Implementation Guide for Patient Generated Health Information in Healthcare Organizations

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INTRODUCTION

What is PGHI?

PGHI refers to patient generated health information. Traditionally, health information is generated mainly by healthcare professionals. It is reported by a clinician in the form of examination findings, care assessments and plans, lab results, etc. PGHI is different from this traditional health information in two ways: 1) patients, not healthcare professionals, are responsible for capturing and recording this data, and 2) patients have the ability to decide how they will share this data with their healthcare provider and with others. PGHI includes health-related patient information including:

- health history
- symptoms
- biometric data
- lifestyle choices (NeHC, 2013b)

Patient generated health data, or PGHD, is another term that is often used interchangeably with PGHI. For the purpose of this guidebook, they can be considered synonymous. PGHI is created, gathered, recorded, or inferred by or from patients or their designees to help address a health concern (NeHC, 2013b). PGHI is not new, but the ways of collecting it are continually adapting. Historically, a provider may have asked a patient to monitor their health condition using an at-home blood pressure monitor. They may have been asked to record their daily blood pressure readings in a notebook that they were encouraged to bring to their next appointment. These readings, generated and recorded by the patient, are an example of PGHI. However, as we progress further into the information age, PGHI is taking on a new form. Today, PGHI may originate in wellness and health-related applications for mobile devices, home health devices (e.g. a blood pressure cuff) or other self-tracking tools (Conn, 2014). Some PGHI may even be sent wirelessly and automatically to the provider,

without a patient ever interacting with it (NeHC, 2013b). This guidebook focuses itself on modern PGHI technologies that utilize information technology to empower the patient.

Traditional PGHI Example:

Patient records daily blood pressure readings in a paper notebook. Patient brings notebook to their next physician appointment, where the provider can review the readings, offer feedback, and alter the patient's care plan accordingly.

Information Age PGHI Example:

Patient records daily blood pressure readings in a health-related mobile application offered via their provider. The data is transmitted to the healthcare facility where it is monitored, either automatically or manually. If the readings are too high or too low, the patient will be contacted by the facility.

Why is PGHI Important?

PGHI is intended to offer cost savings, quality improvements, increased care coordination, and stronger patient engagement (NeHC, 2013a). PGHI is meant to supplement existing clinical data, allowing healthcare professionals to gather a more comprehensive picture of the patient's ongoing health. It can help close gaps in information and offer providers a way to monitor a patient's health status in between medical visits (HealthIT, 2012; NeHC, 2013b). PGHI allows a way to gather information on a continual basis, rather than at a single point in time. Some PGHI can provide the foundation for real-time care management programs tailored to a single patient and their condition (HealthIT, 2012; HIMSS, 2014a). It can also aid in the management of chronic and episodic conditions, such as cardiac dysrhythmias, congestive heart failure, and diabetes (HIMSS, 2014a). By providing relevant information about a patient's condition and health status, PGHI technologies can drive healthy behaviors and increase the success of preventive health and wellness programs (HealthIT, 2012; HIMSS, 2014a). Other benefits include a reduction in errors and improved patient

safety (e.g. by increasing the accuracy of an allergy list) (HealthIT, 2012) and a stronger patient-provider relationship, with opportunities for shared decision-making (HIMSS, 2014a).

PGHI can be used to obtain a more accurate scope of a patient's health (HIMSS, 2014a). Although the research on this topic has been relatively limited due to recent and rapid advances in PGHI technologies, studies have indicated that PGHI is of quality and is useful in clinical settings. For example, it has been found that a higher amount of valid patient health history data can be obtained when it is self-entered by the patient via a patient portal than when it is obtained by a provider (Murray, 2013). A similar study that focused on the emergency room setting found that the quality of health data generated by the patient met or surpassed the quality and completeness of provider-generated data (Porter et al., 2010).

By collecting data and information continuously over a period of time, PGHI can assist in knowledge discovery (Huba & Zhang, 2012). If a patient enters blood pressure data into a system on a continual basis, this data can be analyzed, allowing trends to be identified. This provides efficiencies for the provider and offers convenience for the patient. If the patient record is the main location for PGHI, clinical variations can be reduced, potentially dangerous information gaps can be avoided, and the coordination of care can occur more smoothly (HIMSS, 2014a). Three patient-reported measurement systems--Group Health, Karolinska, and Dartmouth-Hitchcok--use PGHI to produce various findings, such as patient-specific summary reports, clinical population health status reports to assess and improve care, health outcomes reports to share with the public, and data sets for retrospective and future research (The Dartmouth Institute for Health Policy and Clinical Practice, 2012).

The benefits of PGHI are of particular importance in rural and underserved areas. Many rural residents experience difficulties in making frequent visits to their healthcare provider, perhaps due to the absence of reliable or affordable transportation (AHRQ,

2010). For these individuals, PGHI technologies offer a feasible way to play a key role in their health, and providers are able to monitor their patients' conditions from afar. A recent study of patients with diabetes found that those who used technology to help manage their condition were likely to have better control over their blood glucose, blood pressure, and lipids than those who did not use technology (Sakar et al., 2011). In communities that are plagued by high rates of these chronic health conditions, PGHI can play a key role in the management, and perhaps prevention, of these conditions.

