Uncover Beliefs About Patient-Generated Health Data

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Speaker Introduction

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Conflict of Interest

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Is a salaried employee of WebMD

Jamie DeMaria, PhD, MBA
Is a salaried employee of WebMD
Agenda

• What is PGHD?
• Why it matters
• Survey Results
• Conclusions
• Implications and recommendations
Learning Objectives

• Compare and contrast physician and patient perceptions of the value of PGHD/PRO
• Identify physician barriers and success factors to use of PGHD/PRO
• Identify patient barriers and success factors to collecting and reporting outcomes to their physician

PGHD=Patient Generated Health Data
PRO=Patient Reported Outcomes
An Introduction of How Benefits Were Realized for the Value of Health IT

- Patient
- Provider
- Data reporting
- Enhanced communication
- Data sharing
- Patient education/engagement
Patient Generated Health Information/Data

• Health-related data created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern
  – Medical/family health history, symptoms, medication lists/side-effects, biometric data, lifestyle choices, outcomes

• Not a new phenomena, however technology can offer solutions for effectively collecting, sharing and using data

Office of the National Coordinator for Health Information Technology, April 2012.

Fig 1: Types of PGHD
HIMSS 2014
Why do PGHD/PROs Matter?

- Within 5 years, the majority of clinically relevant data will be collected outside of the clinical setting (Gregory Abowd, AMIA keynote, 2011)—what happens BETWEEN visits
- Exemplifies patient empowerment/engagement and supports shared decision making—essential for patient-centered care!
- Improves provider-patient communication
- Helps providers make recommendations based on a patients expressed needs, values, preferences and goals—what matters most to patients!
- Improves the patient’s skills, knowledge and confidence in self-management
- Has the ability to improve safety, quality, care coordination and reduce cost
- Under MACRA, outcomes measures, including PROs, are considered among the most important measurements

Practical ways to include PGHD/PRO in clinical decision making are needed, NOW!
Challenges to Use of PGHD

**CLINICAL 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
Survey Results
Patient Generated Health Data Surveys

**HEALTHCARE PROVIDERS**
- Medscape Education (members)
  - Physicians, NPs, Nurses, PAs
  - >20 patients/month
- October 10 to November 27, 2016
- n=1211
- No remuneration provided

**CONSUMERS/PATIENTS**
- WebMD.com (visitors)
  - US resident
  - >18 years of age
  - Seen provider in last 12 months
- October 10 to November 27, 2016
- n=1762
- No remuneration provided
PGHD Defined in Our Survey

“Logs, diaries or lists of health-related information, measured, recorded or gathered by the patient, or by their family members or care givers. The gathering of health data could be done manually (written down) or by an electronic device (for example, a fitness tracker or Smartphone APP).”
Survey Results

Demographics
## Office-Based Healthcare Provider Demographics

<table>
<thead>
<tr>
<th>DEMOGRAPHICS</th>
<th>Total</th>
<th>Area of Practice</th>
<th>Gender</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Female</td>
<td>Employed</td>
</tr>
<tr>
<td>Physician</td>
<td>27%</td>
<td>23%</td>
<td>77%</td>
<td>84%</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>66%</td>
<td>77%</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>Physicians Assistant</td>
<td>7%</td>
<td>77%</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>Primary Care (FM and Pediatrics)</td>
<td></td>
<td></td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>Specialist</td>
<td></td>
<td></td>
<td>77%</td>
<td></td>
</tr>
</tbody>
</table>

Office-based n=92
Office-based Healthcare Provider Demographics

### DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Years in practice</th>
<th>Office Based n=92</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>36%</td>
</tr>
<tr>
<td>16-30</td>
<td>10%</td>
</tr>
<tr>
<td>31+</td>
<td>54%</td>
</tr>
</tbody>
</table>

### Solo vs group practice

<table>
<thead>
<tr>
<th>Solo vs group practice</th>
<th>Office Based n=92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Solo</td>
<td>14%</td>
</tr>
<tr>
<td>2-7 providers</td>
<td>31%</td>
</tr>
<tr>
<td>≥8 providers</td>
<td>42%</td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
</tr>
</tbody>
</table>

