Patient Generated Health Data: Best Practices in the Integration into Clinical Care

Presenters:
Terry Newton, M.D., Director of Clinical Analytics
Office of Connected Care (OCC), U.S. Department of Veterans Affairs

Christina M. Armstrong, Ph.D., Clinical Psychologist, Implementation Strategies,
Office of Connected Care (OCC), U.S. Department of Veterans Affairs

John J. Murphy, M.D., Clinical Lead of Connected Health
Office of Connected Care (OCC), U.S. Department of Veterans Affairs
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**Terry Newton, MD**  
Director of Clinical Analytics  
Office of Connected Care  
U.S. Department of Veterans Affairs

**Christina Armstrong, Ph.D.**  
Connected Health Implementation Strategies  
Office of Connected Care  
U.S. Department of Veterans Affairs

**John Murphy, MD**  
Clinical Lead  
Office of Connected Care  
U.S. Department of Veterans Affairs
Learning Objectives

At the conclusion of this training session, VA staff should be able to:

• Be familiar with common definitions of health technologies and components of patient-generated health data (PGHD).
• Describe the benefits of using PGHD in clinical care.
• Demonstrate how PGHD can support clinical management and decision making in a model of continuous care.
Agenda

• Introduction: Leveraging the ‘White Space’
• What is Patient Generated Health Data (PGHD)?
• Use and Benefits of PGHD
• What VA Staff Need to Know About PGHD
Leveraging the “White Space”
525,600 minutes
LTG Horoho on “The White Space”

https://www.youtube.com/watch?v=Lft0yDVH2tA
EHR Data informs Episodic Care

EHR + PGHD informs Comprehensive and personalized Care
Pen and paper
Digital Tools
What is Patient-Generated Health Data?

- Vital signs
- Lifestyle data
- Quality of life data
- Other health data
Patient-generated health data (PGHD) is health-related data created, recorded, or gathered by patients, their family members, or caregivers.

- Patients capture and record PGHD. Data is captured through clinical apps, wearable devices, devices such as glucometers, or input from patients.
- PGHD is usually distinct from the data generated in clinical settings and through encounters with clinicians.
- Patients decide whether to share the data with providers.
Use and Benefits of PGHD
What health technologies do people use?

**TECHNOLOGIES USED TO MANAGE HEALTH**

- Websites: 56% (2018), 58% (2016)
- Mobile phone/tablet: 46% (2018), 36% (2016)
- Electronic health records: 38% (2018), 27% (2016)
- Social media: 35% (2018), 23% (2016)
- Wearable technology: 33% (2018), 26% (2016)
- Smart scales: 27% (2018), 15% (2016)
- Online communities: 25% (2018), 14% (2016)
- Remote consultation: 16% (2018), 12% (2016)
- Remote monitoring: 14% (2018), 9% (2016)

*(Consumer Survey on Digital Health: US Results, 2018; N=2,301)*
• 325 million (Piwek et al. 2016) and estimated to increase to 929 million by 2021 (Statistica, 2018)
• Increasingly used as the primary assessment and/or treatment modality (Hermens & Vollenbroek-Hutton 2008; Hilty et al. 2021; Kvedar et al. 2014).
• Transition from a cross-sectional, manual transfer of data at a healthcare appointment to a 24 × 7, longitudinal framework (Areàn et al. 2016; Luxton 2016; Torous and Roberts 2017; Ariga et al. 2019).

• Makes the collection, processing, and sharing of data more integrated and provides the opportunity for real-time feedback based on the ecology (home, health, lifestyle, social) of patients in natural settings (Seko et al. 2014).

• These data support “in-time” clinical decision support (Rohani et al. 2018; CDS) (Greenes et al. 2018) and automatic monitoring systems (Garcia-Ceja et al. 2018; National Academy of Sciences, Engineering and Medicine 2020).
Who do you want to share wearable data with?

- Your doctor: 90% (2018; 90% 2016)
- Your nurse or other healthcare professional: 88% (2018; 87% 2016)
- Friend or family member: 76% (2018; 72% 2016)
- Your health insurance plan: 72% (2018; 72% 2016)
- Online communities/other app users: 47% (2018; 38% 2016)
- Your employer: 38% (2018; 31% 2016)
- A government department/agency: 41% (2018; 41% 2016)

(Consumer Survey on Digital Health: US Results, 2018; N=2,301)
What wearable data are people willing to share?