Case Study: Veterans Health Administration

The Veterans Health Administration (VHA) has been utilizing PGHI to engage patients in collaborative care. Through various sources, including their MyHealtheVet patient portal, mobile applications, and wearable devices, the VHA collects an abundance of PGHI from patients. In 2003, the VHA initiated Care Coordination/Home Telehealth (CCHT), a home care program that is designed to provide care management for over 100,000 patients with diabetes, congestive heart failure, and other chronic conditions that are commonly seen in older veterans. The program uses biometric monitors and messaging devices to record, share, and monitor large amounts of PGHI. Care coordinators, such as nurses or social workers, review the data. Over time, this program has been able to identify harmful health-related behaviors, recommend interventions, and uncover knowledge gaps. Over the course of four years, the program yielded a 25 percent decrease in bed days of care, a 19 percent reduction in hospital admissions, and extremely high levels of patient satisfaction (NeHC, 2013a).

More Case Studies:

Appendix A is a compilation of additional case studies. Each example outlines a PGHI initiative and its outcome.

IMPLEMENTATION GUIDELINES

Planning and Development

Implementing and leveraging PGHI in healthcare organizations requires individuals to change their behavior, which can be an extremely difficult and daunting undertaking. Change is required of patients, providers, and support staff; thus, there are various stakeholder groups that need to be identified, considered, and involved during the implementation process. The following activities should be conducted during the planning stages and involve multiple stakeholder groups:

- *Ensure leadership offers strong support for PGHI initiatives and implementation.* Leaders should understand that increasing the use of PGHI can strengthen patient involvement in communication, decision-making, and care management.
- *Assign responsibility and decision-making authority.* The individual or group who is accountable for the program's success should be identified. A steering committee may be developed.
- *Create a technical roadmap.* The roadmap should describe how information systems will receive and manage the data coming from new data streams.
- *Plan a realistic, comprehensive budget.* The budget should include both initial costs (e.g. software upgrades) and ongoing costs (e.g. software maintenance, training)
- *Involve providers and support staff.* The planning group should understand existing workflows and ask what type of PGHI would be useful and how they would make use of the information.
- *Engage the patient.* It is wise to allow patients to participate in the designing and testing process to encourage the success of the project and to promote partnership.

- *Plan ahead for education and training needs.* Ongoing technical assistance will be necessary for all users.
- *Identify success criteria.* It is important to build in measurement from the beginning of the project for evaluation purposes. (NeHC, 2013b)

Rural providers and those serving underserved populations will want to take extra care during the planning and development stage, as most HIT initiatives are expensive and, if not carefully implemented, will yield minimal benefits. For rural facilities operating on limited budgets, choosing the wrong approach could be catastrophic (Turman, 2013). There should be an increased emphasis on researching characteristics of the surrounding community. Special health characteristics and needs of the population must be considered (Mudd-Martin et al., 2014; Turman, 2013). Please see "Case Study: Genetic Screening in the United Arab Emirates" for an example of a health-related program that found success due to the implementers' knowledge of local culture, smart planning, and clever strategy.

In addition, because most PGHI technologies require patients to electronically document and submit data via the Internet, aspects such as access to Broadband services, digital and eHealth literacy, etc. must be understood to ensure the community can support such a project (NeHC, 2013b). If an organization is struggling and does not know where to start, it might be advantageous for planners to consult surveys and data sets conducted by the government to get a general idea of the patient population and move forward using the information gathered from that research.

Case Study: Genetic Screening in the United Arab Emirates

There is a high frequency of consanguinity (blood relationship) among tribes found throughout the United Arab Emirates (UAE). Because of this, there is a high risk of inherited genetic disease. Although the genetic screening is easy and inexpensive, the local, conservative population saw it as an unwelcome intrusion. The UAE Genetic

Diseases Association launched a project to help change this. They started by recruiting twenty-one student ambassadors at each of the nation's several universities. These individuals, who were selected because they were educated in the sciences and were able and willing to educate others, were taught the basics of genetic screening. They were encouraged to spread the word and explain the testing to their college peers. Surveys conducted showed a rise in awareness of genetic screening among college students from 6 percent in 2004 to nearly 80 percent in 2006. As the university population became aware of the importance of genetic screening, they brought up the conversation with their extended families. They, in turn, spread the word within their own communities. Due to the demand from the local community, universities and healthcare organizations developed informational pamphlets for individuals to help educate their peers. This program greatly helped win widespread support for genetic screening. Today, thousands of UAE couples agree to premarital genetic screening every year (Laurance et al., 2014). This experience is an example of success that can be found when project planners couple carefully researched population characteristics (both cultural and health related) with strategic planning.

Organizational Needs Assessment: Your organization should perform a needs assessment in the early stages to evaluate what your facility is already doing, if anything, to collect PGHI. An assessment of current patient engagement techniques, e.g. a patient portal, should be conducted to understand where collecting PGHI or a different form of PGHI would be valuable. For example, your organization might already have a patient portal in place where patients can jot down information in the form of a journal or diary. To make this patient input more usable, changes could be made to collect structured data elements rather than free text.

A comprehensive needs assessment will involve a combination of methods that allow the organization to "see the full picture." It is vital that multiple approaches are utilized to form a valid and reliable assessment. The needs of the organization, as well as the surrounding community, should be accounted for (University of Florida Center for Arts

in Medicine, 2012). Included in this document is a Needs Assessment template, specifically developed for a PGHI-project (Appendix B). Please note how this tool considers technical, cultural, and organizational factors. A provider can use this template to guide their own organizational needs assessment activity.

