

# Patient Reported Outcomes Oncology

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President-Elect  
American Society of Clinical Oncology

# Defining Value in Oncology

- Clinically meaningful survival gain
  - Distinguish from statistically significant
  - Risk of losing a weak signal
- Value Based Framework: patients and populations
  - Beneficial Outcomes
  - Toxicity
  - Cost

# Patient Reported Outcomes

- Beneficial Outcomes: Disease symptom improvement
- Patient Experiential Outcomes
  - Obtaining personal goals
  - Tracking over the cancer journey
- Toxicities of Therapy: Epic-26, PROMIS
- Cost: deductible, co-pay

# Cancer PROs

- Disease Management: ASCO Quality of Care Committee & PROs Workgroup
  - Nausea post chemotherapy: NCI PRO CTCAE
  - Pain advanced cancer: MD Anderson Brief Pain Inventory
- Long Term Survival: ASCO Survivorship & Guidelines Committees
  - Anxiety & Depression
  - Neuropathy
  - Fatigue



**QOPI®** THE QUALITY ONCOLOGY  
PRACTICE INITIATIVE

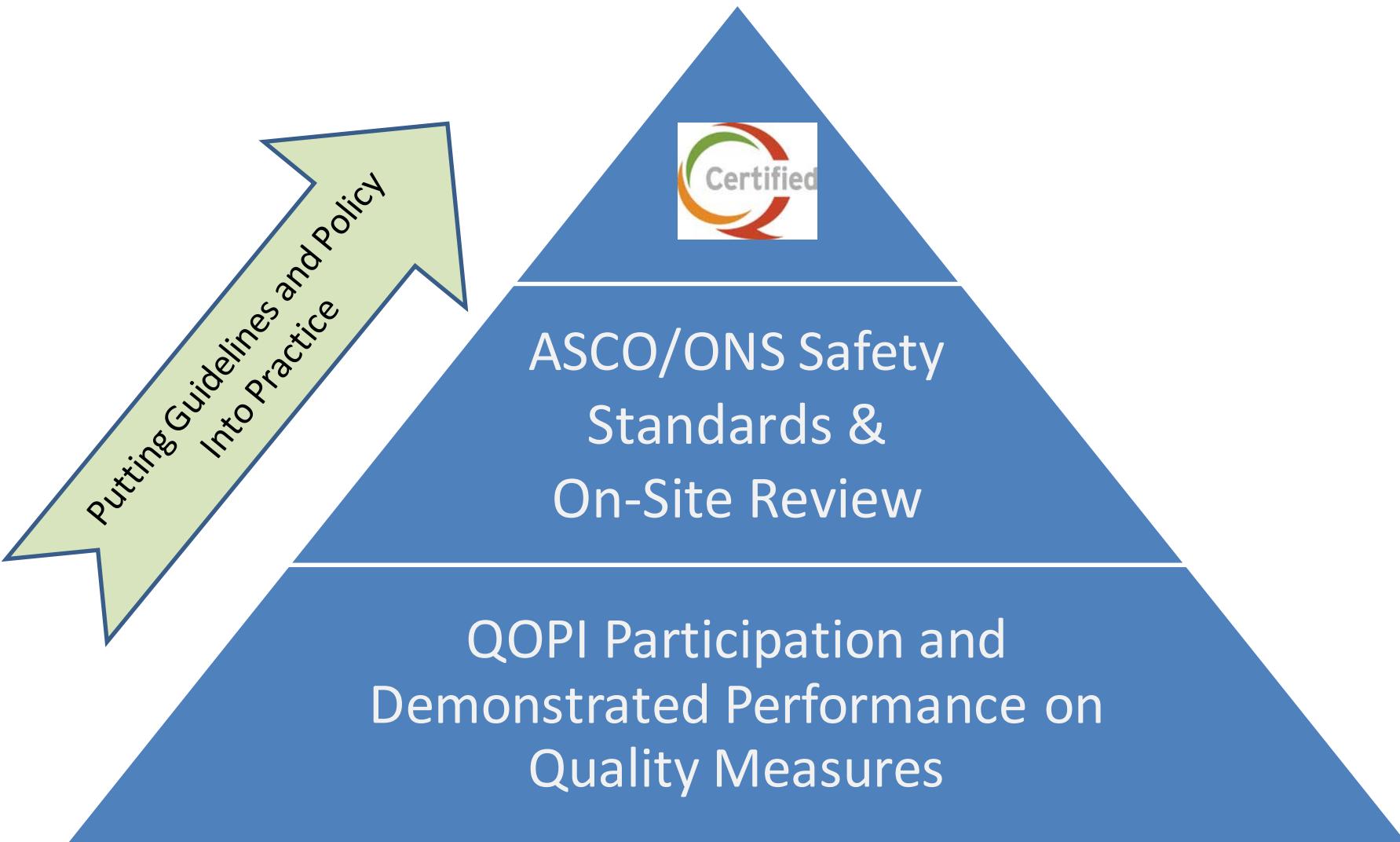
Quality Cancer Care: Pursuing Excellence

**QCP**  
QOPI® Certification Program

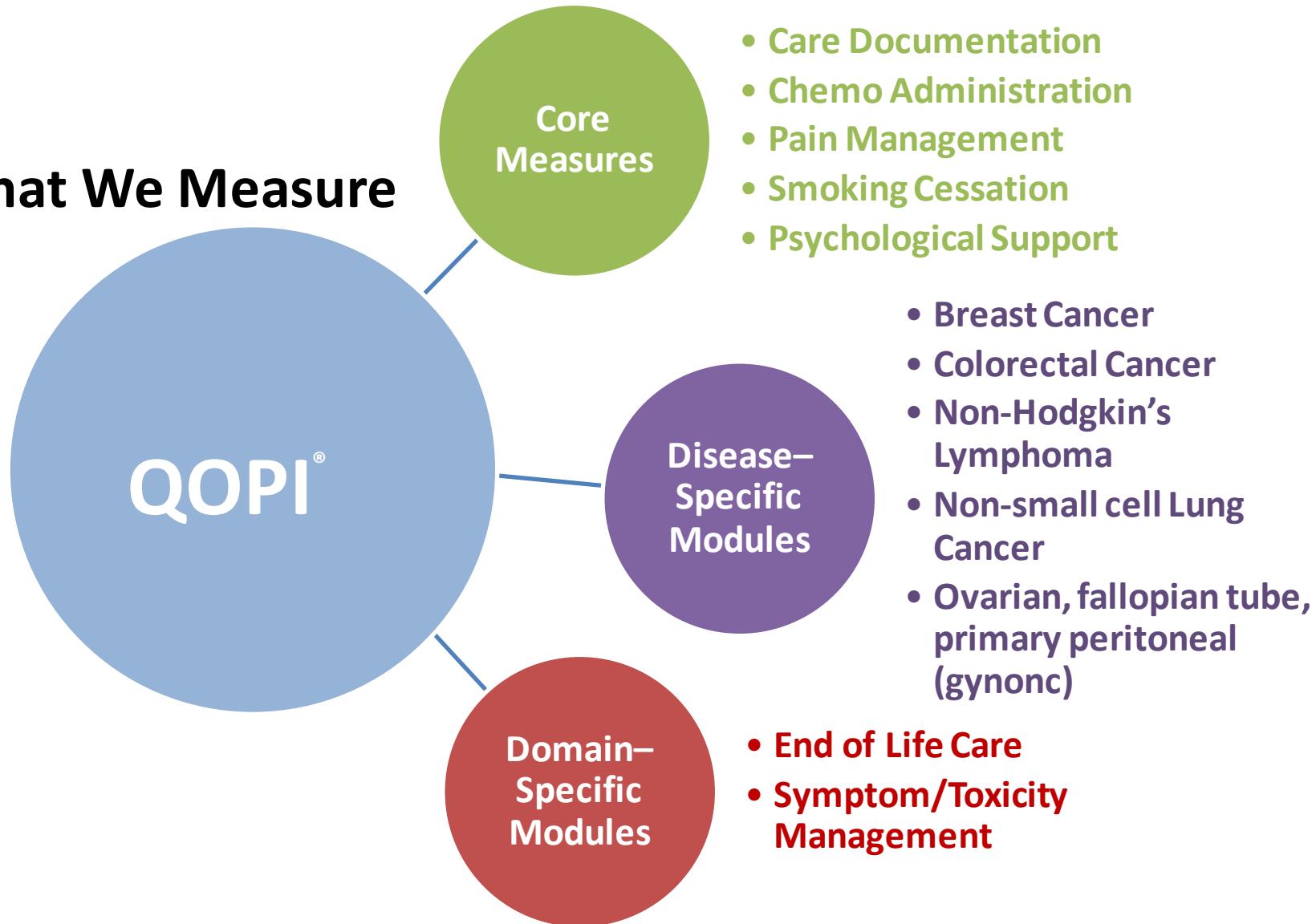
Quality Cancer Care: Recognizing Excellence

**QOPI®**  
&  
**QOPI® Certification Program**

The primary goal of the QOPI® Certification Program is practice improvement.



