



## Collaboration of the Health IT Policy and Standards Committees

Policy and Standards Federal Advisory Committees on Health Information Technology to the National Coordinator

# Consumer Task Force

## Summary of Feedback on the PGHD Draft White Paper

---

Patty Sengstack, Chair  
Leslie Kelly Hall, Member

March 30, 2017



# Agenda

- Review of Charge
- Presentation: The Importance of Patient-Generated Health Data (PGHD)
  - » Elise Sweeney Anthony, ONC
- Presentation: Overview of the PGHD Draft White Paper
  - » Emily Mitchell, Accenture Federal Services
- Presentation: Consumer Task Force Feedback on the PGHD Draft White Paper
  - » Leslie Kelly Hall, Consumer Task Force Member
- Joint Committee Discussion

# Membership

Member	Organization	Role
<b>Patricia Sengstack</b>	<b>Bon Secours Health Systems</b>	<b>Co-Chair</b>
Susan Hull	Cincinnati Children's Hospital Medical Center	Member
Brian Ahier	Medicity	Member
Susan Brown	Telligen	Member
Kevin Fowler	Kidney Health Initiative	Member
Leslie Kelly Hall	Healthwise	Member
George Mathew	Hewlett Packard Enterprise	Member
Carolyn Kerrigan	Dartmouth-Hitchcock Medical Center	Member
John Derr	JD & Associates Enterprises, Inc.	Member
Angela Kennedy	Louisiana Tech University	Member
Mark Savage	National Partnership for Women & Families	Member
Andrea Hartzler	Group Health Research Institute	Member
Jenna Marquard	University of Massachusetts Amherst	Member
Kim Schofield	Lupus Foundation of America	Member
<i>Margeaux Akazawa</i>	<i>ONC</i>	<i>ONC Lead</i>

## Consumer Task Force Charge

- Convened on an as needed basis, the task force will provide insight on ONC/HHS projects/initiatives with a consumer focus to ensure the person remains at the center, engaging the experience and feedback of both patients and providers.
  - » Focus: The Task Force will be charged with providing feedback on [Patient-Generated Health Data](#) (PGHD) deliverables

# **1** **ONC: The Importance of Patient-Generated Health Data**

## **2** **Accenture:** Patient-Generated Health Data Draft White Paper

## **3** **Consumer Task Force:** Patient-Generated Health Data Draft White Paper Feedback

# What are patient-generated health data?

**Patient-generated health data (PGHD)** are health-related data created, recorded, or gathered by or **from patients** (or family members or other caregivers) **to help address a health concern.**

PGHD include, but are not limited to:



Health history



Treatment history



Biometric data



Symptoms

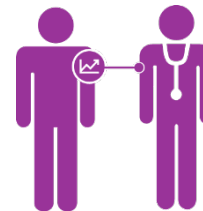


Lifestyle choices

PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways:



**Patients**, not providers, are **primarily responsible for capturing** or recording these **data**.



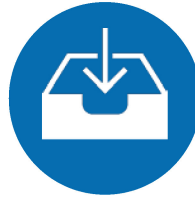
**Patients decide how to share** or distribute these **data to** health care **providers** and others.

# Why are patient-generated health data important?

## PGHD can:



Provide information relevant to preventive and chronic care management



Gather health information on an ongoing basis



Provide important information about how patients are doing between medical visits

## The use of PGHD offers potential opportunities for:



Increased patient engagement



Cost savings, such as by avoiding readmissions and reducing the need for tests



Improvements in quality, care coordination, and patient safety

# Health IT Certification Criteria: Patient Health Information Capture

## 2015 Edition HIT Certification Criteria Patient Health Information Capture §170.315(e)(3)

### Enable a user to:

- 1 Identify, record, and access information directly and electronically shared by a patient (or authorized representative).
- 2 Reference and link to patient health information documents.

---

Intent of this provision is to establish at least one means for accepting patient health information directly and electronically from patients in the most flexible manner possible.

---

The criterion does not seek to define the types of health information that could be accepted as we believe this should be as broad as possible.