Determining PGHI Needs: It will need to be determined what data is most important and will be of the most value for the patient, the provider, and the overall care process. NeHC (2013b) reports the following as a priority list of PGHI as determined to be most valuable to both patients and providers:

Safety-Related:

- Medication list (including medication, adherence, reactions/symptom reporting, medication reconciliation, medication updates and non-adherence)
- Allergy list (medication allergies, environmental and nutrition allergies, procedure intolerances)

Treatment Plan-Related:

- Information requested by the provider (e.g. blood pressure readings)
- Patient health and care goals (e.g. a nutrition plan)
- Patient reported outcomes (e.g. current pain level)
- Recent changes that could prompt a modification of the treatment plan:
    - Biometric data (e.g. blood pressure, blood sugar, exercise, heart rate, imaging, nutrition, smoking status, temperature, weight)
    - Chronic disease care and outcomes data
    - Behavioral health related outcomes information (e.g. depression)
    - Advance directives
    - Social determinants (e.g. availability of transportation)

    - Cultural preferences (e.g. religious fasting that could affect recommendations for treatment)
    - Functional limitations; services and supports necessary for independent living (e.g. use of a wheelchair)

A New Patient Concern:

- Unexpected or worsening symptoms (e.g. the patient reports experiencing heart palpitations after starting a new medication)
- Information the patient feels important to document and share (e.g. the patient has started a new exercise regime)

Care Process:

- High impact on care process
    - Advance directives
    - Key demographic information
    - Preferred facilities & locations (e.g. pharmacy, clinic)
    - Insurance information
- Care team information (support roles and contact information)
- Communication preferences (communication channel preference, permission for sharing information, cultural and language preferences)

NeHC (2013b) recognizes that the value of PGHI is very contextual and will vary for different specialties and patient populations. Before implementing any kind of PGHI project, providers and patients should work together to determine what kind of PGHI is of most value. What kind of PGHI would best serve the patient in a given care situation, considering both health outcomes and convenience? What type best fits with the care process, both within the provider's workflow and the patient's ability? Determine the most important PGHI and start there. Be sure to consult the technology department during this process, ensuring that the technology and resources needed to support the collection of this PGHI is available (please see "Technology Considerations" section below for more details). HealthIT (2012) suggests taking an implementation approach that utilizes small pilot programs. Start small, focusing on a

single type of PGHI, such as symptom tracking, that is the most valuable to the organization. Implement, monitor, make changes as needed, and build on successes.

Policies & Procedures

Establishing and maintaining transparency regarding PGHI is of utmost importance. When sharing personal information such as PGHI, many patients exhibit concerns relating to trust and confidence. These concerns are generally grouped into four categories:

1. Communication expectations (e.g. "Did my doctor see the information I sent them? When will they reply?")
2. Information security expectations (e.g. "Is my information being transmitted securely?")
3. Information sharing expectations (e.g. "Is the information shared with my insurer? Will it be used for clinical research?")
4. Doctor-patient relationship expectations (e.g. "How will the information I share be used to help me?") (NeHC, 2013b)

Patient expectations must be expertly managed. Patients should be instructed to use a different form of communication if they are exhibiting urgent symptoms or have time-sensitive concerns. Concerns regarding liability can be greatly reduced or even eliminated when a mutually agreed upon set of policies and procedures is clearly outlined and available (Hall, 2014). Questions regarding collection, sharing, and access must be addressed and answered. Will family caregivers be able to enter data about a patient? Will parents be able to review their children's PGHI? What are the secondary uses of the data? In the past, these uncertainties have surrounded personal health records and patient portals and are no less important regarding PGHI (Wager, Lee, & Glaser, 2009). NeHC (2013a) advises to offer the patient a way to opt out of providing sensitive data and the ability to block having their PGHI used for research purposes.

Any information or data that is maintained or incorporated into a patient's health record becomes a part of the legal health record. Thus, any patient health record is subject to all federal and state regulations regarding privacy, security, maintenance, use, and disclosure (AHIMA, 2015). As with all other forms of healthcare data, any PGHI entered into the patient record must have the characteristics of quality data, including accuracy, currency, timeliness, consistency, and completeness. All HIPAA requirements must be met, and all interfaces and data streams must be secured. Information sharing must be conducted in a secure manner, utilizing encryption and password protection where possible to comply with standard requirements. Vendor-based solutions can help with this, but training staff to comply with safety requirements is an utmost priority. When applicable, patients should also be asked to recognize a HIPAA privacy rule compliance statement (Gephart & Effken, 2013).

An information governance program and committee can help support PGHI quality initiatives and ensure the information is being collected, used, and managed in a safe way. A strategic governance framework and plan should be outlined in the PGHI planning stages. Needs and concerns of providers and patients should be addressed during the creation of this framework. IT leadership and HIT vendors should be included to ensure the technology meets both clinician and consumer needs as well as quality standards from a technical and legal standpoint (AHIMA, 2015).

Technology Considerations

Providers need to be able to do the following four activities with PGHI: receive, review, respond, and record (Hall, 2014). As such, PGHI needs to be collected in a way that is readable by both humans and machines. Information systems must be able to properly capture and store both low and high volume PGHI over a period of time. The transmission of data must be secure, and encryption options may be necessary

(Deering, 2013). The way these needs are met greatly depends on the organization's specific selections regarding PGHI, such as what device or software is to be utilized.

