Democratizing Patient Data: A Story of Patient Empowerment

Session 251, March 8, 2018
Kristina Sheridan, Principal Investigator, The MITRE Corporation
Kate Sheridan, Student, George Mason University

© 2018 The MITRE Corporation. All rights reserved. Approved for public release. Distribution unlimited. Case number 18-0189
The Patient Perspective
The Caregiver Perspective
Research to Enable Sustained Patient Empowerment
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
Kate Sheridan
Student, Health Administration and Policy
George Mason University
Healthy to Sick
Overwhelmed
Coordinated Care
My Identity
Currently, 1/2 of Americans have at least one chronic condition

Innovation Opportunity

Rising costs

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


Poor Outcomes


Kristina Sheridan
Principal Investigator
The MITRE Corporation
Our Solution
Current State

One-Directional Communication

Psychiatrist
GP
Patient
Caregiver
NP
PT
Provider
Patient
Future State

Bi-Directional Communication

© 2018 The MITRE Corporation. All rights reserved. Approved for public release. Distribution unlimited. Case number 18-0189
Patient Needs

Self-Management Support

Bi-Directional Communication

eHealth Technology


Remotely engaged: Lessons from remote monitoring in multiple sclerosis

Matthew M. Engelhard*, Stephen D. Patek†, Kristina Sheridan‡, John C. Lach†, Myla D. Goldman*

© 2018 The MITRE Corporation. All rights reserved. Approved for public release. Distribution unlimited. Case number 18-0189
Capabilities to Empower

*Prototype developed for clinical studies
### Symptoms

#### Which symptoms should we track?

- **Blurry vision**
- **Fleas**
- **Dry irritated eyes**
- **Photophobia** (intolerance to light)
- **Psychiatric (Mental Health)**
- **Anxiety without clear explanation**
- **Fear of people, places or things**
- **Mood swings**
- **Irritability**
- **Uncontrolled restlessness**
- **Thoughts of feeling trapped**

### Symptom Tracker

#### Report Date
04/25/2018 07:27 AM

<table>
<thead>
<tr>
<th>symptom</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety without clear explanation</td>
<td>0</td>
</tr>
<tr>
<td>Body aches</td>
<td>0</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>0</td>
</tr>
<tr>
<td>Dry irritated eyes</td>
<td>0</td>
</tr>
<tr>
<td>Fatigue</td>
<td>0</td>
</tr>
<tr>
<td>Forgetful, short term memory loss</td>
<td>0</td>
</tr>
<tr>
<td>Headache</td>
<td>0</td>
</tr>
<tr>
<td>Irritability</td>
<td>0</td>
</tr>
<tr>
<td>Muscle aches or pains</td>
<td>0</td>
</tr>
</tbody>
</table>
Tracking Medications

- patient toolkit interface
- medication list: Methylprednisolone, Morphine, Lisinopril, Methylprednisolone, Methylprednisolone, Methylprednisolone
- treatment details: Name: Methylprednisolone, Date: January 21, 2018
- enter report details:
  - Date: Jan 22, 2018
  - Scheduled Time: 8:30 AM
  - Report Time: 7:36 AM
  - Medication Status: Taken

© 2018 The MITRE Corporation. All rights reserved. Approved for public release. Distribution unlimited. Case number 18-0189
Appointment Preparation

Life Notes

Provider Note

1/23/18, 9:20 PM

My knees are extra painful today.

APPOINTMENT GOALS

- Be able to walk 30 mins without getting out of breath
- Reduce pain levels

QUESTIONS

- Why is my headache still so bad?

SYMPTOMS

- Dry irritated eyes
- Forgetful; short term memory loss
- Muscle aches or pains

Today

Pick up bread

Dr. Jones Appmnt. with Dr. Dave Jones 1/22/18, 2:00 PM

Description:

Check on foot pain

© 2018 Image Source: The MITRE Corporation
Sharing Data

Patient Toolkit

View and Edit Data

Last 7 days:

Average Symptom Severity: 3.48

- Anxiety without clear explanation: 5.26
- Body aches: 4.19
- Forgetful, short term memory loss: 3.65
- Dry irritated eyes: 3.48
- Difficulty concentrating: 3.42
- Fatigue: 3.10
- Irritability: 2.97
- Headache: 2.81
- Muscle aches or pains: 2.45

Active Medication Compliances:

- Propranolol (Oral Pill): 7% (Prescribed 01/21 to 02/14)
- Midodrine (Oral Pill): 67% (Prescribed 01/21 to 01/27)
- Lisinopril (Oral Pill): 100% (Prescribed 01/21 to 02/14)

Inactive Medication Compliances:

- The time period to calculate your feeling statistics:

View Symptom Data

Feeling

Time Period

- Last week
- Last 30 days
- Last 90 days
- Last 6 months
- Last year

Select Date

February 10, 2018

Overall On This Date

2.28

List By Date

February 14, 2018

February 13, 2018

February 12, 2018

February 11, 2018

February 10, 2018

February 9, 2018

February 8, 2018

February 7, 2018

February 6, 2018

February 5, 2018

- Forgetful: short term memory loss - 10:52 AM
- Dry irritated eyes - 10:52 AM
- Muscle aches or pains - 10:52 AM
- Body aches - 10:52 AM
- Difficulty concentrating - 10:52 AM
- Fatigue - 10:52 AM
- Irritability - 10:52 AM
- Headache - 10:52 AM
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 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

Fee for Service

- No Relative Value Unit for Patient Engagement

Chronic Care Management

- Reimburse 20 mins for Comprehensive Care Plan
- Does not require inclusion of Patient Generated Health Data (PGHD)

Clinical Quality Measures

- Bi-directional communication not prioritized
- Only one CQM under meaningful use with PGHD, none in 2016 HEDIS Measures

ACO Models

- Incentivizes patient communication and patient tools
- Adoption of patient-facing tools limited by size, resources and location

---

2. 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

Kristina Sheridan
Principal Investigator, The MITRE Corporation
ksheridan@mitre.org
@k_sheridan1
https://www.linkedin.com/in/kristina-sheridan-b880168/

Kate Sheridan
Student, George Mason University
ksherid4@masonlive.gmu.edu
@kate_sheridan1
https://www.linkedin.com/in/kate-sheridan-62a016127/

Please complete online session evaluation!