Using a Sidecar Strategy to Integrate PROs with EHRs: CF Health Check

User’s Guide for Integrating Patient-Reported Outcomes in Electronic Health Records

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Alexandria, VA

Eugene C. Nelson, DSc, MPH
Aricca Van Citters, MS
The Dartmouth Institute

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Case 4

Mr. Toad’s Wild Ride
Flow

- Project Aim & Background
- General Model
- Case: Adapting Model to Cystic Fibrosis
- Lessons Learned
Project Aim & Background

Project Aim

• **Short-term:** To develop coproduction dashboards -- for use by CF patients, families, CF clinicians and care teams - - to use at the point of care to co-assess health status, co-decide on treatment plans, and support the co-delivery of treatments

• **Long-term:** To develop a registry-based learning health system for coproducing health, improvement and science
“Would you like to help the Robert Wood Johnson Foundation import an innovation?”
Lindblad: Swedish Rheumatology Quality Registry

RA remission rates improving across all of Sweden

Feed Forward Innovation
Patient Registering Data on Swollen and Tender Joints on her Touch Screen

The SRQ Approach

https://www.youtube.com/watch?v=Kmqzy1hqcOw
Case in point:
Swedish National Quality Registry ...
This patient is doing better ...
N of 1 experiment...
Response to biologics
RA Disease Burden in Sweden Decreasing*

* CRP (C reactive protein) levels in RA patients
Margolis: Improve Care Now

IBD remission rates improved from 55% to >80%

2007

Remission by Month for Individuals with Inflammatory Bowel Disease

- 55%
- 78%
General Model: Registry-Based Learning Health System

Patient & Family

Feed Forward PRO Data

Partnership for Co-production

Provider & Care Team

Feed Forward Clinical Data

Shared Information Environment

Personal Health Records
Patient Facilitated Networks

Registries

Electronic Health Records
Collaborative Improvement Networks

Optimal Health and High Value Care for Patients and Populations

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See BMJ July 2016, Nelson et. al.
When Things Will Really Get Interesting

Traditional Enterprise EHRs (Epic, Cerner, etc)

Consumer-facing IT (pt portals, apps, sensors, etc)
Patient focused registries can improve health, care, and science

Eugene Nelson and colleagues call for registries of care data to be transformed into patient centred interactive learning systems

Eugene C Nelson professor\textsuperscript{1}, Mary Dixon-Woods professor\textsuperscript{2}, Paul B Batalden professor\textsuperscript{1}, Karen Homa researcher\textsuperscript{3}, Aricca D Van Cittters researcher\textsuperscript{1}, Tamara S Morgan researcher\textsuperscript{1}, Elena Eftimovska professor\textsuperscript{4}, Elliott S Fisher professor\textsuperscript{1}, John Ovretveit professor\textsuperscript{4}, Wade Harrison researcher\textsuperscript{1}, Cristin Lind professor\textsuperscript{5}, Staffan Lindblad professor\textsuperscript{4, 5}
Case Example: Cystic Fibrosis

**Purpose**
- PROs: Point-of-care decision support, Self-management, Research
- Enhance patient-provider partnerships through direct patient access to registry data

**Path Forward**
- 5 pilot sites: co-design and test
- Determine IT strategy
- Proof of concept testing
Context: Cystic Fibrosis Foundation

- **Cystic Fibrosis:**
  - ~ 30,000 people in US
  - Pulmonary and digestive systems
  - Care burden (self-management / care encounters)

- **Stakeholders:**
  - Patients, Providers, CF Care Centers, Patient advocacy organization (CFF)

- **Data IT Systems:**
  - EHR, Registries, Personal health devices/apps

- **Compliance:**
  - IRB, BAA, Hospital IT regulatory boards, FDA Part 11
Coproduction of CF Healthcare Services (Initial design)

My Current Health Priority/Goals:

Possible Barriers:

Care Plan / Agreed Upon Action Steps:

Concerns / Requests
What do I want to discuss at my next visit?

