



# Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024

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## **PRACTICAL GUIDE**

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## Introduction

The Office of the National Coordinator for Health Information Technology (ONC) defines patient-generated health data (PGHD) as health-related data created and recorded by or from patients outside of the clinical setting to help address a health concern.<sup>1</sup> Patient health information, such as activity level, vital signs, symptoms, and medication effects, is predominantly collected by members of the care team in a clinical setting, as reported directly to them by patients and their caregivers, supported in some cases by data from in-home medical devices. However, the frequency, amount, and types of PGHD available are increasing due in part to the recent proliferation of consumer health technologies, such as mobile applications (apps), wearable devices, and online questionnaires. These advances can enable patients and their caregivers to independently and seamlessly capture and share their health data electronically with clinicians and researchers from any location to achieve a more holistic health picture.

ONC contracted with Accenture to research and provide analysis on the capture, use, and sharing (hereafter, often referred to more simply as “use”) of PGHD in care delivery and research settings through 2024. The project is divided into two components:



The first component consisted of a white paper entitled *[Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data \(PGHD\) in Care Delivery and Research through 2024](#)*. ONC published a white paper in January 2018 that describes the current state of PGHD, envisions the future of PGHD, and discusses the challenges, opportunities, and enabling actions to bring the use of PGHD to the health and research ecosystem.



The second component consisted of two pilot demonstrations that tested the concepts in the PGHD draft white paper in real-world clinical care and research settings. Lessons learned informed this document for other organizations to leverage. Further information about the pilot demonstrations can be found in the appendix of the final white paper.

## Purpose of Practical Guide

This document is a practical guide that offers suggested practices and questions to consider for the implementation of the capture, use, and sharing of PGHD in clinical and research settings. The intended audience of this document includes patients and caregivers, clinicians, researchers, health information technology (IT) professionals, and health care administrators. Depending on the size of the clinical or research organization (e.g., large health system, solo practitioner), considerations or requirements that influence how the guide is applied at that organization may differ.

## Practical Guide

Based on best practices identified from the pilot demonstrations, the following four sections and the corresponding considerations can assist organizations in conducting thoughtful discussions and performing actions that will provide the foundation for successful implementation of the use of PGHD:



Strategic Planning



Implementing



Defining Requirements



Monitoring and Adapting

<sup>1</sup> “Patient-Generated Health Data | Policy Researchers & Implementers,” *HealthIT.gov*, September 30, 2015, <https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data>.







## Strategic Planning

The use of PGHD offers the potential to empower patients to actively participate in their health care and better manage their health outcomes. For clinicians, the use of PGHD may provide a holistic view of patients’ changing health status over time. For researchers, the use of PGHD may provide access to a more expansive and diverse dataset. Before starting to capture, use, or share PGHD, an organization should consider the potential value of such activities to its stakeholders.

### Defining objectives

To develop a common understanding of the opportunities presented by using PGHD in the larger health care and research ecosystem and to determine how those opportunities relate to the organization’s priorities and objectives. Documenting and communicating these opportunities will help create strategies for increasing PGHD use in a way that corresponds with broader organizational strategies. This common understanding will help align everyone involved – from front desk staff to care team members to executives – and is vital to the implementation of the use of PGHD. Possible strategic objectives for adoption and use of PGHD could include the following:

| Objective  | Description   |
|--|---|
|  <p><b>Improving patient health outcomes</b></p>           | <p>Tracking progress against agreed-upon health goals between in-person clinical visits provides the opportunity for real-time monitoring of day-to-day changes in health status. This process can be used to help patients and caregivers engage in their care planning and provide clinicians and researchers with more detailed information on the patient’s health, helping clinicians to make better-informed decisions to improve outcomes.</p>                         |
|  <p><b>Enhancing the patient experience</b></p>           | <p>PGHD can be used to enhance the patient experience by involving patients and caregivers in shared decision-making and actively engaging them in their care planning and management, which may ultimately improve patient satisfaction and help organizations to retain patients. Receiving and reviewing PGHD before a clinical encounter can help the care team to prioritize and focus discussions during patient encounters.</p>  |
|  <p><b>Alerting care teams for early intervention</b></p> | <p>Effective monitoring of PGHD and sharing the right information at the right time can help identify high-risk patients and opportunities for early intervention with the potential to avoid costly care encounters, such as emergency room visits, hospitalizations, or surgical interventions.</p>   |
|  <p><b>Take advantage of new reimbursement models</b></p> | <p>New reimbursement models, such as <a href="#">alternative payment models</a> (APMs), are shifting from payment for individual services to payment for episodes of care or overall management of a patient’s health. These new payment models provide clinicians incentives to manage patient care outside of office visits by monitoring their health status in ways that reduce the need for face-to-face encounters and patient use of emergency and inpatient care.</p> |