Interoperability: Integration and interoperability is absolutely critical. Using structured data elements that make use of existing health IT standards is highly recommended. Munro (2014a) offers an interview with Anna McCollister-Slipp, a woman with Type 1 diabetes, reported using four prescription medical devices--including an insulin pump and a continuous glucose monitor--as well as other, non-prescription devices--including a Bluetooth blood pressure monitor and various mobile applications--to help manage her condition. However, it is nearly impossible to combine the data from these devices to understand trends and patterns because they all use different data streams, data standards, and do not communicate with each other. This negatively affects her ability to manage her health condition.

Standards in data terminologies, analytics, and communication protocols are crucial for the effective, interoperable use of PGHI (Watzlaf, 2013; NeHC, 2013a). Initial standards must exist to support and guide the implementation of PGHI initiatives, and room for these standards to evolve must be present to allow for innovation (Deering, 2013). Common health IT standards and terminologies should be leveraged where possible--e.g. LOINC for lab results, RxNorm for medication terminologies--however, it is likely that, due to the demands and needs of the various stakeholders involved (patients, providers, EHR vendors, application developers, etc.) new standards will have to be developed (Shapiro et al., 2012). As healthcare recommendations, standards, and policies are constantly evolving, flexibility should be built into the new technology to allow for rapid response to change (NeHC, 2013a).

It is likely that the PGHI technology will integrate with the organization's EHR. Integrating outside data sources into the EHR is difficult because there are no industry standards for this activity, and EHRs are often designed to be a proprietary feature (The Dartmouth Institute for Health Policy and Clinical Practice, 2012). This can have a

significant impact on both project time and cost: The Dartmouth Institute for Health Policy and Clinical Practice (2012) reports a budget of up to $50,000 may be necessary for these development concerns.

Data Provenance: One of the largest concerns facing PGHI is in regards to data provenance, or the process of tracing and recording the source of the data as it enters the system and moves across databases. The ability to capture and record contextual and source information ensures PGHI is useful, as these details impact the provider's understanding of the information and enhances their trust in the data (NeHC, 2013b). This is a policy-related issue as much as it is a technical one, as standards must still be developed. The following provenance considerations are crucial:

- Data Source
  - Organization
  - Provider
  - Data entry staff
  - Device details
- Level of documentation
  - Entire document (e.g. full record has a single source listed)
  - Section (e.g. medication section lists its own source)
  - Individual data element (e.g. a source is listed for each individual medication)
- Updates when importing/exporting
  - List original creator as source
  - List receiving organization as source (Office of the National Coordinator for Health Information Technology, 2013)

Currently, many organizations mark provenance at the document level only. This is problematic as it results in insufficient granularity and creates issues regarding data integrity. There is currently no dominant provenance model or standard within healthcare, although the HL7 Data Provenance project is currently developing an

implementation guide that can help address these issues (Office of the National Coordinator for Health Information Technology, 2013).

IT Infrastructure: One of the main technology considerations is the infrastructure necessary to implement PGHI. This includes ensuring that the infrastructure can support not only the initial installation, but also its maintenance (Wager et al., 2009). Any PGHI initiatives should build upon the facility's existing health IT infrastructure. There is no one-size-fits-all solution for implementing PGHI. The IT department, along with technology vendors, need to work closely with PGHI project leaders to ensure the best fit for the organization.

Hardware and Devices: There is a wide breadth of hardware and devices that can be used to support PGHI. Types of hardware/devices include:

- Standalone, multipurpose computing form (e.g. smartphones, desktop or laptop computers, tablets)
- Transcutaneous (e.g. a skin patch)
- Wearable form (e.g. wristbands, belt clips)
- Hybrid form (e.g. smartwatches) (HIMSS, 2014a; Wood, Bennett, & Basch, 2014)

Many of these devices contain biosensors, which are analytical devices that provide information regarding physiological or chemical processes (HIMSS, 2014a). Depending on the form, data entry may be either active--meaning a patient manually enters the data, perhaps by typing in their blood pressure reading into an application on their iPad--or passive--meaning data is automatically collected without the patient manually entering it.

Which Type of Device Should You Choose?:

With so many types of devices available, selecting the best one may be difficult. The answer is different for every facility, patient population, and type of PGHI. Work with patients and providers to determine what types of devices would provide the most value to both parties. Also, ensure that the community and/or region can meet the minimum technology requirements needed for the device (e.g. widespread access to Broadband Internet).

Who Pays?

Budgets are tight everywhere, but someone has to pay for the devices. Should it be the organization? The patient? Some facilities report significant overhead regarding purchasing PGHI devices and managing inventory that adds substantial cost to the programs and greatly affects return-on-investment (Kvedar, 2014). Some agree that a BYOD (bring your own device) approach that utilizes software applications on a patient's existing standalone device is preferential (Davis, 2013; Kvedar, 2014). This, of course, presents new concerns regarding privacy and security. If going down this route, it is crucial to ensure that the facility's policies include BYOD security. It is also important to consider the characteristics of the population. Many individuals in underserved areas cannot afford to purchase a computer or a device (Connolly & Crosby, 2014), which would likely make taking a BYOD approach very difficult.

