Value of Patient-Generated Health Data (PGHD)

Patients are at the center of healthcare, yet healthcare reform initiatives through federal and state programs are largely directed at providers and payers. These programs (e.g., accountable care organizations (ACOs), new payment programs) are targeted to help meet the "**triple aim**"[1]: improving the patient experience of care; reducing the overall cost of healthcare; and achieving and maintaining a healthier population of citizens. Since "**99 percent of patient activity happens outside of the hospital or clinic, beyond the scope of the [electronic health record] EHR**",[2] it is evident that information collected directly from patients is increasingly important. While patients are willing to share this data with their clinicians, few are able to do so due to barriers, such as lack of user-friendly applications; patient portals not having the capabilities to accept PGHD; stand-alone applications not integrated into clinical information systems or not part of the clinician workflow; and clear understanding of the privacy of the data.

This briefing will:
  ➢ Define PGHD
  ➢ Demonstrate the value of PGHD
  ➢ Review the key obstacles from a provider, organization and patient perspective

What is Patient-Generated Health Data?
According to a **National eHealth Collaborative Technical Expert Panel**, [3] PGHD is health-related data-created, recorded, gathered or inferred by or from patients, family, personal caregivers or designees to help address a health concern. **Figure 1** shows the types of data PGHD can include.

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[1] Healthcare Executive (Institute for Healthcare Improvement): Triple Aim, Optimizing Health, Care and Costs, 2/2009; http://www.ihi.org/engage/initiatives/TripleAim/Pages/default.aspx

[2] Brian Drozdowicz; Why Moving Beyond the EHR is Needed For Population Health; April 9, 2014 http://ehrintelligence.com/2014/04/09/why-moving-beyond-the-ehr-is-needed-for-population-health/
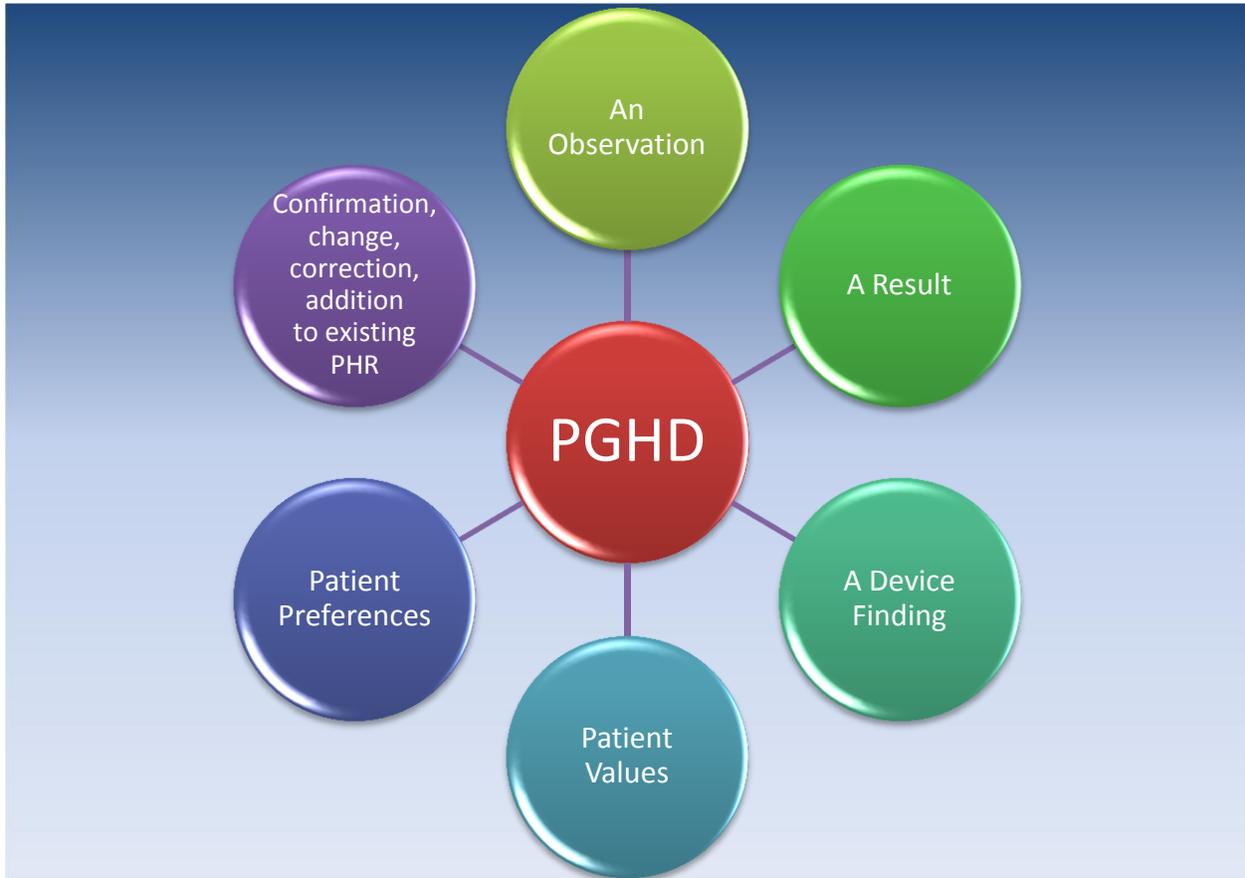
Figure 1: Types of PGHD

