

How Improved Data Sharing Can Shape the Next Generation of Healthcare



Public health agencies are inundated with data, but they are grappling with how to maximize this valuable resource to improve outcomes, deliver community-centered care and implement a no wrong door approach, as well as other strategic initiatives.

Today, using data is far from frictionless within agencies — stakeholders often struggle to access it, put it into a usable format and share it with internal and external partners.

More effective data sharing, in particular, can pave the path to next-generation healthcare. Agencies can employ several strategies to safely and securely share information and unlock the full value of their data, but they must first overcome the roadblocks that prevent effective data sharing across the healthcare continuum.

Current Barriers to Data Sharing

Several factors currently prevent health agencies from sharing information with other agencies and organizations.

First, data maturity varies by agency. Many organizations lack an accurate inventory of what the data they have, who has access to it and what processes each data set supports. Agencies also struggle with lack of data visibility and access to real-time information, mostly because of inadequate policies and tools for data integration.

A lack of data standardization is another issue. It's difficult to get data into a usable format. Manual data clean-up and preparation is far too cumbersome, making it more difficult to apply artificial intelligence (AI) and (ML) to data and generate analytics.

Organizational constraints also inhibit effective data sharing within health agencies. Funding for advancing an organization's data maturity is often siloed, even though data may be used across public health programs.

These budgetary issues also extend to staffing resources. To maximize the value of data, agencies need skilled talent. However, there's currently fierce competition for IT professionals, and many agencies are losing talent to private sector organizations that offer higher compensation and fully remote work.

However, the most persistent barrier to effective data sharing may actually be a cultural one. Many leaders aren't willing to take the risk of sharing data more broadly due to complex and easily-misunderstood federal and state regulations and compliance requirements. The fears of a breach and the reputational and

regulatory risks associated with these events often outweigh the perceived value agency leaders believe they can reap with more open access to data.

Still, accelerated digital transformation since the onset of the pandemic — and a clearer need to increase government's responsiveness and resilience, especially during major public health crises — has created a prime opportunity for agencies to advance their data maturity.¹ This changing landscape has opened up the possibility for more collaboration within agencies, across departments and with non-governmental partners who can help agencies improve public health outcomes.

Creating a Culture of Data Sharing

As health agencies in state and local government seek to transform data into a true strategic asset, they can implement several strategies to make secure, seamless data sharing more of a standard operating practice.

Close data governance gaps

First, agencies must start by understanding what data they have, where it lives, how it flows across their organization and who has access to it.

Strengthening their enterprise architecture practice is one of the most effective ways agencies can increase their data visibility, because this will enable them to better understand interdependencies within their ecosystem and better align data sets to the business processes they support.

Assess your data maturity

Agencies must also have a keen sense of their current data maturity to understand what's possible. For example, if most of an agency's data isn't standardized through a common lexicon and glossary, or is trapped in various formats within multiple applications and databases, the organization may have to get it into an understandable and usable format before it can transform this data into advanced analytics.

Set your strategic vision

Once an agency assesses its data maturity, leaders can set a realistic strategic vision for how their organization uses data. Leaders should begin by identifying their agency's main

use cases for data – whether it’s to more accurately measure program effectiveness or to implement and track targeted population health initiatives.

Leaders should align data to desired outcomes and clearly and continually communicate how it will help the organization achieve its mission. They must crystallize for rank-and-file employees that data doesn’t just exist for data’s sake, but that the organization can harness this valuable resource to make people’s lives better.

◦ Establish robust data sharing and use agreements and frameworks

While agencies can create their own data sharing frameworks, they also can use external resources as a jumping off point.

For example, the Actionable Intelligence for Social Policy (AISP) at the University of Pennsylvania has created a “Quality Framework for Integrated Data Systems,” a new legal framework designed to streamline data sharing.² By using this framework, one state agency in the Southeast has experienced a 90% reduction in the amount of time it takes to formalize data use agreements. This just showcases the accelerated time to value agencies can achieve when these agreements are in place.

◦ Begin with a small test case

Agencies can begin with a small use case to prove the value of data within their organization and then build from there. Leveraging federal and state grants or one-time funding may be helpful for supporting these test cases. For example, some states have used Medicaid funding to create an all claims FAIR database, which can serve as a single source of truth and centralized repository for other data-driven initiatives in the future, such as tracking readmissions, specific treatment outcomes or the healthcare utilization of certain populations.

◦ Find avenues to reduce data sharing risks

Public health agencies can facilitate secure data sharing in several ways. Some jurisdictions have used synthetic data sets or de-identified data to generate population health insights, while reducing data sharing risks. Others, like the state of Virginia, have created a data trust to centralize information-sharing.³ The Commonwealth Data Trust, implemented by Virginia’s Office of Data Governance and Analytics, has established consistent requirements to allow members to securely and compliantly share data. Members can choose what data to share and there are common rules for data security, privacy, and confidentiality that ensure proper governance and protection of the information.

◦ Create a data steward or data custodian

As part of their data governance program, agencies can establish a data governance board composed of data, IT and line-of-business leaders across the enterprise. They can also develop a data sharing function or designate a specific stakeholder to own the data sharing process, such as a Chief Data Officer (CDO), rather than adding this to a CIO’s growing slate of responsibilities. By last count, over half of states had a CDO,⁴ so there’s room for government agencies to grow in this area and build more data-focused teams.

◦ Leverage an enterprise cloud data management platform

Rather than build data integration tools in-house, agencies can leverage a cloud-based data management platform to accelerate data sharing.

They should look for AI-powered, no-code/low-code, security-compliant solutions that facilitate automated, scalable data ingestion from databases, applications, and other sources. The platform also should automate data aggregation, clean-up, and categorization, make it simple to derive advanced analytics from data, leverage APIs to streamline data integration from new and existing sources, and allow for real-time data access to support a variety of digital applications and evolving use cases.

Conclusion

Data is an invaluable resource for public sector health agencies, but several barriers prevent these organizations from putting data to its highest and best use.

Now more than ever, agencies need to harness all the resources at their disposal to advance their mission. Data is one of the most powerful tools they have to make a difference in the lives of those they serve. By leveraging an intelligent data management platform, establishing data stewards, and creating strong data sharing frameworks, agencies can use data to usher in the next generation of healthcare.

This piece was written and produced by the Center for Digital Government Content Studio, with information and input from Informatica.

Endnotes

1. <https://www.oecd.org/gov/digital-government/use-of-open-government-data-to-address-covid19-outbreak.htm>
2. <https://aisp.upenn.edu/quality-framework-for-integrated-data-systems/#>
3. <https://www.odga.virginia.gov/>
4. <https://www.governing.com/now/cdos-are-growing-now-more-than-half-of-us-states-have-them.html>

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