Patient Generated Health Data Beyond Wearable Devices
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.**

Source: PGHD page on ONC website, [www.healthit.gov](http://www.healthit.gov)
EXAMPLES OF PGHD
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

Source: PGHD page on ONC website, www.healthit.gov
TAPCLOUD – Symptom Cloud

Keyword due to known progression of complication
Keyword double tapped to indicate high intensity
Keyword due to complication

Centered, differentiated Keywords depicting previous responses
Keyword from medication Side-effect profile
### TAPCLOUD – Patient Panel

#### ALERT: Quick View:
**Wed, 12/9 7:20 PM CST** – Pain Level Alert:
Patient reported a pain level of 8
**Wed, 12/9 7:20 PM CST** – Patient Note:
“The incision on my knee looks very red.”

#### ALERT: Quick View:
**Tues, 12/8 7:52 AM CST** – Patient Note:
“Felt warm all night, I think I have a fever.”
TAPCLOUD – Patient Dashboard

Begin Phenytoin

Headaches Reported
**Reduced Unnecessary Utilization**

<table>
<thead>
<tr>
<th>Orthopedic Surgery</th>
<th>Readmission Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>General 5.1%</td>
</tr>
<tr>
<td>TapCloud Users</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

**Sustained Patient Utilization**

![Graph showing usage duration (Days)](image)

- Start Date: Newest (4/25/17) - Oldest (1/31/16)
- Usage Duration (Days): 0 - 300

**TAPCLOUD RESULTS**
41 Year Old, Male, Depression

Feb 11: Just annoyed today, but it did get better as the day went on.

Feb 16: This ain't a bad app. I was able to check in at 7 because I'm home. A nice thing to do is have custom times for this.

Feb 25: I took missy out for ice cream (I bet you're jealous). It was also my dads bday and I survived being around everyone. I set a reminder to do this every night.

Feb 26: I hung out with missy today and it was fun. Saw my brother and I need to charge him for helping him with his android crap. Missy and I also helped a person who was in a car accident when I was taking her to her moms place

Feb 27: So since Friday I been feeling really good lately. Positive, happy, calm, and just a good feeling. I also been remembering to do this, aren't you impressed?

Feb 28: Talking to Stacey about her work, I'm a little worried it might not be open for long. They are so slow and asking coworkers to bill out stuff just to get money in.

Mar 1: Not as bad as yesterday.

Mar 4: Went to the chain of rocks bridge and it was fun. I was so proud that stacey walked the whole thing. I know it t wasn't easy for her. I feel great today :) 

Mar 8: Worried about my mom. She had a cable issues and I helped her, but she started to cry and I know everything is getting to her. My siblings need to stop having my parents be their personal babysitter.

Mar 10: Had a good day today. Took tony out for lunch and had a date with stacey.

Mar 15: I am trying this again. So after I did this yesterday I learned that 1 year ago yesterday was when I called to start getting better. I told Karen today (HR) and she hugged me.
Where are things going with Patient Generated Health Data?

Dan Foltz
President and Managing Director
Parnassus Consulting
In five years, patient-generated data will join clinical, cost and genomic data as the most useful sources of health care data.

March 9, 2017
Why PGHD? Orthopedic Surgery Pilot Results

333 Patients - Full joint replacement - 11 months

RESULTS

<1%
Patients Readmitted
(baseline: 5.1%)

61%
Patient Sign-up Rate

15,888
Patient Interactions

MONITORING

Care Team Alerted

2,210 Notices of Completed Pre-Surgical Activity
1,116 Clinical Alerts (potential patient at risk)
398 Nurse Interventions

Care Team Usage

1,233 Views
2 hours: Total Nurse hours/day using TapCloud

COMMUNICATION

<table>
<thead>
<tr>
<th></th>
<th>From Patient</th>
<th>From Clinician</th>
<th>System Generated</th>
</tr>
</thead>
<tbody>
<tr>
<td>In App Notes</td>
<td>275</td>
<td>401</td>
<td>n/a</td>
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<tr>
<td>Secure Messages</td>
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<td>64</td>
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<tr>
<td>Email</td>
<td>n/a</td>
<td>n/a</td>
<td>708</td>
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<tr>
<td>Incision Site Photos</td>
<td>44</td>
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<td>n/a</td>
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</tbody>
</table>
Why PGHD? Role in Real World Evidence Generation

FDA project to demonstrate a generalizable approach to gather info from a consumer app and link it to health plan data.

