National
eHealth
Collaborative

Patient Generated Health Information

Technical Expert Panel

FINAL REPORT

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I. Executive Summary

This report summarizes the deliberations and outcomes of the Technical Expert Panel (TEP) on Patient Generated Health Information (PGHI) convened by National eHealth Collaborative (NeHC) on behalf of the Office of the National Coordinator for Health IT (ONC). The TEP was a highly engaged group of leaders with diverse perspectives and expertise that met monthly throughout 2013. The result of the TEP's work provides insight on PGHI and its value, patient and provider concerns, examples and case studies, factors impacting PGHI, practical guidance on how to implement PGHI, and where additional work is needed to advance PGHI. The ONC plans to make the TEP's findings broadly available and to leverage the TEP's work in the development of practical guidance for PGHI implementers.

The initial focus of the TEP's work was to identify existing good practices for the use of technology to enhance patients' input into their care, with an emphasis on the relevant Meaningful Use Stage 3 (MU3) recommendations. The outcome of the initial phase included identifying specific types of information that are valued by providers and patients. The effort included an environmental scan, extracting promising practices and challenges from both the literature and a wide variety of case studies. In a second phase, the TEP examined emerging technologies; societal trends; evolving patient activities, including shared decision-making; transformation of medical practices; and potential future barriers.

The findings in this report reflect that PGHI is in an early stage of development and likely to become more common as a result of provider, consumer, organizational, and societal drivers. While providers and patients have some concerns about PGHI, those with experience are generally optimistic about its promise to improve care. Using PGHI can improve the quality, safety and effectiveness of healthcare, helping to avoid common problems due to missing or inaccurate patient information and enhancing patients' engagement in their health and care. A broad range of data types, workflows, policies and approaches to using PGHI in daily practice are needed to accommodate the many different examples in use.

II. Background and Purpose

During 2013, NeHC convened the PGHI TEP and supported its work on behalf of ONC. The TEP included providers, patients, patient advocates, caregivers and other stakeholders who are recognized experts in their fields. The TEP was co-chaired by Dr. Jonathan Wald, Director of Patient-Centered Technologies at RTI International's Center for the Advancement of Health IT and Dr. Danny Sands, Co-Founder of the Society for Participatory Medicine and Assistant Clinical Professor of Medicine at Harvard Medical School.

ONC tasked the TEP with identifying use cases and good practices for sharing information between patients[1] and providers and making recommendations on parameters, expectations and important criteria for the successful implementation of PGHI. The outcomes of the TEP's work are intended to be helpful for providers who may be concerned about receiving PGHI and to improve care by enabling patients to provide information to inform their care. The TEP saw this project as an opportunity to change assumptions about the feasibility of receiving and reviewing patient generated information by determining the information providers need that patients can provide electronically and suggesting ways to manage that process. The TEP agreed that any recommendations they made should support an open and communicative shared decision-making process between patients and providers. The outcomes of this project are also intended to inform policy-makers and other interested stakeholders.

The TEP addressed the following key questions related to both policy and real world implementation through a two-phase work plan:

- What is the most important PGHI that will be useful to the largest number of patients and providers?
- What requirements must be in place to support the appropriate management of PGHI review and response?
- How can PGHI be best reviewed for consistency, accuracy, appropriateness and standardization – where possible – before it is published in the patient record?
- When should PGHI become part of the record? Are there circumstances in which it should not be included in the patient's record?
- How can large amounts of PGHI be distilled in a way that will make it most actionable?

Phase I

The goal of Phase I was to identify existing good practices for the use of technology to enhance patients' input into their care, with a focus on the relevant MU3 recommendations. At the time, MU3 recommendations included:

- Provide 10% of patients with the ability to submit patient-generated health information to improve performance on high priority health conditions, and/or to improve patient engagement in care (e.g. patient experience, pre-visit information, patient created health goals, shared decision making, advance directives, etc.). This could be accomplished through semi-structured questionnaires, and EPs and EHs would choose information that is most relevant for their patients and/or related to high priority health conditions they elect to focus on.

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[1] Throughout this document, "patient" is often used as shorthand for patients, family, personal caregivers or designees. In some care settings, patients may also be known as consumers, clients or recipients of care.

- Provide patients with the ability to request an amendment to their record online (e.g., offer corrections, additions, or updates to the record) through VDT [view, download, transmit] in an obvious manner.

By focusing on MU3 recommendations, the TEP sought to suggest supportive requirements that certified electronic health records (EHRs) could accommodate. For example, providers can use EHR systems to support personalized nomograms, tracking and analyzing a patient's data to identify and highlight individualized outliers. By coupling this capability with a real-time alerting system tuned to a provider's workflow, an automated mechanism could be created that allows providers and their staffs to quickly and easily sort through a large quantity of data and identify incoming PGHI that requires follow-up action.

The TEP, with NeHC and ONC staff, undertook a broad environmental scan, extracting promising practices and challenges from the ONC PGHI whitepaper, various PGHI-related hearings and a wide variety of available case studies that show high value for those who have currently incorporated PGHI into the clinical record and care decisions.

The TEP's Phase I presentation identifies specific types of information that are valuable for providers and patients, including a priority subset of "nearly always valued" information.[2] The TEP focused on the types of information that cut across multiple disciplines and conditions in search of a set of data elements that patients are uniquely positioned to provide and that add value to their care.

On July 18, 2013, TEP co-chair Jonathan Wald presented the TEP's initial findings to the Consumer Empowerment Workgroup of the Health IT Policy Committee.

Phase II

Phase II of the TEP's work looked beyond the lens of Meaningful Use to ways in which providers can prepare, prioritize information types and incorporate PGHI into their practice. In this phase, the TEP examined emerging technologies; societal trends; evolving patient activities, including shared decision-making practices; transformation of medical practices; and potential future barriers. The TEP tried to be visionary, broadly leveraging its wide range of expertise and experience to provide both thoughtful, future-oriented insight and practical guidance.

The TEP's Phase II findings include a step-by-step set of recommendations on how providers and patients can best manage and use PGHI to bring the most value and greatest impact on patient care in ways that are convenient for both the practice and the patient, and that help the patient be an active partner in their own care management.

Phase II also outlines a number of gaps remaining around PGHI, highlighting different aspects of this topic that require additional attention. Some of these gaps include policy areas relating to

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[2] It should be noted, however, that this area is highly contextual; the TEP recognized that not every area of PGHI will apply to every context. In other words, PGHI will vary by specialty and patient population.

effective engagement of providers, patients and payers, or necessary workflow adaptations; issues relating to human performance, such as health literacy or behavioral motivation and impact; appropriate architectures for future decision support; methods for measuring PGHI, such as how frequently patients should provide it, how providers should manage it, and the corresponding impact on patient care; and how PGHI can inform the development of a Learning Health System.

III. Introduction to Patient Generated Health Information

Defining PGHI

PGHD Expectations

Health IT Standards Committee

Can improve care
Can improve accuracy
Can cause confusion
Can cause angst
Can empower and engage patients.
"Isn't it better to know?"
....Farzad Mostashari

In traditional medical care, information is generated largely by medical professionals – reported by a clinician in the form of history obtained from the patient, physical examination findings, assessments and plans, as well as lab results and procedure reports from specialists. This information is typically recorded and archived in a medical record that serves as documentation of medical care, medical decisions and billing practices. The medical record also serves as a legal record. It largely reflects and represents the voice of the professional.

In contrast, there are many examples of medical information that is generated, reported, recorded and used in care directly from the patient or a caregiver – someone outside the role of a medical professional. This type of information, in which the patient is responsible for the accurate capture, recording and sharing of information that will be used in medical care, is known as patient generated health information or patient generated health data.

