

SUBJECT: The impact of DoH on the Inferred Medical Record problem

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TWIMC,

I work on and around the difficult problem of healthcare data privacy. Along with several others in various patient communities I submitted an FTC complaint against Facebook. Our complaint sought to hold them accountable for their problematic treatment of the online patient communities that gather on Facebook platform.

Discussing the problem with Facebook has been very difficult, until the movie "Social Dilemma" was released. This movie illustrated the process of a digital platform conducting ongoing proactive experiments in order to data mine information and ensure ongoing interactions.

Now it is simpler to describe the problem that I focus on. The ongoing use of digital monitoring and digital profiling to infer health information as people use cell phones and interact online. For instance, if your cell phone GPS reveals that you visited a cardiologist, whichever apps have access to the GPS information might infer that you, or someone you love, has heart disease. A visit to a wig website, might be used to infer that you are bald from chemotherapy treatments.

Unlike credit card information, passwords or bank account information, many health details are impossible to change when they are released onto the dark web. These personal details, unlike other digital details tend to grow in value over time, which is reflected in the price of medical records on the dark web. The fact that every major Internet company knows whether we are sick, and what we are sick from, sometimes even before we ourselves know makes us vulnerable in countless ways that we do not yet understand.

I am convinced that the only way to begin to address these problems is start carefully attending to how information leaks to third parties online. Once I have looked up the DNS for a rare disease non-profit 20 or 30 times over the course of the same number of days, it is entirely possible that each domain lookup has informed some random Internet provider that I have that rare disease. Ironically, they might not even understand that this is what their DNS records contain, and only in subsequent data breaches, which inevitably become sold and resold on the dark web, is the implication of this data release fully realized.

For this reason, I am strongly in favor of Mozilla and other browser providers moving to encrypt DNS lookups by default. I do not think major problems like the Medical Record Inference Problem are solvable unless this, and several dozen other major structural problems are addressed in favor of personal privacy.

Thank you for your continued commitment to privacy. It matters in ways that we have yet to fully imagine.

Regards,

-Fred Trotter