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Researchers aim to improve rare disease care through Epic database

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Epic's research division aims to improve treatments for rare diseases through a large database drawing from millions of patients' electronic health records.

Panelists representing the Verona-based company discussed Epic's rapidly growing Cosmos database during a Wisconsin Technology Council luncheon held yesterday in Madison. Dr. Jackie Gerhart, vice president for clinical informatics at Epic, discussed a "Look-Alikes" software application being developed to help guide doctors' treatment of patients with very rare conditions.

By searching the database containing health information from more than 163 million people, physicians could match their current patient with others who may have the same disease to gain insights, she explained. Without learning any identifying information about those other patients, they could contact their doctors to get advice on testing, medications and more.

"It's not just looking at what drugs might work — although that's true and it's definitely meant for personalized medicine — this is the future of really trying to personalize and even hopefully speed up the ability for you to respond," she said, referring to how doctors treat their patients.

Caleb Cox, lead data scientist for Epic Research, shared a personal story about his father's medical journey to illustrate the potential impact of Cosmos. He said he was only able to get treatment for a rare heart condition due to a series of coincidences that led him to find one of the few specialists in the world studying that specific disease.

"There's a lot of 'happened to' in that story," he said. "The idea behind Look-Alikes is we can make that a lot less circumstantial."

Gerhart said Cosmos broadly supports "evidence-based medicine findings." She said only 10 to 20 percent of medicine is "truly evidence-based" while most decisions are driven by expert consultations or previous practices.

“Our mission is really to take the real-world evidence and use it for good, and try to get good information out quickly so the public and others can act on it,” she said.

The database includes patient records from more than 170 health care organizations that use Epic software for digital patient records. Cox noted Cosmos information is not for sale, and has been scrubbed of identifiers for privacy concerns. Participants have to provide their own data in order to use the database and related tools, panelists explained.

According to Cox, the Cosmos database can help scientists conduct research more quickly and efficiently through the database’s framework, drawing from a much larger pool of information than they would typically have access to. Panelists also stressed that information is much more representative of the diversity of the U.S. population than most research cohorts.

“You can click a button, and a process that used to take weeks or months and thousands or tens of thousands of dollars is ready for you in like 90 seconds,” Cox said. “It makes it so much faster to be able to do research. And ultimately we expect that this could actually also bring the cost of doing research down.”

See more on the database here: https://cosmos.epic.com/

–By Alex Moe