

PROMS: A QUALITY IMPROVEMENT TOOL

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Flow of Session

1. PROMs Overview: a QI tool that can do many jobs
2. Classic case studies on PROMs: 1998 - 2023
3. How to get started
4. Key point, questions & discussion

Why PROMs?

*Hypothesis: Using PROMs provides the best leverage to improve care **experience**, health **outcomes**, healthcare **value & science** in ways that matter to patients*



What are PROMs?

- Outcomes: Patient reports on health status changes over time (**PROMs**)
- Experience: Patient reports on experience of receiving care (**PREMs**)
- Personal Benefit: Ratings of person-centered outcomes & goal achievement (**PCOMs**)



PROMs come in 3 flavors

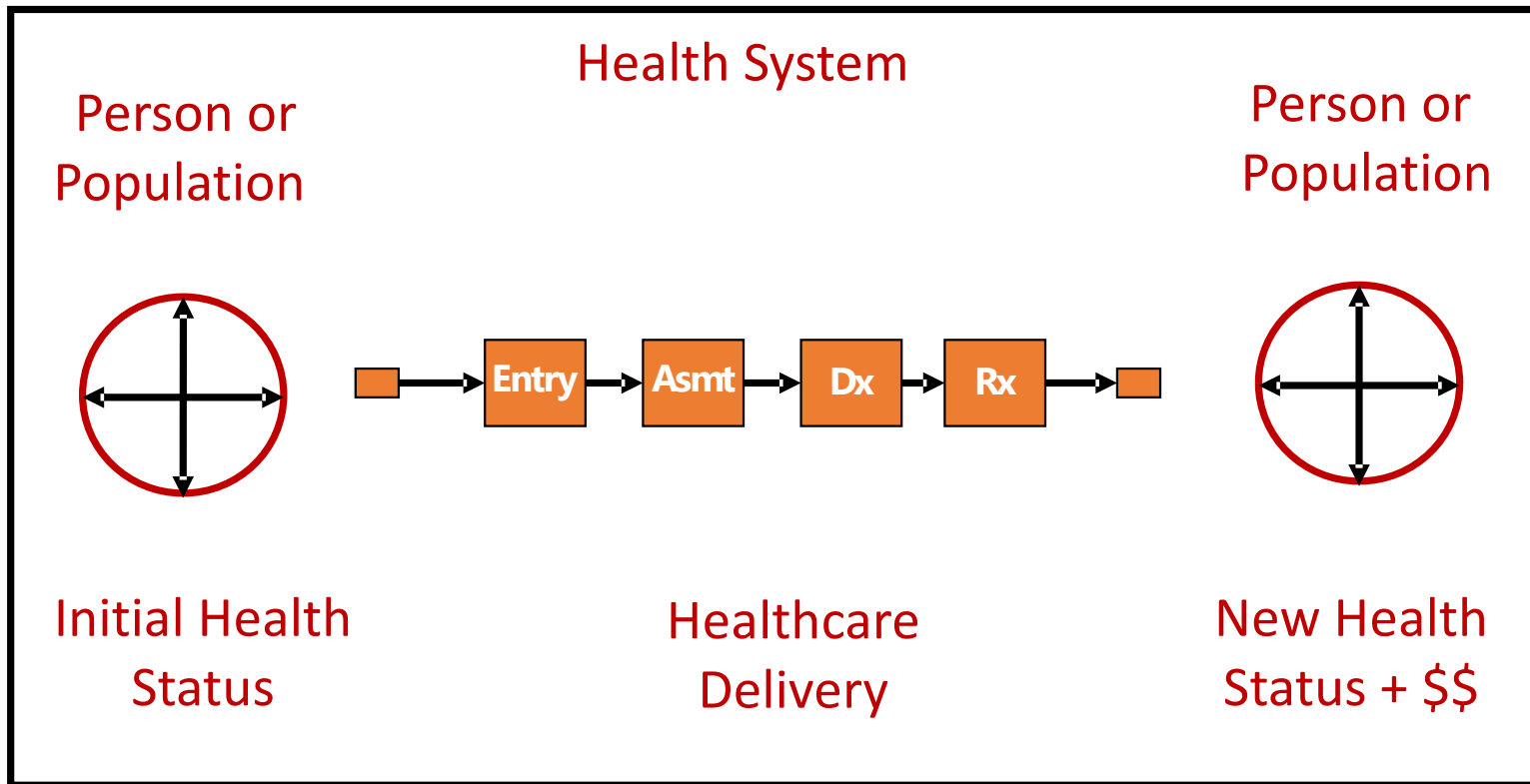
What is service value?

- Technical Answer
 - Quality of service in relation to costs to purchase service
- Simple Answer
 - What you get for what you spend
 - The goodness of the service experience and the outcomes in relationship to what it costs to receive the service



Value: a good buy

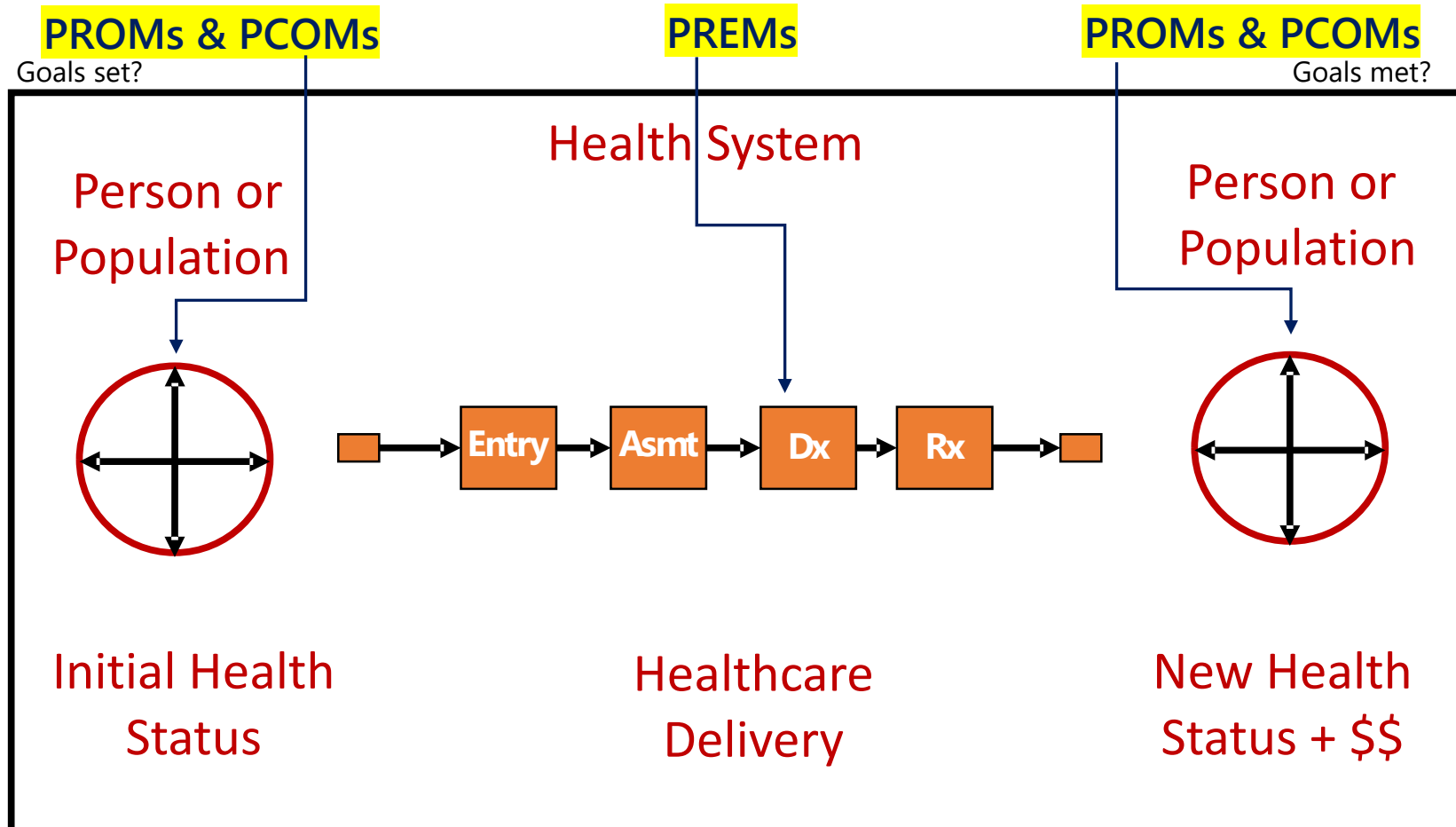
What is healthcare value?



Value is a function of
clinical & functional
outcomes & experiences
& costs

Healthcare Value & Patient Reported Measures

PROMs and PCOMs and PREMs are “happening” in flow of care as the patient’s journey unfolds ... Challenge is to measure them and use them