Software and Mobile Applications: Many PGHI initiatives involve mobile applications and software frameworks. Developments in this area are rapidly occurring and include well known names from both the technology and healthcare fields. In mid-2014, Apple, in partnership with Epic Systems and the Mayo Clinic, announced HealthKit. HealthKit is a software framework that is included in Apple's latest mobile operating system (iOS 8). The framework allows a way to collect, maintain, and present health information in mobile applications that have been designed to communicate with it. Many of these applications are often associated with wearable

sensors for collecting health or fitness data. These applications may be built by Apple or by a third-party developer. By partnering with Epic and Mayo, Apple offers the idea that the data collected via sensors and applications that communicate with HealthKit can be uploaded into EHRs like the Epic MyChart. The data from MyChart could, at some point, be available on a patient's Apple iPhone (Munro, 2014b). Similar offerings have been announced by Google Fit, Samsung S Health, and WebMD's Healthy Target (HIMSSb, 2014).

Most of these technologies are very new, and not all are created equally. A good PGHI technology will drive interoperability, streamline communication, and mesh well with the health ecosystem (HIMSS, 2014b). Several projects are in development or have been launched recently to help providers sort and select the tools and technologies that are best for them. One of these resources is AppScript by IMS Health. This software-as-a-service solution sorts and assesses the 40,000+ mobile healthcare applications that are currently available for the iOS and Android Platforms. Each application is ranked on functionality, peer and patient reviews, certifications, and their potential to better patient outcomes and minimize the cost of care.

Vendors vs. In-house Development:

One decision an organization must make is if the technology is going to be developed in-house or make use of an existing vendor solution. Will your organization use an existing application or one of the thousands already developed? An organization might choose in-house development when resources are abundant and when the existing products on the market do not adequately meet their needs. Although developing a new technology in-house can offer a significant competitive advantage, the time and cost involved may be very high (Wager et al., 2009).

Interface design: Interface design is significant to the success of PGHI initiatives. Interfaces should be friendly, fun, and engaging for the user (Wager et al., 2009). As patients experience innovation and improvements in non-health related technologies and websites, their expectations for health technologies are subsequently raised (NeHC, 2013b). Attention to the user interface to ensure it supports the patient and promotes patient adoption is crucial. Using consistent terms that the patient can understand as well as displaying information in a way that adheres to universal design principles makes navigating through the technology easier for the patient (Gephart & Effken, 2013). It is expected that patients are more likely to use and get more value out of a technology that can easily be integrated with other technologies and systems. The interface design should support this integration. It is advisable for organizations to conduct user evaluations, asking for their input on interface options, before an option is selected and has gone live.

Understanding Population Characteristics is Crucial for Successful Interface Design:

Traditionally, computer applications have posed an accessibility barrier for illiterate or semi-illiterate users. The heavy use of text--from navigation menus to website content--presents difficulties for those who are unable to read fluently (Medhi, Sagar, & Toyama, 2005). However, technology applications today can employ multi-media techniques to engage patients. Graphics, animation, video, and audio can engage some users in a way that text cannot (Huenerfauth, 2002). Concentrated interaction with the surrounding community is needed to comprehend characteristics affecting the success of the project. An understanding of needs, traits, and real responses to test interfaces should be sought. In populations with low literacy rates, it is not surprising that designs that utilize little to no text are strongly preferred over text-based interfaces (Medhi et al., 2005).

Where to Start?

Although the type of PGHI that is to be collected will greatly narrow down the list of choices, there are still several decisions to be made regarding exactly what type of technology to use. If the goal is to have PGHI interact with the EHR, it is advisable to consult with the EHR vendor and listen to their offerings and recommendations for implementing PGHI technologies. Vendors offering patient portal and personal health records are likely watching PGHI developments closely and may already offer PGHI solutions. Keep in mind that PGHI technologies are still very new with many still "in the works."

Operational Considerations

It is important to ensure that adequate resources are dedicated to both implementing and supporting the PGHI initiative, including the technology and its users. IT staff must be able to provide assistance to users and be able to maintain and update the technology. If the existing IT department is unable to accommodate the new technology, some organizations may choose to budget for hiring an new employee who can devote a significant portion of their time toward this support role (The Dartmouth Institute for Health Policy and Clinical Practice, 2012). Although it is ideal, smaller facilities or those with limited budgets may not be able to offer local, in-house support. In a case such as this, a facility may choose to partner with a neighboring organization to share support staff or partner with a local technology firm that can provide support assistance (Wager et al., 2009).

Data volume is a PGHI-related concern that needs to be addressed as it relates to both technical and personnel spectrums. Can the IT system support the increased influx of data that will be streaming in? Cloud-based data and data management services can help reduce architectural barriers (NeHC, 2013b). Are staff members able to handle the abundance of data? With the increased data flow, how will these individuals take on the task of reviewing all of the PGHI? Technologies that offer automated or semi-

automated analysis, reporting, and notification based on incoming data are important to the successful use of PGHI (NeHC, 2013b). An example of this is a built-in alert that is triggered when a monitoring device records a critical value.

For the provider and other healthcare staff, reviewing and managing the information should be seamless and consistent with existing workflows (NeHC, 2013a). If it is too much of a hassle, they are likely to look for a way to avoid using it. Although it is likely that, in the early stages, the technology will consume extra time, one of the ultimate goals is to improve provider workflows by making better use of time at clinician visits (The Dartmouth Institute for Health Policy and Clinical Practice, 2012).

