The Case for Data Sharing in Public Health and Medical Care

COVID-19 has highlighted opportunities in public policy and supporting public-private efforts.

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With public leaders continuing to emphasize the value of patients having easy access to their health data, focuses on data sharing, a centralized health information network and evolving data exchange standards can allow the health care industry to grapple with the ongoing COVID-19 pandemic.
Current efforts around the pandemic across government include strategizing telehealth tech, anticipating supply chain shortages, developing a vaccine, releasing stimulus funds, and more.

Despite the challenges the pandemic has presented in the health care industry, some industry leaders say it's revealed opportunities to lower technical and technological barriers for quick and efficient data-sharing capabilities.

“It opened up the eyes of public health,” said Dick Thompson, CEO and executive director of Quality Health Network, at a HIMSS20 Digital virtual event. “It’s shown more and more that the standards matter and being nimble matters — we try to do all of those things every day — but the movement is toward the value of the data itself rather than just moving it.”

The value of health information exchanges isn’t just in the collection and distribution of health data, but also in the capability to perform large-scale health data analytics to identify incident trends and help people respond accordingly. This includes capacity planning and understanding the frequency of COVID-19-like symptoms, as well as using those insights to inform public health policy.

Another use case would be supporting the timely delivery of treatment as soon as a patient’s viral test results are known.

“When you order from a lab, they need to know where to deliver results back to and, hopefully, what your medical record number is," said CommonWell Health Alliance Executive Director Paul Wilder. "The labs are not set up to do that. It’s a strange gap. It's not the lab’s job to call you to give you your results — it's the ordering physician that does that."

This situation is an operational barrier for the testing facilities and providers and causes unnecessary reporting delays. Those who test positive could then potentially unknowingly spread the virus to others.
“It’s harder than it seems to go find that person,” explained Wilder, “and part of that is because the data has to get back to the ordering physician — that’s where it marries back with the EHR, gets identifiers put back into it, and they make the contact out. The reality is that in those two days between lab tests and finding the person, a lot of bad things can happen in a pandemic.”

The challenge of getting these results to the right person at the right time is also compounded by missing personal identifiers. According to Wilder, approximately half of the COVID-19 tests sent to labs are missing an address or zip code, and many are missing phone numbers as well.

From a source-of-infection, syndromic surveillance perspective, there is also an opportunity to stand up a standardized health information network in areas that have not generally been served so as to limit deleterious health outcomes for at-risk groups — such as those in homeless clinics, hospice care, long-term care and assisted living facilities.

“There is a key value proposition for a network that includes those kinds of endpoints,” noted Scott Stuewe, president and CEO of DirectTrust. “There’s the ability to move data around very effectively to these places that are not served by EHR systems.”

Additionally, more individual health information and connectivity would provide a more complete, holistic approach to care — with searchable information available on someone’s medical testing history — which would save time, money and improve the health of the people being served.

“It seems pretty clear that if we’re really going to improve the health of our country and our region and our localities, we’re going to have to move upstream a bit and address some of the social drivers of health and engage the social determinants of health space,” said Thompson, noting that this effort would involve strong industry partnerships and continuously working with the Department of Health and Human Services on evolving data exchange standards. “That’s a very fertile area for information exchange so that we understand a whole person’s needs beyond just health care.”
The Office of the National Coordinator for Health IT's proposed Trusted Exchange Framework and Common Agreement (TEFCA) is one effort that aims to bridge this gap within the health care ecosystem. The agency is currently working with health care stakeholders to create baseline standards that enable seamless data exchange between qualified health information networks that didn't exist before.

“Providers will be able to get more data on their patients so that they can better give care,” said John Rancourt, director of the Interoperability Division at ONC’s Office of Policy, in a previous interview.

It’s also one piece in the picture of true interoperability and getting health data into the hands of patients.

“TEFCA is on the horizon. We see that as a contractual and technical way of ensuring that we have national networks that are able to coordinate with each other as well as regional and the like, which can interoperate with each other,” Wilder said. “I think innovation is going to happen beyond TEFCA, but TEFCA is going to set a pretty darn good minimum bar to make sure something gets through.”

As established by the 21st Century Cures Act of 2016, ONC finalized rules on interoperability and information blocking this March. Once officially enforced, the rules will require providers to give patients access to their data using standards-based application programming interfaces. The rules will also grant patients the option of further portability of the data through the development of a subsequent "app economy," as ONC's National Coordinator for Health IT Don Rucker has described.

To further improve health data exchange, the need for a national personal identifier for patients to track and access their health records seems necessary.

“The most important thing for us to have is a robust conversation around identity,” said Stuewe, suggesting that looking at use cases in the financial and banking industry could uncover solutions.
Providers must also continue to modernize common, outdated patient-authorization methods, like faxing, so that patients can obtain their digital health records without physically visiting one or more health care facilities and risking potential contagion.

“The last thing we wanted in a heavy COVID-19 network environmentally was for a well person to walk into a clinic and try to get their patient portal credentials,” said Wilder. “It’s not that hard to solve — it’s just going to take us all working together in ways we didn’t expect to right now.”