race can be used to harm, intentionally or not, those communities, potentially by erecting barriers to treatments. However, when used appropriately, such data can help reduce harms to, or benefit, those communities instead. For instance, diverse and complete data can help large community datasets better reflect the true diversity of communities. Every actor in the health industry should be working together to process data in ways that allow for creative solutions to health care challenges.

3. *Helping Prevent Inequities Through Appropriate Collection and Use of Data About Disability*

Like many of us, disabled people interact and share their health information with others to access community-based services. Data collection, sharing, and use approaches must consider if and when data about a person’s disability is being used for health purposes like doctor directed treatments. When possible, these data practices should protect people’s data as much as possible and avoid engaging in secondary or unintended uses, or otherwise infringe on individual choice.

4. *Improving Research Practices That Make Use of Consumer Health Information*

Research that uses consumer health information collected from underrepresented populations must be transparent and benefit those communities. Specifically, the benefits of research using consumer health information should be communicated

by a study's sponsors not only to the people whose data will be collected, but also to trusted members and leaders within those communities. Researchers should allow communities to help set the research questions so that research is responsive and directed toward issues that are of concern to the community.

5. *Diversifying Data*

Data collection and categorization present major equity issues. Any system, either human-reviewed or done with artificial intelligence or machine learning, that makes health care decisions about people based on data that does not adequately reflect the diversity of the population can harm marginalized communities. Entities collecting consumer health data should actively consider and include data diversity and equity issues throughout the entire lifecycle of their consumer health offerings, covering key questions like: What are the intended data uses? How can the offerings address the nuanced needs of communities? Are currently deployed artificial intelligence and machine learning systems harming marginalized communities or causing disparate impacts?

Conclusion


The burden to protect health data properly belongs with the entities collecting and using the data, rather than with individuals who are already burdened by their health issues. These data management obligations should include clear secondary use prohibitions and increased transparency provisions. When done properly, health data processing allows for dramatic improvements in health outcomes. However, current laws and regulations do not prevent harmful health data practices. Those laws should be updated and rooted in the types of fair and equitable principles discussed above.


This work and [our previously Proposed Framework](#) are made possible with the support of the Robert Wood Johnson Foundation, and with assistance from our steering committee. Many thanks to everyone who has assisted us on this project, especially our partners at Executives for Health Innovation (EHI).

When done properly, health data processing allows for dramatic improvements in health outcomes. However, current laws and regulations do not prevent harmful health data practices. Those laws should be updated and rooted in the types of fair and equitable principles discussed in CDT's report.

 cdt.org

 cdt.org/contact

 Center for Democracy & Technology
1401 K Street NW, Suite 200
Washington, D.C. 20005

 202-637-9800

 @CenDemTech