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

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CAHO & ISQua: March 2, 2021

The Dartmouth Institute
for Health Policy & Clinical Practice
Coproduction Laboratory
International Coproduction Health Network at Dartmouth

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

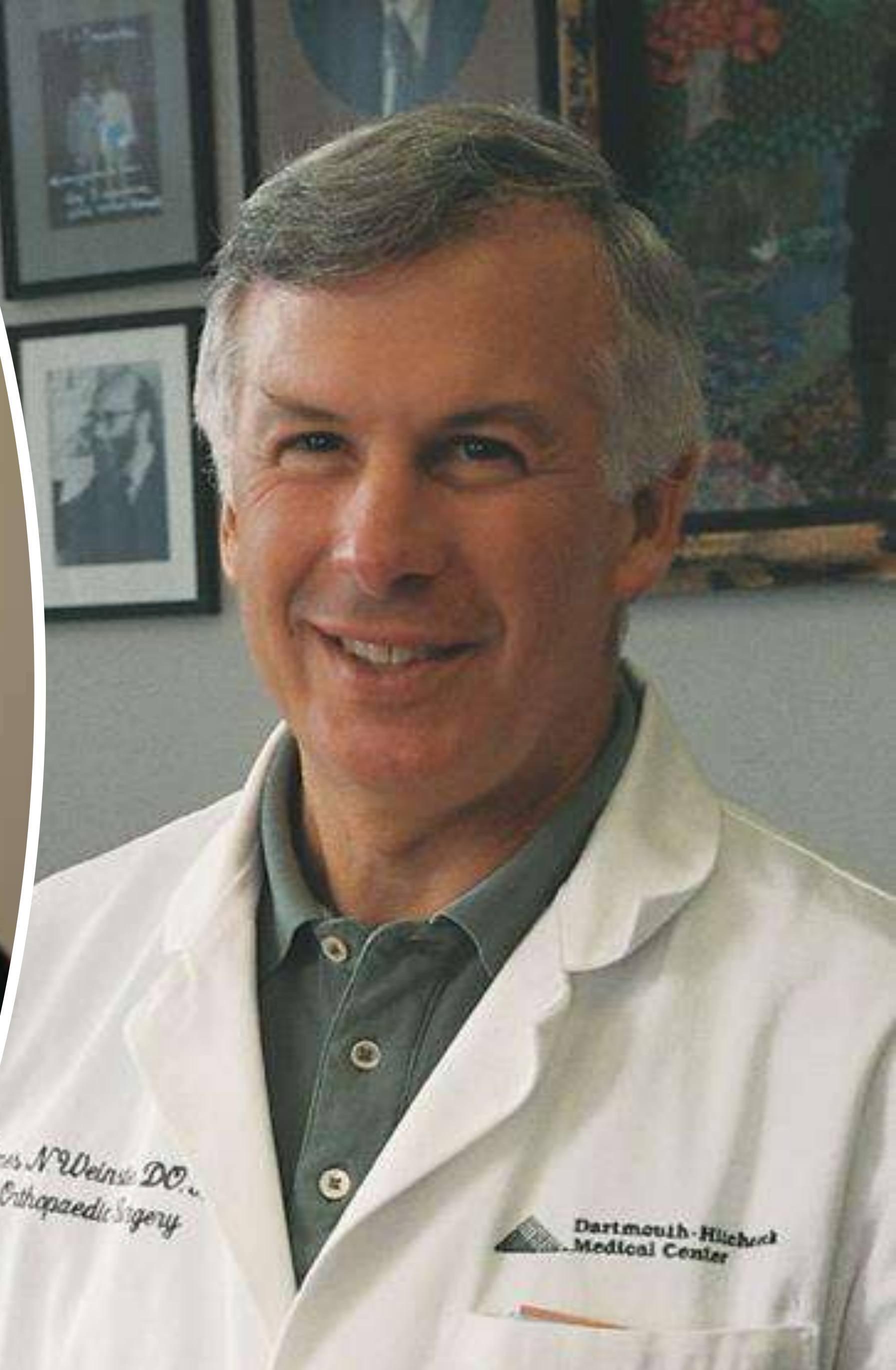
"Skating to where the puck is going to be"

Wayne Gretzky

Case: Dartmouth Spine Center Inspiring Swedish Quality Register

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

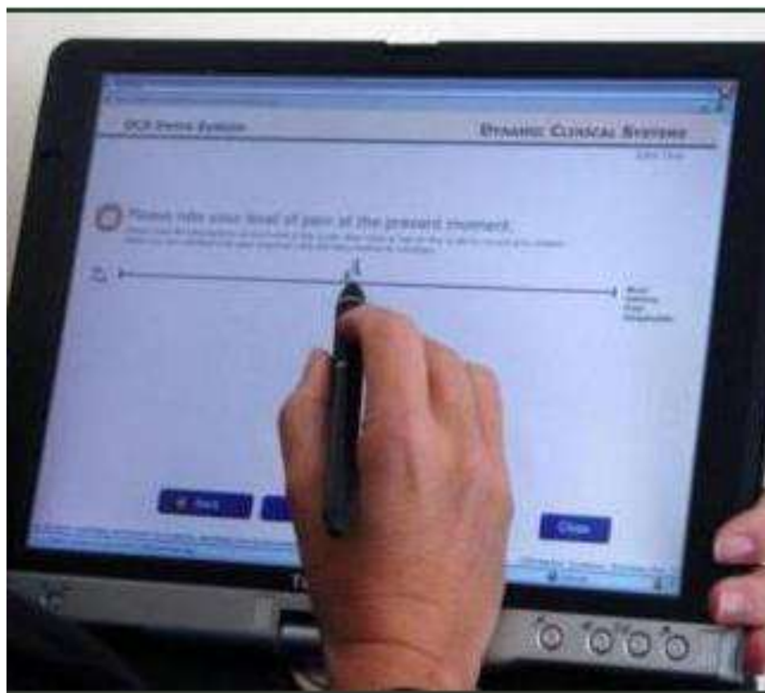
1998



Lisa Weiss, MBA

Jim Weinstein, MS, DO

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

PROMs: SF-36, Oswestry

History of Present Illness

Red Flags

Risk Factors

History & Review of Systems

Clinical Status & Pain

PCOMs: Patient Satisfaction With Treatment Outcomes

Improving communication on patient's expectations & outcomes

Patient: Patient,Demo; 000031

Report Date: 08/24/2006

NO Photo On File

Appointment: Spine
Survey Group: Spine Followup; completed on 08/24/2006; 5 mins
Reason for visit:

Personal Summary *(as of 08/24/2006)*
Demographics: White; Male; 57 yrs old; Divorced/Separated; Graduated from high school or GED
Primary Language: English
Working Status: Currently working, Disabled and/or retired ... 29 hours

Work Disability *(as of 08/23/2006)*
Job requirements: A little strenuous
Legal action: None - I am not considering any legal action
Worker comp disability: No - I am not planning to apply for Workers Compensation

Health History *(as of 08/23/2006)*
Current conditions: Back or neck pain; Ulcer; Depression
Condition history: Back or neck pain; Ulcer; Depression
Family history: Depression
Medications: Muscle relaxant, Other over-the-counter
Medication allergies: Antibiotics

Health Habits *(as of 08/23/2006)*
BMI: 37.3 (Obesity); 260 lbs; 5 feet, 10 in
Smoking: Never smoked
Alcohol AUDIT: 3: low risk

Review of Systems
Const: Not Sure
ENT: Not sure
Eyes: Patient denies any eye symptoms
Resp: Cough
Cardio: Patient denies any heart symptoms
GI: Patient denies any GI symptoms
Uro-gyn: Frequent urination; Dribbling
M/S: Other symptoms with joints or muscles
Neuro: Patient denies any neurological symptoms
... tient denies any blood/lymph node
... acted
... in

History of Present Illness *(as of 08/2...)*
Chief complaint: Upper back, Lower back, ... Right buttocks, Left hip, Right hip
Initial Visit: 08/23/2006
Length of symptoms: More than 3 years
Date of episode: 10/01/2005

Red Flags / Considerations
Med allergies: Antibiotics (e.g., amoxicillin, sulfa, penicillin, etc.)

Clinical protocols / measures

Patient-reported scores (see graphs on next page)
ODI: 26 (lower = better)
AUDIT:
Physical Function: 49 (Norm: 49)
Role Physical: 50 (Norm: 49)
Bodily Pain: 41 (Norm: 50)
General Health: 39 (Norm: 50)
Vitality: 49 (Norm: 52)
Social Function: 46 (Norm: 51)
Role Emotional: 52 (Norm: 51)
Mental Health: 56 (Norm: 52)
MCS: 54 (Norm: 52)
PCS: 42 (Norm: 49)

	Expectations	Expectation met
Symptoms Relief:	Somewhat likely	Probably yes
More Activities:	Very likely	Probably yes
Sleep Better:	Very likely	Probably not
Return to job		
Exercise / R...		

SF-36v2
Initial Current Norms
75, 0
Better, Worse
Phys. Func., Role Phys., Bodily Pain, Gen. Health, Vitality, Soc. Func., Role Emot., Mental Health, PCS, MCS

Longitudinal MCS/PCS
PCS MCS
75, 56.25, 37.5, 18.75, 0
46, 54, 36, 42
Better, Worse
8/23/06, 8/24/06

Oswestry Disability Index

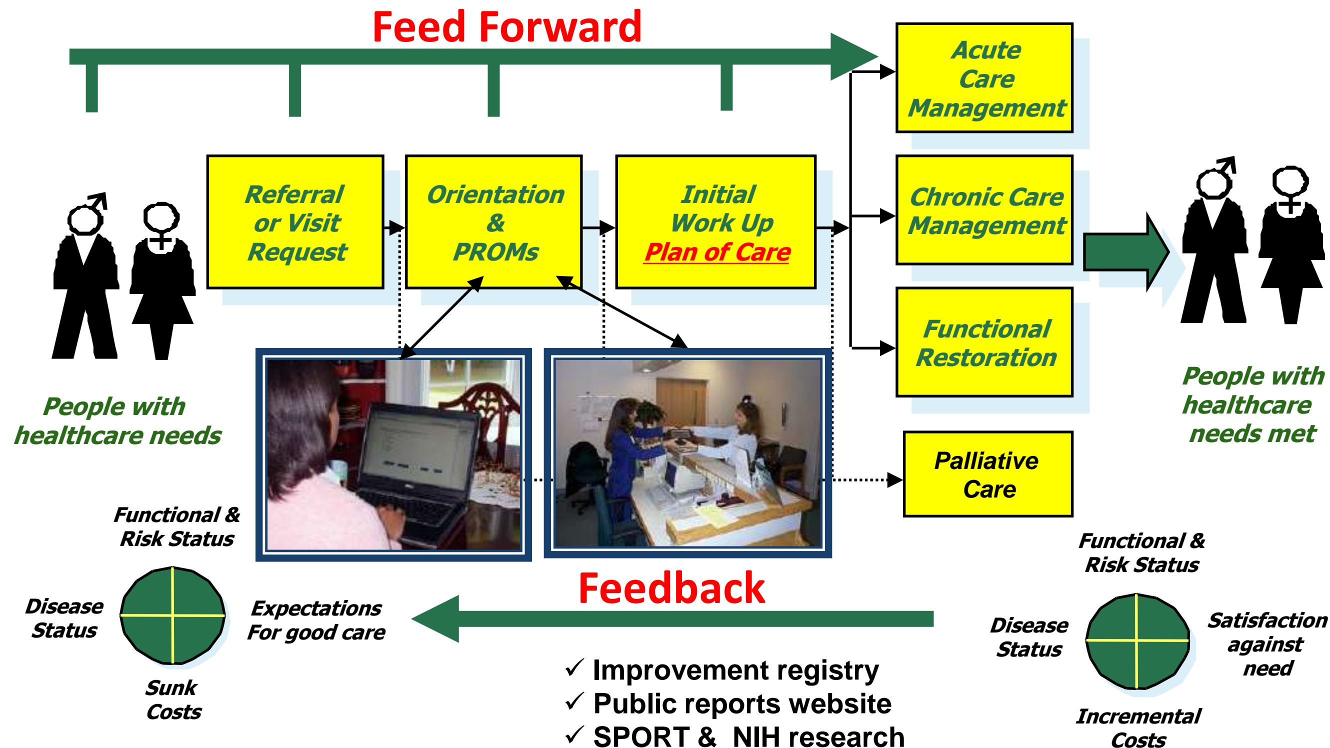
Activity	Initial Survey (08/23/2006)	This Survey (08/24/2006)
Dressing	2-slight	2-slight
Lifting	3-moderate	2-slight
Walking	3-moderate	2-slight
Sitting	2-slight	2-slight
Standing	5-severe	4-substantial
Sleeping	2-slight	2-slight
Social life	2-slight	2-slight
Sex life	3-moderate	2-slight
Travel	2-slight	2-slight

