Integrating patient voices into health information for self-care and patient-clinician partnerships: Veterans Affairs design recommendations for patient-generated data applications

Susan S Woods, Neil C Evans, Kathleen L Frisbee

ABSTRACT

Electronic health record content is created by clinicians and is driven largely by intermittent and brief encounters with patients. Collecting data directly from patients in the form of patient-generated data (PGD) provides an unprecedented opportunity to capture personal, contextual patient information that can supplement clinical data and enhance patients’ self-care. The US Department of Veterans Affairs (VA) is striving to implement the enterprise-wide capability to collect and use PGD in order to partner with patients in their care, improve the patient healthcare experience, and promote shared decision making. Through knowledge gained from Veterans’ and healthcare teams’ perspectives, VA created a taxonomy and an evolving framework on which to design and develop applications that capture and help physicians utilize PGD. Ten recommendations for effectively collecting and integrating PGD into patient care are discussed, addressing health system culture, data value, architecture, policy, data standards, clinical workflow, data visualization, and analytics and population reach.

Keywords: Patient-generated data, self-care, personal health record, consumer participation, activities of daily living, patient-relevant outcome, physician-patient relationship, patient-reported outcome, mobile phone app, electronic data capture

INTRODUCTION

Most people interact with a healthcare system for only mere minutes each year. Even individuals with complex health issues and multiple providers must learn to cope on their own, managing their own health and care day-to-day in between appointments with clinicians. When individuals do interact with the healthcare system, these interactions often follow the agenda of the healthcare providers, who, amidst their own busy schedules, focus on diagnosis, treatment, and quality measures. Therefore, patients’ electronic health records (EHR) embody encounter-based data, which are filtered through the clinicians’ eyes and are often missing important contextual and personal information about the patient. Providers underestimate patients’ “invisible work” as well as patients’ expertise about their own health issues and self-care.

Among US adults, 87% use the Internet, 90% own a cell phone, and, currently, 64% own a smartphone (up from 35% in 2011). New health-related mobile applications (apps) are published at a rate of approximately 1000 every month. As these always-on and always-carried devices become the gateway to networked connections, the patient. Providers underestimate patients’ “invisible work” as well as patients’ expertise about their own health issues and self-care.

VA’S JOURNEY TOWARDS PGD INTEGRATION AND UTILIZATION

VA is a national pioneer of providing patients with electronic access to their health records. In early 2015, VA passed a 2-year milestone of offering patients the ability to download clinical notes and test results through My HealtheVet. The VA Connected Health Office has committed to developing web and mobile apps that allow patients to collect PGD and share it with their healthcare providers, thereby using PGD to foster patient self-care and support virtual care delivery. This paper presents perspectives gained from the early stages of our endeavor and offers design recommendations for effectively collecting and integrating PGD into patient care.
patients for better care. With a vision that PGD would become a core component of patient care, we sought to identify “what patients want from their care,” explored clinician perspectives on PGD, and developed a taxonomy of data types, contributing to a path forward for integrating PGD into clinical workflows.

Patients Voice Their Care Needs

To bring patient perspectives on how to “collect and use PGD for connected health,” a team of VA researchers, informaticists, and human factors experts drew from and expanded upon an existing rich data source — The Voice of the Veteran Report. The Report summarized military Veterans’ views about the most important characteristics of healthcare, based on the responses of 54 focus groups conducted with Veterans across the United States in 2011. Although technology was not the focus of the report, the focus group participants discussed healthcare issues that have implications for digital health tools. Our team reviewed interview transcripts from The Voice of the Veteran Report, extracting statements related to communication, information-sharing, and transactions with VA. These statements were subsequently synthesized into simple, specific patient needs. The team used design thinking to extrapolate potential technology solutions to meet these needs, regardless of our current technological capabilities. For example, the patient statement, “send me information before my appointment date” was synthesized to a patient’s need to be notified of PGD – ranging from updating contact information, to be acceptable. Clinicians felt that it is essential that patients be informed that staff would not regularly review the data they submit, that the tools reinforce patient feedback to drive self-care, and that patients be alerted to seek medical attention if PGD breached particular parameters.