- **2016**
  - Vital signs: 12%
  - Fitness and lifestyle: 16%
  - Both: 53%
  - Neither: 18%

- **2018**
  - Vital signs: 11%
  - Fitness and lifestyle: 16%
  - Both: 53%
  - Neither: 20%

(Consumer Survey on Digital Health: US Results, 2018; N=2,301)
Veteran Benefits of PGHD

- Empowers Veterans by gaining a greater understanding of health and wellness.
- Provides supplementary information to help Veterans and their care teams make health care decisions together.
- Veterans control their PGHD and decide whether to share this data with their care teams.
Patient Attitudes Toward Use of PGHD

- 75% understanding your health condition
- 73% engaging in your own health
- 73% monitoring the health of a loved one
- 69% improves overall quality of care
- 69% patient/physician communication
- 69% accuracy of the medical record
- 66% patient satisfaction

(Consumer Survey on Digital Health: US Results, 2018; N=2,301)
Healthcare Staff Benefits of PGHD

- Leverage the ‘white space’
- Augment their understanding of patients’ health and wellness
- Support clinical decision-making and delivery of care
- Identify meaningful trends than can explain or predict health-related outcomes
What VA Staff Need to Know About PGHD
If the provider requests that the patient collect and share PGHD, or if a patient begins sharing PGHD with VA, that provider should discuss how PGHD will be viewed and acted upon with the patient.

- Set expectations for patient sharing and provider viewing PGHD, and for care decisions to be made.
- Inform the patient that it is their responsibility to make the VA provider aware of situations in which the patient believes that they may be experiencing a medical issue or need medical attention based on their PGHD.
- Document any agreement regarding the collection, monitoring and use of PGHD in a note within the patient’s EHR.
Accessing and Documenting PGHD

- PGHD is stored in a secure VA database.
- Providers can access PGHD through Virtual Care Manager.
- PGHD is not considered a part of the patient’s official medical record unless the provider actively adds the data to the Electronic Health Record (EHR).
Key Take-Aways

- Patient-generated health data (PGHD) helps both Veterans and providers gain a greater understanding of patient health and wellness.
- While PGHD does not replace standard medical care, it can provide supplementary information to help Veterans and their care teams make health care decisions together.
- Patients are primarily responsible for capturing and recording PGHD, and for deciding whether to share this data with their care teams.
- It is the responsibility of VA providers to inform patients about how they intend to use PGHD in care.
Questions
Backup
*Veteran chooses which data goes into the PGH Database
VA PGHD Policy

Department of Veterans Affairs
Veterans Health Administration
Washington, DC 20420

VHA DIRECTIVE 8506
Transmittal Sheet

(Date)

REVIEW AND USE OF PATIENT-GENERATED HEALTH DATA UNDER THE OFFICE OF CONNECTED CARE

1. REASON FOR ISSUE: This Veterans Health Administration (VHA) directive establishes policy and responsibilities for Department of Veterans Affairs (VA) staff who have access to review and use patient-generated health data (PGHD) submitted by Veterans through the Office of Connected Care (OCC) mobile health applications.

2. SUMMARY OF CONTENT: This directive:
   a. Defines PGHD that is submitted by Veterans and stored in OCC's PGHD database and provides background on how it is collected, accessed and used, and by whom.
   b. Establishes expectations for how providers will communicate with Veterans about PGHD.
   c. Describes provider responsibility for documenting any agreed upon plans, as were agreed to by the Veteran, for access and use of PGHD.


4. RESPONSIBLE OFFICE: The Office of Connected Care (OCC) is responsible for the content of this directive. Questions may be addressed to VHA12CCConnectedCareAction@va.gov

5. RECISSIONS: None.

6. RECERTIFICATION: This VHA directive is scheduled for recertification on or before the last working day of [DATE]. This VHA directive will continue to serve as national VHA policy until it is recertified or rescinded.
• PGHD is stored in VA’s PGHD database which meets all Federal and VA requirements for security and privacy.
• This data is governed by its own Privacy Act System of Records Notice (SORN) “VA Mobile Application Environment (MAE)-VA”, 173VA005OP2.
• PGHD is not part of the Veteran’s official health record unless a provider actively migrates or pastes adds the data into the electronic health record (EHR).
• Any data that is copied and placed added into the EHR by a provider becomes part of the official VHA health record and subject to all rules associated with the Privacy Act SORN, “Patient Medical Records-VA”, 24VA10A7.
Applicable Competency Domains Across Clinical Workflow

1. Person informally uses wearable sensors in lifestyle
   - Patient care
     - Use principles of effective Clinical Decision Support
     - Educate on technology and inquire about preferences
     - Interpersonal and Communication Skills
     - Asks about goals and preferences and be of service to clarify questions
     - Medical knowledge
     - Learn pros and cons of different technologies
     - Assess if an app is evidence based
     - Practice-based learning
     - Assess literature and learn/apply evidence base specific to a technology or intervention
     - Professionalism
     - Join professional community