Longitudinal ODI
ODI
100, 75, 50, 25, 0
38, 26
Worse, Better
8/23/06, 8/24/06

RIGHT LEFT LEFT RIGHT

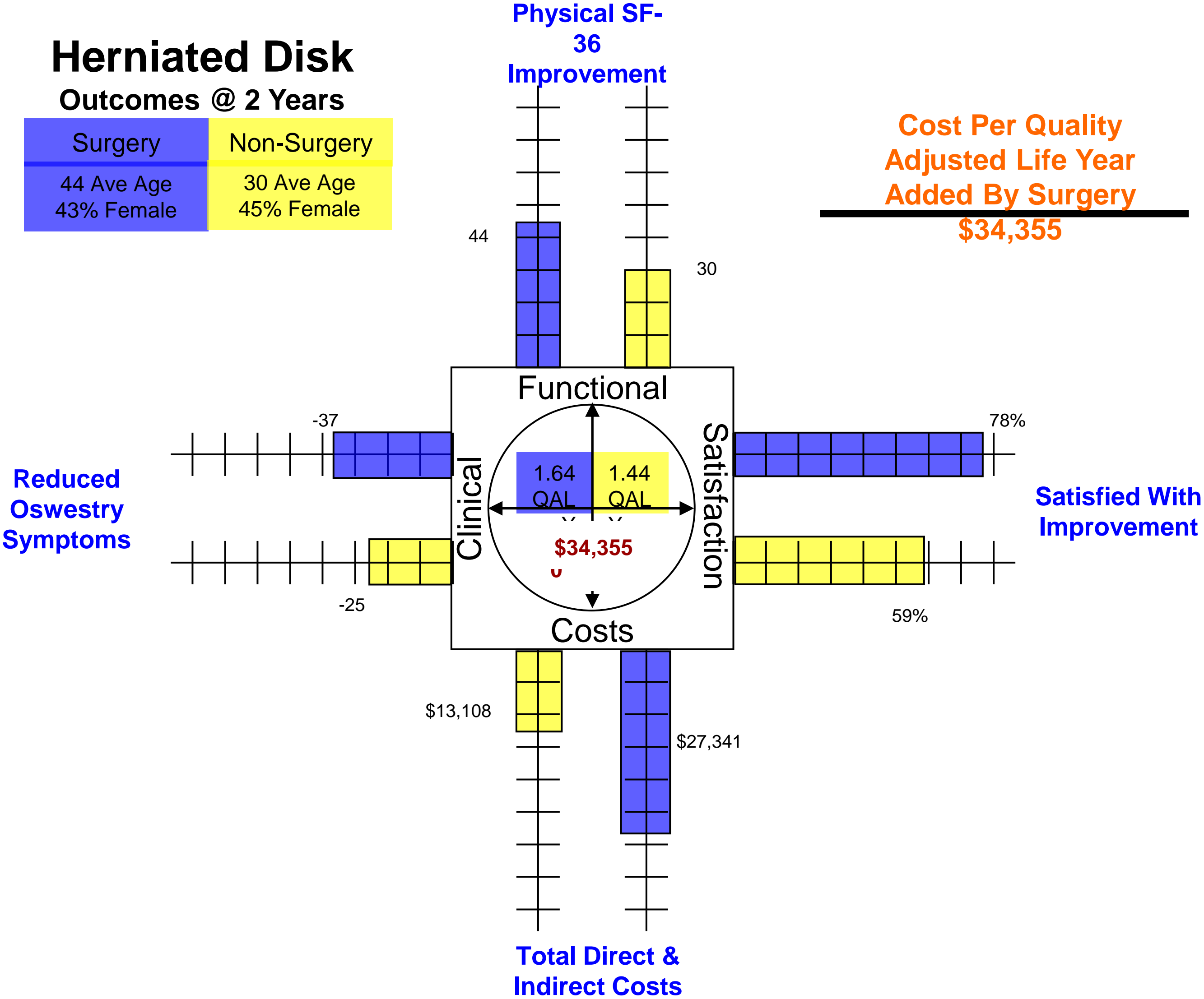
Numbness (191 pts)
Pins and Needles (185 pts)
Burning
Aching (112 pts)
Stabbing
Other

Dartmouth Spine Center: A Learning System



Using feed forward data for better conversations and turning it into registry feedback data for value improvement & science

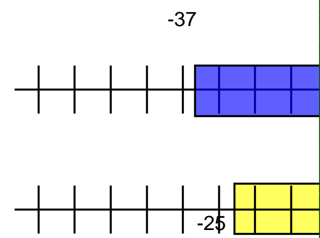
Research on Value of Surgery: NIH RCT Trial



Personalized Predictive Medicine

Physical SF-36 Improvement

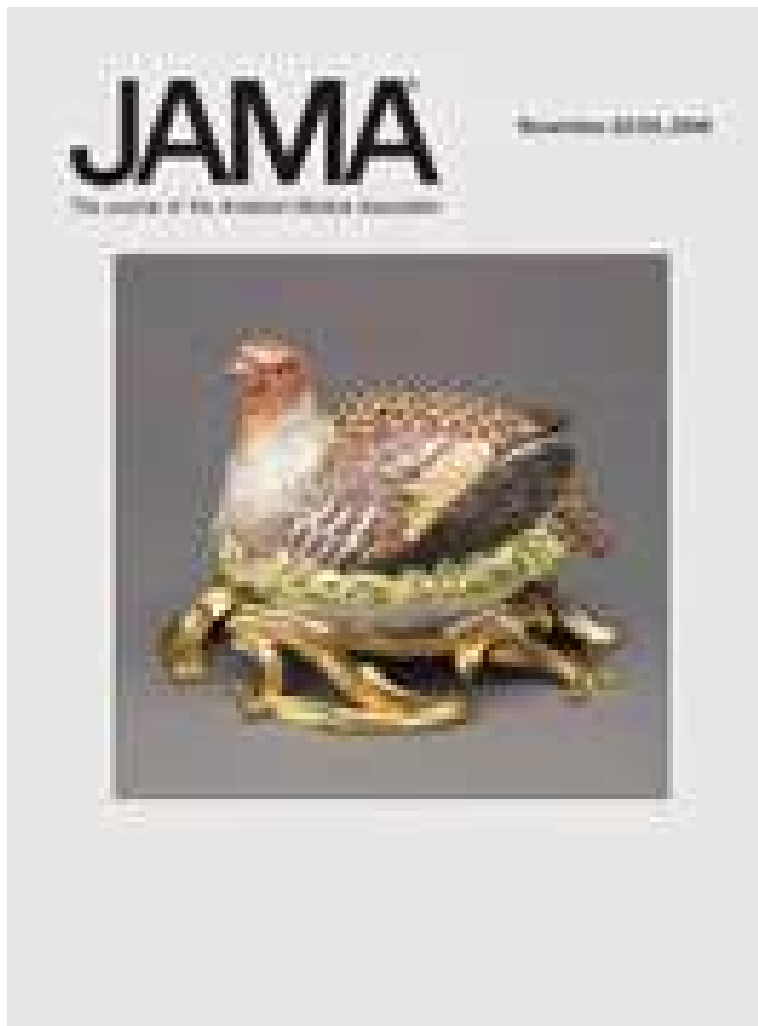
Reduced Oswestry Symptoms



Degenerative Spondylolisthesis Treatment Calculator

Indirect Costs

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

Staffan Lindblad, MD, PhD

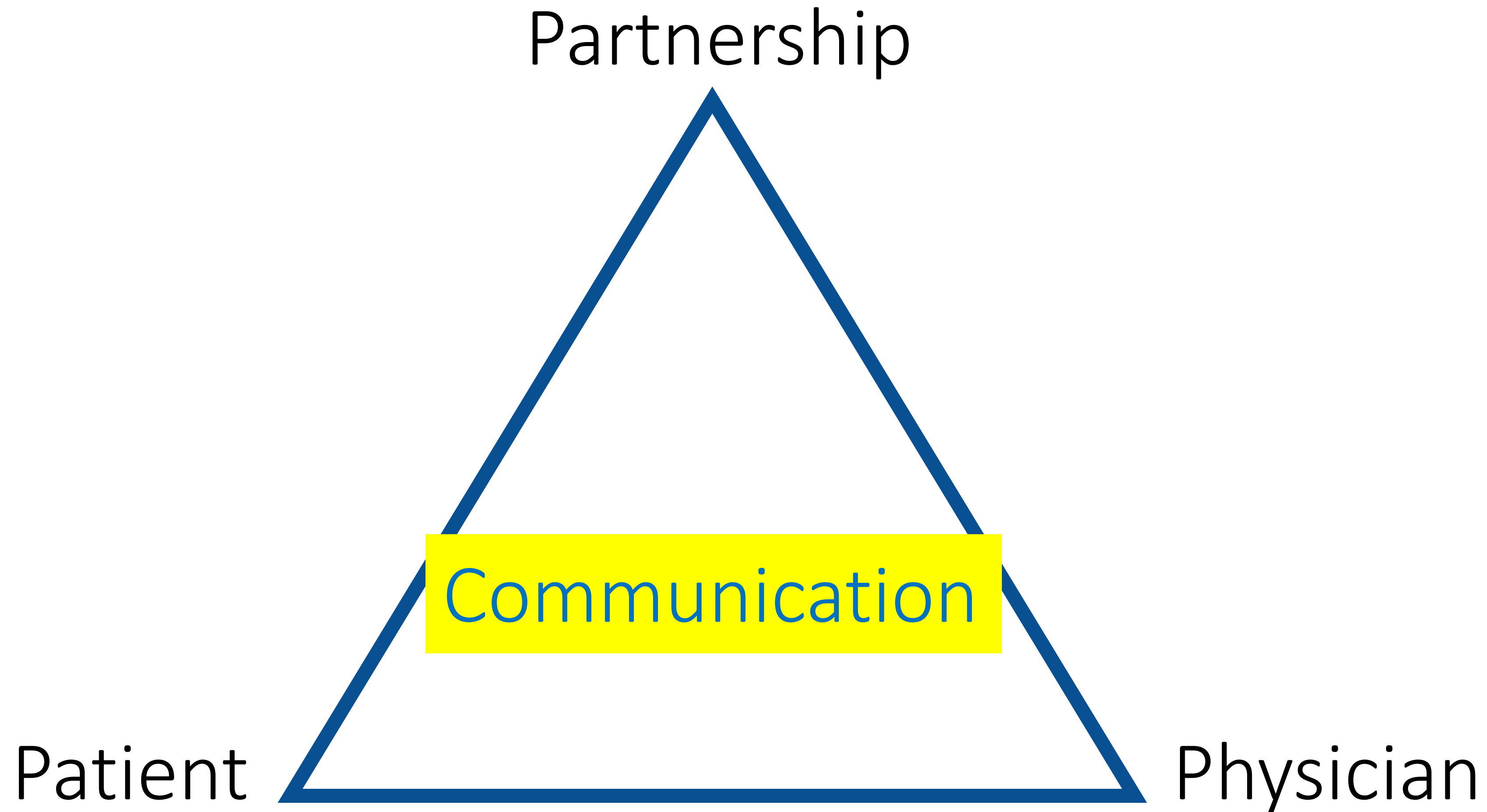
2000

Swedish Rheumatology Quality Register

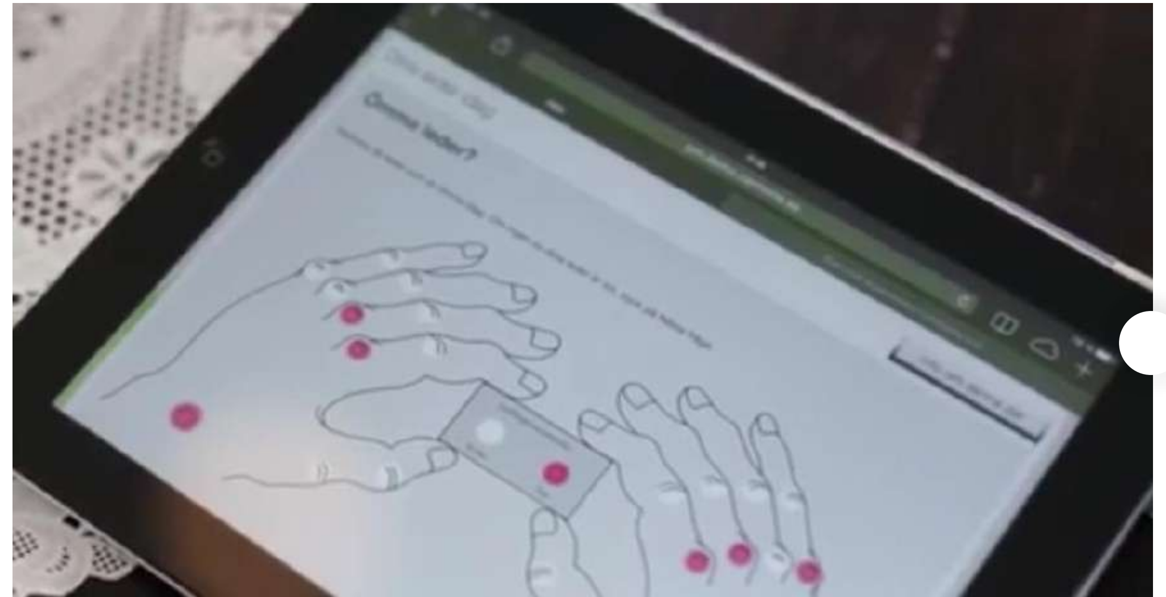
RA remission rates
Improving Across all of Sweden
since 2002

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

“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

Patient Module

Your joints today

Info

Swollen joints?

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

Color legend

Not swollen Swollen

<< Previous

Will not or cannot answer

Next >>

Part 3 of 6

Your joints today

Info

Painful joints?

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

Color legend

Not painful Painful

<< Previous

Will not or cannot answer

Next >>

Part 3 of 6

Your joints today

Info

Mark the joints (sholder, elbow and knee) that are swollen today

If none is swollen please continue to the next question.

Color legend

Not swollen Swollen

<< Previous

Will not or cannot answer

Next >>

Part 3 of 6

Your joints today

Info

Mark the joints (sholder, elbow and knee) that are painful today

If none is painful please continue to the next question.