**THE PATIENT'S
JOURNEY: FOLLOW
THE STEPS OF
PATIENTS AS THEY
TRAVEL THROUGH THE
HEALTHCARE SYSTEM
TO TRACK VALUE!**

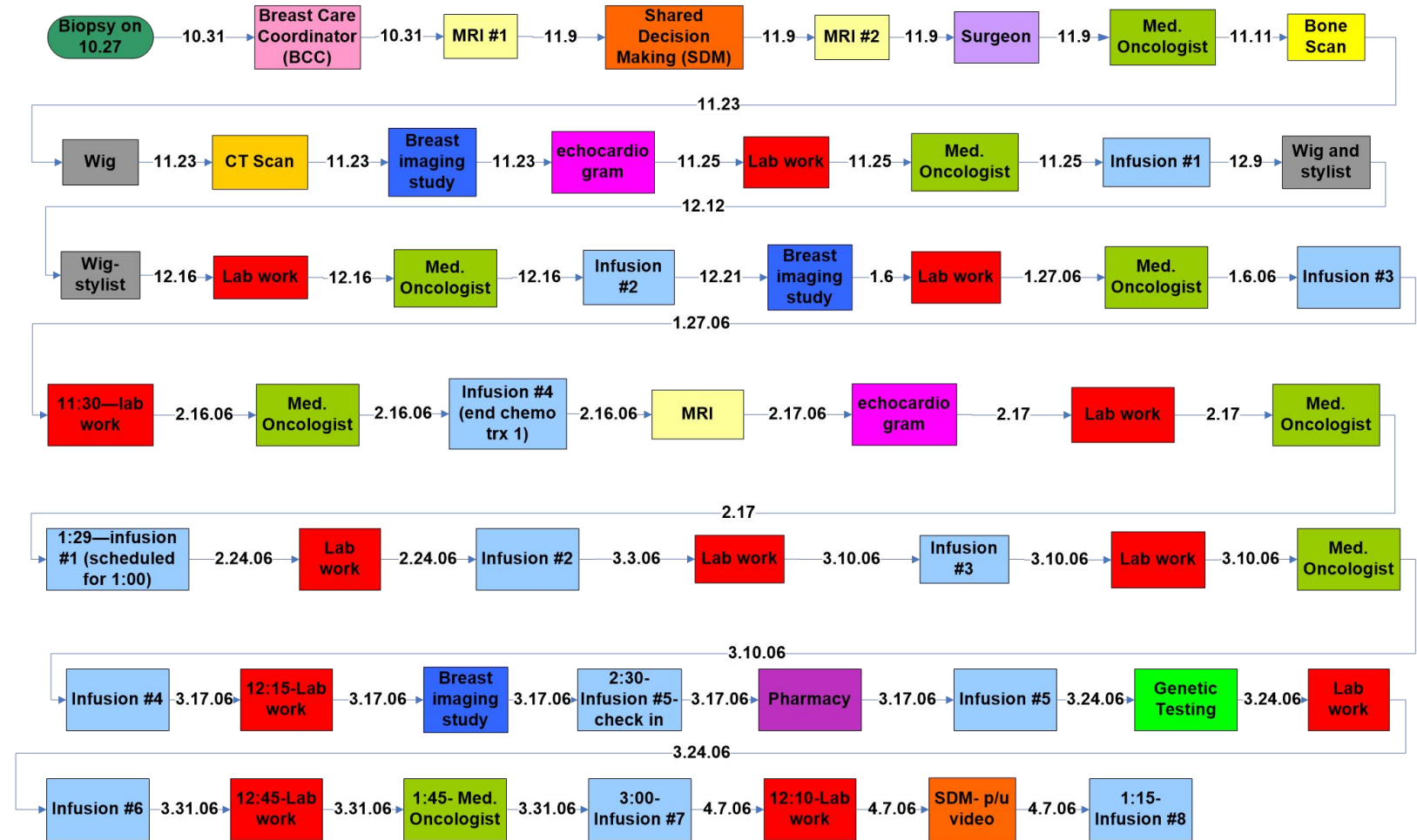


Meet Amy...

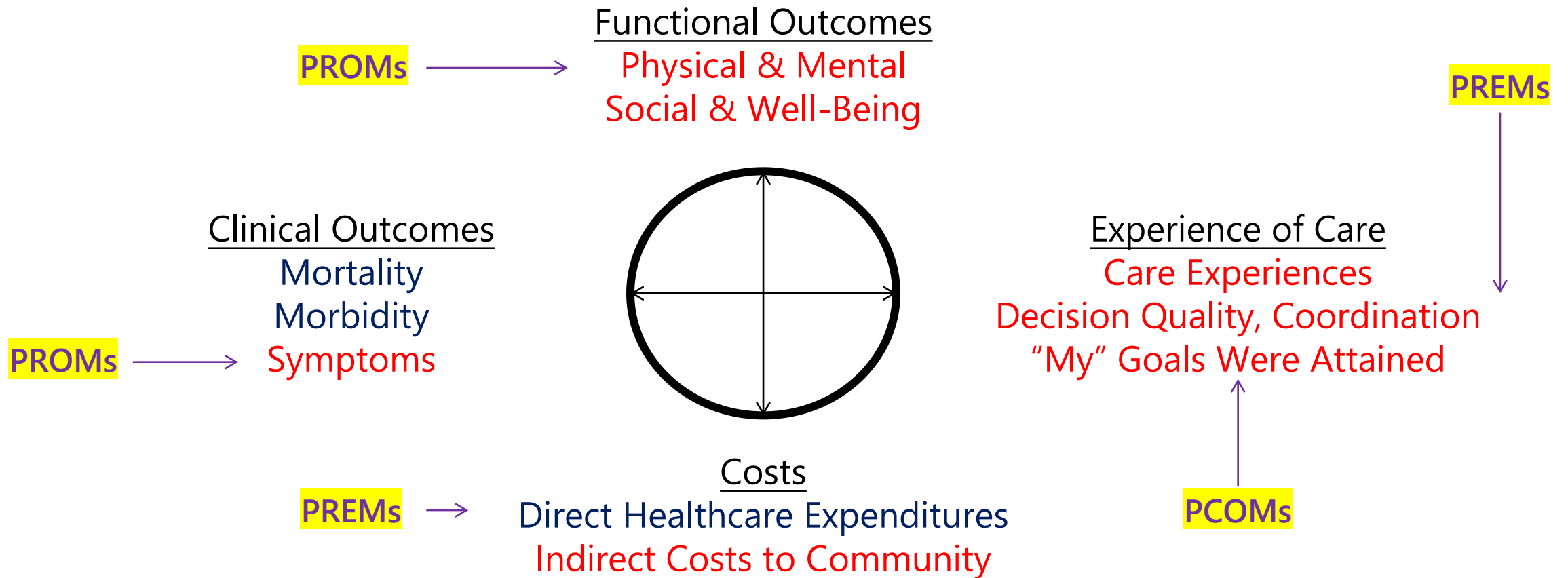


- 6 Months
- 14 Different Microsystems
- 21 Visits

Did Amy's journey produce the best outcomes?
 How good was her experience?
 How much did it all cost?

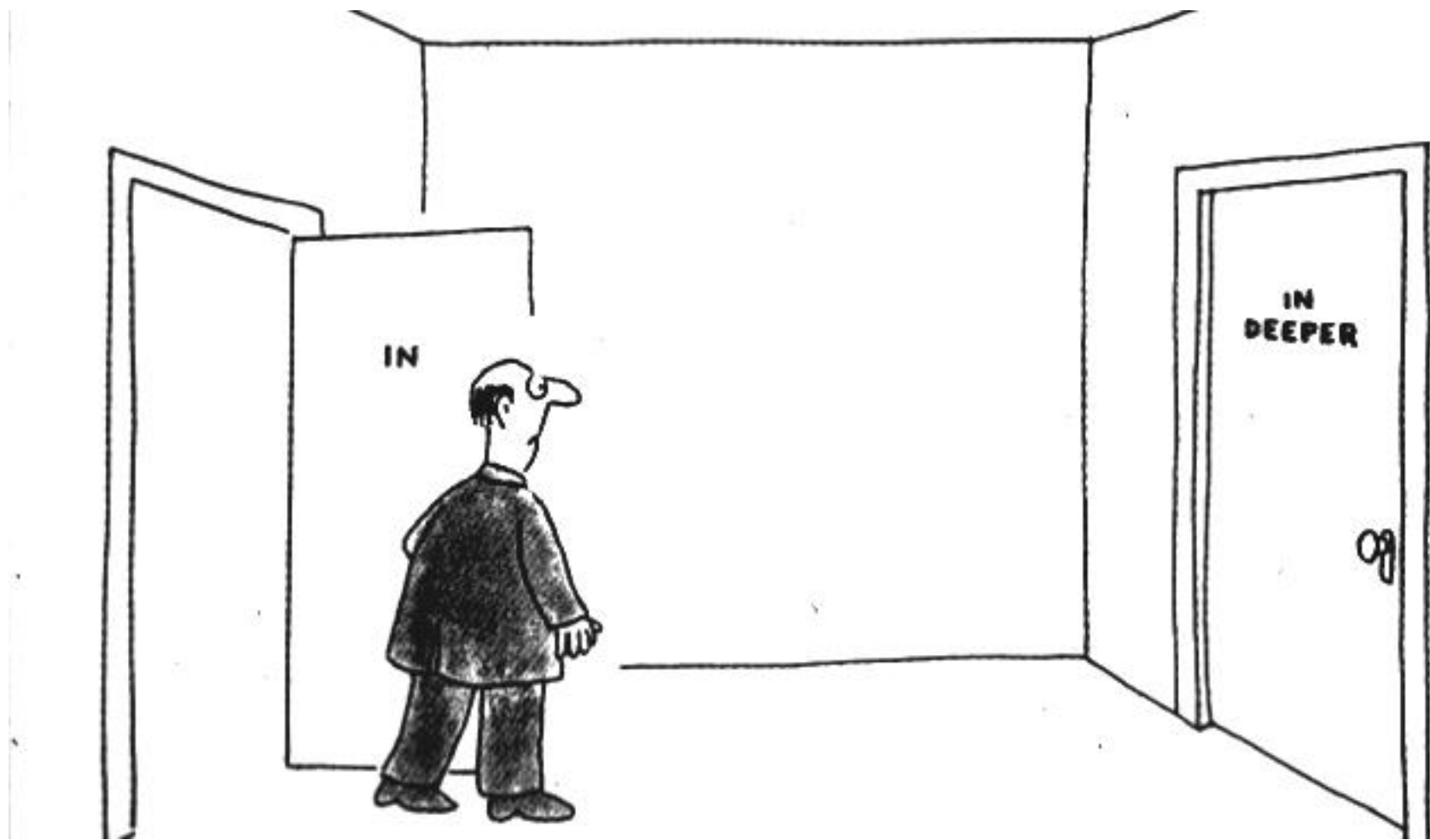


Value Compass: A Set of Value Measures



Red = patient reported data

Blue = clinical or administrative data



2. Classic Cases

1998 to 2023

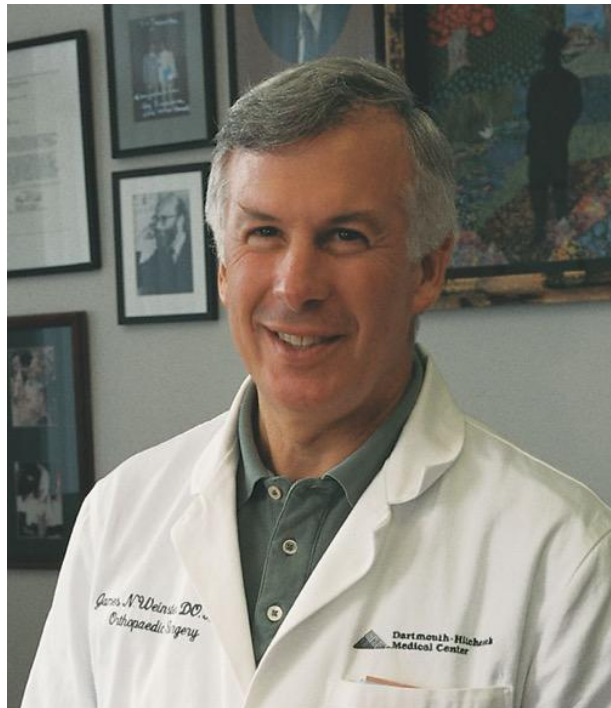
1. Spine Conditions
 - Dartmouth Spine Center
2. Rheumatoid Arthritis
 - Swedish Rheumatology Quality Register
3. Metastatic Solid Tumors:
 - Memorial Sloan Kettering
4. Inflammatory Bowel Disease:
 - IBD Qorus



