Sparking the Data Revolution in Healthcare

During the Fall, 2023 semester, HSI co-presented a series of lunchtime seminars with Doug Williams from the Martin Trust Center for MIT Entrepreneurship on the latest major wave in health tech, data sharing via APIs. In the US, this data sharing is regulated by Fast Healthcare Interoperability Resources (FHIR, pronounced “fire”), which is a set of standards, rules and specifications for exchanging electronic healthcare data quickly and efficiently.

The three-seminar series focused on government, industry and innovators in turn. As with most HSI seminars, the audience included current students, alumni, entrepreneurs, and even some people who were brand new to healthcare, but interested in learning about recent innovations.

The overarching theme for the series was data interoperability across siloes and stakeholders. The challenge is moving data among organizations, not within organizations. This challenge is being addressed in an environment where the largest insurer in the country, Medicare, continues to move to a value-based care model from the current fee-for-service model. The push is to move to paying for quality and value rather than for quantity of services.

A key part of this transition is dealing with the tsunami of data that are now available from a wide array of sources. These data inform the rules that value-based care requires, that is, how to measure value and knowing what the best care is in any given situation. Measuring quality is crucial to implementing value-based care. However, data availability alone is not enough.

The raw data are in so many different forms and systems. The challenge is how to make those data usable. This seminar series focused on the usable piece. Practitioners from industry, government and innovative startups all spoke about usability from their perspectives and fielded questions from the audience that formed the basis for lively discussions.

The first seminar, Healthcare Industry’s Role and Outlook, featured speakers who are working on the nuts and bolts of creating the FHIR standards and infrastructure in service of implementing nationwide value-based care. Da Vinci Project Program Manager Jocelyn Keegan stated succinctly that the end goal is to make data flow at the right time among the players leveraging FHIR APIs to solve problems such as prior authorizations. Realizing this goal takes teamwork, Keegan noted, “Can we put all the stakeholders in the room at the same time to do what is right for patients and not what is just in their own best interest?”

The Da Vinci Program works on data movement. Another speaker, FHIR at Scale Taskforce (FAST), Program Lead, Dana Marcelonis, spoke about security and data matching. The goal of FAST, she said, “is to address the infrastructure needs in order to scale FHIR.” There needs to be a way to verify digital identity so that all the data about a specific person really are about that specific person. Again, Like the Da Vinci Project, FAST is considering only models that can be deployed nationwide.

The third panelist focused on the larger issue of social determinants of health and health equity. Program Lead Health Equity for Project Gravity, Vanessa Candelora, spoke about both
the importance of including social data and the difficulties of doing so due to lack of standardization of both assessments and data. The difficulty, she said, “is often the people who are best able to address the immediate local needs are not informaticists. They are not thinking about repeatable systems and scaling. They are just trying to get people in the right bed or seat.” Project Gravity focuses on bringing standardization and scale to social data so that funding can be appropriately allocated to these crucial programs.

Anesh Chopra, Co-Founder and President of CareJourney, headlined the second seminar. In 2009, President Obama appointed Chopra as the first Chief Technology Officer of the United States, which focused primarily on nationwide healthcare challenges. He had a front-row seat to moving policy objectives toward a “value-based care delivery infrastructure (digital) and a technical standard that did not exist in nature and was not asked for by the customers to exist in nature. And then in five years it became the standard for health plans and health systems.”

In 2012, as Chopra was transitioning out, he wanted to focus on how to put those conceptual standards into production. The ONC announced the API requirement. Vendors agreed not to compete on how to meet the regulations individually. Chopra went on to explain that the project team of a small number of industry representatives worked together, and APIs for patient access were the result.

Chopra called out Apple as “the hero” of this story. He explained, “I give [the chief security officer] an insane amount of credit for having us deliver a real work production of the FHIR API standard ... that’s created a virtuous cycle of improvement and expansion. And now we’re got a beautiful ecosystem and voluntary engagement of payers and providers in the ecosystem that is not mandated or funded.”

The point that Chopra drove home is that individual companies worked together rather than creating their own competing APIs. Even Apple participated rather than developing in their “usual secretive way.” A few people “were willing to step out on a limb” and delivered a standard that is necessary to operationalize so much of the work that others have done with data standardization, and that others will do to prod the country toward value-based care.

The third seminar in the series looked toward the future and what these recent FHIR developments mean for innovators. The speaker, Ricky Sahu, Founder of @GenHealth.ai, started the company to build healthcare tools using generative AI to predict patient outcomes. GenHealth.ai was spun out of @1up.Health, which Sahu founded previously. 1up.Health is a platform company that also has access to deidentified data on several million patients. GenHealth.ai used those data to develop algorithms that predict the best course of action for any individual patient. For example, a provider can use the tool to confirm that a particular medication is beneficial for a patient and thereby bypass the usual long multistep process of prior authorization.

Clinical decision support is only one of the cases where Sahu envisions his company making an impact. His company has identified more than 30 use cases where this technology can be
applied. So far, only deidentified data has been used to train the AI, which means that data about mental health and substance use disorder have not been included. HIPAA regulations and patients’ expectations of confidentiality naturally force the company to be very mindful. In the future, Sahu anticipates being able to include these crucial details, which may change recommendations that result, but he is certain that the method is adaptable to those data.

The seminars as a series explored the FHIR API story, from the challenges of creating them to an example of making them the foundation of a start-up’s business. This story is one of stakeholder cooperation in service of creating a system that could truly be useful to as many people as possible. The potential benefits that can be realized from implementing FHIR APIs are still being discovered.