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The Value of DATA GOVERNANCE in Healthcare



Health Care

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INTRODUCTION

Data is one of the most valuable assets in any organization and is necessary to sustain current and future business models. **As healthcare transitions into a more analytically driven industry, managing data is especially relevant.** Organizations are grappling with ways to manage continual changes in health information technology (IT), IT infrastructure, and the huge volume of data collected across the healthcare industry. The push toward value-based care has amplified the need for efficient exchange of quality patient data, which fills gaps in information and offers providers and payers a more complete picture of the patient. Data-centric strategies focused on managing the entire lifecycle of healthcare data are particularly important in today's environment.

The policies and procedures to manage, protect, and govern information across a healthcare enterprise falls under data governance. Data governance includes data modeling, data mapping, data audit, data quality controls, data quality management, data architecture, and data dictionaries. A strong data governance structure is a critical component of any healthcare organization, as it provides a structure for analytics and other complex data initiatives.

Data Governance

In Spring 2018, eHealth Initiative Foundation and the LexisNexis® Risk Solutions healthcare business hosted the first in a series of roundtable meetings on data governance in healthcare. The meeting convened senior executives from stakeholder groups, including payer, provider, professional organizations, health information exchanges (HIEs), research, public health, laboratory, and pharmaceuticals. The goal of the meeting was to gather expert opinions on how to make data accessible, close quality gaps, turn insight into action, and protect sensitive patient information. **This brief addresses the value of data governance in healthcare; existing challenges related to data governance; and key takeaways from the meeting.**

DATA GOVERNANCE AND ITS ROLE IN HEALTHCARE

“Healthcare currently lacks robust data governance.”

*-Katherine Downing,
American Health
Information
Management
Association (AHIMA)*

With the emergence of Electronic Health Records (EHRs), HIEs, and Continuity of Care Documents (CCDs), and the use of Social Determinants of Health, health organizations have no lack of information from which to gather insights. Data governance offers the ability to acquire, maintain, and prepare data for analytics and enables operational efficiency that improves patient safety and health outcomes. It supports the responsible management of data that is used in population health research and surveillance and clinical trials. An effective data governance strategy improves workflow and the ability to share data.

When data is used for decision making, it creates knowledge for common understanding. Knowledge in turn creates the development of best practices which, applied over time, help achieve organizational goals. More importantly, it delivers the promise of better health. Data governance addresses numerous challenges, including disparate data sources, inconsistent standards and definitions, and inaccurate reports. Organizations with a formalized data governance program in place can increase regulatory compliance and advance business intelligence, while decreasing threats to data, reducing costs, and improving healthcare quality and patient outcomes. With data governance, the source of data is identified, the data is stored in the appropriate place, and a framework for design and execution facilitates

planning for data needs and quality assurance that is in concert with the strategic information needs of the organization. **Through comprehensive and proven data management practices, data governance ensures usable and reliable data.**

Data integrity is crucial for patient safety and care quality. In the absence of standardization across healthcare, data governance guarantees that data can be trusted and that there is a level of accountability for negative occurrences related to poor data quality. Data governance ensures that people, process, and information systems can identify the source of the data, the original author, and rules for the data. **Knowing the source of data is critical**, especially as data is aggregated for population health management using repositories containing data from various sources.

“Better workflow, better data sharing, and better treatment lead to better outcomes and lower likelihood of readmissions. Lower cost and more productivity in the work place – that’s your business case.”

*-Colby Tiner,
American Heart Association*

DATA STEWARDSHIP AND ACCESS

“The aggregation of data should not be the sole goal of healthcare organizations. They must also focus on the ongoing authentication of data.”

*-Josh Schoeller,
LexisNexis Risk Solutions*

A strong data governance plan is key to keeping sensitive information safe. Data governance establishes the policies for access, management, and permissible uses of data and identifies those who would use data and the conditions under which data access can be granted. To protect this increasingly valuable data from threat actors, organizations should understand their data and the actors who require access sensitive information. **Data stewardship—who is managing the data, where it is being sent, who is accessing it—is vital to privacy and security.** The purpose of stewardship is to realize the greatest possible benefit from the effective and appropriate use of data while minimizing the risk of harm. For example, data stewardship is essential for population health when community data repositories acquire data from many different sources.

