A REGISTRY ENABLED CARE AND LEARNING SYSTEM: A PROPOSAL TO THE RWJF FOUNDATION

EUGENE C. NELSON, DSC, MPH
STAFFAN LINDBLAD, MD, PHD
JOHN OVRTVEIT, C.PSYCHOL., PHD
THE DARTMOUTH INSTITUTE AND KAROLINSKA INSTITUTET

PCPI OCTOBER 23, 2014
TOPICS

1. The PCPI’s interest in registries
2. Origins of Swedish/RWJF registry project
3. Description of the Swedish Rheumatology Quality Registry
4. Conceptual model and proposal
5. Reflections & opportunities
6. Discussion
National Quality Registry Network (NQRN®) - A voluntary network of organizations operating registries and others interested in increasing the usefulness of clinical registries to measure and improve patient health outcomes

Goal
• Increase the uses and usefulness of registries

Objectives
• Establish and disseminate leading practices for registries
• Advocate for and support a learning network to accelerate national progress on registry development, growth and use
• Develop resources for the clinical registry industry
HOW MANY SOCIETIES SUPPORT REGISTRIES?

A recent inventory of national clinical registries found that 68 organizations currently support 122 registries.

Source: NQRN National Clinical Registry Inventory, Oct. 2014
2. ORIGINS OF PROJECT

“Gene, would you be interested in looking at the prospects for importing the SRQ approach for use in the United States?”
EVOLUTION OF REGISTRIES

- Codman (Boston, 1910)
- O’Conner (New England, 1988)
- Weinstein (Dartmouth, 1998)
- Lindblad (Sweden, 2014)
USING FEED FORWARD PROMS WITH PATIENTS: DARTMOUTH SPINE CENTER & NATIONAL REGISTRY

Feed Forward

- Referral or Visit Request
- Orientation & PROMs
- Initial Work Up
  - Plan of Care
- Acute Care Management
- Chronic Care Management
- Functional Restoration
- Palliative Care

Feedback

- Improvement registry
- Public reports website
- SPORT & research

© 2000, Trustees of Dartmouth College, Batalden, Nelson, Wasson
Report generated from patient-reported data is used by clinician to guide care for the patient: **same page care**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appointment:</strong> Spine</td>
<td><strong>Survey Group:</strong> Spine Followup; completed on 08/24/2006; 5 mins</td>
<td><strong>Reason for visit:</strong></td>
</tr>
<tr>
<td><strong>Personal Summary (as of 08/24/2006):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demographics:</strong> White; Male; 57 yrs old; Divorced/Separated; Graduated from high school or GED</td>
<td><strong>Primary Language:</strong> English</td>
<td><strong>Work Disability (as of 08/23/2006):</strong></td>
</tr>
<tr>
<td><strong>Condition history:</strong> Back or neck pain; Ulcer; Depression</td>
<td><strong>Work requirements:</strong> A little strenuous; Legal action: None - I am not covered</td>
<td><strong>Worker comp disability:</strong> No - I am not covered</td>
</tr>
<tr>
<td><strong>Family history:</strong> Depression</td>
<td><strong>Health History (as of 08/23/2006):</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Medication allergies:</strong> Antibiotics</td>
<td><strong>Current conditions:</strong> Back or neck pain; Ulcer; Depression</td>
<td><strong>Condition history:</strong> Back or neck pain; Ulcer; Depression</td>
</tr>
<tr>
<td><strong>Health habits (as of 08/23/2006):</strong> BMI: 37.3 (Obesity); 260 lbs; 5 feet, 10 in</td>
<td><strong>Fatigue:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Review of systems:</strong> Const: Not sure; ENT: Not sure</td>
<td><strong>Cough:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Eyes:</strong> Patient denies any eye symptoms</td>
<td><strong>Cardio:</strong> Patient denies any heart symptoms</td>
<td><strong>GI:</strong> Patient denies any GI symptoms</td>
</tr>
<tr>
<td><strong>Resp:</strong> Cough</td>
<td><strong>Uro-gyn:</strong> Frequent urination; Drumbling</td>
<td><strong>M/S:</strong> Other symptoms with joints or muscles</td>
</tr>
<tr>
<td><strong>Neuro:</strong> Patient denies any neurological symptoms</td>
<td></td>
<td><strong>Hemo/Lymph:</strong> Patient denies any blood/lymph node symptoms</td>
</tr>
</tbody>
</table>

