Patient Reported Outcomes, Coproduction and Collaboratories: A Registry Enabled Learning Health System

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Managing to Outcomes for Complex Patients
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Topics

1. Origins of Swedish/RWJF registry project
2. Description of the Swedish Rheumatology Quality Registry
3. Conceptual model and proposal
4. Discussion
5. References
“Gene, would you be interested in looking at the prospects for importing the SRQ approach for use in the United States?”
Evolution of Registries and Collaboratories

A Very Short List

Codman
Boston
1910

O’Conner
New England
1988

Weinstein
Dartmouth
1998

Lindblad
Sweden
2002

Margolis
CCHMC
2007
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

People with healthcare needs → People with healthcare needs met

Feedback

✓ Improvement registry
✓ Public reports website
✓ SPORT & research

1998

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Dashboard generated from patient-reported data is used by clinician to guide care for the patient: *same page care*

"Practicing without it ...feels like I am flying blind"
SPORT NIH Trial

- 13 Centers
- 3 spine conditions
- Feed forward PROMs
- Prospective controlled trial
- 6 years of follow up
- 50+ publications
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>

Functional
Clinical
Costs
Satisfaction

Reduced Oswestry Symptoms

Physical SF-36 Improvement

1.64 QALY
1.44 QALY

$34,355

Total Direct & Indirect Costs

Moving research results back to patient care … risk calculator used at point of care for Shared Decision Making

Cost Per Quality Adjusted Life Year Added By Surgery $34,355
2. Swedish Rheumatology Quality Registry

RA remission rates improving across all of Sweden

Patient Reported Outcomes
Feed Forward Data
Transparent Reports
Quality Improvement
New Care Model
Research Collaboratory
Patient Registering Data on Swollen and Tender Joints on a Touch Screen
Case in point: Swedish National Quality Registry …
This patient is doing better …
N of 1 experiment…
Responded to biologics
RA Disease Burden in Sweden Decreasing

starting Open-Tight clinics

RED Sweden

BLUE Gavle

2002 2012
From Sweden ............ to the United States
3. RWJF Proposal

• 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
Collaboratories …

A curious word … Journal Science

Science 2.0

Ben Shneiderman

Traditional scientific methods need to be expanded to deal with systems meet technological innovation.
A Registry Enabled Care & Learning System

Aim: We aim to build a learning health system where patients, providers, and researchers partner to co-produce optimal health and high value care.

Key Mechanisms: A registry-supported care and learning system that integrates: data feed forward systems, patient-centered clinical decision support “dashboards”, meaningful reports available to patients and providers, patient and provider networks, and multi-stakeholder learning collaboratives.

Learning Health System
For More Effective Action by Patients, Providers, and Researchers

Optimal Health and High Value Care for Patients and Populations

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Path Forward

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

2. Engage key collaborators: CFF, NQRN, ABMS, ABIM, ACR, CCFA & 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 support from CFF
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 complex condition
- Improving quality for practices and clinical programs
- Promoting practice based research
- Advancing patient-centric facilitated networks
- Fostering continuous professional development & transparent public reporting
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
"This is important work. You can count on ABMS 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  ABP & ABMS Emeritus
Acknowledgements

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Organizations: Board of Internal Medicine, American Board of Medical Specialties, American College of Rheumatology, CCHMC, Cystic Fibrosis Foundation, The Dartmouth Institute, Dartmouth-Hitchcock, Karolinska Institutet, Robert Wood Johnson Foundation.
Selected References

15. PROMIS Measures: www.promis.nih.org/ (last accessed December 31, 2013)