2. Person and clinician discuss use of sensors in treatment
   - Medical knowledge
     - Understand information system components (e.g., network, software)
   - System-based practice
     - Learn safety/risk issues (e.g., physical, privacy)
     - Recognize need for efficient and equitable use of resources
     - Communicate data and workflow in EHR to team
     - Use reporting system for problems
     - Professionalism
     - Join professional community for peer support and input on technology
     - Practice-based Learning
     - Ensure quality care by adjusting options short- and long-term
     - Reflect consistently and integrate performance feedback
     - Interpersonal and Communication Skills
     - Adjust to preferences and clarify options

3. Data processing
   - Data Display

4. Person views data and makes health behavior changes based on results
   - Medical knowledge
     - Understand information system components (e.g., network, software)
     - System-based practice
     - Learn safety/risk issues (e.g., physical, privacy)
     - Recognize need for efficient and equitable use of resources
     - Communicate data and workflow in EHR to team
     - Use reporting system for problems
     - Professionalism
     - Join professional community for peer support and input on technology
     - Practice-based Learning
     - Ensure quality care by adjusting options short- and long-term
     - Reflect consistently and integrate performance feedback
     - Interpersonal and Communication Skills
     - Adjust to preferences and clarify options

5. Person and clinician view data and make treatment adjustments based on results
   - Patient care
     - Effectively locate wearable data in EHR
     - Use principles of Clinical Decision Support
   - Practice-based Learning
     - Ensure quality care by adjusting options short- and long-term
     - Reflect and integrate performance feedback
     - Interpersonal communication skills
     - Develop skill with text and e-mail
     - Avoid technical jargon
     - Access mobile technologies
     - System-based practice
     - Communicate workflow in the EHR to team and report problems
     - Plan for effective transitions across settings
     - Discuss possible quality gaps for care delivery

VA providers are encouraged to make patients aware of the potential benefits of sharing their PGHD with their care team. This can include:

- Discussing how apps and devices can be used to collect PGHD
- Describing benefits and limitations of PGHD
- Understanding that patients may consider PGHD an important part of their care
- Connecting the patient to designated VA staff members who can offer more information, as needed
PGHD is a viable source of clinical data in situations where:

• There is high patient buy-in and patients see clear benefits to tracking data
• Clinicians and care teams are utilizing a holistic approach that lends itself to data from multiple sources
• PGHD will be used to drive decisions within a holistic treatment plan; or in cases where validated specificity and sensitivity are not required
  – e.g. building out a normal baseline of blood pressure to monitor long term changes rather than gather accurate daily readings
  – Examples of use cases include: Whole Health or Mental Health
• Barriers to patient use and syncing data exist, but we are actively working toward breaking down these barriers. Ideally, data should sync automatically or with minimal effort on the patient’s behalf
PGHD Resources

Using Patient-Generated Health Data in VA Care

Patient-Generated Health Data (PGHD) enables U.S. Department of Veterans Affairs care teams to offer continuous care to their patients. PGHD gives VA care teams greater insight into patients' health and empowers patients to be more engaged in their care.

What is PGHD?
PGHD is health-related data that patients and their family members or caregivers create or gather outside of a clinical setting. For example, patients can log health and lifestyle information such as diet, mood, sleep, and weight, or they can use wearable devices and sensors to gather data such as blood pressure, glucose levels, and heart rate. PGHD is distinct from the data generated in clinical settings and through encounters with providers.

Patients can create or gather PGHD using a variety of tools, including:
- Health-related VA Mobile apps, such as Apple Apps for Veterans, Mobile VA, and My VA Images.
- Devices that are connected to the Sync My Health Data apps, such as accelerometers, glucometers, and smartwatches.
- My HealtheVet, VA's online patient portal.

As new technologies become available to patients, VA's PGHD database may expand to include additional data sources.

Introduction to Patient-Generated Health Data for VA Staff

4-Part Video Series (for healthcare staff and Veterans)
References


Department of Veterans Affairs (2020). Ethical principles for access to and use of Veteran data. (Memorandum VIEWS #01256748) https://www.oit.va.gov/about/ethical-data-use/index.cfm


VA Virtual Care Resources

Office of Connected Care Communication Toolkits [https://connectedcare.va.gov/outreach-toolkit](https://connectedcare.va.gov/outreach-toolkit)

Connected Care Academy [https://vaots.blackboard.com](https://vaots.blackboard.com)

Connected Care Discussion Series [https://mobile.va.gov/discussion-series](https://mobile.va.gov/discussion-series)

Connected Care Integrated Care Series (email VHA10P8TELEIPT@va.gov to be put on distribution list)

VA Connected Care Community of Practice (email chimplementation@va.gov to be put on distribution list)

My HealtheVet [https://myhealth.va.gov](https://myhealth.va.gov)

VA Mobile [https://mobile.va.gov/Appstore](https://mobile.va.gov/Appstore)

https://Tinyurl.com/tech-into-care
Thank you!

www.connectedcare.va.gov