PROMs are QI tools that can do many jobs for many different types of patients

Dartmouth Spine Center A Pioneering Learning Health System

JIM WEINSTEIN



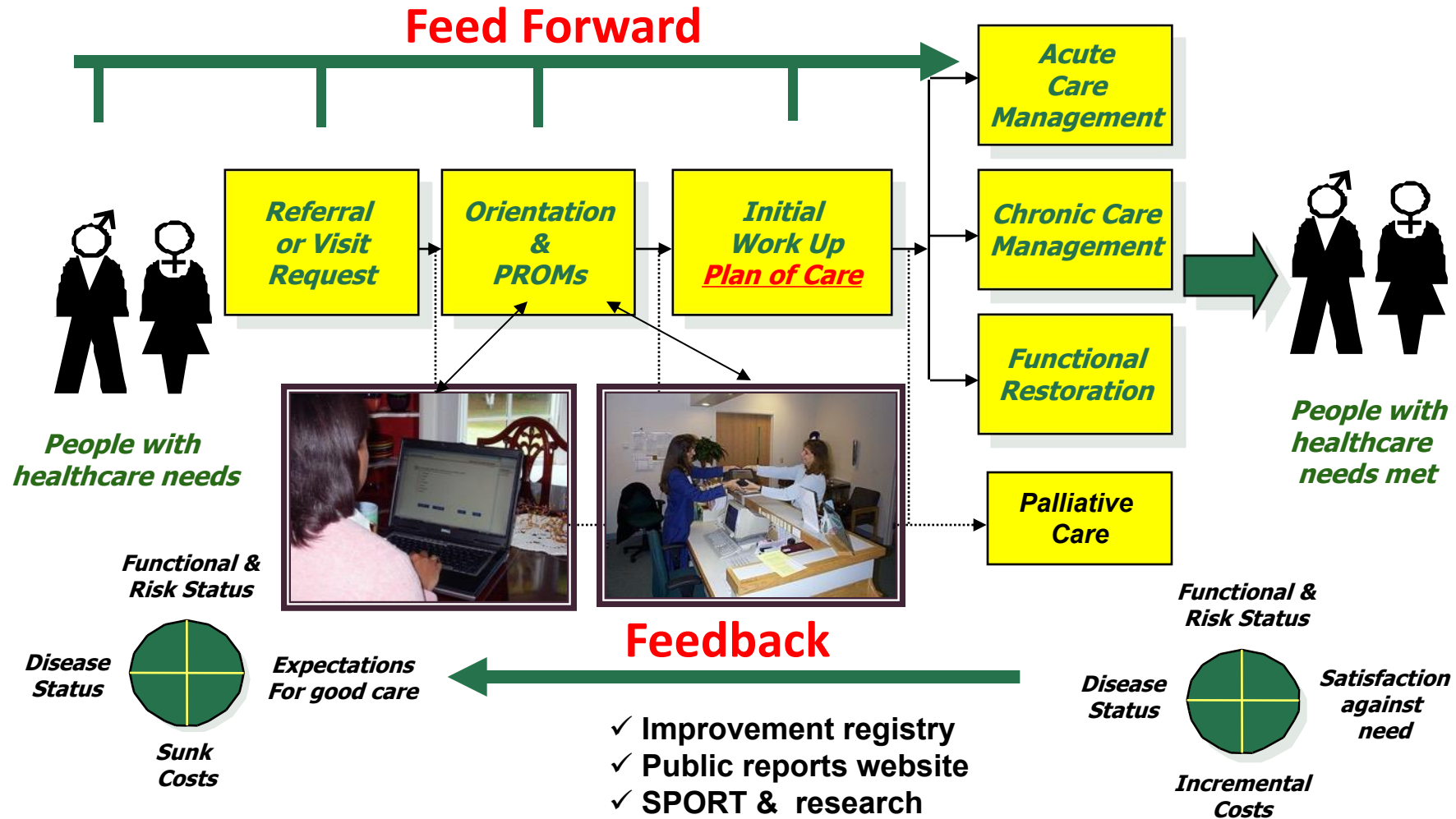
LISA WEISS



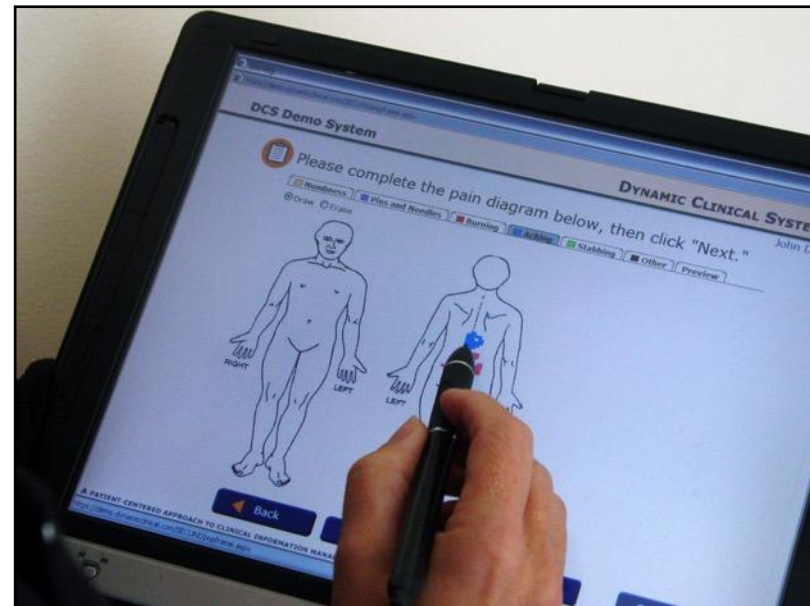
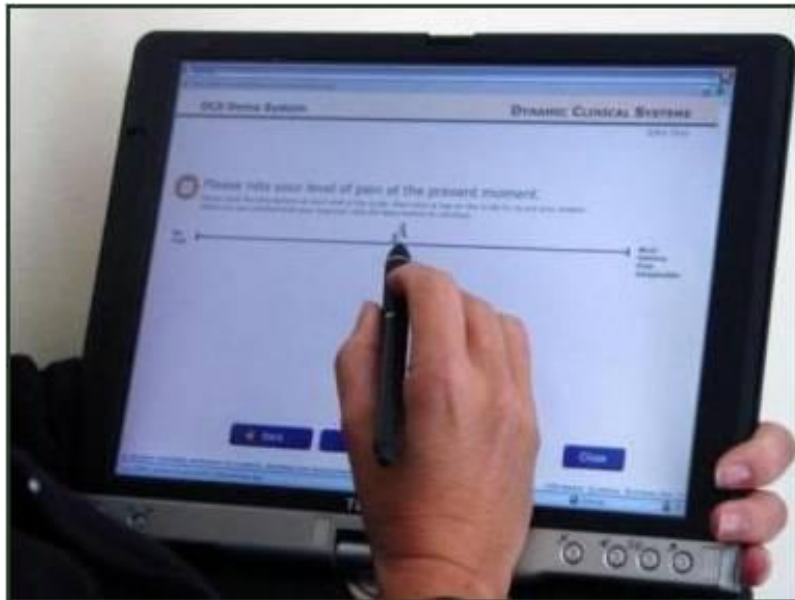
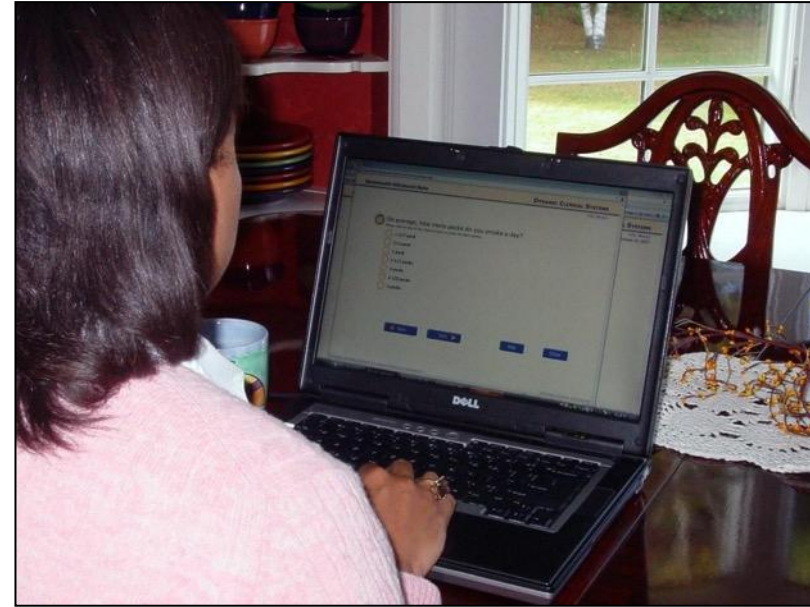
1998

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

Dartmouth Spine Center: Feedforward System



Patient Completing the Health Status (PROMs) Survey



SHARE SUMMARY INFORMATION WITH PATIENT



Coproduction Dashboard: Tracking Health for Individual Patient

PROM:
SF-36,
Oswestry

History of Present Illness

Red Flags

Risk Factors

Patient: Patient, Demo
Report Date: 08/24/2006

Appointment: Spine
Survey Group: Spine
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

