Improving Health, Healthcare Value and Outcomes Science: A Workshop on Starting a Coproduction Learning Health System

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Disclosures: Glyn Elwyn founded the Option Grid ™ patient decision aids, now developed by EBSCO Health, and consults for PatientWisdom Inc. and abridge Inc.

Getting ready...

Please take a seat toward the front of the room.

On a sticky note, write down the focus of your work

- **Population** (example: older adults with mental illness)
- **Place** (example: senior housing)

Agenda

Coproducing Care in a Learning Health System

- Using data to support decisions, improvement, and science (15 min)
- ***Exercise: Starting a Learning System in Your Community (20 min)***
- ***Share your ideas (15 min)***

Real-life Examples

- Collaborative QI and research: *Multiple Sclerosis (5 min)*
- Patient and clinician co-design: *Palliative Care (5 min)*
- ***Exercise: What questions do you have on getting started? (15 min)***

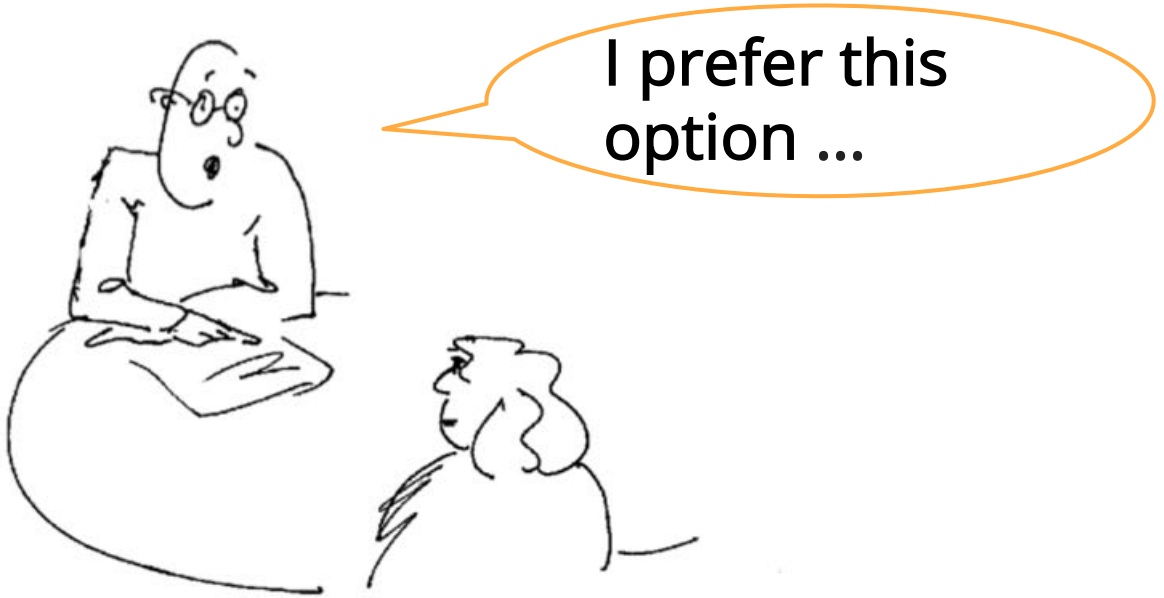
Wrap-up

- Join a “community of practice” (5 min)

Objectives

- Describe components of a coproduction learning health system (CLHS)
- Identify tools that support coproduction, shared decision-making, and collaborative goal setting.
- Identify practical steps to starting a CLHS in your community.
- Know how to connect, learn, and share with others in a community of practice

Coproducing Care in a Learning Health System


I prefer this option ...

How much effort was made to help you understand your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

How much effort was made to listen to the things that matter most to you about your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

How much effort was made to include what matters most to you in choosing what to do next?

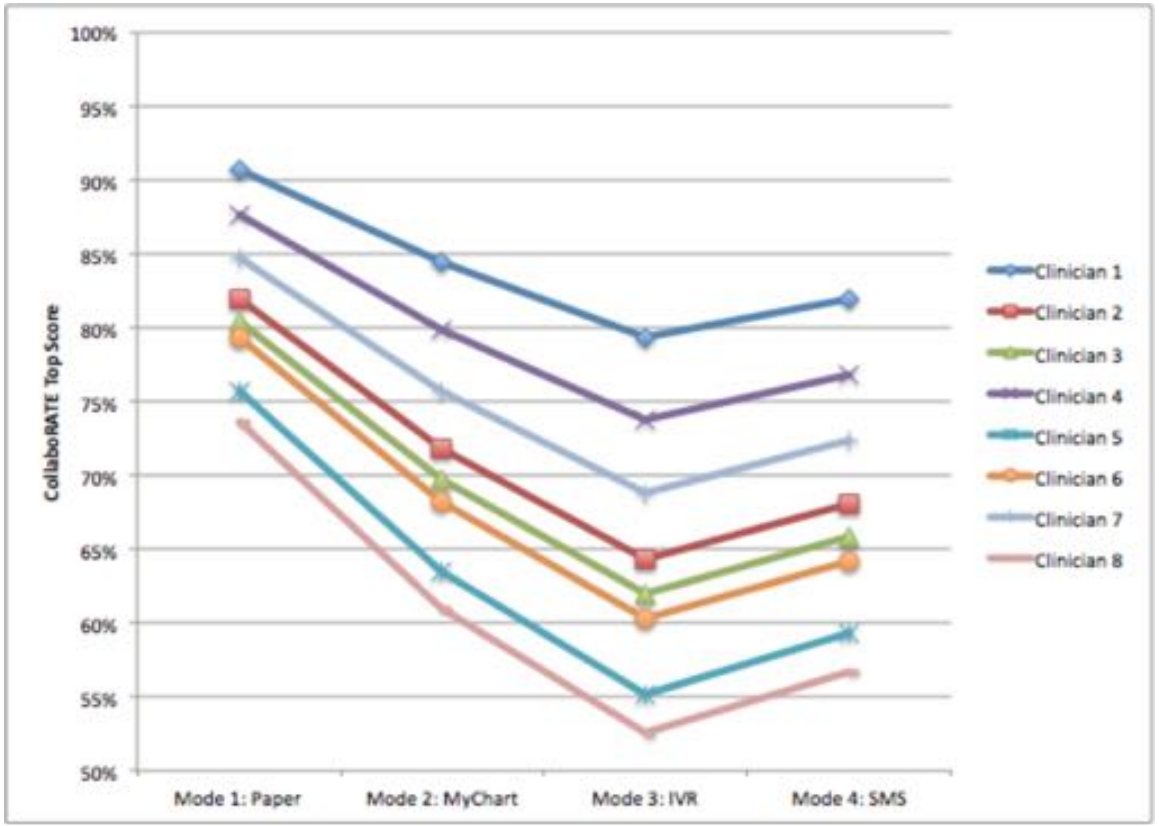
0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

27

64%

collaboRATE scores 8 clinicians

%



Four data collection methods

collaboRATE™

Developing collaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters. Patient Educ Couns. 2013 Jun 11;93(1):102–7.

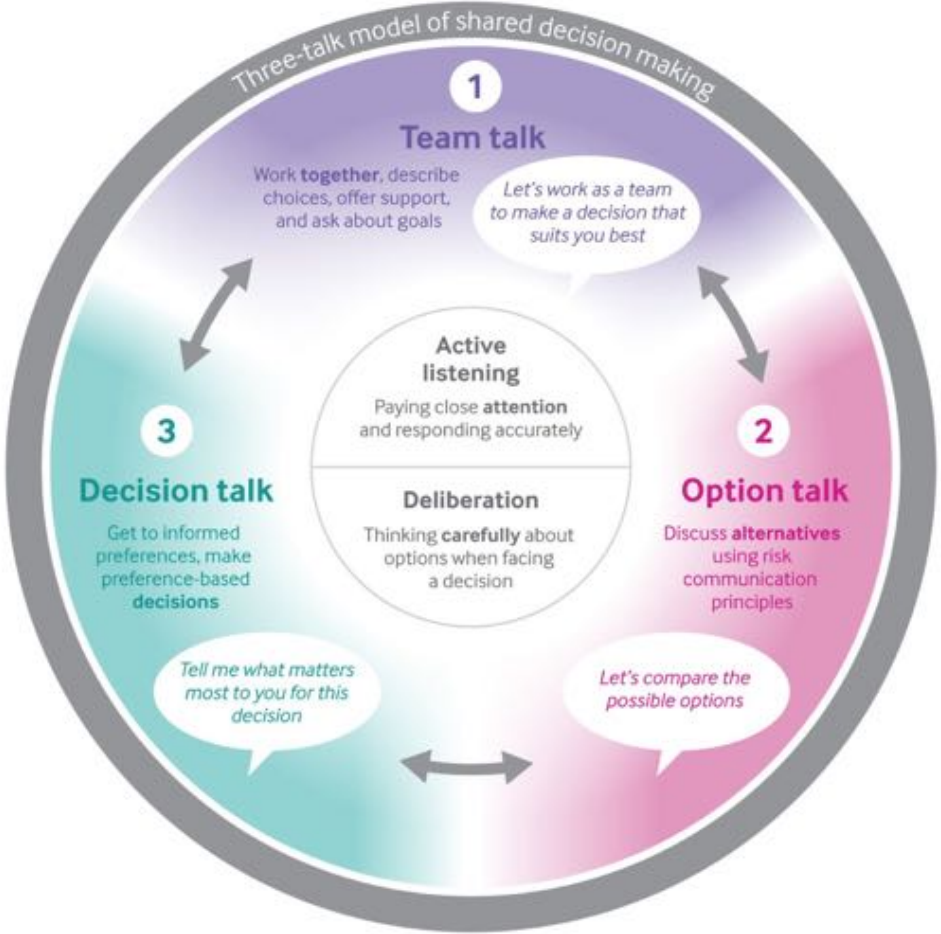
The psychometric properties of collaboRATE. A fast and frugal patient-reported measure of the shared decision-making process. J Med Internet Res. 2014 Jan 3;16(1):e2.