For example, PGHI has been described[3] as health-related data created, recorded, gathered or inferred by or from patients, family, personal caregivers or designees to help address a health concern. This data could be an observation, a result, a device finding, a confirmation or a change/correction/addition of data in the patient's existing health record.

In this report, we use the term patient-generated health information, or PGHI, because what the patient captures may reflect a discrete measurement at a point in time (e.g. data, such as a glucose measurement) or something less discrete (e.g. "my pain is 2 out of 5 this morning, improved from the night before"). PGHI takes many forms and its uses are evolving.

PGHI is not a new phenomenon. While the term may be relatively recent, the idea is old. Many patients have recorded and shared information on their health and wellness with their provider and other members of their healthcare team. For example, whenever a patient visits a provider and brings a copy of their medical and family health history, that information is PGHI. When the patient describes their medication list or comments on the side effects they have been feeling

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[3] Excerpt from ONC PGHI whitepaper definition (see Appendix)

from those medications, that information is PGHI. When the patient's caregiver expresses concern about recent new symptoms, that information is PGHI.

In the past, and indeed currently, PGHI is often shared through conversation between patient and provider. It may also be the result of a questionnaire provided by the healthcare team and completed by the patient. Or a provider may request that a patient or caregiver keep track of a particular set of information on the patient's condition and report that at the next appointment or during a follow-up telephone contact.

As we move further into the information age, PGHI is taking new forms entirely. Health apps on smartphones are keeping track of wellness data that can be shared with a provider. At home monitoring equipment is keeping a digital record of results that can be uploaded through a patient portal. That same patient portal may also have a place for patients to keep a health diary. Some PGHI is being sent wirelessly to the provider or an intermediary data-holder without the patient ever interacting with it.

In addition, patient reported outcomes and patient reported outcome measures (PROMs) have been recognized as essential inputs for measuring health results (as well as mortality and clinical parameters) and have become a very high priority as quality measures for improvement, public reporting and accountability.

This report is not intended to encompass all the traditional forms of PGHI in a paper-based world but to focus on the opportunities and challenges associated with PGHI in the information age as use of electronic information and patient-provider exchange of information outside of in-person encounters increases.

Taxonomy

In examining the complex set of elements that can be considered PGHI, it is helpful to have a common language that describes the characteristics of those examples. The TEP felt that an exercise in taxonomy might provide that common language. According to the TEP, in addition to the various people involved, the processes and technologies necessary for each PGHI initiative vary depending on its categorization along predictable axes, and understanding this concept can help organizations better prepare.

The TEP subcommittee worked to develop a high-level taxonomy that would:

1. Provide a common language to discuss, compare and contrast PGHI examples
2. Permit categorization of planned PGHI implementations to help organizations prepare people, processes and technology in their institution

The technical and functional taxonomy developed by the TEP Taxonomy Subcommittee is included in the appendix. It should be noted that any categorization reflected here is a work in progress, as new technologies arise and more is learned about PGHI.

The TEP also found it important to not only identify the available types of PGHI, but to identify the provenance, or source, of patient generated information. This is important to its usefulness, as any medical information source (e.g. laboratory, radiology service, biometric device or medical record EKG report) impacts provider understanding of the context, veracity and reliability of the information. Capturing and recording contextual and source information helps assure the usefulness of PGHI. In short, the more clarity around PGHI, the more useful. For example, some TEP members suggested the term “patient-directed” to distinguish information flowing from one source system to another system in which the data is unalterable by the patient, family member or caregiver. In contrast, if the data or information can be altered or shaped by the patient, family member or caregiver, it can be termed “patient-generated.”

IV. The Value of Patient Generated Health Information

PGHI provides an opportunity to capture needed information for use during care, with potential cost savings and improvements in quality, care coordination and patient engagement.

Receiving information directly from the patient can be valuable in many ways. It can strengthen the patient-provider relationship, provide opportunities for shared decision-making and amplify the voice of the patient. PGHI is part of a partnering process involving the patient, who learns about their condition, more actively participates in self-monitoring and self-management, and provides useful information, and the provider, who expresses interest in receiving the PGHI, reviews the information, and reflects on it during the care process. PGHI may be useful for a single decision-maker or important for the entire care team, including the patient’s family and caregivers. PGHI helps those in the patient’s support system to provide quality care, avoid medical mistakes and errors, and minimize misinformation or miscommunication.

When PGHI is managed electronically, it provides a host of additional benefits. For example, utilizing the patient record as the central location for PGHI means that multiple care team members are all working from the same page and can avoid potentially harmful information gaps and poor coordination. Administratively, PGHI allows a practice to leverage the patient as a record keeper and resource in the care process, which can have a significant impact in providing both efficiencies for the provider and added convenience for patients.

Not all PGHI is reviewed by the provider. Policies and workflow that allow a provider to delegate responsibility for review of certain types of PGHI, or PGHI for certain patient populations, to a designee such as a nurse, care manager or office staff, are common.

Pre-encounter information collected asynchronously is particularly useful because it informs decisions that are about to be made during the synchronous in-person or virtual encounter. In other words, with time in the near future to review, analyze and discuss PGHI during a patient/provider interaction, there is a higher likelihood that PGHI will add value.

The types of pre-visit information collected from the patient depend on the nature of the visit. For a ‘new patient’ visit, a more extensive medical history, surgical history, review of systems, and gathering of patient preferences are often appropriate, and tools are increasingly available for the electronic capture of these kinds of information. For a returning patient who is followed over time for a chronic condition, repeated measures such as blood pressure, glucose readings, weight, pain intensity, mood scores, activity level, nutrition, and other medical or lifestyle indicators are often useful for documentation and in decision-making, especially when collected directly from the patient or caregiver.

Similarly, post-visit capture of treatment response, side effects, behavioral changes and other patient-supplied information is often very useful for clinical decision-making, medication adjustments and providing support to the patient in their plan of care. Growth in the use of EHRs and other forms of health IT in many physician practices and hospitals provides essential infrastructure that can be leveraged in the capture of electronic information from the patient.

The following are specific examples of PGHI that can be especially valuable:

Safety-Related

The patient and their caregivers often are the most knowledgeable, or even the only, ones who know how closely the patient is following their treatment plan. Instituting a process to receive and monitor PGHI can help providers stay current on important factors that can impact the patient’s safety and ultimately affect the outcome of their care. For example, allowing the patient to easily report changes in their medications or the discovery of new allergies or intolerances gives the provider and the patient an opportunity to intercept potential contraindications without undue delay.

Treatment Plan-Related

Regular reporting on a patient’s condition is another way in which PGHI can enable a better outcome. As discussed above, this reporting can take many forms, from “patient-generated” documentation that is requested by the provider to “patient-directed” documentation that is reported directly from a home care device, such as a wireless blood pressure cuff or glucose monitor. A review of this incoming data, whether manually by the provider or staff, or electronically through a provider’s EHR or dedicated app, provides an opportunity for intervention when the reported information exceeds a patient’s normal range.

In another example, allowing room in the patient record for the patient to explain additional barriers to care, such as a need for childcare or transportation to medical appointments, can provide an opening for care managers and other supporters to address these barriers, mitigating a potential negative impact on the patient’s health outcome.