## Assessing the business case

In support of the organization's objectives for implementing the use of PGHD, it is important to develop a business case. This activity should define the metrics for measuring success and determine the scope and scale to which the organization will use PGHD. The business case should articulate how using the use of PGHD adds value to the organization's strategic objectives (e.g., improved clinical outcomes, increased efficiency of care delivery, improved patient experience) and how investments in technology required to support PGHD use can be leveraged across the organization. It should also consider how PGHD use could impact existing revenue models for the organization, including reimbursements received for care that uses PGHD. Additionally, the business case should assess the budget available and determine the costs to implement the use of PHGD as well as any cost savings it may produce. Potential expenses to consider and plan for include:

- Any devices that might be provided to patients including repair or replacement if devices fail
- New software services including services for PGHD collection and transport
- Data analysis platforms and services; costs to build new analytic models
- Technical support, including labor for operations and program support
- Training needs for clinicians, care team members, patients, and caregivers
- Labor for additional clinical services

The organization can address possible disruptions, mitigate patient safety risk, and reduce financial impact by running pilot demonstrations with a small sample of patients to validate new operational models and workflows before increasing the scale. Additionally, these potential expenses can be balanced by benefits achieved from the program objectives. Potential savings may arise from:

- Reducing complications, hospitalizations, and readmissions due to early intervention using remotely monitored PGHD
- Customizing individual patient care with real time PGHD
- Achieving better health outcomes by engaging patients using PGHD in their care planning
- Increasing the organizations ability to manage quality metrics with PGHD
- Creating staff efficiencies with workflow design that incorporate PGHD use

### Questions to Consider

- What are the organization's objectives for the use of PGHD?
- Where and how will the use of PGHD add value for the patient in the delivery of care or execution of research?
- Why is the use of PGHD critical for success?
- How does the capture, use, or sharing of PGHD solve a problem or refine a service in a new or novel way?
- How will the organization finance the implementation of PGHD-related technologies and associated costs?

## Securing executive sponsorship and recruiting support at all levels

All staff involved should understand and support the objectives for the PGHD use. A shift toward the use of PGHD can be disruptive in the short term, involving possible changes to processes, workflows, and roles. Change management is critical for overcoming these disruptions. A key executive sponsor should be identified to champion the use of PGHD and lead the organization through the changes; an executive sponsor with clinical, financial, operational and IT credibility is ideal. In larger organizations, key staff members from relevant departments (e.g., clinical, IT, administration) should be engaged in the planning and serve as advocates who can represent their perspectives and requirements. In smaller

organizations, representatives from leadership, the care team, and staff should be included in the planning and implementation process. Obtaining support from all parties will promote continued alignment during the implementation of the use of PGHD.



### Defining Requirements

Adoption and use of PGHD will likely involve new technologies or modification to existing systems. Technologies may be needed for one or more of the following processes: the capture of PGHD; transmission of PGHD; storage of PGHD; analysis, interpretation, and display of PGHD; alerts, reminders, and communications driven by PGHD review. Organizations should define requirements that will be needed for the processes to work effectively. Outlined below are some of the key considerations for evaluating information technology systems to implement the use of PGHD.

### Gathering requirements

The current state of the care delivery or research model, technical and integration requirements, and workflows should be documented at the outset of the implementation project. The organization should also determine how the use of PGHD in the future state will impact existing IT systems and whether it will require additional support systems. Gathering these requirements will help to identify necessary changes that result from establishing PGHD-enabled systems.

Integrating the PGHD with existing systems (e.g., an electronic health record [EHR]) will require careful analysis and planning, as there are implications for data storage, the legal medical record, and overall system architecture. The organization should determine where and how it will store the PGHD. The organization should consider whether to record all PGHD in the patient record or establish an intermediate storage area for PGHD, such as a staging data repository. Using this staging approach has the added advantage of enabling the data to be cleaned, normalized, and interpreted before being applied to patient care. Any PGHD that are needed to support patient care can be extracted from the repository and included in the legal medical record.