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

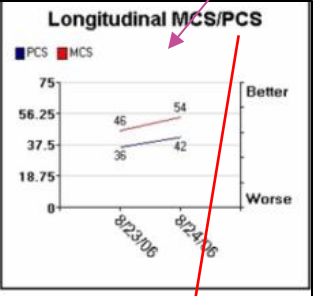
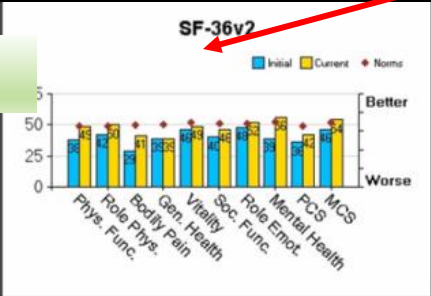
Review of Systems
Const: Not Sure
ENT: Not sure
Eyes: Patient denies any eye symptoms
Resp: Cough
Cardio: Patient denies any heart symptoms
GI: Patient denies any GI symptoms
Uro-gyn: frequent urination; Dribbling
M/S: Other symptoms with joints or muscles
Neuro: Patient denies any neurological symptoms
Hemo/lymph: Patient denies any blood/lymph node symptoms
Psych: Easily distracted

History of Present Illness (as of 08/23/2006)
Chief complaint: Upper back, lower back, Left buttocks, Right buttocks, Left hip, Right hip
Initial Visit: 08/23/2006
Length of symptoms: More than 3 years
Date of episode: 10/07/2005

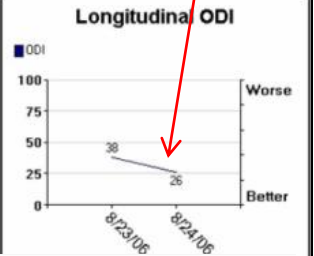
Red Flags / Considerations
Med allergies: Antibiotics (e.g., amoxicillin, sulfa, penicil etc.)

Clinical protocols / measures

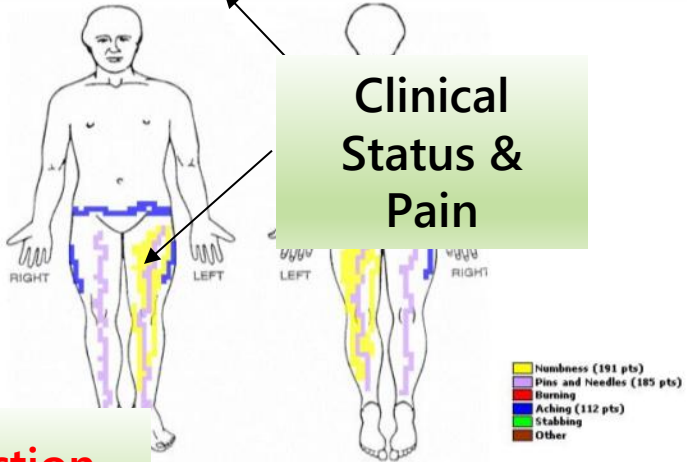
Patient-reported scores (see graphs on next page)
ODI: 26 (lower = better)
AUDIT:
Physical Function: 49 (Norm: 49)
Role Physical: 50 (Norm: 49)
Bodily Pain: 41 (Norm: 50)
General Health: 39 (Norm: 50)
Vitality: 49 (Norm: 52)
Social Function: 46 (Norm: 51)
Role Emotional: 52 (Norm: 51)
Mental Health: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



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



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



History & Review of Systems

PCOMs: Patient Satisfaction With Treatment Outcomes

JAMA[®]

The Journal of the American Medical Association

ORIGINAL CONTRIBUTION

JAMA

November 22/29, 2006



Nov 26 2006

SITES... 11states / 13 sites



May 31 2007

Original Contributions

Surgical vs Nonoperative Treatment for Lumbar Disk Herniation: The Spine Patient Outcomes Research Trial (SPORT): A Randomized Trial

James N. Weinstein; Tor D. Tosteson; Jon D. Lurie; Anna N. A. Tosteson; Brett Hanscom; Jonathan S. Skinner; William A. Abdu; Alan S. Hilibrand; Scott D. Boden; Richard A. Deyo

JAMA. 2006;296:2441-2450.

[ABSTRACT](#) | [FULL TEXT](#) | [PDF](#)

Surgical vs Nonoperative Treatment for Lumbar Disk Herniation: The Spine Patient Outcomes Research Trial (SPORT) Observational Cohort

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The NEW ENGLAND JOURNAL of MEDICINE

THE NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Surgical versus Nonsurgical Treatment for Lumbar Degenerative Spondylolisthesis

James N. Weinstein, D.O., Jon D. Lurie, M.D., Tor D. Tosteson, Sc.D., Brett Hanscom, M.S., Anna N.A. Tosteson, Sc.D., Emily A. Blood, M.S., Nancy J.O. Birkmeyer, Ph.D., Alan S. Hilibrand, M.D., Harry Herkowitz, M.D., Frank P. Cammisa, M.D., Todd J. Albert, M.D., Sanford E. Emery, M.D., M.B.A., Lawrence G. Lenke, M.D., William A. Abdu, M.D., Michael Longley, M.D., Thomas J. Errico, M.D., and Serena S. Hu, M.D.*

NIH Trial: 12 Centers
Over 100 publications

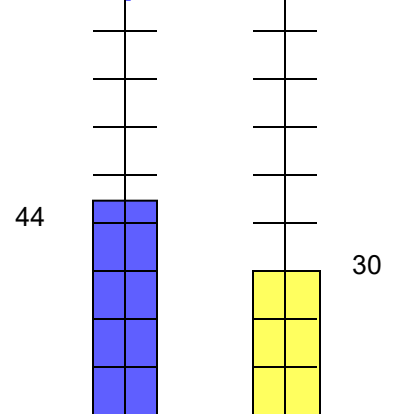
NEW EVIDENCE:
A TRUE LEARNING HEALTH SYSTEM

Herniated Disk

Outcomes @ 2 Years

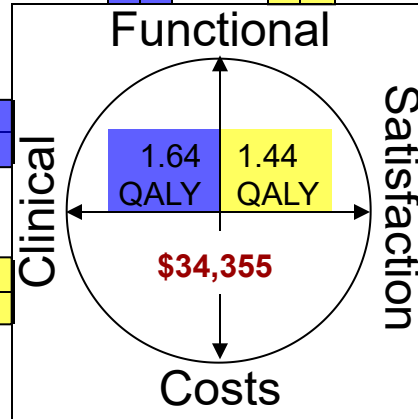
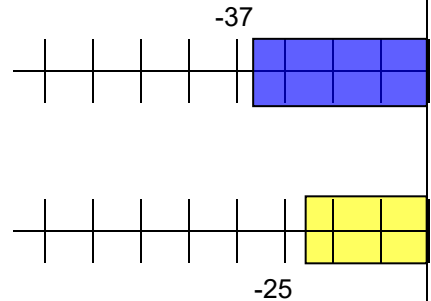
Surgery	Non-Surgery
44 Ave Age 43% Female	30 Ave Age 45% Female

Physical SF-36 Improvement



Cost Per Quality Adjusted Life Year Added By Surgery \$34,355

Reduced Oswestry Symptoms



Satisfied With Improvement

\$13,108

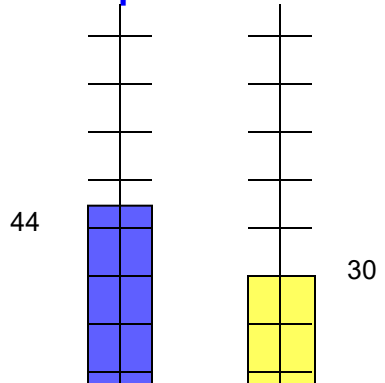
\$27,341

Total Direct & Indirect Costs

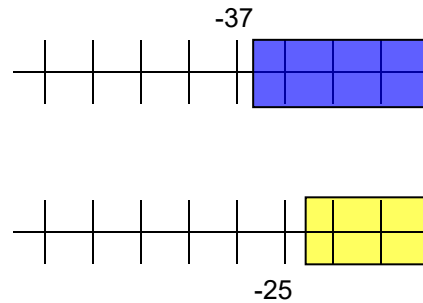
Measuring Value

Personalized Medicine

Physical SF-36 Improvement



Reduced Oswestry Symptoms



Patient-Specific Prediction based on evidence
86 vs 55 better
6 vs 26 worse

\$13

Degenerative Spondylolisthesis Treatment Calculator

Your age: Your sex: Male Female

Please choose what you are hoping to improve with treatment for your back pain (you can come back and choose another later):

- 1. Physical Activity
- 2. Pain
- 3. Overall Health

On a 0 to 6 point scale, please rate the following symptoms according to how bothersome they were in the PAST WEEK.

Symptoms	Not bothersome		Somewhat bothersome		Extremely bothersome		
	0	1	2	3	4	5	6
1. Leg pain?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Numbness or tingling in leg, foot or groin?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Weakness in leg or foot?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Leg pain after walking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Your score now is on a scale of 24, where 0 is best and 24 is worst.

Click on the submit button below and the calculator will show on a graph how this score might change over 24 months after surgical or non-surgical treatment.

Detailed information about SPORT is available at <http://www.dednouth.edu/sport/>
 Please email questions or comments to sportcalculators@dednouth.edu

Pain Score After Treatment

The pictograms below show how many out of 100 patients get better, stay the same, or get worse 12 months after beginning treatment.

Treatment	Better	Same	Worse
Surgery	86	8	6
Non-surgical	55	19	26

Choose another time:
 3 months 12 months 24 months

Swedish Rheumatology Quality Registry



RA remission rates
Improving Across all of
Sweden

Feed Forward Innovation



The SRQ Approach

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



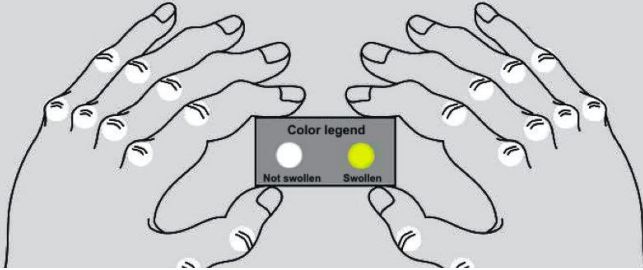
<https://www.youtube.com/watch?v=Kmqzy1hqcOw>

Your joints today

Info

Swollen joints?

