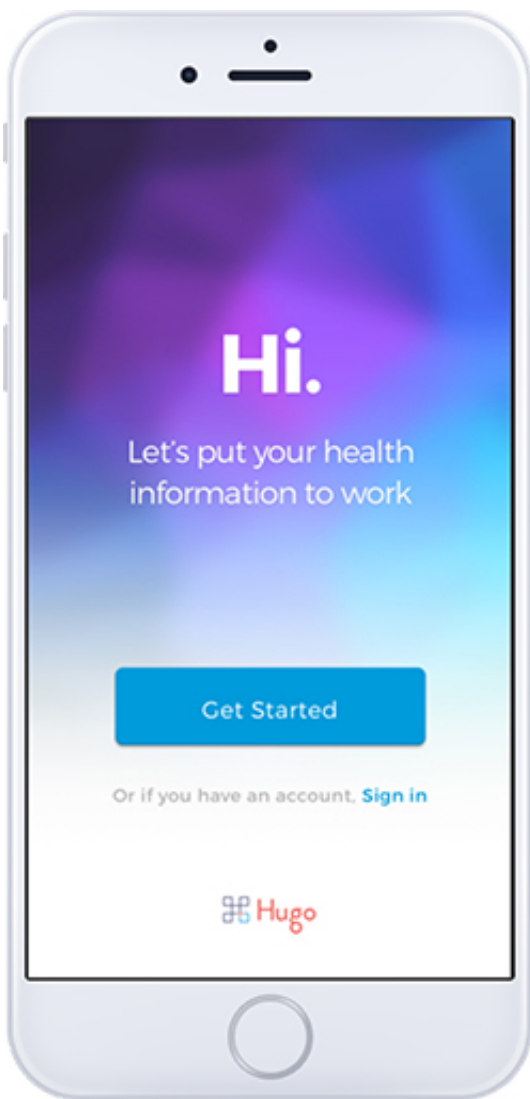


# New technology will allow patients to become partners in research

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Researchers at the Yale School of Medicine are launching a novel approach to research that engages people as true partners in science. Using an innovative health information technology platform called Hugo, which was developed in partnership with Yale New Haven Health System, people will be able to acquire their health-related data and use it to participate in studies.

Hugo is a highly secure cloud-based personal health platform that enables people to access their [electronic health records](#) (EHRs) from multiple health care systems and synchronize them with a research database. Designed to be user-friendly, it also allows people to contribute information from wearable devices and questionnaires.

"This could be a game changer. Hugo harnesses the very latest in digital health technology and puts patients in the center, making them true research partners," said Dr. Harlan Krumholz, the Harold H. Hines Jr. Professor of Medicine, director of the Center for Outcomes Research and Evaluation (CORE) at Yale-New Haven Hospital, and a developer of Hugo.

"By leveraging digital data with a technology that puts people in a position to easily and securely acquire and share their data, the Hugo technology holds great promise to accelerate our progress toward next generation breakthroughs," said Dr. Jerome P. Kassirer, former editor of The New England Journal of Medicine and Distinguished Professor at Tufts University School of Medicine.

Krumholz and Dr. Allen Hsiao, associate professor of pediatrics and of emergency medicine and chief medical information officer for Yale School of Medicine and Yale New Haven Health System, are leading the first research study that will use Hugo. The study will examine hospital readmission and emergency department use after hospital discharge. Approximately 20% to 30% of patients who need to be readmitted to the

hospital are admitted to a different facility. This presents challenges when studying readmission rates and risk factors because researchers must manually track down and collect this information.

With Hugo, patients will be able to authorize researchers to use their data, which can be pulled from disparate EHR systems and will be synchronized, and organized so that it is suitable for research. The study supports Sync-for-Science, a concept promoted by the National Institutes of Health Precision Medicine Initiative, which seeks to better engage people in research and promote their ability to obtain their own data and decide whether they want it used for research. "The time has arrived for research to be understood as a partnership between researchers and participants," said Debra L. Ness, president of the National Partnership for Women & Families.

"We believe this is going to be a new era of discovery," said Dr. Robert J. Alpern, dean of the Yale School of Medicine. "It's going to ensure that we're doing research better, less expensively, and in a way that fully respects and honors those who participate."

Hugo's ability to harness large amounts of data that is controlled by patients has attracted the attention of industry. There is a pressing need for new technologies that promote patient engagement and enhance data quality while reducing the cost and burden of data acquisition, according to Rick Kuntz, MD, MS, Chief Scientific, Clinical and Regulatory Officer of Medtronic.

"In the future we want to conduct research in partnership with people—not as subjects, but as our partners," said Joanne Waldstreicher, MD, Chief Medical Officer of Johnson & Johnson. "Hugo holds the promise to empower people with their data and will create innumerable opportunities for them to participate in programs and projects that are customized to their interests and needs—and provides opportunities to

be part of communities that contribute to knowledge that will help us all."

The benefits of enabling data to flow more easily extend beyond research. Patients face the same hurdles as researchers in accessing their health information from different health systems. Hugo is designed to enable patients to acquire their data in a single platform for their own use, for example when seeking a second opinion, and increase transparency in health care. It will also allow them to be the carriers of their longitudinal [health](#) records.

The Yale Center for Clinical Investigation, Yale School of Medicine, Yale-New Haven Hospital and the Yale Medical Group are providing support for the study. Although the study is on a small scale, it will help build a foundation for researchers to be able to do large studies much less expensively than before and in far greater partnership with patients, Krumholz said.

Provided by Yale University

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