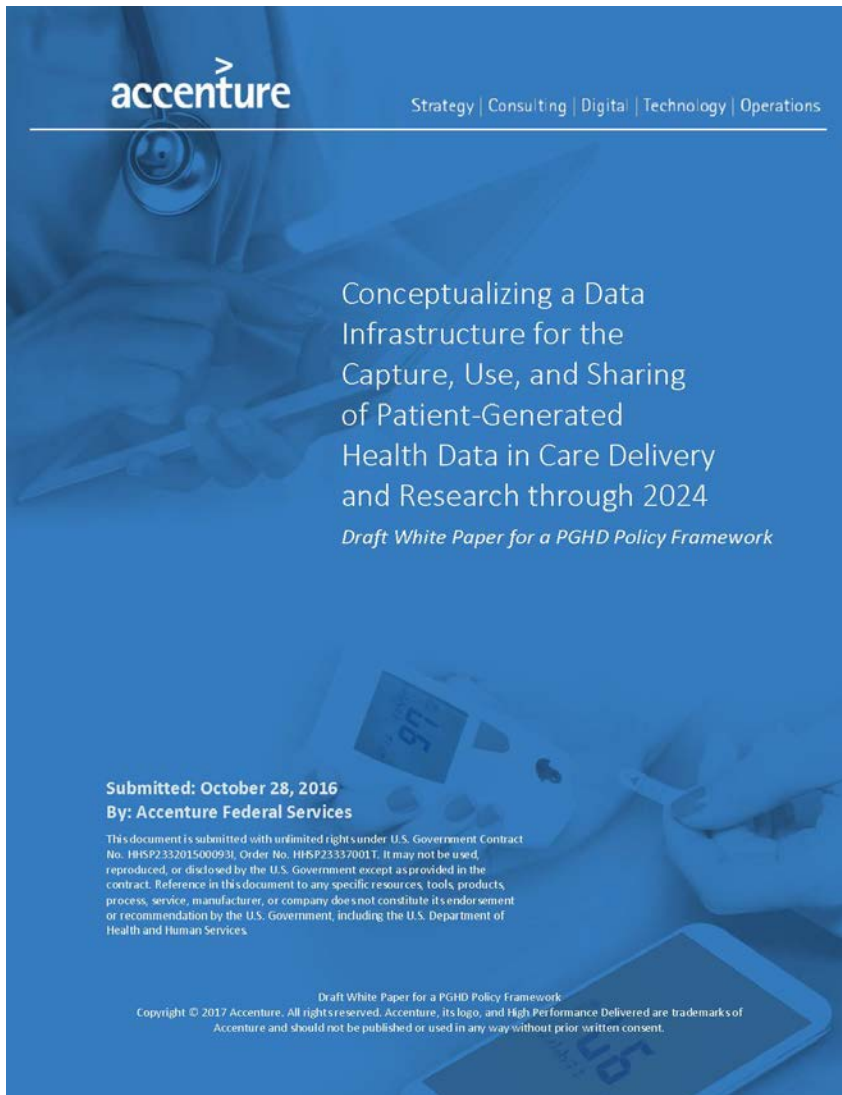


# 1 **ONC:** The Importance of Patient-Generated Health Data

## 2 **Accenture:** Patient-Generated Health Data Draft White Paper

## 3 **Consumer Task Force:** Patient-Generated Health Data Draft White Paper Feedback

# PGHD Draft White Paper



- **Title:** “Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024”
- **Author:** Accenture Federal Services
- **Posted:** January 10, 2017
- **Available at:**

[https://www.healthit.gov/sites/default/files/Draft\\_White\\_Paper\\_PGHD\\_Policy\\_Framework.pdf](https://www.healthit.gov/sites/default/files/Draft_White_Paper_PGHD_Policy_Framework.pdf)

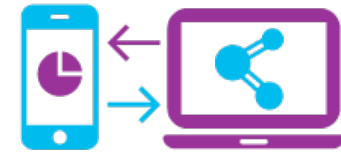
# PGHD Draft White Paper: Research Topics



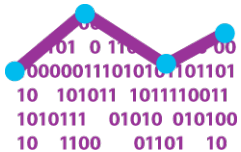
**1** Collection and Validation of Data and Tools