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

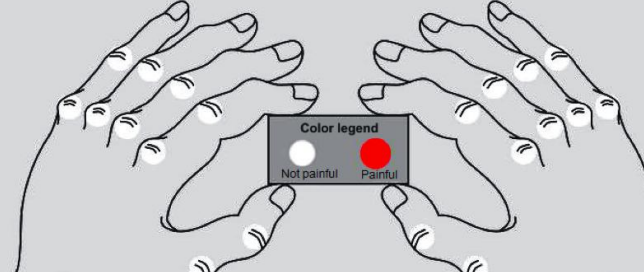


Your joints today

Info

Painful joints?

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



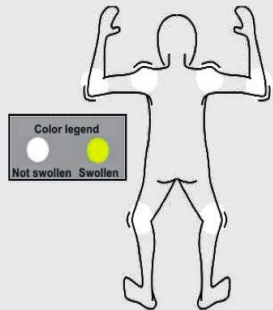
Patient Module

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.

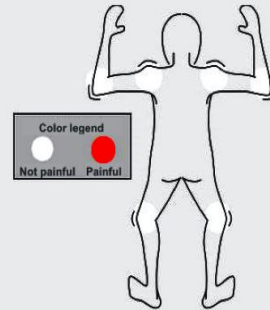


Your joints today

Info

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

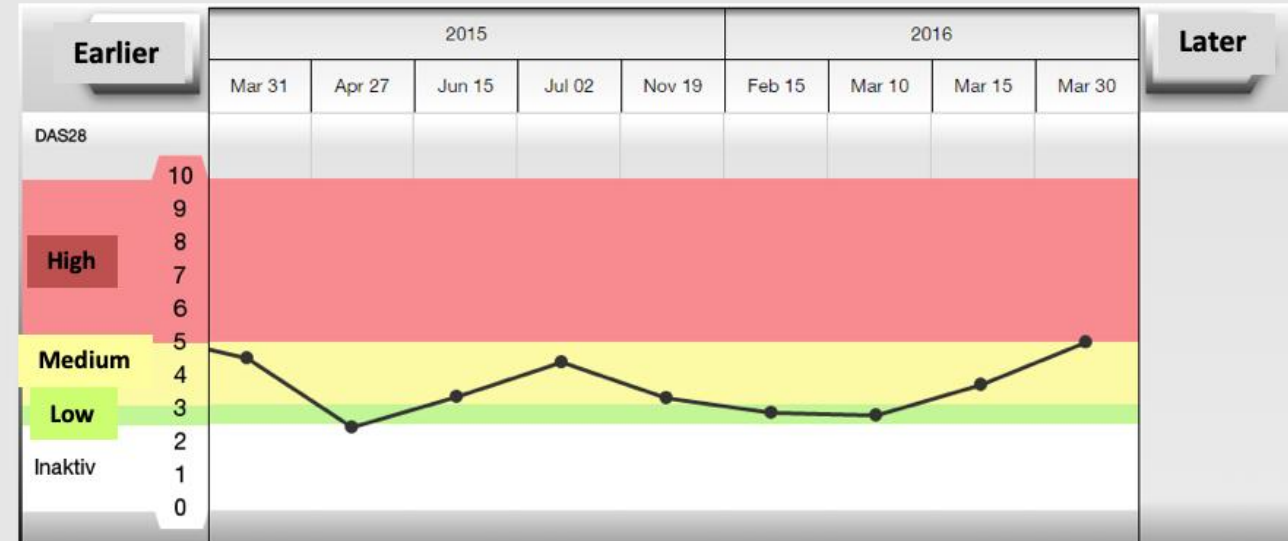
If none is painful please continue to the next question.



Patient's Overview

Your Disease Activity

Din behandelning



<<Previous part

Print the whole summary

CLINICIAN MODULE



SRQ Clinician Coproduction Dashboard

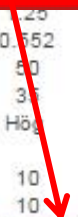
Case in point:
Swedish National Quality
Registry
This patient is doing better!
N of 1 experiment...
Response to biologics

Changed medication

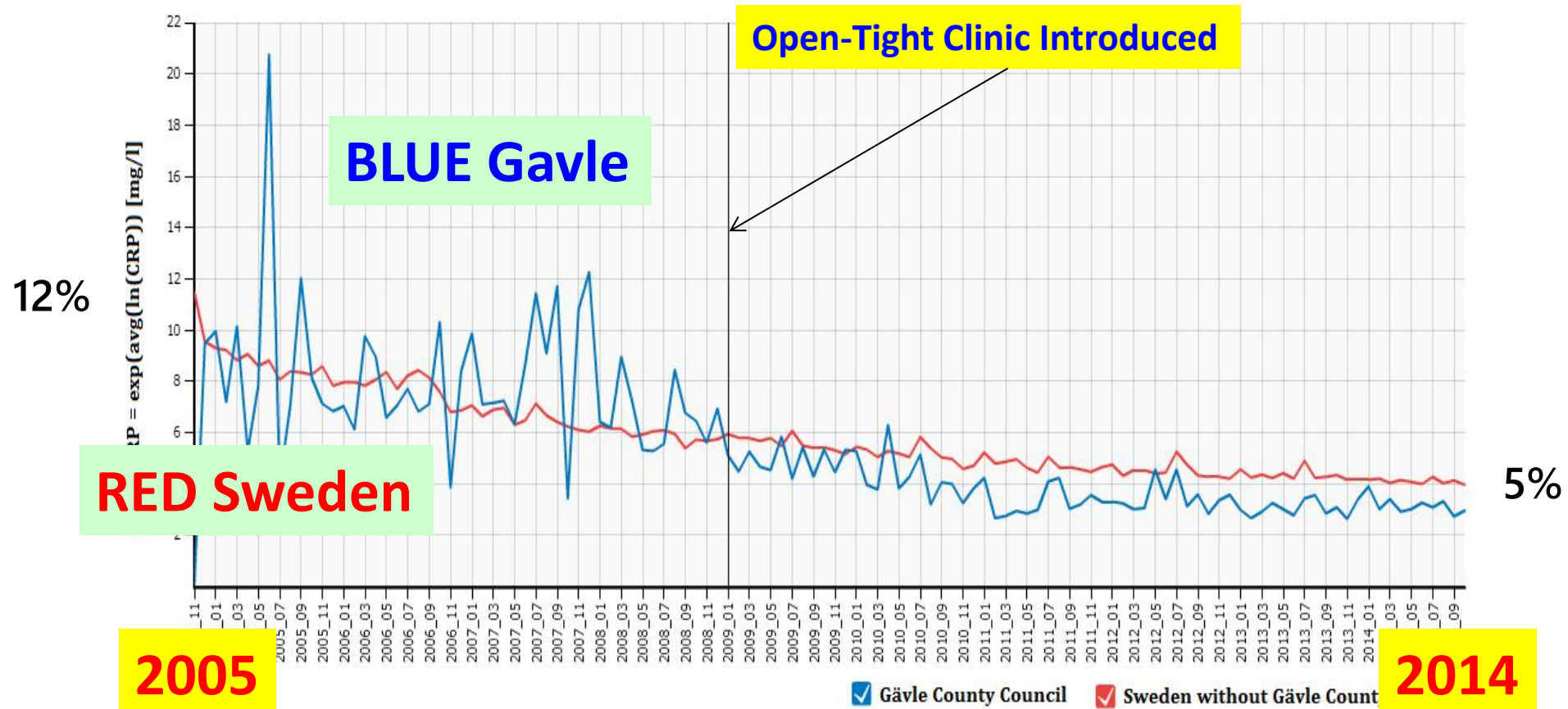
Tabellöversikt										
	Längd / Vikt		Grafisk översikt - Reuma							
Besökstyp										
År	2015	2015	2015	2015	2015	2015	2015	2016	2016	2016
Dag Månad	04-aug	17-sep	24-sep	23-okt	26-nov	23-dec	25-jan	29-feb	01-apr	
Årskontroll										
Kopiera										
Arbetsförmåga	/40	/40	/40	/40	20/40	20/40	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	0,5-1 h	
Stillasittande	7-9 h	13-15 h						17-19 h	17-19 h	
Allmän hälsa	9	11	50	35	50	80	45	30	30	
Smärta	16	26	21	35	60	25	22	34	64	
HAQ	1.00	0.00	0.80	1.13	1.25	1.38	0.75	1.25	0.88	
EQ5D	1	1	1		0.52			0.516	0.689	
SR			20	45	50	45	35	10	7	
CRP			10	15	35	30	15	7	2	
Läkarbedömning			Låg	Måttlig	Hög	Hög	Måttlig	Låg	Ingen	
Läkarens bedömning av allr										
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	6.18	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 Decreasing*



