Enterprise data sovereignty in life sciences and health care
A new model of sharing for stewards of health information

Enterprise data sovereignty is a two-sided coin. There is a growing recognition that information can’t realize its full potential if it’s locked away and compartmentalized, so organizations in many fields are revisiting their architectures in an effort to “set data free.” But a desire to share knowledge doesn’t mean one can wish away the mandates of privacy and security, where both the threats and the stakes are growing fast.

Many public- and private-sector organizations, even regulated entities such as financial services institutions, are heeding the call to open up the flow of data. Every entity will find its own new balancing point between control and access.

As in so many other areas, life sciences and health care represent a special case. In this industry, regulations can make it harder, not easier, to move data from place to place. Yet the industry also needs freely available data to function well. How can it reconcile these two facts? A possible future, consistent with Centers for Medicare & Medicaid Services (CMS) directives, is one in which sovereignty over the data rests with the patient, and the patient entrusts third parties with the management of it. That management might be for the patient’s own benefit in administering care or for other uses such as participation in clinical research.

The operative difference would be a shift from today’s document-centric approach to an intervention-driven one. In a permission-based, managed system with the patient at the hub, decisions won’t have to hinge on where the chart is filed or who completed which form. Instead, patient-provider interactions will drive the flow of data. A patient can arrive at a clinic to find only the data necessary for that visit is already there waiting. This is a step beyond the creation of electronic medical records (EMRs) that has occupied so much attention in recent years. EMRs are just digital versions of the same old pieces of paper. The change has to be what messages flow where, when, and under whose authority.

Today, different parties often find they have no incentive to share what they know—which means a simple need might lead to multiple,
Challenges to overcome

What stands in the way? It is commonplace to point to regulations as the inhibitor to more sensible information flows in health care. But there are just as many nonregulatory-based obstacles inside the industry. This kind of message-based sharing is already at work in other industries—that’s how, for example, an online retailer knows what ads to show you based on a web search you performed hours earlier on a different machine. The health care industry—with its tradition of high-volume, siloed, duplicative information management—has to embrace this concept before it can put the methods to use. An example of what’s possible might be the availability of a patient’s previously tested genomic data for the design of a custom therapy for a chronic condition—or something as simple as an emergency room far from home knowing a patient’s blood type and allergies. The point is to coordinate needed resources, not the entire weight of a person’s medical history, at the right time.

Another challenge is nonstandard document practices. If we don’t get to the point of standardization, then we likely won’t be able to collect data in a uniform way and will continue to chase this idea of readily shareable data. Data acquisition and standardization is a big obstacle in the way of achieving the promise of data analytics and data use. The way past that obstacle might involve consortia within the industry that use standard ontologies and vocabularies. The idea of these consortia is not new, but existing ones are still narrower and less standardized than this vision requires. When broad data—for example, not only diagnostic information but also lab notes—can flow readily (using tools like natural language processing, or NLP), it can inform processes that guide better, faster decisions.

What can pave the way forward? The industry’s opportunity to overcome these issues of relevance and accessibility is to shift the focus away from a document-centric approach to one that’s event-driven and message-centric, and to provide only the relevant data needed at specific points to determine the next best action. It’s one thing to know everything associated with a care plan; it’s another to be able to tailor that plan so it’s addressing the needs of the patient dynamically and in real time, as events unfold.

Agreeing to share data is ultimately not the hard part. Participants must also share workflows. The true definition of interoperability lies in the middleware platforms that can share and integrate information based on a shared understanding of the processes the data exists to support. If real data sovereignty in the health care space is about message-based access and responsible stewardship, these portals between entities are where the gatekeeping will happen.

Prospects by sector

Health Care Providers

What bedevils a hospital? Avoidable admissions and needless readmissions. What bothers a patient? Receiving five different calls to ask about the same follow-up condition or medication adherence. What can eliminate pain points like these? A more integrated use of real-time, event-based data. When information across all the events
associated with a person's care—or a population's care—is available to help monitor treatment effectiveness, reduce duplication, or make critical adjustments, the integration of the data corresponds directly to integration of the care delivery itself.

