Three Strategies to Overcome Data-Sharing Challenges to Improve the Social Determinants of Health

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This piece identifies and compares three examples of successful data sharing that sought to improve housing and health outcomes, ultimately improving the lives of vulnerable groups. Data strategists should first consider proving out the benefit in consultation with diverse stakeholders, mitigating legal risks from the beginning, and starting with a minimal data prototype.

Over ten years ago, Cooper Health System family physician Jeffrey Brenner started a very challenging project: sharing data.

Puzzled by “high utilizers” who frequently come to the emergency room for treatment, he sought to answer where they came from. Answering this question was not easy. These healthcare high utilizers account for just 5% of the U.S. population, but account for 50% of healthcare spending. Data on these utilizers—often vulnerable, low-income individuals who have complex and multiple healthcare needs—were dispersed across multiple organizations and not easily accessible. Despite this barrier, Brenner was able to aggregate emergency room and other data on these high utilizers to create a more complete picture of who they were and why their needs were so distinct, all while protecting their privacy. With this data, Brenner could coordinate care and services with fire departments and housing county agencies. With this data, he created a more complete picture and could coordinate care, saving both the lives of these vulnerable groups and his emergency room nearly $500,000 per month.

Data sharing is critical to cross-sectoral innovations like these. Yet, more often than not, data are not shared.

Janet Marchibroda, executive director of the CEO Council on Health and Innovation at the Bipartisan Policy Center, agrees. Marchibroda notes that while sharing data information “plays a critical role in improving the cost, quality, and patient experience of healthcare, there is very little electronic information sharing... despite considerable investment in health information technology.”

What are the challenges to data sharing? At core, what keeps organizations from embracing collaboration are beliefs that sharing is not a priority, is too risky, or is too complex. But, as we argue here, there are alternatives, building on a framework for trustworthy data sharing.

INNOVATION KILLER #1: “YOU DON’T UNDERSTAND MY PRIORITIES”

To address this strategic barrier, data strategists should address the needs of diverse stakeholders and fashion a way to help them by starting small.

Brenner learned the importance of identifying needs early when he served as a member of Camden’s crime commission. After pulling data to identify crime hotspots, he pushed for a policy that would encourage Camden’s police chief to assign shifts based on where there was the most crime. The police unions—a stakeholder he did not include until later—disputed the rationale behind his policy, which eventually did not pass.

“He has no clue,” said the president of the city police superiors’ union in the Philadelphia Inquirer. “I just think that his comments about what kind of schedule we should be on, how we should be deployed, are laughable.”

Take, in contrast, his later efforts to share hospital data to identify emergency room hotspots. Before advocating for a broad data-sharing policy, he started by talking to a diverse set of stakeholders to assess their needs, while also sharing information about how his effort might help them.

His initial discussions included a diverse set of colleagues—emergency room physicians and social workers from around the city—to discuss how he could help their most difficult patients. As a physician himself, he understood that hospital readmissions and operational costs were thorny issues. He shared his initial data-driven findings drawing from data across sectors. For instance, he showed that a few individuals accounted for large portions of emergency room costs and that they clustered from two specific locations: a nursing home and a low-income housing block. One patient, for instance, had 324 emergency room admissions in 5 years. The most expensive patient cost insurers $3.5 million.

By combining data from housing locations, social services, hospital usage, and costs, Brenner argued that an intervention attuned to these social determinants would have tremendous value.

After understanding their needs and offering a way to help them, his colleagues were happy to send him their data.
most difficult patients. Attuned to their social circumstances, Brenner’s intervention not only included nurse practitioners making home visits but also social workers to help needy patients apply for social services, such as disability insurance and housing assistance. By showing value to the patients, too, some of whom led much healthier lives after his intervention, they consented to share data with him directly as their primary care physician, allowing him to pool more data to identify the effectiveness of his cross-functional intervention.

It was only after showing the value of his program that Brenner garnered grants and executive sponsorship to scale his work with more sophisticated data systems. For instance, doctors across the city could see holistic medical and cost data about their patients from all the hospitals in town, arming them to make better decisions and work more effectively with nurse practitioners and social workers.