Patients may struggle to access their health information due to ambiguous security protocols and inadequate interoperability, both of which can be improved through data governance. Patient access is a key factor of data governance. **Data governance supports patient engagement strategies by allowing patients greater access to their electronic health information.** Some providers maintain a level of hesitancy around access and are fearful patients may misinterpret the information doctors have placed in their medical records. However, when transparency, accuracy, and integrity of information exist, patients have greater confidence in their providers and become more engaged in their care. Furthermore, while federal regulations require patients have complete access to their *entire* medical record, provider workflows and systems are not always designed to accommodate requests.

“The patient is supposed to get access to their data and share it with whomever they want.”

-Brian Ahier, Aetna



There are a number of tools that can assist with data stewardship, including **blockchain**. Private blockchain networks facilitate the secure storage and exchange of confidential information, where only the entities that are involved in a transaction have knowledge and access. Blockchain has the potential to put patients in charge of their data, while enabling physicians from different organizations to access data and inform treatment. Blockchain manages metadata well and maintains a complete audit trail of every person and entity that has accessed the data.

However, blockchain is as an emerging technology which will take years to be fully developed, adopted, and widely deployed within healthcare.

CHALLENGES

Even as healthcare has a great need for data governance, many organizations are grappling with various challenges in its implementation. Data governance can be difficult, especially when organizations have different strategies and the industry lacks a forum to share best practices around data governance. Challenges include:

Interoperability. Numerous factors are at hand for data management, with interoperability at the core. Organizations need data and information governance to exchange data with their patients, intra-organizationally, and between various entities. Problems in exchanging patient data include, but are not limited to, physician reluctance to share data, high cost of exchange fees, lack of incentives, different approaches to linking data, and technology variations.

Standards and regulations. Stakeholders have different requirements for the manner in which data is received, matched, and distributed and are hoping that standards and regulations change this dynamic. Many hospitals find that organizations they connect with are not using current standards within their electronic medical records. Variations in provider office workflows contribute to a lack of standardization.

Big data versus small data. It is important to understand the differences between the big data that is used to manage population health and the small data necessary to manage individual-level care. Small data brings more timely, meaningful insights, allowing organizations to find solutions and achieve results. It can be challenging to balance data requirements for real-time care with larger questions related to population health.

“It is necessary to think about what can be done in real-time to address small data questions to sum up a population.”
*-Ira Klein,
Johnson & Johnson*

Patient matching. The difficulties associated with patient matching have been a longstanding issue with providers and health plans alike. Existing patient matching techniques use a number of demographic elements such as name, address, and social security number, but not every system has the same number or type of variables and not every provider has a high enough level of data integrity to feed the algorithms required for matching. A record that is incomplete, incorrect, or outdated can negatively impact a patient’s treatment, affect reimbursement rates and patient satisfactions scores, contribute to denied claims, and require staff to take time to correct records. Coordinating patient matching across registries is also critical. An inability to do so diminishes the potential capacity of databases and creates silos of data.

“Claims data is great, but it’s not the whole picture.”
*-Sagran Moodley,
UnitedHealthcare*

Bringing clinical, social determinants of health, and claims data together to build a more complete picture of the patient. Leading studies indicate social and environmental factors account for nearly 70 percent of all health outcomes¹, making the addition of data around social determinants of health critical to the equation. There is also value in accessing and sharing clinical data for quality reporting, measurements, registries, and patient care. Mapping claims, social determinants, and clinical data together is



challenging for a number of reasons. For example, a significant amount of clinical data is trapped in physician notes and are not easily extracted, which creates a hinderance to data mapping. Additionally, the meaning of “social determinants data” is not completely clear as the concept is still being defined.

