

PHYSICIAN, REVEAL THYSELF

Advancements in healthcare are hampered by the industry's concerns about collected data, says Brunswick's RICHARD MEREDITH

The data collected by doctors, hospitals and healthcare companies can help save lives, heal the sick, improve medical research and lower costs. Yet, like a patient who refuses to take his medicine, the industry is allowing concerns over public perceptions of data privacy to keep that potential bottled up, sitting on a shelf.

The hesitancy is as understandable as it is unhealthy. A deep public mistrust hinders data collection in general, partly as a result of high-profile breaches. In the recent case of leading US healthcare insurer Anthem, hackers were able to gain access to as many as 80 million records that included Social Security numbers, addresses and other personal information. Anthem operates several major insurance brands, including Empire Blue Cross and Blue Shield, and though the company says medical information was not accessed in the break-in, public trust was undoubtedly damaged.

Businesses are naturally reluctant to invite negative attention from the public, media, politicians and regulators by discussing their data policies. Yet the size and usefulness of healthcare data of all types is growing exponentially. Also, Brunswick research (see Page 10) shows investors want to see a clear data strategy covering both security and monetization.

BY 2011, IN THE US ALONE, healthcare data had reached 150 exabytes, according to the journal *Health Information Science and Systems*. To put that in perspective, a gigabyte can hold 1,000 400-page books;

each exabyte holds more than a billion gigabytes. "After decades as a technological laggard, medicine has entered its data age," says Nanette Byrnes in a 2014 article in the *MIT Technology Review*. "The sum of this information could transform medicine."

In addition to helping create better treatments, data is also making inroads in aftercare. "Doctors can now know 12 months in advance, with an accuracy rate of 98 percent, which of their patients may fail to take their medicine," Byrnes says.

Organizations also want to boost the effectiveness of preventative care by predicting health issues. "One in four cancer cases is diagnosed in an accident and emergency department," says Eve Roodhouse, Director of the UK's newly established care.data program. Such patients have poorer survival rates than those diagnosed in routine checkups. Collected patient information makes it possible to ensure that patients in all regions have access to such checkups. "Better data on the outcomes of these patients and understanding geographic variations in patterns of diagnosis is key to improving life expectancy," she says.

The care.data project expedites improvements in care and research by collecting data from various sources, including hospitals and general practitioners. However the initial roll-out of the UK program in 2014 was suspended for six months on concerns the public had not been properly informed of their options regarding the use of their data. Some doctors fear patients will be less forthcoming about



the details of their lives if they think that data may be shared elsewhere. Public opposition remains strong, and care.data has redoubled efforts to establish trust.

"It is important to set out the benefits as well as the risks and how they are mitigated, so that members of the public can make informed choices," Roodhouse says. In Scotland, the sharing of National Health Service data on diabetes patients has resulted in a 40 percent drop in amputation rates, according to a recent article in *The Economist*. NHS officials hope to reduce hospital costs associated with diabetes that currently total £300 million (\$450 million) a year.

THE HEALTHCARE SECTOR as a whole, however, has been slow to realize



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Co-Founder and CEO, Big Health**

the potential of sharing patient data, hampering progress, says Peter Hames, Co-Founder and CEO of behavioral medicine company Big Health. “Much of the old healthcare system is highly risk averse,” says Hames. However products aimed at individual consumers are

helping patients see the value in sharing their health data, he says. “This goes way beyond analytics. This data will allow us to create interventions of a kind that have never before been possible, where the digital is the drug.”

Tech companies are creating products using Apple’s HealthKit, which allows developers to access user health data collected by Apple’s Health program. Others are asking for volunteers to share medical histories, circumventing privacy regulations while establishing databases and baselines against which they can test products. This could spark a broader trend, with the public becoming more accustomed to sharing their medical records. “In essence it will create a market for data,” says Hames.

All parties are increasing pressure on companies to tell their data story as part of the overall corporate narrative, says Martin Richards, Professor Emeritus at Cambridge and Chair of the Nuffield Council on Bioethics, a UK advisory panel. “There is a real need for healthcare organizations to communicate who is using data, for what purposes and how it is stored,” Richards says. “They should be clear about the benefits of data use, both in terms of treatment and broader service efficiency, and also the risks of both using and not using data.”

In the US, the industry faces restrictive healthcare privacy laws that limit the use of patient data in research. Companies that aggregate data from physicians’ offices need explicit authorization from each of those offices every time a piece of data is used in a study. The commercial healthcare industry can help loosen those restrictions by addressing the public concerns that are at the heart of those laws.

“My personal view is that the positive aspects of data use in healthcare clearly outweigh privacy considerations,” says Ulrike Deetjen, a specialist in healthcare data collection at the Oxford Internet Institute. Individuals value privacy, she says, but they also see how their data is valuable in medical research and improving efficiency. “They are often quite happy for their data to be used.”

The application of data analytics is changing healthcare, and the world, for the better. The use of data remains controversial in the minds of the public and politicians, but investors want to see the industry take the bull by the horns and patients are eager for innovations that will make their lives easier.

Companies stand to gain, and to benefit society as a whole, by being more open about the information they have while making the strongest argument they can for the methods and benefits of its use.

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