Furthermore, his programs protected the privacy of his patients. For instance, Brenner’s program to share data with faith leaders incorporated consent and data minimization. Congregants opted into a program where they shared their hospital visits with their faith leaders, who received an email notification. The faith leaders, furthermore, only received this notification; Brenner’s program excluded sensitive medical data and even the context for the hospitalization. One faith leader, Bishop Swain at New Life Church Ministries, recalled one congregant who was absent from his services for several weeks. But later discovering she consented to Brenner’s program, Swain contacted her to see how he could support her during her time of need. Reflecting on his visit to the congregant, Swain realized that “when people are by themselves, it always feels great when someone reaches out... if no one saw you before you left this world, it would feel like no one cares at all.”

In contrast to his early experience advocating for changes to police schedules, Brenner’s approach was radically bottom-up. He involved key stakeholders from the beginning, understood their needs, started small, and then showed how cross-sectoral data sharing could in fact improve patient health—before scaling up a solution to do so. These strategies helped him build the credibility to build an unparalleled health-data-sharing system.

To be sure, health data sharing does not guarantee a beneficial intervention. Researchers found, for instance, that Brenner’s multifaceted program did not significantly reduce the rate of hospital readmissions. However, it is precisely his interest in data that encouraged him to validate the program. It is also precisely his interest in data that allowed him to identify a crucial yet missing evidence-driven aspect in their work: housing. He discovered firsthand data that showed, for instance, that a single “missed rent payment can spiral into a major setback,” instances which short-circuited the success of Brenner’s program. Data like this pushed Brenner to start his own housing program.

**INNOVATION KILLER #2: “IT’S TOO RISKY”**

To address this strategic barrier, data strategists should assemble a diverse core group to address legal risks together.

However, too often this does not happen until too late. Consider this all-too-common scenario. Data strategists want to launch a health-data-sharing program. Only once the program is designed is the organization’s legal and compliance group engaged, and they argue the program lacks a “legal basis” for sharing sensitive data. Efforts to provide data-sharing toolkits and examples from other organizations launching similar programs fail to persuade. With trust already lost, clarifications on these legal concerns are delayed and result in ambiguous answers. The lack of support from the legal and compliance team will severely block the progress of any data-sharing initiative.

In contrast, consider the data-sharing efforts of San Francisco’s housing agency, which involved a legal and compliance viewpoint from the beginning of the process. Charles MacNulty, the agency’s data strategist, wished to share data with other agencies and the public to improve transparency and operations.

Yet given that housing program data are extremely sensitive, the legal team initially decided that the data would be subject to a default “do not share” position. Groups served by the city’s housing program tend to be vulnerable and marginalized. Their identities could easily be placed in the public’s attention, given that housing is an extremely politicized topic in San Francisco, one of the US’ most expensive cities.

To address this challenge, MacNulty first convened a meeting of the heads of his department, from those leading homeownership to community development programs. Just as Brenner did with his program, MacNulty identified needs and connected the data-sharing effort to a benefit that mattered to them. These department heads wanted a renewed business process to reduce privacy risks and increase operational efficiency in sharing data with other departments and the public. In particular, the data strategist persuaded them that this process would standardize data collection and reporting, which took significant amounts of his time.

Unconventionally, and significantly, MacNulty focused the meeting exclusively on a legal document: San Francisco’s data-sharing toolkit. The toolkit arose from discussions with legal scholars and the city’s own lawyers and data officers—Joy Bonaguro, the city of San Francisco’s chief data officer, and Erica Finkle, the data program manager—identifying a methodology and a set of templates to weigh the benefits versus the costs of sharing a dataset, and if shared, mitigating the legal and ethical risks in data sharing.