collaboRATE™


integRATE™


considerRATE™

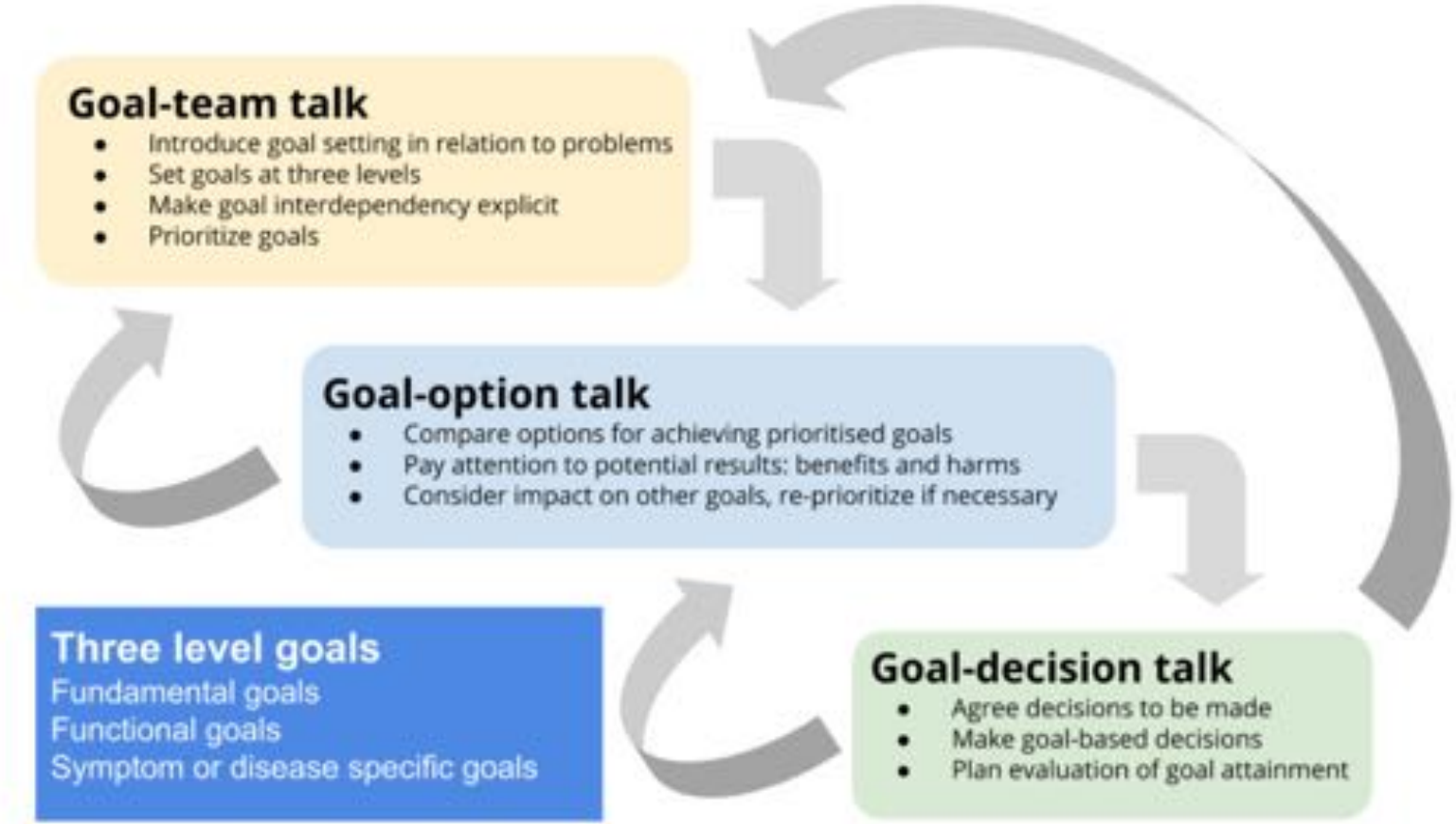

cooperRATE™



Three-talk model of shared decision making

thebmj

Goal Setting



Goal-based shared decision making Journal of Patient Experience October 2019

Patient-Professional Partnerships

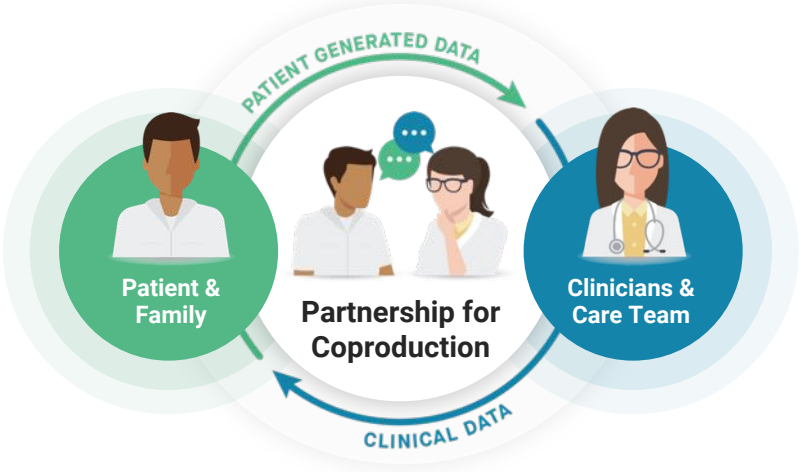
Research Registries

Patient & Family Support Networks

Care & Quality Improvement networks

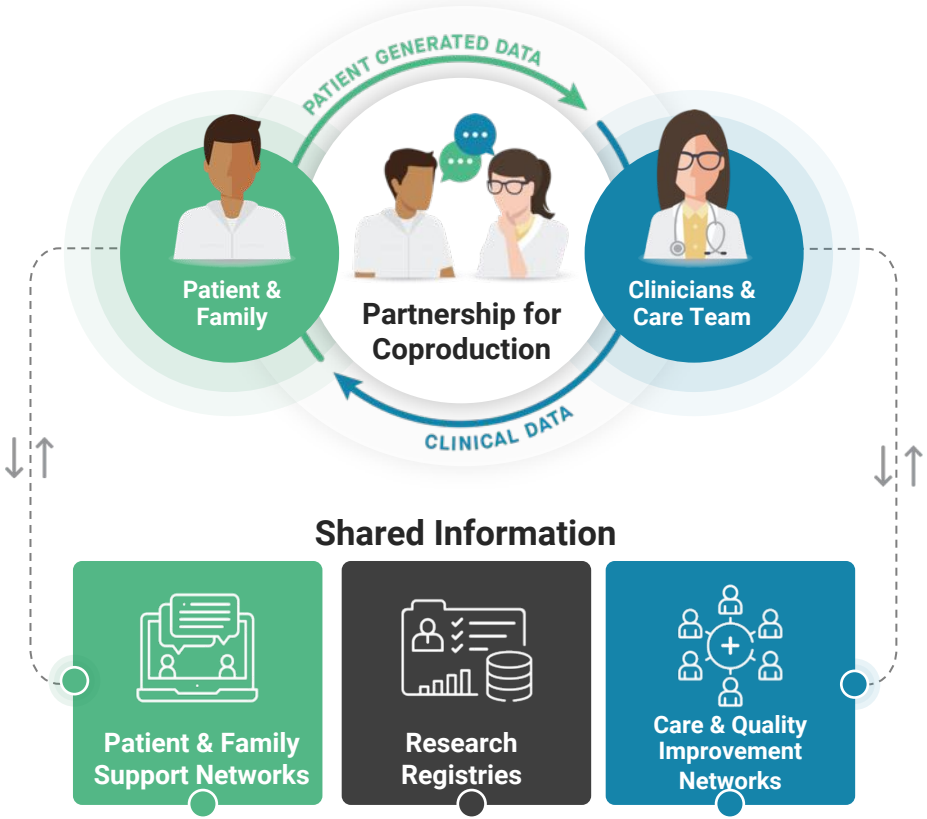
Coproduction-based Learning Health System

Life world



Clinical world

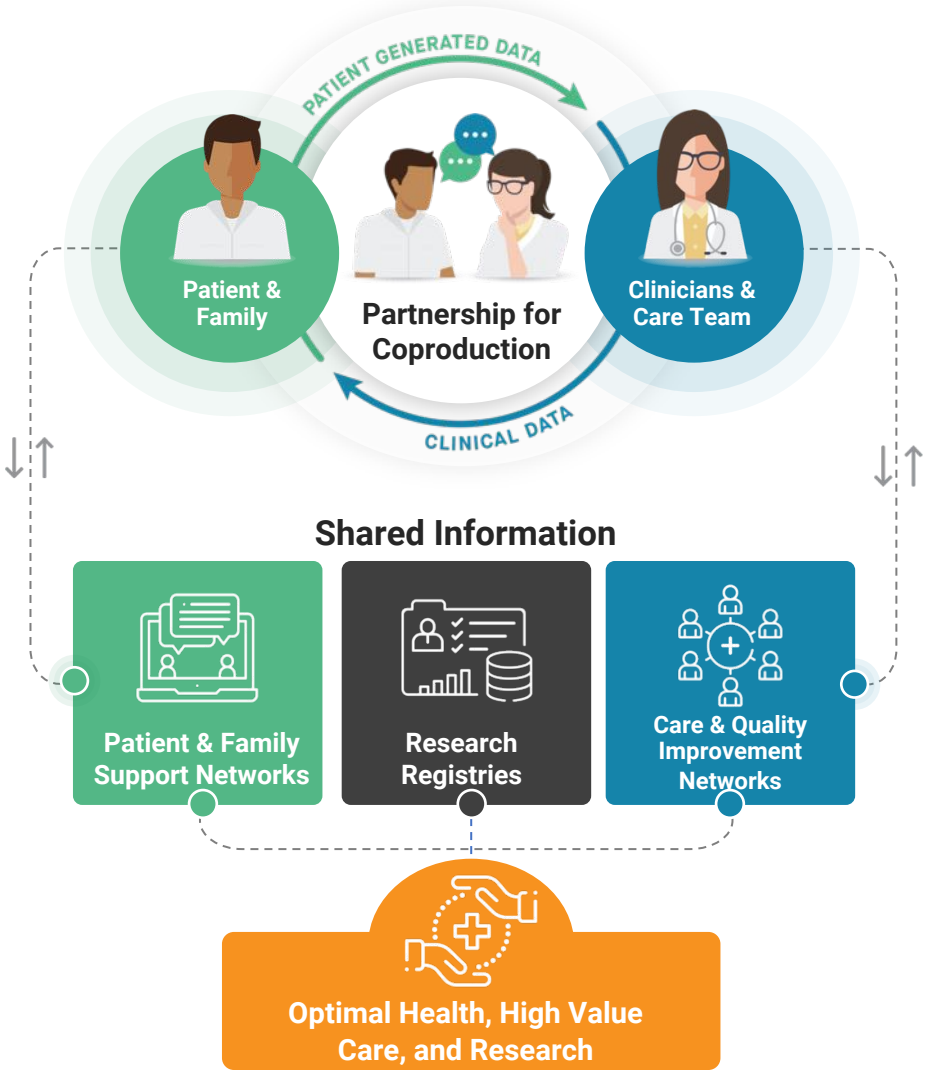
Coproduction-based Learning Health System



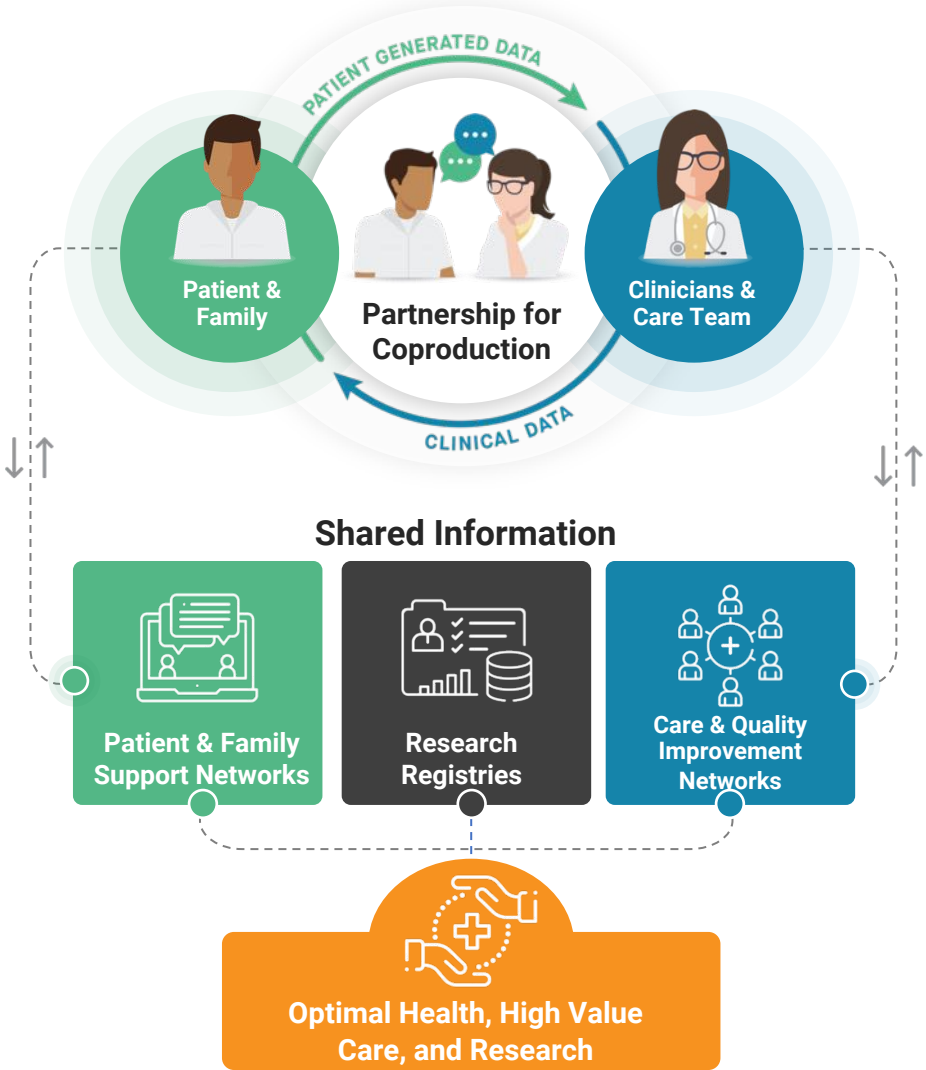
Patient-facilitated networks & personal health records

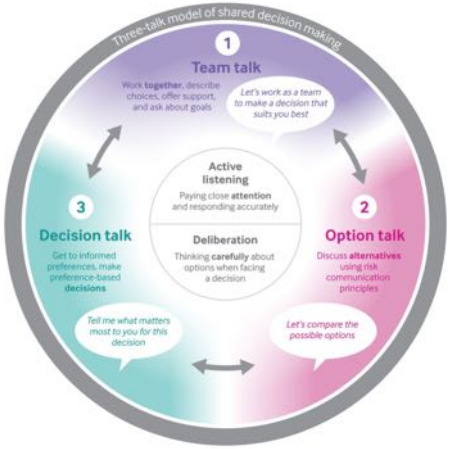
Improvement networks & clinic-based electronic health record system

Coproduction-based Learning Health System



Registry-based data for use to support planning, research, quality improvement, and implementation


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


Three-talk model of shared decision making
1
Team talk
Work together, describe choices, offer support, and ask about goals
Let's work as a team to make a decision that suits you best
2
Option talk
Discuss alternatives using risk communication principles
Let's compare the possible options
3
Decision talk
Get to informed preferences, make preference-based decisions
Tell me what matters most to you for this decision
Active listening
Paying close attention and responding accurately
Deliberation
Thinking carefully about options when facing a decision