What can pave the way forward?
The industry’s opportunity to overcome these issues of relevance and accessibility is to shift the focus away from a document-centric approach to one that’s event-driven and message-centric, and to provide only the relevant data needed at specific points to determine the next best action.

The need for data to be shared and “free” is essential to allow health care providers to truly access and understand the full patient journey. However, providers—and the software companies serving them—have typically been resistant to sharing data, not only due to regulations but based on their own desire to protect their platforms and maintain a competitive edge.

Today, however, many providers and vendors are under pressure to rethink their business models and garner the ability to innovatively share data across various platforms. Early adopters of automation, NLP, and artificial intelligence (AI) are finding exciting new ways to collaborate that improve health care practice standards for the benefit of all stakeholders, especially patients.

Without running afoul of HIPAA or other privacy regulations, it is possible for health care providers to enact structures in cooperation with health plans that make the follow-up and adherence data available to anyone who needs it. Collect the data one time, and use it as many times and in as many places as required. A new definition of data sovereignty that shares stewardship across the sectors can lay the groundwork for greater cooperation and “integrated care” that lives up to its name.

Similarly, cross-referencing lab results with aggregated, anonymized patterns from previous patients can help fuel analytics that predict the likelihood of readmission in time to prevent it. In examples like these, responsibly shared data helps drive real-time decisions instead of shedding a light on what went wrong weeks or months after the fact.

Indeed, in this new health care ecosystem, data and analytics breakthroughs are redefining care, streamlining operations, and bolstering the reputations of providers. As an example, two of the largest US EMR vendors have agreed to share patient health data between their systems. This is allowing two North Carolina health systems to quickly gain access to portions of patient medical records from the other—a key step to improving care.

Health Plans
As with providers and life sciences companies, health plans, while realizing the promise of what data analytics can offer, are often failing to deliver because so much of the data is locked away in native proprietary data sets. While most enterprises have sufficient quantities of data, they lack access to an integrated superset of data that can offer an enterprise-wide view. Thus, synergies are few, and obvious connections between data points are missed or misunderstood, making effective collaborations more difficult.

To align with a new approach to data sovereignty, health plans should consider three principal areas of investment: data and analytics, workflow coordination, and interoperability.

On the data and analytics front, the tools are better known than the ways to deploy them. Many people have heard about AI, robotic process automation, and similar technologies. But simply buying them won’t solve any problems. The challenge is to design and deploy the use of these tools in ways that turn discrete infusions of data into useful information—such as the alert that will trigger a critical intervention days before a hospital discharge instead of after the patient is already home.

In workflow coordination, plans face the same mandate their provider and life sciences counterparts do—to participate in a broader community that uses resources in a smart, integrated way instead of preserving a myopic focus on individual data transactions such as “specialist to primary care” or “plan to provider.” Tools associated with other industries, such as customer relationship management (CRM), may contribute to these changes.

Interoperability is where event-driven, message-specific data sharing happens via the management of discrete interchanges that facilitate the required degree of openness while respecting the need for patient consent and regulatory compliance.

In a future state characterized by investments such as these, real-time analysis and exploration of well-protected and well-tracked data across an enterprise can offer valuable benefits to all. For instance, the ability to analyze social determinants, claims and enrollment information, prescription data, and physician-reported health records at the point of care can help predict undiagnosed conditions that can lead to better (and more cost-effective) treatment.

Life Sciences
For organizations that create lifesaving products, a new system of data sovereignty has the potential to improve the quality of scientific analysis. For example, drug adherence information referenced across factors like age and disease type can add context to the understanding of a product’s real-world performance.
that drive the sharing and use of data should be broad enough to include all participants in the system and deep enough to include all the information that can make a difference in a given moment.

A system that keeps ownership of the data with the patient, while ceding management of it to various players in the industry, requires incentives. How does it benefit the patient to allow the necessary sharing? The main answer may lie in convenience.

The rise of the chief data officer

One question arising in many companies as data is taking center stage is who should own transformative efforts around data—and who should own a company’s approach to data in general. In several industry sectors, organizations are turning to a new executive role of chief data officer (CDO) to lead the development and execution of enterprise data strategies. The introduction of the CDO role at an executive level affords companies the heft necessary to advocate for appropriate levels of focus and investment.