A New Patient Concern

PGHI often offers a convenient way for patients and their caregivers to bring information of concern to the provider’s attention in a timely way. In a visit-centric model of medical practice (often fee-for-service), patients highly value the availability of non-visit-based ways to report unexpected worsening symptoms or other worrisome symptoms that come about following a new or changed treatment. PGHI shared as part of a new patient concern, however, may or may not be useful to both the patient and their providers. A description and picture of a new rash, for example, may be sufficient for making a diagnosis and ordering treatment – especially for an established patient in the practice. In other cases, PGHI about a new patient concern may be of limited value, such as when the information provided by a cardiac patient is insufficient by itself to assess the new concern.

Note that it is very important to manage patient and provider expectations around this type of PGHI. A provider's instructions to the patient to use another form of communication when symptoms are urgent or time-sensitive should be explicit and repeated. Patients sharing PGHI of personal concern must have an especially clear understanding of when and by whom their information will be reviewed in order to maintain confidence in the overall process.

Administrative and Important

Not all PGHI is valuable strictly for its impact on a patient's treatment plan or health outcome. It can also help to ensure that administrative functions run smoothly. For example, PGHI could include the contact information of non-medical stakeholders on the patient's care team so they can stay better coordinated. PGHI could include keeping the patient's insurance information or preferred facilities list up-to-date, thereby lowering the overall cost of care. PGHI can also make the process of care more efficient by recording a patient's preferences around communication channels, permissions to share information, or relevant cultural and language issues/factors.

V. Concerns

Patient Concerns

In addition to the potential benefits of PGHI in the care process, both patients and providers have some significant concerns that must be addressed. It is important to recognize and acknowledge these concerns when developing a plan for implementing PGHI.

Engaged patients are motivated to provide PGHI if they believe that it will improve their health and quality of life. However, before taking the time and making the effort to record and report their data, most patients needs reassurance that their role in the process will be appreciated, that the PGHI they provide will be reviewed, managed and placed in their records (if appropriate) in a timely manner, and that their interest and role in partnering will be highly valued.

According to the TEP, the primary concerns of patients relate to trust and confidence, generally falling within four categories: communication expectations, information security expectations, information sharing expectations and doctor-patient relationship expectations. Patients want to know:

- Communication expectations:
    - Did my doctor/care team see the information I sent? Did anybody see it? Did they see it today? Will I receive a reply? When?

- Information security expectations:
    - Is the information I sent secure? Do you know it was me (or my delegate or device) that sent the information? Who will access my information? Did I authorize that access?
- Information sharing expectations:
    - Is the information I sent saved in my chart? Shared with my insurer? Shared with my parents, separated spouse/partner? Will it be used for clinical research or is it subject to other secondary uses?
- Doctor-patient relationship expectations:
    - Is the information I sent valued and well received by my doctor and care team? How will it be used to help me? Will it contribute to my personal care plan?

Provider Concerns

Providers also have concerns and expectations, often falling within a business context. The TEP found that providers' concerns are most likely to focus on questions of liability, workload and financial impact.

First, providers are concerned about taking on additional risk or liability, especially given the additional financial risk many providers are already shouldering as part of newer healthcare payment models. If, through the increased use of PGHI, providers and patients are engaged in more continuous care, does more responsibility (and liability) shift to the provider? Does failure to review information that is sent to the provider, or not acting upon that information in a timely way, create liability for events that used to be outside the care process, but now are within it?

Specifically, the TEP heard concerns from providers that they might be liable for PGHI that falls short in some way – is not received in a timely manner, is missing information critical to the decision-making process, contains erroneous data or is less than useful by the time it reaches the provider. Providers are also concerned that incoming data may not be appropriately linked with the correct patient or that the source of the data may not be available or trustworthy.

TEP members had mixed opinions about whether such liability concerns will be borne out in practice, especially with good policies and procedures in place and thoughtful use of PGHI. Some even felt that liability would be diminished because of improved expectation setting, communication and documentation.

Second, providers are concerned about the potential volume of PGHI and the additional workload that may be placed on them to review this data. In an environment of pay-for-volume, providers seek to minimize unreimbursed care activities. Providers worry about a potentially negative impact on productivity with new streams of data for them to review, as well as disruptions to existing workflow caused by PGHI.

Third, providers are uncertain about the financial impact of PGHI. In cases where patients already directly provide information, more systematically collecting and using PGHI in the care process may create greater efficiencies and financial benefits. In other cases, especially when patient-generated information is not routinely captured and reviewed during care, PGHI may be an additional cost. The overall financial impact of PGHI is difficult to determine without understanding the specifics about how PGHI impacts expenses, time, revenues and contractual requirements – in other words, how it fits into the overall business model of care. Finally, providers are concerned about expectations. What would the increased risk be to the provider (and the patient) if a patient had unreasonable expectations about when or how their data would be reviewed and whether that data was taken into account in making treatment decisions – especially in cases of emergency?

Critical Success Factor: Balancing Expectations from Patients and Providers

Hearing the concerns of patients and providers led the TEP to an important conclusion: regardless of the PGHI submitted or not submitted, accepted or not accepted, it is of the utmost importance that expectations be managed well. Providers and patients must have a shared understanding about what information would be most valuable, how data should be shared and what will happen after they share the data. Absent this understanding, unrealistic expectations could develop and easily lead to undesired consequences for both patients and their providers. When PGHI capabilities are implemented properly, including having an established set of policies and procedures in place for handling PGHI and maintaining transparency about the use of a patient's information, concerns are addressed and potential liability may be reduced and mitigated.

VI. Examples of Valued Patient Generated Health Information

In order to address concerns about handling the volume of incoming data as PGHI becomes a common practice, the TEP considered ways to implement a system for handling PGHI that was rolled out over time. One of the ways to do this is by managing information from patients in stages. As a starting point, the TEP developed a priority list of valued PGHI that is important in the care process. They sought to answer the question: What information would always (or almost always) be useful and worth knowing if provided by the patient (in a given context)?

The following is the priority subset of PGHI determined by the TEP to be most immediately valuable to both patients and providers:

Safety-Related

- Medication List
    - Medication (history, current)
    - Medication adherence (including over the counter)
    - Medication reactions/symptom reporting
    - Validate medication reconciliation
    - Medication updates, non-adherence

- Allergy List
    - Medication allergies (e.g. medications, new reactions, history of non-tolerated medications)
    - Environmental and nutrition allergies
    - Procedure intolerances

Treatment Plan-Related

- Information requested by the provider
- Patient goals for care/health
- Patient reported outcomes (e.g. functional status)
- Recent changes that might prompt a change or reconsideration of the treatment plan
    - Biometric data (e.g. blood pressure, blood sugar, imaging, weight, smoking status, exercise, temperature, nutrition, heart rate, oximetry, spirometry)
    - Chronic disease care/outcomes data, including PROMs
    - Behavioral health related outcomes information (e.g. depression)
    - Advance directives
    - Social determinants (e.g. availability of transportation)
    - Cultural preferences (e.g. no blood products, religious fasting that may affect treatment recommendations)
    - Functional limitations; services and supports necessary for independent living (e.g. use of wheelchair)

A New Patient Concern

- Unexpected symptoms or worsening symptoms
- Information deemed by the patient to be important to capture and share

Care Process

- High impact on care process
    - Advance directives
    - Key demographic information (e.g. updated contact information)
    - Preferred facilities/locations (e.g. pharmacy, lab, clinic, hospital)
    - Insurance information
- Care team information
    - Support roles
    - Contact information

    - Communication preferences
        - Communication channel preference
        - Permission for sharing information
        - Cultural and language preferences

It should be noted that the value of PGHI is highly contextual; the TEP recognized that not every type of PGHI will apply equally in every context. The value of PGHI will also vary for different specialties and patient populations. Providers and patients should determine the types of PGHI that would best serve a given patient care situation, relative to both health outcomes and convenience, and best fit with the care process, within a provider's workflow, and with a patient's ability and workflow. Part of this consideration should include a discussion of the options for sharing PGHI (e.g. secure messaging, specific online applications, questionnaires), including automated methods or systems that can increase the efficiency and effectiveness of the process. A sampling of existing technologies for electronically capturing PGHI might include clinical device monitors (e.g. vital signs, glucose levels, weight), mobile applications (e.g. lifestyle monitors: fitness, nutrition; image capture devices; messaging devices), and online e-Journals used for patient observations, accessed via a patient portal or other online platform.

