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Learning Through Coproduction: A Model for Improving Health Outcomes, Healthcare Services and Research

HIS QI Connect 2016
Global WebEx Series

Eugene C. Nelson, DSc, MPH
The Dartmouth Institute

July 27, 2016
“Gene, would you like to help the Robert Wood Johnson Foundation import an Innovation?”
Patient Registering Data on Swollen and Tender Joints on her Touch Screen

The SRQ Approach

https://www.youtube.com/watch?v=Kmqzy1hqOw
Patient Module

Your joints today
Swollen joints?
Mark the joints that are swollen today. If none is swollen please continue to the next question.

Your joints today
Painful joints?
Mark the joints that are painful today. If none is painful please continue to the next question.

Patient’s overview
Your disease activity

<table>
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<th>Earlier</th>
<th>2015</th>
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<th></th>
<th>2016</th>
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SRQ
Case in point: Swedish National Quality Registry ... This patient is doing better ... N of 1 experiment... Response to biologics

SRQ Coproduction Dashboard

<table>
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<th>Tabellöversikt</th>
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<tr>
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<td>200 / 8v</td>
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</table>
RA Disease Burden in Sweden Decreasing*

* CRP (C reactive protein) levels in RA patients
Improve Care Now: IBD Remission Rates by Month:
Registry Based Learning Health System

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

Swedish Rheumatology Quality Registry

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Coproduction

“All services, at some level, are coproduced.”

Paul Batalden
“I dream of the day when I can electronically display both clinically derived and patient reported information to the patient at the time of the visit and make a meaningful patient centered treatment plan coproduced with the patient.”

Dino Kazi, MD
Professor
Clinical Leader ACR RISE Registry
“learning health system”

“a learning health system ... generates and applies the best evidence for the collaborative health care choices of each patient and provider ... (and) drives the process of discovery as a natural outgrowth of patient care”

IOM Roundtable on Value & Science-Driven Health Care
Potential Benefits

• Improve outcomes for people with a chronic condition
• Improve quality for practices and clinical programs
• Promote practice-based research and advance science
• Advance patient-centered facilitated networks
• Foster continuous professional development
• Produce transparent public reporting
Path Forward: Proof of Concept

1. Starting with **CF** (5 centers in US & 4 in Sweden) and **IBD** (20 practices) ... arthritis next with support of Arthritis Foundation & Genentech Foundation

2. Engage key **collaborators**: CFF, CCFA, ABMS, ABIM, ACR, payers, IT vendors

3. Form multi-stakeholder **co-design team**: patients, parents, clinicians, registry leaders, scientists

4. **Test model** in diverse settings: prototype, alpha, beta, spread ... from small to all
Lung Function (Drill-down screen)

Patient Name / ID: ________  DOB: ______  Genotype: ________

Adjastable scale

Coughing at night

Time (2 year default; adjustable range)

Pulmonary: 
- FEV₁
- FVC
- Sputum (Color/volume)
- Fevers
- Breathing difficulties
- Chest pain
- Coughing at night
- Coughing up blood
- Exacerbation Score (CRISS)
- Other...

Nutrition:
- Body Mass Index (BMI)
- Weight
- Height
- Nutritional risk classification
- Stools
- Reflux
- Appetite
- Other...

Other health areas:
- Exercise (amt/tol)
- Sinus issues
- Mood
- Pain
- Overall health
- Diabetic control
- Culture history
- Laboratory values
- Other...

Interventions:
- Medications (by category)
- IV antibiotics
- Oral antibiotics
- Supplemental feed
- Hospitalization
- ER Visits
- Transplantation
- Surgeries
- Other...

CF Sweden: Home Tracking Clinic Visits & Patient Networks
Inflammatory Bowel Disease Dashboard

[Image of a digital dashboard for Inflammatory Bowel Disease (IBD) management]
Sam Cooper
Patient ID- MRN3001
IBD Diagnosis- CROHN'S
Phenotype- Disease Site- Diagnosis Date- 05/30/2016

RECENT SYMPTOMS

Most Important Concern as of 04/09/2016
Feeling good about using this dashboard and managing my own health

Symptoms and Disease Activity

WELL BEING
Slightly Under par

RECTAL BLEEDING
Obvious blood seen with >= 50% of stools

STOOL FREQUENCY
Normal number of stools

ABDOMINAL PAIN
Mild

CRP
--- mg/L

SYMPTOMS AND DISEASE ACTIVITY

Severity
Best

Worst

Well-Being
Rectal Bleeding
Stool Frequency
Abdominal Pain
CRP

PHYSICIAN’S GLOBAL ASSESSMENT
Current PGA: Severe
Enter New PGA

CONNECT
Report Symptoms
New Pre-Visit Survey
View Last Pre-Visit Survey
Report IBD Visit
Report Medication

CARE TEAM
Dr. Doo Little
Gastroenterology

CLINICAL EVENTS

Ciprofloxacin

Rituximab
Early Reflections on Coproduction Model

Patients on coproduction

• “Helps me move from feeling guilty … it’s my fault that I’m in the hospital to … How can we fix this together?”

• “My Doctor trusted my expertise … and recognized my talks (part of my job) are important to me.”

• “Can’t build on broken so focus on what we have as strengths.”

• “I do a lot of tracking. I can solve problems by tracking.”

• “They heard me out before responding to my concerns. Didn’t brush them off & responded with a solution supported by … similar cases.”

Clinicians on coproduction

• “Each visit is a 20 minute sprint, and now I feel like I’m getting a head start”

• “We are already doing coproduction; we are just doing it poorly.”

• Having the dashboard gives me a “hardstop. Before going into see the patient I see what their goals are and what they want to get out of the visit.”

• “It’s like having 2 experts in the room!”

• “Without my dashboard I can’t be a good doctor. I’m flying blind.”
Using Model Sets Up a Triple Play

1. Coproducing health, healthcare services & patient daily care capability

2. Coproducing quality improvement & professional development

3. Coproducing research and scientific knowledge
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 professor¹, Mary Dixon-Woods professor², Paul B Batalden professor¹, Karen Homa researcher³, Aricca D Van Citters researcher¹, Tamara S Morgan researcher¹, Elena Eftimovska professor⁴, Elliott S Fisher professor¹, John Ovretveit professor⁴, Wade Harrison researcher¹, Cristin Lind professor⁵, Staffan Lindblad professor⁴ ⁵
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Selected References: Coproducing health, improvement and science


