Digital Patient Engagement Data: Are you already falling behind?

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Patients’ appetite to use digital platforms to help manage their health is growing fast. The massive uptick in their use during the pandemic has cemented the case for their value to patients, HCPs, and pharma alike.

But this is new territory and the possibilities are not yet being exploited at scale. The healthcare paradigm too often still considers the job done post diagnosis and when a treatment plan has been created. This should just be the beginning. Pharma, used to thinking about the point up to product launch, is still working out how to make the most of these new possibilities.

The result is that patients are still often left to fend for themselves in the absence of guidance. Confused, a quarter don’t take their first dose. Gathering the right data to understand unmet needs, learn about adherence patterns and tweak and improve adherence, will be to everyone’s benefit.

The potential for pharma to fill in blanks in patient journeys and to understand the context in which treatments are prescribed and adhered to (or not) is vast, says Lee Shapiro, Managing Partner, 7wire Ventures.

Such data have value across pharma functions from R&D to marketing and patient support, says Shapiro. “Clearly there is a need for a greater degree of RWE to help pharma better understand what is occurring with regard to use of their product and how patients are managing conditions beyond the pill. You can look across populations using various medications and share those insights with providers. Everyone benefits, all folks in the chain of custody.”

Imagine, for example, if digital data around opioid prescriptions had been widely available, suggests Shapiro. “Would we have tolerated such an addiction epidemic for as long?

Stuck in learning mode
The scope for learning is enormous, adds Shapiro. “A former chairman of one of the world’s largest pharma companies, recently said that everyday 300 million people are taking one or more of their products and they know nothing about those people. Once the product goes into the supply chain they only know it has been prescribed and sold.

“The data chain is also laden with confusing signals. The physician might prescribe one drug but the patient gets another branded or generic drug. Perhaps the patient is also taking a concurrent medicine that will react and pharma does not know.”

Extracting insights and learning the right lessons from these insights, in particular, is an area where pharma is still developing its competencies, says Omri Shor, co-founder and CEO of Medisafe. “They are early on the curve still.”

Acting on data from digital patient apps is still the exception and all too often pharma still generates patient insights from conventional market research, offering only limited and often skewed patient cohorts. “These are unique subsets of patients who are willing to collaborate, often because of an incentive,” says Shor. “This is not the real world.”

“Data and visibility into patient challenges will really help companies grow much faster.”

An example of a deeper insight that digital patient data has revealed relates to a periodically injectable drug that physicians recommended patients take on the weekend. “They recommend this because you will be at home and relaxed but for me as the patient the weekend is the most
hectic time, family time, and the last thing I want to do is think about my illness and condition,” says Shor. “So patients recommended to inject it at this time will in fact do it a few days later. The outcome is that you have lost two or three lost doses a year and you are not getting the same efficacy.

“We have found that Tuesday and Friday are the best days to recommend them to inject and now they are working to communicate that to physicians. That data that would never be discovered from market research.”

**A competitive edge**
Developing such insights via digital patient data will rapidly become a source of important competitive advantage, says Shor. A pharma brand that uncovers previously unseen key access challenges and then acts upon them, will likely grow faster than those who remain ignorant of such patient challenges, says Shor. “Data and visibility into patient challenges will really help companies grow much faster.”

While strategically pharma understands the broad applicability of digital patient data, many companies have not gone much further than pilot mode and are not backing it with senior internal sponsorship, says Shor. “The question is: Is there already a VP or director assigned to the strategy, or are we still in a learning mode?”

“Digital tools were a clear patient priority, she says. “It was the number one thing patients were asking for.

A few, however, are well underway on this journey and learning fast.

Patients’ use of digital platforms to help manage and take greater control of their health is growing at Otsuka, which offers digital support for patients with rare diseases as well as central nervous system health.

**What patients want**
There is a clear desire from patients for one-stop shop visibility into their own data across their disease state and for a range of functions and assistance, including insights into monthly lab results, safety information, specialty pharmacy information, payments, risk mitigation strategies and even wellness information, says Desiree Priestley, Senior Director, Patient Support, Otsuka.

Digital tools were a clear patient priority, she says. “It was the number one thing patients were asking for. We co-created the solutions with patients and carers to make sure it was delivering on what they needed.”

Key to ensuring digital patient data gets generated is developing apps that patients will actually want to use in the first place. This requires agile development, says Priestley. “We’ve gone through a couple of iterations with caregivers and patients. It’s a test-and-learn approach.”

Improvements so far have included updates to make sign-ons simpler, to improve cross-platform integration, as well as improvements to risk management and lab work functionality. The results have been well received, says Priestley. “It’s moving when you hear patients talk about the options it gives them.”

How Otsuka acts on the data is an evolving process, says Priestley. “We give HCPs and patients complete visibility but we don’t have that ourselves.”

Otsuka instead works with a data aggregator to pull together insights into areas such as utilisation statistics, time spent in certain areas of the application, satisfaction rates and so on, much akin to how website data metrics are assessed.

Future scope for improvement includes integrating co-pay and claims data to help build longitudinal patient journeys. Another key to creating long-term value from the data is tokenising it so that each data set has an
identifier to enable greater synthesis between complementary sources of data and so improve omnichannel capabilities.

**A strategic approach**

Such successes need to be scalable to realise the full potential and this requires pharma to take a strategic approach, says Shapiro. “This needs to be a platform decision. Don’t think product by product or brand by brand. You need to be thinking holistically as an organisation and having capability to build this for an enterprise.”

Internally developing digital companions piecemeal just won’t work, he adds. “Pharma doesn’t have the internal muscle to do this. Every product in the portfolio should be emerging from a common set of procedures and rules to capture data on all those products. It should be for everything, all products, long established and new.”

Senior leaders will have to sponsor such efforts to avoid “a balkanised set of efforts done in different ways,” says Shapiro.

As well as senior sponsorship, a patient–first approach to design is essential, adds Shapiro. “Start with the consumer in mind. Too often this becomes the province of the CTO or CIO. They think in terms of a system approach and what works best for their operations at corporate level but the design needs to be from the consumer up, not the other way round.”

Starting with the consumer also means addressing the issue of trust and data use, Shapiro adds. “Consumers will willingly share data with permission if they feel there is an opportunity to improve their health.”

**Operating in the dark**

The importance of technology designed to help care for patients remotely as well as empowering them to do more to manage their own care, will only grow in the face of growing demand on healthcare services that are also dealing with the ‘great resignation’ of health professionals, says Shapiro.

“We need to provide more access rapidly and affordably to more people and the use of tools like remote monitoring, telehealth and the ability of individuals to manage conditions on their own or with guidance has allowed us all to be better stewards of our health.”

There would be huge value in providing a digital companion for every medicine, says Shapiro. “I believe that should happen every time a prescription is written for a patient to help them manage their medical condition. Right now we have this archaic way of instructing individuals about their health – printing forms and attaching it to a [prescription] bag. They have to rip open the bag and typically throw away the paper.

“We need to give people the ability to help stay on track with taking their meds, be adherent and address common questions, yet we’re still in the Dark Ages operating in a room without a light switch right now.”