PGHD is not a new phenomenon**.** Patients have always recorded and shared some form of information on their health and wellness with their provider and other members of their healthcare team. For example, whenever a patient reports medical and family health history, that information is PGHD. When the patient describes a personal medication list or comments on medication side-effects, that information is PGHD. When the patient's family caregiver expresses concern about recent new symptoms, that information is also PGHD.[3]

The Empowered Patient

Today, technology enables tracking of wellness data that can be shared with a provider via the internet or a patient portal that feeds an electronic health record (EHR). At home, monitoring equipment can keep a digital record of results that can be sent wirelessly to the provider or an intermediary data-holder without the patient ever interacting with it.

PGHD provided by patients and caregivers complements clinical data to offer a comprehensive view of an individual's health. PGHD can improve the accuracy of data stored in an EHR as

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[3] HIMSS, National eHealth Collaborative Technical Expert Panel Final Report, December 2013; http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28740

demonstrated in Geisinger Health System initiative that allows patients to provide electronic feedback on their medication lists' accuracy before a doctor's visit.[4] Simultaneously, that feedback option empowers patients and their caregivers to be active partners in their health and healthcare. When patients share their health goals (**Figure 2**) with the clinical team, they provide information that helps put their needs into context.
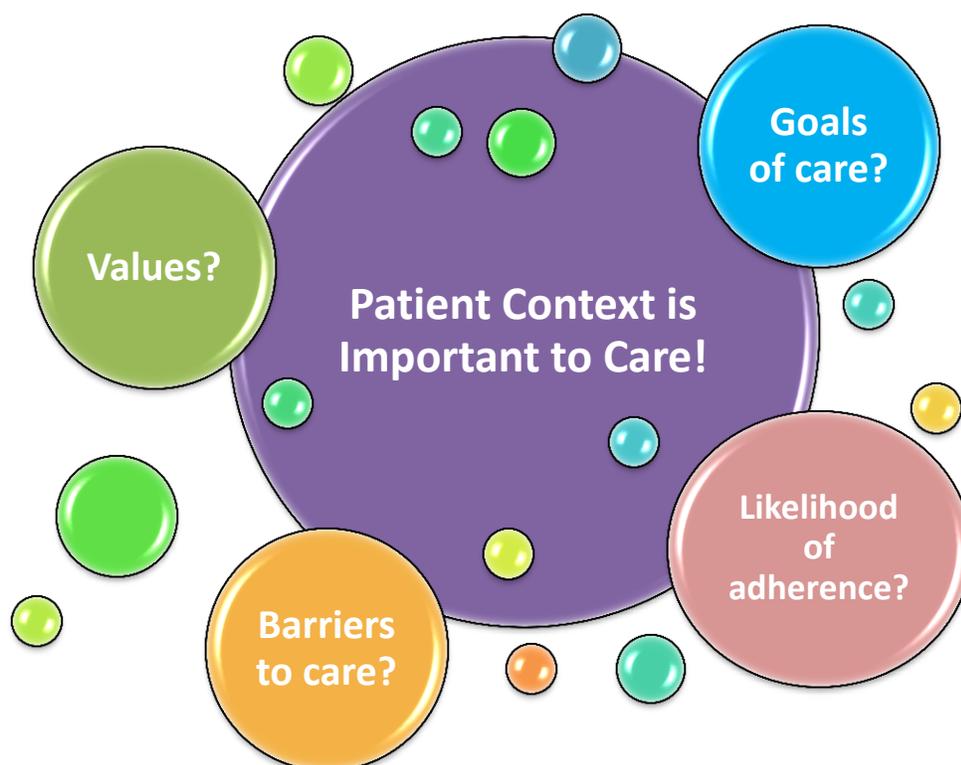

