

# *Learning Health Systems: Using Patient-Reported Outcomes to Improve Care Delivery And Real-World Discovery Research*



# CHOIR

Collaborative  
Health Outcomes  
Information Registry

**Sean Mackey, MD, PhD**

Redlich Professor

Chief, Division of Pain Medicine

Director, Stanford Systems Neuroscience and Pain Lab

Stanford University

<http://paincenter.stanford.edu>

<http://snapl.stanford.edu>

[smackey@stanford.edu](mailto:smackey@stanford.edu)

Twitter: @DrSeanMackey



# Disclosures – Funding Sources

NIH Pain Consortium – Partial funding for CHOIR

- HHSN 271201200728P

National Center of Complementary and Integrative Health (NCCIH)

- P01 AT006651
- R01AT008561

National Institutes of Drug Abuse (NIDA)

- K24 DA029262
- T32 DA035165
- R01DA035484

Redlich Pain Research Endowment

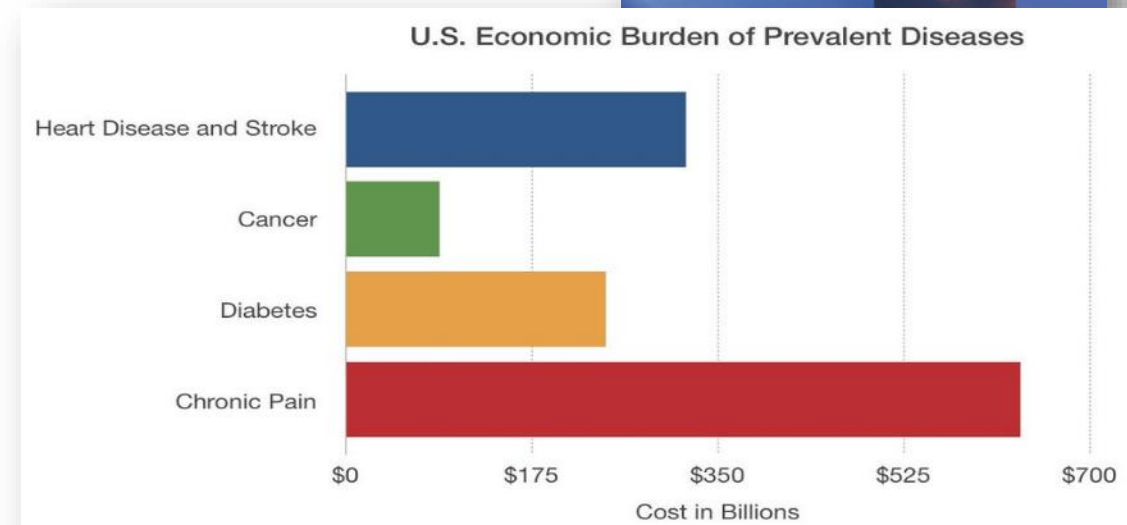
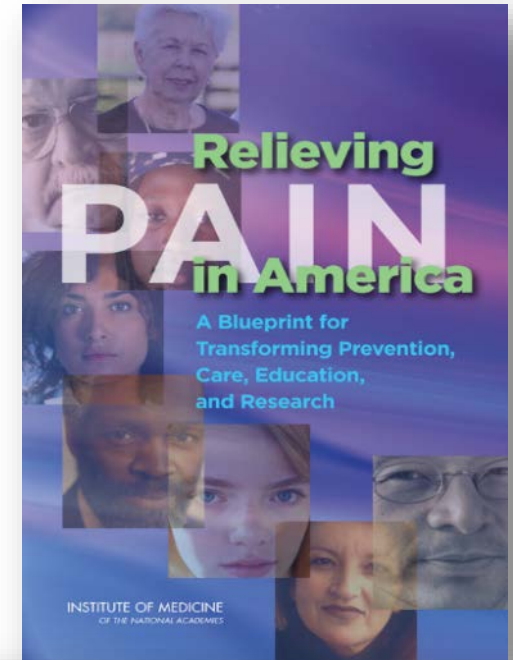
Dodie and John Rosekrans Pain Research Endowment

