



Digital health

How patients can turn their medical data into money

Wave of start-ups offer to aggregate information for research opportunities



Health data are increasingly likely to be generated by a wearable rather than a consultation in a doctor's office or a hospital stay © Alamy

Sarah Neville, Global Pharmaceuticals Editor APRIL 22, 2019

When John Silberlicht goes walking, he is never alone. As he tramps around rural Connecticut, following doctors' advice to take exercise after undergoing his fourth cardiac surgery in January, he wears a Fitbit that registers every step he takes and every beat of his reinvigorated heart.

The information is not simply a source of personal reassurance that his recovery is on track; it is also a trove for medical researchers.

Alongside the data from the wearable on his wrist, his medical and pharmacy records, and his responses to texted or emailed queries about his wellbeing, are collected on his behalf and stored securely in his account in the cloud. With his permission, a group of clinicians is now using the information to evaluate how to improve post-operative treatment for others.

Mr Silberlicht, who has been in and out of the operating room since he was a toddler, explained: "As [my doctor] put it, I'm a unique individual. With all the previous heart surgeries I've had, I'm one of those candidates that they'd like to learn a little bit more from, how I recovered."

He added: "If I can help one person with my data, then I'm doing something right."

In a world where health data are becoming an ever more valuable and diffuse commodity — increasingly likely to be generated by a wearable rather than a consultation in a doctor's office or a hospital stay — a small industry of companies is starting to emerge, offering to aggregate data on behalf of patients and introduce them to research opportunities.

Behind these moves lies a belief that the bargain that has underpinned the digitisation of other industries — that in return for their data consumers will receive a better service — has largely

cluded people when it comes to their own health, despite its potential to accelerate breakthroughs and improve prognoses.

Harlan Krumholz, a professor of medicine at Yale University who devised the platform that collects Mr Silberlicht's data, said companies such as Amazon or Tesla are adept at "getting smarter with every click; they learn from every interaction, they're better as a result".

"And then you look at medicine and we still have fragmented data, we are still acting like it's the 1950s, we're not harnessing even a fraction of what's possible from the digital transformation."

You can negotiate for fair market value; if it's used without your permission it's a form of theft

Richie Etwaru, chief executive of Hu-manity.co

Dr Krumholz and his wife Leslie co-founded Hugo Health in 2015. It now has 1,200 users on its platform and has entered into research partnerships with prominent pharma and health companies, including J&J and Medtronic, as well as the Food and Drug Administration, the US regulator.

For Richie Etwaru, the solution is to offer people legal title over their data. His company, Hu-manity.co, which deploys blockchain technology, came into being in April 2018, with \$5.5m in seed round funding from two anonymous angel investors.

Even with little in the way of marketing, about 16,000 people from 70 countries have signed up and it has attracted the attention of some large pharma companies.

Mr Etwaru, who estimated that the global value of all human data at \$150bn to \$200bn annually, said: "Property is very distinct so we act as a title company in the United States which means we give you a title for your data, much as you have a title for your car, a title for your home."

He added: "You can negotiate for fair market value; if it's used without your permission it's a form of theft."

Mr Etwaru believes the prize for pharma is the acquisition of a much richer stream of data, and the chance to build an active relationship with the patients who supply it, eliminating many of the industry's concerns about inadvertently falling foul of privacy laws.

The current model, through which pharma buys data aggregated from multiple sources that has supposedly been "de-identified" to protect the anonymity of individual patients, is no longer safe or sustainable, he argued.

"After you buy prescription data, [electronic medical record] data, lab data, geolocation data, [genomics company] 23andMe data, Fitbit data, it's not long before you can say, oh, yes, that's actually Sam Smith, it's no longer patient 1234879," he said.

By going through Hu-manity.co, "pharma gets to operate above-bar because now they don't have to worry about the risk of re-identification because now they have the explicit permission to be in a relationship with their patient", he said.

The company is to launch pilots with three top 20 pharma groups, which it declines to identify, within the next three months.

Kate Merton, who heads JLABS in New York, Boston and Philadelphia, part of Johnson & Johnson Innovation which supports pharma and healthcare entrepreneurs, agreed that the chance to build a deeper relationship with the patient is valuable.

She said: “As a scientist, you always want to have the best data set at your disposal. Now, if that data set is coming from a patient, they themselves are going to be able to give you that most comprehensive data, and if they own it, it just means that you are probably going to have access to higher quality data in order to make decisions.”

It is an approach that may have found its moment. In Oregon, the state legislature is considering a draft measure that would require a signed authorisation from consumers before their de-identified data could be sold on to third parties.

According to a summary of the bill, individuals “should have the right to assert a property interest in the health information such that the individual may receive remuneration in connection with the commercial sale”.

Hu-manity, which is lobbying for its passage, helped to provide the draft language, according to Floyd Prozanski, one of the sponsoring state senators.

A key conundrum remains how data should be priced. Mr Etwaru expects the price to be set at \$120 for a year’s lease of an individual’s health data, although this sum could be earned several times over if, for example, more than one pharma company wanted the data set.

He also believes that the value of data will rise exponentially as the need and desire for it increases, in an era in which pharma companies are under increasing pressure to prove the efficacy of their medicines once they are in day-to-day use: so-called “real world evidence”.

The culture of the research world, however, is often to treat data as the property of the researchers and their organisations, and the patients who have generated them may never discover what insights they have yielded.

It is an approach that Eric Schadt, dean for precision medicine at the Icahn School of Medicine at Mount Sinai in New York, is determined to challenge. “We definitely want to disrupt the model of hoarding data, keeping it closed, building things off the back of fellow humans without their necessarily getting much direct benefit,” he said.

Eighteen months ago he became chief executive of Sema4, a Mount Sinai spinout that offers to manage genetic test data on behalf of the patient, who has access to it and can decide whether to share it for the purposes of clinical research.

The company, together with the Mount Sinai health system, has recently agreed to work with Sanofi, the French drugmaker, on a five-year asthma study. The project will follow nearly 1,200 people with asthma and collect a range of data, from traditional clinical data to genomics, immunological, environmental and sensor data from mobile devices in what the company says will be the largest study of its kind.

For Mr Etwaru, health is just the first step. He believes that people should own all the other information they automatically generate, such as “geolocation” data, which can form the basis of targeted advertisements.

Back in Connecticut, Mr Silberlicht suggests that having control over his data via the Hugo app is itself aiding his recovery. But how would he feel about being paid for his data? That, he suggested, would depend on how it was going to be used.

“Sometimes the big pharmaceutical companies do these things, and it’s not in the best interests of everyone else. If it’s in the best interests, coming out with a new medication or helping do surgery a certain way . . . I’m all for it”, he said.