



# EXPLORING THE POTENTIAL OF **PATIENT-GENERATED** HEALTH DATA

**Innovative digital health technologies have made it dramatically easier to capture, use, and share patient-generated health data (PGHD). It's now possible to gather PGHD using a variety of digital health tools—from online questionnaires and personal health records to mobile apps, wearables, and connected medical devices.**

**Whether monitoring chronic illnesses or tracking fitness levels, consumers have become much more interested in capturing their own health data—and engaging more in their own wellness. This unprecedented collection of information can potentially provide clinicians with a more holistic view of patients' lives outside the clinical setting. It's also a treasure trove for health researchers—particularly since cloud computing, big data analytics, and other technological innovations have made it feasible to gather and analyze massive information sets in new and innovative ways.**

**Yet PGHD is not yet widely used for clinical care and research in part because of several barriers across the health ecosystem. Indeed, we're just beginning to understand how to achieve the full potential of PGHD use so we can overcome the challenges and seize the opportunities.**

# PUTTING PGHD UNDER THE MICROSCOPE

## **The U.S. Department of Health and Human Services – Office of the National Coordinator for Health Information Technology (ONC) is helping to explore the potential of PGHD.**

After identifying PGHD use as an important issue for advancing patient engagement, care delivery, and research, ONC initiated a series of activities to gain more information about its value and approaches to implementing it. Building on prior policy work, ONC began collaborating with Accenture Federal Services in 2015. The goal: to dig deep into what’s possible, what’s standing in the way, and options for overcoming those barriers.

Accenture conducted research and industry outreach to better understand how organizations are currently using PGHD, as well as the challenges impeding its successful utilization. The project team explored seven different policy topic areas relevant to PGHD, developed extensive environmental scans and literature reviews, met with more than 60 industry subject-matter experts, and coordinated two pilot demonstrations to test the findings in a real-world clinical setting. The research helped to identify best practices, gaps, and opportunities for progress in the capture, use, and sharing of PGHD.

The resulting white paper, *Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024*, suggests actions that patients and caregivers, clinicians, researchers, policymakers, developers and standards bodies, and payers and employers can take to collaborate and advance the use of PGHD. Ultimately, it lays the groundwork for creating a well-defined yet flexible policy framework to help in unleashing PGHD’s potential for all healthcare stakeholders.

Recognizing the need for guidance and best practices for incorporating PGHD into care delivery and research, the team also created a Practical Guide that offers suggested practices and questions to consider when implementing PGHD capture and use.

With this project, ONC and Accenture leveraged techniques perhaps most associated with software development, embracing an agile approach to researching and informing potential policy options. The team focused on iterating on ideas—getting quick feedback and addressing it rapidly rather than using a longer “waterfall” approach for review cycles. That approach included engaging with stakeholder groups early in the process, with ONC releasing a draft white paper and inviting public comment for four months. Working with the two pilot demonstrations, the team was able to test and refine assumptions from the draft white paper in real-world settings for inclusion in the final white paper.

# DISSECTING THE CHALLENGES

**The team set out to understand the key barriers to greater use of PGHD. The white paper points to a number of challenges around the capture, use, and sharing of PGHD. Among them:**

**Patients** may not understand the advantages of capturing and sharing their data with clinicians and researchers. Not all patients have access to technologies that capture, use, and share PGHD. Patients may have varying levels of health and technology literacy. What's more, their concerns about data privacy and security may prevent them from participating.

**Healthcare systems, clinical practices, and research institutions** may not have the technical infrastructure, functional workflows, workforce capacity, and training to support PGHD intake. They may be unsure how to generate actionable insights from the voluminous data. And, they may worry about how PGHD could add to their workloads and disrupt their workflows.

**All healthcare stakeholders** may face data- and device-related concerns. For example, consumers may abandon their devices, and researchers may be challenged to verify the accuracy and validity of PGHD from wellness devices. For clinicians, PGHD use may introduce new liability concerns. What if inaccurate PGHD is used in clinical decisions? What if a physician chooses not to review or act on PGHD received? Meanwhile, the devices introduce new security risks, and they produce data which need to be standardized against other formats before it can be helpful.