Requests to the care team for the visit:

Additional Information
Problem List
Culture history
Laboratory values

Medication refills / Pharmacy

Trends in Health and Well-being

Mental health
Today
Good

Physical health
Fair

Quality of life
Good

FEV₁

Weight

X FEV₁
X Weight (Lbs)
X Physical health
X Mental health
X Quality of life

My goal: FEV₁
My goal: Weight

Time (2 year default; adjustable)

Additional details: Drill down view

Health Maintenance Reminders & Testing Timelines (Next due)

Decision Point: EHR or “Sidecar” approach to collect /display PROs

EHR: Benefits
• Fitting into clinician workflow
  – Single access/data entry point
  – Documentation in the right place
  – Established patient-provider communication systems (e.g., messaging, refill requests, etc.)
• Increasing functionality/use of patient portals

EHR: Challenges
• Key clinical data not in field-defined locations (e.g., PFT)
• National scale:
  – Diverse EHR platforms
  – Consistency & accessibility to programmers
  – Variation in patient’s access to EHR portals
  – Portability of record
• Limited graphical display options

Sidecar for Proof of Concept:
• Portable, standard platform, allowing integration of registry data with PROs
• Extraction of EHR data to registry (Smart Form template)
Survey Development: Co-design and Pilot Process

- Age-specific PRO surveys
  - Clinician, patient, researcher input

- Pilot tested in 6 CF care programs (MN, IL, NH)
  - Feasibility (e.g., time to complete)
  - Acceptability (understanding of questions)
  - Distribution of responses

- Modification and finalization of survey
## Condition-specific PROs

**GI Scales**
- **GI Symptom Tracker**
- Behavioral Pediatrics Feeding Assessment Scale (BPFAS)

**Pulmonary**
- Akron Children’s Hospital Criteria for Pulmonary Exacerbation (Akron PEx)
- **Cystic Fibrosis Respiratory Signs (CFRSD 0-6 & 7-11)**
- **Chronic Respiratory Infection Symptom Scale (CRISS)**
- CF - Observer-Reported Outcome (ObsRO)
- Sino-Nasal Outcome Test (SNOT-16)

**General**
- Cystic Fibrosis Questionnaire (CFQ)
- **Cystic Fibrosis Questionnaire-Revised (CFQ-R)**
- Study SmartPill CFQR Modified Symptom Sub-Scale
- Northern New England CF Consortium (NNECFC) Exercise Survey

## General PROs

**Experience:**
- Goal attainment scoring (GAS)
- Treatment Satisfaction Questionnaire for Medication (TSQM)

**Exercise capacity**
- 1 Min Sit-to-Stand test (STS)

**Quality of life**
- Alfred Wellness Score for CF (AweScore-CF)
- Healthy Days Core Model (CDC HRQOL-4)
- **PROMIS 10**
- **PROMIS Pediatric Global Health (PGH-7)**
- **PROMIS PGH-7+2**
- **PROMIS Global Health Scale**
- PROMIS Global Health Short Form
- Memorial Symptom Assessment Scale (MSAS)

## Mental health
- Center for Epidemiologic Studies Depression Scale (CES-D)
- Generalized Anxiety Disorder 7-item (GAD-7)
- Patient Health Questionnaire (PHQ-4)
- Patient Health Questionnaire (PHQ-9)

## Pain
- Brief Pain Inventory
- Brief Pain Inventory (short-form)
- Pain Catastrophizing Scale

## Other
- Spine Patient Outcomes Research Trials (SPORT survey)
- Clinical Outcome Assessment Compendium (COA Compendium)

**Standardized scales coupled with clinical intake surveys used at Pilot Sites**
## PRO Testing

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 0-6</td>
<td>28</td>
</tr>
<tr>
<td>Child 7-11</td>
<td>18</td>
</tr>
<tr>
<td>Child 12-17</td>
<td>23</td>
</tr>
<tr>
<td>Adult 18+</td>
<td>39</td>
</tr>
</tbody>
</table>

**110 Total Surveys**

### Time to Complete Survey

- **Child 0-6**: 28 surveys
- **Child 7-11**: 18 surveys
- **Child 12-17**: 23 surveys
- **Adult 18+**: 39 surveys

### Understanding of Questions

- **Child 0-6**: 28 surveys
- **Child 7-11**: 18 surveys
- **Child 12-17**: 23 surveys
- **Adult 18+**: 39 surveys

#### PROMIS: Age 12+

- **Overall health**: 0
- **Quality of life**: 20
- **Physical health**: 40
- **Mental health**: 60
- **Social satisfaction**: 80
- **Social activities**: 100
- **Physical activities**: 80
- **Emotional problems**: 60
- **Fatigue**: 40
- **Pain**: 20

#### Pain Distribution

- **Less than 5 min**: 0
- **6-10 Min**: 5
- **Greater than 10 min**: 10

#### Understanding Distribution

- **All questions**: 100%
- **Most questions**: 90%
- **Some questions**: 10%
CF Health Check to Collect / Display PROs

CF Health Check

Our CF Center is working with the Cystic Fibrosis Foundation to test a new way to understand how you (or your child or children) are doing. We will use these questions to help plan for the upcoming care visit and to make sure we try to meet your needs. Some of the answers on symptoms and health outcomes will also be used for longer-term goals, such as improving your care experience and the quality of care.