Color legend

Not painful Painful

<< Previous

Will not or cannot answer

Next >>

Part 3 of 6

Pain Points

Disease Severity

SRQ

Clinician Module

SRQ

SRQ Point of Care Coproduction Dashboard

Case in point: Swedish National Quality Registry
This patient is doing better!
N of 1 experiment…
Response to biologics

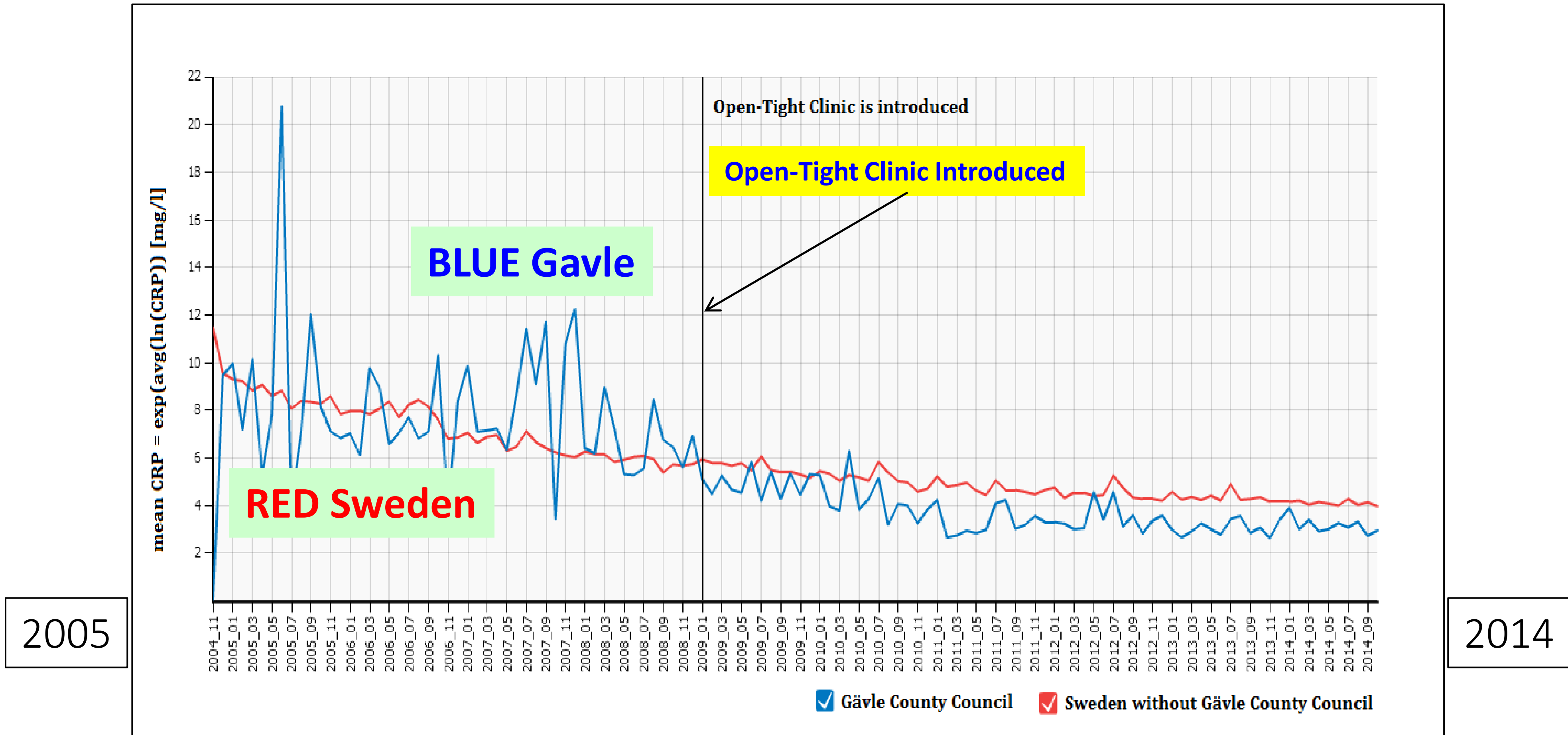
Tabellöversikt | Längd / Vikt | Grafisk översikt - Reuma

Besökstyp									
År	2015	2015	2015	2015	2015	2015	2016	2016	2016
Dag Månad	04-aug	17-sep	24-sep	23-okt	26-nov	23-dec	25-jan	29-feb	01-apr
Årskontroll									
Kopiera									
Arbetsförmåga	/40	/40	/40	/40	20/40	20/40	20/40	20/20	/40
Fysisk träning	> 2 h	< 0,5 h			0,5–1 h			< 0,5 h	< 0,5 h
Vardagsmotion	> 5 h	< 0,5 h			0,5–1 h			0,5–[illegible] h	1,5–2,5 h
Stillasittande	7–9 h	13–15 h			[illegible]			13–1[illegible] h	7–9 h
Allmän hälsa	9	11	50	45	80	[illegible]	[illegible]	[illegible]	30
Smärta	16	26	21	[illegible]	[illegible]	25	22	34	64
HAQ	1.00	0.00	0.50	1.13	[illegible].25	1.38	[illegible].75	1.25	0.88
EQ5D	1	1	1		0.552			0.516	0.689
SR			20	45	[illegible]0	45	35	10	7
CRP			10	15	[illegible]5	30	15	7	2
Läkarbedömning			Låg	Måttlig	[illegible]	Hög	[illegible]ttlig	Låg	Ingen
Läkarens bedömning av allm									
Svullna leder 28		0	4	3	10	8	3	1	0
Ömma leder 28		0	3	4	10	8	3	2	0
DAS28			4.33	4.9	6.51	6.16	4.57	3.1	1.78
DAS28CRP			4.05	4.19	6.03	5.69	4.04	3.2	1.78
CDAI									
NSAID									
KORT	PRE	PRE	PRE	PRE	PRE	PRE	PRE	PRE	PRE
KORT dos	15 /1d	15 /1d	15 /1d	15 /1d	20 /1d	20 /1d	20 /1d	20 /1d	15 /1d
DMARD 1	MTX	MTX	MTX	MTX	MTX	MTX	MTX	MTX	MTX
DMARD 1 dos	25 /1v	25 /1v	25 /1v	25 /1v	25 /1v	25 /1v	25 /1v	25 /1v	25 /1v
DMARD 2									
DMARD 2 dos									
DMARD 3									
DMARD 3 dos									
Bioläkemedel 1	REM	REM	REM	REM	REM	ORE	ORE	ORE	ORE
Bioläkemedel 1 dos	200/8v	200/8v	200/8v	200/8v	200/8v	125/1v	125/1v	125/1v	125/1v
Bioläkemedel 2									
Bioläkemedel 2 dos									

Nov-Dec

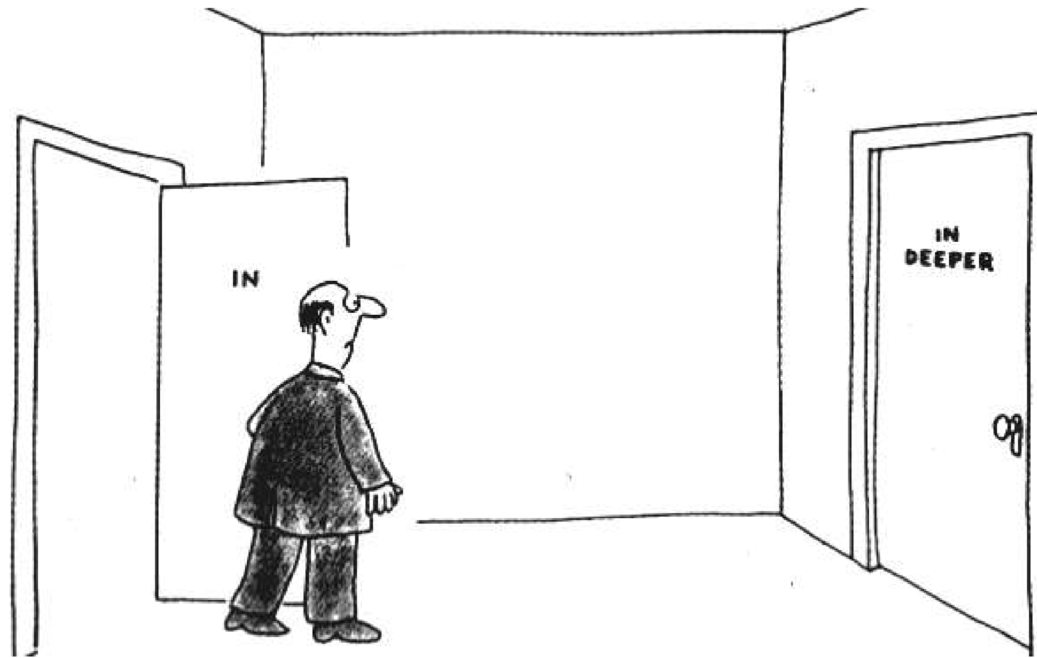
Jan-April

RA Disease Burden in Sweden “Cut in Half”



SRQ

* CRP (C reactive protein) levels in RA patients



Then I got a call from my friend at RWJF ...

