Coproducing Health, Healthcare Value and Science: Cases, Concepts and Conversations

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CAHO & ISQua: March 2, 2021
Hypothesis: Person-centered, registry enabled learning health systems can successfully coproduce better health, value, science ... by leveraging conversations & data

1. Early Cases
2. Key Concepts
3. Evidence on Impact
4. Using Coproduction Model at D-HH
5. Conclusion

“Skating to where the puck is going to be”

Wayne Gretzky
Weinstein JN, et al. The SPORT value compass: do the extra costs of undergoing spine surgery produce better health benefits? Medical Care 2014 Dec. 52(12):1055-63
A Patient Completing their Health Status (PROMs) Survey
Share summary information with patient ... Using PROMs for better conversations to focus on outcomes achieved vs outcomes wanted.
Coproduction Dashboard: Tracking Outcomes for INDIVIDUAL Patient

History & Review of Systems

Risk Factors

Clinical Status & Pain

PROMS: SF-36, Oswestry

Improving communication on patient’s expectations & outcomes

PCOMs: Patient Satisfaction With Treatment Outcomes

History of Present Illness

Red Flags
Dartmouth Spine Center: A Learning System

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

Feedback

✓ Improvement registry
✓ Public reports website
✓ SPORT & NIH research

Disease Status
Sunk Costs
Expectations For good care

Functional & Risk Status

People with healthcare needs met

Dartmouth Spine Center: A Learning System

Using feed forward data for better conversations and turning it into registry feedback data for value improvement & science
Research on Value of Surgery: NIH RCT Trial
Personalized Predictive Medicine

Patient-Specific Prediction based on evidence
86 vs 55 better
6 vs 26 worse
NIH RCT Trial: 12 centers, over 100 publications

A TRUE COPRODUCTION LEARNING HEALTH SYSTEM
IMPROVING OUTCOMES, VALUE & SCIENCE
Swedish Rheumatology Quality Register

RA remission rates Improving Across all of Sweden since 2002

Person-centered, registry-enabled learning health system ... on a national scale

Staffan Lindblad, MD, PhD
“Gene, this is what we need to focus on.”
The SRQ Approach

Patient is Registering Data on Swollen and Tender Joints on her Tablet

https://www.youtube.com/watch?v=Kmqzy1hqcOw
Clinician Module

- Patient Reported Outcomes
- Clinical Outcomes
- Rx Prescribed
Case in point: Swedish National Quality Registry
This patient is doing better!
N of 1 experiment...
Response to biologics
RA Disease Burden in Sweden “Cut in Half”

* CRP (C reactive protein) levels in RA patients
Then I got a call from my friend at RWJF ...
Concepts: Developing a Conceptual Model

“Gene, why don’t you draw up a model for our brainstorming session tomorrow?”
Registries + Learning Systems + Coproduction: A New Conceptual Model

Social System Innovations
Patient/Family Networks + QI/Research Networks

Technological Innovations
Registries + HIT Enabled Networks + Feedforward Feedback Data Flows

October 16, 2013
A Learning Health System for Coproducing Health, Value, Science & Conversations
Co-assess the patient’s health status and how the treatment plan has been working to improve patient’s health and well-being

Co-deliver the treatment plan that usually involves daily self-management and adherence to plan and occasional treatments by a professional clinician or clinical team

Co-design the treatment plan for daily care and professional interventions to attempt to minimize the BURDEN of TREATMENT

Co-decide on what the next steps in the patient’s treatment plan should be based on relevant evidence and past experiences to MINIMIZE the BURDEN OF DISEASE

“There are two experts in the room.”
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
A Learning Health System for Coproducing Health, Value, Science & Esprit de Corps

Now co-designing & implementing the model for:

- Cystic Fibrosis: US & Sweden
- Adult Crohn’s & Colitis: IBD Qorus
- Peds & Adult Rheumatology: US, Canada, & UK
- Palliative Care/Serious Illness: D-HH & US
- Cancer: Northwestern & D-HH
- Kidney Disease: Northwestern
- Multiple Sclerosis: MS-CQI
Model Based on Two Core Concepts

**Coproduction:** Elinor Ostrom

- Tragedy of the commons
- Raw competition
- Common pool resources
- Cooperative coproduction
- Nobel Prize winning concept

**Learning Systems:** Peter Senge

- The Fifth Discipline
- Leading organizations must be learning systems and continuously improve ability to achieve their mission
- IOM popularized “learning health system” concept
Coproduction and Economics

Coproduction can create services that are more efficient and effective and sustainable.

