

Patient Privacy a Relic for Everyone Outside the Exam Room



By Jamie Wells, M.D. — February 25, 2019



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www.thoughtcatalog.com [1]

From hospital inpatient “wealth screenings” for potential donors to digital geofencing cell phones in emergency rooms, the erosion of patient privacy is a prominent reality. While health care professionals are duty bound by more than the fundamental principles of bioethics and HIPAA laws to keep confidential protected personal health information, it appears no one else seems too bothered by the concept. Branding the rampant practice as “data sharing” doesn’t soften the blow that the act is routinely coercive and violates an individual’s right to autonomy.

This recent article in the [Wall Street Journal](#) [2] presents the latest assault in this apt headline:

“You Give Apps Sensitive Personal Information. Then They Tell Facebook: Wall Street Journal testing reveals how the social-media giant collects a wide range of private data from developers; ‘This is a big mess’”

The information shared without people’s consent ranged widely from heart rate and body weight to tracking women’s personal ovulation and menstrual cycles to pregnancy status. This occurred for those not even on the social media Facebook site and readily included very intimate, sensitive details. To appreciate the extent and review Facebook and app developer official statements, review these pieces [here](#) [3] and [here](#) [2].

This is no great surprise given the recent spotlight the behemoth has gotten on such topics and their reflexive back peddling hasn’t made meaningful gains in terms of public trust. But, Facebook

and these app developers aren't the sole proprietors of the evaporate personal health privacy domain.

While our culture is preoccupied with violations of consumer data privacy yielding targeted marketing for shoes, travel or food preferences, law and advertising firms are leading a more nefarious erosive charge on patient privacy. Unbeknownst to emergency room visitors, companies are setting up digital geofences around hospital perimeters that capture mobile phone entry to the premises. This initiates a cascade of events that allows marketing agencies hired by personal injury law firms, for example, to solicit patients directly with ads to their phone (while still in the ER). Though these ads can be cast while in a clinic or other medical locale, the system is sparked by arrival to the emergency room.

Think about that for a moment. Whether you voluntarily go to seek urgent health services or are taken there while unconscious, your most personal and vulnerable of life events is shared to strangers without your consent. When the choice becomes avoid the ER and risk your own or loved one's life in an effort to preserve your autonomy, we as a society are opting for coercion as the rule of law. To learn more, read this [piece](#) [4].

Imagine you are unexpectedly admitted to the hospital for an urgent medical condition -not something for which there is an alternate option. Let's assume you are conscious, anxious and in tremendous pain as you quickly complete the admitting paperwork to expedite the situation. Because your attention is focused on your own survival and preoccupied by the many *what ifs*, you might have missed that unless you expressly opt-out you have passively consented to permit your protected health information (PHI) to be used in wealth strategy programs by the health system's fundraising apparatus.

Though there are supposed safeguards not to place an undue burden on patients to opt-out or decline participation, this active measure in itself appears to place an unnecessary burden on patients seeking medical care. The fact physicians are uneasy about such intrusions into the doctor-patient relationship is also no surprise given their role is to treat patients not influence donor pools. The conflicts abound. Read more [here](#) [5].

The expectation of privacy while receiving medical care is being used for sport. Rhetoric is replacing truly informed consent, consider the overselling of routine DNA sequencing in primary care by a health system that is also a health insurer as but one example. Controversial direct-to-consumer genetic tests fall in this mix. Review [here](#) [6] for greater depth.

For everyone in the exam room, a thoroughly and comprehensively informed patient consent is the gold standard. It is the only path to healing while doing no harm. As government officials call for investigations to stop these [consumer privacy invasions](#), [3] their delays reflect a reactive not proactive response. And, one that altogether lacks an iota of urgency. While the snail's pace continues, it might be good individual policy to opt-out actively if this is important to you. Having such considerations on your radar is a necessary first step.

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[1] <https://thoughtcatalog.com/>

[2] https://www.wsj.com/articles/you-give-apps-sensitive-personal-information-then-they-tell-facebook-11550851636?mod=hp_lead_pos1

[3] <https://www.cbsnews.com/news/facebook-reportedly-received-sensitive-health-data-from-apps-without-consent/>

[4] <https://www.acsh.org/news/2018/06/03/patient-privacy-threatened-end-legal-decency-13041>

[5] <https://www.acsh.org/news/2019/01/28/patient-privacy-already-pass%C3%A9-13761>

[6] <https://www.acsh.org/news/2018/05/25/precision-medicine-overselling-routine-dna-sequencing-primary-care-13014>