Figure 2: Patient Context is Important

Patients also use technologies, such as personal health records, portals and mobile applications to aggregate and disseminate data. This is particularly valuable when a patient sees multiple providers at different health systems that use EHRs from different vendors. As an example, **Figure 3** describes the different perspectives and priorities for providers and breast cancer patients.

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[4] Marla Durben Hirsch: Patient review of medication lists can improve accuracy of their EHRs; October 6, 2014
http://www.fierceemr.com/story/patient-review-medication-lists-can-improve-accuracy-their-ehrs/2014-10-06
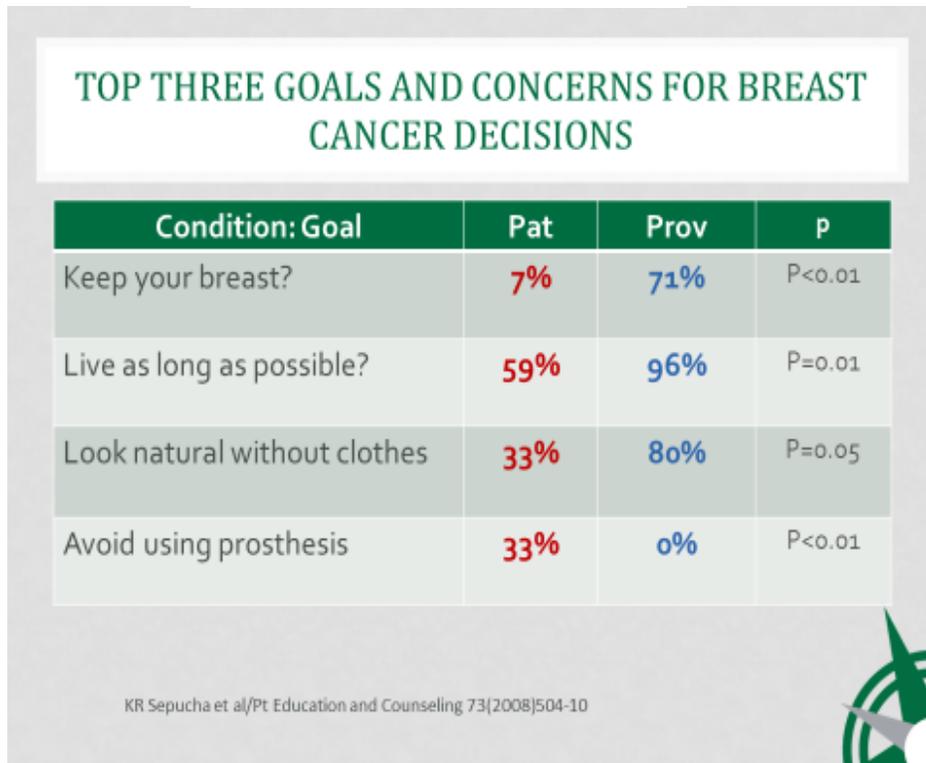
Prov = Provider; Pat = Patient