Elinor Ostrom
Nobel Laureate
All services, at some level, are coproduced.

Paul Batalden, MD
Coproduction Defined

The interdependent work of patients and professionals to design, deliver, assess and improve the relationships and actions that contribute to the health of individuals and populations through mutual respect and partnership that leverages each participant’s unique assets, expertise and actions.
“Learning organizations” are those organizations where people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning to see the whole together."
Learning Health System Defined

“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.”
Real World Cases: Learning Health Systems Selected Evidence of Impact

   - Northern New England Cardiovascular Study Group (NNE)

2. Cystic Fibrosis: 1992
   - CFF Registry Enabled Learning Health System

3. Rheumatoid Arthritis: 2002
   - Swedish Rheumatology Quality Register (SRQ)
Northern New England Cardiovascular Study Group: CABG Mortality “Cut in Half” in 10 Centers

The 30-Year Influence of a Regional Consortium on Quality Improvement in Cardiac Surgery.
CF Foundation Registry Enabled Learning System: 10-year Gain in Life Expectancy in 185 Centers

10-year gain in life expectancy from 1990 - 2012 before breakthrough protein modulators developed
Swedish Rheumatology Quality Register: RA Disease Activity Reduced 12% to 3% in Sweden

*Figure*: Split limits Xmr Statistical Process Control (SPC) chart (in green) with superimposed longitudinal trend fit line (in red) of C Reactive Protein Levels in RA patients followed by the SRQ from 2002-2017. Mean CRP levels are depicted by black lines. Upper and lower control limits are depicted by dashed green lines.

Dartmouth’s Learning Health System in Oncology
Dartmouth’s Learning Health System in Oncology

Designing for **Better Outcomes, Experience, Value and Science**

Together, we bring the full power of our **collective expertise** to provide the best possible care to our patients, our people and our communities.
Tools & Innovations to Support Teams

Serious Illness Conversation Model of Care

Patient Wisdom

Point of Care Dashboards

Peer-to-Peer Facilitated Support Network

Data, Measurement & Scholarship

Collaborative Learning Network
Learning, Measuring, Sharing, and Improving Together
The **Serious Illness Conversation Guide** is a framework to make conversations about seriously ill patients’ priorities more efficient, higher quality and more meaningful.
More, Earlier, Better, and Visible

Use of the SICG in oncology and high risk primary care settings led to:

✓ Earlier discussions before EOL

✓ Increased EOL discussions before death

✓ Higher quality discussions followed best practices

✓ Documentation highly visible in eMR

Lakin, Health Aff, 2017; Paladino, JCO 2015 (suppl 29S; abstr 9); Bernacki, JCO 2015 (suppl 29S; abstr 39)
Clinicians using a guide more frequently elicited patients’ goals and values

Control: 44%

Intervention: 89%

p<0.001

Intervention patients had lower rates of moderate to severe anxiety

Anxiety

Percent of patients with moderate or severe anxiety

Baseline | 14 | 24 | Weeks

p=0.048 | p=0.02

Patients report meaningful behavior changes

“Making changes to my will. Plan my funeral.”

“More realistic in my approach with family and friends about my prognosis.”

“Made a complete list of all my last wishes, such as when I can no longer go to the bathroom myself I want hospice house care.”

“I am doing the same stuff as before, just feeling less anxious about the future (hope for the best, prepare for the worst).”

“I have started to think about what my priorities are in terms of quality of life.”

“Mostly the conversation brought us closer (Dr. X).”

The SIC Model of Care aims to systematically increase conversations between oncology teams and seriously ill patients to understand their goals before complications arise, while making conversations more efficient, higher quality, and more rewarding.

<table>
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<th>Year</th>
<th>Jan 2021</th>
<th>Sept 2021</th>
<th>June 2022</th>
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<td>Transplant and Cellular Therapy</td>
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<td></td>
<td>Melanoma</td>
<td>Melanoma</td>
<td>Lymphoma &amp; Leukemia</td>
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Serious Illness Conversation - complete form below and go to documentation to save as note.