Using Data to Guide Decision Making

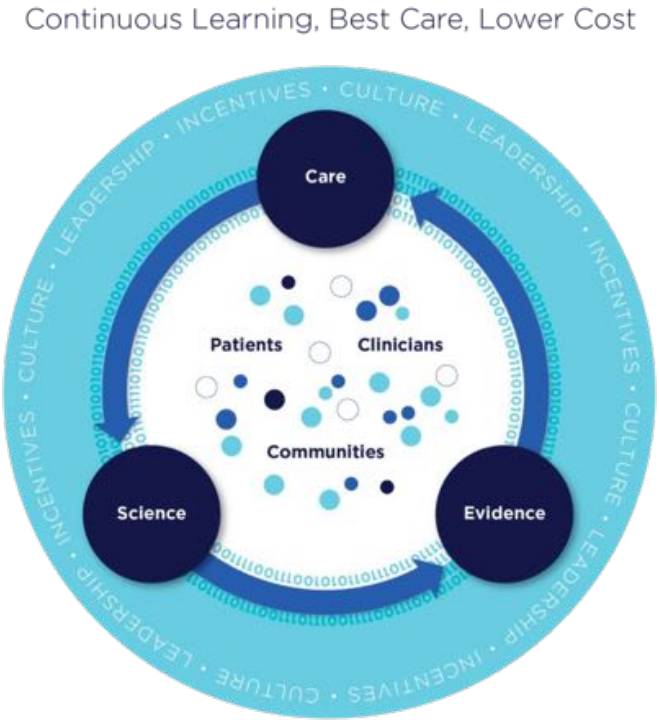
Rheumatology
Inflammatory bowel disease
Cystic fibrosis

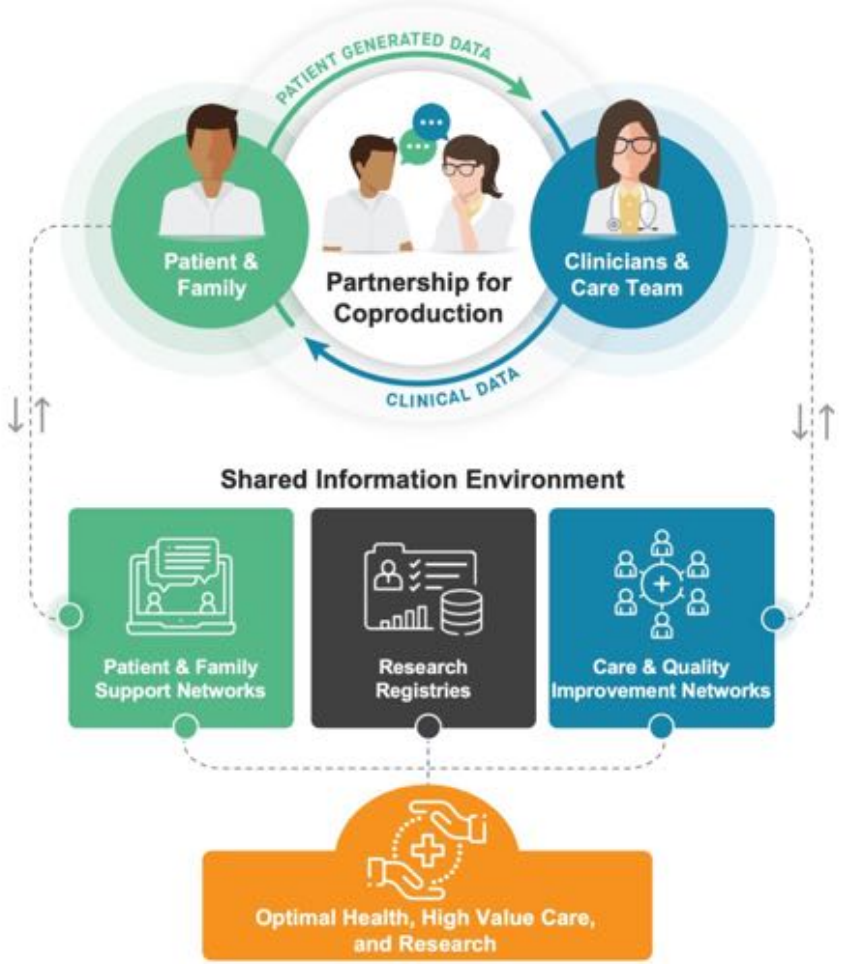
Learning Health Systems (IOM)

"…Generates and applies the best **evidence** for the **collaborative health care** choices of each patient and provider…

(and) drives the process of discovery **(science)** as a natural outgrowth of patient care…

(and) ensures **innovation, quality, safety, and value** in health care"





Model is Being Used for Many Different Populations

- Rheumatology
- Inflammatory Bowel Disease
- Cystic Fibrosis
- Multiple Sclerosis
- Palliative Care
- Serious Illness *
- Cancer *

* LHS based in medical center

SRQ Clinician Coproduction Dashboard

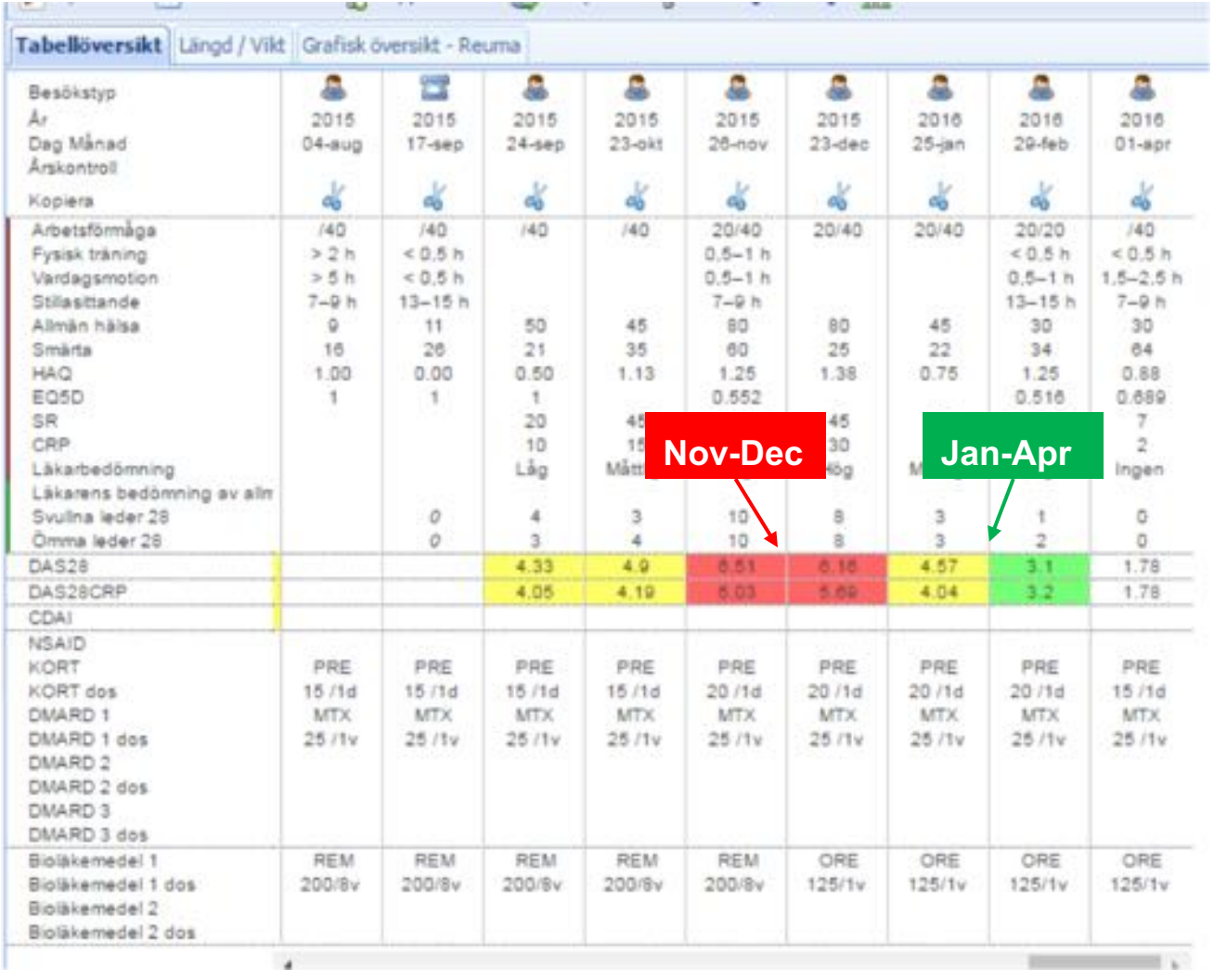
Case in point:

Swedish Rheumatology Quality Registry

This patient is doing better!

N of 1 experiment…

Response to biologics



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			0,5–1 h	1,5–2,5 h
Stillasittande	7–9 h	13–15 h			7–9 h			13–15 h	7–9 h
Allmän hälsa	9	11	50	45	80	80	45	30	30
Smärta	16	26	21	35	60	25	22	34	64
HAQ	1.00	0.00	0.50	1.13	1.25	1.38	0.75	1.25	0.88
EQ5D	1	1	1		0.552			0.516	0.689
SR			20	45		45			7
CRP			10	15		30			2
Läkarbedömning			Låg	Måtti		Hög	M		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									
Läkemedel 1	REM	REM	REM	REM	REM	ORE	ORE	ORE	ORE
Läkemedel 1 dos	200/8v	200/8v	200/8v	200/8v	200/8v	125/1v	125/1v	125/1v	125/1v
Läkemedel 2									
Läkemedel 2 dos									

IBD QORUS™

Quality driven. Care focused.

Most Important Concerns as of 07/10/2018

I have a family vacation coming up. I want to enjoy the time with my family and not worry about my symptoms.

Symptoms and Disease Activity

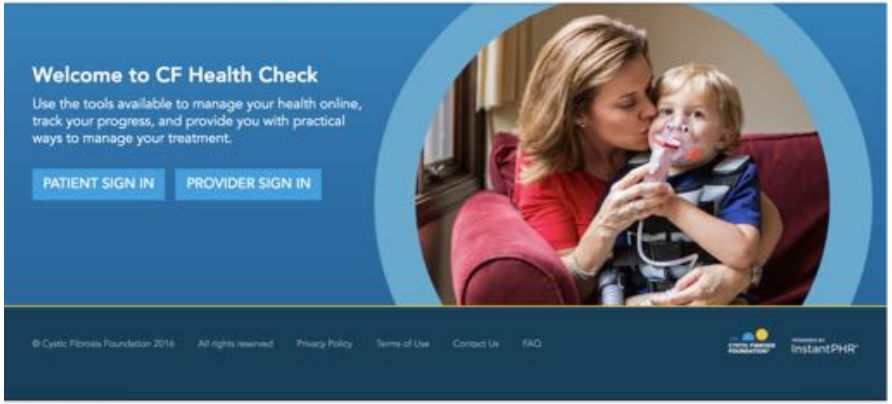
WELL BEING	RECTAL BLEEDING	STOOL FREQUENCY	ABDOMINAL PAIN	CRP
Poor	No blood seen	3-4 stools per day more than normal	Moderate	

SELECT DATES: 07/11/2017 TO 07/10/2018 Run Charts

SYMPTOMS AND DISEASE ACTIVITY

CYSTIC FIBROSIS FOUNDATION®

CF Health Check



What is my #1 concern or goal related to CF?

Add New Item

Date	Notes
1/3/2018 2:06 PM	Becoming an adult.
1/3/2018 2:02 PM	I am wondering why I do this at every appt.
12/8/2017 12:35 PM	Running with out coughing

1 2 3 4

What do I want to discuss at my next visit?

Add New Item

Date	Notes
1/3/2018 2:06 PM	Lab Results
1/3/2018 2:02 PM	Lab Results
12/7/2017 10:53 AM	Coping with CF

1 2 3 4 5 6 7 8 9

Trends in Health and Well-being

Toggle the switch below the graph to turn on or off the display of each aspect of your health. Hover over data points on the graph to see values.