The system design will also need to provide technical solutions for sharing PGHD. These solutions are crucial to data interoperability because they ensure that all parties involved have access to the data when needed and in a form that can be understood by each user. When thinking about sharing PGHD, organizations will need to consider several factors, including the consistent structure, terminology, and meaning of the data points across systems and sources, privacy and security concerns, and the provenance of the data, which refers to tracing and recording the origins and exchange of the PGHD.

Some formative standards show promise in overcoming the challenges associated with collecting and sharing PGHD. Standards development organizations are producing and promoting technical standards to increase the exchange and integration of electronic health data, and industry standards associations are working to enable end-to-end interoperability of personal connected health devices and broader health IT systems. Organizations will need to work with their health IT systems product developer to engage in discussions on what standards are being used and how to ensure data interoperability is being achieved.

### Identifying patient-facing technologies

When selecting patient-facing technologies for the capture, use, and sharing of PGHD, the organization should keep in mind that the technologies may have different workflow, technical, and regulatory requirements based on the source of data. Examples of common PGHD sources include:



| PGHD Source                       | Source Description   | Examples   |
|-----------------------------------|--|--|
| <b>Registered Medical Devices</b> | <u>Medical instruments</u> intended for use in the diagnosis of disease, regulated by the Food and Drug Administration (FDA).  | Glucometers, digital blood pressure devices, heart rate monitors |
| <b>General Wellness Products</b>  | <u>Devices or apps</u> that have an intended use of maintaining or encouraging a general state of health or healthy activity. The FDA does not currently regulate these devices. | Activity or sleep trackers, wellness and health apps             |

Both medical devices and general wellness products can also enable the collection of patient-reported outcome (PRO) measurements, which can capture “the status of the patient’s health condition directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.”<sup>2</sup> An example of a standardized PRO instrument is the SF-36 Health Survey.

The needs and preferences of the patient should be at the forefront of the process of selecting technologies for PGHD capture. It is crucial to ensure that these technologies are or can be made available to the intended patient population. However, providing a device to all patients participating in a program using PGHD may be beyond the financial constraints of the organization. With that consideration in mind, some organizations choose to adopt a “bring your own device” (BYOD) policy. It is important to weigh what a BYOD approach means to integration and validity of the PGHD and resulting impacts to the workflow, study, or trial. For example, a BYOD approach may introduce a variety of device standards and operating systems that require varying technical capabilities and support.

Additionally, the organization should consider whether the technologies are accessible to and usable by the target patient population. For example, the PGHD collection technology may need to accommodate patients with cognitive or physical impairments and patients with limited English proficiency and technical understanding. Caregivers may support data collection on behalf of the patient, and selected technologies should meet the needs of caregivers as well.

Finally, the organization will need to assess data privacy and security implications when selecting patient-facing technologies. For example, the organization should understand how the device or app might use or share the patient’s data beyond the scope of sharing with the intended clinician or researcher. When patients begin using an application, they may be presented with an End User License Agreement (EULA) that grants permission to use the submitted PGHD to both the technology company and any provider who has contracted to support the patient. If this is the case with the selected device or app, the organization should help patients understand their rights and options during the consent process.

#### Questions to Consider

- What health IT systems or care delivery and research models within the organization will be impacted by using PGHD?
- What source(s) will be used to support the collection of PGHD?
- What steps are needed to ensure seamless integration of PGHD collected with other existing health IT systems?

<sup>2</sup> National Quality Forum, “NQF: Patient-Reported Outcomes,” accessed July 27, 2017, [https://www.qualityforum.org/Projects/nr/Patient-Reported\\_Outcomes/Patient-Reported\\_Outcomes.aspx](https://www.qualityforum.org/Projects/nr/Patient-Reported_Outcomes/Patient-Reported_Outcomes.aspx).



## Implementing

Implementing the use of PGHD may initially increase workloads and change workflows in the organization. The volume of PGHD, as well as the timing of when PGHD will be shared and reviewed, introduces new considerations for care teams or researchers. The activities outlined below can occur concurrently as the PGHD program implementation is ongoing.

