ABSTRACT
Researcher access to EHR data has traditionally been limited to institutional settings where data from a single clinical system or a small network of collaborating systems are available to researchers within the network. Through an NIH-funded and ONC-supported effort called Sync for Science (S4S), a new approach for sharing EHR data has been developed to allow research participants both inside and outside of research network systems to share their EHR data with a research project in a wholly digital manner. To accomplish this, S4S leverages HIPAA and Meaningful Use to engineer a workflow that helps researchers get EHR data from willing participants. Real-world implementations of S4S are just now becoming available from several major EHR vendors. Their EHR systems now provide a HIPAA-compliant workflow that enable patients to approve sharing their structured clinical data with research (and other) apps through a standards-based API.

The All of Us Research Program will begin trial of S4S this month. Other research studies have now begun exploring how to use S4S, too.

In this talk, I will describe the key features of Sync for Science, including its technology, our initial use case assumptions, and the scope of the S4S trial in the All of Us Research Program. Digital futurists point to how things that become digital usually begin with deceptively slow growth and then disrupt and democratize entire products and services. Accordingly, I will also look past our initial S4S deliverables and describe the steps we are taking to increase the value of S4S to researchers, including exploring how S4S would influence the design and execution of future informatics research.

BIO
David Kreda has been a consultant to Harvard Medical School’s Department of Biomedical Informatics (DBMI) since 2010. His current work on Sync for Science (S4S) began in 2016 and includes NIH and ONC relationship management, product support planning, research protocol authoring (for the All of Us IRB), user interface guideline writing, and designing a standard way to return of EHR data to research participants, which dovetails with his role as a member of All of Us Return of EHR Information Task Force. Mr. Kreda’s first engagement at DBMI was as the Translation Advisor for the SMART Health IT project (2010 - 2014). On that project, he collaborated with numerous medical and informatics experts. He also oversaw the design and development of several SMART apps, including: the Pediatric Growth Chart (which receive a 2013 Red Dot Design Award), the Genomics Advisor, the Diabetes Monograph, and the Multi-Disease Monograph. As part of his project work, he also co-led the SMART C-CDA Collaborative, which influenced subsequent Meaningful Use regulations. In 2014-2015, Mr. Kreda was responsible for negotiating a novel data sharing and use agreement among over 20 academic parties to the NIH-funded Undiagnosed Diseases Network (UDN). Mr. Kreda has co-authored a number of peer-reviewed informatics journal articles.