Regardless of the method for collecting PGHI, there are some good practices being demonstrated already that can inform a provider's decision-making around managing PGHI. First, it is most helpful if PGHI can be collected in a way that is both human- and machine-readable, such as by using structured data elements that leverage existing health IT standards. The ability to capture both low-volume and high-volume PGHI over time should also be considered during process development. The most critical aspect to successfully integrating PGHI, however, is to ensure that the process for capturing and sharing information is easy for the patient to understand and follow, and for the provider to review and manage, and is consistent with patient and provider expectations, especially provider workflow. Patients and caregivers having trouble using the method requested by their provider are less likely to use it, and providers offered PGHI that they are not ready to process will look for ways to reduce or avoid it.

VII. Case Studies

To better understand the application of PGHI in today's healthcare landscape, the TEP reviewed multiple real world examples of how organizations are currently utilizing PGHI. The TEP's review focused on extracting key issues, lessons learned, challenges, guiding principles and critical success factors in design and implementation. The examples below demonstrate some of the most successful applications of PGHI. Links to additional information on each case study are available in the appendix.

Dartmouth-Hitchcock Spine Center:
Patient-Reported Information Improves Health Outcomes and Healthcare Value

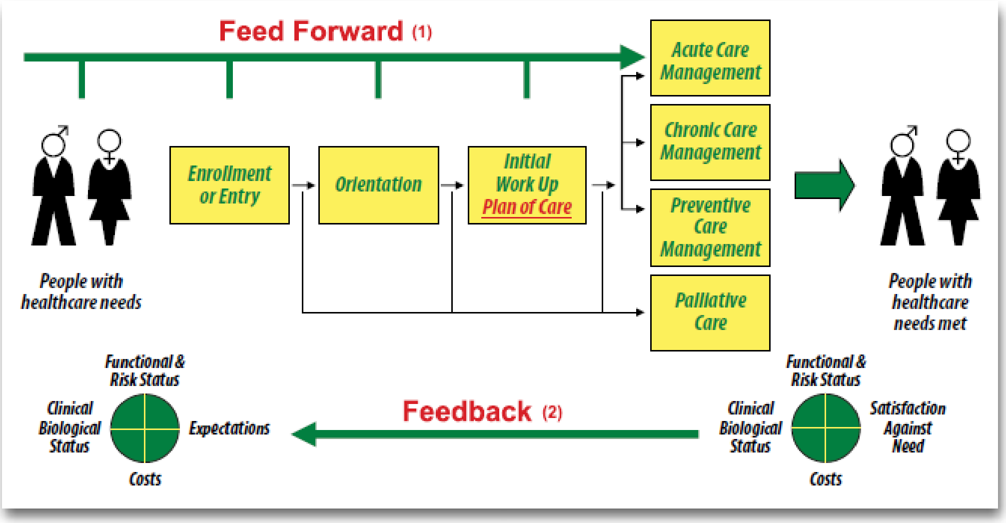
Dartmouth-Hitchcock Spine Center has developed a process for accepting PGHI through an online questionnaire in advance of a patient's visit. The goal of this program is to provide team based care and co-development of the feed forward, feedback process that makes extensive use of PGHI and PROMs.

Patients making an appointment are invited to complete a questionnaire at home prior to their office visit. The survey can also be completed in the waiting room prior to the appointment with the care provider, but is not recommended. A friend or family member can also help the patient complete the survey. The scheduling workflow at the Spine Center was altered to adopt the new process. Clinical staff must commit to using the data and summary in the office visit through a process embedded into their workflow.

> "The challenge is to design and implement information-rich systems that are affordable and practical while they 'feed forward' and 'feed back' core, patient-reported data on changes in health status to supplement other data on quality and costs."
>
> - Dartmouth-Hitchcock Spine Center Case Study

To access the survey from home, patients log into the Spine Center's patient portal. Logging in authenticates the patient, who then provides consent for their survey information to be used by their care team, like any other clinical document. This data routes directly into the medical record, even if the patient does not actually see the provider.

The Dartmouth project enables patients to generate a health report through a structured set of



Feed Forward and Feedback Data Flow

Diagram illustrating use of feed forward and feedback data in flow of care for patient care, improvement and research.
1. Feed forward to keep data about the patient with the patient as care is delivered (in multiple settings) over time.
2. Feedback to provide summary data on clinical populations to improve care in individual programs, collaborative networks and to provide research data base.

questions involving standard measures of physical and mental health. The summary report generated from the survey is available for shared decision-making at the appointment. The summary instantly evaluates and scores the patients' condition-specific disease status, physical health and mental health. The summary also reviews the patient's disability status, risk factors, perceived benefits of treatment and quantitative trends in functional status over time. The survey is designed to display the data in a way that works for both the patient and provider, making the scores easy to understand and explain.

The Dartmouth PGHI summary report has evolved into a "must have" for clinical staff at the Spine Center and the process has become a cultural norm. Alongside the PGHI evaluated scoring metrics, the data collected becomes a moving picture of the changing health outcomes reported by the patient.

Veterans Health Administration:
Using Care Coordinators and PGHI to Manage Chronic Conditions

The Veterans Health Administration (VHA), the healthcare arm of the U.S. Department of Veterans Affairs, believes that PGHI is a key component in engaging patients in collaborative healthcare. The VHA collects a wide variety of PGHI from multiple sources, including their MyHealth*e*Vet personal health record portal, point of service kiosks, mobile applications, home telehealth and wearable devices.

In 2003, the VHA initiated Care Coordination / Home Telehealth (CCHT), a home care program designed to provide care management for more than 100,000 non-institutional patients with diabetes, congestive heart failure (CHF), depression and other chronic conditions common to older veterans. The program utilizes biometric monitors and messaging devices to communicate and monitor PGHI. Provider concerns about how to manage large amounts of patient-generated data were addressed by assigning care coordinators (nurses or social workers) to review monitored data.

Care coordinators, formal patient assessments, selection of patient-appropriate technologies and training for patients and caregivers were all planned prior to rollout. The CCHT has been able to improve performance on high priority health conditions by identifying knowledge deficits and negative health-related behaviors that suggest the need for intervention. Over four years, the program has achieved a 25% reduction in bed days of care, a 19% reduction in hospital admissions and very high levels of patient satisfaction.[4]

MyGeisinger:
Patients Are Eager to Provide Accurate Feedback

Forty-two Geisinger Health System clinic sites in 31 rural Pennsylvania counties have the potential to enable patients to request an amendment (an update or correction) to their record.

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[4] Cited in ONC PGHI whitepaper (see Appendix)

Geisinger demonstrated this capability in a 2011 pilot project designed to test an electronic patient feedback process.

As of February 2013, 1,500 Geisinger patients with at least one chronic condition (e.g. asthma, chronic obstructive pulmonary disease [COPD]) have been invited to complete a medication feedback form prior to their visit. Through the MyGeisinger patient portal, patients complete a structured questionnaire that is pre-populated with their EHR medication list. Using this tool, patients can submit questions and request EHR corrections, such as removing old medications from the active medication list or adding a new over-the-counter medication.