### Training staff

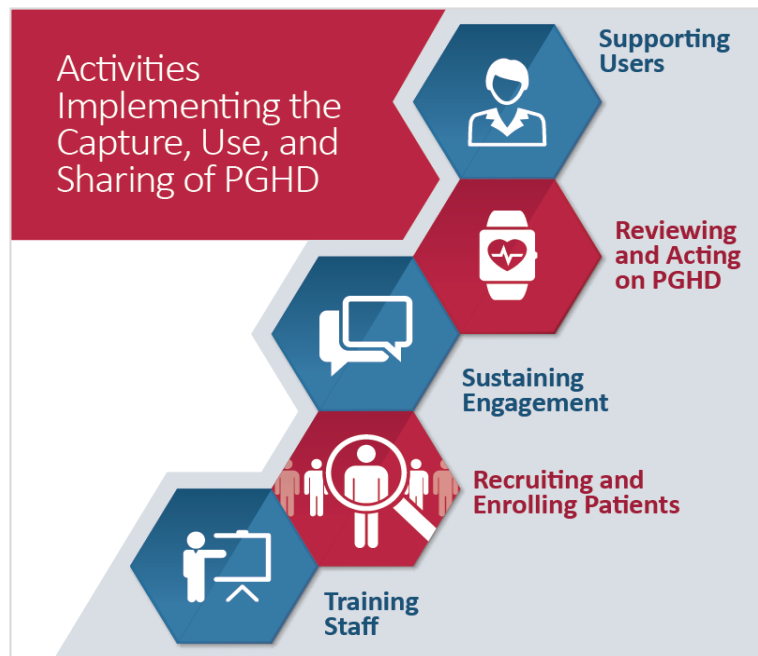
The optimal use of PGHD requires specific and explicit processes. The care and research staff must know how to use the selected technologies within the context of their clinical and research workflows. They should be comfortable using the technologies and able to provide the appropriate guidance to patients. All members of the care and research teams need to understand at a basic level how to use the selected technologies – both the clinical dashboard and any patient-facing apps and devices.

Before training the staff, the organizational workforce capabilities and needs should be reviewed to determine the necessary training requirements. There may be distinct roles in monitoring a panel of patients or using the PGHD for individual patient care, and these roles may require different types and levels of training. Nonetheless, training will increase the understanding of the data, so the staff can trust that the PGHD provided to them are valid and reliable for use in clinical decision-making or research studies and trials.

### Recruiting and enrolling patients

The organization should define the patient populations that will be the focus of implementation. Once those parameters have been defined, patient recruitment and enrollment can be conducted in-person, online, or through the use of registries that the organization may have already created. For example, an organization can recruit patients through conversations with their care team during an office visit. This technique may offer an added level of trust because a clinician whom the patient trusts is initiating the conversation and can answer any questions in person. However, this method may be time-consuming and limited in reach because it requires face-to-face conversations between a patient or caregiver and a care team member, which is limited by how often patients visit the clinic. Alternately, organizations may rely on marketing emails or messages sent via a patient portal to recruit and enroll patients. This method offers the benefit of reaching a greater number of patients, but it lacks the personal touch of in-person recruitment.

Once recruited, it is essential to set clear expectations with enrollees about the objectives of using PGHD and how it supports the patient's goals. The expectation-setting process should discuss how the PGHD will be used and responded to by the care team. In addition, patient consent and privacy expectations





should be addressed. If the data will be shared with another entity (e.g., a researcher), the privacy and consent forms should clearly communicate what data will be shared with whom and how other entities will use this information. The onboarding team should ensure that patients fully understand what they are consenting to, including who has access to their PGHD and how the data may be used, and confirm with the patient that they are willing to participate. In parallel, the onboarding team should actively seek input from patients about their experiences, challenges, and concerns. This information can aid in system improvement and help to proactively address patient concerns.

At the outset of implementing PGHD use, the organization should establish a process for patients withdrawing from the program at any point, as patients may decide that they no longer wish to participate. Planning for this event should include descriptions of what happens to the PGHD collected by the patient and other ways that the organization can provide care. It may be beneficial to future PGHD-related initiatives to inquire why the patient no longer wants to participate.

### **Sustaining engagement**

Positive feedback loops have been shown to be important in encouraging patients to continue to donate their PGHD. Possible feedback mechanisms include acknowledgment from the care team to the patient that they have reviewed the patient's PGHD and that the data were helpful to the care team, either for making a decision or starting a conversation with the patient or caregiver (e.g., "I noticed that your glucose levels are high before bed..."). Some technologies may also provide feedback loops in the form of reminders to capture or share PGHD (e.g., "It has been two days since your last glucose level was recorded.") and messages that provide context about the data ("Your glucose levels are within a normal range."). Patient engagement levels may vary over time and can be impacted by the objectives for PGHD collection. For example, if PGHD are collected for acute care, such as postoperatively, patients may stop capturing and sharing their PGHD once they have regained normal function. However, it is essential for staff to assess changes in the level of patient engagement to be able to continue refining workflows.