*No industry conflicts*

# Pain is a Public Health Problem

## *Relieving Pain in America A Blueprint for Transforming Prevention, Care, Education, and Research*

- Up to \$635 billion annually
- Chronic pain can become a disease in its own right
- Reduces quality of life
- Undertreated
- Disparities in prevalence and care
- **Need better data!**





### Prevention & Care

Increase substantially the accessibility and quality of pain care



High Impact Pain



Chronic Pain



Acute Pain

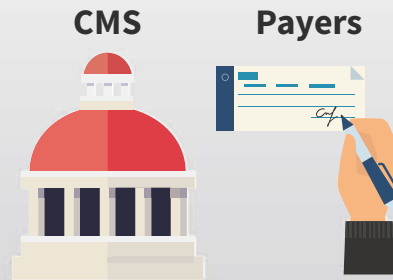
### Population Research

Improvements in state and national data are needed



### Disparities

Under-treatment and inappropriate treatment of pain among racial and ethnic minorities



### Services & Reimbursement

Public health entities have a role in pain care and prevention

Nursing Psychology

PCP

Pain MD

APP

PT



### Professional Education

Improve professional education of all providers



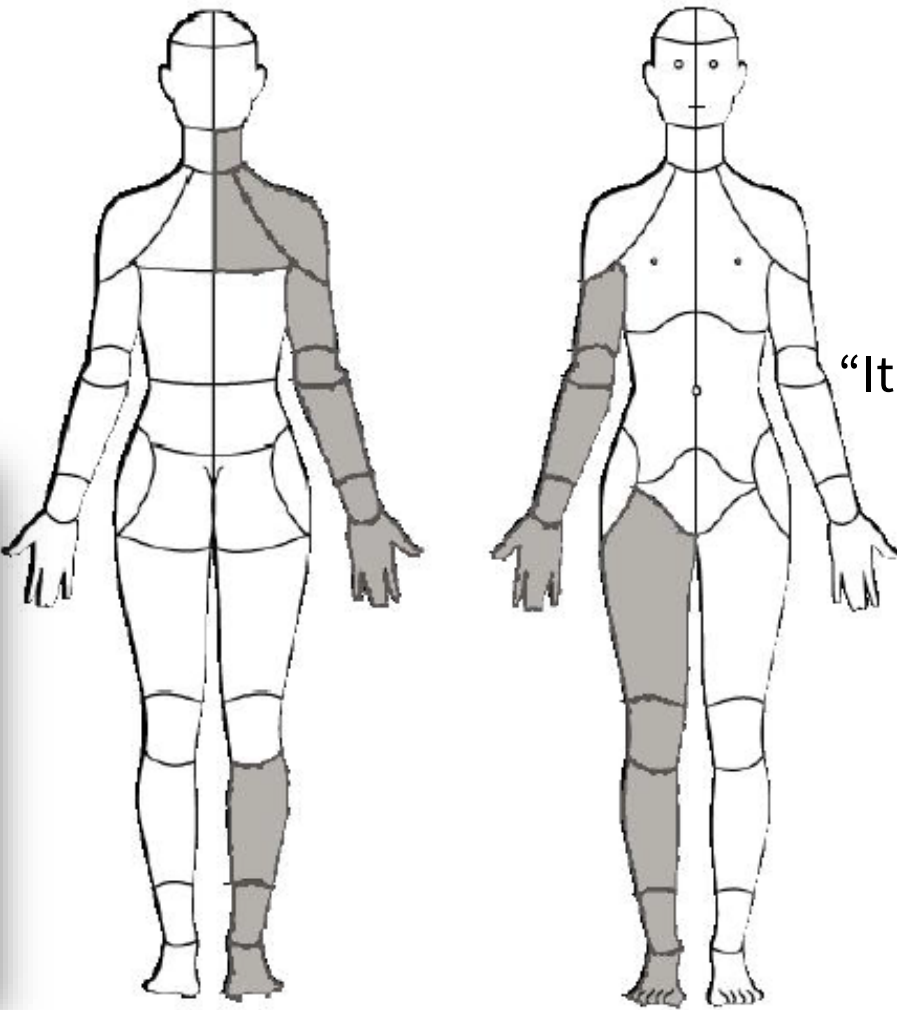
### Public Education & Communication

High quality, evidence based education programs for patients and the public

# National Pain Strategy



# Sandra with Complex Regional Pain Syndrome (CRPS)

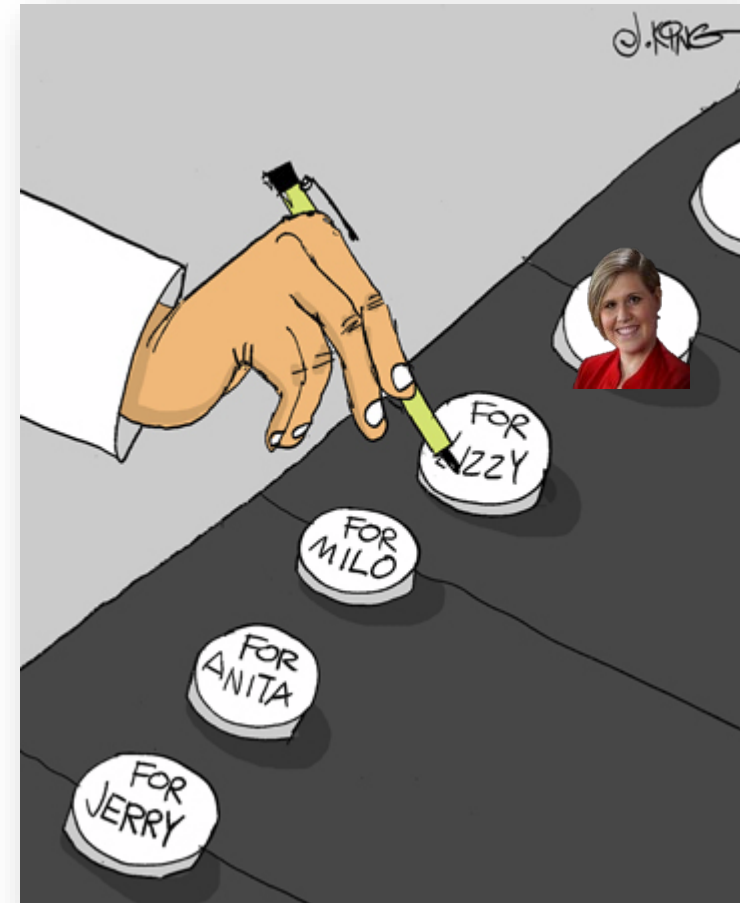


“It’s that feeling, if you’re digging through the bottom of a cooler, and you just get that burning sensation because your arm is so cold,”