TOP THREE GOALS AND CONCERNS FOR BREAST CANCER DECISIONS

Condition: Goal	Pat	Prov	p
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

KR Sepucha et al/Pt Education and Counseling 73(2008)504-10

FIGURE 3: Top Three Goals and Concerns for Breast Cancer Decisions[5]

PGHD has been proven to reduce readmission rates, hospitalization days, and lower cost. The **Care Beyond Walls & Wires**[6] pilot project through the Northern Arizona Healthcare system investigated new care delivery models that utilized mobile technologies. Through the use of mobile devices and the application of secure texting they were able to:

- Decrease readmissions by 44%;
- Decrease in average number of days hospitalized by 64%; and
- Decreased average total charges by 72%.

Patients are now using self-monitoring devices and tools to improve their health, which is a welcome sign for providers – especially those participating in accountable care organizations. However, patients are willing to share the results with providers only if they trust that this information will: be private and secure, improve their care and lower the cost of their care. As providers accept more financial risk, self-monitoring devices can help keep the patient: living healthier, and longer, while also, preventing or delaying an acute episode of care.

Challenges to use of PGHD

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[5] K R Sepucha et al/Pt Education and Counseling 73(2008)504-10;
http://www.clevelandclinic.org/collective/postproceedings/Mon_420pm_Wexler,%20Richard.pdf
[6] Connect2014 by Qualcomm Life; Care Beyond Walls & Wires; Gigi Sorenson, RN, MSN;
http://www.qualcommlife.com/connect/pre-con/GigiSorenson_PreCon_NAH_FINAL.pdf