# What We Measure



# QOPI Measures Amenable to PROs

- Pain assessment and control plan
- Constipation related to narcotics
- Performance status
- Emotional well being
- Dyspnea

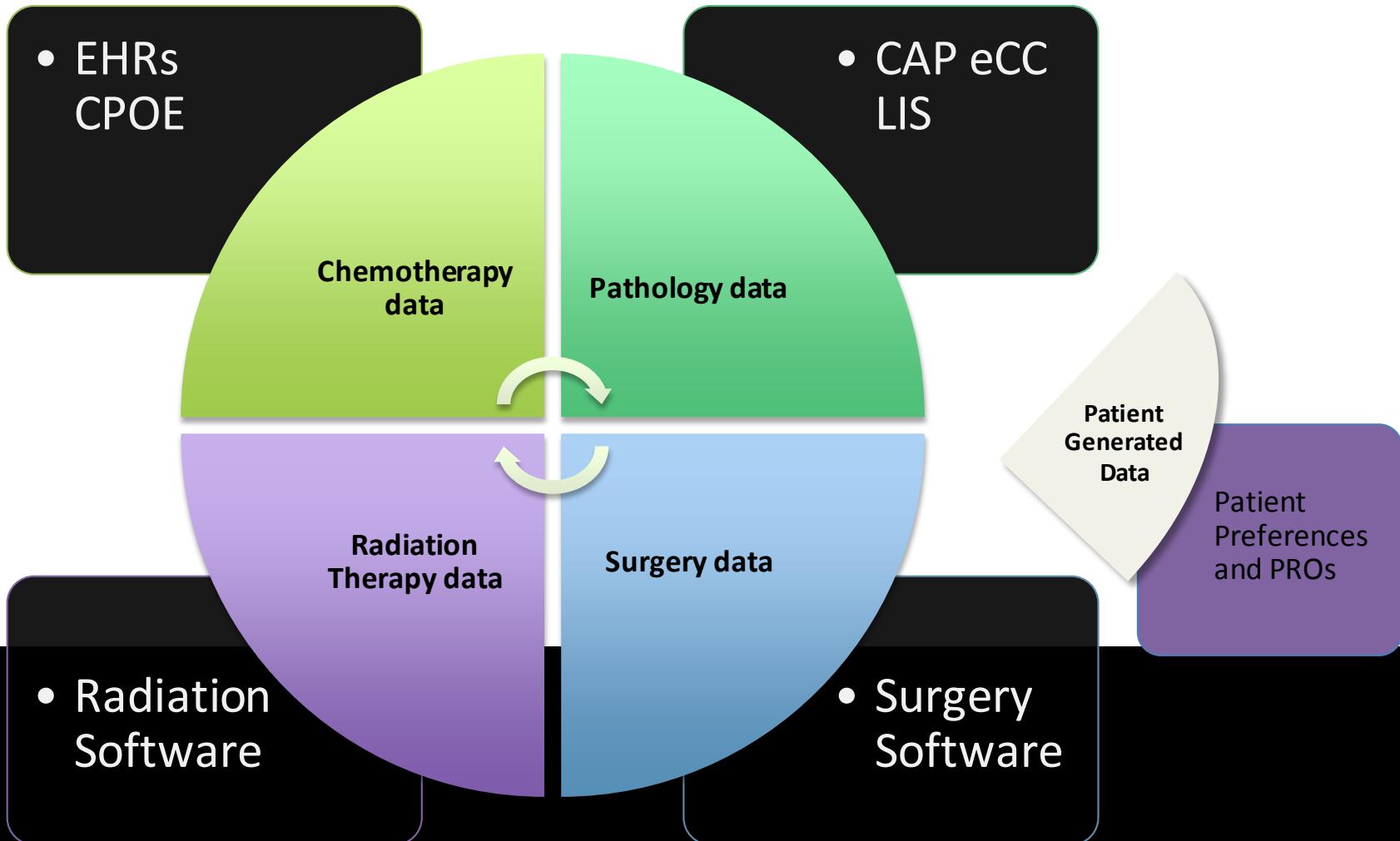
# Cancer LinQ: ASCO

- Rapid Learning Health System
- More than Registry
- Accepts health data from diverse sources including patients
- Central premise: motivation for sharing
- eQOPI

# Cancer LinQ Users

- See their own data over time
- Overlay intervention over symptoms
- See comparison group
- See provider quality performance

# Data Liquidity Documents



# ASCO HL7 Breast Cancer Document

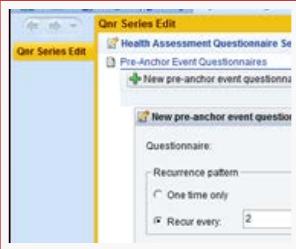
- Approved as HL7 draft standard October 2013
- Based on HL7 cCDA architecture, it is modular and extendable
- ONC Project Inspire: UC System and CADPH

# Palo Alto Medical Foundation

- Integrated Multidisciplinary Medical Group
- 900,000 patients, 1,000 physicians
- PAMF Research Institute: Shared Decision
- Epic EHRs 1999
- 75% of patients active users of MyChart
- Initially used non integrated software for diabetes management

# What is PRO?

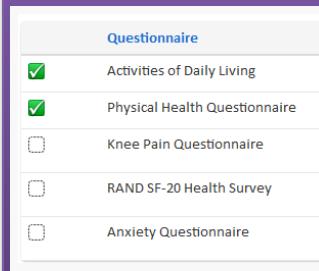
Questions: what, when, and how



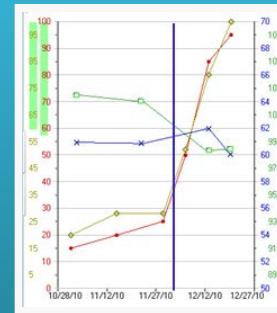
Assign to patients



Collect answers



Track a single patient



Analyze data across many patients



The Workflow:

- Define the questions you want to ask – standardized questionnaires e.g. Epic-26
- Select inclusion criteria for patients:
  - Bulk assignment by running a report (e.g. all cancers with prostate cancer)
  - If a patient is not enrolled, provide point of care alerts to enroll patients
- Invite the patient to complete the questionnaire via My Health Online (MyChart)
  - Remind them automatically if they don't reply
- Compare questionnaire responses over time and vs. other clinical parameters like drug treatments
- Use the Epic database for analysis across cohorts of patients

# PRO-Alerts

**Welcome,**  
**Eric Holmes**

**Log Out**

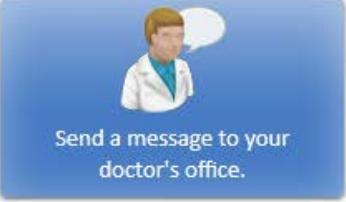
**MyChart** **Epic** Medical Center



[Home](#) [Messaging](#) [Visits](#) [My Medical Record](#) [Billing](#) [Preferences](#) [Resources](#) [Search](#)

**You Might Want To...**

-  View instructions for your appointment on Wednesday, August 14, 2013 with Miriam Fitzgerald, M.D..  
Please fill out your questionnaires before coming.
-  Schedule your preventive care services. You are due for 2 preventive care services.
-  Complete your Expanded Prostate Cancer Index Composite questionnaire, which is available for 6 days, until 8/7/2013.



Send a message to your doctor's office.



Schedule an appointment.



View your health summary.

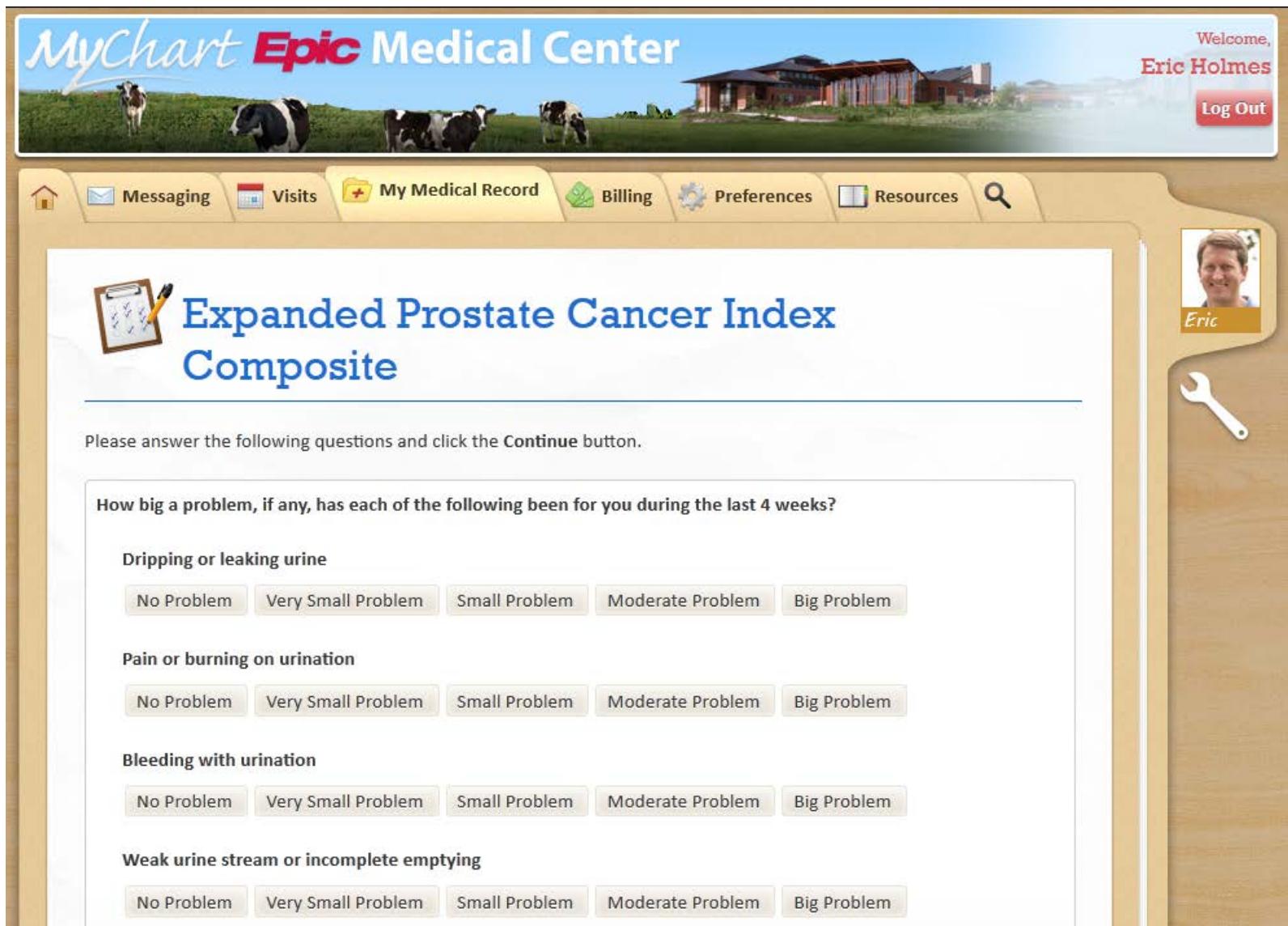


Eric

**MyChart News for You**

The clinic is now pleased to offer you [Classes](#).