Patient access. The healthcare industry has struggled to provide patients with access to their entire medical record. Organizations are facing challenges in giving control of records to the patient, as they must build entirely new workflow processing systems. Some providers may not want patients to see what doctors have put in their medical record, as the patients may potentially misinterpret the information. Then there is the issue of deciding on the right vehicle to use for patient access. With the virtualization of healthcare, the importance of making sure that remote access points have the right authentication and verification components, for providing appropriate access, cannot be understated.

Workflow. Clinicians are overwhelmed with the amount of information they receive at the point of care. Consistently providing incorrect or irrelevant information to providers creates alert fatigue and may cause doctors to ignore information that could actually be useful in treating their patients. The value of data is dependent on timing. Even if data is correct, it is important for the information to reach the physician at the right time. Organizations like LexisNexis have built analytics around social determinants—information that, when properly addressed, can positively impact a person’s health. Organizations are faced with the task of finding a way to deliver information to providers in a manner that is timely, actionable, and ultimately beneficial to the patient.

“Access is a major fail. Patients are still complaining they cannot get access or have to pay for it.”

*-Katherine Downing,
American Health
Information Management
Association (AHIMA)*

EXPERT TAKEAWAYS & CONCLUSION

While the value of data governance is undeniable, the industry still has headway to make in promoting data governance as a business imperative and a priority for leadership. Those hoping to move beyond simple record keeping should consider investing time, money, and resources in a data governance strategy to ultimately realize many long-term benefits. Key takeaways expressed by the experts participating in the eHealth Initiative roundtable on data governance include:

- **Solve patient matching and identification issues.** When patient matching results in silos of data, the opportunity to inform care by taking advantage of data across systems and registries is lost.
- **Support patient engagement and access to their health information.** Patients need complete access to their medical information and to control who receives access. In allowing patients greater access to their electronic health information, data governance supports patient engagement strategies. When patients experience transparency, accuracy, and integrity of information, they will have greater confidence in their providers and become more engaged in their care.
- **Improve the timing and precision of information delivery.** Even if data is correct, information delivery needs to be precise to avoid overwhelming providers at the point of care. Care will be most effective when physicians receive the most relevant information in the right places at the right time.
- **Build a more complete picture of the patient through clinical, social determinants, and claims data.** Industry stakeholder collaboration is needed to establish interoperability standards and encourage electronic transactions. Access to clinical data puts organizations in a unique position to facilitate new, valuable insights.

As healthcare continues to amass huge volumes of data, a robust data governance culture is necessary for industry to thrive. Data governance creates knowledge for common understanding and facilitates conversations around technology and data that ultimately enable healthcare stakeholders to work together to improve interoperability, patient care, and outcomes while promoting data access.

¹ Healthy People/Healthy Economy: An Initiative to Make Massachusetts the National Leader in Health and Wellness. 2015. Data from Network for Excellence in Health Innovation (NEHI) 2013.
http://www.tbf.org/impact/initiatives/~media/TBFOrg/Files/Reports/HPHE_ReportCard_2011.pdf

About eHealth Initiative

eHealth Initiative (eHI) & Foundation is a Washington DC-based, independent, non-profit organization whose mission is to drive improvements in the quality, safety, and efficiency of healthcare through information and information technology. eHI is the only national organization that represents all stakeholders in the healthcare industry. Working with its membership, eHI advocates for the use of health IT that is practical, sustainable and addresses stakeholder needs, particularly those of patients, www.ehidc.org.

About LexisNexis Risk Solutions

LexisNexis Risk Solutions harnesses the power of data and advanced analytics to provide insights that help businesses and governmental entities reduce risk and improve decisions to benefit people around the globe. We provide data and technology solutions for a wide range of industries including insurance, financial services, healthcare and government. Headquartered in metro Atlanta, Georgia, we have offices throughout the world and are part of RELX Group (LSE: REL/NYSE: RELX), a global provider of information and analytics for professional and business customers across industries. RELX is a FTSE 100 company and is based in London. For more information about LexisNexis, please call 866-396-7703 or visit www.risk.lexisnexis.com/healthcare, and www.relx.com.