**History of Present Illness (as of 08/23/2006):**
- **Chief complaint:** Upper back, lower back, left buttocks, right buttocks, left hip, right hip
- **Initial Visit:** 08/23/2006
- **Length of symptoms:** More than 3 years
- **Date of episode:** 10/03/2005

**Red Flags / Considerations:**
- Practicing without it ...feels like I am flying blind

**Risk Factors**

**Functional Status**

**Disease Status**

**Patient Perception of Outcomes**
SPORT NIH Trial

- 13 Centers
- 3 spine conditions
- Feed forward PROMs
- Prospective controlled trial
- 6 years of follow up
- 50+ publications
3. THE SWEDISH RHEUMATOLOGY QUALITY REGISTRY

DR. STAFFAN LINDBLAD, MD, PHD
KAROLINSKA INSTITUTET
VIDEO PRESENTATION
OCTOBER 23, 2014
Aim

• To test the adaptation of the SRQ approach in the United States
• A registry enabled care and learning system … a “collaboratory”
• Several potential benefits for patients, physicians, care teams, researchers, medical specialty societies, payers
From Sweden ............ to the United States
**Aim:** Patient-centered decision support for coproduction of measured health outcomes, high value care, research, continuous learning and professional development.

**Key Mechanism:** Integrating the patient reports into the flow of care to coproduce care plans that reflect needs & values using feed forward and feedback information.

---

**Patient Facilitated Network**
- Patients with shared problems; peer support; condition subject matter expertise
- Information I need for self-care
- Co-curated by patients/professionals
- Personal Health Plan - patient controlled data
- Examples: PatientsLikeMe, C3N, HowsYourHealth, pumpco

---

**Health Information Gateway**
- Designed for

---

**Clinical Registry Network**
- Feed forward PRO data into the point of care for care planning and outcome tracking
- PRO data is designed into work flows
- Comparative data for practice improvement
- Research, quality improvement database as by-product
- Examples: SRQ (Sweden), ACR, and CFF registries

---

**Value Measures**
- Disease
  - Function
  - Competence
- Experience
- Costs
- Risks

---

**Learning Health System**
- Coproduction of Care
- Supported by
  - Patient & Family System
  - Clinical Registry
  - Patient Facilitated Network
  - Clinical Registry Network
  - EHR
  - PRO Data
Living Longer With CF

Increasing Life expectancy but need new care model fit for the future
PATH FORWARD

1. Start with cystic fibrosis and IBD: vision registry enabled care & learning system

2. Engage key collaborators: CFF, NQRN, ABMS, ABIM, ACR & others (e.g., PatientsLikeMe, Epic, payers, etc.)

3. Form multi-stakeholder innovation design team

4. Start to design & alpha test implementation of SRQ/C3N approach in diverse settings: prototype, alpha, beta, spread

Note: CCHMC, Karolinska & Dartmouth have started design phase with funding from CFF and CCFA
1. Start with cystic fibrosis & alpha test in 3 practices
2. Co-design with patients & families, clinicians & care teams, researchers & payers
3. PROMs & clinical data feed forward & feedback for use at point of care & for self-management
4. Include core set of value metrics: outcomes, experience, utilization, expenditures
5. Data flows into EHRs and PHRs and into registry for comparative performance benchmarking, improvement & research
6. Patient facilitated network enabled for patients and practice improvement collaborative enabled for clinicians
7. Evaluate all along the way & if successful spread to other populations such as RA, DM, depression, multi-morbidity patients, etc.
VALUE PROPOSITION

The proposed system has the potential to facilitate more effective coproduction of care by patients and clinicians, improvement and research based on registries, and 24/7 support based on patient-facilitated networks.

• Improving care for people & families with a health condition
• Improving quality for practices and clinical programs
• Promoting practice based research
• Advancing patient-centric facilitated networks
• Fostering continuous professional development & public reporting
5. REFLECTIONS

Opportunities
Challenges
Possible Solutions
FUTURE – LHS

“By the year 2020, 90% of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence.”

