Measuring what matters to patients: concepts & cases

The Health Foundation
Improvement Science Development Group
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The Dartmouth Institute
Dartmouth-Hitchcock Health System

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Short Answer Value:

Outcomes + Experiences + Costs

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**Patient Centered Measures of Value**

<table>
<thead>
<tr>
<th>Specific Aim</th>
<th>Value = ( (\text{Outcomes} + \text{Experience}) ) Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcomes</strong></td>
<td><strong>Experience</strong></td>
</tr>
<tr>
<td>Overall Measures</td>
<td>Overall Patient Experience Rating</td>
</tr>
<tr>
<td>Functional Health</td>
<td>CAHPS: 0-10 rating</td>
</tr>
<tr>
<td>• PROMIS Global-10*</td>
<td></td>
</tr>
<tr>
<td>• Others: CDC Healthy Days, VR-12, EQ-5D</td>
<td></td>
</tr>
<tr>
<td>Health Risk</td>
<td></td>
</tr>
<tr>
<td>• IHME Risk Index¹*</td>
<td></td>
</tr>
<tr>
<td>• Others: Framingham Index</td>
<td></td>
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<tr>
<td><strong>Illustrative Sub-Domain Measures</strong></td>
<td></td>
</tr>
<tr>
<td>Functional Health</td>
<td>Whole Person Orientation - Patient Activation</td>
</tr>
<tr>
<td>• Physical Health: PROMIS-PH-4††</td>
<td>• HowsYourHealth, PAM-13</td>
</tr>
<tr>
<td>- Activities of Daily Living ‡‡</td>
<td></td>
</tr>
<tr>
<td>- Fall Risk ‡‡</td>
<td></td>
</tr>
<tr>
<td>- Instrumental Activities of Daily Living ‡‡</td>
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</tr>
</tbody>
</table>

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Table reproduced from Bechtel, Janet Corrigan, Susan D. DeVore, Elliott Fisher, and Gene Nelson, in *Health Affairs* (May 9, 2013).
Key Patient Outcomes
Experience
Disease
Function
Risks
Competence
Costs

Aim: measures to support co-production of health* & health care in microsystems**

At risk
New condition
Recover/Reduce Burden

Person
Clinician

Co-Production

Key measures

Health Determinants*
- Genetics
- Environment
- Lifestyle
- Health care

** Clinical microsystems, i.e., the place where patients and providers meet and interact for the benefit of patients (12)
An old story ... great **clinical results** & better **functional outcomes** ... because of functional screening

**Case 1**

*Functional Health Status Levels of Primary Care Patients*

Eugene Nelson, DSc; Beach Conger, MD; Richard Douglass, MD; Dale Gephart, MD; John Kirk, MD; Robert Page, MD; Austen Clark, DPhil; Kenneth Johnson, MD; Kevin Stone; John Wasson, MD; Michael Zubkoff, PhD

A cross-sectional study was conducted on functional status of adults visiting primary care practices. Limitations in physical and mental function were assessed independently in 28 practices by patients (N=1,227) and physicians (N=47) using a simple global index of disability. Results indicated 12% of patients rated their physical limitations as major and 8% rated major emotional limitations during the past month. Comparable assessments by to gain a better understanding as to

* Jack Kirk, MD
  Founder
  Dartmouth COOP Project
Using PROMs with Individuals: Dartmouth Spine Center

Feed Forward

Referral or Visit Request → Orientation & PROMs → Initial Work Up Plan of Care → Acute Care Management

Functional Restoration → Chronic Care Management → Functional & Risk Status

Palliative Care → People with healthcare needs met

Feed Back

✓ Improvement registry
✓ Public reports website
✓ SPORT & research

Disease Status
Sunk Costs
Expectations For Good Care

© 2000, Trustees of Dartmouth College, Batalden, Nelson, Wasson
The summary report generated from patient-reported data is critical to a physician's ability to care for a patient: *same page care*

“practicing without it …flying a plane without instruments”
Herniated Disk Outcomes @ 2 Years

<table>
<thead>
<tr>
<th>Surgery</th>
<th>Non-Surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>44 Ave Age</td>
<td>30 Ave Age</td>
</tr>
<tr>
<td>43% Female</td>
<td>45% Female</td>
</tr>
</tbody>
</table>

Cost Per Quality Adjusted Life Year Added By Surgery $34,355

Moving research results back to patient care …
 risk calculator used at point of care for Shared Decision Making about likelihood of outcomes based on different treatments.
Case 3

Sweden: Rheumatology Quality Registry (SRQ)

• SRQ uses PROMs feed forward data in flow of care: better care for individuals, practice improvement, new care models, retrospective & prospective research & better measured outcomes for Sweden RA patients
## Dashboard for a Rheumatology Patient