> "The effectiveness of any tool is dependent on the work system in which it is implemented."
>
> \- MyGeisinger Case Study

A Geisinger pharmacist receives and processes the patient's medication feedback and updates the EHR. The pharmacist also notifies the patient's physician if shared decision-making is needed. EHR corrections submitted online by the patient, once reviewed, are accepted as if they were being received during a face-to-face clinical appointment.

The Geisinger patient portal also supports the sharing of, and patient feedback on, allergies, immunization and demographic data elements. Other promising areas for MyGeisinger-enabled PGHI include smoking status, advance directives and family history.

Patient response to Geisinger's pilot project has exceeded expectations. An assessment conducted by NORC at the University of Chicago showed that 30% of patients responded to the offer to update their record, 85% of which were processed within four days. The NORC study showed that the average patient has requested at least two changes per submitted form and that pharmacists accept the patient's proposed changes more than 50% of the time.[5]

This project clearly demonstrates that patients can be effectively engaged to provide accurate and reliable feedback, effective strategies can be developed to gather and process patient feedback and collaborative processes can be employed to improve the data quality of EHRs.

Other Case Studies

The following hypothetical scenarios were developed by the TEP to demonstrate additional examples of common PGHI collection.

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[5] NeHC University webinar: "Patients Improve the Accuracy of their Medical Records." February 4, 2013. http://www.nationalehealth.org/patients-improve-accuracy-their-medical-records-recorded-webinar

Scenario: PRE-VISIT DATA COLLECTION

Patient completes a health questionnaire in advance of a visit with their provider.

What information is the patient capturing and delivering to the provider?	Family history, social history, demographics, medications, problems and other data known by the patient. May also include patient preferences, values, previous care decisions and existing level of clinical knowledge.
How is the information being transmitted?	Patient completes a form in the patient portal or through secure messaging that is converted to a CCDA document that is sent to the provider
What workflow could be used to effectively handle this information?	Patient completes online form → alert to administrative staff that new CCDA has been received → administrative staff reviews the information and attaches it to the EHR → administrative staff responds to patient with any questions → PGHI is available for use at next patient encounter
What policies are needed to support this workflow?	Policies to ensure that the patient supplied data is available to the provider before the appointment and that the provider has access to the data at the time of the patient encounter
What value is provided by including PGHI in the care process?	Increased patient convenience, sharing of information that may impact shared care decisions, efficient capture of information by the practice
What challenges must be addressed?	Spending time incorporating PGHI in the care process, setting reasonable expectations about how and when PGHI will (or will not) be used, incorporating PGHI into encounter documentation

Scenario: BLUE BUTTON CORRECT

Patient uses Blue Button to see his/her summary record in a continuity of care document (CCD). Patient identifies an error in the record and requests that the record be corrected.

What information is the patient capturing and delivering to the provider's organization?	The corrected data could be any element in the list (e.g. demographics, medications, procedures, allergies, etc.).
How is the information being transmitted?	Patient uses Direct or other secure mechanism to send a CDA document to the provider to highlight or indicate incorrect data
What workflow could be used to effectively handle this information?	Patient sends CDA to provider practice → alert to administrative staff that a new message has been received → provider or delegate reviews the changes and approves a correction in the EHR → automatic notification is sent to patient that changes have been accepted or explains reasons for denial
What policies are needed to support this workflow?	Policies for accepting changes to an EHR and agreements regarding workflow and expectations
What value is provided by including PGHI in the care process?	The accuracy of the EHR information is improved via the patient as a resource in the care process
What challenges must be addressed?	Time and effort required to make corrections may sometimes be perceived as worthwhile, and other times as wasteful

Scenario: PATIENT DIRECTED EXCHANGE

The primary care provider (PCP) has requested that patient have some diagnosis-specific tests and some age/gender-based health maintenance studies. Patient has these done at outside facilities and informs PCP that tests have been completed, including the results.

What information is the patient capturing and delivering to the provider's organization?	Dates, times and locations of the tests with the consequent reports and results (e.g. lab, imaging, procedure)
How is the information being transmitted?	Patient receives information via a personal PHR, then directs the test results and reports via secure email or other mechanisms to their provider
What workflow could be used to effectively handle this information?	Information delivered from the patient's PHR → provider's system via secure messaging with alert to PCP that new data has been received → PCP reviews and approves new data → data is incorporated into EHR with metadata → PCP or delegate responds to patient
What policies are needed to support this workflow?	Practice policies and agreements regarding workflow and expectations, and technical specifications that detail the allowable types and formats of information that can be received
What value is provided by including PGHI in the care process?	Consumer convenience, care quality and efficiency are improved by avoiding duplicate testing

VIII. Factors Impacting Patient Generated Health Information

Going forward, the TEP anticipates that many factors will impact the use of PGHI, which has multiple contexts of use in self-management, care delivery by providers, screening and prevention, and wellness. These factors are grouped into four areas: a) consumerism and the growing empowerment of the patient, b) medical practice changes, c) societal trends and d) technology advances. Factors may impact multiple areas and collectively are anticipated to drive significant PGHI advances.

Consumerism and the Growing Empowerment of the Patient

Patients and caregivers who contribute information that is specific and material to their care create a pivotal opportunity to enhance their engagement in self-care and care with professionals. PGHI complements clinical data generated by providers to offer a comprehensive view of an individual's health. PGHI helps to ensure the accuracy and reliability of data stored in an EHR, while simultaneously empowering patients and their caregivers to be active partners in their health and healthcare.

Consumer online activities such as travel planning, shopping, entertainment, gaming and online social interactions are driving significant changes in consumer experience. People increasingly expect online self-service sites to be simple, easy-to-use and available 24/7/365 to meet their needs. They commonly experience online sites that remember who they are, display their transaction history, store their preferences and give ready access to helpful information and simple how-to guides. Consumers are accustomed to expert information about a topic of interest, wisdom from online peers and broader online crowd-sourced information. Elements of fun and entertainment are frequently interwoven with online tasks in an effort to encourage consumers to return to websites again. The time spent by an average person interacting with computing devices has increased dramatically in recent years, lowering barriers to the use of computers for health-related activities, such as collecting and using PGHI.

Online experience in general may stimulate consumer interest and perceptions of PGHI, or may spark caution. Patients experiencing improvements and innovation in their use of other service websites and technologies cannot help but raise their expectations for health technologies as well. Similarly, those having had poor online experiences may worry about intrusive advertising, the disclosure of personal information to a third party or untrustworthy online services, and may be nervous about sharing PGHI electronically. Designing online interfaces for patients that leverage and emulate other consumer online routines can potentially simplify and improve the experience for both patients and providers.

The rise in social computing – using computers to connect online with family, friends and others with similar interests – is especially significant as a driver for change. Patients are frequently connecting online and sharing health experiences, including the tracking of their own conditions, treatments, symptoms and goals. Patients will adapt quickly to opportunities to share PGHI, especially those already recording information with symptom checkers, community websites, and health fitness devices that connect them to an online community.

Medical Practice Changes

Medical practice changes are driving an increased need for PGHI. Triple aim goals, including cost containment, improving the health of populations and enhancing the patient experience of care (including quality and satisfaction), each stand to benefit from advancing use of PGHI. Practices have long valued the capture of patient information prior to a visit, typically through the use of paper forms filled out in the waiting room or mailed pre-visit forms returned by fax or postal mail. Waiting room computers are sometimes used to shift this to an electronic format and many practices increasingly offer online secure forms for patients through a third party service or institutional patient portal. Shifting information collection to the patient allows practices to adapt the role of staff to perform other useful activities, including the review of patient-entered information and supporting information capture for patients that are less comfortable using online tools.