Office-based n=92
Consumer Demographics

<table>
<thead>
<tr>
<th>DEMOGRAPHICS (N=694/1762)</th>
<th>Age</th>
<th>Gender</th>
<th>Highest level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;54</td>
<td>54-64</td>
<td>65-74</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>14%</td>
<td>26%</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Less than high school</td>
<td>High school graduate</td>
<td>Some college</td>
</tr>
<tr>
<td></td>
<td>&lt;1%</td>
<td>9%</td>
<td>22%</td>
</tr>
</tbody>
</table>

- Less than high school: <1%
- High school graduate: 9%
- Some college: 22%
- Graduated college (associate’s degree): 11%
- Graduated college (bachelor’s degree): 30%
- Post-graduate degree: 28%
## Consumer Demographics

### Provider’s practice settings

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office-based</td>
<td>73%</td>
</tr>
<tr>
<td>Community Hospital/Non-academic Medical Center</td>
<td>9%</td>
</tr>
<tr>
<td>University Hospital/Academic Medical Center</td>
<td>7%</td>
</tr>
<tr>
<td>Government</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
</tr>
</tbody>
</table>
Survey Results

Findings
Less Than 40% of Consumers Have Ever Provided PGHD to their HCP
Patients Provide PGHD Without Being Asked to Do So

About how often do you provide PGHD to your HCP without him or her having asked you to do so? (n=696)

Providers Agree

Responders who provide PGHD

CONSUMERS/PATIENTS

- All or nearly all the time: 30%
- Often: 27%
- Occasionally: 23%
- Rarely: 15%
- Never: 5%
Patients Usually Provide PGHD When Asked, But When They Don’t…They Just Forget

Has there ever been a time or times when you have not provided your PGHD to your HCP even though your provider had requested that you do so? (Select all that apply) (n=1763)

- Yes, why not? (n=126)
  - I didn’t think my HCP would actually use my PGHD. 12%
  - I didn’t see any benefit to making my PGHD available. 15%
  - It was too difficult to collect the requested PGHD. 17%
  - I didn’t have the time to collect the requested PGHD. 18%
  - I thought providing my PGHD was optional, a nice-to-have for my HCP, but not essential. 48%
  - Other 10%

- Yes 7%
- No 81%
- Don’t recall 12%
Patients: PGHD Frequently Discussed When They Bring It

How often would you say the PGHD you took to your medical appointment/discussion with your HCP was actually used or discussed with your provider during that appointment or discussion? (n=696, patients who provide PGHD)
PGHD Use Results in Higher Engagement during Clinical Encounter

In situations where you have used PGHD during office visits, how engaged do you feel patients have been during that visit, compared to visits in which PGHD has NOT been used? (n=92)

OFFICE-BASED PROVIDERS

- 30%: My patients are much more engaged when I do use PGHD during office visits
- 25%: My patients are somewhat more engaged
- 40%: My patients are engaged at about the same level, whether I use PGHD, or not
- 3%: My patients are somewhat less engaged
- 2%: My patients are much less engaged

On average, how engaged do you feel your HCP has been with you during the appointments where you provided PGHD compared to appointments when you have not brought any PGHD? (n=694)

PATIENTS

- 31%: A lot more engaged when I provide my PGHD during office visits.
- 31%: Somewhat more engaged
- 35%: Engaged at about the same level
- 1%: Somewhat less engaged
- 2%: Much less engaged
Providers Believe Patients are only Moderately Motivated to Provide PGHD

How motivated do you find your patients are, on average, about providing their own self-generated health data to you? (1=not at all motivated; 5=highly motivated)

ALL PROVIDERS, Not Office-based
n=414
MEAN=2.95

OFFICE-BASED
n=92
MEAN=3.17
p=0.037
Biggest Motivating Factor to Provision PGHD: Provider & Patients Agree…Understand How Data Will Be Used in Care

How much do you agree with the following statement: The single biggest factor that makes patients motivated to provide PGHD is a clear understanding of how that data will be used in their care. (n=92)

- Agree strongly: 40%
- Agree somewhat: 5%
- Disagree Somewhat: 1%
- Disagree strongly: 4%
- Don't know/no opinion: 5%