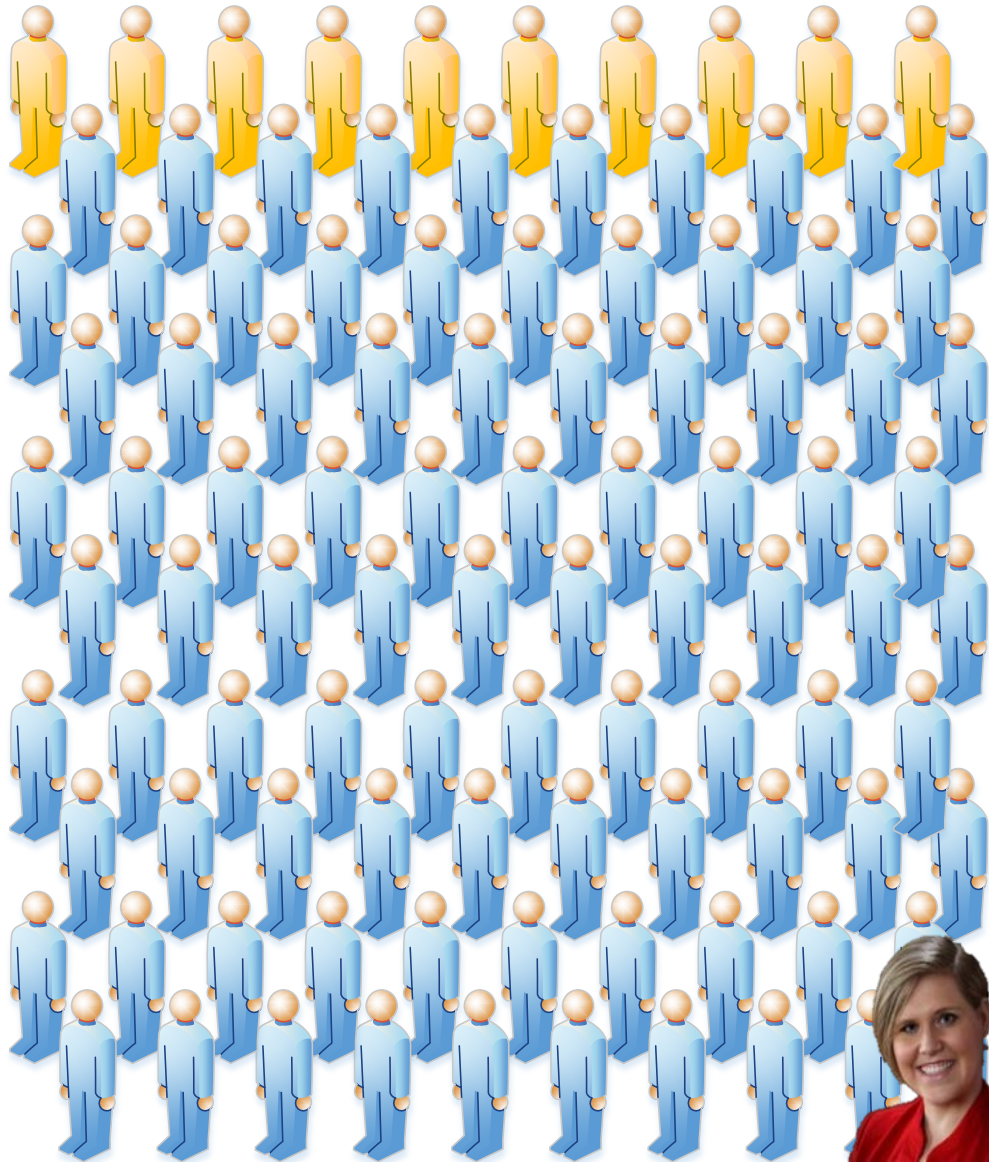
How do you know whether you have made Sandra better?

How do you know when a certain treatment is better than another for a specific patient?





