Using metadata to help translate clinical research into better healthcare

Steve Canham
Christian Ohmann

Video Abstract

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Abstract

Clinical research is crucial to improving medical treatment and healthcare. But with all the associated data spread across various information storehouses, it's often unclear where the improvement process should begin. To a team of researchers from ECRIN, the European Clinical Research Infrastructure Network, it's a classic metadata problem—an issue of cataloguing data about data. Their solution: a universal scheme for labeling clinical research data and documents. With this system, harvesting critical information could become much easier, regardless of where it's located, vastly improving the speed with which researchers, reviewers, and clinicians alike can help translate clinical research into better healthcare. We tend to think that a research paper contains everything there is to know about a study. But it's really only part of the story—especially in clinical settings. Surrounding the research article are the datasets used for analysis, the analysis plans themselves, study protocols, and patient consent forms, among other resources—all collectively known as "data objects". The problem researchers and clinicians face is that these data objects are often stored in a number of different places: sometimes they're placed in dedicated archives; sometimes they can only be found on researchers' hard drives. Searching for this information, therefore, can be a difficult, lengthy, and expensive task—and the growing number of data repositories is only making it harder. To address this problem, the ECRIN team proposed a system for consistently cataloguing the metadata related to all of a study's data objects, across all storage locations. At its core, the scheme uses labels for data objects already provided by other schemes. For example, it retains the well-known digital object identifier system to point to journal articles and datasets. But it also covers gaps in current schemes, such as indicating whether and how a data object can be accessed for free. Several technical issues must be resolved before the system can be implemented. And there's still the challenge of building momentum among potential users and major stakeholders. But by improving the flow of knowledge about promising medical treatments and healthcare practices, this metadata strategy could ultimately help transform clinical research into better care.