# PRO-Question Groups



The image shows a screenshot of the MyChart Epic Medical Center website. The top navigation bar includes links for Home, Messaging, Visits, My Medical Record, Billing, Preferences, Resources, and a search icon. A welcome message for "Eric Holmes" is displayed, along with a "Log Out" button. On the right side, there is a profile picture of a man named Eric and a wrench icon. The main content area is titled "Expanded Prostate Cancer Index Composite" and features a clipboard icon. It asks the user to answer the following questions and click the "Continue" button. The questions listed are: "How big a problem, if any, has each of the following been for you during the last 4 weeks?", "Dripping or leaking urine", "Pain or burning on urination", "Bleeding with urination", and "Weak urine stream or incomplete emptying". Each question has five response options: "No Problem", "Very Small Problem", "Small Problem", "Moderate Problem", and "Big Problem".

**MyChart Epic Medical Center**

Welcome, Eric Holmes

Log Out

**Expanded Prostate Cancer Index Composite**

Please answer the following questions and click the **Continue** button.

How big a problem, if any, has each of the following been for you during the last 4 weeks?

Dripping or leaking urine

No Problem   Very Small Problem   Small Problem   Moderate Problem   Big Problem

Pain or burning on urination

No Problem   Very Small Problem   Small Problem   Moderate Problem   Big Problem

Bleeding with urination

No Problem   Very Small Problem   Small Problem   Moderate Problem   Big Problem

Weak urine stream or incomplete emptying

No Problem   Very Small Problem   Small Problem   Moderate Problem   Big Problem

# If a patient was accidentally not enrolled in PRO, point of care BPA to enroll

The screenshot shows the Epic 2014 software interface. The top navigation bar includes 'Hyperspace - Epic 2014 - EPIC22404', 'Epic' dropdown, 'Review', 'Patient Lists', 'Patient Station', 'My Reports', and 'Print' with a 'Log Out' button. The main patient profile for 'Holmes, Eric' is displayed, showing a photo, demographic information (Male, 52 y.o., 03/13/1961), and clinical details (Allergies: Not on File, Health Maintenance: Due, MRN: 31605, CSN: 353773). The 'Prescriptions' section shows 'None'. A 'Plan' tab is selected. A 'BestPractice Advisory' dialog box is open, titled 'BestPractice Advisory - Holmes, Eric'. It contains a message: 'Track your patients EPIC26 responses' and a checked checkbox: 'Assign questionnaire series to patient: Prostate Cancer Treatment Series'. The dialog has 'Accept' and 'Cancel' buttons. The left sidebar contains icons for 'Review', 'Rooming', 'Notes', 'Plan', 'Wrap-Up', and 'Sign Visit'. The bottom status bar shows 'MIRIAM FITZGERALD' and the time '9:37 AM'.

# Synopsis – Compare PRO vs. other clinical parameters (e.g. drug regimen)

Hyperspace - Epic 2014 - EPIC22404

Epic Review Patient Lists Patient Station My Reports

Holmes, Eric Future

Male, 52 y.o., 03/13/1961,   
None

98.8 °F  
88bpm, 150/83  
5' 7", 172 lb  
BMI: 26.93 kg/m<sup>2</sup>

Allergies: Not on File  
Health Maintenance: None  
MRN: 31606  
CSN: 353781

Prescriptions  
None

Synopsis

Questionnaire Series

Display: Days All 012 8/10/2012 10/11/2012 11/8/2012 12/3/2012 2/6/2013 3/5/2013 5/7/2013 Most Recent

Patient Spotlight  
No data to display.

Epic26

<input checked="" type="checkbox"/> HRQOL Domain Summary Score - Urinary	23	41	70	75	75
<input checked="" type="checkbox"/> HRQOL Domain Summary Score - Urinary	21	54	60	75	75
<input type="checkbox"/> HRQOL Domain Summary Score - Bowel	25	45	67	79	79
<input type="checkbox"/> HRQOL Domain Summary Score - Sexual	18	43	70	77	77
<input type="checkbox"/> HRQOL Domain Summary Score - Hormonal	23	54	69	79	79
Treatment Complete Date: 8/3/2012					

Medications [LPG 10032003] [FSH 9100049]  
 leuprolide (LUPRON) 7.5 MG injection Dose: 7.5 mg Q28 Days... Start: 6/8/12 End: 8/3/12

Vitals [LPG 10032002] [FSH 10032001]

<input checked="" type="checkbox"/> BP	153/94 mmHg	139/88 mmHg	157/92 mmHg	150/83 mmHg
<input type="checkbox"/> BLOOD PRESSURE - SYSTOLIC			150	83
<input type="checkbox"/> BLOOD PRESSURE - DIASTOLIC			88	21
<input type="checkbox"/> HEAD CIRCUMFERENCE			5' 7"	2752
<input checked="" type="checkbox"/> PULSE				
<input type="checkbox"/> RESPIRATIONS				
<input type="checkbox"/> HEIGHT				
<input type="checkbox"/> WEIGHT				
<input type="checkbox"/> SYS BP				
<input type="checkbox"/> Dia BP				

Performance data [LPG 10032001]

	Server time (sec)
Load FSH build	0.0000 seconds
Compile patient encounters	0.0000 seconds
Doc Flowsheet (FSP 5030)	0.0000 seconds
Visit Info (FSP 5060)	0.0000 seconds
Medication (FSP 5000, 5050, 5080, 5090), Injections/Administrations (FSP 6010)	0.0000 seconds
Questionnaires (FSP 6060)	0.0160 seconds
Questionnaire series anchor events (FSP 6080)	0.0000 seconds
Total:	0.0160 seconds

See Epic-26  
“response” vs.  
Lupron  
treatment

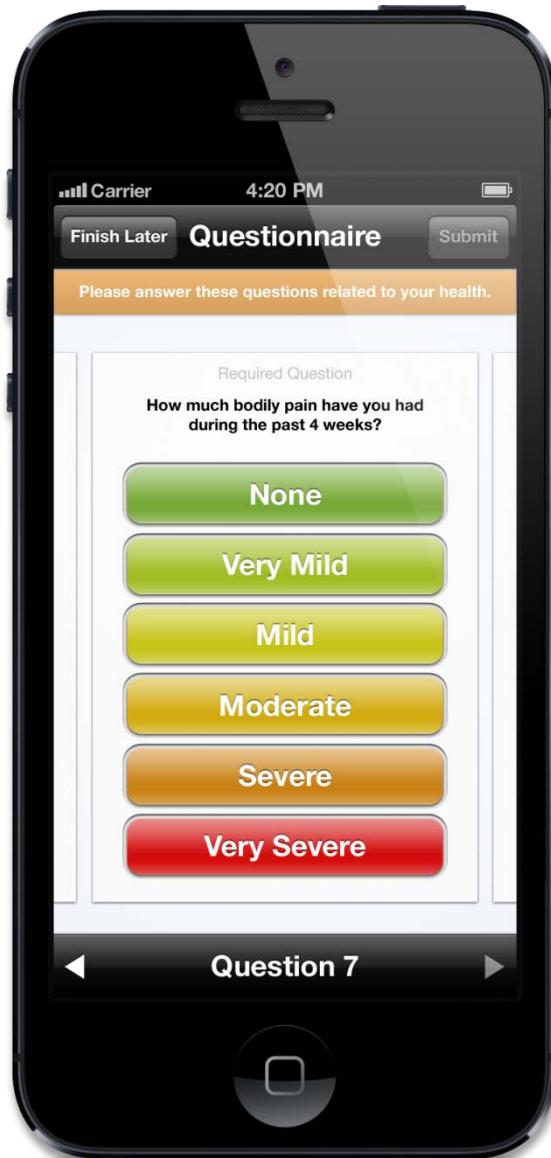
1 Year 05/07/12 – 05/07/13 Today

HRQOL Domain Summary... HRQOL Domain Summary... XBP PULSE

leuprolide (LUPRON) 7.5 MG injection

MIRIAM FITZGERALD CRM Pt Entered Flowsheet 10:09 AM

# Future – Mobile Questionnaires – answer on the phone



# Future – PRO Across Organizations



LAKELAND VALLEY HOSPITAL

Rand 36-Item Health Survey 1.0

Home Message Center My Medical Record Applications My Medical Record Adminstrative Billing & Insurance Preferences My Medical Record Health Library Search

Charlie (Me)

Please complete this questionnaire and click the Continue button. \* indicates a required field.

In general, would you say your health is:

Excellent Very Good Good Fair Poor

Compared to one year ago, how would you rate your health in general now?

Much better than one year ago Somewhat better than one year ago About the same Somewhat worse than one year ago Much worse than one year ago

Does your health limit vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports?

Yes, a lot Yes, a little No, not at all

Does your health limit moderate activities, such as moving a table, peeling a banana, cleaning, bending, or playing golf?

Yes, a lot Yes, a little No, not at all

Does your health limit lifting or carrying groceries?

Yes, a lot Yes, a little No, not at all

Does your health limit climbing several flights of stairs?

Yes, a lot Yes, a little No, not at all

Does your health limit climbing one flight of stairs?

Yes, a lot Yes, a little No, not at all

Does your health limit bending, bending, or stooping?

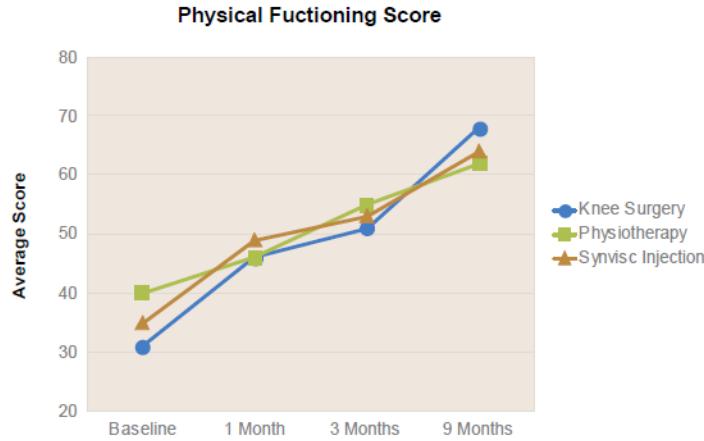
Yes, a lot Yes, a little No, not at all

Does your health limit walking more than a mile?