**2** Ability to Combine PGHD with Medical Record Data in Multiple Ways



**3** Data Interoperability



**4** Big Data Analysis



**5** Data Donation



**6** Regulatory Overview



**7** Patient Recruitment for Research, Studies, and Trials

# PGHD Draft White Paper: Initial Observations

## Positive impact on patient satisfaction



### Characteristics of successful PGHD implementations:



Tend to be focused on a specific disease or population segment



Use of data analytics



Simplified user interface



Well-defined workflow



Care team triages data (not only physicians)

### Opportunities resulting from PGHD use:



Patients/Caregivers: Engage in healthy behaviors, increase treatment adherence, and improve health outcomes



Clinicians: Make timelier and better informed decisions, improve collaboration with patients to create personalized treatment plans



Researchers: Increase access to large amounts of data, connect with patients directly for studies and trials

# PGHD Draft White Paper: Content

- Synthesizes key findings from research and outreach
- Discusses emerging trends and provides a vision for the future that enables PGHD capture, use, and sharing
- Describes opportunities, challenges, and enabling actions for stakeholder groups to support that vision
  - » Stakeholder groups include:
    - Patients and Caregivers
    - Clinicians
    - Researchers
    - Policymakers
    - Technology: Developers and Standards Bodies
    - Payers and Employers

# PGHD Draft White Paper: Opportunities



## Patients

- Improved patient experience and ability to engage in shared decision-making
- Reduced time, effort, and costs of patients visiting a clinical setting or research site and can improve workflow efficiencies



## Clinicians

- Visibility into a patient's adherence to a treatment plan
- Timely intervention before a costly care episode
- Ability to develop personalized care plan based on the needs and preferences of each patient

