Recalibrating Privacy Protections to Promote Patient Engagement

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The past decade has seen the continued growth of evidence-based practices to diagnose and treat disease and deliver health care. The benefits of these advances for patient and population health, however, depend on patient engagement — the active participation of patients in their care. The way for later regret if the outcome is poor. Patients who choose elective procedures while in a hot state and end up with a bad outcome may be at particular risk for regret due to commission bias.

Some researchers believe that the relationship of regret to either action or inertia must be viewed in the context of preceding events. Experiments involving sports may be relevant. A team of Dutch researchers led by Marcel Zeelenberg assessed the regret of a coach who decides to change the roster of players just before his team loses a game. The degree of regret depended on whether the team was winning or losing before the roster change. If the team was winning and the coach changed the players, he felt profound regret; but if the team was losing already and he altered the roster and still lost the game, his regret was minimal. In the case of our acquaintance with an arthritic knee, the “team was losing” — he had tried conservative measures without improvement. After an unsuccessful surgery, he did not feel regret. But in the case of the patient with the thyroid nodule, the “team was winning” — the nodule appeared stable — so she was at increased risk for regret when she “changed the roster.” When she shifted to what proved to be an unnecessary surgery rather than staying with the winning strategy of ultrasound surveillance, her team “lost” and her sense of regret was profound. Interestingly, in a review of patient choices regarding hormone replacement therapy, breast cancer surgery, and prostate cancer treatment, regret was greater among patients who changed their original decisions. As physicians, we are acutely aware of the element of uncertainty in medicine, but we less often recognize its close companion, regret. Regret in all its forms can be a powerful undercurrent, moving patients to act in ways that may baffle us. We should recognize that anticipated regret can leave a patient mired in decisional conflict, unable to choose. For these patients, it is vital to bring anticipated regret to the surface by openly discussing their fears and helping them gain a clear perspective on the risks and benefits of their options in order to move forward. To mitigate the possibility of future experienced regret, we as doctors can try to reduce the emotional temperature and, when feasible, avoid having patients make their decisions while in a hot state. Except in the most urgent circumstances, physicians can set in motion a deliberative process, exploring all treatment options to avert process regret. When patients are heavily influenced by others in making a decision, we can also be alert to the possibility of role regret.

Regret is typically viewed as a negative emotion. It is notable that existing patient regret scales have largely failed to assess for a positive impact of regret. However, awareness of regret can be positive or functional, a potent force in modifying behavior and enhancing decision making. As physicians, we can help our patients make better decisions by understanding the power of regret in all its forms.

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own care. Patient engagement has been called the “blockbuster drug” of the 21st century, but it remains suboptimal, with substantial implications for health care quality and spending. Missed medical appointments are estimated to cost the health care system billions of dollars each year; approximately half of patients who have a myocardial infarction stop taking their evidence-based preventive medications within 12 months; and only 47% of eligible people receive an annual influenza vaccination.

Promising interventions are being developed, tested, and implemented to tackle these problems. Patient portals and Bluetooth-connected biometric devices, such as blood-pressure cuffs and glucose monitors, can facilitate asynchronous interaction between patients and their clinicians. Telephone calls made using interactive voice response systems and short message system (SMS) text messages can remind patients — including those without regular Internet access — about upcoming medical appointments, the importance of cancer screening, and when their medication refills are due. Smartphone applications can help patients manage their health conditions by providing them with medical information, enhancing their motivation, and helping them connect with other patients through social networks.

An expanding literature from behavioral economics and cognitive psychology has revealed that for engagement tools to be effective, they must be accessible, allow for personalized communication, and facilitate instantaneous sharing of information. But Health Insurance Portability and Accountability Act (HIPAA) regulations designed to protect patient privacy may inadvertently be preventing these tools from reaching their full potential.

Passed in 1996, HIPAA mandated the development of privacy and security standards for the disclosure of individually identifiable health information (known as protected health information (PHI)) by providers, insurers, and administrators — so-called covered entities. In 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act extended HIPAA’s reach to include the business associates of covered entities.