What is your understanding now of where you are with your illness? (Select one or describe below)
- Limited/Inaccurate understanding of prognosis of disease trajectory
- Accurate understanding of prognosis or disease trajectory
- Other

How much information about what is likely to be ahead with your illness would you like from me? (Select one or describe below)
- All available information, including time-based prognosis
- Big picture, what to expect
- No information, share with DPOA/Surrogate (specify name of person)
- Other

What prognostic information was communicated to the patient? (Select one or more or describe below)
- Time-based prognosis
- Function-based prognosis "this is as strong as you will feel"
- Uncertain prognosis "difficult to predict, but there is a possibility you could get very sick, very quickly"
- Not discussed with patient, information shared with DPOA/Surrogate (document name of person below)
- Other information given

What are your most important goals if your health situation worsens? (Select one or more or describe below)
- Spend time with family
  - Take care of my family
  - Be at home
  - Be physically comfortable
  - Accomplish particular life goal (describe in text box)

Information preferences:
- All available information, including time-based prognosis
- Big picture, what to expect
- No information, share with DPOA/Surrogate (specify name of person)
- Other

Goals:
- Take care of my family
- Fears and worries:
  - Uncontrolled symptoms
  - Unable to breathe, terrible pain

Strengths:
- Family, faith or spirituality
- Critical abilities:
  - Physical ability (no toileting/bathing self-describe necessary abilities below)
  - Need to be able to do things for myself (bathroom, getting dressed, sitting on the porch outside)

Trade-offs:
- OK with the hospital but no machines (don’t want family to have to pull the plug) and no CPR (when it’s my time, it’s my time)

Family/Agent/Surrogate awareness:
- DPOA/Surrogate present for discussion

Recommendations made:
We aim to have a Serious Illness Conversation with patients who are most likely to experience significant complications, morbidity, frequent hospitalizations or death in the next 2 years.

Graph of function over time adapted from Lunney et al. JAMA 2003
The SIC is efficient, can be shared within teams, adds RVUs

**Median time for conversation:**

- Nurses: 26 minutes
- Physicians: 22 minutes

**Conversation completed by:**

- Nurses: 19%
- Physicians: 37%
- Multiple staff: 44%

Lakin JR, Health Aff, 2017.

<table>
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<tr>
<th>ACP billing code</th>
<th>RVU</th>
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<tbody>
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<td>99497 (&gt;16” on ACP)</td>
<td>1.5</td>
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<tr>
<td>99498</td>
<td>1.4</td>
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Run Chart: Serious Illness Conversations
Combined Data From Head & Neck and Sarcoma Clinics
Dates: 1/1/20-12/28/20

- **PDSA 1-5 Duration (Development)**

- **PDSA 6-7 Duration (Kickoff)**
  - Initiated SIC Coaching and Data Sharing with Team.

- **PDSA 8-10 Duration (Standard Work)**
  - Patient Report Out Defined, Scheduling Script Introduced based on VOC.

- **PDSA 11-12 Duration (Resources)**
  - SIC Completion Timing Defined, Expanded workforce Capacity.

- **PDSA 13 (Expansion)**

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**Total Screened (Encounters):** 
* N=153

**Total Eligible SIC:** 
N=41

**Total Completed SIC:** 
N=22

---

**Percent SIC Completed**

- AIM GOAL 25%

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**Time in Days for Completion of a SIC**

- UPDATED AIM GOAL 50%

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**Total Patients Screened Eligible (N):**

---

**Date**

---

**Total Percent SIC Performed**

- Aim Goal (50%)

---

**Median**

- Median 25.0%

---

**Average Days from SIC Eligibility to Completion**

- 19
The PFA reduced clinicians’ barriers to initiating conversation

“Hearing from a patient that ‘this conversation has value to me’ has a great impact.”

“I was nervous about the words ‘Serious Illness’ being daunting to patients. [The PFA] made me realize, no they want to talk about this and made me more comfortable bringing it up with patients.”