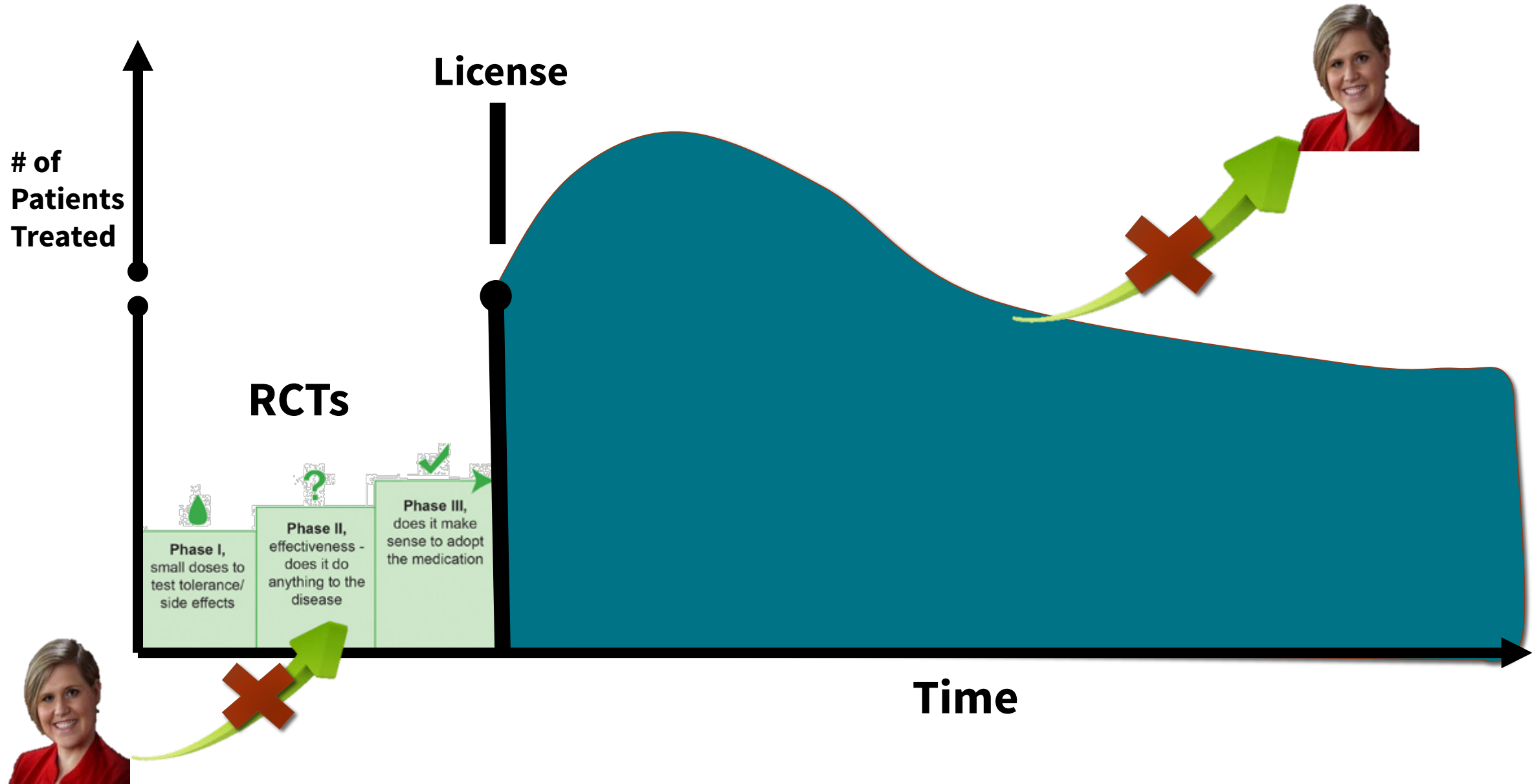
# The Problem with Randomized Controlled Trials and Chronic Pain