<table>
<thead>
<tr>
<th>Submission Info</th>
<th>Survey Title</th>
<th>Survey Progress</th>
<th>Survey Action</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cystic Fibrosis Health Journal</td>
<td></td>
<td>Retake</td>
</tr>
</tbody>
</table>

5/16/2017 9:48:47 AM View / Print
5/15/2017 10:48:31 AM View / Print

Trends in Health and Well-being

Toggle the switch below the graph to turn on or off the display of each aspect of your health. Hover over data points on the graph to see values.

Legend: Quality of Life, Physical Health, Sadness/Emotional Problems, FEV 1 % Predicted Weight

In general, would you say your health is:
- Excellent
- Very Good
- Good
- Fair
- Poor

In general, would you say your quality of life is:
- Excellent
- Very Good
- Good
- Fair
- Poor

In general, how would you rate your physical health?
- Excellent
- Very Good
- Good
- Fair

**CF Health Check**: A new on-line tool being tested by the CF Foundation.
Dashboard  (#1 concerns and topics to discuss)

What is my #1 concern or goal related to CF?

<table>
<thead>
<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/16/2017 9:48 AM</td>
<td>My insurance stopped covering my medication co-pay and I need some suggestions on how to cover the costs of these medications, or whether I can discontinue any.</td>
</tr>
<tr>
<td>5/15/2017 10:48 AM</td>
<td>I have a hard time getting motivated to exercise. I would like help coming up with a plan that I can follow.</td>
</tr>
</tbody>
</table>

What do I want to discuss at my next visit?

<table>
<thead>
<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/16/2017 9:48 AM</td>
<td>Information on patient prescription programs</td>
</tr>
<tr>
<td>5/15/2017 10:48 AM</td>
<td>Other (describe): This disease can feel so overwhelming, when I have so many other things going on in my life. Any thoughts on how to help with this?</td>
</tr>
<tr>
<td>5/15/2017 10:48 AM</td>
<td>Coping with CF</td>
</tr>
</tbody>
</table>
Dashboard (Trends in health and well-being)

Trends in Health and Well-being

Toggle the switch below the graph to turn on or off the display of each aspect of your health. Hover over data points on the graph to see values.

LEGEND: Quality of Life Physical Health Sadness/Emotional Problems FEV 1 % Predicted Weight

Date Range: Last 2 Years

Well-being (Higher scores represent greater well-being)

FEV 1 % Predicted and Weight (kg)
Your clinical markers of CF may be related to your symptoms, functioning, or treatments. Select one or more measures below the graph to see whether they change at the same time as your clinical markers.
# Dashboard (Goals, Care plan, Barriers)

## My Health Goals and Priorities

<table>
<thead>
<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/16/2017 9:14 PM</td>
<td>Run a 5 km race without having to stop to catch my breath.</td>
</tr>
</tbody>
</table>

## Care Plan / Agreed Upon Action Steps:

<table>
<thead>
<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/16/2017 9:09 PM</td>
<td>Increase frequency of pulmozyme to 2 times per day for the next week. It should help you bring up more mucus when you cough.</td>
</tr>
</tbody>
</table>

## Possible Barriers:

<table>
<thead>
<tr>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/16/2017 9:10 PM</td>
<td>Plan to switch health insurance providers in the next month. Unsure of the impact on my medication co-pays.</td>
</tr>
</tbody>
</table>
Sidecar Approach: CF Health Check

• Challenges:
  – Integration with EHR for documentation and internal research purposes
  – Duplication

• Benefits:
  – End user support
  – Flexible graphic displays
  – Minimal site-level programming
  – Patient control of data
  – Benefits of a PHR

Ideal solution: Hybrid system with bidirectional information flow
Summary & Lessons Learned

• Designed for multiple end-users with multiple purpose
• Integration of PROs and registry data
• PROs will support:
  – Shared decision making and self-care
  – FDA-compliant CFF registry-based research program
  – QI collaboratives and initiatives (160+ CF care center network)
• Evolution: Exploring multiple approaches (sidecar, EHR optimization)
  – Interoperability – data standardization
  – Smart data elements, Smart forms, and Notewriter templates
Acknowledgements

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