Together, the group made sense of the legal risks together. By involving the heads of programs who engage with their most vulnerable populations from the beginning, MacNulty could also address concerns about how these populations could be re-identified and face discrimination and abuse. After identifying risks, the group formulated a plan to mitigate the re-identification risks from their most requested housing datasets. With this deeper understanding, they were better equipped to use language and tools the legal and data team understood. In their program activities dataset, for instance, the team shared highly generalized individual-level data, such as race and broad age and income categories of those served by their community development programs. This made the dataset much safer to share for public and interdepartmental use. The data strategist recalled that their meetings, while
challenging, resulted in “deep meaningful discussion for each item and enriched the department’s understanding of the privacy issue.”

MacNulty’s program focused on a legal and compliance viewpoint as the first step, equipping his team to share data in a way that built trust with this important stakeholder. While San Francisco had a culture more set up to succeed, given that the city even offered a data-sharing toolkit, the city’s experience nonetheless underlined the need to build partnerships between legal and data teams from the outset. San Francisco’s data-sharing toolkit represents forward-thinking work—and a strategic legal thinking that helped MacNulty turn potential opponents into champions who challenged entrenched legal thinking and safely promoted innovation.

**INNOVATION KILLER #3: “IT’S TOO TECHNICALLY COMPLICATED”**

To address this barrier, consider starting small, and prioritize a minimal data prototype providing the most value.

Consider the technical struggles and later successes of the Peoria, Tazewell, and Woodford (PTW) County health department’s efforts to create a community-driven health improvement program in Illinois. Prompted by a statewide plan, the PTW created new ways to reduce substance abuse and improve mental health, coordinating a variety of social services that included housing and healthcare programs.

Much like the actions of the prior two successful case studies, these departments convened a diverse committee. It involved first responders, emergency room physicians, a judge, law enforcement agencies, a public health agency, and homeless service workers, all of whom had an interest in criminal justice and health. The group met over many weeks to create a model pinpointing where the criminal justice and health system interacted—and was broken.

Despite these actions, the committee still struggled to share data across more of its stakeholders in order to identify high utilizers of behavioral health services. The key concern was the distrust that the group had the technical capacity to share data safely. For instance, the group was skeptical that it could share data in ways that could be compliant with health privacy laws, such as the Health Insurance Portability and Accountability Act (HIPAA).

The committee was able to overcome these hybrid technical and legal challenges in large part due to its group’s decision to minimize what data were shared. First, like Brenner, the group began by proving the value of data sharing in small ways. They shared limited data between Peoria’s county jail and PTW health departments, showing that much of Peoria’s prison population required behavioral health services. This insight underlined the interactive nature between these two systems, which currently did not share data between each other.

Second, the group shared as few fields as possible to achieve their purpose. Working with their respective legal teams to identify highest risk datasets, the committee reduced the amount of data shared to five fields, which included name, age, zip code, number of contacts with their agency, and type of criminal charge.

Third, the committee also worked with an epidemiologist employed by a trusted party, the Peoria County health department. This epidemiologist received data from the health, criminal, and housing departments, hid sensitive and highly regulated data categories (such as which individuals receive substance abuse treatment or medical treatments) to protect the privacy of these at-risk patients, and then shared the new dataset only with the appropriate recipients, such as the members of the committee, to further minimize the risk that this sensitive data would be used inappropriately.

Through these efforts, the committee was able to prove the value of its data-sharing initiative. Its “high utilizer matrix” listed individuals that had the most contact with two or more government agencies and confirmed a hypothesis that just a few utilizers (in this case, 17) were responsible for consuming most of these departments’ resources. Their analyses specified potential cost savings of over $3 million a year and illustrated the extent to which these systems were failing vulnerable populations. Upon learning of this information, executive sponsors at their respective organizations prioritized helping these high utilizers. For instance, Peoria launched a new strategic vision for the following years, investing in further data coordination activities to adopt health equity strategies, implementing health equity training for health department staff, coordinating maternal and reproductive health initiatives, and researching evidence-based violence reduction strategies.

While the technical challenges of meeting healthcare data privacy regulations were formidable, the committee devised a solution to do so. Perhaps due to the presence of lawyers (including a judge) in its initial stakeholder group, the committee rapidly responded to these legally informed technical concerns. The presence of organizations like health departments also unlocked a resource to work with a data-fluent employee—the epidemiologist—who could help receive and apply privacy protections on the data.