10% of persons with chronic pain qualify for clinical trials

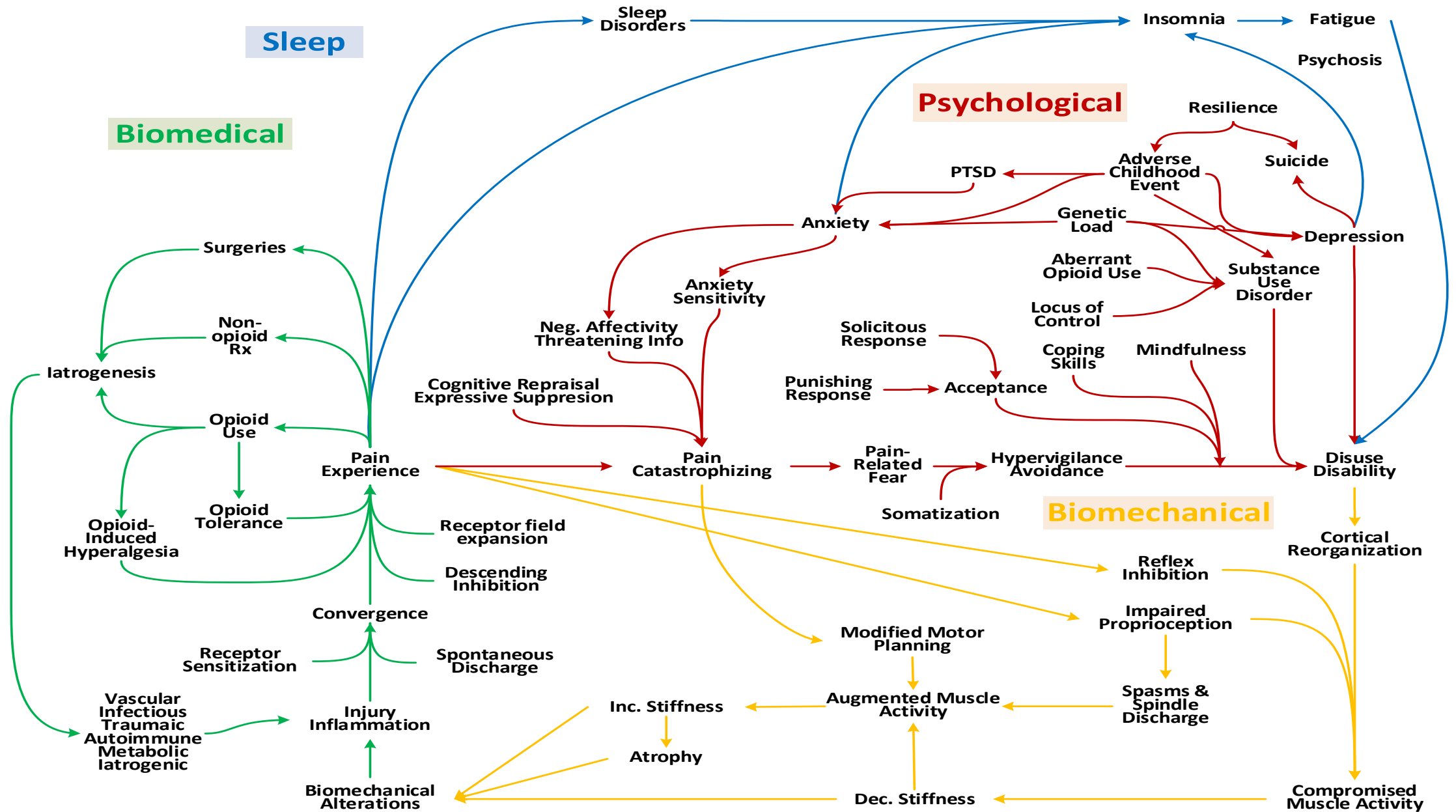
90% do not qualify!!!

# RCTs do not generalize well...and do not