As medical practices and hospital departments increasingly share information electronically with the patient, it is natural to envision that two-way communication (from the patient to the practice or department and reverse) will increase. There are also many ‘best practices’ that can benefit from PGHI, such as shared decision-making (SDM), in which the knowledge and expertise of the patient together with the knowledge and expertise of one or more providers strengthen the decision-making process. For example, self-reported mood tracked over time alongside other behavioral inputs is especially helpful in assessing patient response to antidepressant treatment, just as home blood pressure tracking is an important adjunct to in-office measurement. Almost any clinical assessment may benefit from PGHI if patient measures alone, or in combination with other clinical metrics, can inform progress toward a clinical goal.

A team-based approach to care, important to the Patient Centered Medical Home and medical neighborhoods, increasingly recognizes the role of patients and caregivers as critical members of the care team alongside care managers, providers and administrative staff, with each participant contributing at the top of their capability or license, which further underscores the value of PGHI. Organizations adopting the principles of accountable care are also driving interest in PGHI. With a focus on fee-for-value instead of fee-for-volume, medical practices looking to manage patient care utilization, prevent unnecessary office and hospital visits, avoid the downstream sequelae of hidden medical problems by identifying and treating them early and offer routine care without requiring a face-to-face visit are using innovative approaches to supplement visit-based care. “In-between visit care,” including email and telephone contacts, virtual visits, patient in home and wearable trackers, and remote reminders, offer newly forming accountable care organizations many new opportunities to leverage PGHI. Tracking at-risk patients over time against established goals and metrics is especially promising for proactive chronic condition management using PGHI. Increasing patient financial accountability for health costs and measured patient reported outcomes may also accelerate this trend.

In addition, hospitals and ambulatory care practices participating in federal government stimulus programs for EHR adoption and meaningful use are anticipating additional incentives for PGHI in the next few years. For example, proposed MU3 objectives include the support of patient record amendment requests and the routine collection of PGHI from patients, as the objectives are currently drafted. Some TEP members envision a time in the not-too-distant future when physicians will write prescriptions for devices or apps that help patients reach their therapeutic goals, a natural extension of the behavioral prescription to “walk three times per week for 20 minutes” or “take 2 pills each morning.” PGHI may help accelerate this vision in two ways, as part of (1) screening for patients likely to benefit from an app prescription and (2) monitoring the patient response and participation in the treatment plan.

Societal Trends

TEP members also noted a number of broad, societal trends that are likely to impact PGHI. These include demographic shifts in the U.S., producing an aging population (13.3% of the U.S. population is over age 65) that is anticipated to more than double by 2030 and who will live, on average, an additional 19.2 years past age 65; a more diverse population, both racially and culturally, as minority birth rates exceed non-minority rates; the expansion of non-English languages as the primary or preferred language[6]; and nearly four in ten U.S. adults serving as family caregivers.[7] With disease burden and chronicity both increasing with age, these societal shifts are likely to increase demand for treatment and health-related services, and also mean that more patients, families and caregivers will spend time in self-care and self-management activities to address health concerns.

Communication and sharing of information for decision-making is a critical component of care management and will leverage any useful and available technologies possible. Anticipated growth in mobile phone use, smartphone capabilities, health-related applications and services, and social computing apps (e.g. Facebook, Twitter, Instagram) are speeding and simplifying the process of interacting virtually. The rise in data streams available through social computing, mobile technology use and tracking of routine daily activities (e.g. using the telephone, driving a car, purchasing food), along with greater intentional sharing by individuals of their own data, is fueling intense interest in data aggregation and analysis to improve health. Creating analytics that will process multiple data streams to produce useful and actionable information is a strong focus in research and commercial development that will likely increase demand and broaden the concept of PGHI.

Technology Advances

Members of the TEP identified a number of technology advances they felt would impact PGHI. The most notable ones included the development and growing use of sensors that actively or passively supply relevant clinical data such as biometrics (e.g. blood pressure readings, voice waveform capture), behavioral characteristics (e.g. activity level, geographical location) or environmental data (e.g. toxin exposure, ambient noise). In addition, other data sources that reflect individual activity (e.g. food purchases), social networks (e.g. email, Facebook, Twitter or LinkedIn contacts), life events, personal preferences, financial decisions and retail choices may also be informative by themselves or in combination with other personal or public data.

Mobile devices, whether apps on mobile telephones, tracking devices or wearable computers (e.g. Google Glass), are anticipated to improve the timeliness and ease of data capture and transmittal for use in health-related analysis. As the volume of data expands, technologies to provide automated or semi-automated analysis, reporting, and notification based on the data are already becoming important, such as built-in alerts when a monitoring device registers a critical value or when there is urgency in communicating a significant finding or self-reported information. Cloud-based data and data management services were also felt by TEP members to be important for PGHI because of architectural barriers that may be reduced through more

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[6] U.S. Census Bureau news release: "Most Children Younger Than Age 1 are Minorities, Census Bureau Reports." May 17, 2012. http://www.census.gov/newsroom/releases/archives/population/cb12-90.html

[7] Pew Research Center survey: "Family Caregivers are Wired for Health." June 2013. http://pewinternet.org/reports/2013/family-caregivers.aspx

accessible data, data processing and algorithms ubiquitously available to internet-connected devices.

The fact that 91% of American adults carry and use mobile phones[8] (56% are smartphones) means that a majority of individuals are carrying multifunctional computing and communication devices almost constantly. Through built-in sensors (e.g. accelerometer, microphone, global positioning), native and accessory applications (e.g. symptom loggers, journals, alerts and reminders), and communication tools, mobile phones are extending health-related technology use dramatically. Technology is also becoming less expensive and easier to use, suggesting that age and income are not necessarily barriers to PGHI. According to the Pew Internet Spring Tracking Survey (April-May 2013), 76% of adults aged 65 and older and 86% of households making less than $30,000 per year currently own a mobile phone.[9]

Growing use of patient portals are also drivers for PGHI. By enabling millions of patients to interact electronically and securely with their provider's office or hospital for clinical and administrative health services, barriers are lowered for patients to share symptoms, treatment progress, questions, observations and health information through electronic conversations or file attachments. Many patient portals are adding specific data sharing apps and services to handle PGHI.

IX. Practical Guidance for Implementing Patient Generated Health Information

Preparing for increasing PGHI use among patients, professionals, organizations and health IT systems requires strong leadership and strategy, clear policies and effective adoption practices.

Strong Leadership and Strategy

Incorporating and leveraging PGHI in patient care requires providers, support staff and patients to change their behavior – and change is not easy. A strong case for change is essential and may require initial training or education around the value of PGHI, why the change is important, and PGHI's place in processes designed to improve care, decision-making, documentation and efficiency. Providers, staff, patients, families, caregivers and other stakeholders need to understand the changes that will be taking place and their importance to care improvements and the organization's strategy. A roadmap for change that identifies who is accountable for project and program success, and a technical roadmap that identifies how information systems will accept and manage the flow of new data streams, are essential. Leaders should also recognize and highlight that increasing the use of PGHI can serve to strengthen the voice of the patient in communications, decision-making and care management.