Early conversations improved clinicians’ experience of delivering care

“[having] conversations earlier.. [gives me] a high amount of confidence... it makes me feel like I’m on solid footing when coming up with a plan”

“I’m used to on-the-side-of-the-road conversations.. it’s so nice to say that we’ve started these conversations [early] instead of having to do a lot of extrapolating, or leading, or asking family to tell us what to do. We can point to what the patient said they wanted.. it gives me a sense of security”

The LHS reframed clinicians’ perspective on their role in providing care

Not just what to do with chemo – rather “start a process of [discussing] what is and is not important” to the patient

The conversation “is not about the end point [end of life] – it’s about how you want the journey [of illness] to be”

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Conclusion: Communications and Coproduction

- Coproduction learning health systems can improve health, healthcare value and science
- A key to their success is better conversations that forge better patient/physician relationships that focus on the patient’s goals and on treatment plans that have the best chance of achieving the outcomes that matter most to patients
References & Resources


Website: [www.dartmouth.edu/coproduction](http://www.dartmouth.edu/coproduction)
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• The Crohn’s &Colitis Foundation
• The Gordon & Betty Moore Foundation
• The Couch Family Fund
Appendices
ORIGINS

Ernest Codman
Registries

W. Edwards Deming
Quality Improvement

Elinor Ostrom
Coproduction

Peter Senge
Learning Systems
Results

Risk-Adjusted Rates of Outcomes in the NICU at the 10th, 25th, 50th, 75th, and 90th Percentiles, 2005-2014, With the Dark Blue, Light Blue, and Dotted Red Curves Indicating 10th/90th, 25th/75th, and 50th Percentiles, Respectively
Pediatric IBD: Improve Care Now
Multiple Sclerosis Continuous QI Collaborative (MS-CQI)

Collaborative Proportion Experiencing Relapse by Quarter Dec 2019 n=12,658 (p' Chart)

Collaborative Average (Green Line) = 6.8%

Baseline: 7.2%, 8.1%, 11.4%

Intervention: 6.1%, 5.5%, 4.8%, 4.3%, 5.3%, 3.8%
How did they do it? Selected Exemplars

Table 1. Key change mechanisms associated with major improvements in health outcomes for patients with CABG, CF, rheumatoid arthritis, low birth weight Infants & IBD

<table>
<thead>
<tr>
<th>Population &amp; Program</th>
<th>New Advances in Science: Therapies</th>
<th>Quality Improvement Collaborative</th>
<th>Feed Forward Data at Point of Care</th>
<th>Patient Reported Outcome Measures</th>
<th>Patient Level Registry Database</th>
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<td>NNE: NNE Cardiovascular Study Group</td>
<td>++ 1</td>
<td>++</td>
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<tr>
<td>CF: Cystic Fibrosis Foundation Registry</td>
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<tr>
<td>RA: Swedish Rheumatology Quality Register</td>
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<td>LBW Infants: Vermont Oxford Network</td>
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<tr>
<td>Peds IBD: Improve Care Now</td>
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1. Discovery of Low Output Failure caused by CABG surgery
2. Discovery of new drug therapies: biologics
Power to the people

Everyone gains when researchers partner with the public and policymakers. The knowledge generated is more likely to be useful to society and should be encouraged.

Few sign up to science for a glamorous lifestyle, colossal salary or generous dental plan. They do it to gain insights and knowledge and, they hope, to make the world a better place. Too often, that last objective proves hard to achieve — not because of uncaring researchers living in ivory towers, but because the way in which some types of study are done and rewarded does not set the correct priorities. That needs to change.

Enter co-production: full involvement in research by people who hope to benefit from the work, in partnership with communities, policymakers and other members of the public. Popular since the 1970s among sociologists as a way to help set inclusive policy, the term — and the principle — is spreading throughout academic science. As we highlight in a special issue this week, a growing work can be included as an author (see go.nature.com/2pocpux). Most of all, co-production requires individual scientists to see the opportunities and to want to take advantage of them.

The growth in political populism and rising public dissatisfaction with policies some people see as excluding their interests have made it more important for researchers to produce — and to be seen to produce — research that is both beneficial and relevant to society. Efforts to do so are overdue. The onus is on researchers and those who support them to put systems in place to encourage more collaborations.

"Co-production is better for society. It also leads to better research."

If ivory-tower scientists did cut themselves off from the problems...