address Sandra's condition





# The Systems Challenge and Complexity of Pain



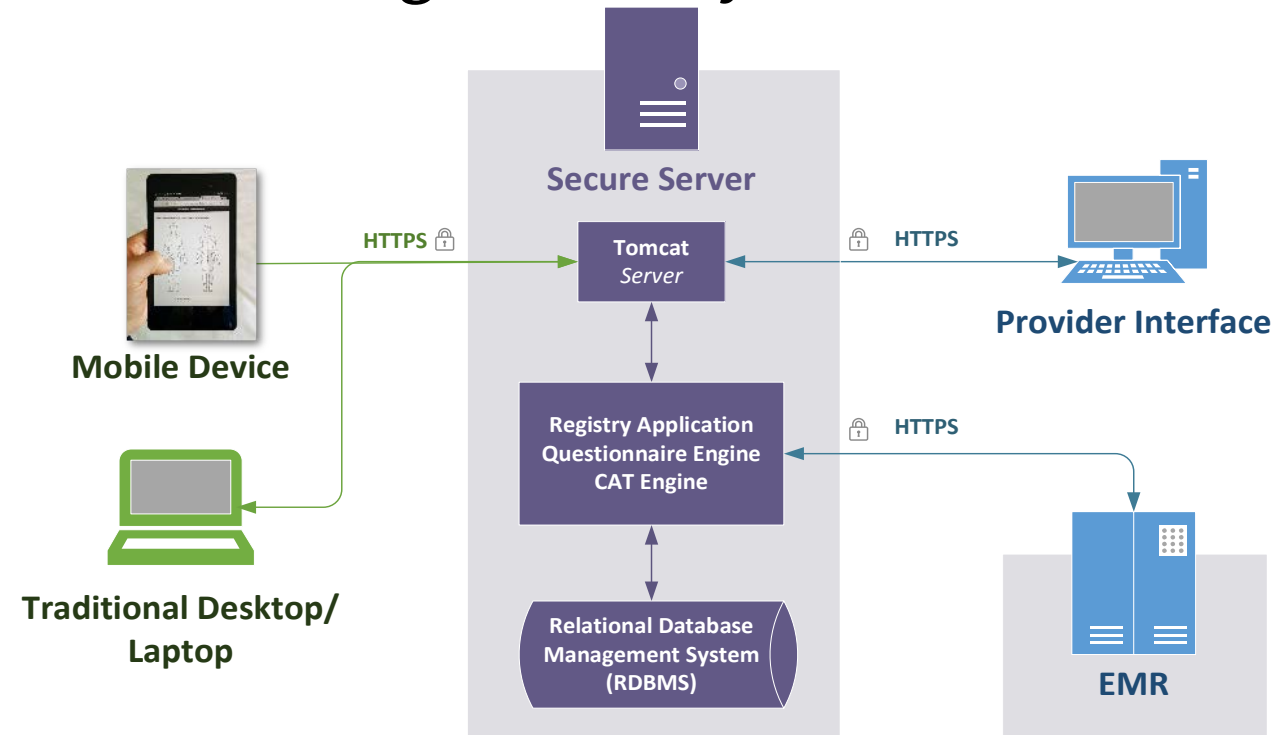
## ***IOM Learning Healthcare Systems:***