How much do you agree with the following statement: The single biggest factor that makes me motivated to provide PGHD is a clear understanding of how that data will be used in my care. (n=695)

- Agree strongly: 61%
- Agree somewhat: 30%
- Disagree Somewhat: 3%
- Disagree strongly: 6%
- Don't know/no opinion: 3%
Patients Say: More Likely to Provide PGHD When Used to Develop Their Care Plan

I am more likely to measure, collect and provide PGHD to my provider if I feel it will be used to develop my treatment plan or care. (n=466)
Most PGHD is Still Handwritten

What types of PGHD do your patients provide? (Select all that apply)

<table>
<thead>
<tr>
<th>HEALTHCARE PROVIDERS OFFICE-BASE (%) n=92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diaries, lists or logs</td>
</tr>
<tr>
<td>List of symptoms they had</td>
</tr>
<tr>
<td>Lists of medication or treatment SEs</td>
</tr>
<tr>
<td>Questionnaires or scales</td>
</tr>
<tr>
<td>Health data measured by trackers/apps</td>
</tr>
<tr>
<td>List of improvements seen in their condition</td>
</tr>
<tr>
<td>List of triggers</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

What types of PGHD do you take with you to your medical appointments or otherwise make available to your HCP?

<table>
<thead>
<tr>
<th>CONSUMERS/PATIENTS (%) n=698</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diaries, lists or logs</td>
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<td>List of improvements seen in their condition</td>
</tr>
<tr>
<td>List of triggers</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>
Electronic Transmission on PGHD…Two Tales

Do you provide patients the opportunity to send PGHD to you electronically? (email, texts, online via a portal, automatic cloud storage, etc. (n=92)

OFFICE-BASED PROVIDERS

- Yes: 41%
- No: 59%

CONSUMERS/PATIENTS

- Yes: 43%
- No: 29%
- Don't know: 28%

Does your HCP make it possible for you to send your PGHD to him or her electronically (n=851)
How is Electronic PGHD Shared?

In what way(s) is your PGHD made available electronically to your HCP? Please select all that apply. (n=146)

CONSUMERS/PATIENTS

- I bring my PGHD to my appointment on an electronic device. 21%
- I email my PGHD to my HCP. 47%
- I go to my provider's website and enter/upload the relevant PGHD. 42%
- It automatically goes from my computer or mobile device to the cloud, where my PGHD is stored for my HCP to access it. 13%
- It automatically goes from my smart phone or tablet directly to my provider for immediate access. 11%
Office-based Providers Consider PGHD Trustworthy, Accurate & Complete

Patients Say: Providing PGHD is Easy, Important & Complete

<table>
<thead>
<tr>
<th>TRUSTWORTHY</th>
<th>ACCURACY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean=3.91</td>
<td>Mean=3.74</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COMPLETENESS</th>
<th>EASY</th>
<th>IMPORTANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean=3.36</td>
<td>Mean=4.53</td>
<td>Mean=4.45</td>
</tr>
</tbody>
</table>

Patients say statistically more complete than providers

(1=not at all; 5=highly)

$p=0.0003$
## Provider’s Attitudes Regarding PGHD

How much do you agree or disagree with the following statements: (5=STRONGLY AGREE, 1=SOMEWHAT DISAGREE) (n=386)

<table>
<thead>
<tr>
<th>Average weight</th>
<th>MOST IMPORTANT</th>
<th>LEAST IMPORTANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.01</td>
<td>Patients would be more likely to provide PGHD if they knew that the provider reviewed the information.</td>
<td>3.10</td>
</tr>
<tr>
<td>3.96</td>
<td>Patients would be more likely to provide requested PGHD if it were easier for them to do so.</td>
<td>2.96</td>
</tr>
<tr>
<td>3.91</td>
<td>The benefits of having PGHD far outweigh any of the disadvantages.</td>
<td>2.88</td>
</tr>
<tr>
<td>3.90</td>
<td>Patients would be more likely to provide PGHD if the provider used the information in the development of the patient’s treatment plan.</td>
<td>2.71</td>
</tr>
<tr>
<td>3.63</td>
<td>PGHD helps to risk stratify patients.</td>
<td>2.68</td>
</tr>
<tr>
<td>3.61</td>
<td>New digital tools have done a lot to increase the quantity of PGHD.</td>
<td></td>
</tr>
<tr>
<td>3.59</td>
<td>Discussing PGHD increases the length of the office visit/discussion.</td>
<td></td>
</tr>
<tr>
<td>3.53</td>
<td>New digital tools have done a lot to increase the quality of PGHD.</td>
<td></td>
</tr>
<tr>
<td>3.46</td>
<td>Patient’s don’t understand the relevance of the health data they collect.</td>
<td></td>
</tr>
</tbody>
</table>

