National Health Data Week

A Look at Challenges, Opportunities, and the Future of Health Data

National Health Data Week is a week of action focused on demonstrating the power of health data to drive positive outcomes for patients and the US healthcare system. Patient health data is the foundation on which the delivery of care is built. National Health Data Week provides the opportunity to highlight the issues facing the management and use of health data, as well as feature the innovative solutions being driven by industry.

Because the American Health Information Management Association (AHIMA) recognizes that health data is the most powerful currency for change in healthcare, the organization hosted its second annual National Health Data Week in June 2026 in Washington, DC. Representatives from across the health data industry including providers, technology vendors, health information (HI) networks, and HI professionals were brought together as thought leaders to discuss the challenges and opportunities with the collection, sharing, and use of health data, and what the next generation of health data exchange might look like.

Challenges within the Health Data Space

Existing challenges related to health data fell into five major categories:



Declining trust

Lack of incentives and resources to implement innovations beyond what is required by regulation

Proliferation of disparate regulations across states and the federal government

Issues with the collection and usability of health data

Problems with the privacy and security of health data

While trust is a broad topic, it runs through many aspects of how health data is collected, shared, and used. Trust begins with ensuring correct identities within the healthcare ecosystem, whether that is at the individual or organizational level, and continues to be a challenge, especially when it comes to patient misidentification. Similarly, ensuring individual authorizations are used and delegated appropriately requires systems that can be trusted to keep and share data.

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Another topic raised was the lack of or misalignment of incentives and resources to improve interoperability. Right now, new technologies and improvements in interoperability are often implemented when required by law. In turn, hospitals and health systems are facing inverse incentives when it comes to improved data sharing. Physicians have more patient data to provide care; however, patients have greater ability to take their health data to another institution, which can lead to a financial loss to the institution and creates a disincentive for interoperability.



Participants noted that smaller hospitals and health systems, such as safety net hospitals, do not have the workforce to deal with challenges that arise with health data including compliance issues. This can lead to a lack of capacity for decision making around health data issues such as improving management of health data and maintaining compliance requirements. Similarly, the workforce managing health data lacks federal resources, including training previously provided by the Regional Extension Centers operated by the Office of the National Coordinator for Health Information Technology (ONC), to aid in the adoption and use of electronic health records (EHRs).

The volume of regulatory compliance was also identified as a challenge. Industry must comply with federal regulations as well as state regulations, making compliance an ongoing issue, especially for organizations that operate across state lines. While the federal government could foster more uniformity, the US Congress has not passed legislation that would preempt state regulation, creating gaps for states to fill, especially around such issues as privacy and artificial intelligence (AI).

Additionally, the collection and usability of data remains a concern. A large amount of work is required to make the data usable, from ensuring the data is complete to deduplicating records. Much of the data stays in medical devices rather than being integrated into the EHR because of the amount of data available. This also applies to wearable health devices, which collect massive amounts of information not integrated into the medical record. The need to parse through large amounts of information to identify what is relevant or actionable is increasing while there are limited resources and manpower to handle it.

Finally, there remain issues around the privacy and security of health data. Security is an area where we find diminishing trust in the system. The number and increasing severity of cyberattacks lessens patients' trust in the security of their information and the institutions that hold it. To combat this, the federal government has focused on punitive versus preventive measures. Threat sharing or near-miss sharing should be encouraged without fear of repercussion. A focus on punitive measures increases the difficulty of preparing for cyberattacks, especially for small or under-resourced hospitals and health systems who already lack resources to upgrade technology and standards. Regarding privacy, participants supported a nationwide health data privacy bill with a carveout for entities covered by HIPAA with stronger guardrails and protections for health data held by non-HIPAA covered entities.

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The Future of Health Data: Next Generation Data Exchange, New Developments, and Artificial Intelligence

The thought leadership session also looked to the future with discussion around new developments in health data, AI, and what a next generation healthcare data exchange might look like.

Participants discussed how data exchange might evolve in coming years. Systems could move toward more automated data exchange, especially with the implementation of AI. Potential exists for exchanging health data without the time-consuming back-end formatting by leveraging AI tools. Hospitals and health systems may also have a better understanding of the provenance of health data as it moves through systems.

The patient experience may also evolve as healthcare moves toward more patient-focused exchange. Healthcare could move toward a system where patients are not restricted to receiving care solely based on where their data lives. Data may also flow in a way that more aligns with consumer expectations. Patients would not have to bear the responsibility of transporting their health data to different medical settings; their clinician would automatically have access to it in a manner that can easily be digested.

The use of AI will also continue to cause shifts in the healthcare ecosystem. AI has the potential to accelerate capacity for work at hospitals and health systems, taking over more basic, time-consuming tasks, freeing employees to do higher-level work such as surveilling and auditing the AI tool and performance. AI has the potential to improve issues with interoperability including the use of Health Level 7's (HL7®) FHIR®. New technologies may help patients receive better care at home, from advances in remote patient monitoring to identifying clinical risk factors in patient care.

The regulatory sphere could also see changes. Some participants suggested that we would see more state-based regulations. There is potential for more focus on regulating health data in general, versus just HIPAA-covered entities. As the adoption of AI becomes more widespread, we will also see the need for more guardrails and regulations around healthcare technology. Issues of liability and accuracy for these tools will need to be addressed. Implementing guardrails around AI in healthcare could further efforts to establish trust and predictability across the healthcare ecosystem.

Key Takeaways

Current challenges with health data include: declining trust, a lack of incentives and resources to implement innovations beyond what is required by regulation, the proliferation of disparate regulations across states and the federal government, issues with the collection and usability of health data, and issues with the privacy and security of health data.

Potential solutions include: increased implementation of AI, a focus on patient-centered data exchange, and a clear federal roadmap for achieving next generation health exchange, which incorporates incentives and provides resources for industry adoption.

To harness these opportunities in healthcare, the federal government can help. Currently, there is no clear roadmap at the federal level to guide industry to the next generation of data

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exchange. Today, organizations have different goals and motives regarding the management of patient health data. Industry is moving in different directions or not moving at all due to limited resources. If we are to realize the promise of health data in a way that reduces costs, improves patient outcomes, and alleviates administrative burden, the US needs to have clear, attainable and shared goals across the ecosystem that provide incentives to move collectively with the resources to support the work. These resources should include funding for technological innovations and real-world testing

Looking to the Future

In bringing together experts from across the healthcare ecosystem at National Health Data Week, clear trends were seen in both the challenges with health data and the potential for future progress. While new technologies show promise in advancing collection, sharing, and use of health data, there is work to be done at the federal level to regulate those technologies and provide incentives to move the industry forward. AHIMA looks forward to working with policymakers and other industry stakeholders to advance the next generation of health data exchange.

National Health Data Week: Hosted by AHIMA

National Health Data Week is hosted by the American Health Information Management Association (AHIMA). AHIMA is more than an association–we are a force for change in healthcare. We are the visionary architect at the center of health information equipping over 67,000+ members and credential holders to uphold the highest professional standards through education and certification. We believe every patient deserves the best possible health care, and that starts with accurate, secure data. We represent the extraordinary individuals who work tirelessly to keep us all safe. Get to know us at https://www.ahima.org.

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