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Perspectives on privacy: Information for compliance professionals

By Pamela S. Hrubey, DrPH, CCEP, CIPP/US; Candice M. Moschell, CISSP; and Shameka N. Smith, CIA

Pamela S. Hrubey (pam.hrubey@crowe.com) is a principal in the Washington, DC, office, Candice M. Moschell (candice.moschell@crowe.com) is a senior manager in the Indianapolis, IN, office, and Shameka N. Smith (shameka.smith@crowehrc.com) is a principal in the St. Louis, MO, office of Crowe.



Pamela S. Hrubey



Candice M.
Moschell



Shameka N. Smith

Anthony has been with his employer for 15 years, always covered by his employer's insurance plan. Recently, Anthony was involved in a weekend accident that resulted in a brief hospitalization for a surgical procedure followed by physical therapy. Anthony spoke highly to friends and colleagues about the medical team that supported him through his accident. Once back at work full time, however, Anthony was bombarded by ads to both his work and personal email addresses that highlighted the hospital's new heart-related CT scanning capabilities. Initially Anthony didn't think much about the ads, but his annoyance grew, especially after he got the bill for his share of his hospitalization and surgical procedures. The ads made Anthony feel as though the hospital cared only about making money on the backs of working people, especially because he didn't give his consent to receive marketing-related information from the hospital. He vented his frustration about the hospital to anyone who would listen, and he typically found a sympathetic ear whenever he brought up the topic of hospital services—related marketing and the rising out-of-pocket medical costs for working people. After learning from an internet search that his physician and physical therapist both worked for practices owned by the hospital organization sending the ads, he and his partner switched healthcare professionals.

Anthony is like the 29% of individuals who, according to a 2020 data privacy survey by Cisco,^[1] have stopped buying products or services from a specific organization because of that organization's data-related practices. While the US healthcare marketplace has grown accustomed to reliably safeguarding protected health information (PHI) under the HIPAA Privacy Rule, which became effective in April 2003,^[2] many healthcare organizations have not contemplated the impact of changing consumer expectations, especially in the area of direct-to-consumer marketing.

Evolving perspectives

Patient care trends continue to evolve toward a focus on consumer needs and wants. We have entered a digital health era, in which patients' perspectives as consumers are advancing. Patients as consumers are increasingly willing to assert their autonomy by choosing healthcare-related services based on available data such as patient ratings of physicians and posted prices of services. Data allows patients to choose the organizations and services that they believe best meet their expectations. In order to compete in this digital era, healthcare organizations

have focused their marketing initiatives on becoming more visible to targeted consumers.

At the same time, patients increasingly understand that their data, both about them as individuals and about their health, is personal and private. In the near future, the use of personal data for marketing purposes might be affected as healthcare organizations will be required to comply with new state-specific privacy regulations being adopted across the United States.

More and more, consumers are being inundated with advertisements via email, text, and print for services they don't need or did not inquire about, including services related to their health. For healthcare organizations, the positive intent behind the advertisements often is lost as patients question whether their healthcare provider and affiliated hospitals can keep personal information private. Consider this scenario: Susan is newly diagnosed with breast cancer, and she elects to not share the diagnosis with her children until she can describe her selected treatment plan. She starts receiving advertisements in the mail and on her mobile device about advanced breast cancer and the related treatment options. Unfortunately, one of Susan's children sees the advertisements, imagines the worst, and becomes upset because of both the diagnosis and Susan's withholding of it. Susan wonders why she started receiving ads that she does not recall requesting at such a sensitive time. She blames the healthcare organization that gave her the diagnosis, and she is extremely concerned about trusting the organization with her personal information going forward.

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