LEGEND: Quality of Life Physical Health Sadness/Emotional Problems FEV 1 % Predicted Weight

Date Range: Last 2 Years

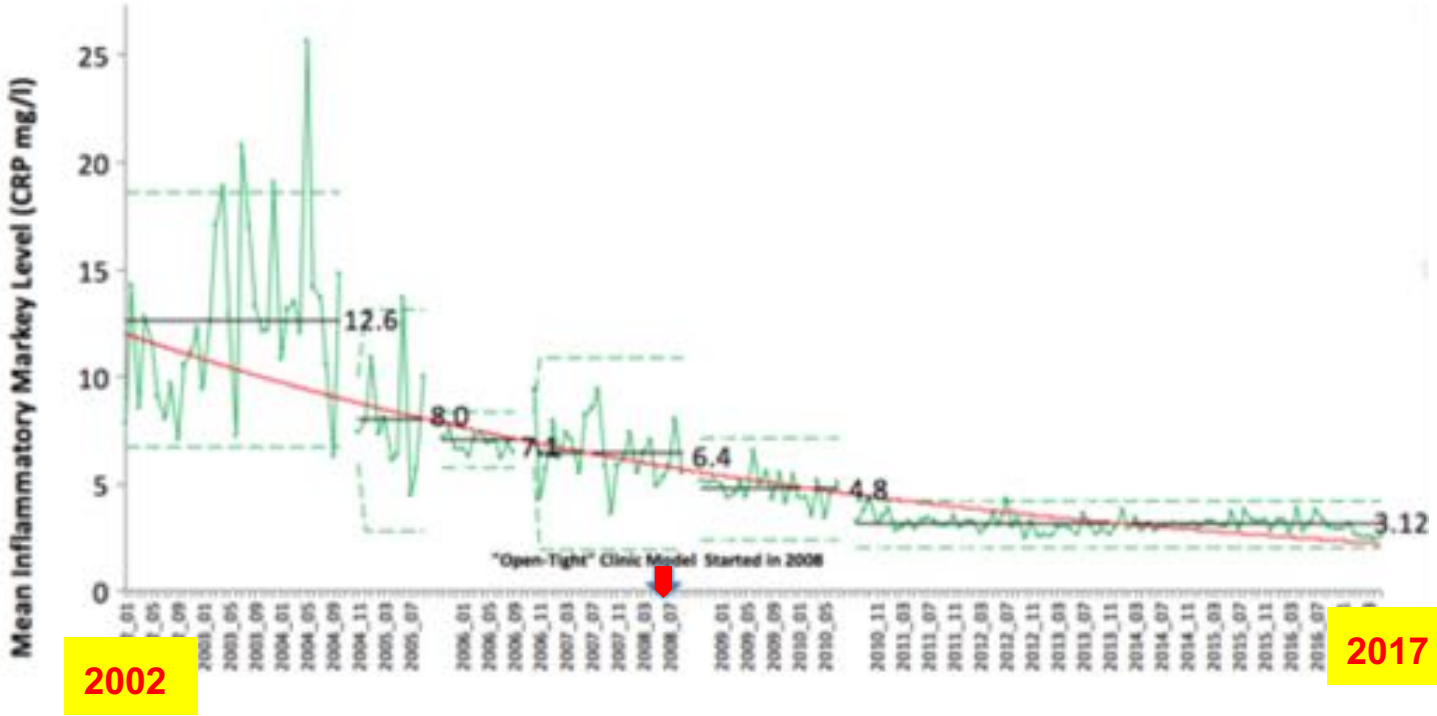
Well-being (Higher scores represent greater well-being)

FEV 1 % Predicted and Weight (lbs)

Growing Evidence of Impact on Improving Health Outcomes

Rheumatology
Inflammatory bowel disease
Cancer

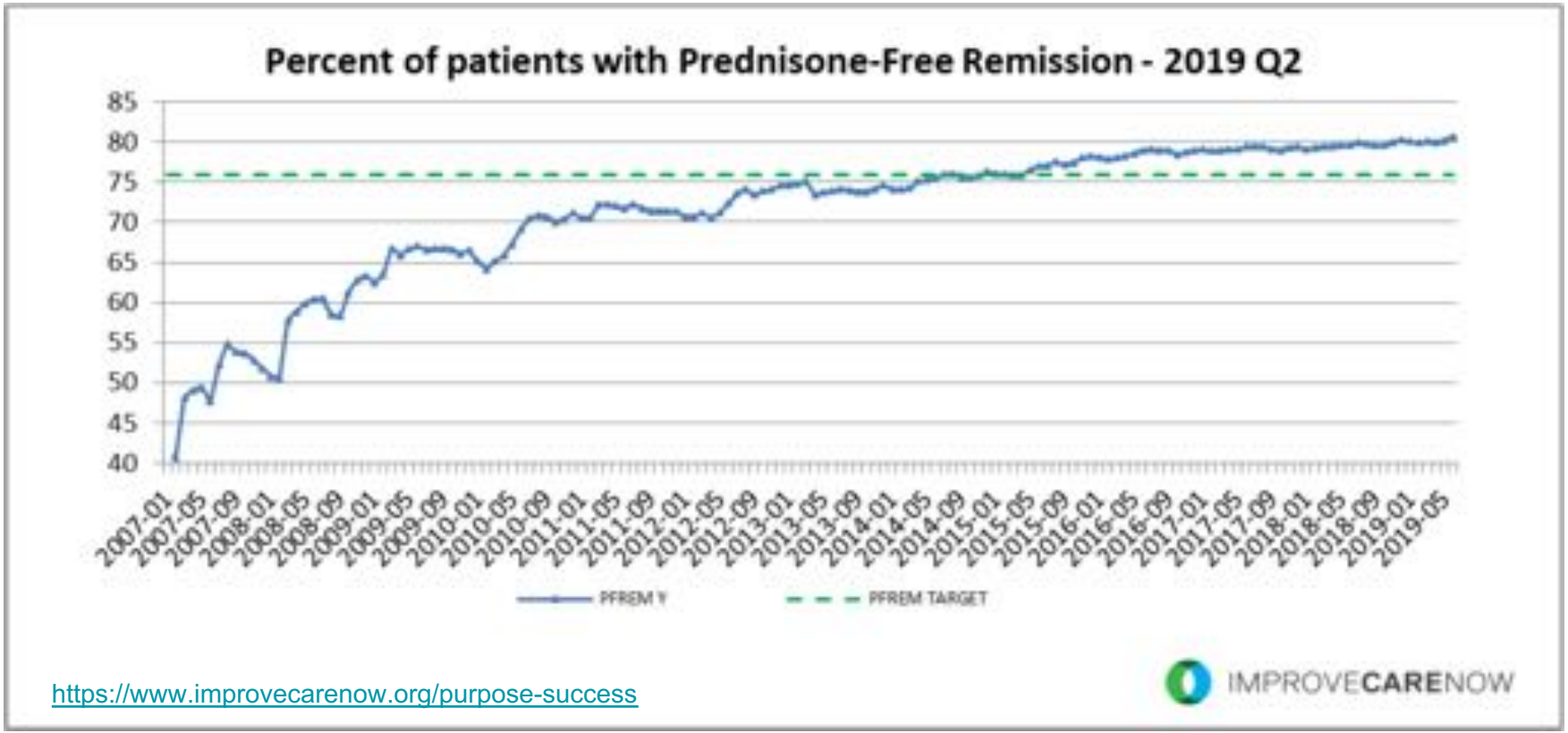
RA Disease Burden in Sweden Decreasing*



* CRP (C reactive protein) levels in RA patients

Godfrey M, Foster TC, Johnson JK, Nelson EC, Batalden P. *Quality by Design: A Clinical Microsystems Approach.* 2nd ed: Jossey Bass; 2018.

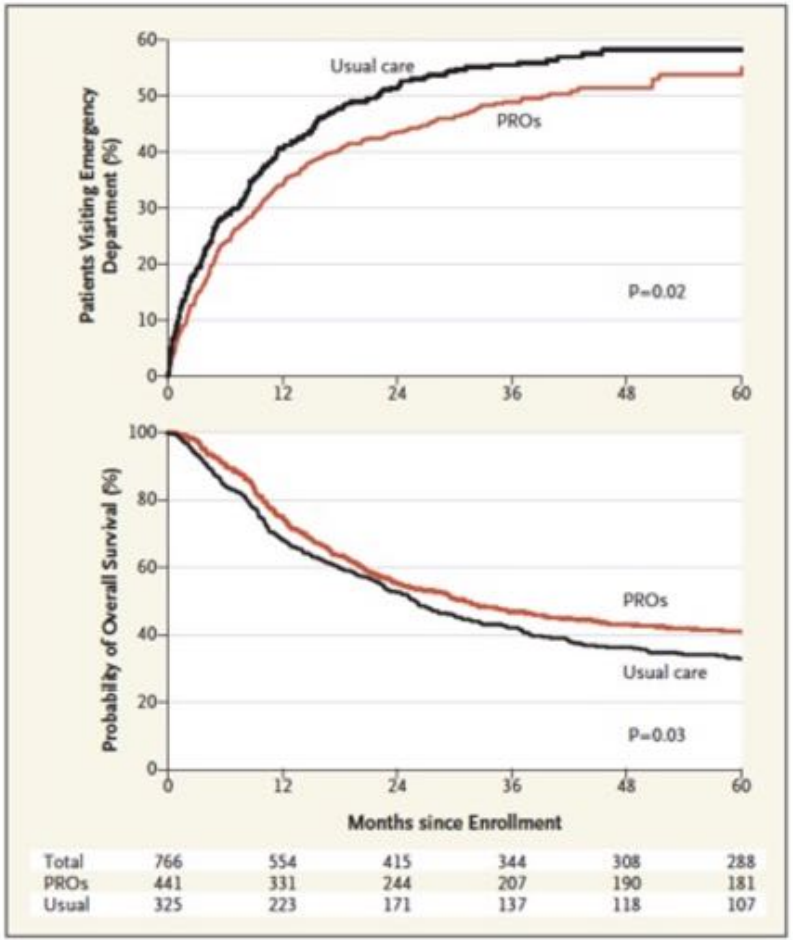
ImproveCareNow (ICN) Network



https://www.improvecarenow.org/purpose-success

Emergency Department Visits and Probability of Survival Associated with Integrating Patient-Reported Outcomes (PROs) into Cancer Care

- ED visits <u>decreased</u>
- Survival <u>increased</u>



Basch E. Patient-reported outcomes-harnessing patients' voices to improve clinical care. New England Journal of Medicine. 2017; 376(2): 105-8.

Take Home Points

Patient-centered learning health systems have the capacity to co-produce better health outcomes, higher quality care, and real world health science.

You can tailor the approach to work in your country for the populations of people that you care for.

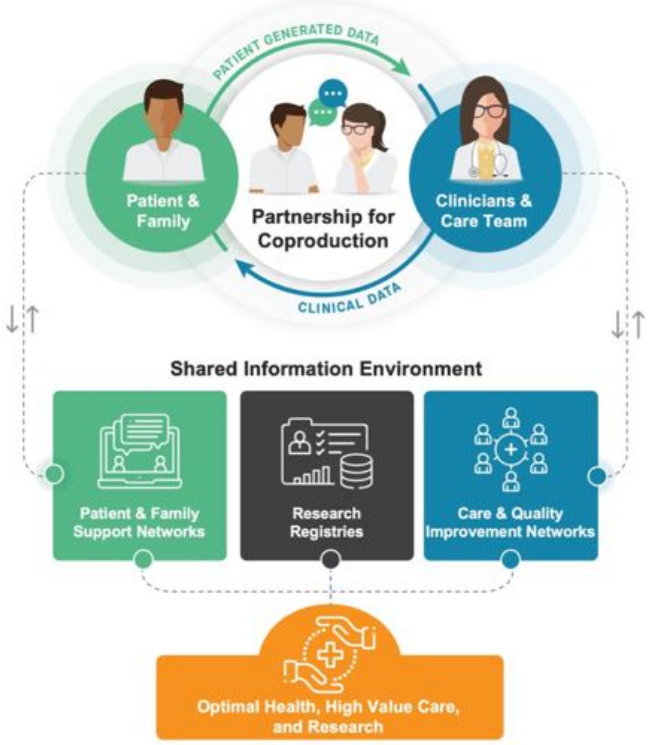
Task:

At your table:

- Decide on a **population**
- Decide on a **context / place**(s) to start a coproduction LHS

Answer these questions...

1) Which **components of the model** are most important for your population and place?
2) Who do you need on **your team?**
3) What **data** would you collect from patients and clinicians, and how?
4) What will **success** look like?
5) What **opportunities** / **barriers** do you expect?



Share...

- The population and place you worked on
- One or two insights gained from the activity

Real-world Examples

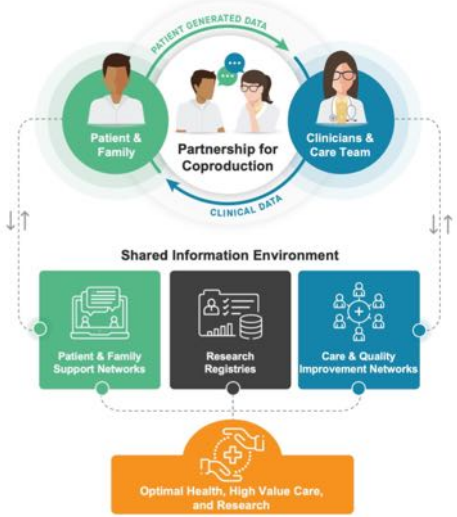
Multiple sclerosis: Lessons in collaborative QI and research

Palliative care: Lessons in patient and clinician co-design

A Research and Improvement Learning Health System (LHS) Collaborative for Multiple Sclerosis (MS)

- MS-CQI is the first improvement science research collaborative for Multiple Sclerosis (MS).
- MS-CQI uses a LHS approach to simultaneously inform clinical care, research, and quality improvement efforts.
- MS-CQI uses clinical and PRO data.