Paul Batalden, MD

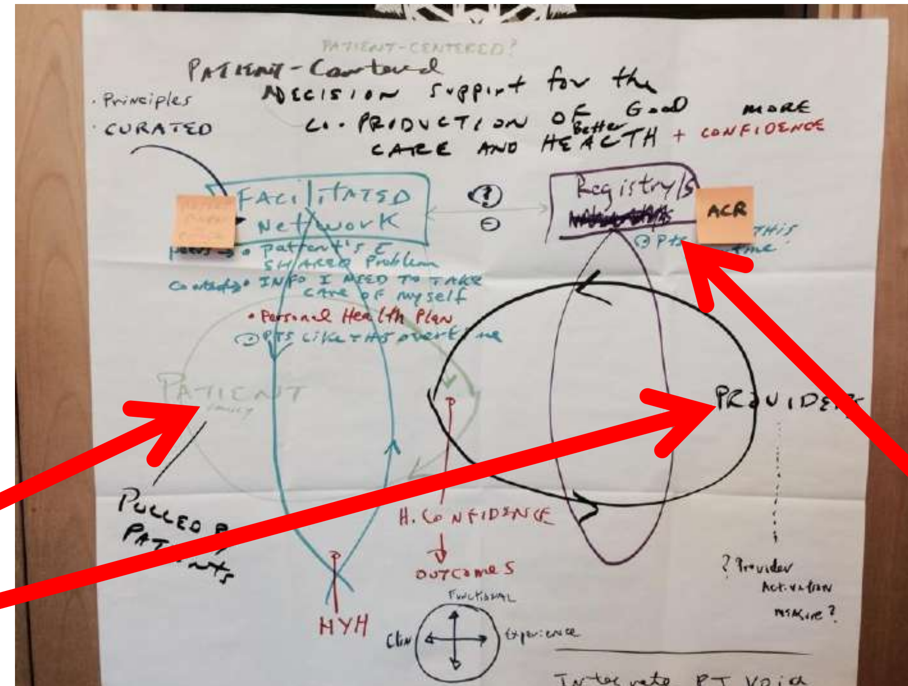
Concepts: Developing a Conceptual Model

"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

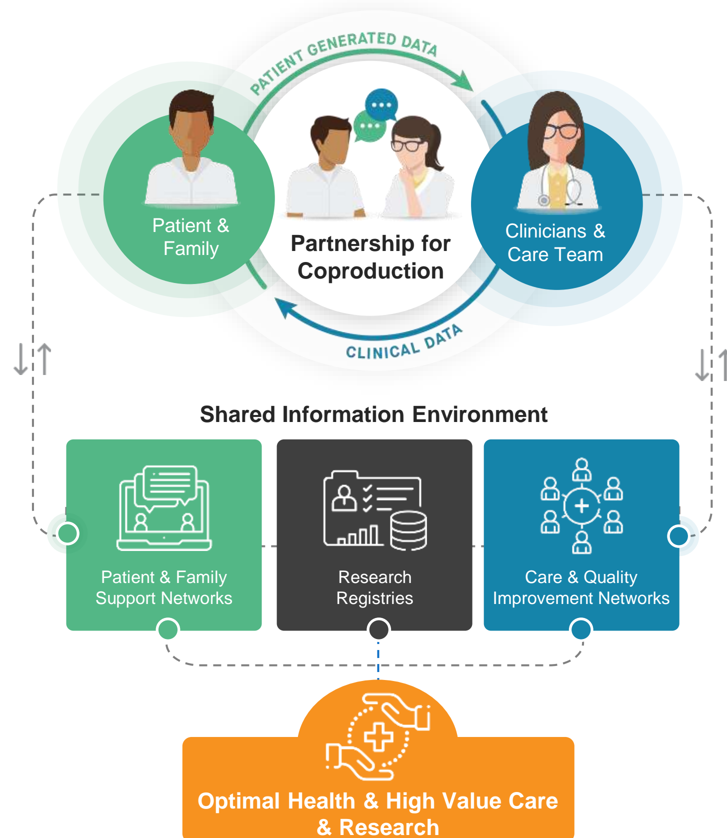


October 16, 2013

Technological Innovations

Registries
+
HIT Enabled Networks
+
Feedforward Feedback Data Flows

A Learning Health System for Coproducing Health, Value, Science & Conversations



PATIENT-PROFESSIONAL PARTNERSHIPS

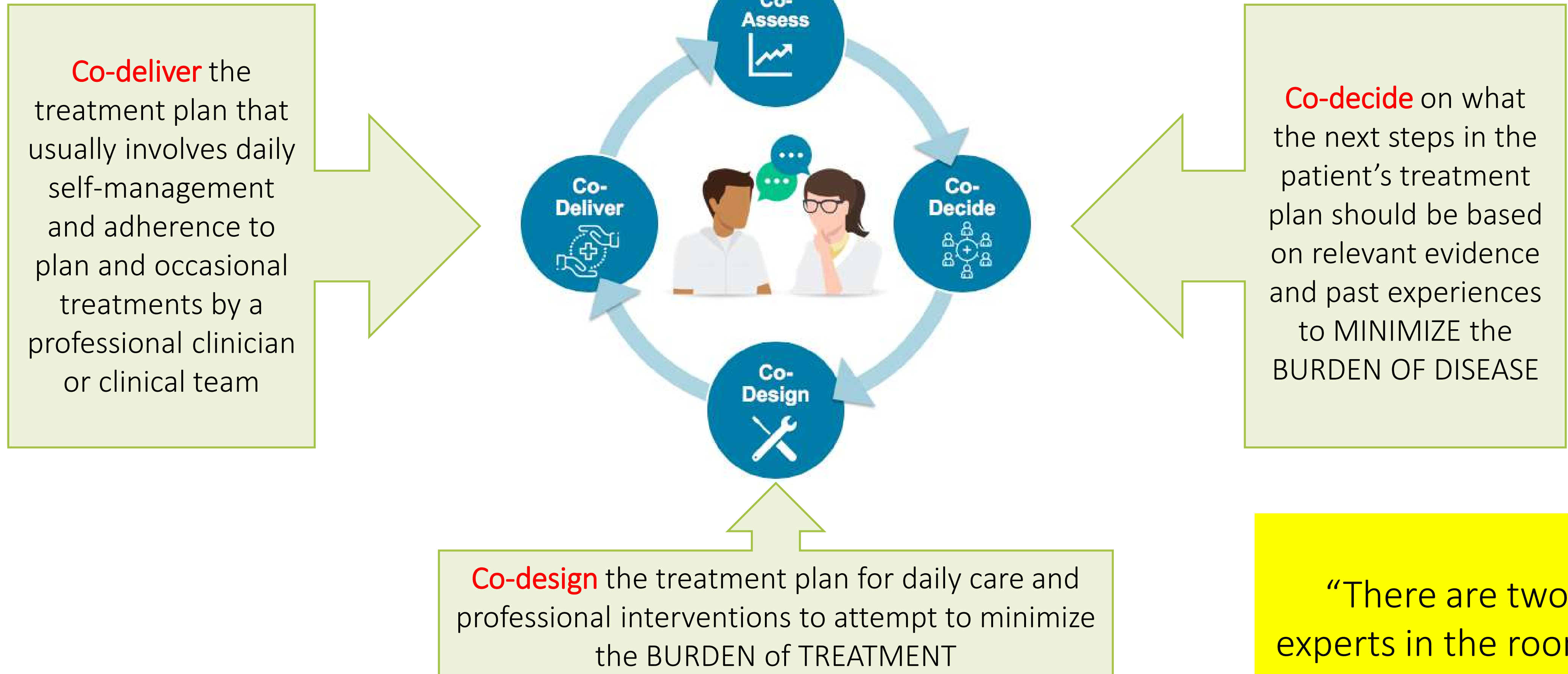
QUALITY IMPROVEMENT & RESEARCH NETWORKS

PATIENT & FAMILY SUPPORT NETWORKS

RESEARCH & PERFORMANCE FEEDBACK REGISTRIES

Core of The Model

Co-assess the patient's health status and how the treatment plan has been working to improve patient's health and well-being



"There are two experts in the room."

thebmj

BMJ 2016;354:i3319 doi: 10.1136/bmj.i3319 (Published 1 July 2016)

ANALYSIS

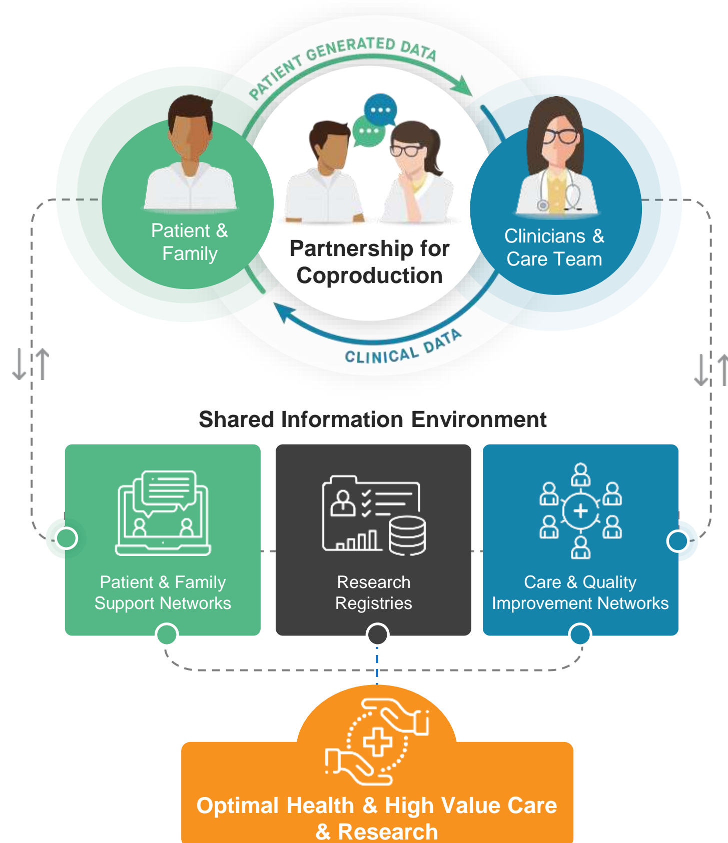
Patient focused registries can improve health, care, and science

OPEN ACCESS

Eugene Nelson and colleagues call for registries of care data to be transformed into patient centred interactive learning systems

Eugene C Nelson *professor*[1], Mary Dixon-Woods *professor*[2], Paul B Batalden *professor*[1], Karen Homa *researcher*[3], Aricca D Van Citters *researcher*[1], Tamara S Morgan *researcher*[1], Elena Eftimovska *professor*[4], Elliott S Fisher *professor*[1], John Ovretveit *professor*[4], Wade Harrison *researcher*[1], Cristin Lind *professor*[5], Staffan Lindblad *professor*[4 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

Coproduction & Health Services

The Big Idea

Paul Batalden, MD

"All services, at some level, are coproduced."

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.

M Batalden, BMJQ&S, 2017. (modified)

Senge On Learning Organizations

“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."

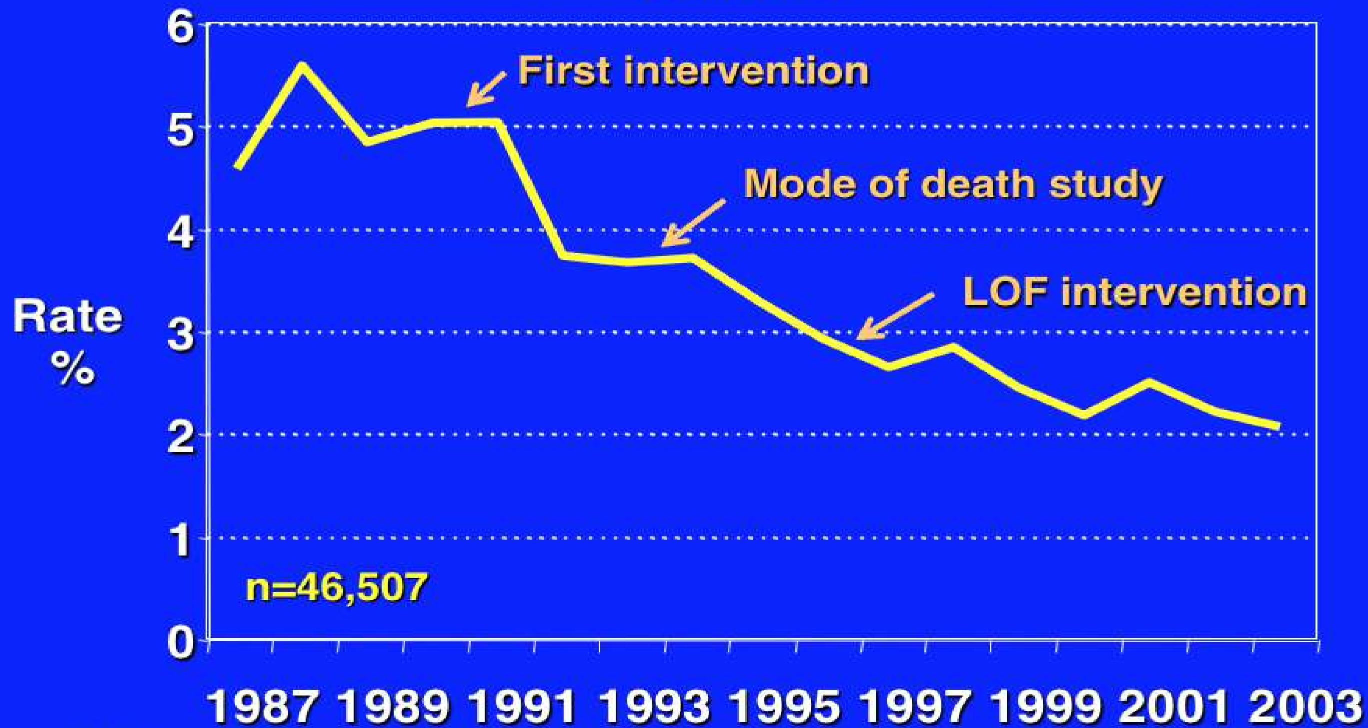
Learning Health System Defined

"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

1. Cardiac Surgery: 1998
   - 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)

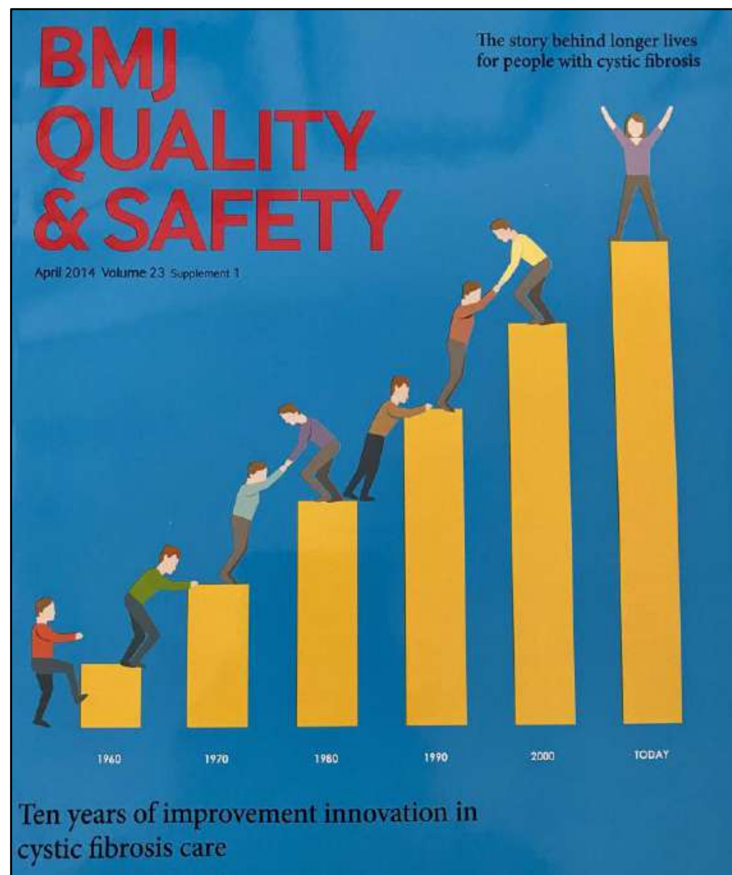
Northern New England Cardiovascular Study Group: CABG Mortality "Cut in Half" in 10 Centers

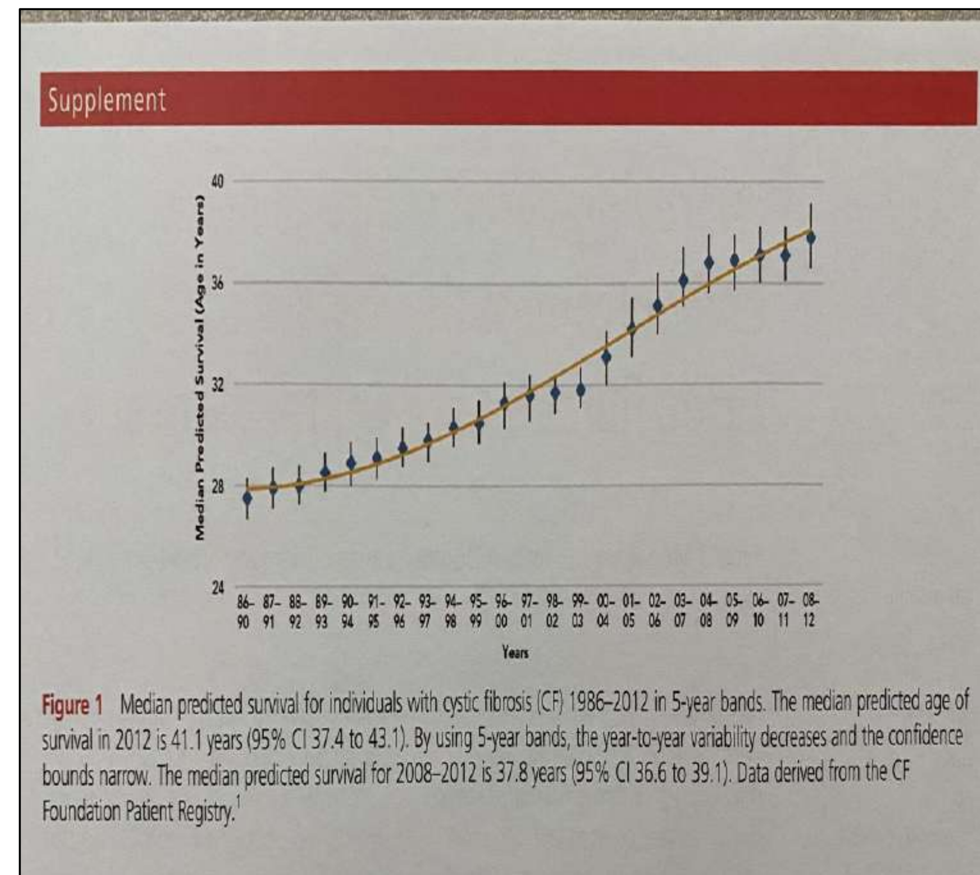


The 30-Year Influence of a Regional Consortium on Quality Improvement in Cardiac Surgery.