Clinical Staff Perspectives on PGD

The VA Connected Health Office sought input from doctors, nurses, pharmacists, researchers, and other clinical staff through robust conversations, to create a framework to integrate PGD into patient care. Participants in these conversations generally agreed that PGD would support patient self-care for chronic conditions and improve patient satisfaction. The participants’ views on PGD’s usefulness varied depending on the type of data. Clinicians wanted to distinguish PGD from other health record data as well as to avoid notification burden. Many anticipated that clerical staff would review administrative PGD and that nursing staff would review clinical PGD, mirroring secure email processes.

Clinicians identified two information models for the clinical review of PGD. Clinicians primarily wanted to review PGD on-demand at the point of care, before or during a patient encounter. Most clinicians stated that they would also find a PGD prescription/subscription model, in which clinicians would “prescribe” an app for a patient and set their own preferences to receive a notification when PGD was available, to be acceptable. Clinicians felt that it is essential that patients be informed that staff would not regularly review the data they submit, that the tools reinforce patient feedback to drive self-care, and that patients be alerted to seek medical attention if PGD breached particular parameters.

Clinicians also identified barriers to clinical adoption of PGD, such as data overload, managing patient expectations, and the extra work

<table>
<thead>
<tr>
<th>Table 1: Potential Technology Solutions Extrapolated from Patient Needs Expressed by Veterans in the 2011 Voice of the Veteran Report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific need (patient voice)</td>
</tr>
</tbody>
</table>
| Personalize my care | Personal profile data entry (web/mobile)
| Notify me | Automated text/SMS, e-mail, and phone calls
| Make sure someone responds to me | Secure messaging, online chatting
| Use my time wisely | Build environments to promote digital tools
| Help me care for myself | Automated bidirectional texting protocols
| Help me understand my health information | Health risk assessment with automated feedback
| Make it easy for me to send you information | Tailored prevention reminders
| Let me see all my health records | Shared health record (tests results, notes, etc.)
| Let me add to my health record | Shared computer screens (remote and in-person)
| Help me manage my medications | Shared health record (tests results, notes, etc.)
| Help me manage my appointments | Secure messaging, online chatting
| Help me understand my health information | Secure messaging, online chatting
| Help me access my help me | Secure messaging, online chatting
| Help me connect with others | Secure messaging, online chatting
| Help me share my information with other (non-VA) providers | Secure messaging, online chatting
| Make the information I provide available across the system | Secure messaging, online chatting
| Customize how I get information | Secure messaging, online chatting
| SMS, short message service; VA, Veterans Affairs. |
| aDigital tools that include patient-generated data. |
| bDigital tools that perform transactions. |
for clinicians involved in reviewing, triaging, and acting on PGD. Although some clinicians expressed hesitancy to utilize PGD if they perceived these data to be inaccurate, others felt that PGD would be more accurate and complete than data collected from the patient in person. Finally, clinicians thought that patients might be discouraged from sharing information if they perceived that their providers had not reviewed their PGD or if patients did not receive timely feedback from a clinician after submitting their data.

PGD Taxonomy
The team developed a PGD-specific taxonomy, covering areas such as: personal information, life goals, values/preferences, health assessments, symptoms, biologic measures, patient-reported outcomes, patient satisfaction, and family history. The full list of data elements is shown in Table 2. The group concluded that patient data exchanged between providers, even if sharing a patients’ data requires patient permission, would not be considered PGD.

RECOMMENDATIONS
Informed by our early efforts to develop a road map for collecting PGD and integrating it into clinical care, and by innovation occurring at other health systems, it became clear that successfully incorporating and using PGD as part of patient care requires a number of interrelated efforts. Collecting, storing, and using PGD became key issues driving the following recommendations.

Advance Organizational Culture Change
Introducing PGD into routine care is disruptive and will take time and effort to normalize. PGD challenges the authority of clinician data and legitimates the power of patient contributions to health records. To integrate PGD into clinical care, health systems need to create a culture in which clinicians believe that PGD is integral to quality care. Health leaders should advance novel types of synchronous and asynchronous interactions with patients, require that training in new skills be added to staff education, and allow for any necessary changes to clinicians’ schedules to deal with PGD (including dedicated time to perform virtual “desktop medicine”).

