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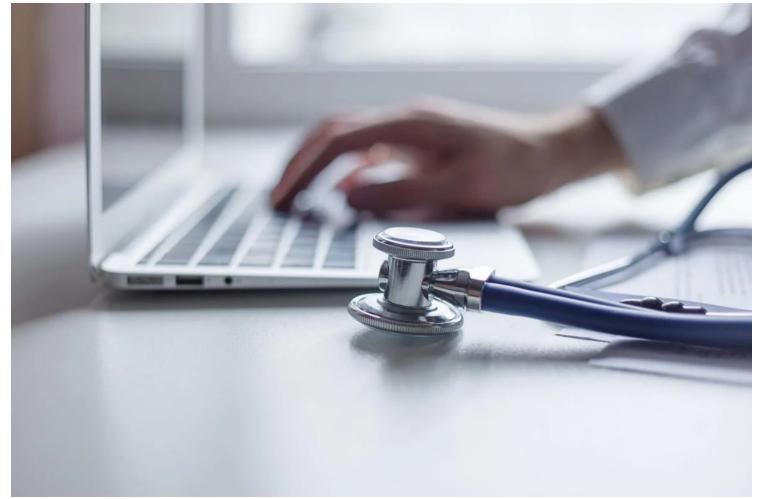
Virtual care has led to a data gold rush for your personal and health information

What is enabling the collection and use of health data in ways insiders themselves describe as problematic?

By Sheryl Spithoff and Danyaal Raza Contributors

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"Some virtual care platforms used patient data — in particular personal health information — to the benefit of pharmaceutical companies," write Sheryl Spithoff and Danyaal Raza. Dreamstime.com

> A visit to your doctor or other health care provider can be a deeply personal experience. It often requires disclosing some of the most intimate details of your life, in order to get the right care, at the right time.

> But what if your medical team weren't the only ones using that information? And what if that data was being used, even sold, without your knowledge?

> Virtual care has rightly become a mainstream health care tool. However, its rapid rise has also led to an explosion of for-profit, direct-to-consumer, online only businesses.

These companies derive profits via payment for clinical services. However, the drive to maximize revenue doesn't end with payment for care. For many companies, like other profitmaximizing online portals, your data is the real gold mine. This includes personal and health information collected as part of your health care visit. While it is generally understood that these companies are commercializing patient data, the <u>Health Tech and Society Lab</u> wanted to better understand what was being done. In a recent study based on anonymous interviews with industry insiders, the Lab provides some answers.

The results are startling.

For example, companies collected data — like names, email addresses, and browsing history — as patients accessed care to display targeted ads for "in-house" or third-party products and services. One insider reports that "if you are frequently looking up dermatology terms on our app, we might offer additional services around dermatology for you."

Often, these services are paid privately with higher markups than publicly-funded services. These were described by another insider as "sell-up conversions," a known feature of other for-profit care.

More surprising, were direct attempts to influence clinical outcomes.

Some virtual care platforms used patient data — in particular personal health information — to the benefit of pharmaceutical companies. Platforms analyzed patient data and adjusted a patient's care pathway to increase the uptake of products from their pharma clients.

For example, one company adjusted the timings of the follow-up virtual patient visits, and the frequency of reminders about a pharmaceutical company's drug sent by their platform, then ran analyses to determine which methods were most effective at increasing use of their client's product. This experimentation included "A/B testing" to ensure as many patients as possible used the drug of interest. All the while, patients were not informed that the platform was conducting these tests.

In other words, patient care delivered through these virtual-only services was being directly altered, to the benefit of pharmaceutical companies.

Some insiders described these business practices as typical, even appropriate.

One remarked that "as a private company, we need to make money, so we would be looking for additional services to recommend to you." Another said, "I don't think it should be a surprise to anyone in health care or the corporate world that this is how these entities function."

Others expressed concerns about patient privacy, pharma industry influence over care and risks to marginalized communities.

On A/B testing, one interviewee said they had "the ability to influence ... the patient's decision-making and health care choices, perhaps more than ideal." Another said, "I would like my care journey to be governed by what's the best care for me, not who paid the most amount of money to get in front of me for my attention." Damningly, yet another described the use of data to promote products and services as companies making "money off [patients'] backs."

What is enabling the collection and use of health data in ways insiders themselves describe as problematic? Confusing and vague privacy policies, difficulty opting out of data uses, a lack of other care options, and high levels of trust in the health care system. One interviewee noted, "when [patients] hear virtual care and they hear licensed physician in Ontario or licensed physician in your region they assume their data are being protected."

These are consequential findings. It is clear that for-profit, directto-consumer virtual care platforms are in the midst of a data gold rush. Patients using these services, health care providers working for them, and policymakers responsible for regulating them must be aware of the implications. After all, virtual care is here to stay. Like any tool, the way in which it's used matters a great deal. Dr. Sheryl Spithoff and Dr. Danyaal Raza are family doctors and assistant professors at the University of Toronto. Spithoff is also director of the Health Tech & Society Lab at Women's College Hospital and Raza is a collaborator.

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