Source:
Jeff Brown, Associate Professor
Department of Population Medicine
Harvard Medical School
We need to formalize & measure new types of utilization

• Patient Check-In
• Biometrics Collection
• Reminders
• App facilitated Patient-Provider Interactions
• Care Giver Interactions
Framework for measuring the impact of PGHD

Source: A Data Science Framework for Mobile Health—Engagement and Outcomes
Mansur Shomali MD, CM1,2; Malinda Peeples, MS, RN, CDE1; Joseph Isenberg, MS1; Anand Iyer, PhD1
1WellDoc, Baltimore, MD, 2MedStar Union Memorial Hospital, Baltimore, MD
Measuring the impact of PGHD

Impact on Utilization & Cost
+ (-) PCP
+ (-) Specialist
+ (-) Pharmacy
+ (-) Urgent Care
+ (-) Rehab
+ (-) ED
+ (-) Hospitalization/Readmissions
+ (-) Observation
+ (-) SNF
+ (-) PMPM Total Cost
Measuring the impact of PGHD

Impact as a Companion to Drug Therapy
- Adherence
- Efficacy
- Safety
- Comparative Effectiveness
Measuring the impact of PGHD
Consumers want digital engagement
First Movers Advantage
Market Share Growth
Brand Enhancement
**PGHD & Interoperability**

<table>
<thead>
<tr>
<th>Sensors</th>
<th>Consumer Apps</th>
<th>EMR &amp; Care Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems: 1,000+ devices</td>
<td>Many conditions, many apps</td>
<td>PGHD Integration &amp; Clinician Usability</td>
</tr>
<tr>
<td>Solutions:</td>
<td>• Device Integration Platform</td>
<td>• Workflow integration</td>
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<tr>
<td></td>
<td>• App Market Consolidation</td>
<td>• Interoperable Apps</td>
</tr>
<tr>
<td></td>
<td>• Multi-Condition Support</td>
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</table>
• PGHD is here and closes an important gap in both patient care and real world evidence generation

• Regulations and standards covering the use and sharing of PGHD are being studied by the ONC

• In addition to fulfilling a clinical purpose, PGHD enables patients to engage with their provider in a new and meaningful way.

• Have you started the PGHD journey?
Panel Discussion

**Moderator**
Tom Riley  
Chief Executive Officer, TapCloud

**Martin Entwistle**  
Executive Director, Personalized Healthcare Programs, Sutter Health

**Daniel Foltz**  
President and Managing Director, Parnassus Consulting

**Kyle Grate**  
Assistant Vice President, Orthopedic Service Line, AMITA Health

**Paul Nutting**  
President, TapCloud

**Phil Traylor**  
Managing Director, KMC Solutions

**Richard Vazquez, MD, FACS**  
Chief Executive Officer and Chief Medical Officer, SafeStart Medical Inc.
Myths & Realities
Engaging Patients
Operationalizing PGHD
Outcomes, Results, and Benefits
Panel Contact Information

**Moderator**
Tom Riley: tom@tapcloud.com

Martin Entwistle: EntwisM@sutterhealth.org

Daniel Foltz: danfoltz@parnassusconsulting.com

Kyle Grate: Kyle.Grate@amitahealth.org

Paul Nutting: paul@tapcloud.com

Phil Traylor: ptraylor@tapcloud.com

Richard Vazquez, MD, FACS: vazquezmd@safestartmedical.com