5 Key Factors to Successfully Leveraging Person-Generated Health Data

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To improve outcomes and care delivery, personalized medicine is the ideal from the point of view of patients and clinicians alike. Digital health tools are helping to make personalized medicine a reality, and wearable devices play a critical role. These instruments capture person-generated health data (PGHD). Put simply, PGHD is health-related data created, recorded, or gathered by individuals, or by their family members and other caregivers. Personal information may be reported directly and continuously at home or on the go using a variety of digital tools, including wearable devices or phones, apps, and electronic surveys. This data is often viewed as the missing puzzle piece needed to provide a holistic, 360-degree view of the patients' lived experience outside the clinic walls.

PGHD represents a big shift from traditional real-world evidence studies, which have been centered around data recorded during visits to a healthcare facility or generated by insurance claims. With PGHD, the question isn't how well the average person is doing, but what outcomes an individual patient can expect when using a particular product or trying a new treatment strategy.

"I am a strong believer that person-generated health data is a better way to measure health in everyday life for patients," commented Bray Patrick-Lake, senior director of strategic partnerships at Evidation. "It's critical that we measure health outside the clinic because that's where patients live their lives versus the minute amount of the time they spend in clinical visits or hospital stays."

Evidation has been at the forefront of efforts that use digital tools to better understand patients' experience with health and disease, and to foster behavior that improves quality of life and health outcomes.

One example of a real-world application of Evidation's approach is a new collaboration with the American College of Cardiology (ACC) to jointly develop a patient engagement program aimed at improving heart health. During a March 10 webinar hosted by Evidation, John Rumsfeld, Ph.D., M.D., Chief Innovation Officer and Chief Science and Quality Officer at the ACC, commented that given the choice, we would never design a health system like the one we have now.

While revamping structures that have been in place for several decades is a tall order, the rapid adoption of virtual healthcare during the COVID-19 pandemic shows the possibilities for change.

That is not to say that there haven't been challenges along the way. Evidation's experts have identified five core necessities to enhance the adoption of PGHD.

Validate data, build clinicians' trust

Data reported directly by patients about their own well-being promises to be a treasure trove for filling in the information gaps between patient visits, while also having the potential to nudge behavior toward better outcomes by providing actionable insights that help get patients on the right treatments faster. The COVID-19 pandemic helped speed the adoption of telehealth, patient-reported outcomes (PROs), and remotely submitted data exponentially.

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“But if the data reported by patients is deemed to be unreliable, the reputation of patient-centered healthcare is hurt,” commented Mikki Nasch, Co-Founder and VP at Evidation. One of Evidation’s key missions is to ensure that data provided is not only accurate but also provides actionable insights and context for both the patient and the clinician.

The collaboration with the ACC is an example of the importance Evidation places on building the evidence base, incorporating clinical pathways that have been developed by experts through a professional society. Whether working with a medical society or a pharmaceutical company, Evidation takes an evidence-driven approach to everything it does in healthcare -- virtual or otherwise -- and translates this experience to deeper engagement with patients.

Using Evidation’s Achievement platform, which includes an app that engages more than four million individuals, the collaboration will initially design an experience for patients living with heart failure.

Manage data overload

Explosive growth in the adoption of wearables by consumers has raised concerns about medical false alarms or false positives. During the Evidation webinar, Rumsfeld noted that cardiologists are interested in person-generated health data, but there is a “lot of rightful concern” that they will get too much raw data and wind up being deluged with information. “Technology solutions can be designed beautifully for consumers, but they will fail if they are not also crafted for the clinicians, and algorithms can help,” he said.

“We still will have to be careful about not having data or information overload,” Rumsfeld said. “But the key is designing with clinicians in mind.”

Evidation’s approach is to use algorithms aligned with clinical guidelines that reduce the noise in datasets and to offer separate sets of summaries with measurements that matter to the patient as well as measurements that matter most to the clinician. Reports include data on a variety of measures, including weight, activity level, patient-reported outcomes on quality of life, and how patients are feeling, thus delivering actionable insights to both patient and clinician.

Support reimbursement

The need for adequate evidence to support reimbursement from insurance companies can present challenges. Yet the ability to identify those who will be future utilizers of resources and address issues proactively promises considerable savings in the future.

“Evidation believes it’s important to show an improvement in quality of life and a reduction in medical burden as well as cost, which in turn will spur better reimbursement,” Nasch said. Payers will want to see data from real-world studies of their own populations, and this may be achieved through real-world studies within their networks, she suggested.

In recent years, the reimbursement picture has been improving. New Medicare payment codes were developed for remote physiological monitoring (RPM), covering the collection of data in a home setting using medical devices. At the end of 2020, the U.S. Centers for Medicare and Medicaid Services stated that the COVID-19 pandemic had “unleashed an explosion in telehealth innovation” and that it was moving to make many of these changes permanent, with dozens of new virtual services available to Medicare beneficiaries.

Evidation is joining with other leading industry and advocacy organizations, making policy recommendations to ensure patient-centered approaches are front and center in value-based healthcare models.

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Protect patient privacy

In the U.S., data in patients' electronic records and claims data are protected through the Health Insurance Portability and Accountability Act (HIPAA), while the Genetic Information Nondiscrimination Act (GINA) prohibits the use of genetic information for discrimination in employment and health insurance.

But legal protections are not yet consistent on a national or international level when it comes to the behavioral health data collected in consumer devices. Evidation believes it is imperative to take a rigorous and transparent approach to ensure individuals are protected. The company never obtains broad consent from users to funnel personal data to third party applications and vendors. "At Evidation, we take the most stringent approach to permissioning data, which is trust-based. When people use the Achievement app, we don't ever use that data without going back to them and getting permission on a per use basis," Patrick-Lake said.

Ensure accessibility, digital equality

A shift toward using devices to monitor patients in the home raises questions about how to ensure people who are less tech-savvy and/or don't own devices don't get left behind. However, according to market research by Deloitte, in 2020, in both developed and developing countries more than 90% of people had cell phones and more than 80% had smartphones.

The ACC's Rumsfeld suggested that some of the best medical grade devices are relatively inexpensive and could be prescribed. Virtual approaches could actually expand healthcare access to individuals in communities that are underserved and have less ability to take time off from work for doctors' appointments or to get to a major hospital for care. Rumsfeld also pointed out that in some developing nations, drone technology is being used to deliver treatments to community centers in otherwise out-of-reach areas.

"They are leveraging technologies but not counting on individuals to have that technology necessarily," Rumsfeld said. "I think we can learn from that."

Additionally, there are promising advancements in ensuring digital equality, with the Biden Administration's commitment to bolstering broadband internet infrastructure to ensure that all Americans have access; and the FCC's Covid-19 Telehealth program, which will support broadband for health-based teleconferencing.

With national efforts like these, as well as the adoption of the five strategies above, we move ever closer to successfully leveraging person-generated health data and using digital tools to better understand patients' experience with health and disease, and fostering behavior that improves quality of life and health outcomes.