Education and Training

NeHC (2013b) recognizes that the aspects most crucial for the success of PGHI implementation concern the patient and the provider. The patient must be able to easily understand and follow the process used to collect and share information. It should be engaging and uncomplicated to use. If the process is a source of confusion, patients are less likely to engage in it. In some cases, the organization may already be collecting information from the patient, e.g. when a patient monitors their blood pressure at home and jots down their readings on a piece of paper. In these cases, the shift to electronically collecting this information fits an existing workflow and thus is easier for the patient to engage in. In other situations where patient information is not routinely collected, e.g. monitoring daily activity levels, the change to electronically collecting PGHI is likely to require a more thought-out process with an increased need for education and support (NeHC, 2013b).

Each user group involved will have different training needs. In addition to the patient and the provider, it is likely that other groups within the organization will also need to be educated on new PGHI initiatives, e.g. support staff. The following questions should be raised and answered when planning education and training for each group:

- How much training is needed?
- Who should conduct the training?
- Who will oversee the training?
- When should the training occur? Will ongoing education and support be needed?
- What training format is best (e.g. one-on-one, small-group, or classroom style training; computer-based training, a combination)?
- How will training be evaluated?

It is important for patients to fully understand HIT tools that are being offered to them (Gephart & Effken, 2013). Every patient should know what PGHI is, the benefits and limitations of providing such health information, and the ways in which they can do so. It is also very important to establish clear expectations regarding the use of such information by the provider; both providers and patients should have a mutual understanding about what information is the most valuable, how this information is shared, and what will and will not happen after it is shared. Without this understanding, both providers and patients could develop unrealistic expectations, resulting in negative consequences for all parties involved. Your organization should take care to not only create and maintain clear policies regarding PGHI, but also ensure these policies are successfully shared with and well understood by the patient and all others involved. Both providers and patients share a common interest: ensuring health information is of high quality and accurate. Explaining that the implementation of PGHI initiatives supports this goal is important for garnering patient buy-in. Role-playing, simulation, and location-specific flow charts help all parties involved understand the benefits of PGHI and how it fits into their life or workflow (NeHC, 2013a, The Dartmouth Institute for Health Policy and Clinical Practice, 2012). Remember: change is not easy, and resistance to the new technology may occur, particularly during the start-up period. It is important not to underestimate the amount

of effort that is required of all parties to make the PGHI initiative successful (The Dartmouth Institute for Health Policy and Clinical Practice, 2012).

For PGHI initiatives, HealthIT (2012) recommends having designated staff members available to assist users with new technologies. Ongoing assistance will be needed, and hands-on and phone support should be available. It may also be advantageous for an organization to select "super-users" or champions. A champion acts much like an ambassador, serving as a resource to encourage and assist other users. For example, a physician who has good rapport with his or her peers can be given extra education and training regarding the PGHI implementation. They can then act as a knowledgeable resource amongst their peers and department. In smaller communities, it may even be valuable to have *patient* champions, who can reach out and speak to the community, promoting the new technology (Turman, 2013).

All organizations, but particularly those in rural or underprivileged areas, should develop training and education programs that are guided by the surrounding community and are culturally appropriate. Many rural residents do suffer from low health literacy (Institute of Medicine, 2005), but most express the desire to learn more (they just do not have the resources to do so) (Braun, Catalani, Wimbush, & Israelski, 2013; Connolly & Crosby, 2014). An in-depth understanding of the population's characteristics is necessary so that education can be dispersed via the most valuable format possible. For example, communities with large populations of Hispanic individuals need to ensure the availability of education and training in the Spanish language. If feasible, healthcare facilities located in areas with low digital literacy rates can help support patients not only by offering classes tailored toward the PGHI technology, but resources to help them learn general technology skills as well.

Evaluation

Evaluations should occur both before and after the PGHI technology has gone live (The Dartmouth Institute for Health Policy and Clinical Practice, 2012). User evaluations with both patients and providers that occur before the technology is launched can help recognize and resolve potential problems before they become too serious (Powell, 2001). In addition, a thorough evaluation of a PGHI project will occur over time, as patients utilizing PGHI are followed and their health conditions and status are monitored (NeHC, 2013a). Any PGHI initiative should be evaluated using various criteria. A health IT project should be scored on the value it brings to the following areas:

- Revenue impact
- Cost reduction
- Patient satisfaction
- Provider satisfaction/work life impact
- Quality of care
- Regulatory compliance (Wager et al., 2009)

Emphasis should be placed on usability. Ask these three questions:

- User: does the system or interface support the user (e.g. the patient entering in their blood pressure reading to a mobile app)?
- Utility: does the system do what it is intended to do (e.g. accurately and safely collect and transmit patient health data)?
- Usefulness: does the system add value (e.g. are clinical outcomes improving?)? (Yen & Bakken, 2012)