In life sciences and health care, most organizations are in the early stages of embracing the CDO role. Ultimately, the CDO can drive business growth by accelerating the integration of data across the organization, shifting the business away from existing models and infrastructure, and breaking internal departmental silos. Companies should define the CDO role to meet their organization’s needs, realizing it likely will evolve and modify over time, and recognizing the need to have a forward look to integration of data within the organization as well as outside, across providers, plans, and life sciences organizations.

Deloitte’s 2018 Real-World Evidence Benchmark Survey revealed that 5 of the 20 global life sciences companies surveyed have a chief data or digital officer or a head of data, and 7 of the 20 companies see value in the role and are considering naming one.
Risk considerations

Any change in the way organizations share and use sensitive data carries the risk of data breaches. Making better use of patient data carries large potential benefits for all involved, but if that data falls into the wrong hands, there is a lot to lose. Introducing new standards of real-time openness and linking data to workflows may only magnify this risk of data breaches.

Organizations in life sciences and health care must also be careful to make sure the power of their tools doesn’t outgrow the validity of the data that fuels them. If there are faults or implied biases in the data, there may be the same biases in the way machine learning and cognitive technologies process that data—a modern take on the timeless “GIGO” principle.

In addition, health care and life sciences players that embrace the stewardship model of data sovereignty should be careful not to drown in the data. There is such a thing as too much, and the proliferation of sensors, wearables, telemedicine, and other sources only adds to the stream. The core idea of this new approach is to share only what’s needed, when it’s needed—not that proverbial 80-page PDF—and without the governance to adhere to that intention, acquiring more data won’t lead to more benefits.

High on the list of security-driven upgrades is the development and enforcement of more rigorous policies regarding third-party data sharing. Taking a “Secure. Vigilant. Resilient.” approach to cyber risk can ensure that data sovereignty initiatives can safely move forward with all deliberate speed.

Conclusion

The volume and speed of data in health care is growing. Is its usefulness keeping pace? A system that contains terabytes of a patient’s data in one location may not be as helpful as its designers intended, because the data can’t follow the patient across the street, or it isn’t available at the moment it’s needed.

A system that revolves around documents, whether on paper or in EMRs, can be structurally unfit to meet these needs. A system built around permission-based management has the potential to replace it without sacrificing the security protections that have been built into the traditional way of doing things.

To make that happen, the life sciences and health care industry must look beyond updates and tweaks. This is a mandate to reinvent the way data lives in the larger ecosystem and moves among its constituent parts. Providers, plans, and life sciences organizations need to chart a new path that makes their use of data not open, which is easy and dangerous, but rather smart, which is difficult and more secure. The industry needs to assume active, responsible stewardship of data—to treat it as a resource that doesn’t “belong” to any of them but fuels a new era of effectiveness for all.

For more on enterprise data sovereignty, visit: www.deloitte.com/insights/enterprise-data-sovereignty
Authors

**Health Care Providers**

**Tim Smith**  
Principal  
Deloitte Consulting LLP  
timsmith@deloitte.com

**Josh Nelson**  
Principal  
Deloitte Consulting LLP  
jnelson@deloitte.com

**Tony Jurek**  
Managing Director  
Deloitte Consulting LLP  
tjurek@deloitte.com

**Emily Schulte**  
Senior Manager  
Deloitte Consulting LLP  
eschulte@deloitte.com

**Health Plans**

**Jason Wainstein**  
Principal  
Deloitte Consulting LLP  
jwainstein@deloitte.com

**Michael Montalto**  
Managing Director  
Deloitte Consulting LLP  
mmontalto@deloitte.com

**Life Sciences**

**Todd Konersmann**  
Principal  
Deloitte Consulting LLP  
tkonersmann@deloitte.com

**Deborshi Dutt**  
Principal  
Deloitte Consulting LLP  
ddebdu@deloitte.com

**Deepak Kannangala**  
Senior Manager  
Deloitte Consulting LLP  
dkannangala@deloitte.com