Using Data and Analytics Across the Research Lifecycle to Improve Population Health

The challenge of improving population health is multifaceted. The drivers of health affect each individual or community differently. With growing data volumes and new analytic platforms, health care providers have more insights than ever. Now the focus is shifting to putting those insights into action to improve the health outcomes of individuals and the larger population, while also addressing issues of ethics, equity, education and security.

SAS recently brought together some experts in health research to share examples of how they are balancing those challenges with using data and analytics to inform population health strategies.

The panel included:

- Dr. Katherine Tossas, Assistant Professor & Harrison Endowed Scholar in Cancer Research. Department of Health Behavior & Policy (Epidemiology Faculty Affiliate). School of Medicine, Virginia Commonwealth University
- Dr. Joe Grzymski, PhD, Principal Investigator, Healthy Nevada Project; Chief Scientific Officer, Renown Health; Research Professor, Desert Research Institute
- Wendy Bohner, Global Solution Architect Lead, Healthcare, Intel Corporation

Dr. Meghan Schaeffer, EdD MPH, MPA, National Public Health Advisor, Epidemiologist at SAS, moderated the discussion, which covered a range of issues, including:

- Identifying and addressing societal and structural barriers that prevent many from receiving adequate care
- Combining vast amounts of disparate data into a meaningful structure for downstream analysis
- Predicting a patient's risk for future chronic disease
- Quantifying regional health disparities and addressing gaps in care

- Studying patient cohorts to understand the real-world data on patient safety and treatment efficacy
- Using analytic visualizations to engage community leaders in policy decisions

The entire discussion is available online. Here are some highlights.

Data and Resource Equity

"My vision is one of data democracy," said Dr. Tossas. "We need to think about the communities we serve and not just collect data for an academic exercise, but rather to make data translatable and available."

There are structural obstacles to inequity that are sometimes perceived as individual failings, she explained. For example, she cited two cases: Dr. Eric Topol of The Scripps Research Institute, who self-diagnosed a kidney stone using a device on his iPhone; and a colleague of hers who owns the same iPhone but can only use it in one particular spot in his house because he lives in rural Virginia.

In another example of uneven access, she described the cases of Dr. Eric Dishman, former director of the All Of Us Research Program at the National Institutes of Health, and Timothy Jones, a popular Chicago DJ known as Timbuck2. Both men were diagnosed with kidney cancer when they were young – Dishman at 19, Jones at 33. Dishman survived thanks to genomic sequencing of his tumor, which gave doctors more and better options for treatment. Lacking such care, Jones died in just over a year, despite contracting cancer decades after Dishman did.

"It's fascinating," Dr. Schaeffer commented, "there are so many different factors that go into this. It's not just seemingly about poverty, or diagnosis, or employment, or the things that we typically look at in research in terms of improving outcomes."

Dr. Tossas agreed. "We need to move away from attributing some of these factors to individuals, and understand that individuals are indeed different, but when we peel off those differences, as we get more and more data, what we're going to recognize is that indeed, there's a common factor and that common factor may be structure.

"We need to acknowledge that because otherwise, we're going to keep spinning our wheels. We have gotten really good at measuring disparities, at developing bigger datasets and much more complex analytics. But we also must understand that continuing to amass these data sets and focusing on the individual is not going to eliminate existing disparities on their own."

"That's a great segue," Dr. Schaeffer said, "into some of the work that Dr. Grzymksi is doing, pulling all that information together, pulling in genetic information, but then also making it something that people in Nevada can experience and researchers can explore."

Educating Patients and Physicians

"Nevada is a vast, vast state," said Dr. Grzymksi. "We have one tertiary care health system that has to cover the area of New York, Pennsylvania and New Jersey combined."

That's one of the challenges for the Healthy Nevada Project, whose mission is to improve clinical care, accelerate research and drive patient engagement. Healthy Nevada Project uses "investigator-focused method," Grzymski explained, to study CDC Tier 1 inherited conditions in the population. These conditions lead to a 30-year disease acceleration on average, meaning that people with the inherited condition risk developing the underlying disease almost 30 years earlier than those without it. But the conditions are rarely detected in normal care.

"So we started returning these results to individuals and then studying how they are impacted by their journey through the health system and then addressing those problems," Dr. Grzymski explained. "And what we found is we really severely overestimated clinicians' ability, particularly at the primary care level, to deal with these inherited conditions.

"How do you deal with a 35-year-old who has Lynch Syndrome? Our primary care doctors didn't know how to do it. And we were, frankly, naive and aghast about this. But of course, not all physicians know about the cutting edge of genetics. This is what these studies are teaching us."

His advice to colleagues in other states: "You cannot over-communicate or over-educate. Get buy-in with your clinicians who are going to be managing patients who have these really severe conditions, but aren't going to quite know what to do, particularly at those early risk years. it's an ongoing challenge across the United States of just engaging patients and engaging their providers to know where these gaps in knowledge are."

Data: Balancing privacy and access

Wendy Bohner explained how federated learning — a machine learning technique that trains an algorithm across multiple data sets without merging them — can balance the competing imperatives of access and security.

She offered an example of three hospitals with their own data sets. "The algorithm moves to the data," Bohner explained. "The analysis will be run at hospital A, at hospital B and then at hospital C, and then you bring all of the results together and aggregate it and come up with a more diverse data set. The processes repeated over and over again until the model is improved."

In 2018, Intel worked on a project like this with the University of Pennsylvania and 28 other

institutions around the world. The effort led to a model with an accuracy of 85.7 percent, compared to the approximately 70 percent accuracy each participant could have achieved on its own.

"It's an exciting technique, and a new way to approach interoperability," Bohner said. "We're making it more interoperable by providing better access to that data and also incorporating security throughout the whole process."

The future is bright

Researchers and clinicians are making great strides in using data to inform individuals and populations of possible health risks. To make the biggest impact on health outcomes we also need to focus on equitable access for all. This is where data and analysis can guide and impact health policy decisions, and lead to action plans that directly address the challenges. Data can only suggest the way forward; professionals need to lead.

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