Approaches that raise the likelihood of success include small pilots, rapid iteration, building on successes, tailoring to situational and local requirements and context, setting clear and realistic

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[8] Pew Internet Project, May 2013. http://pewinternet.org/Commentary/2012/February/Pew-Internet-Mobile.aspx
[9] Ibid.

“success criteria” at the start of an effort, and building in measurement so the PGHI project can be evaluated. Placing a focus on the “service” value – respecting and strengthening the patient voice in the care process – as well as improving clinical care helps to anchor the PGHI as part of a broader change effort. Finding ways to engage the patient in a meaningful way to participate in designing and testing approaches to PGHI can help with early success and promoting a culture of partnership. Just as dialogue with patients is key to collaboration on an individual level (during patient care), patient dialogue is also key to the systematic integration of PGHI into practice and patient non-visit activities.

Clear Policies

Policies for the handling of PGHI often evolve from, and coexist with, traditional medical in-person encounters between patient and provider. These typically include the professional’s commitment to “first do no harm,” to thoroughly understand the patient history and examine the patient, to develop an appropriate differential diagnosis, to order appropriate tests and follow up procedures, and to develop a plan of care with the patient and initiate treatment.

When PGHI is used in the context of a clinical encounter (such as pre-visit PGHI), organizational policies should address topics such as what information will be “accepted” by the provider organization from the patient, when (e.g. how far in advance) PGHI should be shared, when (after it is received) PGHI will be reviewed and by whom, how PGHI will be documented in the record and what happens to the process of accepting, reviewing, and documenting PGHI if a future visit does not occur. PGHI received in the context of ongoing care for an established patient may be handled differently than information from a new patient who has never before been seen.

PGHI that arrives in the context of continuous care for an established patient may be handled similarly to information communicated via a phone call or letter. Policies for handling biometric data such as glucose level, patient weight, blood pressure, or other status indicators, whether actively or passively captured during remote monitoring, should identify the frequency and mechanism for communicating the data, who will be notified and is responsible for reviewing the information, and what happens if data arrives unexpectedly or exceeds the capacity of the receiver to review and interpret it. Policies should acknowledge that time is required to review the PGHI, to judge its relevance in the context of patient care, and to avoid mishandling that might raise liability concerns.

Policies that make clear the accountability for security and confidentiality of PGHI as it moves from the patient into the realm of the provider organization are important. Patients, caregivers and all stakeholders in PGHI want reassurance that the confidentiality of personal data will be maintained, that information they have shared will reach and be used appropriately by the intended recipients, and that actual use of information will align with its intended use. Agreements may be more formal in the case of research data that is regulated by an institutional review board, or more informal in the case of an email to a provider reporting how an antibiotic seems to be working, but in each context, establishing and maintaining trust and confidence among users is critical.

This policy area is evolving. While senior leadership commitment to protecting data and safeguarding the interests of users in a visible and believable way is paramount, policies that describe the intended, allowable and prohibited uses of PGHI may vary from one situation to another. Organizations should establish at what point PGHI is considered protected health information (PHI) and should then provide the same protections that other PHI would receive. Strong technical and procedural safeguards should be established before PGHI is received to assure that the source is identified and authenticated, the patient identity is verified and non-repudiable and the transmission of PGHI is encrypted with data integrity protections in place. Matching PGHI to the correct patient in the provider's EHR is essential but not always easy, and reassignment of PGHI to another patient record may be necessary in the case of an error. Whether PGHI is being stored passively, being processed, or in transit, accountability and verification policies and methods that allow patients to review a record of transactions involving their data should offer clear mechanisms for reporting and investigating a patient concern, a provider concern or a potential breach.

Effective Adoption Practices

Implementing PGHI as a component of health IT adoption requires attention to training, support, system configuration, provider workflow, patient and caregiver workflow, and messaging patterns and responsibility within a practice. In cases in which patient information is already being collected from the patient in some manner (such as home blood pressure shared on paper or via email, secure messaging or telephone voicemail), the shift to PGHI in an electronic form may fit an existing workflow. In cases in which patient information is not routinely collected (e.g. family history, medication review post-visit, daily activity level), the shift to PGHI requires more process design, piloting and iterative adjustments to be effective and sustainable.

Adapting workflow to accept and manage PGHI often requires iterative changes in both the use of technology and in the human tasks that define the workflow. Valuable learning takes place not only from successes, but especially from gaps and failures. As PGHI becomes incorporated into the routine of medical practice, it is important to capture the learning and, over time, to get it right.

No single technology approach for PGHI is appropriate for all patients or provider workflows. Provider and organizational workflows and policies naturally vary. PGHI captured electronically (e.g. by email, secure messaging, device interfaces, phone texts, smartphone apps and other evolving modes), the focus of this report, often coexists with useful information captured by other methods (e.g. by handwritten telephone message, letter, fax, printed or handwritten report). Sometimes there may be several electronic forms rather than one. Coexisting forms of information is not ideal, but is often hard to avoid. Policies, workflows and communication about PGHI must balance the diverse needs of individuals with the need for common and scalable approaches.

Incorporating PGHI into daily use requires attention to the clinical information (i.e. how it is captured, stored electronically, transmitted, stored in EHRs or in proximity to EHRs and used) as well as to patient communication workflows. Message handling (e.g. telephone answering machines, front office triage, nurse triage, email and secure message auto replies, message queuing and routing, and direct physician contact) often will be adjusted as PGHI flows into a medical setting. Guidance to information handlers and to patients to help avoid the use of electronically submitted PGHI in time-sensitive situations (e.g. 911 or when an immediate response is needed) is strongly recommended. Patients should be reminded that any urgent or time-sensitive information they might wish to share with a provider should be communicated directly rather than via an electronic asynchronous channel such as secure messaging or a PGHI submission, and that PGHI is typically reviewed within one to several business days after it is received, depending on staffing and context.

Staff and providers responsible for reviewing PGHI should do so consistently and within clearly stated timeframes or service levels, with escalation if delays are experienced. This helps to meet patient expectations, ensures that information receives a timely review by the provider and helps to identify any unanticipated PGHI volume that may require additional resources.

The TEP recognized that the value of PGHI is sensitive to many factors, including the content of the PGHI, its timing, patient and provider workflow, technology usability and user expectations. For example, patient-updated medications sent to a provider may enhance safety if a dangerous drug interaction is avoided, or may have no perceived benefit if not. Home-monitored blood pressure can have high value if a medication adjustment is modified or canceled based on the new information, or is of no value if not used in decision-making or planning. A patient may be disappointed to learn that PGHI sent to their clinician was not reviewed, even if the PGHI would have had no impact on a medical decision. Similar to other information in the clinical record, it is reasonable to anticipate that sometimes PGHI will be very useful, but not all the time. Setting appropriate expectations among patients and providers is important for positioning PGHI for success. Engaging the PGHI end-users in the design process can help to ensure that the process of collecting and reviewing PGHI is of high value.

The breadth of content that may be contained in PGHI (i.e. almost any type of information that a patient can report) makes it difficult to generalize about the use of data standards used to encode PGHI. In some cases, such as when PGHI contains medication data, it is advisable to use standards that allow matching of PGHI to EHR medication data such as RxNorm. However, depending on the context of use, it may not be advisable or necessary to require the patient to identify a medicine to the same level of specificity as a provider writing an e-prescription. If the intended task is to ask the patient to review an EHR medication list, responding with PGHI, then matching each patient response to an item on the EHR medication list makes sense. In short, data standards will likely evolve differently for specific types of PGHI.