Yes, a lot Yes, a little No, not at all

Does your health limit walking several blocks?

Yes, a lot Yes, a little No, not at all



River Hills Medical Center

Welcome, Stan Reeks Mychart

Home Log Out

Rand 36-Item Health Survey 1.0

Please complete this questionnaire and click the Continue button. \* indicates a required field.

In general, would you say your health is:

Excellent Very Good Good Fair Poor

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Yes, a lot Yes, a little No, not at all

Does your health limit walking more than a mile?

Yes, a lot Yes, a little No, not at all

Does your health limit walking several blocks?

Yes, a lot Yes, a little No, not at all

Does your health limit walking over one block?

Yes, a lot Yes, a little No, not at all



# What's Value of Using PROs in EHRs: A Triple Play or a Grand Slam?

**Eugene C. Nelson, DSc, MPH**

**Carolyn Kerrigan, MD, MSc**

**Director Population Health &  
Measurement**

**Dartmouth- Hitchcock**

**Professor, Community and Family  
Medicine**

**The Dartmouth Institute**

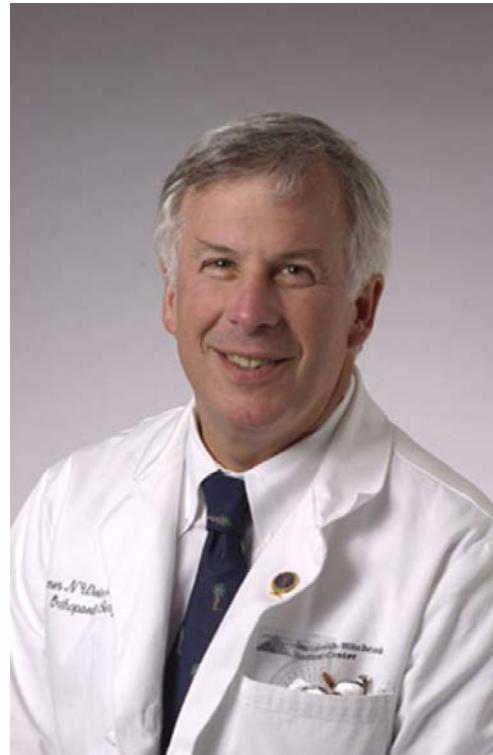


Acknowledgements: J. Weinstein, R. Reid, S. Lindblad, J. Wasson, C. Kerrigan, M. Mastanduno, P. Batalden, et al

# **“I can’t be a good doctor without this.”**

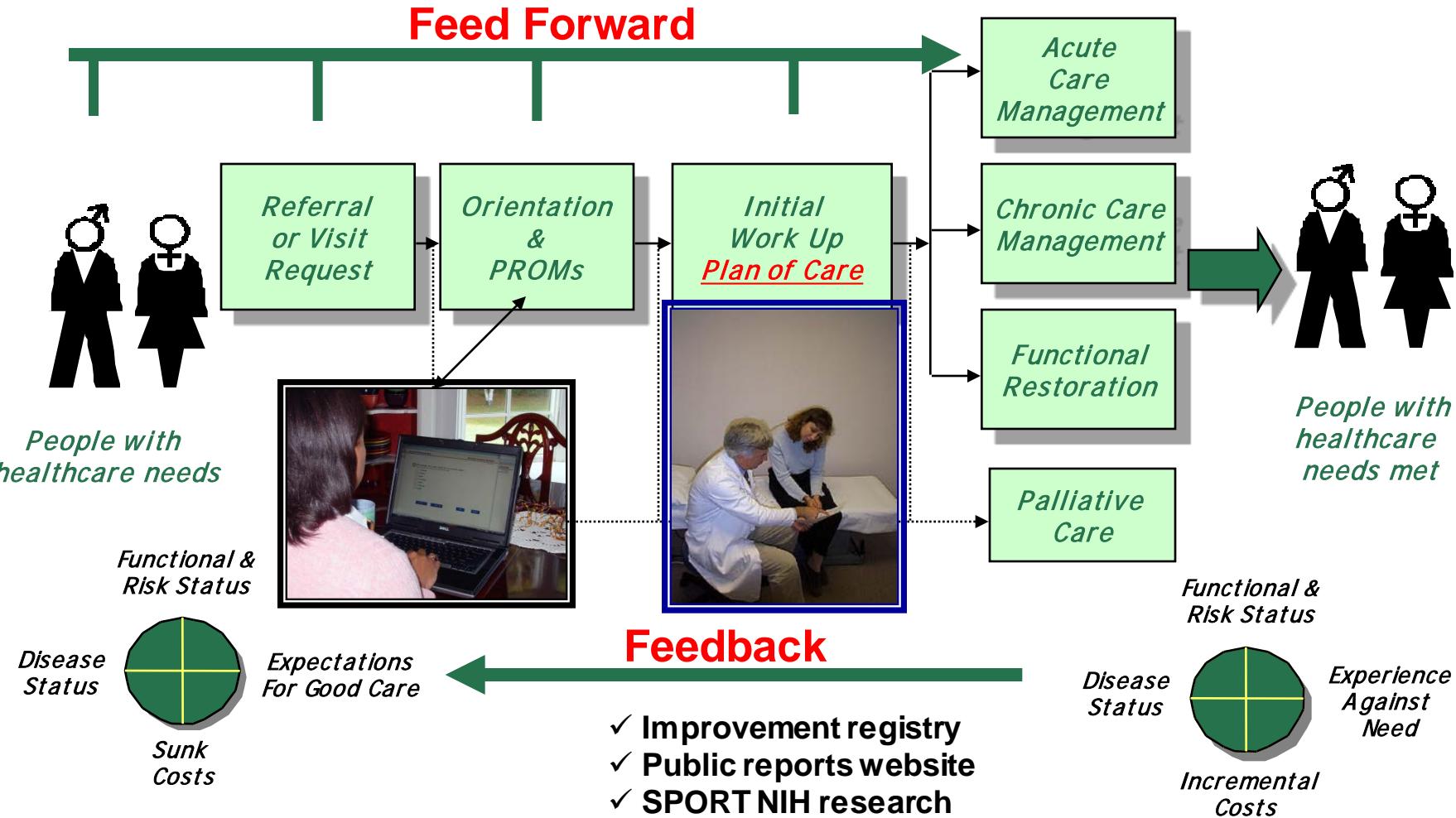
**J. Weinstein, President D-H**

- Feed forward PROs data in flow of care & in EHR
  1. Better care for this person matched to needs & preferences
  2. Comparative data to improve clinical programs based on outcomes
  3. Outcomes data for collaborative CE research



Yesterday

# Using PROs with Individuals: Dartmouth Spine Center



# The summary report generated from patient-reported data is critical to a physician's ability to care for a patient: same page care

Patient: Patient,Demo; 000031 Clinician: Clinician,Real E Report Date: 08/24/2006

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, Disabled and/or retired  
hours

## Red Flags

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: 10/01/2005

### 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)

### 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

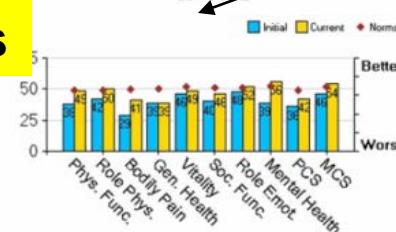
Hemo/lymph: Patient denies any blood/lymph node symptoms

Psych: Easily distracted

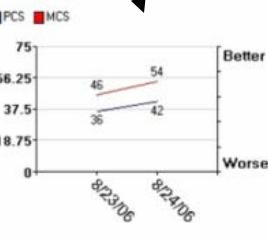
Skin/Hair: Dry skin

## Functional Status

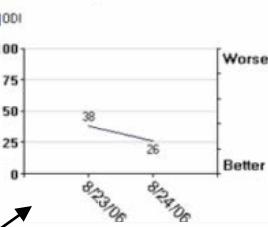
SF-36v2



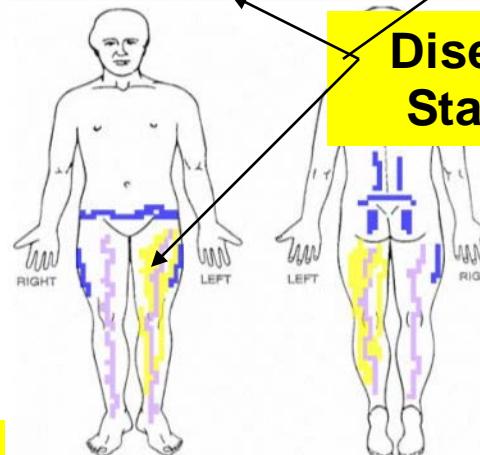
## Longitudinal MCS/PCS



## Longitudinal ODI



## Disease Status



	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

## Patient Perception

Legend:  
 Yellow: Numbness (191 pts)  
 Purple: Pins and Needles (185 pts)  
 Blue: Burning  
 Red: Aching (112 pts)  
 Green: Stabbing  
 Brown: Other