**Swedish National Quality Registry** … patient is doing better … *N of 1* experiment… Responded to biologics

### Functional Outcomes

<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>2010 05-Jan</th>
<th>2010 23-Feb</th>
<th>2010 28-Mar</th>
<th>2010 03-Jun</th>
<th>2010 05-Sep</th>
<th>2010 08-Dec</th>
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</thead>
<tbody>
<tr>
<td>År</td>
<td>Dag Månad</td>
<td>Årskontroll</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Månads-Kontroll</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>8</td>
<td>11</td>
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<tr>
<td></td>
<td>MK-grupp</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>9</td>
<td>12</td>
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</table>

### Clinical Outcomes

<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>2010 05-Jan</th>
<th>2010 23-Feb</th>
<th>2010 28-Mar</th>
<th>2010 03-Jun</th>
<th>2010 05-Sep</th>
<th>2010 08-Dec</th>
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<tbody>
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<td>År</td>
<td>Dag Månad</td>
<td>Årskontroll</td>
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<td>Arbetsförmåga</td>
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<tr>
<td></td>
<td>Allmän hälsa</td>
<td>75</td>
<td>75</td>
<td>71</td>
<td>35</td>
<td>35</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>SR</td>
<td>54</td>
<td>63</td>
<td>48</td>
<td>25</td>
<td>15</td>
<td>5</td>
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<tr>
<td></td>
<td>Läkarbedömning</td>
<td>Hög</td>
<td>Hög</td>
<td>Hög</td>
<td>Måttlig</td>
<td>Låg</td>
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<tr>
<td></td>
<td>EQ5D</td>
<td>-0.045</td>
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<td>0.808</td>
<td>0.931</td>
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<tr>
<td></td>
<td>CRP</td>
<td>35</td>
<td>35</td>
<td>20</td>
<td>8</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Spond.artrit, Ank.spond. BASFI</td>
<td>1.75</td>
<td>1.75</td>
<td>1.63</td>
<td>0.88</td>
<td>0.88</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Svullna leder (66)</td>
<td>81</td>
<td>80</td>
<td>75</td>
<td>40</td>
<td>30</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Ömma leder (68)</td>
<td>12</td>
<td>18</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>1</td>
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<tr>
<td></td>
<td>Daktylit</td>
<td>12</td>
<td>18</td>
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<td>18</td>
<td>11</td>
<td>2</td>
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</tr>
</tbody>
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### January - March

- **DAS28**
  - 2010 05-Jan: 6.75
  - 2010 23-Feb: 6.86
  - 2010 28-Mar: 6.49
  - 2010 03-Jun: 4.11
  - 2010 05-Sep: 2.95
  - 2010 08-Dec: 2.7

### June - December

- **DAS28**
  - 2010 05-Sep: 6.21
  - 2010 08-Dec: 5.84
  - 2010 03-Jun: 3.61
  - 2010 05-Sep: 2.41
  - 2010 08-Dec: 2.79

- **KORT**
  - PRE
  - 1/10
  - 1/15
  - 1/10
  - 1/10
  - 1/10
  - 1/10

- **DMARD 1**
  - MTX
  - MTX
  - MTX
  - MTX
  - MTX

- **DMARD 2**
  - SAL
  - SAL

- **DMARD 3**
  - 20/1
  - 20/1
  - 20/1

- **DMARD 4**
  - 2000/1
  - 2000/1

- **Uppfölj månad**
  - 0
  - 0
  - 3

- **Uppföljt läkemedel**
  - ENB
  - REM
  - REM

- **Läkemedelsdosis**
  - 50/1
  - 200/8
  - 200/8
  - 200/8
  - 200/8
By the way … Swedish health system is doing better

All Patients in the SRQ, from 1994 – 2006*

*Black line shows DAS at initial visit and blue after 6 months and turquoise after 12 months.

Patients sicker at 1st visit

From front line practice to national policy

Patients better at 12 months
What measures matter most to patients at the front lines is DYNAMIC

Patient Reported Metrics + Clinical Metrics = Guidance System for Getting It Right …

• Health care decisions right for Amy
• Health care plans right for Amy
• Health care outcomes best for Amy
• Thus, Amy is able to co-produce her care
Lessons Learned

- If we fail to use patient reported outcomes to plan care we may be flying blind (1980s)
- Patient reported information can be used to guide shared decision making, build a care plan & track treatment outcomes (1990s)
- Outcomes are co-produced by people & clinicians who are guided by health status measures & the person’s goals that evolve over time (2000s)
Selected References

15. PROMIS Measures: www.promis.nih.org/ (last accessed December 31, 2013)
Aim: Patient-centered decision support for co-production of good care, better health & more competence in self-management.

Key Mechanism: Integrating patient’s voice into flow of care & EHR to co-produce care plans that reflect needs & values.

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