Iribarne A, Leavitt BJ, Westbrook BM, et. al.; Northern New England Cardiovascular Disease Study Group. Ann Thorac Surg. 2019 Nov 23. pii: S0003-4975(19)31738-2. doi: 10.1016/j.athoracsur.2019.10.008.

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

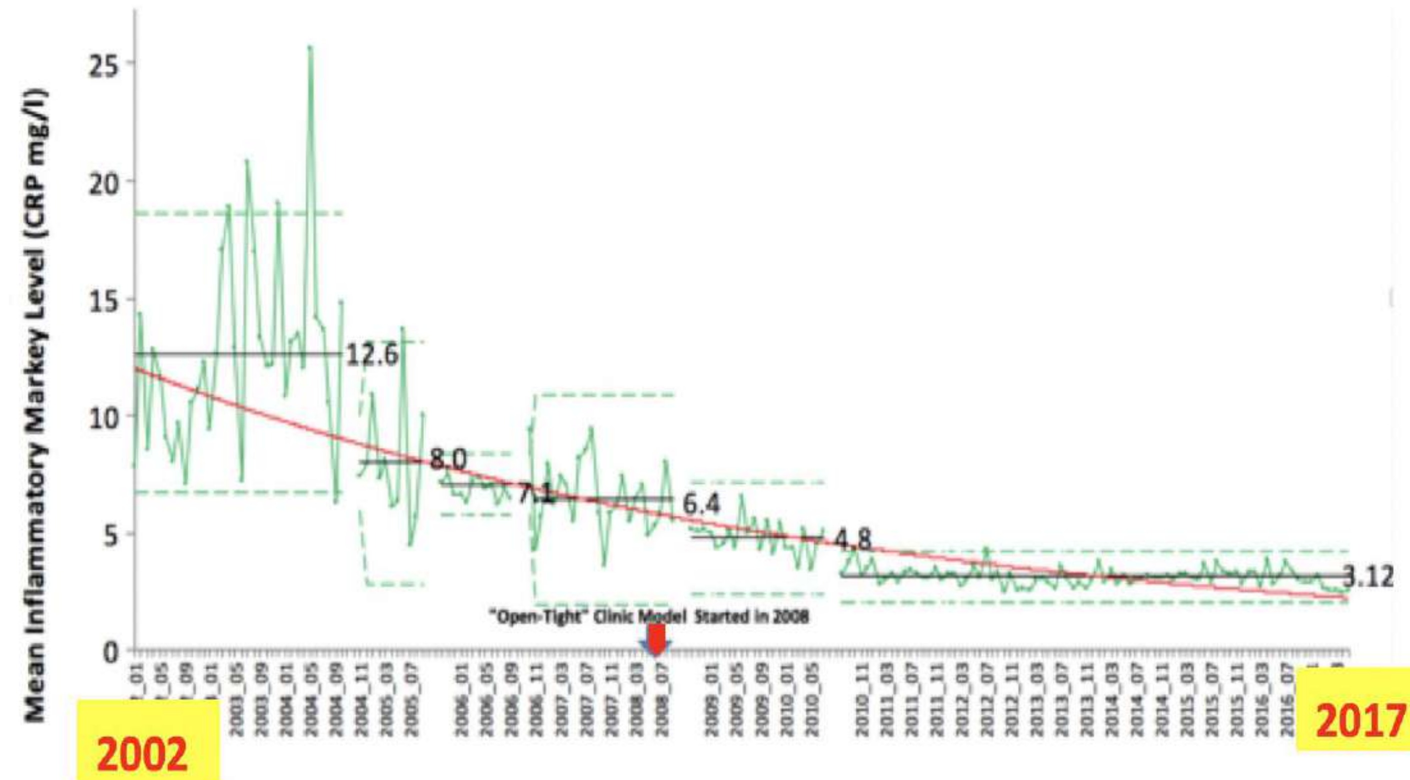


Figure: Split limits XmR Statistical Process Control (SPC) chart (in green) with superimposed longitudinal trend fit line (in red) of C Reactive Protein Levels in RA patients followed by the SRQ from 2002-2017. Mean CRP levels are depicted by black lines. Upper and lower control limits are depicted by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

Credit: Oliver BJ (2018). In Godfrey M, Foster TC, Johnson JK, Nelson EC, and Batalden P. *Quality by Design: A Clinical Microsystems Approach*. 2nd Ed. Jossey Bass.

Dartmouth’s Learning Health System in Oncology

Dartmouth's Learning Health System in Oncology

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

Our
Patients

Our
People

Our
Community

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**.

www. ariadnelabs.org

Serious Illness Conversation Guide

Dartmouth-Hitchcock

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – is this okay?"

"I'll be using this Guide to help me assure I don't miss any important information."

IF RESISTANT:
Hope for best/prepare for bumps in the road; Benefit to family of planning ahead; No decisions necessary today

ASSESS

"What is your **understanding** now of where you are with your illness?"
FOLLOW-UP PROMPTS:
"What is your understanding of what the future may hold with your illness?

"How much **information** about what may be ahead with your illness would you like from me?"
FOR EXAMPLE:
"Some patients like to know about time, others like to know what to expect, others like both."

SHARE

"I want to share with you my understanding of where things are with your illness…"

Uncertain: "It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility."

Time: "I wish we weren't in this situation, but I'm worried that time may be as short as [give a range]"

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you feel, and things are likely to get more difficult."

Best Case/ Worst Case: "It can be difficult to predict what will happen with your illness. I hope in a best case ____; I worry that in the worst case ____. The most likely outcome is _____."

EXPECT & RESPOND to EMOTION (see over)

EXPLORE

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"
FOR EXAMPLE:
"Some people need to be able to do things for themselves, like toileting, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"
FOLLOW-UP PROMPTS:
"What experiences have you/family members had with serious illness, and what did you learn from those experiences?"
"Is there anything you are certain you WOULD NOT want to go through?"

"How much does your **family** know about your priorities and wishes?"
CONSIDER:
Inviting patient's healthcare agent/surrogate and/or family to discuss together "so they know what's important to you".

CLOSE

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend ____. How does this plan seem to you?"

"We will do everything we can to help you through this."

DOCUMENT in the **ACP NAVIGATOR**

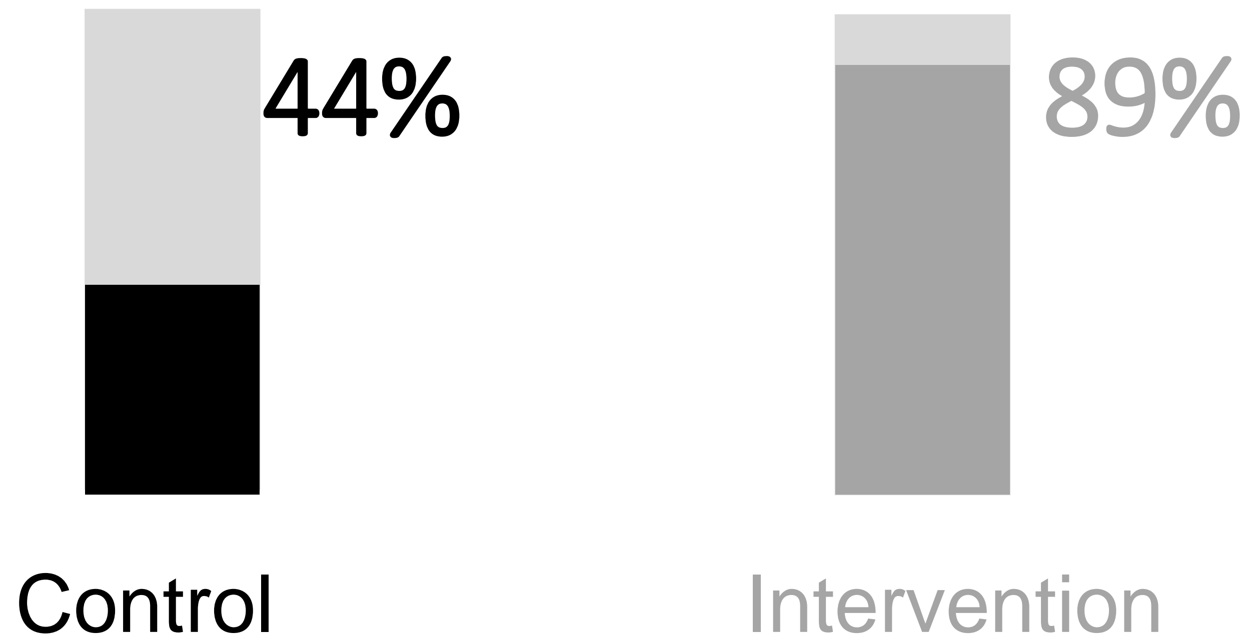
More, Earlier, Better, and Visible

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



p<0.001

ARIADNE LABS

Paladino J, *JAMA Oncol.* 2019;5(6):801–809.

Intervention patients had lower rates of moderate to severe anxiety

Control
Intervention

20%
10%
0%

Anxiety

Percent of patients with moderate or severe anxiety

Baseline
14
24
Weeks

p=0.048
p=0.02

ARIADNE LABS

Bernacki R *JAMA Intern Med.* 2019;179(6):751–759.

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.”

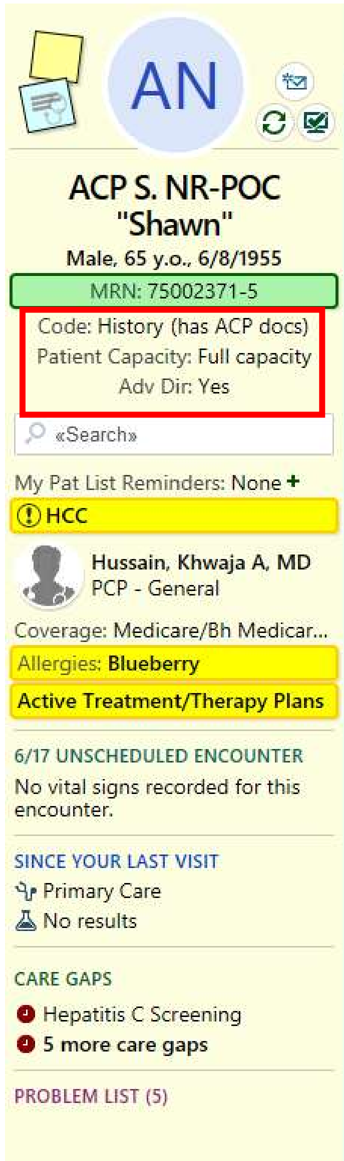
“Mostly the conversation brought us closer (Dr. X).”

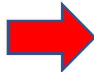
ARIADNE LABS

Paladino J, *JAMA Oncol.* 2019;5(6):801–809.

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**.

2020	JAN 2021	SEPT 2021	JUNE 2022
Head & Neck	Neuro Onc	Transplant and Cellular Therapy	GYN
Sarcoma	Thoracic	Breast	GU
	Melanoma	Lymphoma & Leukemia	GI





Advance Care Planning

No FYI Flags

PATIENT STATUS
Status

CAPACITY CHECKLIST
1. Instructions
2. Capacity Docu...
3. Agents/Surrog...
4. Aid to Assess...

NOTES
Documentation

GOALS OF CARE
Serious Illness C...
SIC Most Recent
SIC Training

ORDERS FOR SCOPE OF TREATMENT
Code Status

LEGAL DOCUMENTS
Filed Documents

Serious Illness Conversation - complete form below and go to documentation to save as note.

Serious Illness Conversation

Discussion with:

Agent/Surrc

What is your understanding now of where you are with your illness? (Select one or describe below)

For example, what is your understanding of what the future holds with your illness?

- (●) Limited/inaccurate understanding of prognosis or disease trajectory
- ( ) Accurate understanding of prognosis or disease trajectory

How much information about what is likely to be ahead with your illness would you like from me? (Select one or describe below)

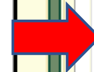
- (●) All available information, including time-based prognosis
- ( ) Big picture, 'what to expect'
- ( ) No information, share with DPOA/surrogate (specify name of person)

What prognostic information was communicated to the patient? (Select one or more or describe below)

- [ ] Time-based prognosis
- [x] 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, informatin 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
- [x] Take care of my family
- [ ] Be at home
- [ ] Be physically comfortable
- [ ] Accomplish particular life goal (describe in text box)



My Note Signed

ACP (Advance Care Planning) 10:18 AM

Tag | Details

Service: Internal Medicin

Summary:

«Insert SmartText»

Serious Illness Conversation
Date of Conversation: 7/15/2020
Discussion with: Agent/Surrogate

Understanding of illness:
Limited/inaccurate understanding of prognosis or disease trajectory
-

Information preferences:
All available information, including time-based prognosis
-

Prognostic information given:
Function-based prognosis ""this is as strong as you will feel"" -
-

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 (eg, 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:

Pend | Sign | Cancel

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

1st SIC

Revisit/update SIC at key times

?

?

?