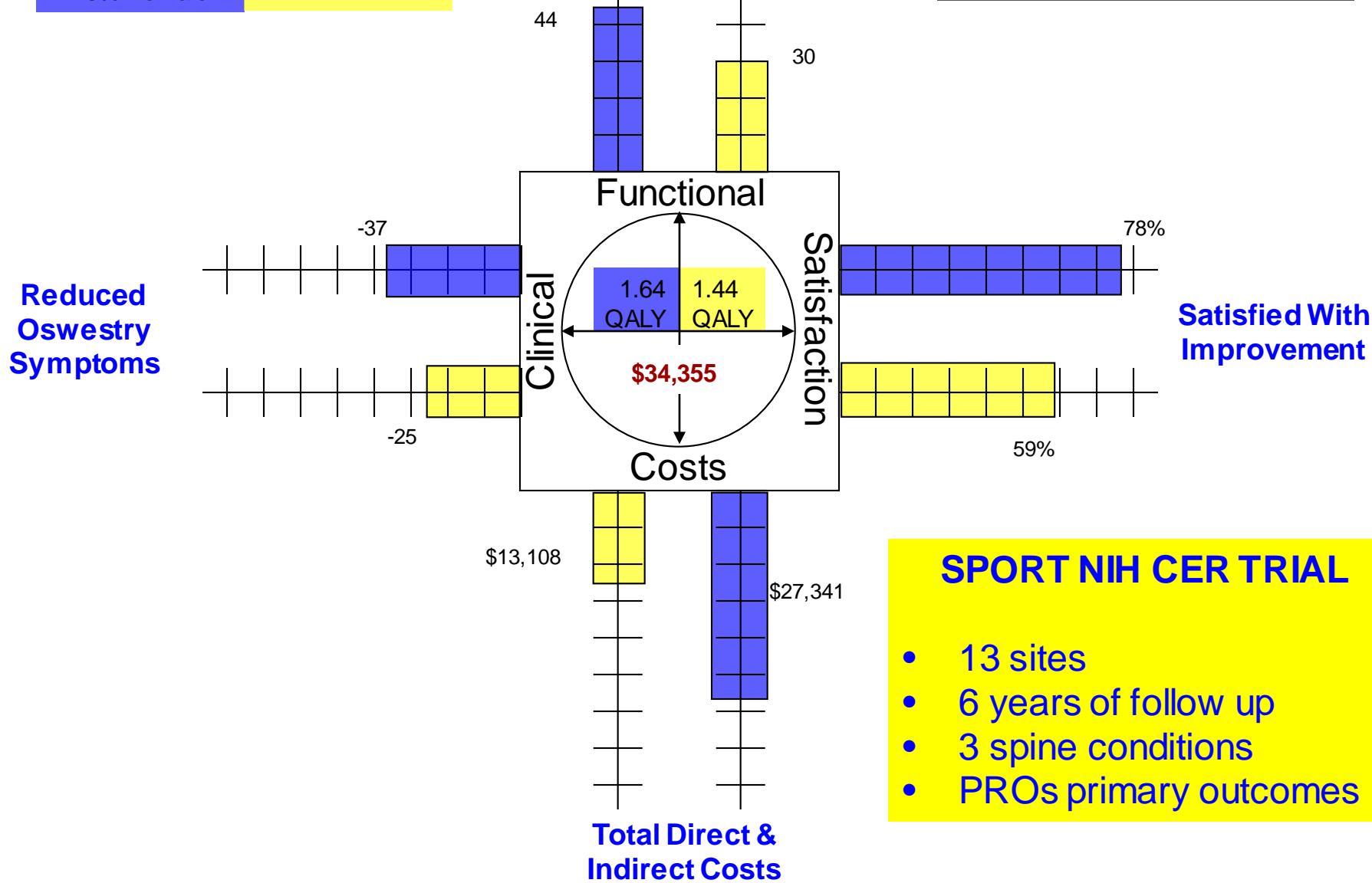
## History & Symptoms

# Herniated Disk

## Outcomes @ 2 Years

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

### Physical SF-36 Improvement

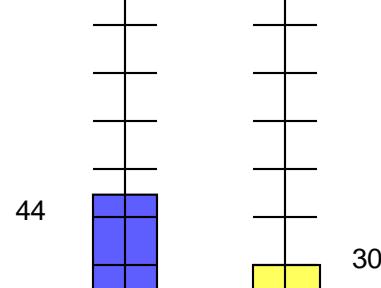


# Herniated Disk

## Outcomes @ 2 Years

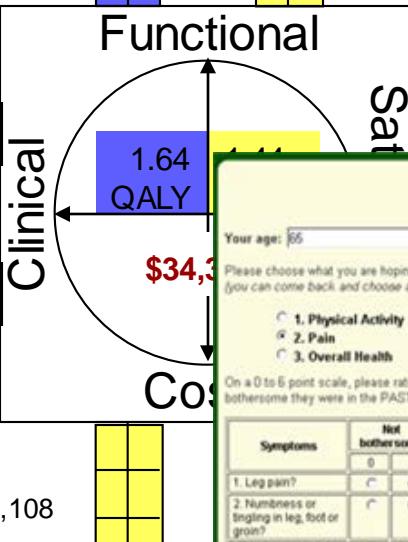
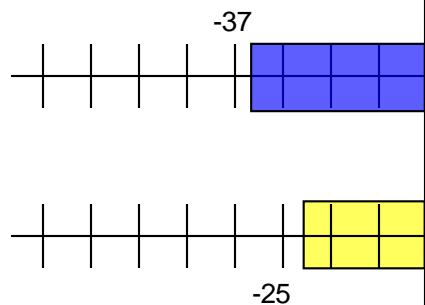
Surgery	Non-Surgery
44 Ave Age	30 Ave Age
43% Female	45% Female

## Physical SF-36 Improvement



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

## Reduced Oswestry Symptoms



**Personalized risk assessment  
based on people like me ...  
From research back to patient care**

**Total Direct  
Indirect Costs**

Detailed information about SPORT is available at <http://www.dartmouth.edu/sport.html>  
Please email questions or comments to [sportcalculators@dartmouth.edu](mailto:sportcalculators@dartmouth.edu)

15

is 15 on a scale of 24, where 0 is best and 24 is worst.  
submit button below and the calculator will show on a graph how this  
change over 24 months after surgical or non-surgical treatment.

## Degenerative Spondylolisthesis Treatment Calculator

Your age: 65 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				
1. Leg pain?	0	1	2	3	4	5	6
2. Numbness or tingling in leg, foot or groin?	0	1	2	3	4	5	6
3. Back pain?	0	1	2	3	4	5	6
4. Numbness or tingling in back after coughing or sneezing?	0	1	2	3	4	5	6
5. Back pain after coughing or sneezing?	0	1	2	3	4	5	6
6. Back pain after coughing or sneezing?	0	1	2	3	4	5	6

### 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.



Choose another time:  
 3 months  12 months  24 months

# Swedish Rheumatology Quality Register

Today

- Feed forward PROs data in flow of care
  - 44 of 61 centers adopted feed forward
  - 90% of RA patients covered
  - Practice improvement & new care models
  - National outcomes transparency
  - Integrated with EHRs in some settings
  - Better outcomes faster for RA patients in Sweden



# EHR + PHR: Same page care for people living with RA

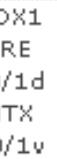
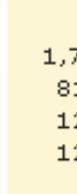
PROs entered by patient  
(HAQ)

Clinical data entered by  
physician (DAS-28 & labs)

Together review “next” care  
plan based on new  
outcomes (co-production)

År	2010 05-Jan	2010 23-Feb	2010 28-Mar	2010 03-Jun	2010 05-Sep	2010 08-Dec
Dag Månad						
Årskontroll						
Månads-Kontroll	0	2	3	5	8	11
MK-grupp	1	3	3	6	9	12
Arbetsförmåga	/	/	/	/	/	/
Allmän hälsa	75	75	71	35	35	36
SR	54	63	48	25	15	5
Läkarbedömning	Hög	Hög	Hög	Måttlig	Låg	Låg
EQ5D	-0,045		-0,045		0,808	0,931
CRP	35	35	20	8	2	1
Spond,artrit, Ank.spond.						
BASFI						
Svullna leder (66)						
Ömma leder (68)						
Daktylit						
Entesit						
Funktionsneds, - HAQ	1,75	1,75	1,63	0,88	0,88	0
Smärta	81	80	75	40	30	27
Svullna leder (28)	12	12	11	2	0	1
Ömma leder (28)	12	12	11	3	1	2
Leucocyt						
8	6.75	6.86	6.49	4.11	2.95	2.7
AI						
8CRP	6.21	6.21	5.84	3.61	2.41	2.79
D	COX1	COX1	COX1	COX1	COX1	COX1
-	PRE	PRE	PRE	PRE	PRE	PRE
- dos	10/1d	15/1d	10/1d	10/1d	10/1d	10/1d
D 1	MTX	MTX	MTX	MTX	MTX	MTX
D 1 dos	20/1v	20/1v	20/1v	20/1v	20/1v	20/1v
D 2	SAL	SAL				
D 2 dos	2000/1d	2000/1d				
D 3						
D 3 dos						
D 4						
D 4 dos						
Öljd månad				0	0	6
... Sjlt läkemedel				ENB	REM	REM
Läkemedelsdos				50/1v	200/8v	200/8v