Inspiration for the development of MS-CQI

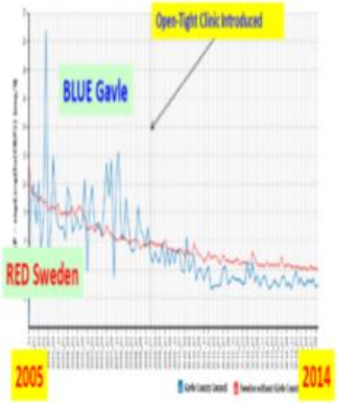


Nelson et al. (2016)

CLHS Potential

- There is ***precedent for CLHS improvement*** approaches in other complex, costly, chronic disease populations.
- In Sweden, a national-level CLHS initiative using feed-forward PRO data to risk stratify ***rheumatoid arthritis*** population resulted in improved disease control and improved access to care (Lindblad et al., 2014).
- In the United States, a randomized prospective study of 766 oncology patients demonstrated ***improved life expectancy*** in patients engaged in care using a PRO-based CLHS approach (Basch et al., 2017).

RA Disease Burden in Sweden Decreasing*



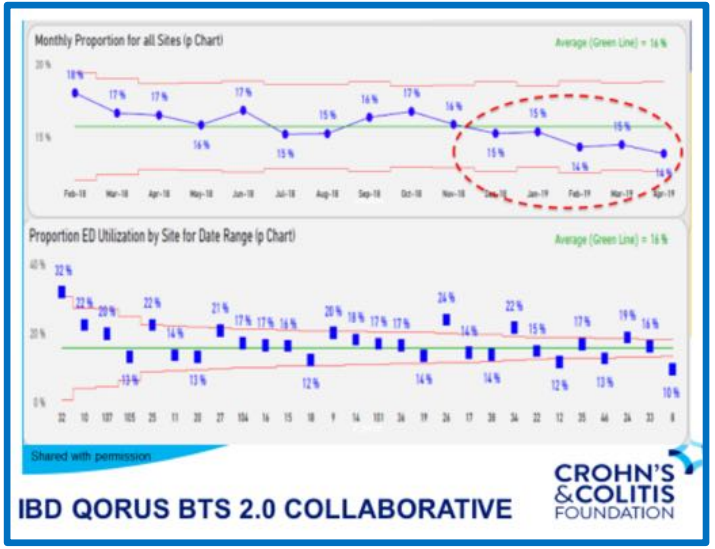
Accelerating the rate of improvement in cystic fibrosis care: contributions and insights of the learning and leadership collaborative

Marjorie M Godfrey,[1] Brant J Oliver[2]

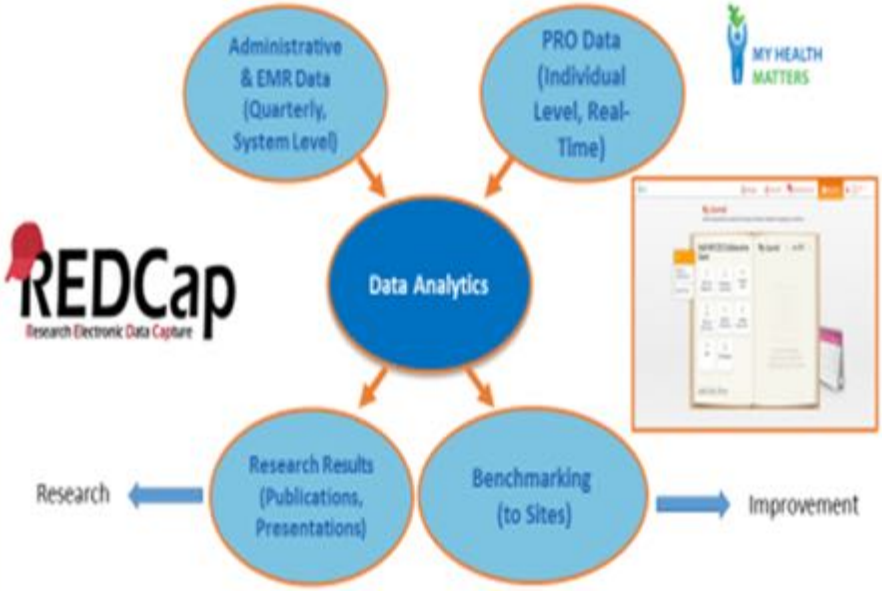
ABSTRACT

INTRODUCTION

METHODS



Data Pathways

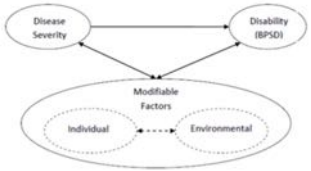


Dartmouth-Hitchcock
A CULTURE OF CARING

Based on Co-Production Learning Healthcare System Model (Nelson et al., 2015)

MS-CQI COLLABORATIVE
IMPROVING MS CARE TOGETHER

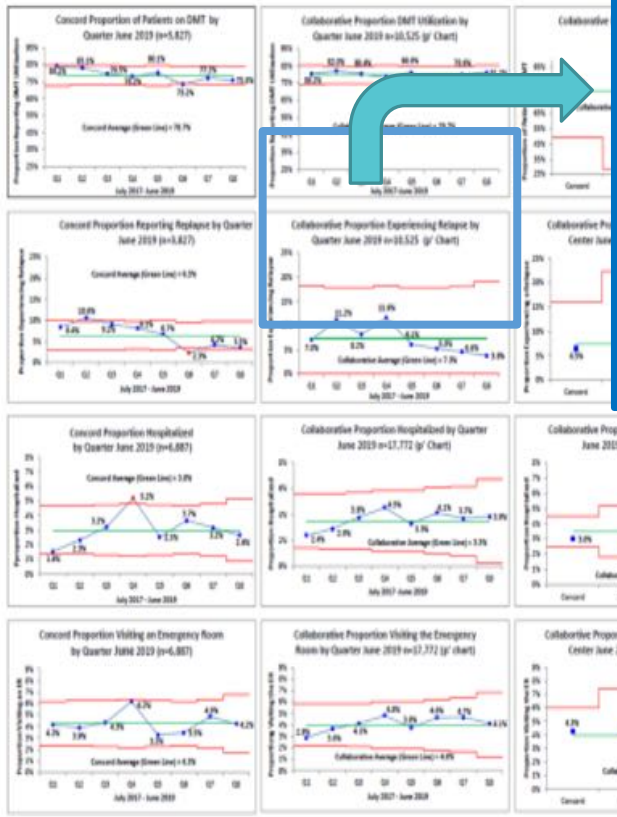
Beginning of the Journey:
WHO Biopsychosocial Conceptual Model of Disability

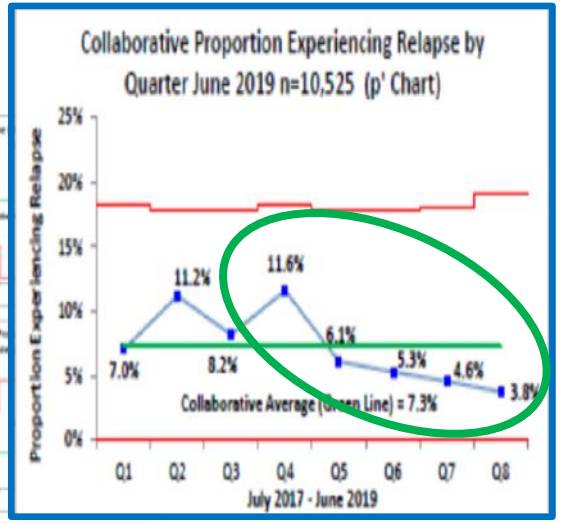


Dartmouth-Hitchcock
A CULTURE OF CARING

Domain	Examples of Measures in Category
Clinical Outcomes	• Relapse rate by quarter • Percentage on DMT by quarter • % MRI in last year • Patient Determined Disease Steps (PDDS)
Functional Health	• Neuro-QoL, WPAI (Work Productivity), PROMIS Fatigue$_{MS}$ PHQ-9 (depression)
Experience & Satisfaction	• CG-CAHPS, BAI, TSQM-9, Qualitative
Cost & Utilization	• Healthcare resource utilization (OV, MRI, ED, hospitalization, urgent care)

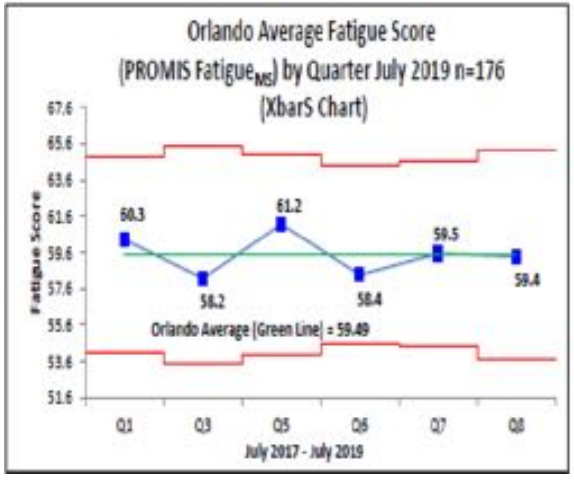
Feed-Forward & Feedback Data

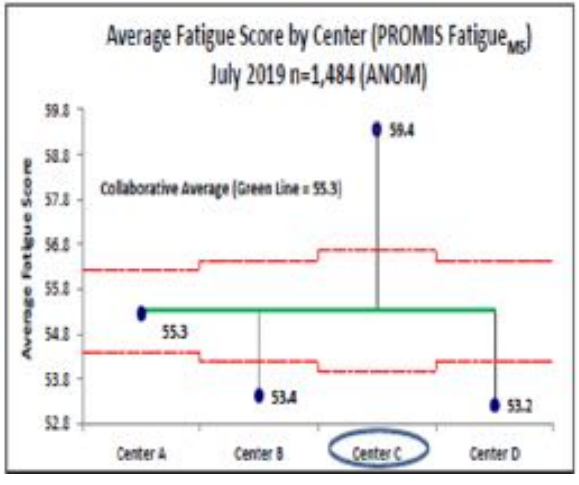


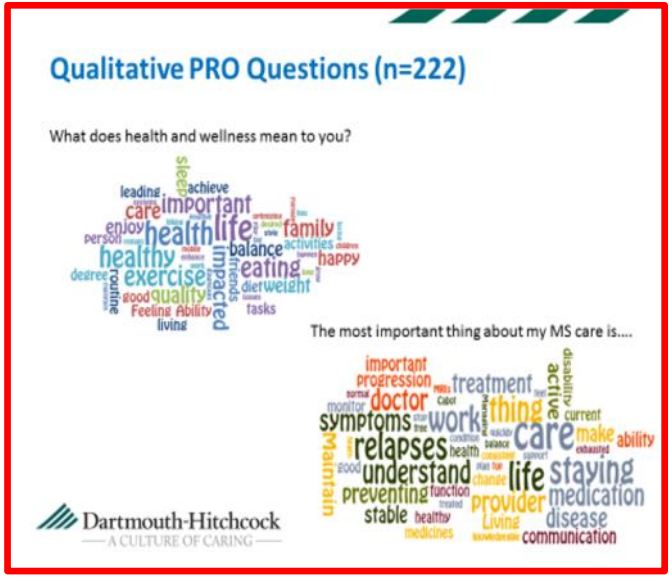


MS-CQI COLLABORATIVE
IMPROVING MS CARE TOGETHER

LHS: Research & Improvement







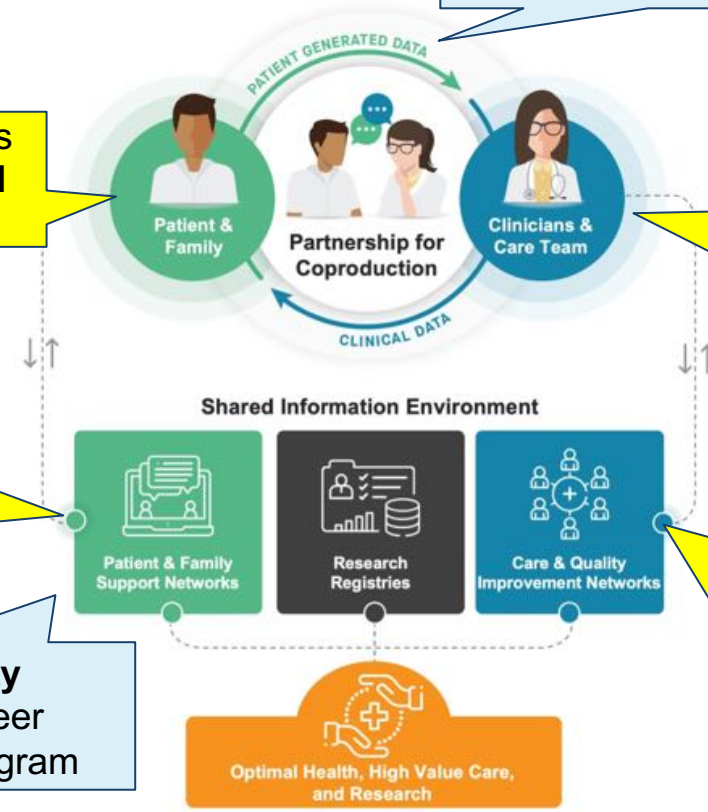
Patient Reported Outcome Measure (PROM)	Center A			Center B			Center C			Center D			MS-CQI (Total)			ANOVA	Between Sites
	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	Significant	Significant
Patient Determined Disease Steps (PDDS)	57	1.5	1.8	71	1.5	2.2	45	2.3	2.3	57	1.6	1.8	230	1.7	2.0		
Depression Severity (PHQ-9)	47	6.0	3.6	73	5.8	5.1	58	8.2	5.2	66	5.7	4.3	244	6.4	4.8	*	(B-C),(D-C)
Fatigue Severity (Promis Fatigue-MS)	44	21.4	5.5	72	19.9	7.2	53	24.4	8.1	65	21.2	7.3	234	21.6	7.3	*	*(C-B),(B-C)
Neuro-Qol Anxiety	66	17.2	6.6	84	17.2	6.2	55	19.2	7.5	66	16.0	5.7	271	17.4	6.5	0.055	*(C-D), (D-C)
Neuro-Qol Cognitive	65	29.6	7.6	83	31.9	7.1	55	28.9	7.8	66	32.2	6.2	269	30.8	7.3	*	
Neuro-Qol Lower Extremity Function	59	35.1	6.0	70	34.8	7.7	46	33.2	7.8	57	34.9	7.3	232	34.6	7.2		