Patient Function

Hospitalizations

Clinic visits

New line of treatment

Serious illness diagnosis

Time

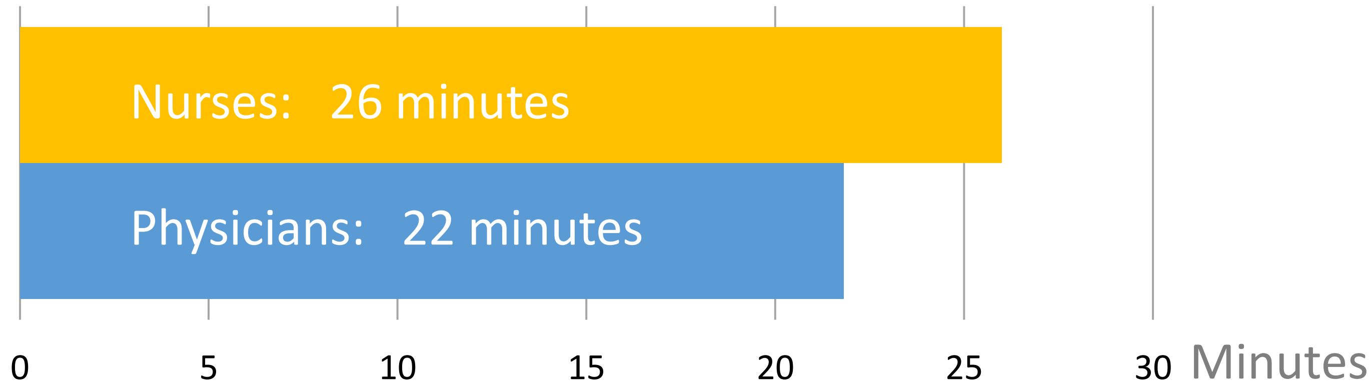
Death

Slide created by K. Kirkland, MD, DH Palliative Care Section

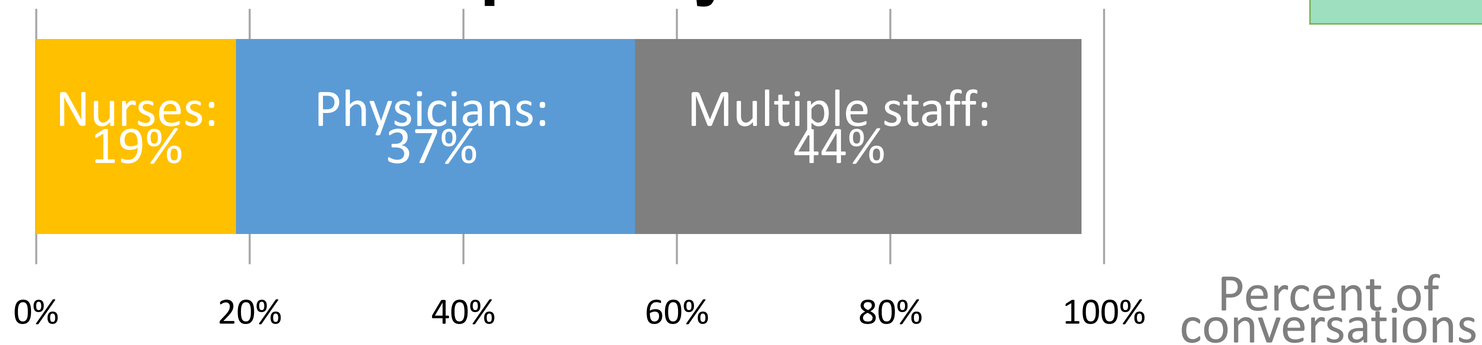
Graph of function over time adapted from Lunney et al. JAMA 2003

The SIC is efficient, can be shared within teams, adds RVUs

Median time for conversation:



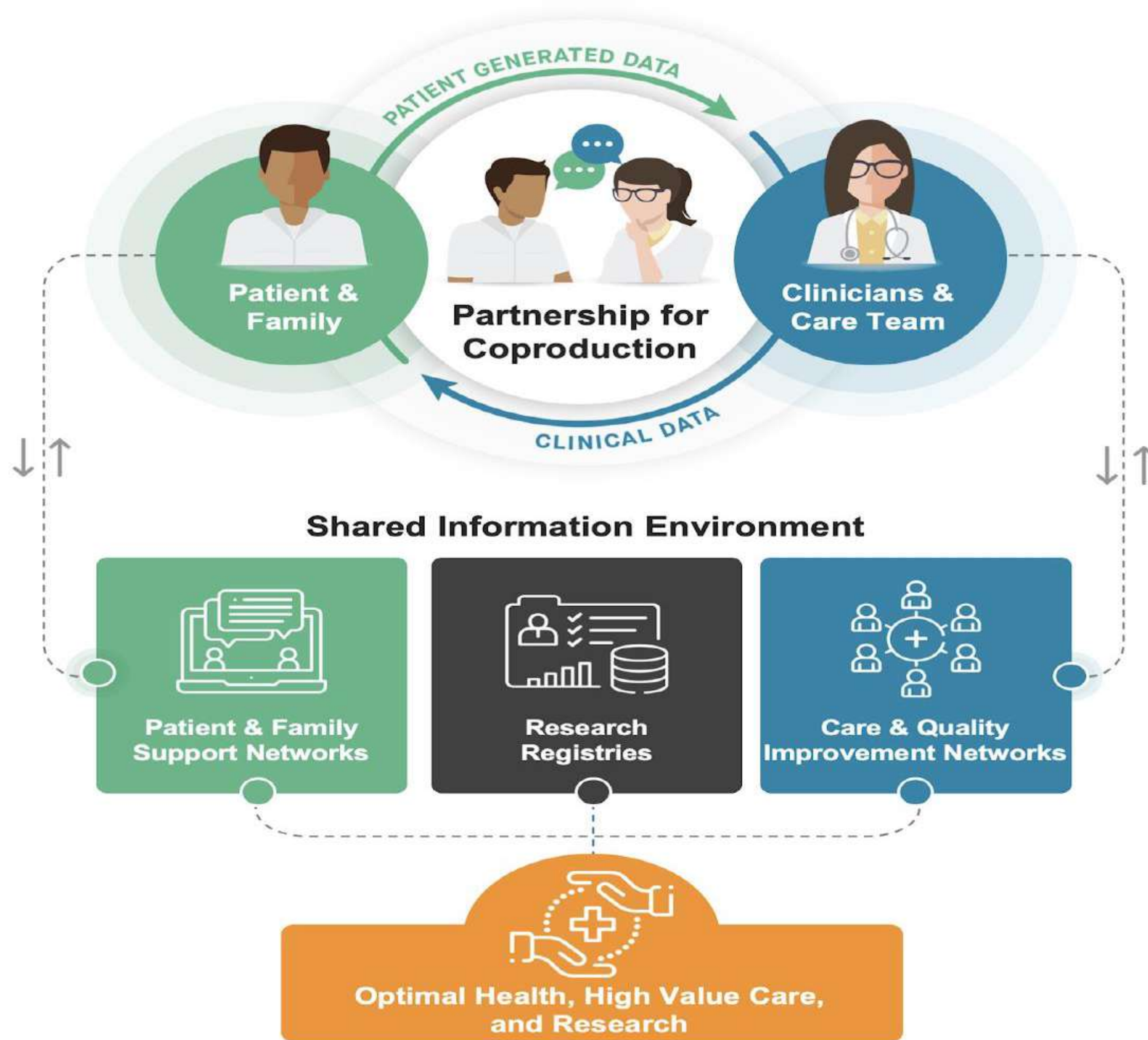
Conversation completed by:



Lakin JR, Health Aff, 2017.

ACP billing code	RVU
99497 (>16" on ACP)	1.5
99498	1.4

DARTMOUTH-HITCHCOCK POPULATION HEALTH VITALtalk ARIADNE LABS


PATIENT GENERATED DATA
Patient & Family
Partnership for Coproduction
Clinicians & Care Team
CLINICAL DATA
Shared Information Environment
Patient & Family Support Networks
Research Registries
Care & Quality Improvement Networks
Optimal Health, High Value Care, and Research

Serious Illness Conversation Guide

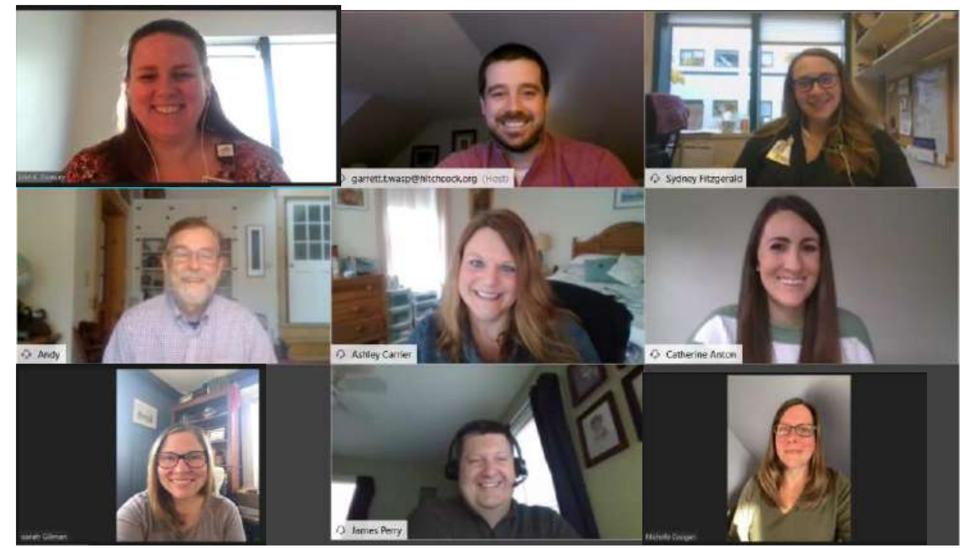
Dartmouth-Hitchcock

SET UP	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – **is this okay?**" "I'll be using this Guide to help me assure I don't miss any important information." IF RESISTANT: Hope for best/prepare for bumps in the road; Benefit to family of planning ahead; No decisions necessary today
ASSESS	"What is your **understanding** now of where you are with your illness?" FOLLOW-UP PROMPTS: "What is your understanding of what the future may hold with your illness?" "How much **information** about what may be ahead with your illness would you like from me?" FOR EXAMPLE: "Some patients like to know about time, others like to know what to expect, others like both."
SHARE	**"I want to share with you my understanding of where things are with your illness…"** *Uncertain*: "It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility." *Time*: "I wish we weren't in this situation, but I'm worried that time may be as short as [give a range]" *Function*: "I hope that this is not the case, but I'm worried that this may be as strong as you feel, and things are likely to get more difficult." *Best Case/ Worst Case*: "It can be difficult to predict what will happen with your illness. I hope in a best case ____; I worry that in the worst case ____. The most likely outcome is ____."
	EXPECT & RESPOND to EMOTION (see over)
EXPLORE	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" FOR EXAMPLE: "Some people need to be able to do things for themselves, like toileting, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" FOLLOW-UP PROMPTS: "What experiences have you/family members had with serious illness, and what did you learn from those experiences?" "Is there anything you are certain you WOULD NOT want to go through?" "How much does your **family** know about your priorities and wishes?" CONSIDER: Inviting patient's healthcare agent/surrogate and/or family to discuss together "so they know what's important to you"
CLOSE	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** ____. How does this plan seem to you?" **"We will do everything we can to help you through this."**

DOCUMENT in the **ACP NAVIGATOR**

Advance Care Planning

Serious Illness Conversation - complete form below and go to documentation to save as note.



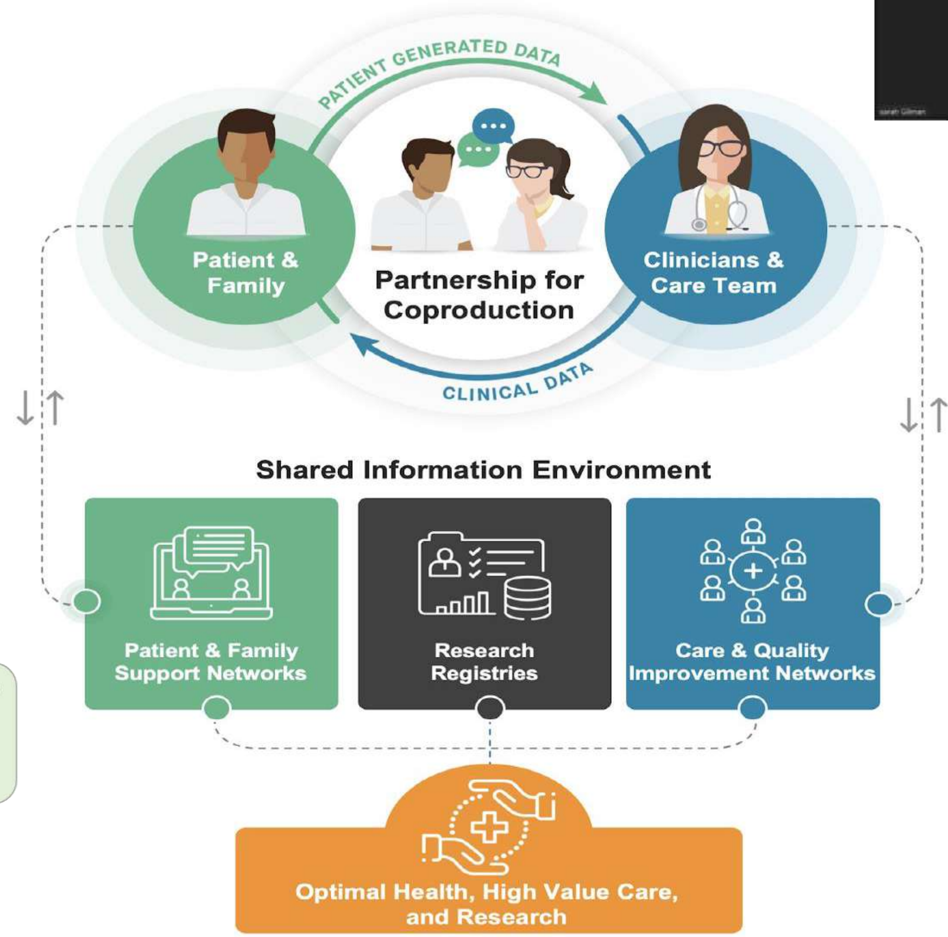
What will be challenging for you?