*p=0.0002*  
*p<0.0001*
Number of Portals Providers Reference

On average, how many different electronic health portals do you have to access in order to manage your patient panel? (i.e., EHR, Lab, Radiology, etc.) (n=119)

OFFICE-BASED PROVIDERS

- 1: 28%
- 2: 13%
- 3: 22%
- 4: 21%
- >5: 7%
- Don't know: 5%
- 4%
Providers Believe Biggest Barriers to Patients Providing PGHD: COMPLEXITY of Technology & TIME

What do you think are the biggest impediments to patients providing PGHD electronically? (Select up to three) (n=119)

CONSUMERS/PATIENTS

- Patient portals are too difficult to use. 33%
- It's simply too overwhelming for sick patients to do this task themselves, and not everyone has a caregiver. 31%
- Patients don't want to have to remember to do record-keeping. 30%
- Generating PGHD is too time-consuming for patients. 30%
Survey Results

PGHD Barriers/Facilitators
Barriers PGHD: Patient Perceptions

- Forget to collect/share
- Thought providing PGHD was optional
- Too difficult to collect
- TIME: Didn’t have the time to collect it
- USE: Didn’t think the provider would actually use; Didn’t see the benefit
- TIME: Office visits too short

PE

Thought providing PGHD was optional

Too difficult to collect

TIME: Didn’t have the time to collect it

USE: Didn’t think the provider would actually use; Didn’t see the benefit

TIME: Office visits too short

SAT

PE

eData

PE

PE

PE

PE
Barriers PGHD: Provider Perceptions

Don’t always review data or use it to develop the treatment plan

- Lack of relevance, organization and record integration
- Not enough TIME to consider the data
- Patients don't want to have to remember to do record-keeping
- Patients do not believe that PGHD makes a difference in their treatment
- Patient portals… too difficult to use
Facilitators PGHD: Providers

- Providers need to ask for PGHD information
- Providers need to explain why PGHD is important and how it will be used in care
- HCPs must listen and use the information provided by the patient
- Make data collection easy (standardized, digital)—to insure data relevance, organization, reliability and accuracy
- Better technology solutions for data integration into the EHR are needed
- More time

Sat PE eData
Survey Results

Conclusions
## Provider Conclusions

<table>
<thead>
<tr>
<th>Vicious Cycle:</th>
<th>Trust PGHD:</th>
<th>Useful but time consuming:</th>
<th>Handwritten</th>
<th>Net/Net</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Providers don’t think motivated to gather/provide PGHD</td>
<td>PGHD is largely accurate, complete and trustworthy</td>
<td>When PGHD used in a clinical encounter, Patient Engagement increased, as well as time it takes to complete the encounter</td>
<td>PGHD typically provided in form which is not ideal for recording/documenting</td>
<td>The benefits of PGHD outweigh the disadvantages</td>
</tr>
</tbody>
</table>
Patient Conclusions

Patients don’t provide PGHD when they are not asked to do so.

Patients are motivated to collect/share PGHD if they understand why it’s important and how it will be used.

Collecting PGHD is easy and important.

Patients largely collect PGHD in handwritten, non-digital form.

Net/Net
Patients engage more when their PGHD is discussed.
An Introduction of How Benefits Were Realized for the Value of Health IT

- Patient
- Provider

- Data reporting
- Enhanced communication
- Data sharing

- Patient education/engagement
Questions?

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Thank you!

Remember to Complete Your Evaluation