CANCER: USING PROMS AS EARLY WARNING SYSTEM TO INCREASE QUALITY OF LIFE AND SURVIVAL

3



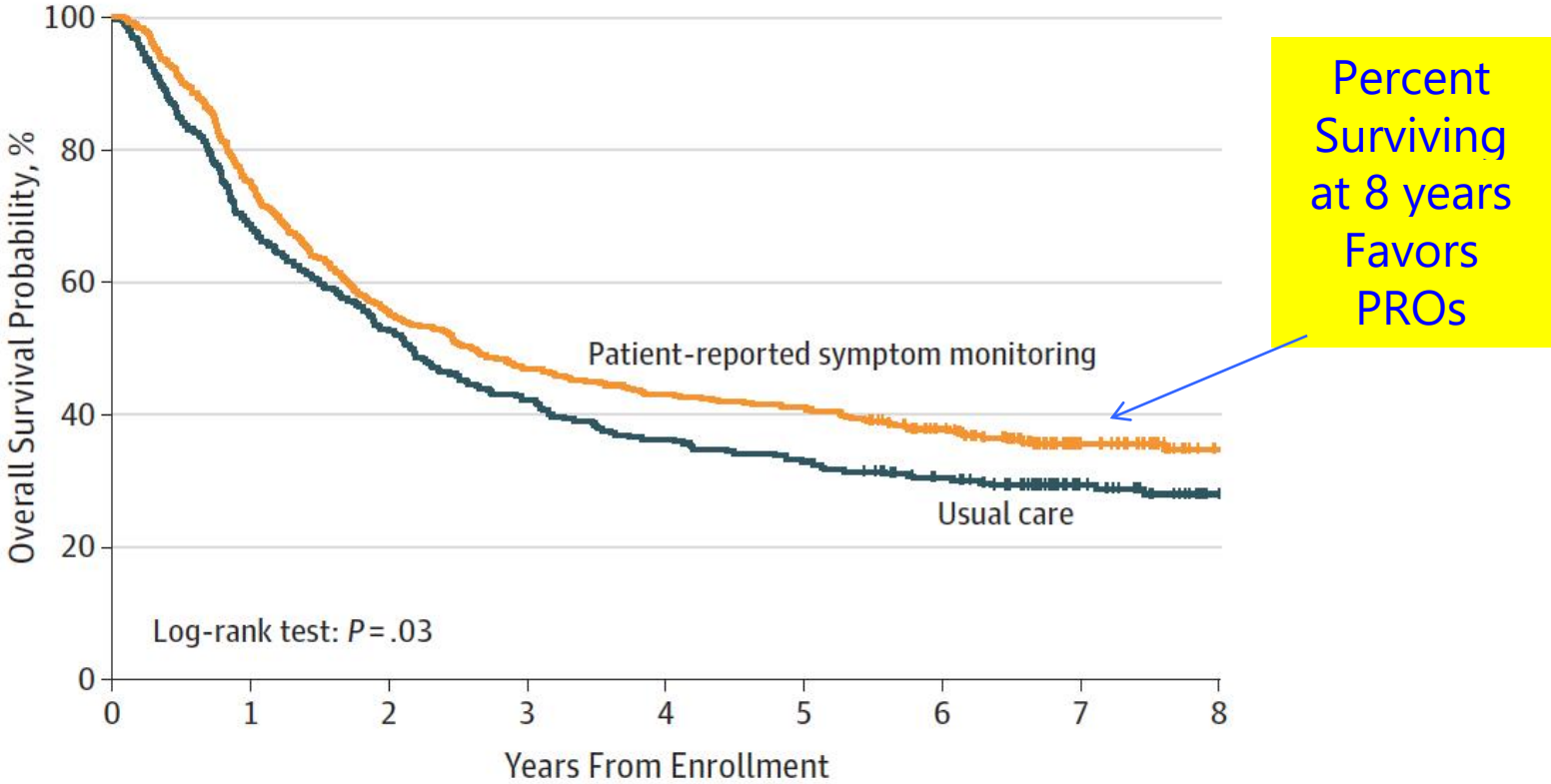
Ethan Basch, MD, MPH

- RCT: N= 766 metastatic cancer patients
- Patients assigned to Usual Care or PROM symptom monitoring
- PROMs focused on Sx reports for 12 Sx associated with adverse events
- Sx reports between visits & at time of follow-up visits
- *RNs alerted if Sx reports worsening*
- Results: PROM group significantly better on
 - HRQOL at 6 months
 - 1-year quality-adjusted survival
 - Long term survival

2017

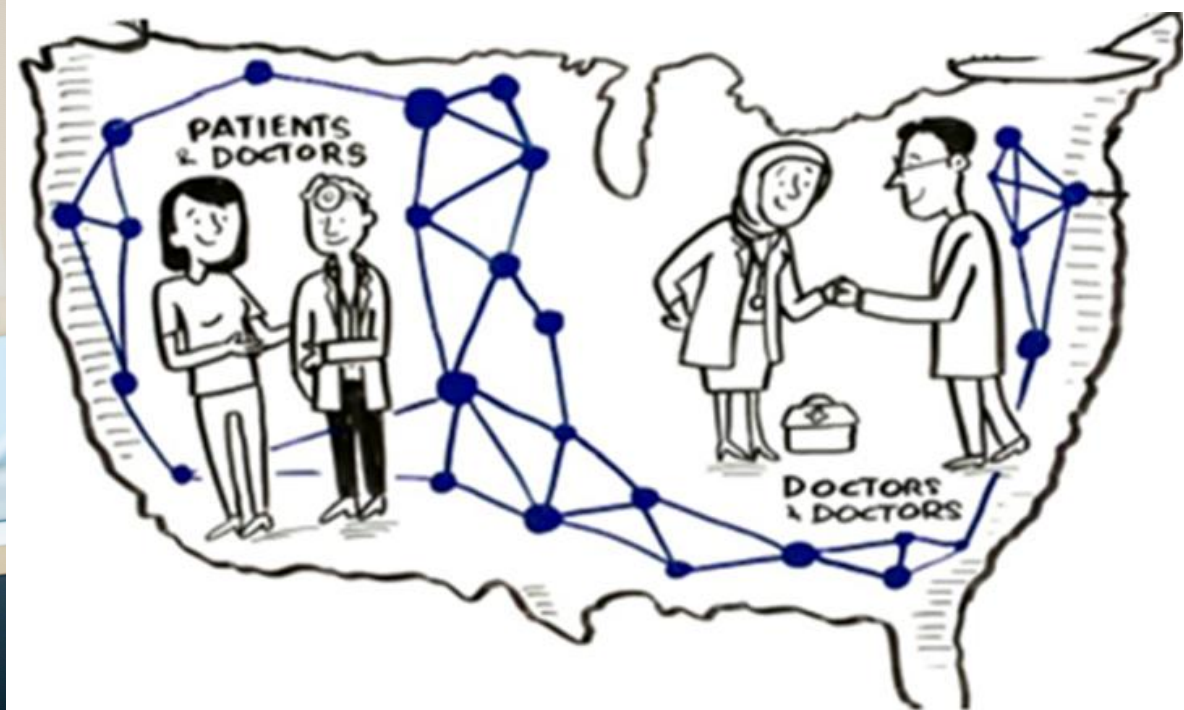
PRO PATIENTS VS. USUAL CARE PATIENTS HAD EXTENDED SURVIVAL: 31.2 MONTHS VS. 26.0 MONTHS

Figure. Overall Survival Among Patients With Metastatic Cancer Assigned to Electronic Patient-Reported Symptom Monitoring During Routine Chemotherapy vs Usual Care

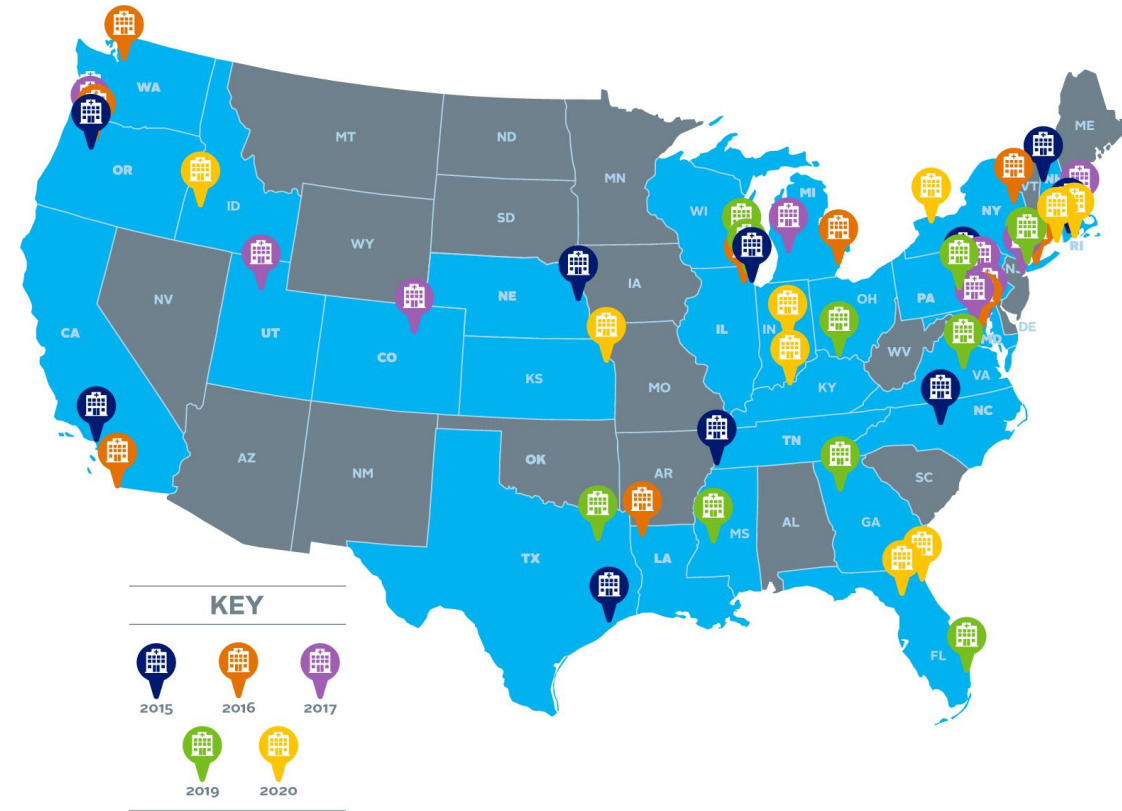


No. at risk	0	1	2	3	4	5	6	7	8
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27