Find Shared Value
Apps that collect and render PGD at-scale will exist at the intersection of demonstrating clinical benefits and meeting patient needs. Clinicians are likely to accept types of PGD that fit a biomedical model, eg, blood pressure and blood glucose readings. Data that help clinicians meet performance goals, such as patient depression screenings, will also be embraced – particularly if these data satisfy collecting measures for practice performance. PGD can also personalize patients’ health record data, imparting often-concealed contextual information and, thus, providing a more complete snapshot of a patient. Health systems can use evidence or collect data from their patient populations and clinical groups to guide their approach and prioritize PGD integration strategies. In addition, the value of PGD extends beyond clinical goals, eg, remote data collection can substitute for visits with a clinician, thereby helping patients avoid the costs associated with traveling to a potentially far-away clinic.

Establish Intended Use
Health systems must develop a clear and common understanding of the purpose of each PGD app, how data is collected, who is authorized to access the data, and when (if at all) data will be reviewed. Although using tools that include PGD can foster stronger partnerships between patients and clinicians, most of these data do not need to trigger notifications or alerts to healthcare teams. PGD should be used for patient self-care, with patients and their delegates having the primary responsibility for tracking the data. To realize these goals, PGD tools should require in-app notifications and alerts to patient users, as well as information on when to seek urgent care, for continuous self-care and learning.

Table 2: Patient-Generated Data Taxonomy and Data Elements

<table>
<thead>
<tr>
<th>Data type</th>
<th>Possible data elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal profile</td>
<td>Life goals, values, “who I am,” “what matters to me,” preferred name, caregiver(s), photograph</td>
</tr>
<tr>
<td>Preferences</td>
<td>Notifications (eg, text reminders, broadcast messaging)</td>
</tr>
<tr>
<td></td>
<td>Communication (eg, secure e-mail, online communities)</td>
</tr>
<tr>
<td></td>
<td>Delegation or individual(s) acting on the patient’s behalf</td>
</tr>
<tr>
<td>Health data review</td>
<td>Comments on review of health record data – medications, allergies, problem list, etc.</td>
</tr>
<tr>
<td>Health history</td>
<td>Supplemental medical, surgical, and military history</td>
</tr>
<tr>
<td>Family history</td>
<td>Supplemental family history</td>
</tr>
<tr>
<td>Patient agenda</td>
<td>Previsit agenda identifying issues and needs</td>
</tr>
<tr>
<td>Medication information</td>
<td>Review of current health record data</td>
</tr>
<tr>
<td>Health assessment</td>
<td>Prescription and over-the-counter medication inform, externally prescribed and/or obtained</td>
</tr>
<tr>
<td>Biometric tracking</td>
<td>Health risk appraisal</td>
</tr>
<tr>
<td></td>
<td>Condition screening (eg, depression)</td>
</tr>
<tr>
<td>Symptom tracking</td>
<td>Blood pressure, pulse, weight, blood glucose level, temperature, etc.</td>
</tr>
<tr>
<td></td>
<td>Telehealth uploaded via app or device</td>
</tr>
<tr>
<td>Patient reported outcomes</td>
<td>Symptoms, condition reporting, and side effects</td>
</tr>
<tr>
<td></td>
<td>Patient-reported targeted assessments</td>
</tr>
<tr>
<td>Multimedia observations</td>
<td>Condition, quality of life, and experience assessment</td>
</tr>
<tr>
<td>Care goals</td>
<td>Photograph or video assessment to support a virtual healthcare visit</td>
</tr>
<tr>
<td>Patient experience</td>
<td>Specific steps or SMART goals</td>
</tr>
<tr>
<td></td>
<td>Patient review of healthcare team goals</td>
</tr>
<tr>
<td>Documents and forms</td>
<td>Patient satisfaction with their care or their customer experience</td>
</tr>
<tr>
<td>Ad hoc requests</td>
<td>Advanced Directive and other documents</td>
</tr>
<tr>
<td>Administrative data</td>
<td>Request for health data amendment</td>
</tr>
<tr>
<td></td>
<td>Demographics, contact information, and caregiver(s)</td>
</tr>
</tbody>
</table>

SMART, specific, measureable, attainable, realistic and timely.
Establish Enterprise PGD Architecture
An integrated technology platform for a health system should be capable of collecting data manually and through devices, have open application program interfaces (APIs) that leverage both PGD and clinical system data, and include dynamic, real-time data that are interoperable across applications. As health systems gain experience with PGD, new types of data and creative methods of using those data will emerge. Collecting and storing video and other multimedia data or integrating a technology platform with telephony systems and cellular network capabilities, such as short message service/multimedia messaging service (SMS/MMMS), raise challenges for platform architecture, sizing, and technologies used to deliver PGD services. Close working relationships between clinical staff, information technology staff, and developers are essential to overcome these challenges.