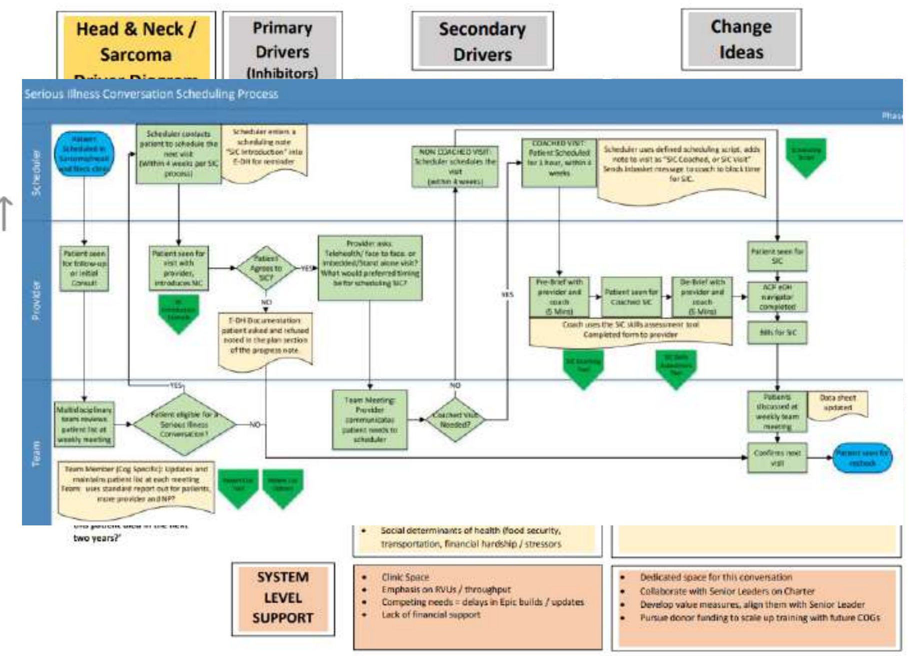
What skill or part of the Guide could help you with that challenge?

How did it go? What did you do that worked well?

Was there anything you wish you'd done differently?

What will you take away that you can use in your next conversation?

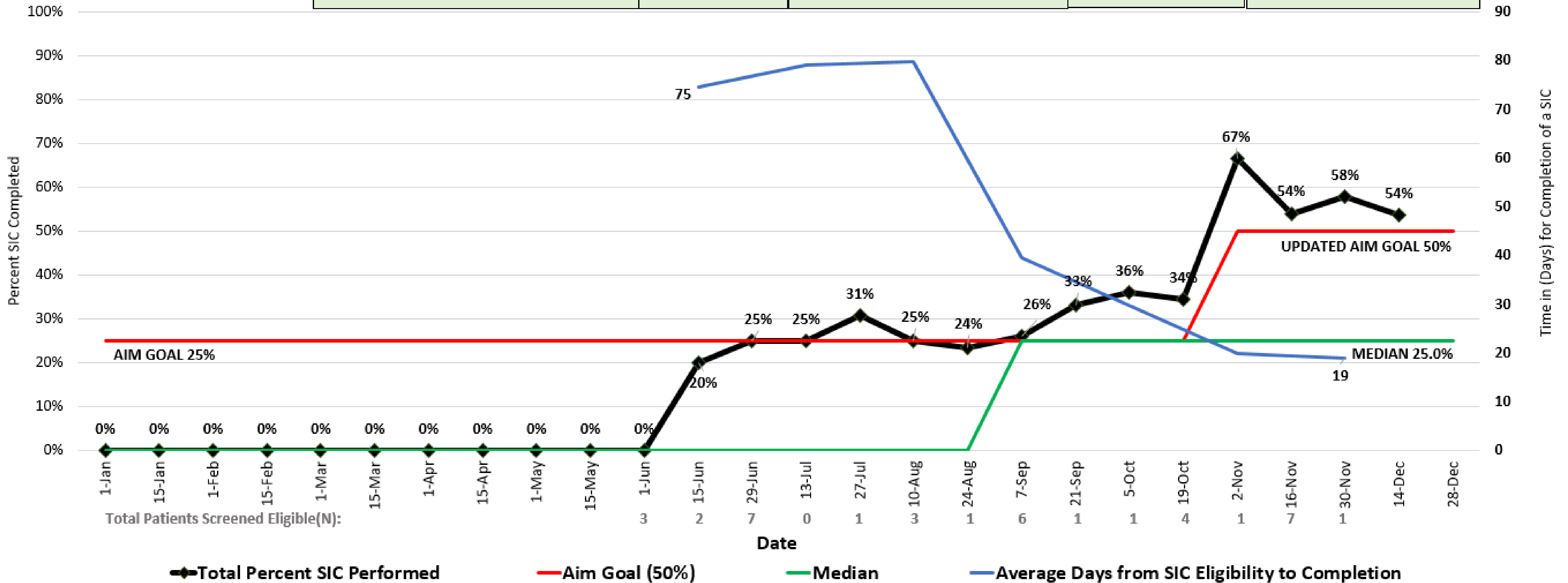


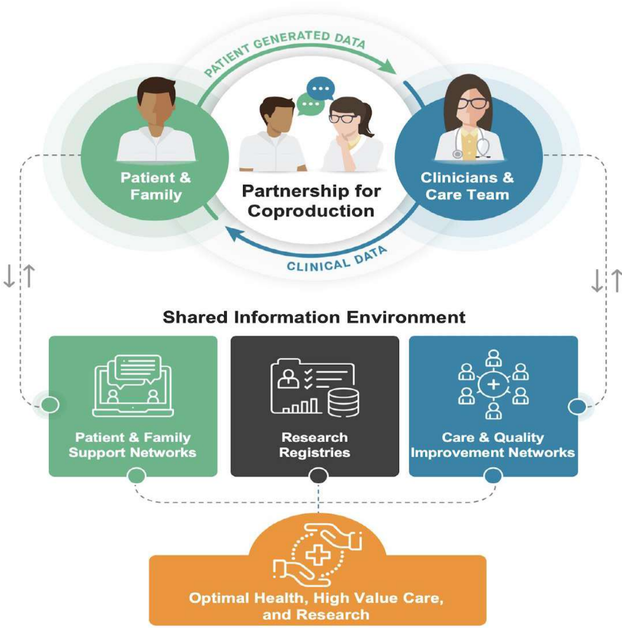


Run Chart: Serious Illness Conversations
Combined Data From Head & Neck and Sarcoma Clinics
Dates: 1/1/20-12/28/20

Total Screened (Encounters): *N=153
Total Eligible SIC: N=41
Total Completed SIC: N=22

PDSA 1-5 Duration (Development)	PDSA 6-7 Duration (Kickoff)	PDSA 8-10 Duration (Standard Work)	PDSA 11-12 Duration (Resources)	PDSA 13 (Expansion)
SIC Team Formed, Weekly Huddles Initiated, Patient Eligibility Defined, Provider Training Defined, Workflow Mapping Completed.	Initiated SIC Coaching and Data Sharing with Team.	Patient Report Out Defined, Scheduling Script Introduced based on VOC.	SIC Completion Timing Defined, Expanded workforce Capacity.	

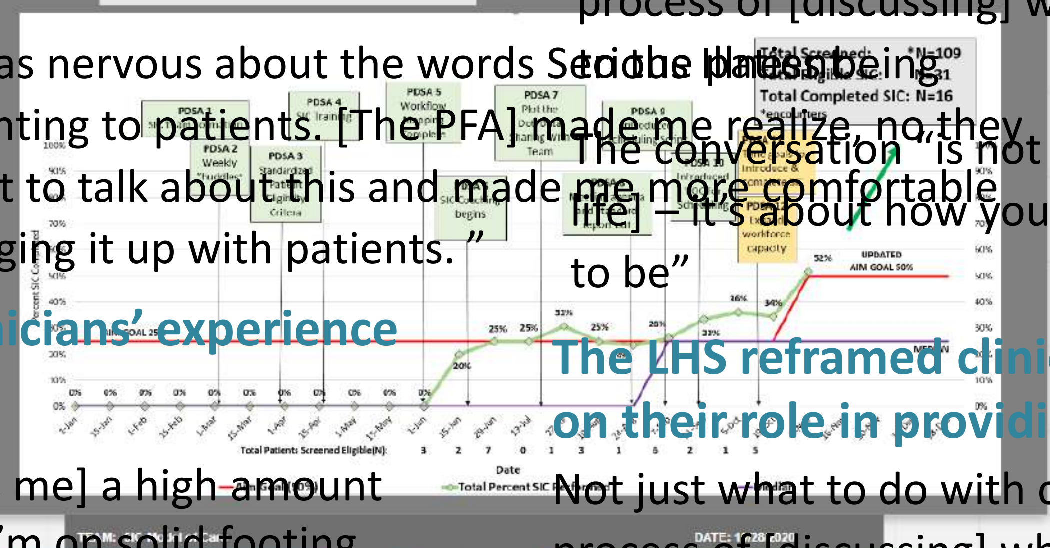




The PFA reduced clinicians’ barriers to initiating conversation

“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. ”



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”

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

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”

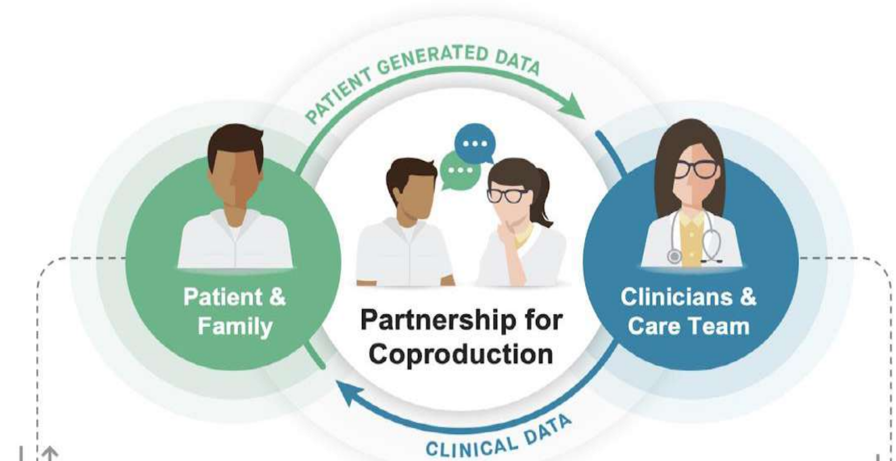
“I’m used to on-the-side-of-the-road conversations.. it’s so nice to say that we’ve started these conversations [early] instead of having to do a lot of extrapolating, or leading, or asking family to tell us what to do. We can point to what the patient said they wanted.. it gives me a sense of security”

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”

PHYSICAL ISSUES (pain, nausea, or tiredness)	PRACTICAL ISSUES (housing, insurance, bills, transportation, food)	EVERYDAY ISSUES (changes in appearance, eating, or getting around)
COMMUNICATION ISSUES (talking with family or healthcare providers, access to interpreters)	FAMILY ISSUES (dealing with children or partner, or intimacy)	EMOTIONAL ISSUES (worry, loss of interest in usual activities, or anger)
SPIRITUALITY ISSUES (finding purpose or meaning, finding rejuvenation, challenges to your faith or spiritual practices)	PLANNING AHEAD (what to expect with your health, what matters most, talking about your wishes, or completing an advanced directive or living will)	EXTERNAL STRESSORS impacting you (global pandemic, environmental, social, or cultural stressors)
I'm having OTHER ISSUES that I would like to discuss.	I'm here for a ROUTINE VISIT (med refill, etc.).	



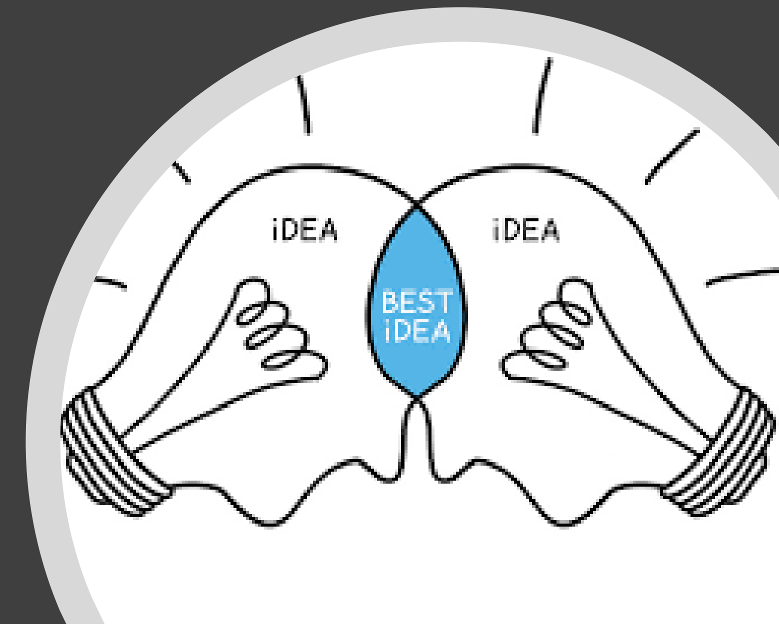
Shared Information Environment

eDH Serious Illness Point-of-Care Dashboard

Palliative Care Workspace

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



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Website: www.dartmouth.edu/coproduction

Acknowledgements

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- The Robert Wood Johnson Foundation
- The Arthritis Foundation
- The Crohn's &Colitis Foundation
- The Gordon & Betty Moore Foundation
- The Couch Family Fund