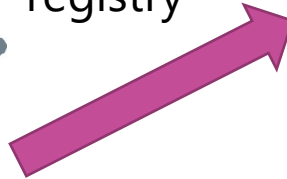
INFLAMMATORY BOWEL DISEASE



One Data, Multiple Purposes



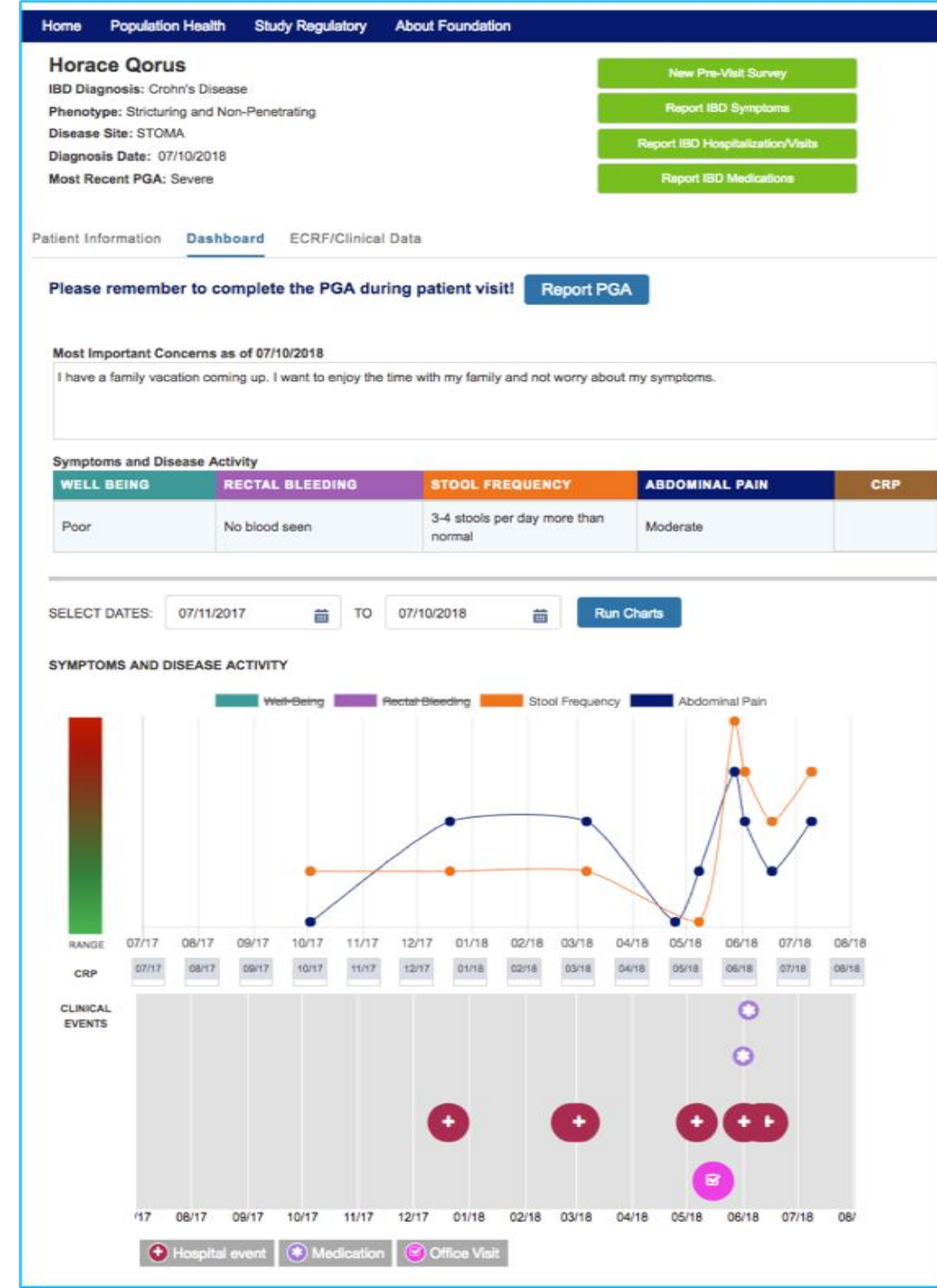
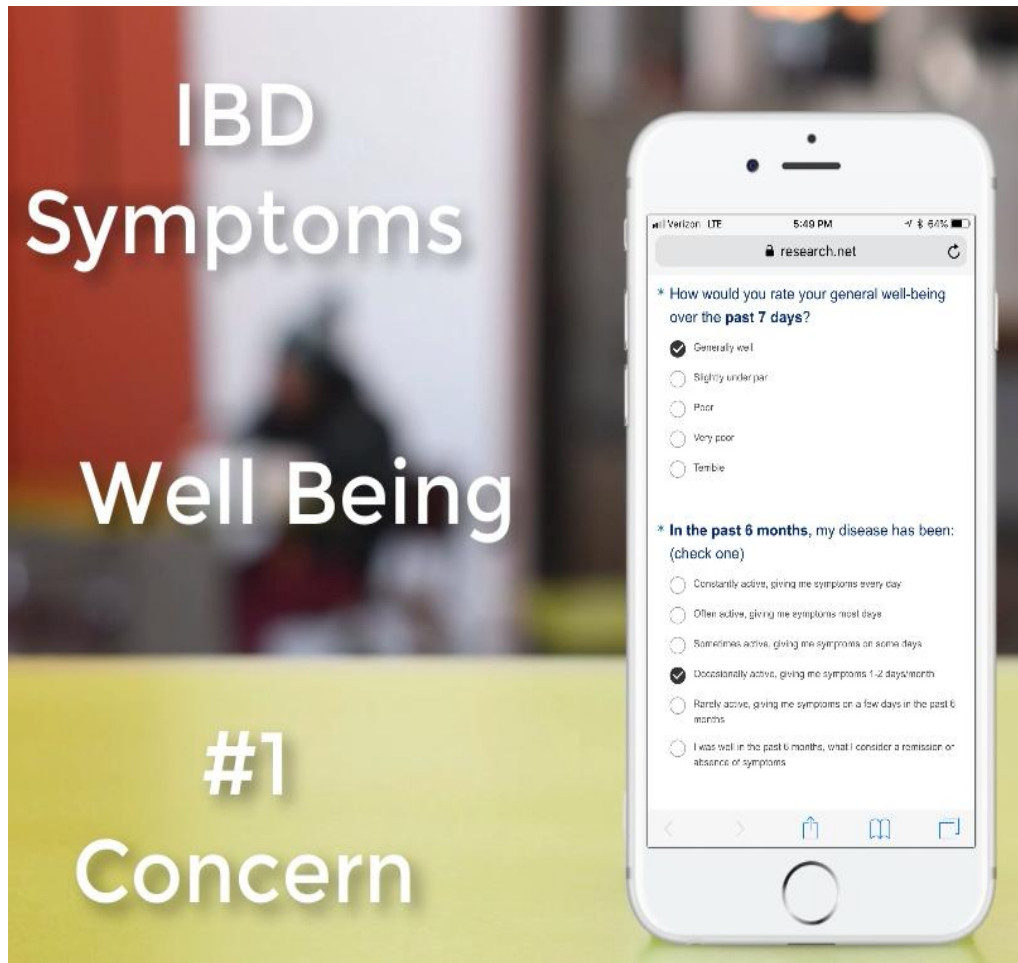
Data fed forward to registry



Data fed back to clinical sites



Patient-facing symptom management dashboard in development.



Patient Reported Outcomes: The IBD Qorus Pre-Visit Survey

IBD QORUS PRE-VISIT SURVEY

Marking Instructions:

CORRECT ● INCORRECT ⊗ ⊘ ⊙ ⊚

- Use a No. 2 pencil or blue or black ink pen only.
- Make solid marks that fill the circle completely.
- Make no stray marks on this form.
- Do not fold, tear, or mutilate this form.

Please help us understand how Inflammatory Bowel Disease (IBD) affects you

1. Currently, what is your number ONE concern or goal related to your IBD? This could be related to a specific symptom (e.g., diarrhea), worry for the future (e.g., need for surgery, cost of care) or how IBD might impact an upcoming life event (e.g., wedding, travel). Or you can report that you have no current concerns or goals.

My number ONE concern is: _____

2. IBD includes Crohn's disease and ulcerative colitis. I have been diagnosed with (Choose ONE response):
 Ulcerative Colitis Crohn's Disease Other (specify): _____
3. Do you believe you would benefit from a change in your Crohn's disease or ulcerative colitis treatment?
 Yes No I'm not sure

Date

MO	DAY	YEAR
0	0	0
1	1	1
2	2	2
3	3	3
4	4	4
5	5	5
6	6	6
7	7	7
8	8	8
9	9	9

Now, tell us about your current symptoms. Over the past 7 days...

4. What is your average number of liquid or very soft stools per day?
 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20+
 Not Applicable (I have an ostomy)

5. What is your daily stool frequency? (Choose one)
 Less stool than normal 3-4 stools more than normal
 Normal number of stools 5 or more stools more than normal
 1-2 stools more than normal Not applicable, I have an ostomy

6. Daily abdominal pain (Choose one)
 None Mild Moderate Severe

7. Blood in stool (Choose one)
 No blood seen Blood less than 50% of the time Blood 50% or more of the time

8. In the past 7 days, have you had bowel movement(s) when you passed blood alone? Yes No

9. How would you rate your general well-being over the past 7 days? (Choose one)
 Generally well Slightly under par Poor Very Poor Terrible