### **Reviewing and acting on PGHD collected**

All relevant organizational governance stakeholders, which could include clinicians, researchers, health IT staff, and administrators, should work together to establish clear processes for collecting PGHD and enforce policies and protocols for managing and storing PGHD. This group should also determine the workflow for how, when, and by whom the PGHD will be interpreted, displayed, and acted upon. Given the potential volume of data captured and shared by the patient whether requested or unsolicited by the care team, managing PGHD could be perceived as cumbersome to the care team. Here are some tips the organization can employ to support care teams:

- Provide tools that can simplify interpretation and analysis of the PGHD, such as customizable data dashboards that visualize data over time but also provide raw data points.
- Develop methods for identifying significant values or thresholds for individual patients or populations and for visually displaying the PGHD to help identify trends.
- Utilize clinician-facing dashboards that allow the care team to sort a panel of patients, which is useful for prioritizing patient interactions.
- Customize notification settings to push notifications to patients, caregivers, and the care team.

Once the PGHD are collected by clinicians, the data may become part of the patient medical record and processes for data privacy and security could apply. The organization should determine whether PGHD will be stored in the patient's medical record. Access to the data should be restricted to specified care

team members and audited regularly. Furthermore, some organizations might choose to store only the PGHD that are used to inform clinical decision-making for specified clinical situations or in support of particular programs.

### Supporting users

There are a wide range of issues that users, including patients and caregivers, clinicians, researchers, or care team members, will experience that could lead to a high level of frustration if not handled promptly and efficiently. Unfortunately, some of these challenges will be outside the realm of responsibility of the health system, e.g., problems with the operating system of the patient's smartphone. Nonetheless, processes for handling all issues need to be organized to avoid potential user issues, including:

- **Patients and Caregivers:** Inability to connect devices or upload data; device malfunctions; missing data points; lack of knowledge about clinical implications of data
- **Care Team Members:** Patient complaints about devices, apps, and uploads; issues with integration of PGHD with existing health IT systems

How each organization addresses these potential issues will be unique to the needs and programs of the organization. However, the importance of robust technical support and the time required to address the technical issues that can arise should not be underestimated. If not addressed promptly and properly, these issues may impact the work of clinical team members or research associates or the experience of the patient and may become a source of frustration and complaint. A support team and troubleshooting manuals should be assembled early on and made available when technical or analytical issues arise. It may be appropriate for the care team to know how to address basic patient concerns within the context of a clinical encounter. For more complicated issues, the IT team or individuals with specialized IT knowledge may need to become involved.

#### Questions to Consider

- Who is responsible for each step of the workflow? Who will have access to the PGHD?
- How will the PGHD be collected, validated and interpreted? How will the care team incorporate PGHD into the workflow? How will PGHD be used in care delivery or research?
- When and how will patients share their PGHD? When will the PGHD be reviewed? When will the PGHD be responded to, if at all?



### Monitoring and Adapting

With the abundance of data and new types of data entering into the patient's record, concerns about liability, privacy, and security arise. Standards of care for the use of PGHD are still forming, leaving clinicians with limited guidance to date on how to address these concerns. However, with the increased use of telehealth in patient care, practice guidelines are emerging, including some that may apply to PGHD use. It is prudent to establish specific processes to actively and regularly seek feedback from users to get the earliest insight into potential issues that need to be modified and addressed.

## Addressing clinician or researcher data-related liability concerns

Examples of possible liability concerns and corresponding mitigation strategies are discussed below:

| Liability Concern  | Liability Description   | Possible Mitigation Strategy  |
|--|---|---|
| <b>Accuracy of data</b>  | PGHD may be inaccurate because of user error or improperly calibrated or validated devices, resulting in hesitancy to use the data for decision-making.                   | <ul style="list-style-type: none"> <li>• Limit PGHD source variety available to the implementation.</li> <li>• Encourage the use of devices that support direct and automatic electronic capture.</li> <li>• Provide technical support and training for patients and caregivers.</li> </ul>   |
| <b>Concerns about increased clinician workload due to volume of PGHD</b>             | Given the potential volume of PGHD, reviewing and reacting to the data could be perceived as cumbersome to the clinician or researcher.                                   | <ul style="list-style-type: none"> <li>• Carefully design workflow and responsibilities to consider how to minimize negative impacts to care team members.</li> <li>• Utilize analytics and dashboards to help identify relevant data, quickly and easily.</li> </ul>   |
| <b>Integrating PGHD with the medical record and relevance to clinical management</b> | Unsolicited PGHD without interpretation or specified use case may introduce confusion to the clinical decision-making process.  | <ul style="list-style-type: none"> <li>• Only accept data from patients formally enrolled.</li> <li>• Only accept agreed-upon data types.</li> <li>• Only store information that is relevant to clinical decision-making in the medical record.</li> </ul>  |
| <b>Responsibilities for acting based on PGHD</b>                                     | Clinicians and researchers may be deemed responsible for monitoring all data points that come in at any time of day and the implications of using or missing data points. | <ul style="list-style-type: none"> <li>• Establish and agree upon ‘terms and conditions’ that define responsibilities when abnormal values are received.</li> <li>• Set explicit, patient-consented expectations for how and when care team members will review PGHD</li> <li>• Use organization protocols to design an automated system to help identify abnormal values or trends and provide alerts to care team members.</li> </ul> |
| <b>Privacy and security of PGHD</b>  | Due to the large volume and varying types of data entering the system, additional privacy and security concerns may arise.  | <ul style="list-style-type: none"> <li>• Store and transmit data with the same rigor as other PHI.</li> <li>• Communicate to the patient who will have access to the data, and how/if it will be shared.</li> </ul>   |

## Understanding and adhering to the relevant privacy and security laws and regulations

Before implementing the use of PGHD, organizations should conduct a scan of relevant laws and regulations to ensure compliance. While the use of electronically-captured PGHD may be relatively new, and therefore not yet highly regulated, it may be covered by established laws and regulations for patient health data more generally. For example, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule aims “to assure that individuals’ health information is properly protected while allowing the flow of health information needed to provide and promote high-quality health care and to protect the public’s health and well-being.”<sup>3</sup>

### Questions to Consider

What state, federal, or organizational laws and regulations are relevant to the implementation of the capture, use, and sharing of PGHD or impact the target patient population?

## Additional Resources

Below is a sample of additional resources that can be utilized to further research information around the implementation of the capture, use, and sharing of PGHD.

- Office of the National Coordinator for Health Information Technology, Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024, White Paper (2018). Available at [https://www.healthit.gov/sites/default/files/onc\\_pghd\\_final\\_white\\_paper.pdf](https://www.healthit.gov/sites/default/files/onc_pghd_final_white_paper.pdf)
- Cohen, Deborah J, Sara R Keller, Gillian R Hayes, David A Dorr, Joan S Ash, and Dean F Sittig. “Integrating Patient-Generated Health Data Into Clinical Care Settings or Clinical Decision-Making: Lessons Learned From Project HealthDesign.” JMIR Human Factors 3, no. 2 (October 19, 2016). doi:10.2196/humanfactors.5919.
- Office for Civil Rights, Resources for Mobile Health Apps Developers, (June 2017). Available at <https://www.hhs.gov/hipaa/for-professionals/special-topics/developer-portal/index.html>
- McGraw, Deven, Robert Belfort, Helen Pfister, and Susan Ingargiola. “Going Digital with Patients: Managing Potential Liability Risks of Patient-Generated Electronic Health Information,” December 18, 2013. <http://www.iopm.org/perspective/narratives/2013/12/18/going-digital-with-patients-managing-potential-liability-risks-of-patient-generated-electronic-health-information/>.
- Office of the National Coordinator for Health Information Technology Consumer eHealth, Patient-Generated Health Data Webpage, (2017). Available at <https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data>
- Office of the National Coordinator for Health Information Technology, Patient Engagement Playbook, “Chapter 4: Integrate Patient-Generated Health Data.” Available at <https://www.healthit.gov/playbook/pe/chapter-4/>
- “The cHealth Blog.” The cHealth Blog. Accessed June 27, 2017. <https://chealthblog.connectedhealth.org/>.

<sup>3</sup> Office for Civil Rights, “Summary of the HIPAA Privacy Rule | HHS.gov,” July 26, 2013, <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>.