The HIPAA Privacy Rule requires covered entities to take reasonable steps to protect against intentional or unintentional disclosure of PHI. Although the Privacy Rule allows covered entities to disclose PHI to third parties for the purposes of treatment, payment, or health care operations without patient authorization, it limits such disclosures to the minimum amount of information necessary. Disclosure of protected information to patients themselves is not similarly restricted.

The HIPAA Security Rule applies to electronic PHI. It mandates that covered entities adopt administrative, physical, and technical safeguards to protect against reasonably anticipated risks of unauthorized access to electronic PHI. For example, such parties must encrypt e-mail messages that contain protected information, if doing so is reasonable and appropriate. Covered entities that do not believe encryption is necessary must justify their conclusion and implement a reasonable and appropriate alternative safeguard if one is available.

HIPAA establishes minimum privacy and security requirements; states may enact stricter safeguards. In addition, heightened federal protections exist for certain types of information and communication. For example, the Telephone Consumer Protection Act prohibits the use of automated dialing systems for calls or texts to cell phones and artificial or prerecorded voice messages in calls to landlines absent express consent, with the notable recent exception of noncommercial health care–related messages.

Given the possibility of stiff penalties for noncompliance, covered entities have understandably interpreted HIPAA conservatively, limiting their use of PHI in patient outreach. To mitigate the risk of unintentional disclosure of protected information, for example, hospitals often prohibit the inclusion of PHI in unencrypted e-mail, determining that encryption is reasonable and appropriate. Instead, the patient is alerted to the existence of a new message, which must be decrypted using a unique key or accessed by means of an encrypted portal. Similarly, when leaving messages about upcoming appointments, medical offices routinely use only a patient’s first name and don’t mention the specialty of the provider the patient will be seeing. Because SMS text messaging relies on unencrypted transmission of data between carriers, some covered entities have also prohibited inclusion of PHI in text messages.

Although such policies are intended to protect privacy, they can hamper clinicians’ ability to meaningfully engage patients and may not reflect what patients want or require. Asking patients to log on to an encrypted portal to read an e-mail message of unknown
importance from one of their health care providers, to return a nondescript call from a physician's office, or to decipher a generic SMS text message decreases the likelihood that the patient will follow through, undermining the potential benefits that these engagement tools offer.

Attempts to comply with HIPAA also constrain personalization, which a growing body of peer-reviewed literature has found is critical to engagement. According to a recent meta-analysis, for example, the effect of SMS text messaging on medication adherence was 70% greater when interventions incorporated patient and medication names than when they did not.¹

The tension between the increasing availability of technology to promote patient engagement and existing privacy and security requirements under HIPAA highlights the need for reform. At a minimum, we believe it will be important to reassess what levels of privacy and security are reasonable and appropriate for providing effective patient care.

Additional guidance from the Department of Health and Human Services Office for Civil Rights (OCR) — the body charged with enforcing HIPAA — could help in this regard. Specifically, the OCR could elaborate on criteria that organizations can use to determine when encryption of PHI may not be necessary. It may be the case, for example, that current efforts to encrypt or anonymize communication between health care providers and their patients are overly cautious in certain situations.

More broadly, it is worth considering what should be the default privacy and security standards for sharing PHI as part of efforts to engage patients. Some health systems have started allowing patients to sign a form waiving stringent protections. However, it is unclear whether other covered institutions would consider such a policy to be in compliance with HIPAA. What's more, opt-out systems involve additional costs and tend to benefit people who are already the most engaged with their own health care.

Patients might be better served if providers chose to implement a system requiring patients to opt in to current privacy and security standards for sharing PHI with them. Such a change could require amending existing HIPAA regulations and might lead some patients not to protect their privacy as much as they would like. However, it could also meaningfully improve patient engagement with the health care system — and therefore health outcomes — while respecting patient autonomy. Whether the trade-off is warranted is ultimately a question of societal values.

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