10. Have you been to an Emergency Department (ED) in the past 3 months due to your IBD? Yes No

11. Have you been hospitalized in the past 3 months due to your IBD? Yes No

12. Are you currently taking prednisone by mouth for your IBD? Yes No

13. Are you currently taking opioids (pain medications) for your IBD? Yes No

14. How confident are you that you can control and manage most of your health problems related to IBD? (Choose one)

Not confident at all 0 1 2 3 4 5 6 7 8 9 10 Very confident

15. Sex at birth: Male Female Other

16. Age (in Years): Less than 21 21-30 31-40 41-50 51-60 61-70 71-80 Greater than 80

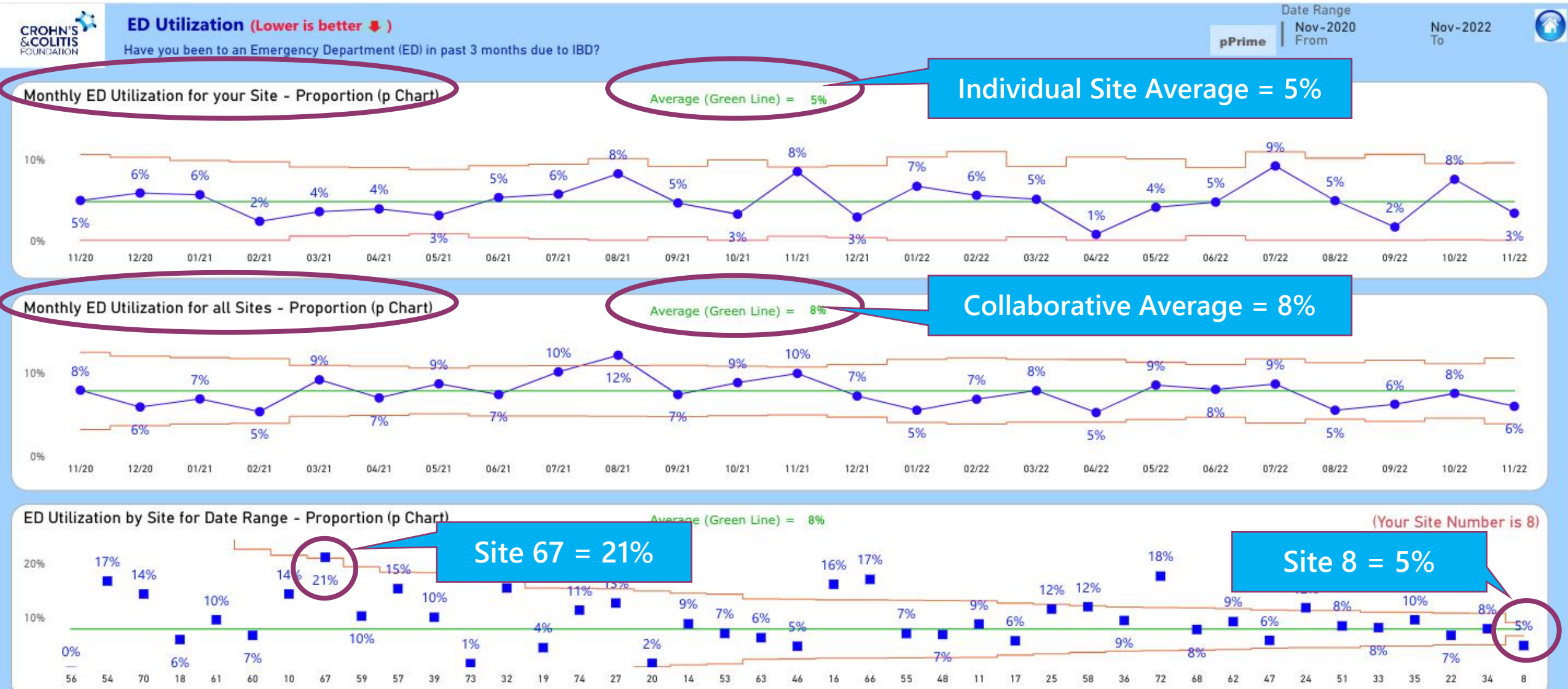
Current focus QI Indicators:

- Do you believe you would benefit from a change in your treatment?
- Have you been to the ED in the last 3 months?
- Have you been hospitalized in the last 3 months?
- How confident are you that you can control and manage your symptoms related to IBD?

Comparative Performance Feedback Reports Using SPC: My Site vs. All Sites

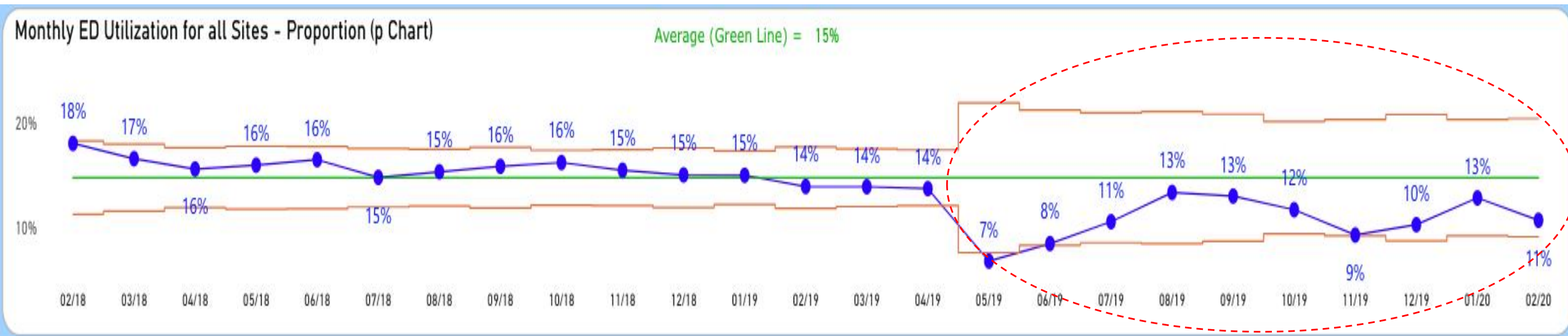
Patient Reported ED Utilization November 2020-November 2022 (by Month)

(n= 14,346)



Using PROMS For QI: Patient Reported ED Utilization February 2018- February 2020 (by Month, all sites)

(n=24,343)



Urgent Care QI Initiative
Feb 2018-April 2019

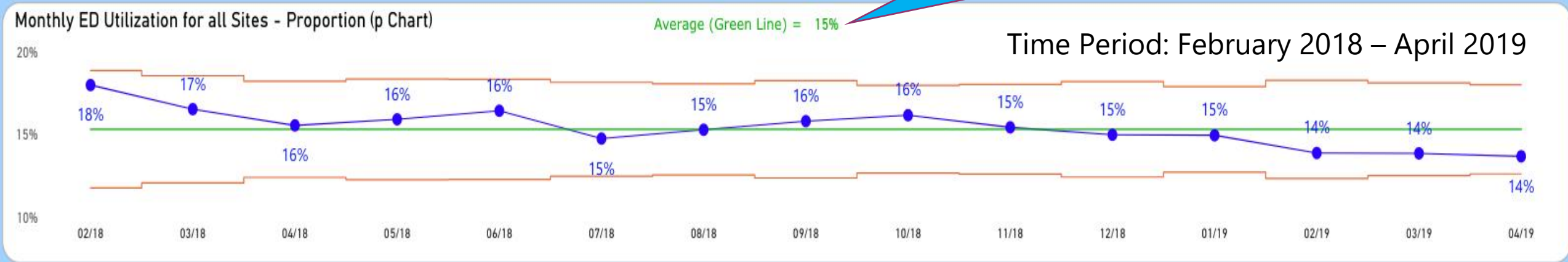
Sustaining the Gains: A Split Limit Analysis

Patient Reported ED Utilization February 2018 - November 2022

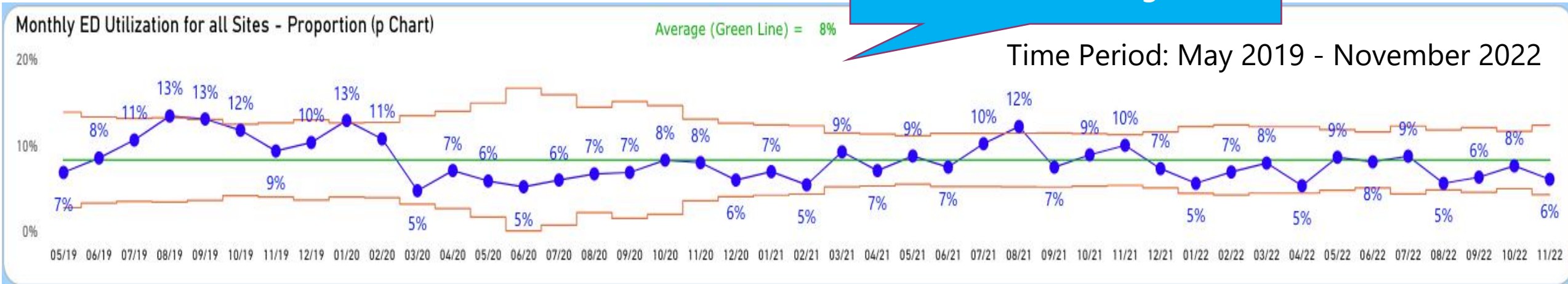
(by Month)

Collaborative Average = 15%

(n=40,249)



Collaborative Average = 8%



For further learning about measurement for Quality Improvement:
 Oliver & Ogrinc, Eds, 2022. Practical Measurement for Healthcare Improvement. Oak Hills: Joint Commission Resources. <https://store.jcrinc.com/practical-measurement-for-health-care-improvement/>

Case studies show that PROMs are QI tools that can do many jobs

1. **Improve Self-Management:** Show trends in the patient's health status over time for self-management at home by patient & family
2. **Avoid Exacerbations:** Connect self management & symptom monitoring with trusted clinical team to avoid exacerbations and to take timely action
3. **Improve Care Experience:** "Jump start" office visits using a point of care dashboard & thereby improve patient-clinician communication, relationship, trust and care experience
4. **Shared Decision Making:** Promote shared decision making (i.e., building the care plan based on clinical evidence & patient preferences)
5. **Predictive Analytics:** Provide data for predictive analytics based on treatments and outcomes for similar patients
6. **Patient Registry:** Contribute patient reported data to a patient-centered registry for improvement & research
7. **Value Measurement:** Provide essential data elements to measure the outcomes, experience, & costs of care for individual patients and populations

Feedforward to do the right thing now for this patient & *Feedback* to improve outcomes, experience, value & science for future patients

3. Getting Started: Basic, Practical Steps

Practical steps for using PROMs to improve health, quality, value and research



Getting Started: Basic, Practical Steps

1. **Co-Design Team:** Start small co-design team covering key roles: patient, receptionist, medical assistant, nurse, doctor, (IT expert), program leader etc. to guide planning and implementation. Identify a PROMs expert to work with you if possible.
2. **Vision/Aim:** What does success look like? Paint a vivid picture of how you would like it to work and how this will improve care & outcomes.
3. **Dummy Data Display:** Use co-design team to make a drawing of what data or topics (PROMs, PREMs, PCOMs) will be displayed in what way for whom to realize the vision.
4. **Measure Selection:** Try to identify, brief, validated measures that patients (or parents) can self-report to measure key outcomes and experiences. Try to use validated measures that have been used for similar purposes and populations.
5. **Questionnaire:** Design a questionnaire or health assessment that includes the questions that you have selected (i.e., the PROMs or PREMs or PCOM measures).
6. **Build:** Build the questionnaire and build the data display to show the results from the questionnaire, and build documentation tools if needed (e.g., in electronic health record).
7. **Pilot Test Process Flow:** One patient, one provider ... and then use PDSA small tests of change and “agile design” methods to make the process of collecting and using the data smooth, and easy and helpful in real time.
8. **Implementation Process:** Once a best method has been worked out, spread it and adapt it to all the practices, or clinics or places that will use the PROMs.

4. Key Point



PROMs are QI tools that can be used to improve **patient-centered**:

- Outcomes
- Experience
- Value
- Science

While also improving **professional** workflows, efficiency and joy in work

Questions & Discussion

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- Carsten Engel, MD, ISQua CEO

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