Democratizing Patient Data: A Story of Patient Empowerment

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Kristina Sheridan and Kate Sheridan have no real or apparent conflicts of interest to report.
Agenda

- The Patient Perspective
- The Caregiver Perspective
- Research to Enable Sustained Patient Empowerment
Learning Objectives

1. Discuss the barriers preventing clear communication from patients to providers, and describe patient-facing tools and strategies that support bi-directional communication

2. Show how the use of patient-generated health data can improve health outcomes, and discuss how this data can be integrated into the clinical setting

3. Demonstrate, with real-world experiences, how patient-facing tools can be leveraged to engage patients and their caregivers with their health, and empower patients

4. Explain why policies that incentivize the use of patient-generated data, and clinical studies that measure the benefit of this data, are necessary to the availability and use of patient-facing tools
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High Pain Levels
Emergency Shoes

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Currently, 1/2 of Americans have at least one chronic condition.

More than 3/4 of US healthcare dollars are spent on their behalf.

Innovation Opportunity

Rising costs

Yet we only spend 1% of health care venture capital on helping patients manage their own health.\(^1\)

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Current State

One-Directional Communication

Supply

Psychiatrist

Patient

Caregiver

NP

PT

Patient
Future State

Bi-Directional Communication

Provider

Patient

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Patient Needs

Self-Management Support

Bi-Directional Communication

eHealth Technology


Remotely engaged: Lessons from remote monitoring in multiple sclerosis


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Capabilities to Empower

Prototype developed for clinical studies
Tracking Medications

- **Patient Toolkit**
  - **Sort Options**:
    - Sort by Name
    - Sort by Provider
    - Sort by Date
  - **Treatment Details**:
    - **Generic Name**: Methylprednisolone 4 mg Injection
    - **Display Name**: Methylprednisolone Injection
    - **Strength**: 4 mg
    - **Amount at one time**: 1 vial
  - **Treatment Dates**:
    - **Start Date**: January 11, 2018
    - **End Date**: January 27, 2018
  - **Medication Status**:
    - Taken
  - **Additional Information**:
    - 07:00 AM Track HAYF at home

Sharing For Action
Barriers to Adoption

- **COMPLEXITY** of use [2,3]
- **BENEFIT** of technology and data [3]
- **INTERNET** speed and access [1,3]
- **IT SUPPORT** needed [3]
- **SUSTAINABILITY** and funding [4]
- **STORAGE** and privacy [2]
- **WORKLOAD** impact [4]


Mitigate potential barriers to the use of patient empowerment capabilities in a clinical setting for long-term and sustainable impact.
Usability Test

Age Groups

Education

Comunications Technology Use

- Other: 2
- Smartphone: 11
- Tablet: 2
- Laptop: 11
- Personal Computer: 9
- None: 0

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Usability Outcomes

- Single access to features
- Legends, Color, Size
- Simplified reminders
Formative Evaluation

- Patient recruitment procedures
- Internet access and usability concerns
- Care workflow impact
- Feedback procedures
- Patient understanding of features
- Patient perception of tool and ease-of-use
- Provider perception of tool and ease-of-use
- Data collection for analysis
Clinical Study

Measuring impact on:

• Patient self-efficacy in managing symptoms and medical treatment
• Patient activation, engagement, and empowerment
• Health literacy
• Shared decision-making
• Patient/provider communication
• Patient-reported outcomes (patient satisfaction, health status, quality of life)
• Cost of health care
Standards for integration of patient-generated data into Electronic Health Record Systems

Tools and capabilities to capture the patient voice inside and outside the clinical setting

Incentives for the adoption of patient-facing tools and patient-generated data

<table>
<thead>
<tr>
<th>Fee for Service</th>
<th>Chronic Care Management</th>
<th>Clinical Quality Measures</th>
<th>ACO Models</th>
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</thead>
<tbody>
<tr>
<td>No Relative Value Unit for Patient Engagement&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Reimburse 20 mins for Comprehensive Care Plan&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Bi-directional communication not prioritized</td>
<td>Incentivizes patient communication and patient tools</td>
</tr>
<tr>
<td>20 mins for Chronic Care Management&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Does not require inclusion of Patient Generated Health Data (PGHD)</td>
<td>Only one CQM under meaningful use with PGHD, none in 2016 HEDIS Measures&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Adoption of patient-facing tools limited by size, resources and location&lt;sup&gt;4&lt;/sup&gt;</td>
</tr>
</tbody>
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<sup>1</sup> Andrew M. Ryan, PhD, Stephen M. Shortell, PhD, MPH, MBA, Ratricia P. Ramsay, MPH, Lawrence P. Casalino, MD, PhD. Salary and Quality Compensation for Physician Practices Participating in Accountable Care Organizations. Ann Fam Med. 2015 July/Aug; 13(4)  
<sup>2</sup> Department of Health and Human Services, Centers for Medicare and Medicaid Services. Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016.  
Questions

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