



Tech Trends 2018 | Deloitte Insights

Tech Trends 2018 | A life sciences and health care perspective

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,

redundant phone calls. This new model for managing data has the potential to replace the status quo with a more integrated way of delivering care in which patients, providers, payers, and community resources can work more as an orchestrated team. It also offers efficiencies to help drive down the cost of care.

Data can come in many forms: structured data attributes such as lab results, unstructured data like a physician's notes field, and unstructured complex data files such as images and X-rays. The form of the data has to match the functional needs of how the data is being used to make it relevant and accessible. An 80-page PDF of a patient's medical records is not a form of data that's useful to the task at hand of providing patient diagnoses during, say, an emergency room or clinical visit. The form does not match the function.

Further, most of the health information exchange (HIE) systems today provide limited capabilities to share data and control access for the purpose in which it's needed. Records are often provided to outside sources who require them, in read-only form, containing expansive historical data, which requires users to manually dig through to find useful points related to that course of care. Typically missing in the industry is the disciplined focus of matching the form of the data to the functional needs, making it both accessible and relevant to the end user of that data.

No matter who owns or manages it, data will still be generated at multiple points of an encounter; and this will only increase as health care continues to accelerate innovative ways to deliver care. The real challenge is how users can take the data from those encounters and make it easily accessible, freeing it from the control of intermediaries who may delay or silo it. Data, once created, should be put in the control of the patient, even if that control takes the form of authorized management by a third party.

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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.

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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.

Real-world evidence

Increasingly, many biopharma companies are using real-world evidence (RWE)—clinical evidence about a product’s usage, potential benefits, and risks derived from real-world data (RWD)—not only to demonstrate the value of their products but also to address regulatory requirements, drive drug development, support outcomes-based contracts, and reduce products’ time to market.

Deloitte’s 2018 Real-World Evidence Benchmark Survey of global biopharmaceutical companies revealed that:

- 90 percent of companies reported they have either established or are currently investing in building RWE capability for use across the entire product life cycle
- 70 percent of companies are building internal RWE capabilities
- External collaboration is a key area of focus, with respondents ranking strategic partnerships as most likely to have the biggest impact on the future data landscape

As the importance of RWE continues to rise, biopharmaceutical companies should: think enterprise-wide, develop an end-to-end evidence management strategy, look to third parties for data access, and leverage advancements in technology and data science capabilities.

Other possibilities data sovereignty may bring are especially intriguing. For example, a patient with an implanted pacemaker may need to be reminded not to get angry during a stressful situation. What if shared data, moving in real time across coordinated workflows, made it possible for that patient’s physician to call during this event and advise the patient to manage stress reactions?

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. A patient may not want (and indicators show they do not want) the responsibility of being the one who, literally or digitally, carries his or her data around. He or she may find that the primary care provider is the sensible place for the data to “live” and to be managed. Or perhaps the plan can be the hub, and the patient can authorize the plan to grant access to other entities to the data elements needed.

One stumbling block to more effective collaboration has been a lack of standards for data sharing across multiple systems and stakeholders, hampering the ability of investigators, researchers, sponsors, and others to work in a seamless and data-protected environment across the life sciences value chain. The networks

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.

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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
debdudd@deloitte.com

Deepak Kannangala

Senior Manager
Deloitte Consulting LLP
dkannangala@deloitte.com



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