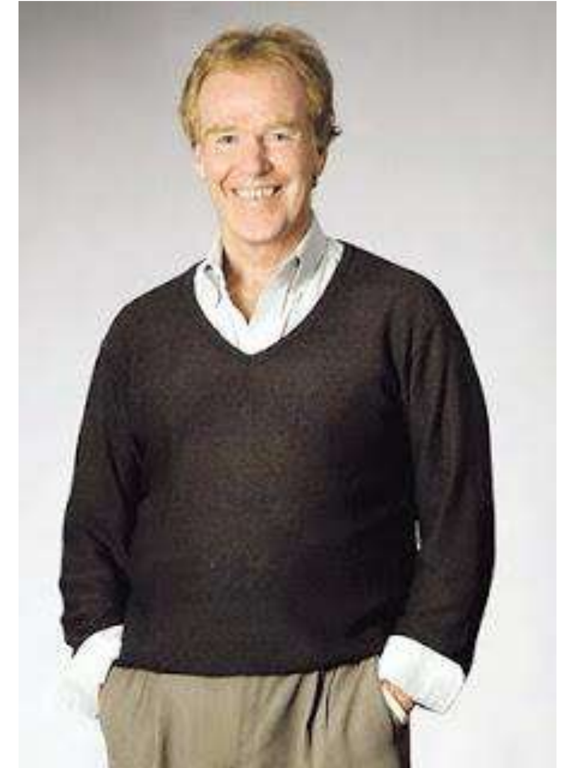
Appendices

ORIGINS

Ernest Codman
Registries

W. Edwards Deming
Quality Improvement

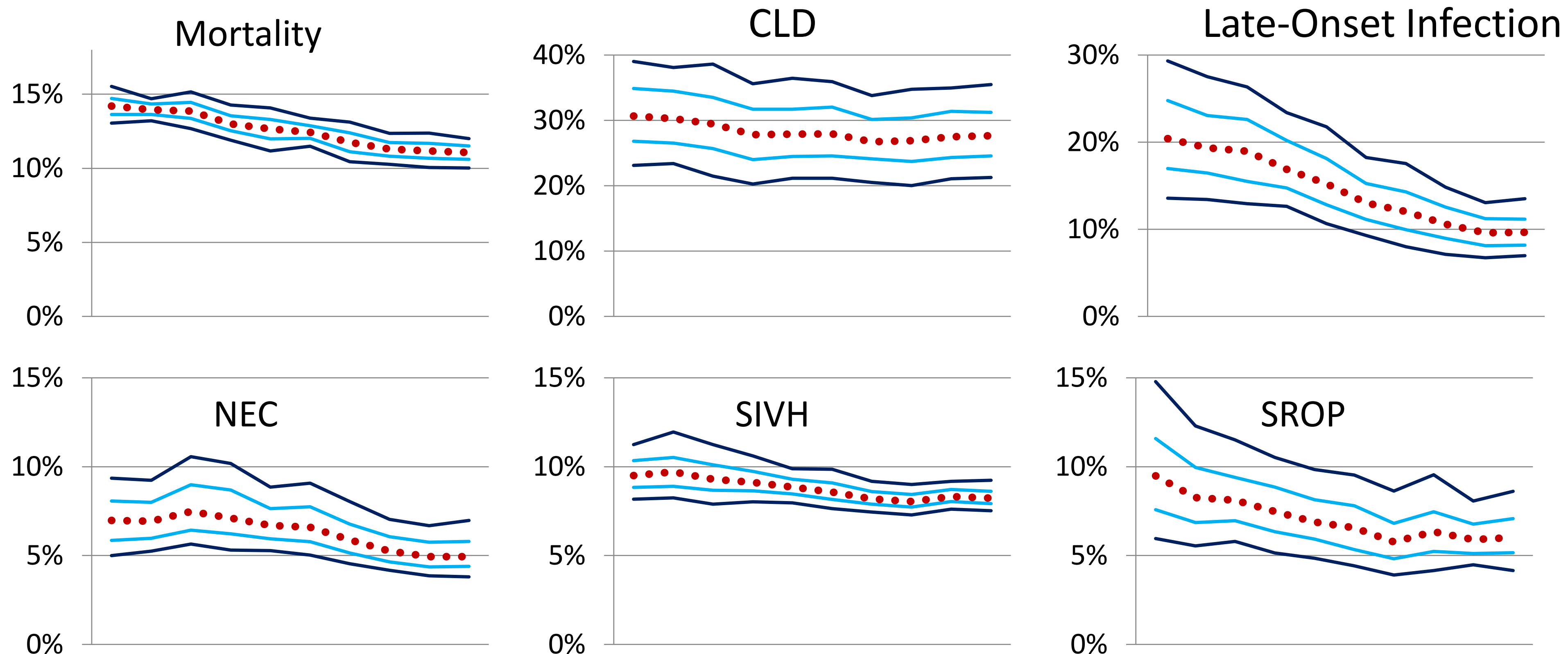
Elinor Ostrom
Coproduction



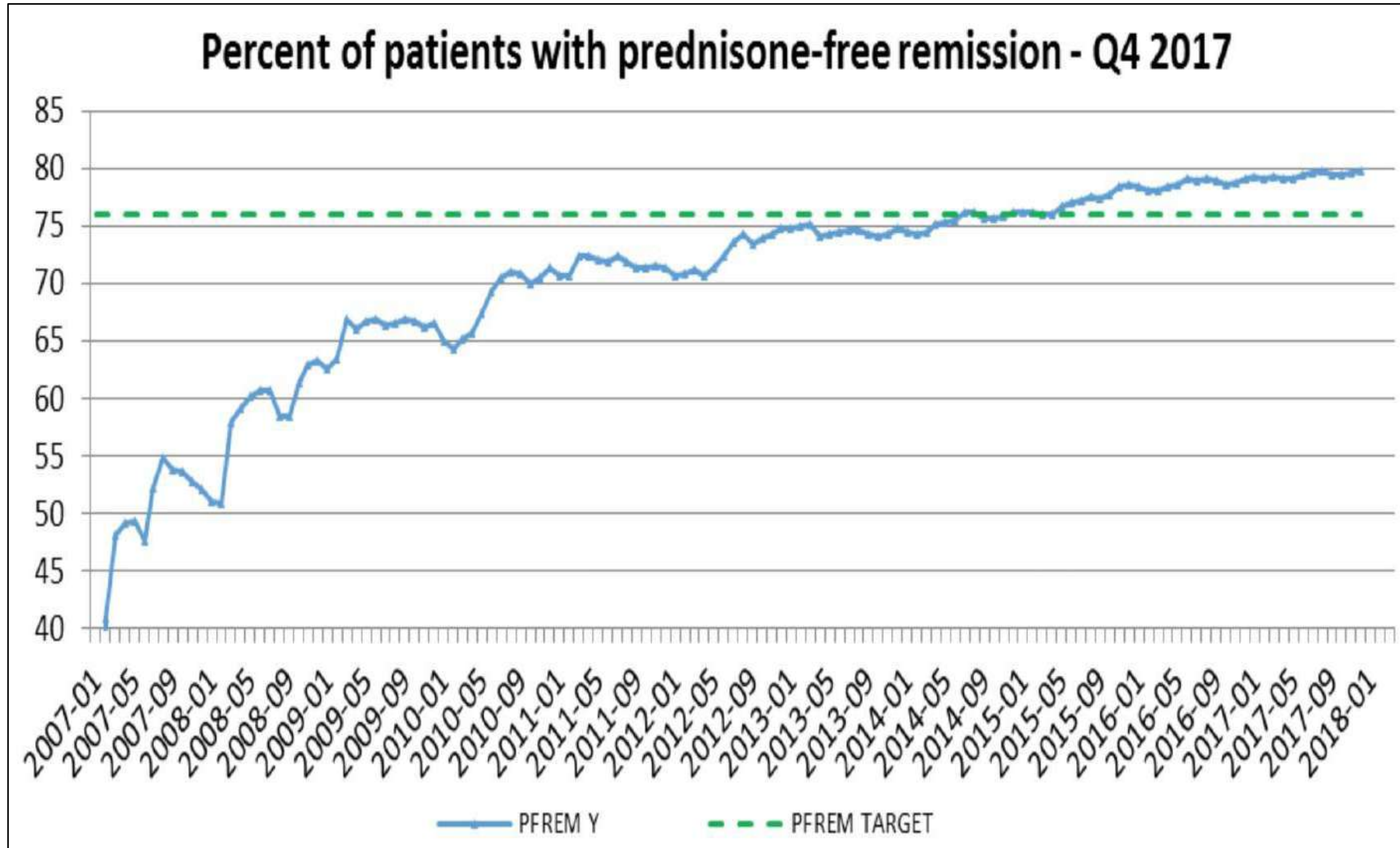
Peter Senge
Learning Systems

Results

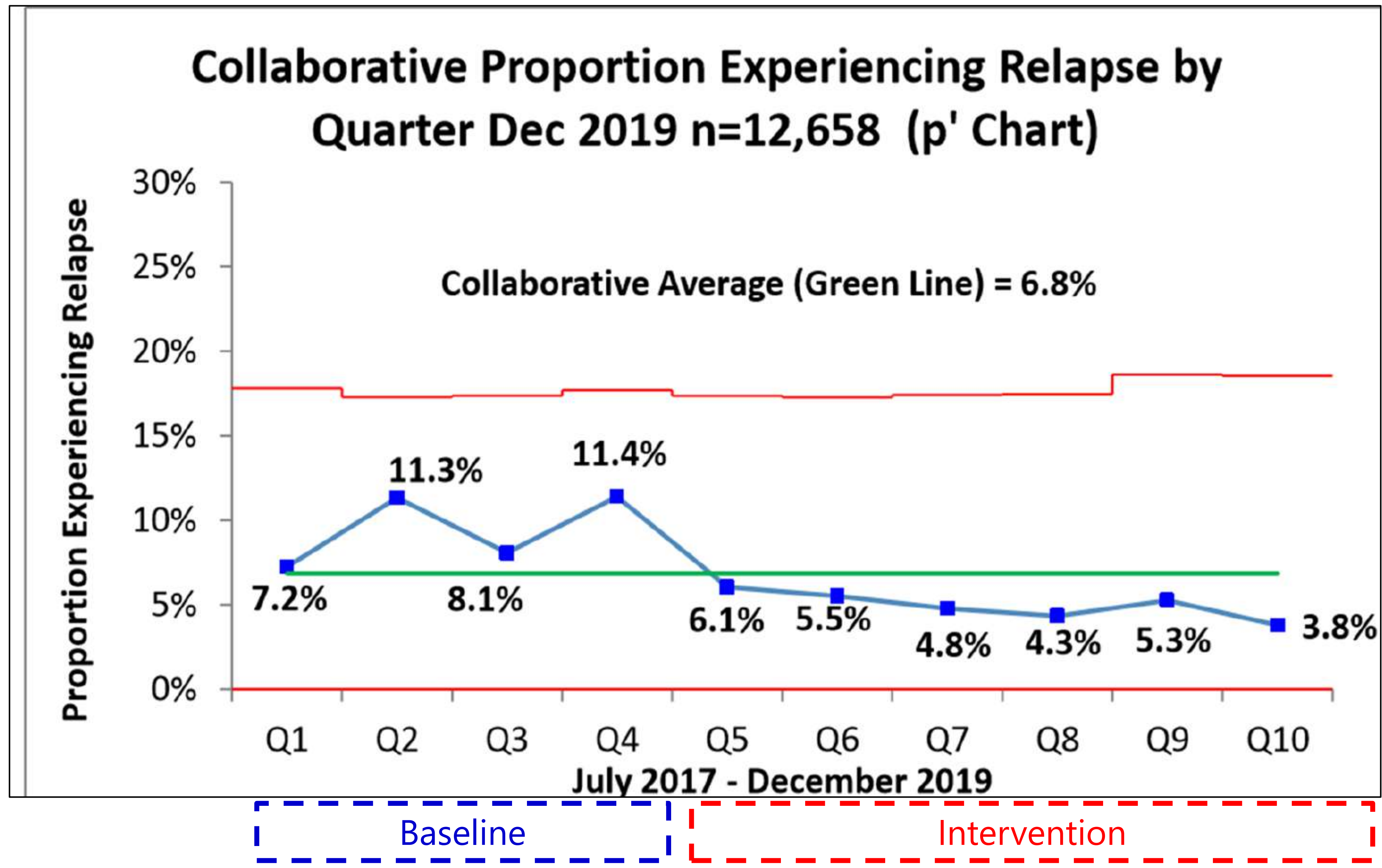
Risk-Adjusted Rates of Outcomes in the NICU at the 10th, 25th, 50th, 75th, and 90th Percentiles, 2005-2014, With the Dark Blue, Light Blue, and Dotted Red Curves Indicating 10th/90th, 25th/75th, and 50th Percentiles, Respectively



Pediatric IBD: Improve Care Now



Multiple Sclerosis Continuous QI Collaborative (MS-CQI)



MS-CQI COLLABORATIVE
IMPROVING MS CARE TOGETHER
mscqi.org

BMJ Open; 8(2): (Suppl 2) A11-A14; doi: 10.1136/bmjoq-2019-ihi.7

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

Population & Program	**New Advances in Science: Therapies**	**Quality Improvement Collaborative**	**Feed Forward Data at Point of Care**	**Patient Reported Outcome Measures**	**Patient Level Registry Database**
NNE: NNE Cardiovascular Study Group	++ 1	++	—	—	++
CF: Cystic Fibrosis Foundation Registry	—	++	++	—	++
RA: Swedish Rheumatology Quality Register	++ 2	++	++	++	++
LBW Infants: Vermont Oxford Network	++	++	++	NA	++
Peds IBD: Improve Care Now	++ 2	++	—	++	++

1. Discovery of Low Output Failure caused by CABG surgery
2. Discovery of new drug therapies: biologics

CO-PRODUCTION OF RESEARCH

A *Nature* special issue

nature.com/collections/coproduction

THIS WEEK

EDITORIALS

TASTE Savour the flavour of a gene-edited tomato **p.8**

WORLD VIEW How farmers transformed climate-science project **p.9**

YELLOWSTONE More endangered than your average bear **p.13**

Coproduction & Science

Nature

October 2018

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