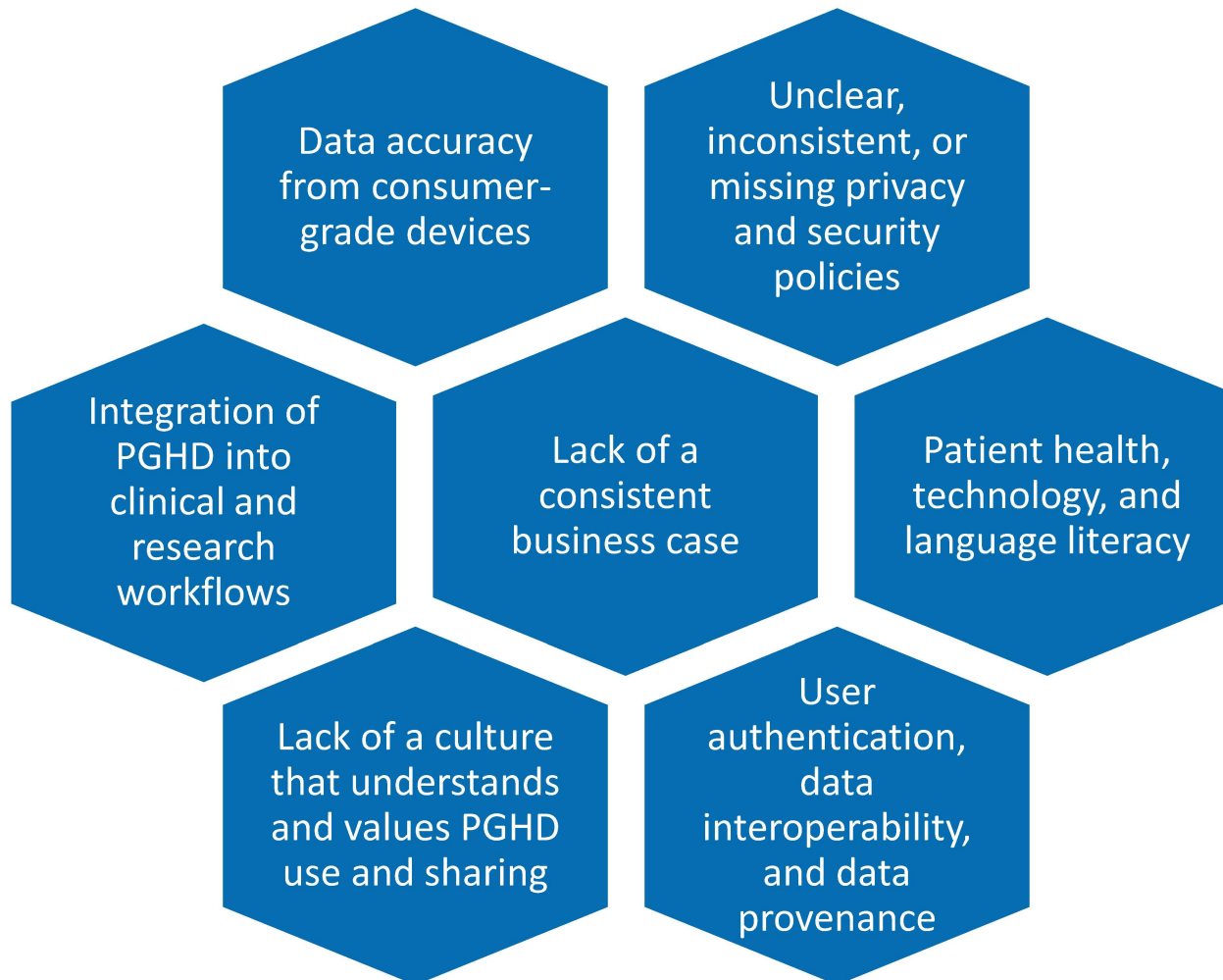


## Researchers

- Access to a larger pool of participants and research data
- Ability to monitor adherence to study protocols

# PGHD Draft White Paper: Challenges

A complex web of technical and cultural challenges may impede the successful capture, use, and sharing of PGHD in research and care delivery settings.



# PGHD Draft White Paper: Some Enabling Actions to Consider



Patients and  
Caregivers

- Collaborate with clinicians and researchers to determine how capturing, using, and sharing PGHD can be valuable for managing their health.



Clinicians

- Identify and communicate benefits, challenges, and best practices of PGHD use to help strengthen the evidence for clinical value and business case.



Researchers

- Call for increased funding for studies that investigate the benefits, challenges, and best practices of using PGHD in care delivery and research.



Policymakers

- Prompt collaboration with industry to strengthen model practices, consumer education, and outreach that support the private and secure capture, use, and sharing of PGHD.



Developers and  
Standards Bodies

- Improve usability and accessibility and implement user-centered design principles into products that capture PGHD.



Payers and  
Employers

- Continue to motivate clinicians to capture and use PGHD through reimbursement programs.



# PGHD Pilot Demonstrations

## Purpose

- To implement and test the policies and workflows identified in the white paper to support the capture, use, and sharing of PGHD in health care delivery and research settings

## Goal

- To use insights from the pilot findings, combined with public comments and feedback from the joint Consumer Task Force of the Health IT Policy and Standards Committees, to inform updates to the draft white paper

# PGHD Pilot Demonstrations



## Validic/Sutter Health

- Validic is working with Sutter Health to test personalized care focused on people suffering from Type II Diabetes using remotely collected PGHD from a multitude of devices to research the infrastructure and workflows needed to implement and scale PGHD initiatives
- The pilot includes ethnography to identify areas of improvement to further patient and provider engagement



## TapCloud/AMITA Health

- TapCloud is working with AMITA Health to gather PGHD and associated clinical results into one application across several medical areas such as orthopedic surgery, behavioral health, bariatric surgery, and stroke
- TapCloud connects patients and clinicians outside the clinical setting with the goal of identifying how patients feel and assessing patient health trajectory

# PGHD Draft White Paper: ONC Contact Information



Comments on the draft white paper may be submitted through May 8, 2017, using the following links:

PGHD web page:

<https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data>

email: [ONC-PGHD-Policy@hhs.gov](mailto:ONC-PGHD-Policy@hhs.gov)

Patient Engagement Playbook:

<https://www.healthit.gov/playbook/pe/chapter-4/>

**1** **ONC:** The Importance of  
Patient-Generated Health Data

**2** **Accenture:**  
Patient-Generated Health Data  
Draft White Paper

**3** **Consumer Task Force:**  
Patient-Generated Health Data  
Draft White Paper Feedback

# Summary of Feedback: Overall Impressions & General Themes

## Overall Impressions and General Themes

- Members highlighted the need to identify priority use cases to build evidence on the benefits, outcomes, and impact of the use of PGHD and to develop proof of concepts that can help to inform standards.
- Members noted that some patient populations, such as special needs populations, low-income/underserved, and those with language barriers, may not be able to participate in PGHD collection and use or have barriers to accessing and using devices that collect PGHD.
- Members thought conversations about PGHD collection and use should expand beyond static data and consider trending data.
- While members appreciated the inclusion of different stakeholder groups, members noted that interdisciplinary collaboration across these stakeholders is critical for advancing the use of PGHD.