Whatever the mechanism for collecting PGHI from patients, a provider organization can begin the process with a small, limited duration pilot that will help uncover good and best practices as well as problem areas. Well-designed pilots have a clear beginning and endpoint, metrics for success that are assessed at the endpoint, full commitment among participants (essential, since the primary goal is to learn) and visibility among more senior staff as well as patient leaders. From a patient/caregiver perspective, the expectations, risks and benefits of participating in a pilot should be clearly communicated, with opportunities to participate in giving feedback and helping to refine the approach to capturing and sharing PGHI.

X. Areas for Additional Work

Additional work will be needed in several key areas to advance the use of PGHI in health and care activities, including (a) the value of PGHI, (b) technologies and architecture, (c) measurement, (d) promising practices and (e) policy areas.

The Value of PGHI

Information from the patient and the patient experience as an essential component for health decisions is not a new concept. However, increasing the use of PGHI in routine care depends in part on demonstrating the role of PGHI in *triple aim* care – better health for populations, reduced per capital cost for care and an improved patient experience of care, including measurable care quality and satisfaction. It is clear that many safety issues, gaps in treatment, suboptimal provider decisions and mistargeted patient behaviors reflect missing or misunderstood information that could be available and applied at the right point in time through PGHI. The value of PGHI is not universal – it often varies with situational factors. Work to identify valuable uses of PGHI in the specific context of an individual's care and in the broader context of care across a population is needed. A better understanding of appropriate secondary uses of PGHI would also be helpful.

Technologies and Architecture

At its core, the flow of information in an electronic form is a vexing challenge in healthcare. Technology and process improvements at each step in the flow, including capturing, transmitting, receiving, documenting, storing and analyzing PGHI, are needed to reduce the cost and complexity while improving the usefulness, timeliness and experience of using PGHI in care and health activities. Many types of health information (including PGHI) captured electronically in one system are needed elsewhere, but transfer to a receiving system can be difficult and/or costly. Advances in technology are needed that will improve the structure, coding, metadata and secondary use of PGHI to make it better suited for machine processing. Methods for recording and preserving the source of PGHI (provenance) as it flows through systems and processes for handling it are not yet mature. Another important area, decision support algorithms to reliably identify situations requiring human notification and review of PGHI, will be increasingly needed to improve workload and reduce liability concerns. Voluminous (or even modest amounts of) PGHI may exceed the human resources available, making technologies that help improve workload essential.

Measurement

Measurement to understand when PGHI is collected, how it is used well, gaps in use and opportunities for improvement are critical to shaping policies and strategies in the future. Members of the TEP felt that consistently measuring the impact of PGHI on desired health outcomes and/or processes would play a strong role in making the case for PGHI and in identifying opportunities for greater impact within each context of PGHI use. For example, sometimes the PGHI itself is important to care. Improved measurement would help in understanding the extent to which PGHI is useful for improving information accuracy, completeness and computability across different PGHI examples. In other cases, the information may be important, but only if it has an impact on decisions, or provider understanding, or patient motivation, or participation in clinical trials, or preventing adverse events. Measurement is needed to help identify whether having access to data such as at-home blood pressure readings or patient preferences captured routinely at the start of a care episode will impact treatment decisions. Measurement and evaluation that help to identify preference-sensitive areas to patients and providers, and show when levels of patient and provider awareness, knowledge, motivation or behavior change, need further work.

Promising Practices

Understanding promising practices in using PGHI is an ongoing area of learning, especially because the information gathered may apply to so many different clinical, administrative, self-care and health focused scenarios. Individual patients and providers will have to determine when to use questionnaires, biometric devices and environmental data in medical decision-making. In the future, it will be feasible to collect information on many different kinds of PGHI, such as patient preferences, patient abilities, communication preferences, decision-making styles, risk aversion or adherence style. Providers and patients will need to determine when to use preexisting PGHI, or when an update should be requested. Additional work will be needed, as electronic records become more and more transparent to the patient and providers, to improve the way PGHI is communicated effectively and meaningfully to all parties when it is needed. Mechanisms are also needed to share learning that takes place in one practice or hospital setting, or one community of patients, with others, ultimately informing the development of a true Learning Health System.

Policy Issues

A number of policy-related issues need to be addressed going forward. Provider concerns about potential liability associated with PGHI should be explored to determine whether some concerns diminish with practice experience and others may better be addressed through policy. For example, uncertainty about how to consistently document PGHI in the provider's medical record, or whose wishes should prevail if a patient and a provider disagree on what to document, might increase with growth in PGHI.

Liability and privacy protections are also relevant to patients and personal caregivers who use second party or third party tools to manage their PGHI – especially if the tools do not work properly, raise the risk of making a poor decision or lead to harm. Similarly, as federated information systems rely on data and decision logic that are distributed across multiple systems, there may be policies needed to promote clear accountability.

If the rising use of PGHI is desirable, policies that stimulate its growth through reimbursement approaches, the use of standards and common practices, and meaningful use incentives may be appropriate and need further development.

Policies may also shape, intentionally or unintentionally, decisions about which validated tools are used routinely for collecting PGHI, which decision support algorithms are favored when evaluating data, and how transparent the decision outcome will be to the providers and patients who rely on the algorithms and data. Discussions about the merit of full transparency of data, of algorithms, and of data collection instruments are likely to shape policy considerations in the future. Policy decisions around appropriate methods for identity-proofing, maintaining data security and confidentiality, enabling a patient to delegate authority for PGHI to be submitted on their behalf or restricting access to certain data depending on the patient's relevant age of consent will also be needed to ensure PGHI can become widely accepted and used.

XI. Conclusions

PGHI that serves providers and patients is being welcomed in diverse clinical settings and its acceptance is expected to accelerate in response to provider, consumer, organizational and societal drivers. There are a number of important areas where PGHI can make a difference, many illustrated in the examples and use cases in this report.

According to the TEP, physicians overall have mixed reactions to PGHI. Some providers are extremely interested in using PGHI to avoid common problems in healthcare, such as delayed treatments, faulty decisions, information gaps and misinformation spread from recopying that arise from missing or inaccurate information. However, at the same time, physician interest is often tempered with concerns about workload, compensation, liability and how to avoid unrealistic expectations about information review. Providers and patients with experience – especially those who already incorporate PGHI into the routines of care – are generally quite favorable about its promise. Where PGHI is in regular use, the policies, workflow and practices have been established; where it is not in regular use, this work has yet to be done. Emerging good practices identified through this project confirm the successful adoption and incorporation of PGHI through policies in multiple practices. The technical methods to capture, store, review, document, and respond to PGHI are context-specific and vary even among individual providers and patients.

There are still many barriers to present-day PGHI, including financial disincentives, workflow disruption for providers, physician worries about liability and workload, incompatible technologies for patients and providers, a lack of technical standards and an underdeveloped case for change. Limited patient health literacy, technology access and stature in the patient-physician relationship may reduce the usefulness or availability of PGHI or the patient's ability to participate – but these barriers are shifting.

A broad range of data types, workflows, policies and approaches to using PGHI in daily practice are needed to accommodate the many different examples of valued use. Given that providers have limited time to review and incorporate PGHI into the workflow of clinical care, automated pre-analysis of PGHI will play an essential role. Transforming large amounts of data in multiple data streams into useful, digestible amounts of information will be challenging. Policies and practices that support the automated work in balance with human review of PGHI will be essential as the PGHI volume grows.

The findings in this report reflect that PGHI implementation is in an early stage of active development – evolving from modest use in selected care settings with some patients to more consistent and widespread use. PGHI has the potential to support significant improvements in care affecting cost, quality, safety, efficiency and the experience of care. Ultimately the human benefit from PGHI, at a reasonable cost, is what matters most.