Trajectory

Shared decision-making for disease management

MyHealth Matters **patient-reported outcome data**

EHR and MyHealth Matters **patient-reported outcome data**



MyHealth Matters Online Platform: Self-management, health coaching, mobile technology

Innovation scholar teams: Clinicians, consumers, innovators, researchers.

Step-wedge randomized improvement interventions

Integrated community partnerships: MSF peer wellness outreach program

MS-CQI COLLABORATIVE
IMPROVING MS CARE TOGETHER

Real-world Examples

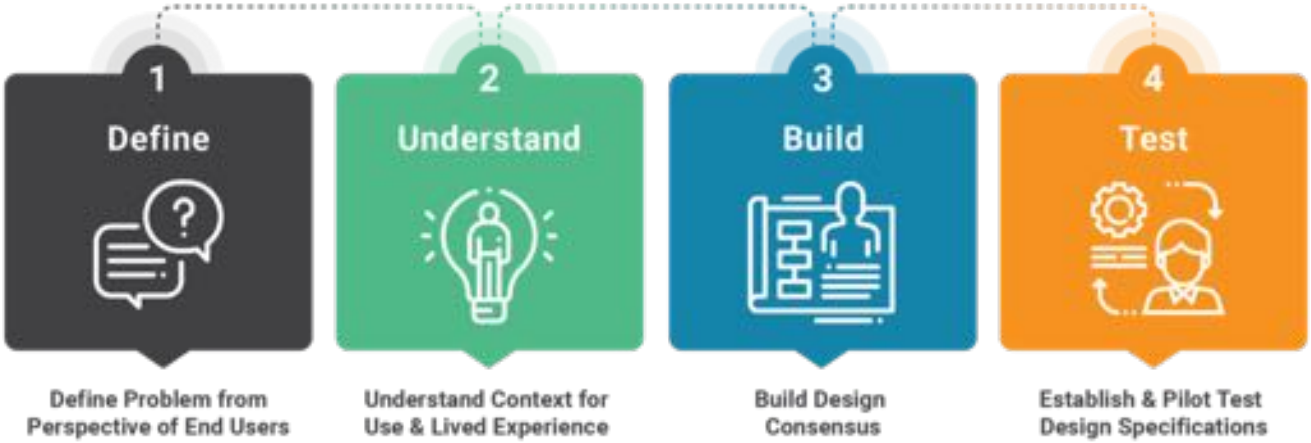
Multiple sclerosis: Lessons in peer-to-peer learning

Palliative care: Lessons in patient and clinician co-design

Patient & Clinician Co-design Process

Co-design team

- Patients
- Family members
- Community members
- Clinicians
- Researchers



Constraint: Development of a dashboard driven by funding source.

Define

Define problem from perspective of end users

Robert Pope, “Family Waiting”, Courtesy of the Robert Pope Foundation

A Person-Centered, Registry-Based Learning Health System for Palliative Care: A Path to Coproducing Better Outcomes, Experience, Value, and Science

Arif H. Kamal, MD, MBA, MHS[1] Kathryn B. Kirkland, MD[2] Diane E. Meier, MD[3] Tamara S. Morgan, MA[4] Eugene C. Nelson, DSc, MPH[4] and Steven Z. Pantilat, MD[5]

aahpm AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

Center to Advance Palliative Care™ capc

PCQN PALLIATIVE CARE QUALITY NETWORK

Global PALLIATIVE CARE Quality ALLIANCE Improving quality through collaboration

Dr. Kathy Kirkland, DHMC Section Chief of Palliative Care

Define

Define problem from perspective of end users

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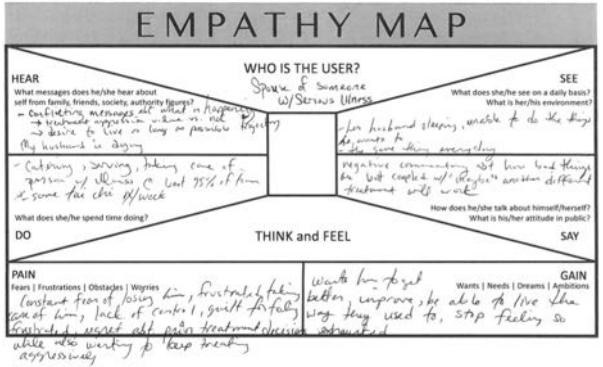
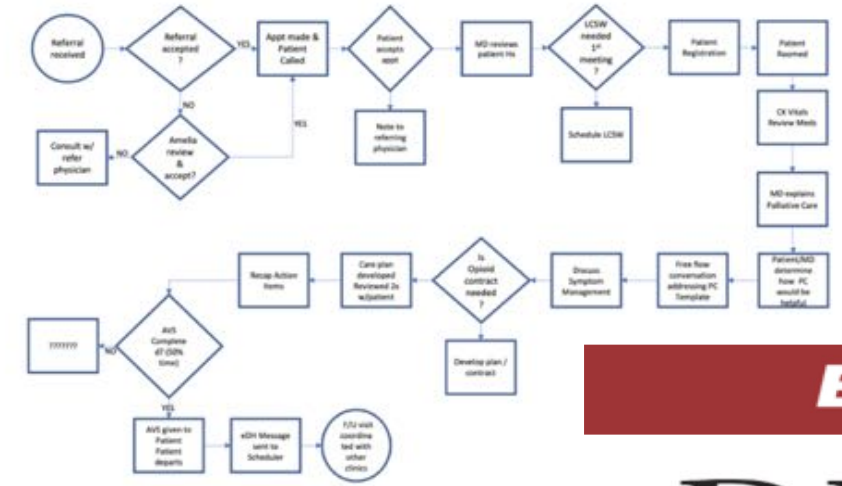
Problem: Ineffective communication between patients, families, and clinicians leads to healthcare services that do not meet the individual needs and goals of people living with a serious illness

Tips: Do background research & clarify the problem you are trying to solve.

Understand

Context of Use & Lived Experience





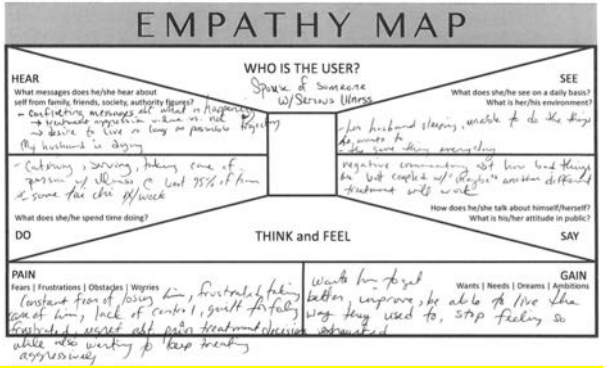
PC Outpatient Clinic Flow – New Patient (draft)

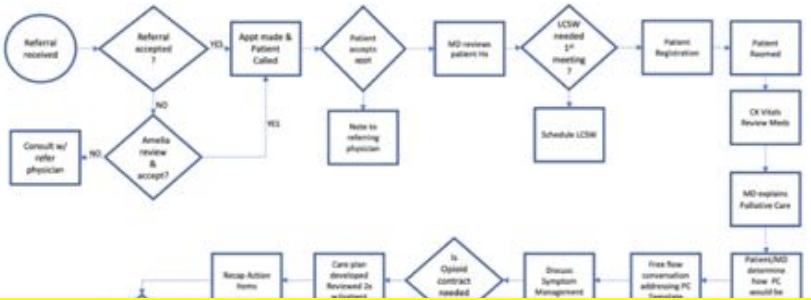
Epic

myD-H

Understand

Context of Use & Lived Experience





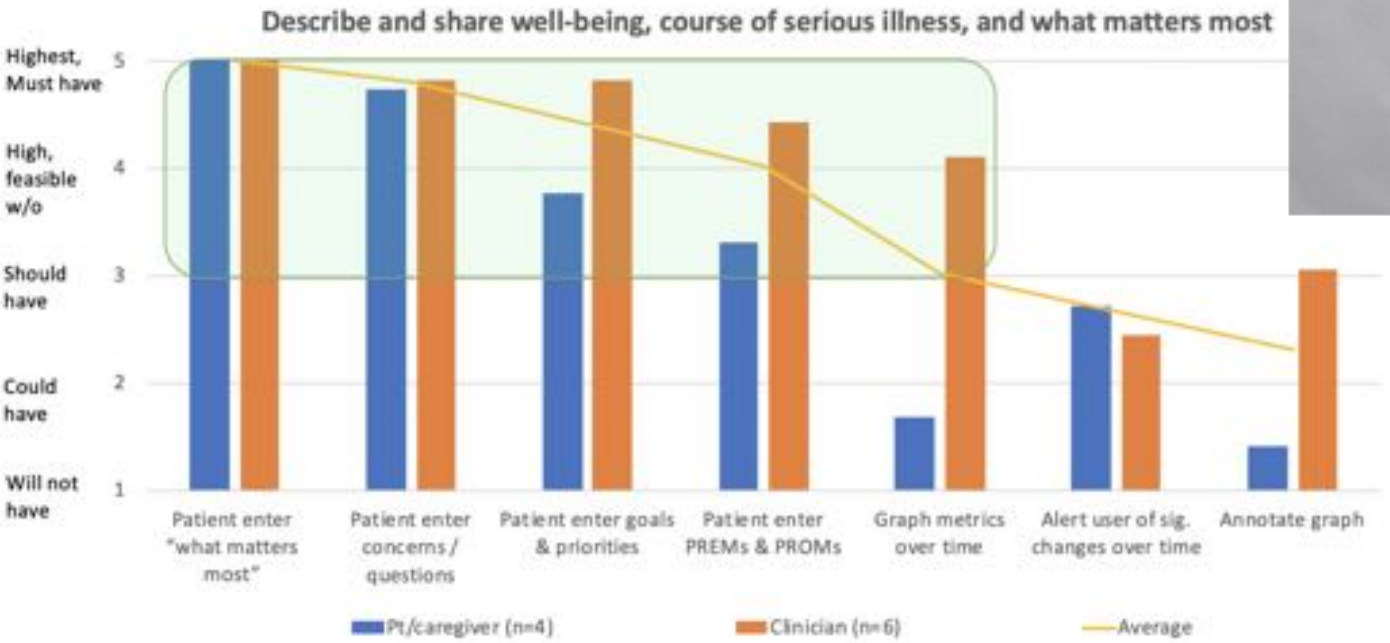
Clinicians use the EHR to review and store data on patients.

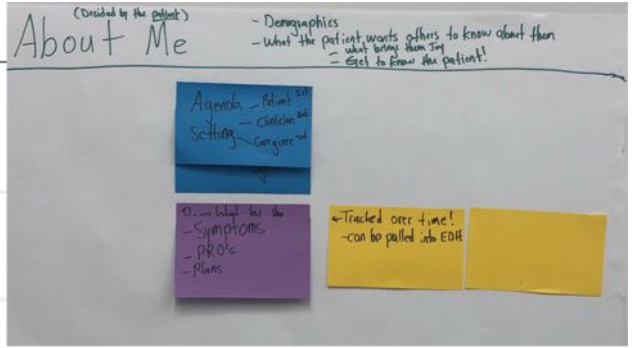
70% of people receiving outpatient palliative care have a patient portal account, but few use it with palliative care.