*“We seek the development of a **learning healthcare system** in which science, informatics, incentives and culture are aligned for continuous improvement and innovation”*



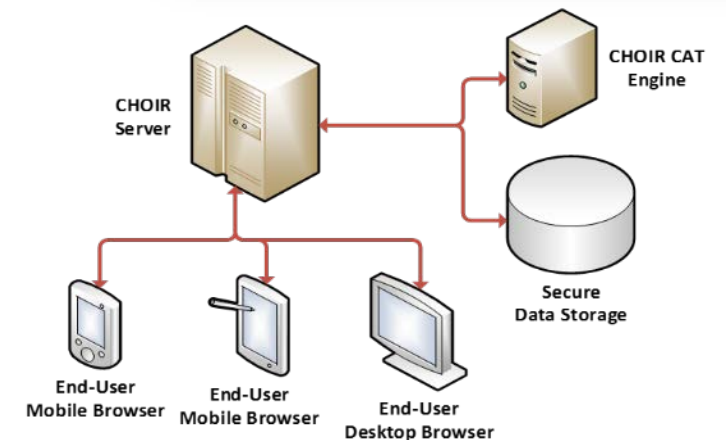
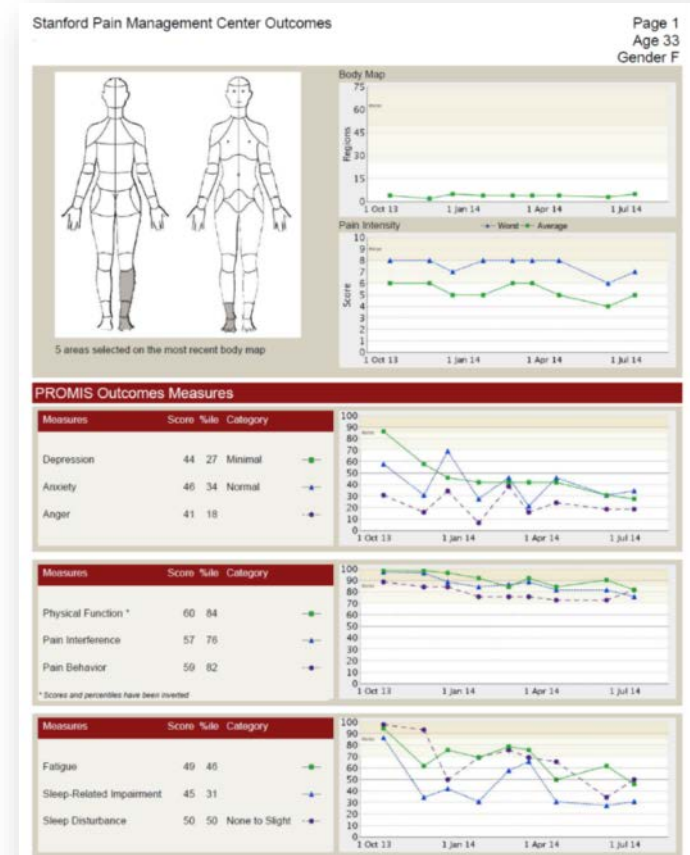
- Open source, open standard, highly flexible, and **free** health and treatment registry and platform for a Learning Health System (<http://choir.stanford.edu>)