# Summary of Feedback: White Paper Strengths & Format Suggestions

## White Paper Strengths

- Members thought the white paper was well-written and clear.
- Members appreciated the inclusion of different stakeholder groups.
- Members liked the enabling actions and real-world examples.

## Suggestions to Improve the Format

- Members suggested incorporating more real-world examples into the final white paper.
- Members recommended using more plain language throughout the document to help make it understandable by diverse audiences.
- Members recommended that the language in the white paper continues to reflect a coordinated approach with related ONC work efforts.

# Summary of Feedback: PGHD Definition & Current and Future States

## ONC Definition of PGHD

- Members suggested that ONC broaden their definition to include phenotypic data, medical history, social determinants of health, text messages, and email.
- Members wondered if the definition of PGHD would vary by setting.
- Members suggested the term be changed to “person generated health data” to expand its scope beyond the clinical setting.

## Current and Future States

- Members suggested re-writing the future scenario so that it is more person-centric and less EHR-centric.
- Members were divided on extent of change likely in future vision. While some thought the scenario presented was an accurate future direction, others imagined more automation in the future and suggested including mention of emerging technologies.

# Summary of Feedback: Patients and Caregivers & Clinicians

## Patients and Caregivers

- Members suggested that greater emphasis should be placed on the caregiver role and should be discussed in more depth throughout.
- Members expressed the need to better understand what patients want in return for sharing their data and what motivates patients to collect, use, and share PGHD.
- Members stated that this section should include more discussion of the use of PGHD for better quality of life outcomes.

## Clinicians

- Members thought that this section should expand upon and provide more examples of the business case of PGHD for clinicians.
  - » Some benefits that members felt could be expanded upon include saving time, generating revenue, enhanced efficiency, and reducing burden for clinicians.
- Members believed this section should address clinician concerns like multiple data types and liability, and provide examples of successful implementation.



# Summary of Feedback: Researchers & Policymakers

## Researchers

- Members felt that researchers should be encouraged to demonstrate the value of PGHD collection and use to patients and to return meaningful feedback to patients following studies.
- Members stated that patients must have an increased role in research that uses PGHD.
- Members indicated that more description is needed about the responsibilities of researchers regarding collecting, using, and sharing PGHD.

## Policymakers

- Members stated that this section should have more content and specifics about which and how federal agencies are engaged in supporting PGHD use.
- Members suggested that this section should emphasize the need for more funding and incentives for PGHD use.
- Members thought that this section should also cover the role of policymakers at the state and local levels, and mention patient advocacy groups who play a role in policymaking.

# Summary of Feedback: Technology Stakeholders & Payers and Employers

## Technology Stakeholders

- Members believed that the discussion should be broadened to include opportunities beyond technology standards.
- Members stated that usability issues are key not just for the technology but also around the integration and presentation of the data in the EHR.
- Members suggested that developers must involve patients and clinicians in the technology design process (Human Centered Design).

## Payers and Employers

- Members thought this section should provide more discussion around the alignment of incentives to encourage PGHD collection and use in ways that ensure data quality.
- Members suggested emphasizing the privacy and discrimination concerns that patients have with giving their data to payers and employers.

## Suggestions for other tools and resources on PGHD

Although possibly outside the scope of the white paper, members had additional suggestions for tools and resources that could encourage PGHD collection and use:

- Develop a table that illustrates types of PGHD by technologies and devices that collect these PGHD.
- Provide actionable advice and guidance on how different stakeholder groups can integrate and use PGHD in their work.
- Create more educational materials on PGHD for different stakeholder groups.
- Identify relevant and actionable information related to PGHD capture, use, and sharing as it relates to new policies and rules supporting MACRA/MIPS and 21<sup>st</sup> Century Cures.



# Collaboration of the Health IT Policy and Standards Committees

Policy and Standards Federal Advisory Committees on Health Information Technology to the National Coordinator

## Consumer Task Force

---

Patty Sengstack, Chair  
Leslie Kelly Hall, Member