Evolve New Standards and Terminology
PGD should be collected and rendered in standardized ways whenever possible, ensuring that data can be received and understood by both patients and clinical staff. Future work in this field must build on the evolving national efforts to advance industry-wide standards for PGD, such as data provenance. Metadata is needed to codify patients as data suppliers, allowing clinicians to differentiate patient-sourced from electronic health record data. Health systems, organizations, and vendors must collaborate on development processes for PGD collection and integration technologies that enforce existing standards. Consumer vocabularies should continuously improve PGD utility, using methods such as consumer crowd-sourcing.

Drive Novel Policies and Procedures
Health systems need effective governance and data stewardship to support the integration of PGD into digital tools. Decision makers must balance enterprise requirements that determine what data are defined as PGD and how they are used, with guidance by clinical stakeholders on best practices to address and review PGD. Such practices are likely to change over time as healthcare systems gain experience with and accrue evidence on the impact of PGD on patient care. Technical requirements that expose health systems’ expectations for PGD “customers” – both patients and clinicians – should align with non-technical requirements that inform how these data are used.

Use Participatory Design to Enhance Clinical Workflow
Patients have always shared information with clinicians verbally and on paper; therefore, digital tools bringing in PGD through new and robust channels should not create unsustainable workflows. A key strategy for converting these data into valuable information is to ensure that nurses and non-physician staff contribute to the design of PGD tools and workflow solutions for PGD, as they are likely to play an essential role in reviewing and processing incoming PGD. Healthcare team members may fear that integrating PGD further into clinical care will result in excessive amounts of data that require review in a timely manner. PGD app functions that facilitate protocol-enabled care alongside traditional triage activities will allow non-clinician staff to efficiently use PGD.

Innovate on Data Visualization and Analytics
To be useful, PGD must be transformed into actionable information. Valuable functionality includes real-time notifications for patients and their delegates and advanced decision support that interfaces with clinical applications. Although data visualization and predictive analytics related to PGD are in their infancy, the field urgently needs to create usable and highly customizable user interfaces for PGD apps. Collaborations with experts outside of the healthcare field may prove fruitful for this endeavor, because skilled professionals working in the energy, education, commerce, and other disciplines are developing “big data” designs and analytics for both individuals and populations. In addition, human factors engineers should be mandatory contributors to PGD app development efforts.

Optimize Clinical Documentation
Externally sourced health data creates both challenges and opportunities for clinical information systems and documentation. Data gathering must not only ensure patients’ privacy and data security, but also be done via trusted and recognized technologies. PGD offers unprecedented prospects for patients to have the authority to contribute content to their own health records. PGD apps should allow for clinicians to pull extracts or summaries from aggregated PGD into a patient’s health record, using structured and non-structured data, in ways that minimize clinician workload while creating a truly shared patient health record.

Reduce Disparities
Not all patients have the desire or capability to access digital tools. Mitigating disparities in how services are delivered to patients remains of the utmost importance, even as the digital divide between patients and physicians narrows. Population reach can be optimized by developing usable tools for the point of care (mobile devices in exam rooms), by embracing “low-tech” solutions such as texting, and offering support services to technology users. Health systems must monitor PGD-related usage and benefits across populations and remain agile, so that they can change course as needed.

CONCLUSIONS
Rapid advances in technology are democratizing healthcare, empowering patients to be more active participants in maintaining their own health. Tools that capture data directly from patients will meet their desire to easily share information and will result in more complete patient health records. As patients generate data, much of it through connected devices, the volume of patient information will rise rapidly. Pioneers in the field of PGD, such as VA, are uniquely positioned to develop technical solutions to collect and manage PGD. Health providers and systems, large and small alike, can drive policy, user design, and clinical workflow solutions that amplify patient voices and offer methods to deliver better patient care.

CONTRIBUTORS
S.S.W. conceived of and led the drafting of the article. All authors made substantial contribution to the concept and the development of the content. All authors approved the final manuscript and agreed to be accountable for all aspects of the work and the integrity of the content.

FUNDING
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

COMPETING INTERESTS
None.

REFERENCES