## ENABLING CHANGE

**While the team focused on articulating the challenges, they also worked to devise potential solutions. To advance the use of PGHD, the white paper proposes a series of “enabling actions” for everyone in the healthcare ecosystem.**



# WHAT ARE PGHD?

## Patient-Generated Health Data

Health-related data created and recorded by or from patients outside of the clinical setting to help address a health concern

# STUDYING POLICY AREAS

**At the heart of the project is the team's examination of seven PGHD policy topic areas:**

- 1 PATIENT RECRUITMENT FOR RESEARCH STUDIES AND TRIALS**  
How PGHD can be used to identify patients for research studies and trials and to connect patients directly with researchers
- 2 COLLECTION AND VALIDATION OF DATA AND TOOLS**  
Exploring existing and emerging tools for capturing PGHD, as well as the types of PGHD that clinicians and researchers collect and how they validate the data and tools
- 3 DATA DONATION**  
Studying patient expectations for sharing data with clinicians and researchers, including existing and emerging methods for “donating” data for research
- 4 ABILITY TO COMBINE PGHD WITH MEDICAL RECORD DATA IN MULTIPLE WAYS**  
Examining opportunities to combine PGHD with clinical data for analysis and patient care, including methods for combining data from multiple sources and standards and technology needed to support this practice
- 5 DATA INTEROPERABILITY**  
Researching benefits of and barriers to increased interoperability between the health IT system and devices used to capture PGHD
- 6 BIG DATA ANALYSIS**  
Assessing the technical and cultural challenges to using PGHD in big data analysis, including patient concerns about data privacy, storing and transmitting potentially large volumes of data, and providing clinically useful presentations of PGHD
- 7 REGULATORY OVERVIEW**  
Discussing the current federal statutory and regulatory paradigms relevant to PGHD, including the tools and technologies used to capture PGHD

# PILOTING PGHD IN REAL-WORLD SETTINGS

**An important goal of the project was to test the initial findings and recommendations in the real world for inclusion in the final white paper. Accenture engaged with two digital health technology organizations and their care delivery partners to see how the concepts would perform with actual clinicians and patients:**

**TapCloud and its partner, AMITA Health**, worked together to collect PGHD across several medical areas—including orthopedic surgery, behavioral health, and bariatric surgery. The pilot engaged patients in identifying and collecting their symptoms, pain ratings, activity levels, and self-assessments of how they felt compared to the previous day. TapCloud and AMITA Health then incorporated that data into a dashboard that clinical staff reviewed. The pilot demonstration showed how a single technology platform enables effective use of PGHD for a variety of medical conditions, clinical settings, clinician roles, and patient populations. Results included a readmission rate drop from a baseline of 5.1 percent to 2 percent for the Orthopedic surgery TapCloud platform users.

**Validic and its partners** conducted a pilot demonstration focused on diabetes care. The project addressed two core goals: to see how PGHD collected from a variety of glucometers could inform diabetes care and to assess the infrastructure and workflows needed to implement and scale these kinds of initiatives.

Historically, many diabetes patients have had to keep written logs of their at-home test results. It's virtually impossible for a physician to review and glean meaningful insights from binders of paper-based data. In the pilot, patients using traditional glucometers were able to simply snap a smart-phone picture of their readings. The Validic technology converted that information into structured data that was then fed into existing workflows and systems. With convenient access to the data, clinicians were able to more readily spot trends and advise patients on ways to improve their levels. The pilot demonstration included ethnography to identify areas of improvement to further patient and provider engagement. Key learnings included the need to proactively engage and sustain patients in ways that could be scalable and sustainable by the healthcare provider.

# FLEXIBLE ROADMAP FOR NEW FRONTIERS

Accenture's work with ONC affirmed the potential value of PGHD in care delivery and health research and provides flexible and actionable recommendations for how healthcare stakeholders can collaborate to realize that value together.

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