For a PGHI project, there should certainly be a focus on the patient, as the adoption of this individual is crucial for project success (Gephart & Effken, 2013). A user satisfaction survey is a beneficial way to discover how patients are finding the new technology (HealthIT, 2012). These surveys should be built in during the

testing/interface design phase, as well as once the technology has gone live and officially been implemented. Appendix C offers a sample user satisfaction survey for patients, specifically developed for a PGHI project. It can be used during any stage of the PGHI project. By administering such a survey and analyzing the results, the PGHI team can make improvements where necessary. For example, a survey conducted on the VA's Blue Button feature--an option built in to the online patient portal that allows veterans to download their health information to their home computer and share it with others, if needed--uncovered that, while satisfaction with users was high, the main issue with the new technology was that veterans were simply not aware of the feature. A two-pronged approach to further the success of the Blue Button was necessary: patients needed to become aware of the feature--including what it is, what it does, and how it can be used to improve their care--and the portal interface needed to be amended for easier usability, with easy-to-follow instructions (Sharp, 2014). These surveys can also help to understand if there is a demand for more health technologies, as well as increasing patient loyalty by demonstrating that their thoughts and opinions are cared about (HealthIT, 2012; Powell, 2001).

Overcoming Barriers:

Remember to consider the challenges of conducting user satisfaction surveys. Barriers include limited budgets and lack of funding, lack of in-house resources and expertise, procuring acceptable response rates and useful data, and translating data into information that guide improvement efforts. These obstacles are particularly noticeable in small facilities (Powell, 2001).

It is important to remember that the physician and other healthcare staff are also users, so their input about the new technology is also needed. Does the new technology support their workflow? Could improvements be made? Do they feel the PGHI being collected helps them do their job? Keep the environment and lines of communication open. An organization might choose to have their "super-users" or champions act as

spokespeople, offering input on what they are doing with the PGHI and if they have additional wants or needs (NeHC, 2013a).

Post-implementation audits of IT projects are important to conduct. These can help identify the value of the implemented technology and what steps may still be needed to achieve maximum results (Wager et al., 2009). It is very possible that adjustments to the technology will need to be made over time.

CONCLUSION

This document serves as a comprehensive guidebook and resource on the current state of PGHI. Approaches and best practices that target all stakeholders--including the patient, the community, the organization, and the healthcare staff--and areas of importance--including planning and development, policies and procedures, technical and operational considerations, education and training, and evaluation--are discussed. In addition to providing a thorough description of the many implementation guidelines when considering a PGHI project, a conversation is started regarding the importance of considering the sociodemographic characteristics and background of the patient population when healthcare organizations plan for and implement a new technology. Barriers common to rural healthcare organizations' relationships with technology were closely researched, with recommendations examined and explored throughout the document. The author has attempted to make this guidebook as comprehensive and thorough as possible, however, it is recognized that new developments relating to PGHI occur on a seemingly daily basis. Readers are encouraged to remain current with the latest advances.

Appendix A: Case Studies

Because PGHI technology is in its infancy, little formal research has been conducted on projects and their outcomes. The following are a few of the only public case studies with descriptions and outcomes noted.

Case Study	Description	Outcome
Brigham & Women's Hospital - Patient Gateway [1]	Patients use eJournal to review clinical information and answer questions about medications, allergies, health maintenance, etc. three weeks before a visit. Providers review and respond to eJournal submissions before visit.	- Increased patient engagement & satisfaction: patients felt the process made them more prepared for their visit - Provider support: providers assessed the system to be time-neutral with no adverse impact of workflow
Dartmouth-Hitchcock Spine Center [2]	Patients completed an online health survey before each visit (at home or using a touch pad computer at the facility). The data is immediately analyzed and displayed in a patient summary report, then inserted into the flow of care. Also, at the time of the visit, the provider enters a small amount of	- Increased patient engagement & satisfaction: patients felt the process made them more prepared for their visit and better enabled to share healthcare decision-making with their provider - Provider support: most providers approve of the system, although 50%

	core clinical data elements that are sent to a data warehouse. Data is used to improve patient outcomes as well as to improve the Spine Center program and provide reports about the quality and cost of care for improvement projects.	believed it added time to their workflow while 50% stated it saved time
EMC Corporation study [3]	Research was conducted for six months in a controlled trial to understand if access to a web-based self-management program led to better blood pressure control. 404 EMC employees with pre-hypertension or hypertension participated. Participants at 3 EMC worksites received an at-home blood pressure cuff that automatically uploaded readings to a website where they could view trends. Participants at the remaining 3 worksites received access	The change in diastolic blood pressure between groups was statistically significant, concluding that participation in an online, automated self-management blood pressure program resulted in improved blood pressure control among the employees.

	to an onsite blood pressure cuff.	
Group Health [2]	Secure messaging and "virtual visits" between patients and providers are actively promoted as a substitute to in-person visits. "Health Profile," an online health risk assessment tool, collects self-reported risk factor information and integrates this data with their Epic EHR. This produces personalized health improvement recommendations for the patient.	- Reduction of in-person visits: approximately 65% of all primary care encounters are virtual.
Veterans Health Administration - MyHealtheVet & Care Coordination/Home Telehealth [1]	Utilizes biometric monitors and messaging devices to record, share, and monitor large amounts of patient-generated data. Over time, this data can be used to identify harmful health behaviors, uncover knowledge gaps, and recommend interventions.	- Increased patient satisfaction - Reductions: program yielded a 25% reduction in bed days of care and a 19% reduction in hospital admissions

[1] Shapiro, M., Johnston, D., Wald, J., & Mon, D. (2012). *Patient-generated health data* [White paper]. Retrieved from http://www.healthit.gov/sites/default/files/rti_pghd_whitepaper_april_2012.pdf

