

FEATURE

THE NEW DIGITAL HEALTHCARE ECOSYSTEM: LOOKING OUTSIDE TO HARNESS FROM WITHIN

BY MICHELE CLEARY

Navigating the digital landscape of patient-provided data—from wearables, to at-home DNA tests, to clinical data registries—grows evermore complex. In this month's feature article, experts in the field provide different perspectives on how best to leverage digital health technologies and to apply the overabundance of data to real-world research.

New Digital Ecosystem, New Opportunities

We welcome this new decade facing a new digital era in healthcare. Ever-growing mountains of digital data produced from new technologies—ranging from wearables and monitors to at-home genomic tests and newly digitalized clinical data—are providing an unprecedented opportunity to improve our understanding of disease onset and progression.

These data can help refine diagnostic methods and improve treatment selection, can accelerate research and development processes by acting as external control arms or by supporting label expansion, and can facilitate targeted patient engagement programs. As Katie Szyman, Corporate Vice President of Critical Care at Edwards Lifesciences heralded, "The data/digital revolution creates a great opportunity for transformation in healthcare."

This new digital era allows us unprecedented insight into the patient experience, making these data resources especially important for value assessment. As our definition of value expands to incorporate different stakeholder perspectives, insight into not just clinical responses, but also patient criteria (eg, social determinants of health, treatment compliance behavior) become critical.

Christopher Boone, Vice President of Global Medical Epidemiology and Big Data Analytics at Pfizer, highlighted the ability of these new digital data resources to provide greater insight into the value discussion, stating, "I think the pharmaceutical industry is now in a position where it has to align its definition of value with payers, providers, and patients. That wasn't necessarily the case before, because we were essentially the purveyors of much of the data and information that was used to make those clinical decisions."

This transition requires health economic and outcomes research (HEOR) professionals to upscale their expertise. Boone continued, "In order to start to facilitate and have these discussions with these stakeholders around value and for value-based agreements, I think we are going to have to be as equally skilled in our understanding and our analysis of these data types as our stakeholders."

But where does the HEOR community stand in its journey into this new digital era?

Slow to Adapt?

Despite the enormous benefits that could be delivered by healthcare's new digital world, many within the HEOR community have been slow to adapt.

This hesitancy may stem from the industry's highly regulated environment. Boone noted that he saw this hesitation in the pharmaceutical industry even 2 years ago. But in Boone's view, "It's not for lack of confidence, it's not from a lack of resources. I think it's just the byproduct of an industry that's very risk-averse."

Biotechnology and other industries that originated in information technology (IT) may help provide critical guidance. Boone cited these types of companies to play a leading role in this transformation, specifically those firms that take many of their guiding principles from legacy Silicon Valley companies. Boone noted this >

IT foundation accelerated many functions inherent to the life science industry. He stated, “These essentially digitally made companies are accelerating the R&D [research and development] process with much more robust commercialization activities and functions. They are accelerating digitization of the industry.”

Collaboration with these types of “digitally made” companies will change the nature of collaboration for many players. “I think this is an opportunity for big pharma to really learn from others rather than others learn from us,” Boone added.

Tackling Infrastructure Demands

Given their origin in IT, these “digitally made” biotech companies tend to be comfortable tackling the enormous processing and analytic infrastructure demands necessary to sustain these digital data resources. Such familiarity with infrastructure challenges is critical, especially given the astonishing pace with which this digital ecosystem is growing.

“The data/digital revolution creates a great opportunity for transformation in healthcare.”

Katie Szyman, Edwards Lifesciences

Currently, the volume of health data collected by providers, insurers, government, researchers, and industry is estimated to double annually.¹ Elean Bonfiglioli, Senior Director of Health Industry (Europe, Middle East, Africa) at Microsoft, highlighted the expansion of digital clinical data alone, stating, “Fifteen to twenty years ago, 20% of health records were digitized. Today, more than 90% are.”

Infrastructure needs mirror this explosive growth in digital data. A recent University of Michigan study estimated that the number of transistors required to process genomic and neuroimaging data increased by 2 orders of magnitude between 2014 and 2016.² And given the growing need for fast and secure data transfer, bandwidth demands are mushrooming, as well.

Many contributors highlighted the need for sound collaborative relationships as the key to tackling many of these issues. Yet despite the astounding growth in infrastructure needs, none of these contributors expressed concern that infrastructure was a primary impediment to developing a sustainable digital ecosystem for the HEOR community. Instead, they focused on more pressing concerns, such as building interdisciplinary teams of experts to improve

operations and to develop public trust in critical data-sharing operations.