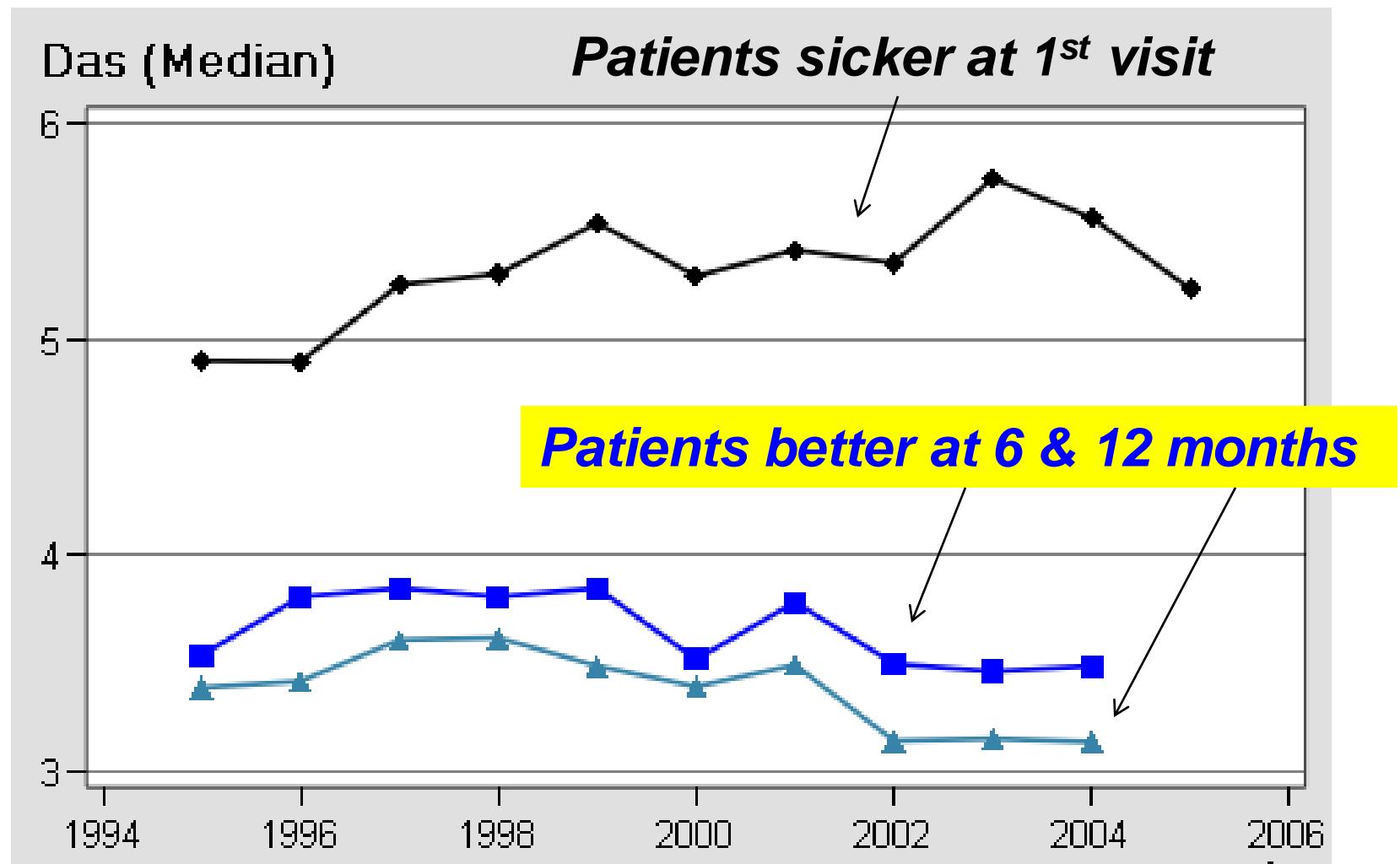
January - March



June - December

Key point: Patients served by Swedish health system are doing better

## All Patients in the SRQ, from 1994 – 2006\*



\*Black line shows DAS at initial visit and blue after 6 months and turquoise after 12 months.

# Triple Play

3rd



2nd



1st



**Tomorrow**

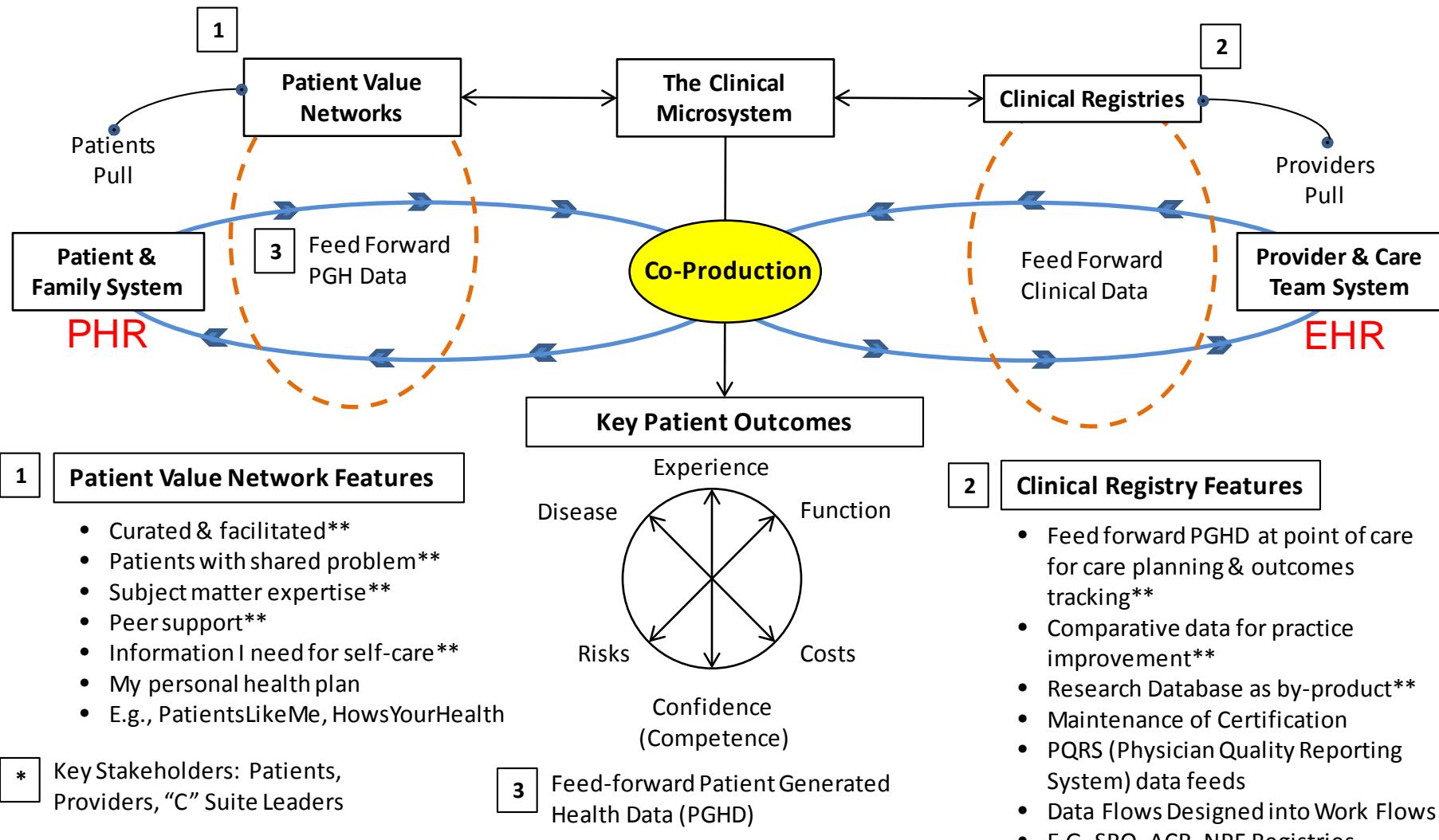
# Feed forward PROs & EHRs: Triple Play or Grand Slam?

- 1. Better care for individuals based on needs and preferences**
  - Co-production of care
- 2. Better data on outcomes for clinical practice improvement**
  - Improvement collaboratives
- 3. Better research data on outcomes for patient centered research**
  - Research collaboratories
- 4. Link patient value networks (& PHRs) with clinical population registries (& EHRs)**
  - integrate world of the patient with world of the practitioners caring for the patients

# How to Make PROs for Individuals Fit for the Future?

**Aim:** Patient-centered decision support for co-production of good care, better health & more confidence in self-management.

**Key Mechanism:** Integrating patient's voice into flow of care & EHR to co-produce care plans that reflect needs & values.



# References

1. Meyer GS, Nelson EC, Pryor DB, James B, Swensen SJ, Kaplan GS, Weissberg JI, Bisognano M, Hunt GC, Yates GR, Hunt GC: More quality measures versus measuring what matters: a call for balance and parsimony. *BMJ Quality and Safety Journal* August 2012. Published Online First: 14August 2012 doi: 10.1136/bmqs-2012-001081
2. Nelson EC, Butterly J, Colacchio TA, Mastanduno MP, Foster TC, Batalden PB. Better Patient and Population Outcomes: Practical Approaches that Health Care Systems Can Adopt for Measuring the Health of Patients and Populations, in *Sustainably Improving Health Care: Creatively Linking Care Outcomes, System Performance and Professional Development* Batalden PB, Foster TC (eds.), Radcliffe Publishing, Ashland, Ohio, 11-31, 2012.
3. Nelson EC, Hvitfeldt HF, Reid R, Grossman D, Lindblad S, Mastanduno MP, Weiss LT, Fisher ES, Weinstein JN. *Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health. Technical Report*. The Dartmouth Institute for Health Policy and Clinical Practice. 2012
4. Nelson EC, Fisher ES, Weinstein JN: A Perspective on Patient-Centric, Feed-Forward “Collaboratories” in *IOM (Institute of Medicine) Engineering a learning healthcare system: A look at the future: Workshop summary*, The National Academies Press, Washington, DC, 149-170, 2011.
5. Nelson EC, Batalden PB, Godfrey MG, Lazar JS: *Value by Design: Developing Clinical Microsystems to Achieve Organizational Excellence*, Jossey-Bass, 2011.
6. Hvitfeldt H, Carli C, Nelson EC, Mortenson DM, Ruppert BA, Lindblad S. Feed Forward Systems for Patient Participation and Provider Support; Adoption Results from the Original US Context to Sweden and Beyond. *Quality and Safety in Health Care*, 18(4); 247-256, October-December 2010.
7. Swensen SJ, Meyer GS, Clancy CM, Nelson EC, Hunt, Jr GC, Pryor DB, Weissberg JI, Kaplan GS, Daley JD, Yates GR, Chassin MR, James BC, Berwick DM: Cottage Industry to Post-Industrial — The Revolution in Health Care Delivery. *New England Journal of Medicine*, e12(1)-e12(4) 10.1056/nejmp0911199 nejm.org, February 2010.
8. Weinstein JN, Brown PW, Hanscom B, Walsh T, Nelson EC: Designing an Ambulatory Clinical Practice for Outcomes Improvement: From Vision to Reality - The Spine Center at Dartmouth-Hitchcock, Year One. *Quality Management in Health Care*, 8(2):1-20, Winter 2000.