**DIVERSE PATHWAYS TO DATA SHARING**

The three stories above illustrate diverse pathways to overcoming data-sharing obstacles. Brenner’s story shows the importance of meeting the needs of key diverse stakeholders before scaling too early. He started with a minor intervention to prove out the value before pushing a larger data-sharing program. MacNulty’s story illustrates one way to build effective and diverse partnerships, such as those with legal and compliance teams. By deliberating over a legally informed data-sharing toolkit from the beginning, MacNulty’s group assessed risk and de-identified data. Finally, PTW’s story underlines the importance of starting with a minimal data prototype to overcome the technical barriers imposed by data privacy regulations.

Similarly, the state of Delaware identifies the most at-risk youth, combining education, criminal justice, and social service data to prioritize services and ultimately reduce youth gun violence. Much like Peoria’s case, Delaware’s effort involved the leadership of a cross-functional “family service cabinet council” to overcome information-sharing barriers and develop pilot programs. Leaders have also proactively navigated the legal requirements around sharing personal health information, using a memorandum of understanding to identify what data will be shared and for what purposes.
Across all of these stories is the recognition that while data sharing may provide immense benefit, it has the potential to create harm and result in stakeholder distrust. Look no further than Google’s data-sharing deal with the major health-care provider Ascension. Referred to as “Project Nightingale,” the deal involved analyzing health data from patients who received care, then using artificial intelligence to recommend care, such as treatment plans or new physician consultations. Despite the potential for good and likely HIPAA compliance, Google severely spooked the public and prompted a federal investigation into the data-sharing deal.

The data-sharing strategies above show the importance of demonstrating the benefit and safely addressing the risks of data sharing from the beginning of any program. These are the same strategies that data leaders can use to build support for their health-data-sharing programs, tackle technical challenges collaboratively, build trust, and ultimately change lives.

REFERENCES

1. PBS Newshour (2017). A way to save money when half of all health costs is spent on a fraction of patients. https://www.pbs.org/newshour/show/way-save-money-half-health-costs-spent-fraction-patients.
2. Healthcare IT News (2014). Why sharing data is so hard. https://www.healthcareitnews.com/news/why-sharing-health-data-so-hard.
3. Gawande, A. (2011). The Hot Spotters. https://www.newyorker.com/magazine/2011/01/24/the-hot-spotters.
4. Gorenstein, D., and Walker, L. (2020). Reduce Health Costs By Nurturing The Sickest? A Much-Touted Idea Disappoints. https://www.npr.org/sections/health-shots/2020/01/08/794063152/reduce-health-costs-by-nurturing-the-sickest-a-much-touted-idea-disappoints.
5. Valenta, B. (2017). How San Francisco is Opening More Data with a Premium on Privacy. https://datasmart.ash.harvard.edu/news/article/how-san-francisco-is-opening-more-data-with-a-premium-on-privacy-1135.
6. Data, S.F.. Open Data Release Toolkit. https://datasf.org/resources/open-data-release-toolkit/.
7. Schmit, C., Kelly, K., and Bernstein, J. (2019). Cross sector data sharing: necessity, challenge, and hope. J Law Med Ethics 47, 83–86.
8. Peoria City/County Health Department (2019). Strategic Plan January 1, 2020 - December 31, 2022. https://www.pcchd.org/DocumentCenter/View/774/2020-2022-PCCHD-Strategic-Plan-PDF.
9. Cohen, J. (2019). Google, Ascension data partnership sparks federal probe. https://www.modernhealthcare.com/information-technology/google-ascension-data-partnership-sparks-federal-probe.

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Dan Wu is a privacy counsel and legal engineer for Immuta, an automated data governance platform for analytics. He’s advocated for data ethics and inclusive urban innovation in TechCrunch, Harvard Business Review, and Bloomberg. He’s helped Fortune 500 companies, governments, and startups on ethical and agile data strategies. He holds a JD and PhD from Harvard.

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