There are many concerns surrounding the use of PGHD from the clinician, organization and patient perspectives. **Figure 4** depicts such concerns:
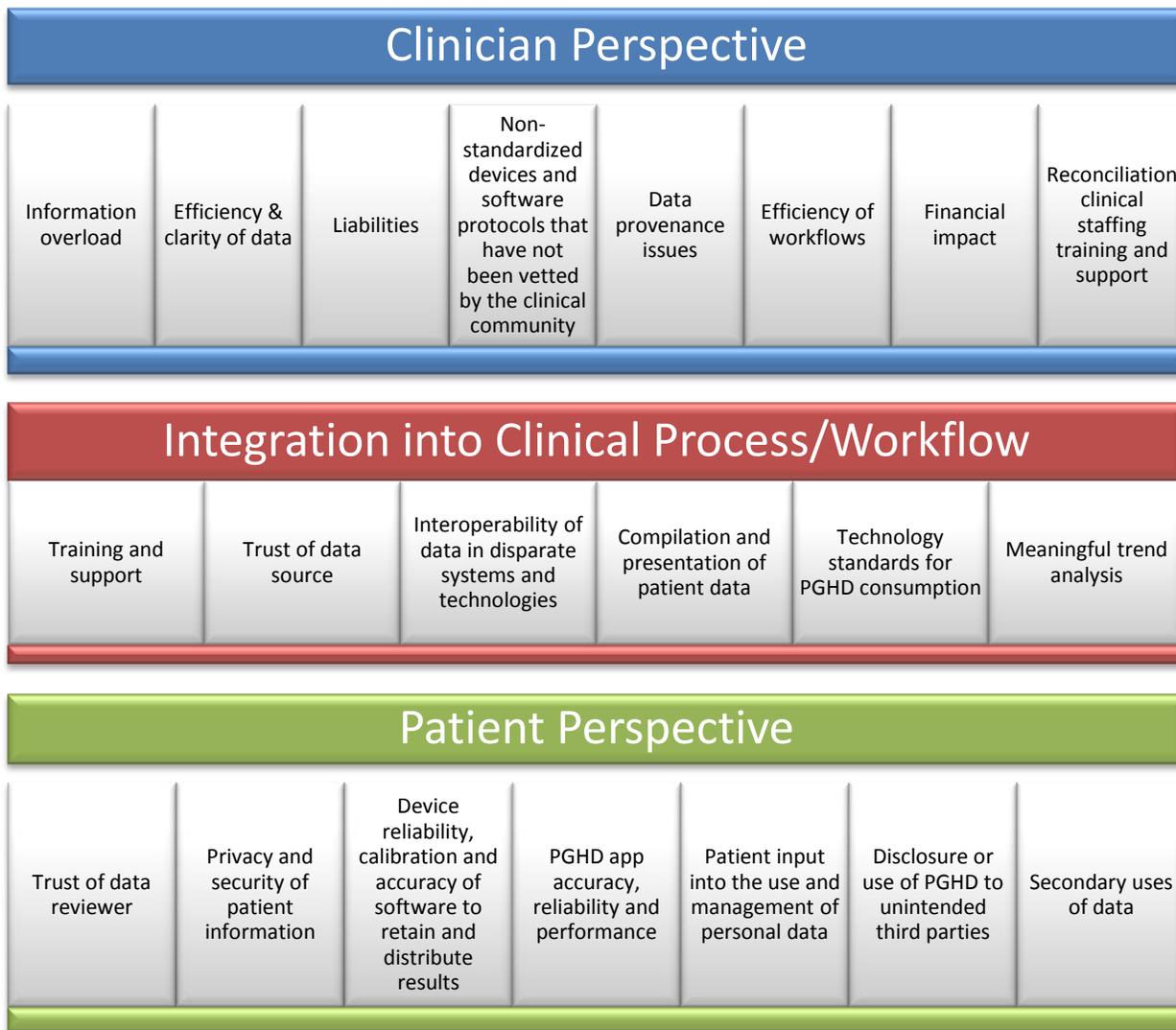
Clinician Perspective

Information overload	Efficiency & clarity of data	Liabilities	Non-standardized devices and software protocols that have not been vetted by the clinical community	Data provenance issues	Efficiency of workflows	Financial impact	Reconciliation clinical staffing training and support

Integration into Clinical Process/Workflow

Training and support	Trust of data source	Interoperability of data in disparate systems and technologies	Compilation and presentation of patient data	Technology standards for PGHD consumption	Meaningful trend analysis

Patient Perspective

Trust of data reviewer	Privacy and security of patient information	Device reliability, calibration and accuracy of software to retain and distribute results	PGHD app accuracy, reliability and performance	Patient input into the use and management of personal data	Disclosure or use of PGHD to unintended third parties	Secondary uses of data

Figure 4: Challenges to Use of Patient-Generated Health Data

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. Without this understanding, unrealistic expectations could develop and easily lead to unexpected consequences for both patients and their providers. When PGHD capabilities are implemented properly, including having an established set of policies and procedures in place for handling PGHD and maintaining transparency about the use of a patient's information, concerns are addressed and potential liability may be reduced and mitigated.[7]

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[7] HIMSS, National eHealth Collaborative Technical Expert Panel Final Report, December 2013; http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28740

Conclusion

PGHD can be a valuable tool to improve the patient experience of care; reduce the overall cost of healthcare; and achieve and maintain a healthier population. Patients can engage in innovative preventative efforts with the use of technology. In addition, patients can be engaged using telemedicine to have an encounter with their provider, often when not previously possible due to distance and other constraints. Information collected directly from patients is important; the process must be user-friendly, trustworthy, and secure, with minimal disruption to the healthcare organization. With clear policies and understanding by the provider and patient of the processes around PGHD initiatives, small and large healthcare organizations, patients, caregivers and families can benefit from the value of PGHD.

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