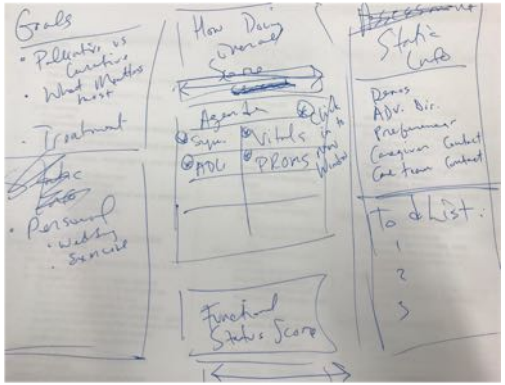
Tips: Understand community strengths and opportunities, map care flow, prioritize needs

Build

Build Design Consensus







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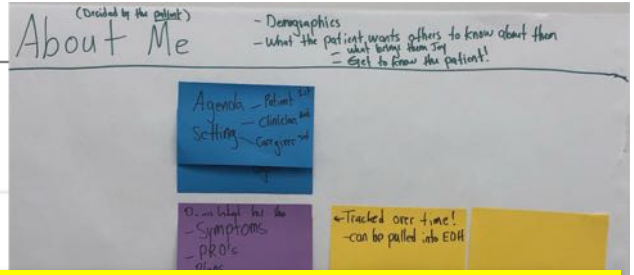


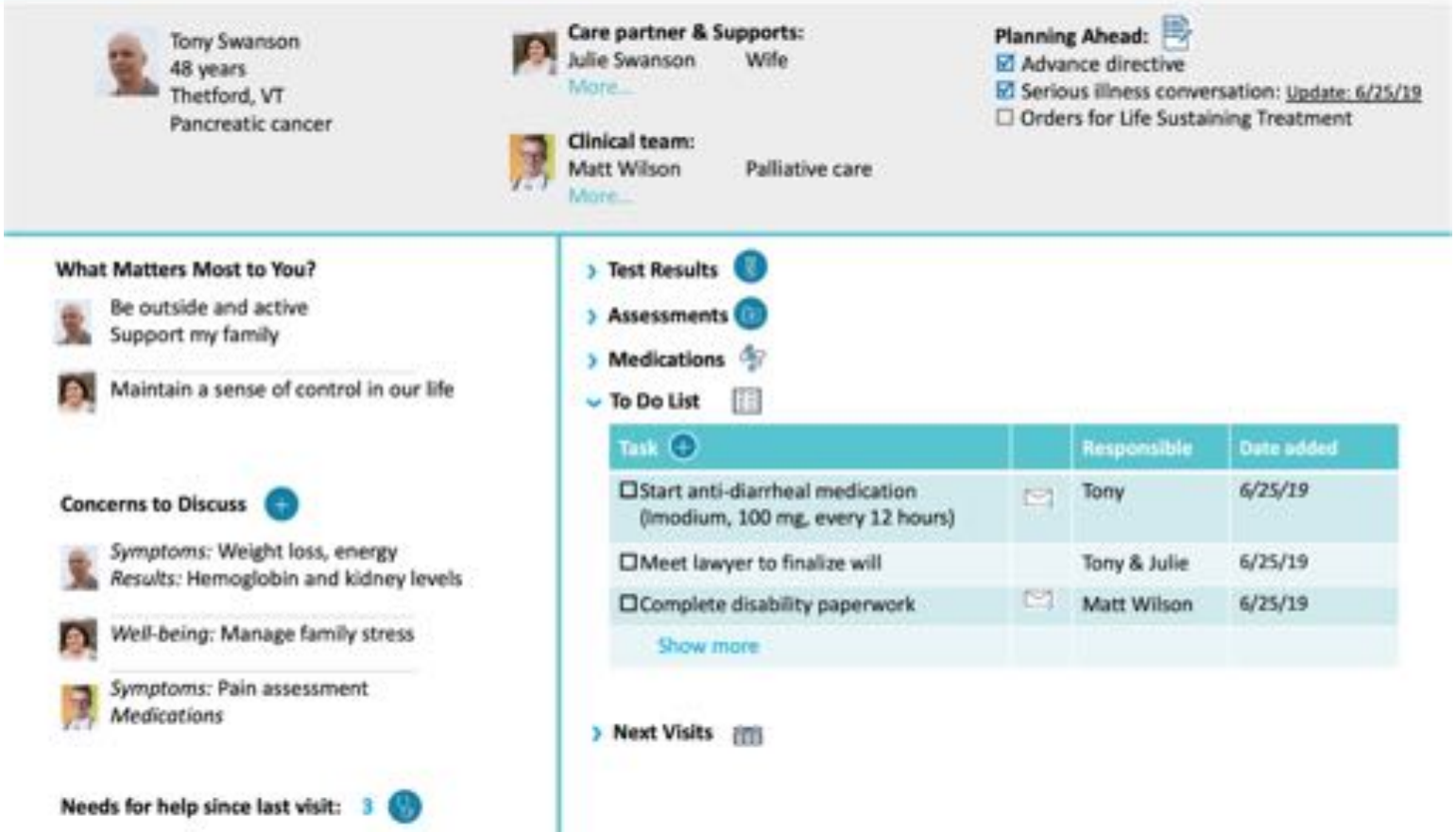
- Support communication in each visit around what matters most
- Improve quality & efficiency of care by capturing, sharing, and displaying data collected before and during a clinical visit.

- Used by patients & clinicians when they are together
- Data collection built into regular flow of work and daily activities, and will feed a registry

Tips: Identify function and form, identify and consider state of the art, prototype

Test

Establish & Pilot Test Design Specifications



Tony Swanson
48 years
Thetford, VT
Pancreatic cancer

Care partner & Supports:
Julie Swanson Wife
More...

Clinical team:
Matt Wilson Palliative care
More...

Planning Ahead:
☑ Advance directive
☑ Serious illness conversation: Update: 6/25/19
☐ Orders for Life Sustaining Treatment

What Matters Most to You?

Be outside and active
Support my family

Maintain a sense of control in our life

Concerns to Discuss

Symptoms: Weight loss, energy
Results: Hemoglobin and kidney levels

Well-being: Manage family stress

Symptoms: Pain assessment
Medications

Needs for help since last visit: 3

Test Results

Assessments

Medications

To Do List

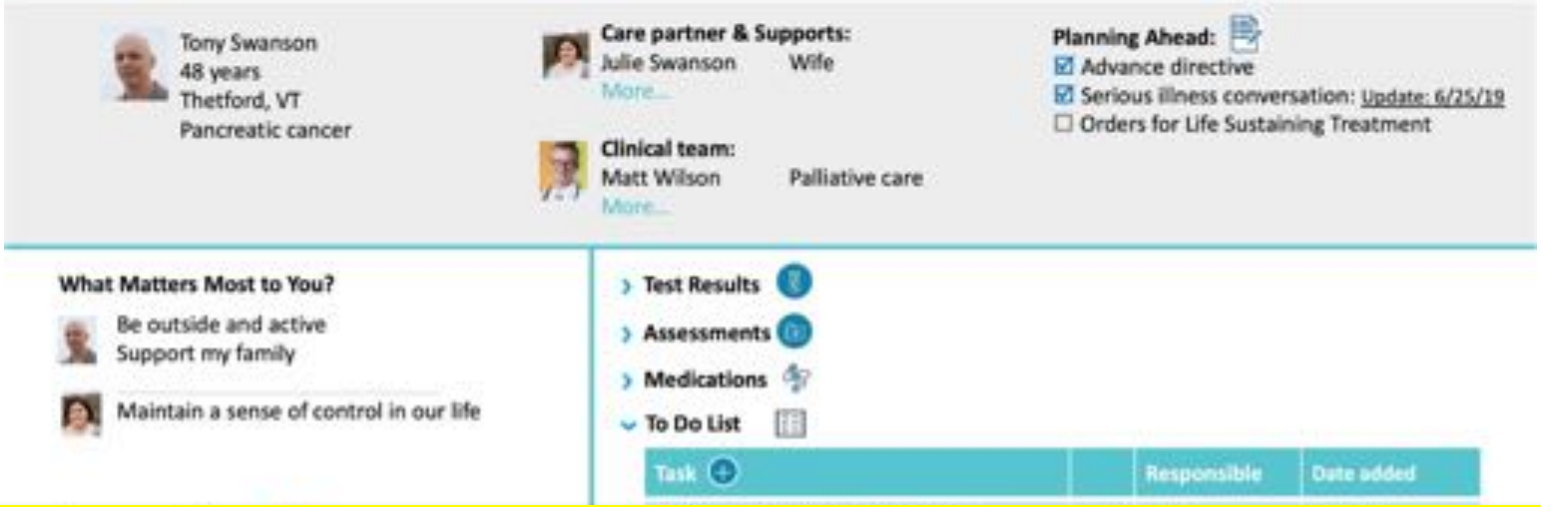
Task		Responsible	Date added
☐ Start anti-diarrheal medication (Imodium, 100 mg, every 12 hours)		Tony	6/25/19
☐ Meet lawyer to finalize will		Tony & Julie	6/25/19
☐ Complete disability paperwork		Matt Wilson	6/25/19

Show more

Next Visits

Test

Establish & Pilot Test Design Specifications



Build dashboard functions into the EHR and patient portal. Test whether dashboard addresses the problem statement.

Tips: Plan and conduct small-scale tests, measure the process and impact

Tips for Getting Started

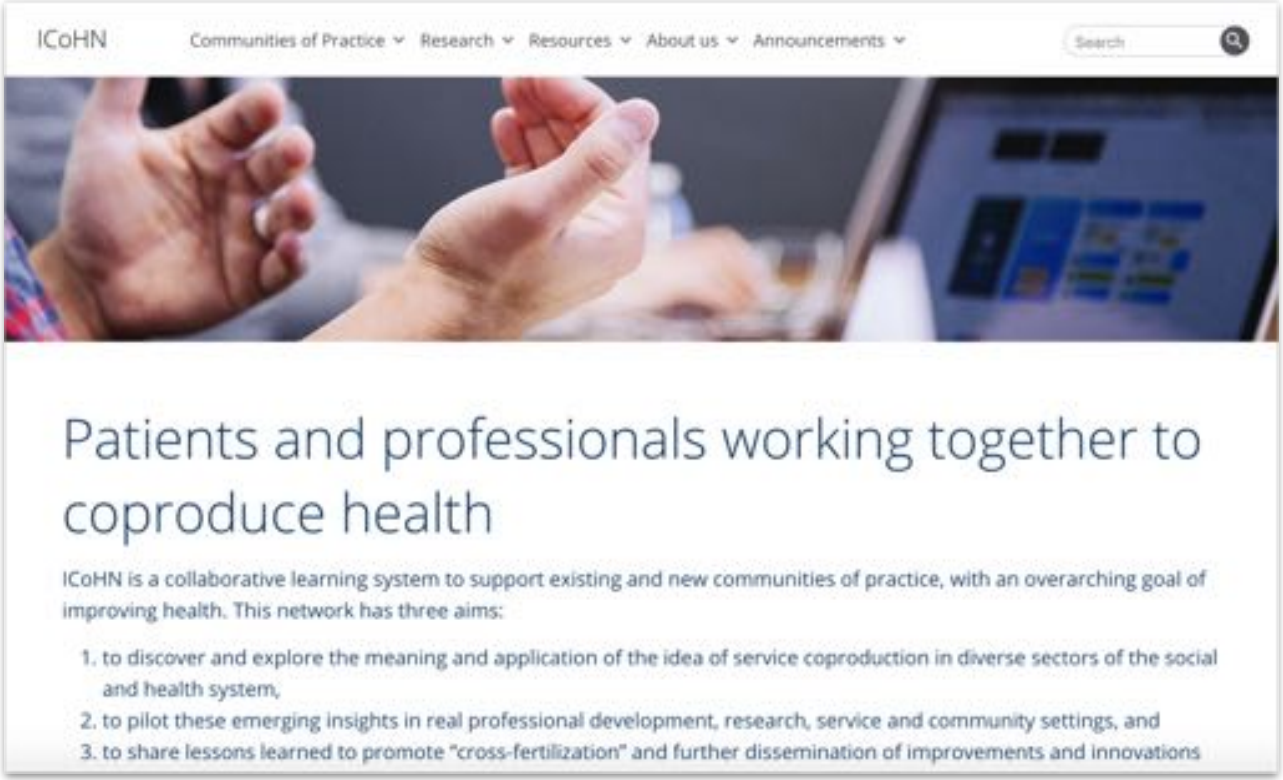
Leadership team:	Meet regularly with small dedicated team
Metrics of success:	Identify desired outcomes
Co-design team:	Meet regularly with a team of patients, families, community members, clinicians, and researchers
Human-centered design:	Develop and prioritize functions (what it does), form (how it looks), and workflows (how to do it) to support new tools
Technology partners:	Work in real-time to develop and test tools
Formative evaluation:	Understand feasibility, utility, and value
Integrate IT systems:	Feed data forward for better health, care, and research