[2] National eHealth Collaborative. (2013a). Appendix of Patient-generated health information technical expert panel. Retrieved from http://www.healthit.gov/sites/default/files/pghi_tep_finalreportappendix121713_files.pdf

[3] Watson, A. J., Singh, K., Myint-U, K., Grant, R. W., Jethwani, K., Murachver, E., . . . Kvedar, J. C. (2012). Evaluating a web-based self-management program for employees with hypertension and prehypertension: A randomized clinical trial. *American Heart Journal, 164*(4), 625-631. doi: 10.1016/j.ahj.2012.06.013

Appendix B: Organizational Needs Assessment

The following questions provide a guideline for your organization to help conduct a PGHI needs assessment.

Current and Future PGHI Needs and Utilization

- Are we currently utilizing any forms of PGHI? If so, what types? Include traditional (e.g. a patient's paper diary of symptoms) as well as modern-age (e.g. a patient's e-diary of symptoms) forms.
- For any traditional PGHI being collected, could it be replaced with an electronic version? What would be the benefits to doing this? The drawbacks?
- What additional PGHI would be valuable to collect?
    - What are the five most significant health concerns in our community? Could utilizing a PGHI technology help?
    - Can existing processes be adjusted to take advantage of PGHI?

Environmental Scan

- Are patients interested in utilizing PGHI tools? Have they expressed any interest in such technologies?
- What is an approximate rate of digital literacy amongst our patients?
- What is unique about the community we serve?
- Can the environment support PGHI initiatives (e.g. does the region have high access to Broadband Internet?)?

Resources

- Is this feasible with our current technology infrastructure?
    - Can the technology be easily integrated into our EHR?
    - Would we have to employ additional technology or staff resources to support the project?

- Is this feasible with our current budget?
- Where will the use of PGHI fit into the current care process? Would changes to existing workflows be required? For whom?
- What education and training will be needed? Who will be available to provide this?
- How will we handle the new influx of data?
- Who will be responsible for the successful implementation of PGHI? (This is a good starting point in the development of a steering committee and/or project team.)

Appendix C: Patient Satisfaction Survey Template

The following is a sample template to help your organization put together its own patient satisfaction survey. The following is a general template; modifications will need to be made that are dependent on the type of PGHI data and PGHI tool you will be implementing. Your organization may choose to record more demographic data, however, it is advised to keep the survey as short and noninvasive as possible. This template, particularly the interface section, can also act as a model for surveys given out to trial participants during the design stage. The IT department in your facility can set up a form-based survey that is dispensed to patients online.

PGHI Tool Satisfaction Survey

Recently, you have been introduced to PGHI Tool, a new technology at XYZ Hospital to help you manage your health. We are committed to continuous improvement and want to empower you, the patient, to take an active role in your healthcare. With your feedback, we can improve PGHI Tool and the healthcare services we provide to you. Please be honest and candid in your answers! Thank you in advance for your participation!

First, tell us a little bit about yourself...

Age:

18-24 *25-39* *40-54* *55-64* *65-79* *80+* *Prefer to not say*

Gender:

Male *Female* *Prefer to not say*

Chronic conditions (check all that apply):

Arthritis *Asthma* *Cancer* *COPD* *Cystic Fibrosis*

Diabetes *Heart Disease* *Obesity* *Osteoporosis*

I am using the technology primarily to help manage my:

Asthma *Blood pressure* *Diabetes* *Fitness/Weight*

I have been using the technology for:

0-30 days *31-90 days* *3-6 months* *6-9 months* *9-12 months* *12+ months*

I use the technology:

Daily *2-3 times per week* *Once a week* *Once every two weeks* *Less often*

Initial Contact

1. This technology was initially recommended to me by:

My physician *My healthcare team* *Another staff member*
A family member *A friend* *An advertisement* *None*
Other

2. My provider clearly explained the technology to me, including the benefits and drawbacks.

Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Disagree* *NA*

3. My provider clearly explained the policies relating to the technology.

Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Disagree* *NA*

4. I needed extra help learning how to get the technology to work.

Yes *No*

5. If you answered yes to the previous question, who did you receive help from?

My provider *Support staff* *A family member* *A friend* *Online resource*

Additional comments:

Technology

1. The technology does what it is intended to do.

Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Disagree* *NA*

2. The technology meets all of my needs.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

3. The technology easily fits in with my lifestyle.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

4. The technology integrates well with my other healthcare technologies.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

Additional comments:

Interface

1. The language used within the tool was familiar and felt comfortable to me.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

2. The tool has a consistent look and feel.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

3. The tool is simple and visually pleasing.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

4. The tool is fun and engaging to use.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

5. The font style within the tool is easy to read.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

6. Navigating the tool was easy.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

Additional comments:

Support

1. I was able to easily request support if needed.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

2. The support staff was responsive to my problems/requests.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

3. The support staff was respectful, friendly, and professional.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

4. I received a resolution to my problem in a timely fashion.

Agree Somewhat Agree Neutral Somewhat Disagree Disagree NA

Additional comments:

Overall, how satisfied are you with the new technology?

Very satisfied Satisfied Neutral Dissatisfied Very dissatisfied

Would your recommend the technology to your friends and family?

Yes No Unsure

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