# Leslie Kelly Hall

## Senior Vice President, Policy

### Healthwise

**HHS: Appointee: Office of the National Coordinator**

**Health Information Technology Standards Committee**

**Chair: Patient/Consumer Technology**

**Health Information Technology Policy Committees**

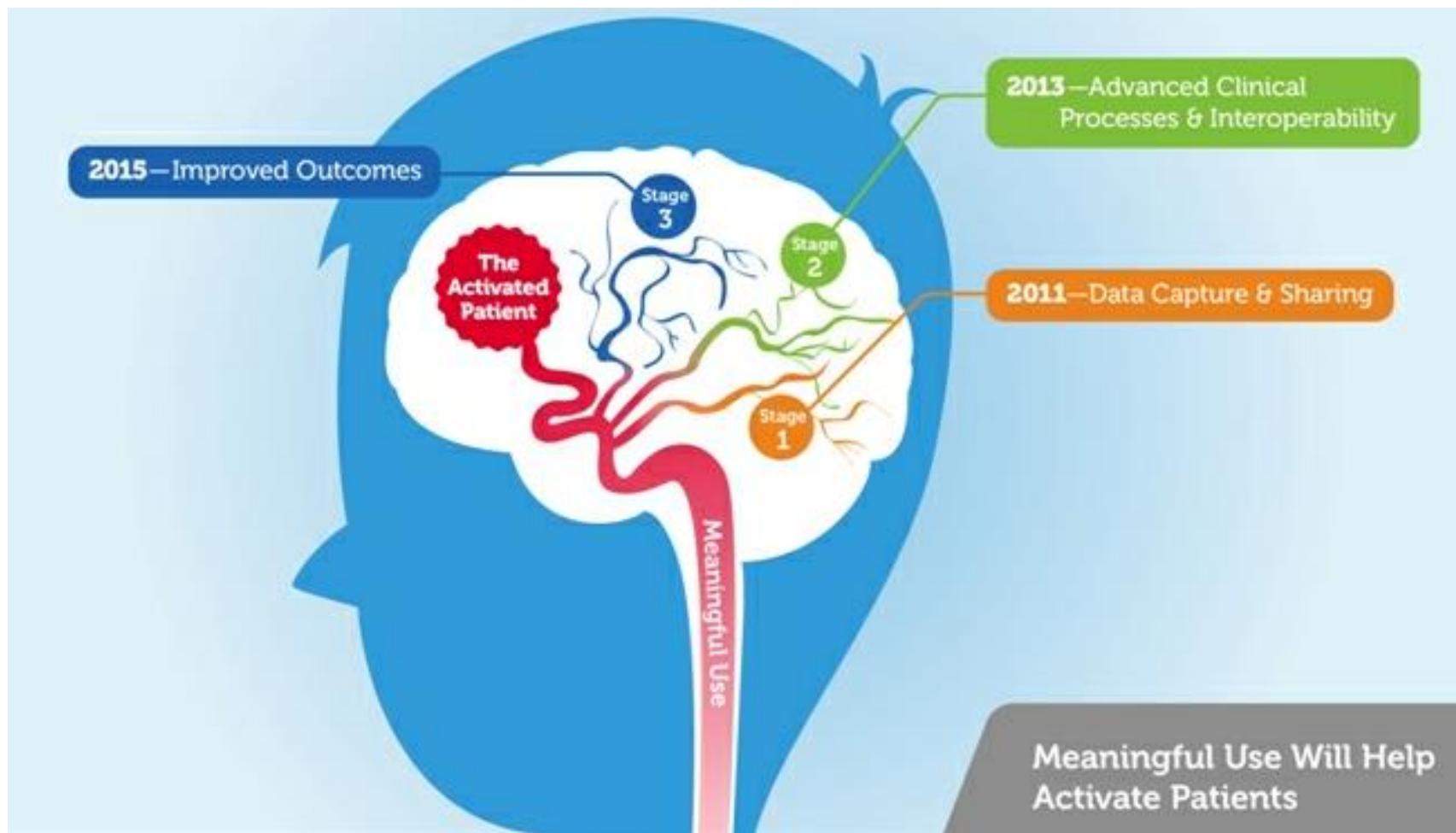
**Patient/Consumer Empowerment**

**Meaningful Use**

**Patient Generated Health Data**

**National E-Health Collaborative: Board Member & Chair Consumer Consortium**

**DirectTrust.org: Board Member & Chair Patient Engagement**



**4019 Hospitals**

**299,402 Providers**

**\$ 15,884,674,565**

<http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/DataAndReports.html>



A portrait of a woman with shoulder-length brown hair and glasses, wearing a pink cardigan over a white shirt. She is looking slightly upwards and to the right with a neutral expression.

# Peggy Jo My Story

*I am a Contributing  
Care Team  
Member...*

*Nothing About  
Me Without Me...*

*How Do I Compare?...*

*PFS should not be  
encumbered by EHR...*

*EHR Action: PFS  
Reaction*

*Nothing About Me  
Without Me...*



# Nothing About Me Without Me

*Understandable to Me:  
Plain language and my  
language...*

# Nothing About Me Without Me

*Communication based  
upon my preference...*

# Nothing About Me Without Me

CC: Me...

*Some or all of my  
records*

# Nothing About Me Without Me

*My preferences inform  
care, safety and  
decisions...*

# Nothing About Me Without Me

*My access should be  
based upon my  
preference...*

*I am a Contributing Care  
Team Member...*



# I am a Contributing Care Team Member

*I am a credible source  
of information...*

# I am a Contributing Care Team Member

*The data I generate is  
material to care...*

# I am a Contributing Care Team Member

*My goals may be  
episodic, chronic, or  
quality of life...*

# I am a Contributing Care Team Member

*I can contribute to  
quality outcomes...*

# I am a Contributing Care Team Member

*I am part of a care  
team reflected in the  
EHR...*

# I am a Contributing Care Team Member

*I am an important  
safety checkpoint...*

# I am a Contributing Care Team Member

*I am a health data exchange of one...*

# I am a Contributing Care Team Member

*I am an important  
participant in shared  
decision making...*

# I am a Contributing Care Team Member

*The messages we  
share are material to  
my health and care*



# *EHR Systems Action: Patient System Reaction*



# EHR Systems Action: Patient System Reaction

*Structured data  
advances all  
systems...*

# EHR Systems Action: Patient System Reaction

*Current workflow can  
adapt to support  
patient engagement...*

# EHR Systems Action: Patient System Reaction

*Expand and harmonize  
standards ...*

# EHR Systems Action: Patient System Reaction

*Create once use  
often...*

# EHR Systems Action: Patient System Reaction

*View, download and  
transfers may be  
directed by me*

# EHR Systems Action: Patient System Reaction

*Orders can be directed  
to me...*

# EHR Systems Action: Patient System Reaction

*I am the only source of  
adherence  
information...*

# EHR Systems Action: Patient System Reaction

*Data reconciliation and  
curating should include  
the me*

# EHR Systems Action: Patient System Reaction

*Metadata helps my  
system too...*

*Patient Facing Systems  
should not be encumbered  
by legacy technology...*



# Patient System: Not Legacy, NEW

*Innovation should be  
encouraged not  
limited...*

# Patient System: Not Legacy, NEW

*Consumer standards  
for EHR data out,  
Provider standards for  
EHR data in ...*

# Patient System: Not Legacy, NEW

*When I view, download  
or transmit I should  
have opportunities to  
be educated...*

# Patient System: Not Legacy, NEW

*Data I generate should  
be interoperable with  
all...*

# Patient System: Not Legacy, NEW

*Accelerate standards  
where patient  
generated data likely...*

# Patient System: Not Legacy, NEW

*Consumer and health  
vocabularies should be  
standardized and  
harmonized...*