IOM Roundtable on Value & Science-Driven Health Care

“a learning health system which generates and applies the best evidence for the collaborative health care choices of each patient and provider; drives the process of discovery as a natural outgrowth of patient care”
"THIS IS IMPORTANT WORK. YOU CAN COUNT ON ABMS’S SUPPORT AND WILLINGNESS TO WORK WITH YOU TO MAKE THIS HAPPEN. THIS REALLY COULD BE THE ‘GOLD STANDARD’ FOR HOW CARE SHOULD BE DELIVERED."

PAUL MILES, MD
SELECTED REFERENCES


15. PROMIS Measures: www.promis.nih.org/ (last accessed December 31, 2013)
SPARES
OVERVIEW OF A RHEUMATOLOGY PATIENT

Case in point: Swedish National Quality Registry ... This patient is doing better ... N of 1 experiment... Responded to biologics

<table>
<thead>
<tr>
<th>År</th>
<th>2010</th>
<th>2010</th>
<th>2010</th>
<th>2010</th>
<th>2010</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dag Månad</td>
<td>05-Jan</td>
<td>23-Feb</td>
<td>28-Mar</td>
<td>03-Jun</td>
<td>05-Sep</td>
<td>08-Dec</td>
</tr>
<tr>
<td>Årskontroll</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Månads-Kontroll</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Arbetsförmåga</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<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>SR</td>
<td>54</td>
<td>63</td>
<td>48</td>
<td>25</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Läkarbedömning</td>
<td>Hög</td>
<td>Hög</td>
<td>Hög</td>
<td>Måttlig</td>
<td>Låg</td>
<td>Låg</td>
</tr>
<tr>
<td>EQ5D</td>
<td>-0.045</td>
<td>-0.045</td>
<td>0.808</td>
<td>0.931</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRP</td>
<td>35</td>
<td>35</td>
<td>20</td>
<td>8</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Spond. artrit, Ank. spond. BASFI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Svullna leder (66)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ömma leder (68)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duktylit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entesit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funktionsneds. - HAQ</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>Smärta</td>
<td>81</td>
<td>80</td>
<td>75</td>
<td>40</td>
<td>30</td>
<td>27</td>
</tr>
<tr>
<td>Svullna leder (28)</td>
<td>12</td>
<td>12</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Ömma leder (28)</td>
<td>12</td>
<td>12</td>
<td>11</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>VIFA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trombocyter</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DAS28</td>
<td>6.75</td>
<td>6.86</td>
<td>6.49</td>
<td>4.11</td>
<td>2.95</td>
<td>2.7</td>
</tr>
<tr>
<td>BASDAI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DAS28CRP</td>
<td>6.21</td>
<td>6.21</td>
<td>5.84</td>
<td>3.61</td>
<td>2.41</td>
<td>2.79</td>
</tr>
<tr>
<td>NSAID</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>KORT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>KORT dos</td>
<td>10/1d</td>
<td>15/1d</td>
<td>10/1d</td>
<td>10/1d</td>
<td>10/1d</td>
<td>10/1d</td>
</tr>
<tr>
<td>DMARD 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 1 dos</td>
<td>20/1v</td>
<td>20/1v</td>
<td>20/1v</td>
<td>20/1v</td>
<td>20/1v</td>
<td>20/1v</td>
</tr>
<tr>
<td>DMARD 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 2 dos</td>
<td>2000/1d</td>
<td>2000/1d</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 3 dos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARD 4 dos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uppföljd månad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uppföljt läkemedel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Läkemedelsdos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
RA Disease Burden in Sweden Decreasing

starting Open-Tight clinics

RED Sweden

2002

BLUE Gavle

2012
VISION: IMAGINE IN A FEW YEARS …

**People & families** living with chronic conditions are competent in self management & can contact similar people & health experts any time night or day

*Care teams* are in contact & can respond to patients & families whenever needed to work with patients to rapidly adjust treatments to coproduce care & achieve better outcomes & can rapidly adopt new best practices

**Scientific collaboratories** use data from patients and clinicians to discover & spread information on what treatments work best for what kinds of patients under what conditions & curb unwarranted variations

**Specialty societies** make learning & improvement, based on relevant data, part of every day practice & continuous professional development & performance reporting