The Importance of Interdisciplinary Collaboration

Navigating this new digital ecosystem will require a broader range of expertise in areas such as machine learning, artificial intelligence, and other data science fields. “A big problem that the industry is facing is that the people making decisions are people without training,” said Julian Isla, CEO of Foundation29 and Professional Development Manager at Microsoft Services (Spain). “Pilots fly planes, but it would be crazy for pilots to make the planes. For that, you need engineers.”

Boone advocated strongly for interdisciplinary teams, saying, “It shouldn’t just be folks that are trained as economists. These teams are going to look much more like traditional data science teams, which have skill sets reflective of many different disciplines working in one group.”

Collaboration with data science experts may also resolve many of the interoperability challenges inherent within these new digital ecosystems, given their dependence on shared data. To operate effectively, these systems require methods that standardize data management, manipulation, data collection, and platforms that provide secure data exchange between stakeholders. Such standards are especially important, given the huge volume of unstructured healthcare data.

“The challenge with digitization is ensuring patients trust the system.”

Julian Isla, Microsoft and Foundation29

The creation of effective interoperability standards for digital healthcare data is progressing. As an example, the Fast Healthcare Interoperability Resources (FHIR), developed by Health Level Seven International (HL7), promotes interoperability across the increasingly digitalized health ecosystem.³ While interoperability challenges persist, interdisciplinary collaboration will help to resolve these operational challenges.

Building Trust in Digital Data Sharing

The need for healthy collaboration extends beyond information technology. Given the extensive sharing of sensitive data, public views must also be considered. Bogi Eliason, Associated Partner at Copenhagen Institute for Future Studies, reflected on how central the patient becomes in the digital future, stating, “We are beginning to work more with patient-reported outcomes. The next level is to link that with different

wearables.” He sees this as leading to real patient engagement, where patients are involved as experts in their care. In other words, “The patient as part of the ecosystem.”

New digital technologies are empowering patients with the ability to organize, control, and share their healthcare information. Today, consumers desire more health information, and they want it within their control.

Are Patients Comfortable With Data Sharing?

Historically, parties making health decisions—providers and the payers—maintained control of health data. Today ownership of these data is shifting, leading some to ask, “who actually owns the data?” More precisely, who controls where these data are sent and with whom they may be shared? Who should control the data?

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Christopher Boone, Pfizer

Boone cited his experience leading the Health Data Consortium, a public-private partnership aimed at democratizing health data, where the consensus has been that the patient owns his/her data.

Yet data sharing requires that patients trust how their data will be used. As Isla stated, “The challenge with digitization is ensuring patients trust the system. This trust may come from gleaning tangible and applicable information so that the benefits of sharing data are clearly demonstrated.”

Transparency is critical. Disclosing how these data will be used and by whom may reinforce acceptance. When patients have more understanding of what is being done with data, they may be more willing to support digital data sharing.

Public acceptance of “big healthcare data” may also be strengthened by their understanding of how their data will be used. For this, Rebecca Miksad, Senior Medical Director at Flatiron Health, proposed a shared vision between patients and digital data teams. She cited the altruism of cancer patients who express a desire to help others through their data. She stated that these patients support sharing their data to help “save someone else from having to go through what they went through...that shared vision is what enables mutual trust.”

Again, collaborative relationships with patient advocacy groups, providers, or other groups already within patients’ zone of trust, may help build public confidence in the value and security of data sharing.

Missteps could significantly impede future data sharing, greatly hindering HEOR goals. Again, strong partnerships may help avoid such potential missteps.

Looking Ahead

This massive transformation of our health data landscape shows no signs of slowing. The new iteration of the 21st Century Cures Act proposed this past November would further expand the digital environment by supporting the development of new digital technologies and developing better methods for collecting and using real-world evidence to transform healthcare.⁴

This rich resource could transform patient care, but the HEOR community must evolve.

Rather than citing specific products or systems to ease the transition into this new digital healthcare ecosystem, contributors continually pointed to the importance of collaboration—partnerships across healthcare with input from IT and the public. By learning from the experiences of other industries, by engaging a broad mix of collaborators, and by building trust across all stakeholders—especially patients—we can leverage this rich data resource to truly transform patient care. •

References

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Additional information

This article was based on the first two plenary sessions at ISPOR Europe 2019. Presentations from this conference can be found at www.ispor.org/conferences.

About the Author

Michele Cleary is a HEOR researcher and scientific writer with more than 15 years of experience in the healthcare field.