# Patient System: Not Legacy, NEW

*New design should be  
with the patient in  
mind...*

*How Do I Compare?...*



# How Do I Compare?

*Patient specific  
dashboards; me  
compared to others...*

# How Do I Compare?

*My trajectory of health  
can be impacted by my  
actions...*

# How Do I Compare?

*I know what research  
is available to me...*

# How Do I Compare?

*I know what research  
has been effective for  
people like me...*

# How Do I Compare?

*I want to know the care I should be getting...*





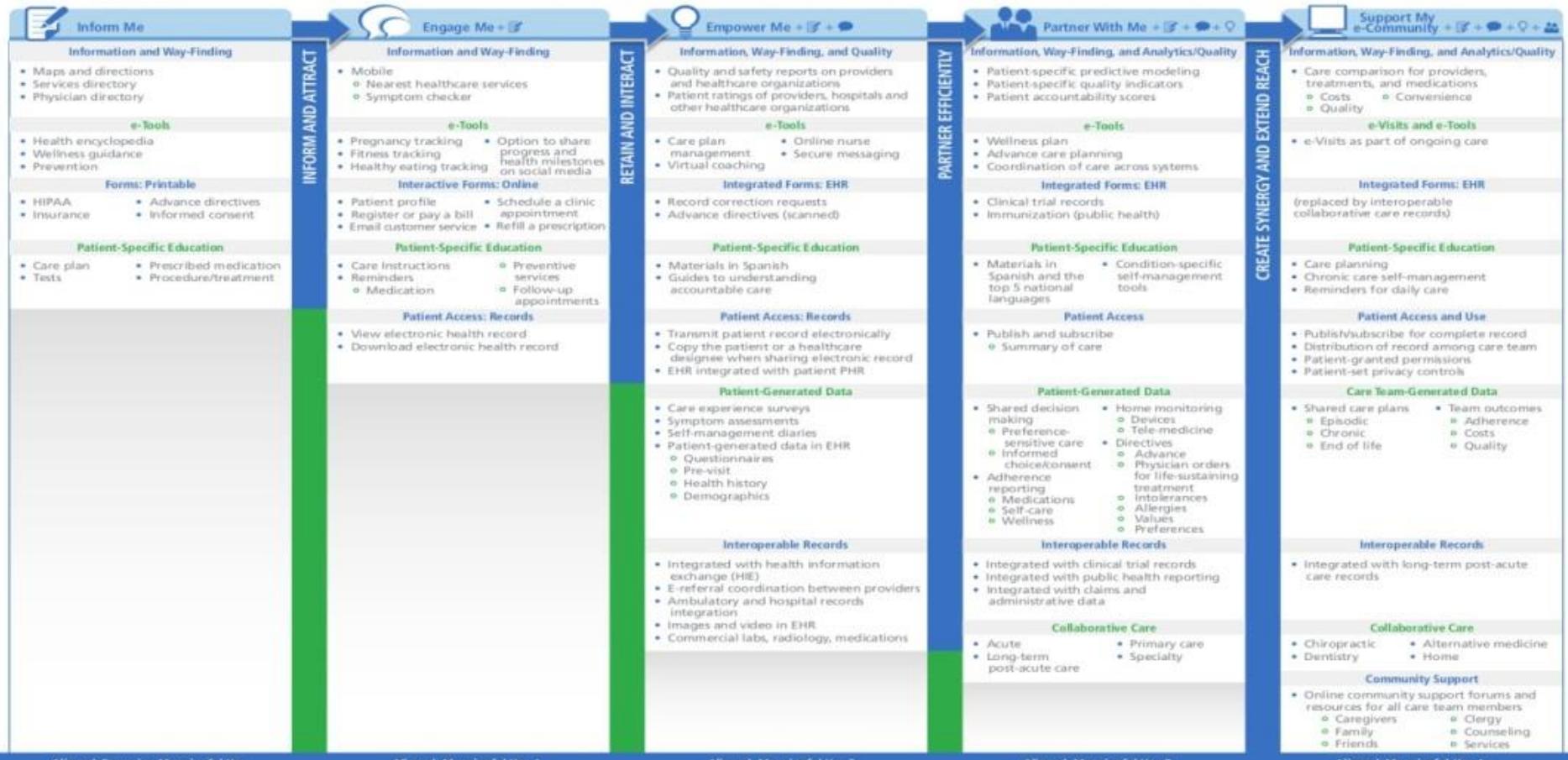


Roadmap



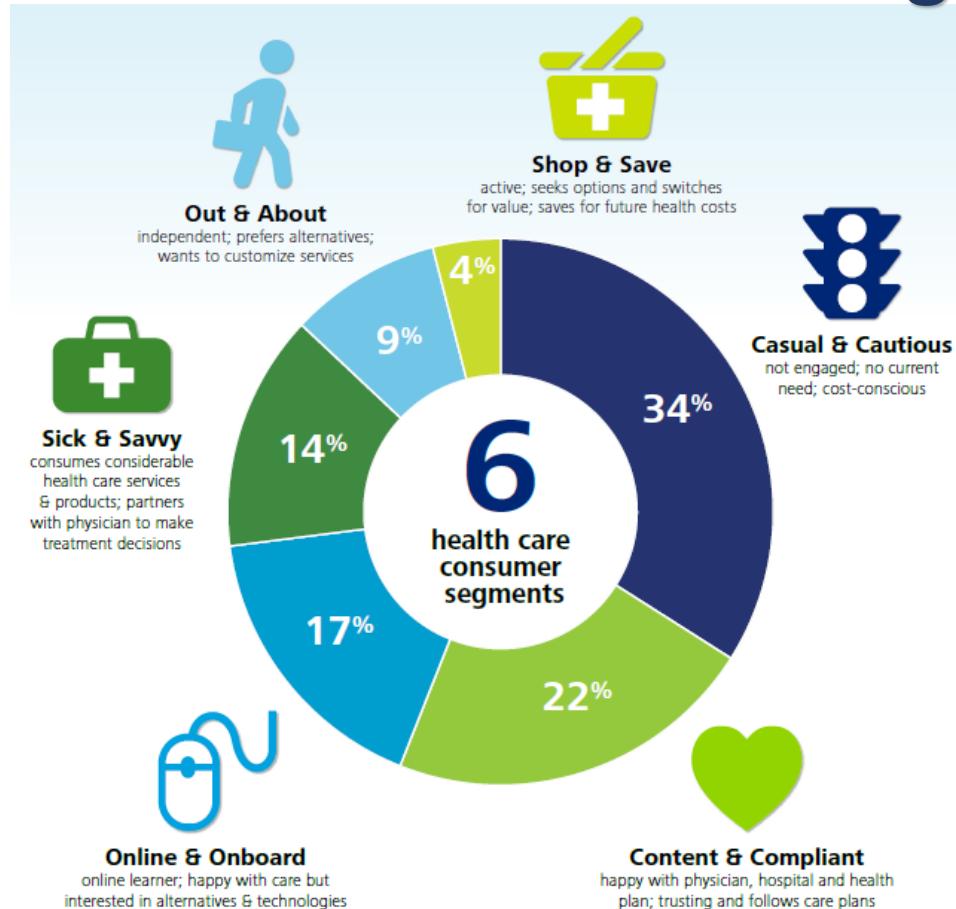


## PATIENT ENGAGEMENT FRAMEWORK





# Six Healthcare Consumer Segments



# DRAFT: My Medical Records Experience Map (within Patient Engagement Framework)

## Key Assumptions We're Making

-----Most patients will seek their records out of necessity, not curiosity..... others

## Patient Journey (first person perspective – in patient's words/language)

PEF Stage:      **Inform Me**      **Engage Me**      **Empower Me**      -----      **Partner with Me**      **Support My e-Community**



## How I'm Using My Record

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## Things I'm Doing

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## Things I'm Feeling

---

## Things I'm Thinking

---

## My Records Experience is About...

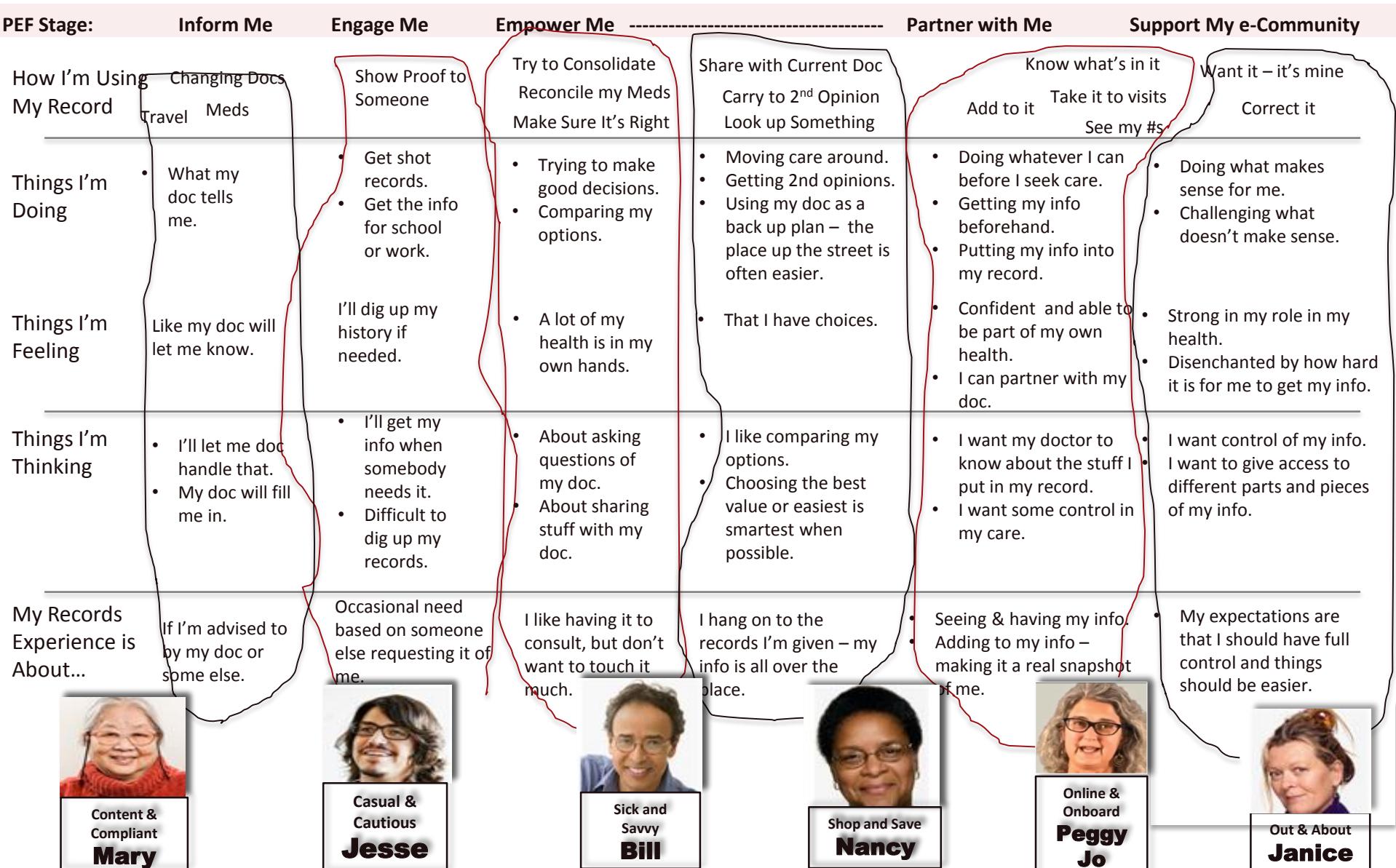
# DRAFT: My Medical Records Experience Map (within Patient Engagement Framework)

Credits: Based on Deloitte's US Health Care Market Consumer Segmentation and the Patient Engagement Framework. Patient Journey Map framework based on published work by Adaptive Path. Stock images used with permission.

## Key Assumptions We're Making (need validation)

Most patients will seek their records out of necessity, not curiosity..... others

## Patient Journey (first person perspective – in patient's words/language)





Thank you!  
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