
Patient data: who's in the driving seat?



With digital technology, there is now more patient data being collected and stored in healthcare systems. Increased data collection provides an important resource for clinicians and researchers in their quest for new a cure or drug. Also, with [consumerism now a growing trend in healthcare](#), more questions now emerge about who owns this data and what it's worth.

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These issues surrounding data ownership and control and empowerment of the patient took centre stage at [HIMSS19's 'Consumerisation of Healthcare Summit'](#). So is the data owned by the patient, provider or payer? Some health tech experts argue this is the wrong way to look at data. They say the issue goes beyond ownership, but who is sitting in the driver's seat when it comes to how that data is used.

Summit participant, Christopher Sealey, cofounder of Coverus, pointed out that the patient can have multiple reasons for giving researchers access to their data.

"I have a question over ownership because individual decisions I make are not pure and my motivation can be compromised by my financial situation, my lack of information etc., and also my individual decisions of what I do with my data could have very big effects on other people and my community and workplace," Sealey said. "So I think when we say the patient should own their data, I think that comes from the ethos of wanting [the patient in control](#), but I think we have to realise that individual ownership may not actually help the patients as much as we think."

Nicolas Schmidt, chief product officer at Embleema, emphasised the need to "empower" patients to take back full control of their data. When this data is used to help create a new treatment, for example, Schmidt said that patients should be compensated for it.

Providing compensation or incentives to patients could also promote the exchange of "clean data", creating a win-win situation for both patients and researchers, according to Kamal Obbad, cofounder and CEO of Nebula Genomics. "The way the system is set up today, the people we want to be winning, aren't winning. The patients aren't winning, researchers aren't winning because they are getting data that isn't clean," Obbad said. "You talk to biopharma, they are telling us that the data sets they are collecting from third-party data brokers are subsets of data and it doesn't make any sense. We do want to find a way to engage patients and incentivise them to participate in this process to share what is clean data, to share what is longitudinally so we get holistic views of health data."

As noted during the summit, research data currently is often fragmented and only captures one piece of a patient's overall health. If patients have incentives to share more about their life it could be a more complete picture. One way to compensate patients for their data is through the use of digital currency. This is exemplified by Nebula Genomics' business model, which includes sequencing consumers' genomes and then letting them trade that data for cryptocurrency.

When it comes to [patients sharing their data in exchange for some form of compensation](#), there are still a lot of questions including value and use. However, as patients continue to move into the consumer role there is no doubt the conversation around their role in data exchange has only just begun.

"I don't think it's just a question of giving people their records and letting them broker it, it is understanding that they hold the key to the most powerful tool," Sealey said.

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