When Patients Control Their Data, Clinical Researchers Win

Why (and How) Decentralizing Patient Data Will Revolutionize the Road to Medical Discoveries

From a young age, we learn to share, but when it comes to the collection and management of clinical research data, the opposite is more often true.

Then why is the question still being asked whether patient data should be shared and accessible by patients themselves? The journey towards betterment is complicated and doesn't happen overnight, but we're on the path forward — and already seeing advancements in both patient-centricity and patient engagement for clinical trials today.

Research organizations and consumers alike are fighting the same battle in hopes to win together — and the potential rewards are unparalleled. The possibility for consumer-mediated exchanges would give patients the chance to donate, track, or correct their records in real-time. This goes beyond patient access to electronic health records, interoperability or Meaningful Use guidelines. It's groundbreaking research in clinical programs and treating rare diseases. It's advancing faster, safer drug development. The speed, quality, and financial costs of human health would be vastly improved for everyone.

Putting Health in the Hands of the Patient — Easier Said Than Done

A lot of players in the system have access to patient data — pharmaceutical companies, EHR vendors, even marketing firms — everyone except patients. Ironically, they seem to be the only ones left who still lack access to their own data.

Why? Because healthcare, by and large, is a complex, highly regulated industry, with aging infrastructures and longstanding incumbents. Under current laws and practices, it's difficult to change the standard ways of working. As a result, patient's needs are oftentimes placed below those of the medical record owner.

But times are changing. For any industry, rapid digitization and non-traditional disrupters work to bridge gaps that create better outcomes for society. Take for example Apple's recent launch of Health Records — one of the latest high-profile attempts at sharing medical data between record owner and patient. Disruptive technologies, especially from brands with wide consumer appeal, have the capability to trigger advancement. Unfortunately, for most regulated sectors such as healthcare, adoption is rarely linear.

The solution is simple, but we can't succeed without the industry's cooperation – so how do we get there?

From Electronic Health Records to Electronic Data Capture: Transforming "Meaningful Use" into Meaningful Research

Only a few weeks ago, the U.S. administration announced its MyHealthEData initiative, aiming to put patients in charge of their own healthcare data and advance health innovation. We're at a critical inflection point where everyone wants to see change, but actions will speak louder than words. Eliminating government burdens and legislative hurdles alone can't rebuild the healthcare industry from the ground-up. In order to advance today's state of healthcare, we need to tackle the backend before researchers and patients will see real-life benefits.

Some of the biggest challenges for clinical trials is patient recruitment and enrollment. This is especially true when evaluating precision medicine or rare diseases. There are very few patients available, and a shortage of specific patient populations required to complete accurate, timely trials. The increased frequency of trials conducted in tandem also creates hurdles. For example, there are more than 1,000 immunotherapy studies underway, and the available patient pool is too small in comparison.

We need to ensure that the right solutions and next-generation platforms can feasibly turn patient-centric care into a reality.

Anthony Costello
VP, Mobile Health
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Through EDC and smarter integration of connected solutions such as eSource, patient scarcity, and the abundance of unusable data is tackled through powerful machine learning tools — providing researchers the ability to advance precision medicine. By optimizing data software, existing trial information is digitally captured with prescriptive analytics capabilities. Data that was previously unused (or unusable) is mined and analyzed — not only faster, but better. As a direct result, new outputs and biomarkers are readily available for researchers that previously didn't exist.

Transforming a historical problem into patient-centric solution requires some legwork, but we're confident that the advancements in human health will be unmatched. Medidata believes that if you build it (and build it well), they will come. When technology leads, consumers believe – and the industry, whether willingly or reluctantly, follows suit.

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