Task:

- Take 2 minutes to write down your own questions
- Discuss at your table
- Be prepared to ask 1 question from your table

The International Coproduction of Health Network (ICoHN)

A collaborative learning system to support existing and new Communities of Practice with an overarching goal of improving health.



www.icohn.org

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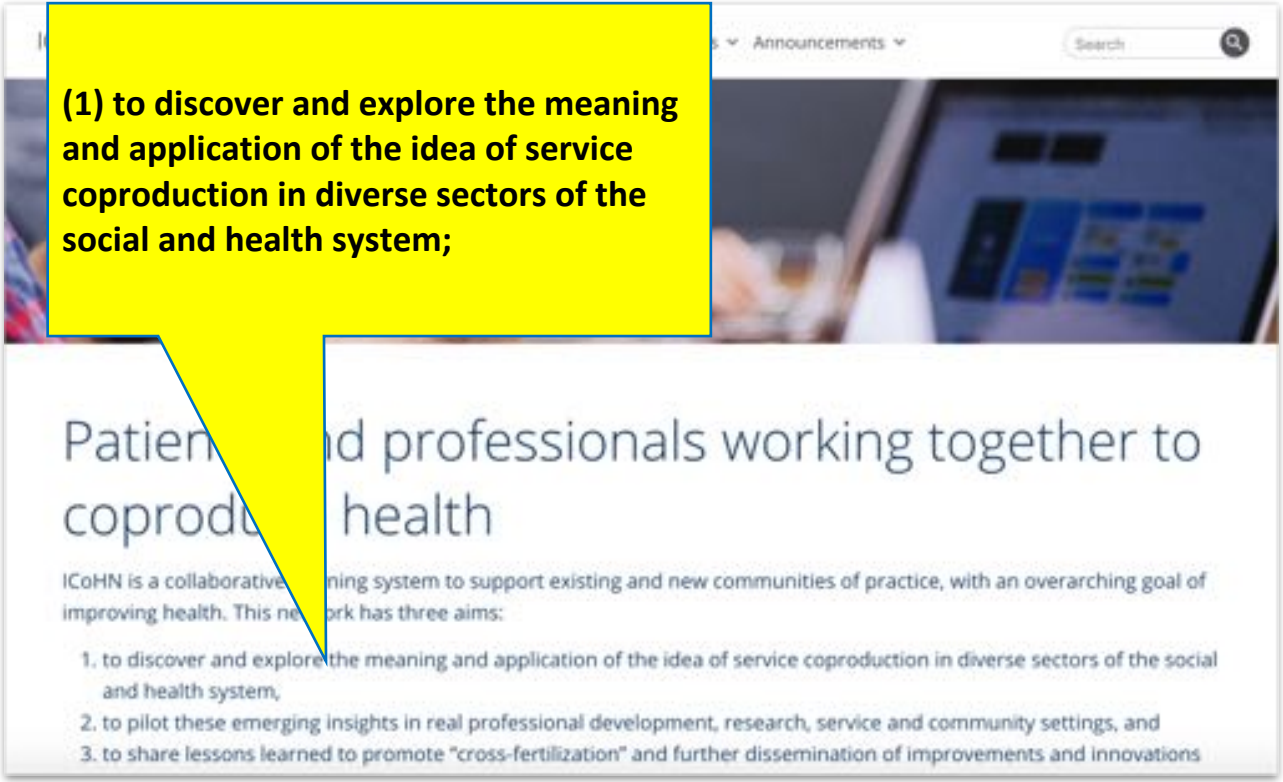

(1) to discover and explore the meaning and application of the idea of service coproduction in diverse sectors of the social and health system;

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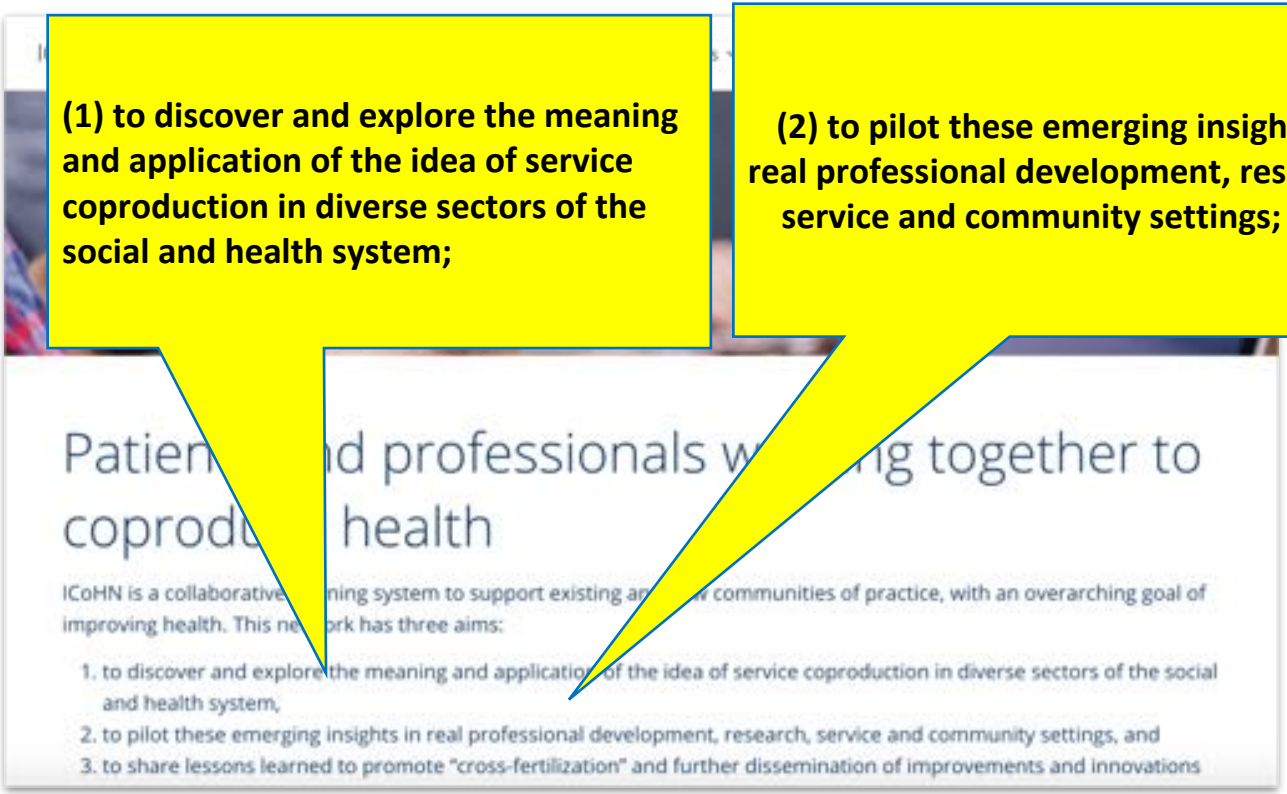

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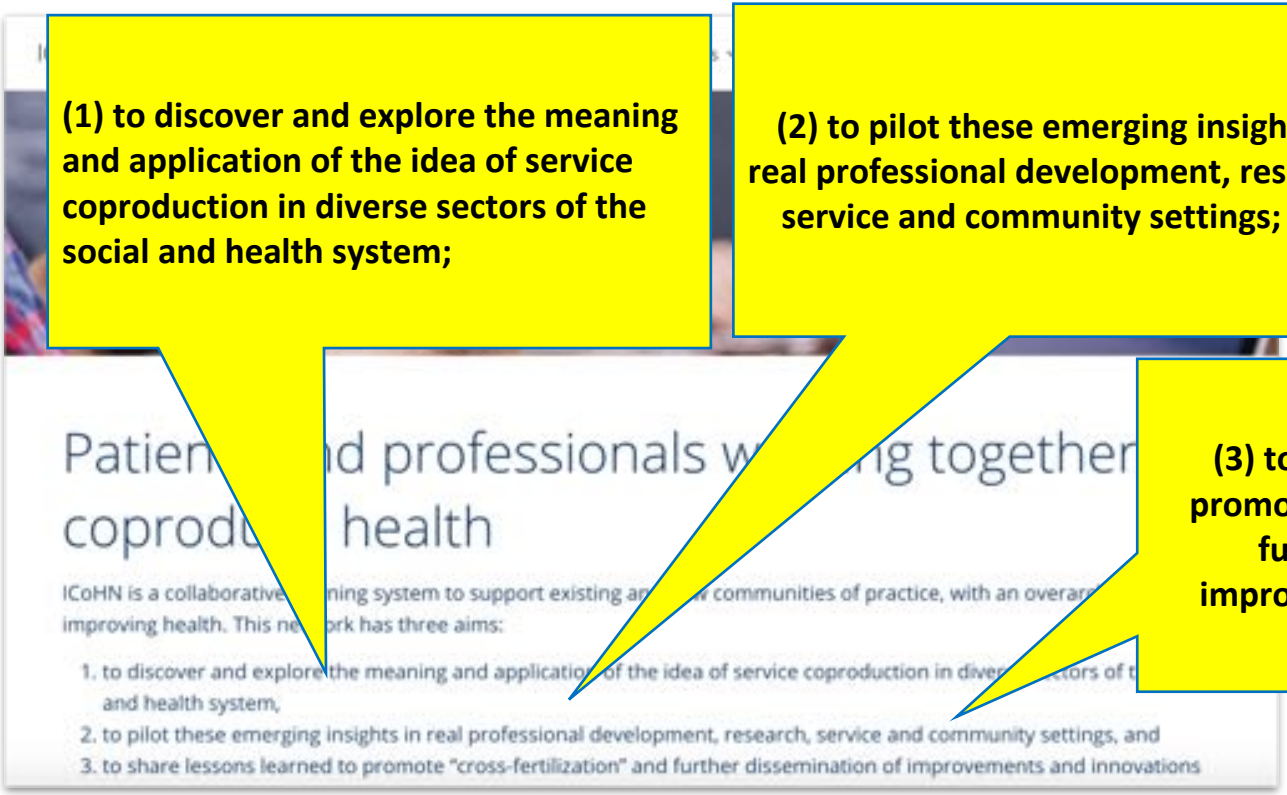
(3) to share lessons learned to promote "cross-fertilization" and further dissemination of improvements and innovations.



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Communities of Practice (CoPs)

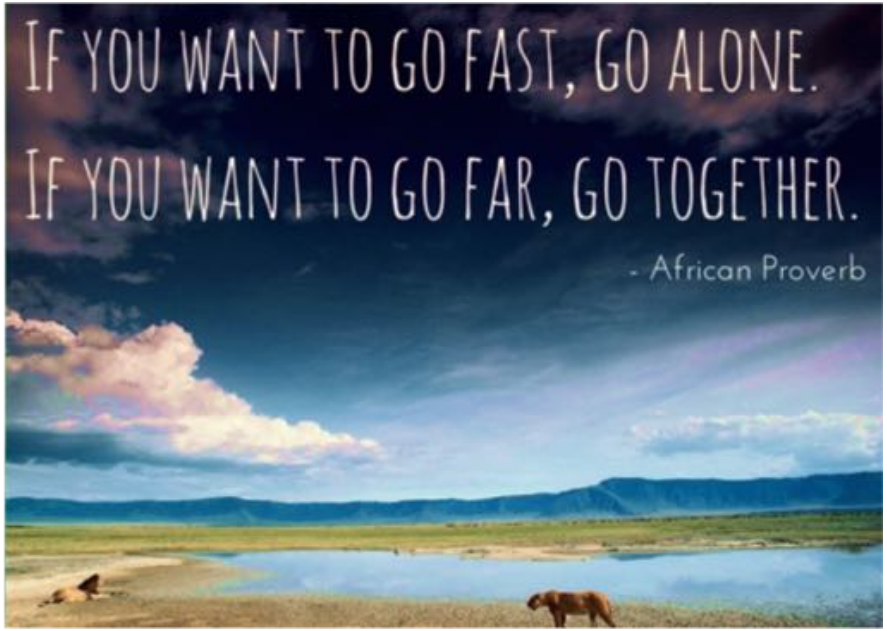
- Defined by Étienne Wenger as a group of people who share a common interest and learn together as they do their work in various contexts.

- Key elements include the domain of interest, the community members, and the practice they engage in.

Wenger E. (1999). Communities of Practice: Learning, Meaning, and Identity (Learning in Doing: Social, Cognitive, and Computational Perspectives). Cambridge University Press, Cambridge, UK. ISBN-13: 978-0521663632.

ICoHN Communities of Practice (CoPs)

- Health System Leaders
- Coproduction Researchers
- Health Professions Educators
- Value Creating Business Model
- Coproduction Learning Health Systems
- ICoHN Coproduction Commons



Find more information

https://sites.dartmouth.edu/coproduction/

Tips for getting started

Learn more about the model

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