- Point of care decision making
- Software based decision making
- Comparative effectiveness research
- Longitudinal outcomes research
- Pragmatic/real-world clinical trials
- Comprehensive assessment of:
  - Physical, psychological and social functioning and global health



# CHOIR: System Features and Status

- Easy to use data entry for patients, staff and clinicians
- Staff and patient engagement
- Clinical workflow support (e.g. notify patient of survey URL prior to clinical appointment)
- Point of care reporting
- Over 20,000 patients and 60,000 longitudinal data assessments
- **Changed the culture of how we care for patients!**



# The Power of PROMIS

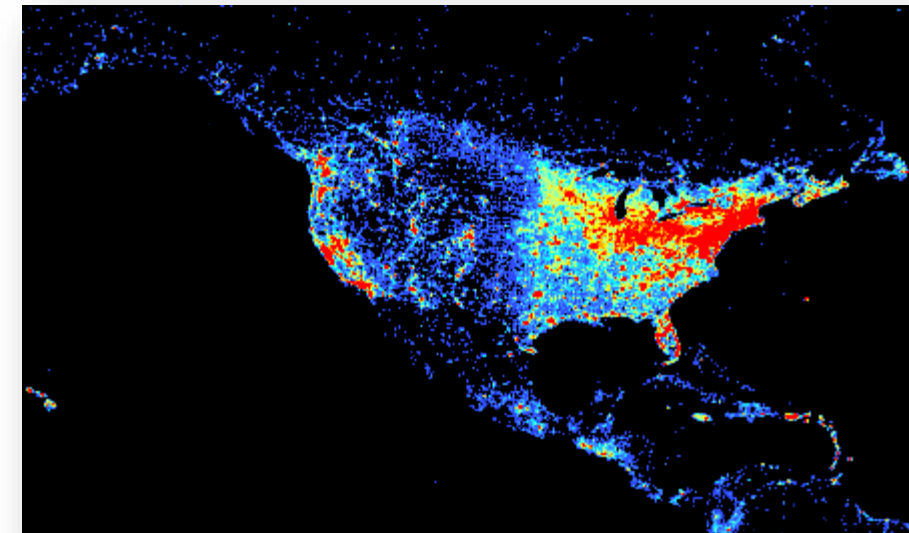


## Computer Adaptive Testing (CAT)

Reduces time to characterize domain of interest

Normative scores referenced to the US general population

Mean = 50, SD = 10





# Stanford Pain Management Center

- Interdisciplinary, coordinated comprehensive approach to pain management
- Use of validated outcomes assuring optimal patient assessment and care
- Over 20,000 patient visits (2016)
- 21 Physician Pain Faculty All Boarded in Pain Medicine
  - Anesthesiology
  - Internal Medicine
  - Physiatry
  - Neurology
  - Addiction Medicine
- 4 Pain Psychologists Faculty
  - Pain Psychology training program
- Physical therapy, Nutrition, Biofeedback, Acupuncture
- Strong connection and translation with pain research group





# Stanford Pain Management Center: Integrated Comprehensive Model of Care

**GI Pain**  
(Collaboration  
with GI  
Medicine)

**Headache**  
(Collaboration  
with  
Neurology)

**Pelvic Pain**  
(Collaboration  
with Urology)

**Orofacial Pain**  
(Collaboration  
with Dentistry,  
ENT, Neurology,  
Neurosurgery)

**Pain and  
Addiction**  
(Collaboration  
with  
Psychiatry)

**Peripheral  
Nerve Pain**  
(Collaboration  
with  
Radiology,  
Plastic  
Surgery)

## **Stanford Pain Management Center**

Pain Medicine Physicians, Pain Psychology, Physical  
Therapy, Nutrition, Acupuncture, Biofeedback,  
Nursing, Pain Registry, Research Infrastructure

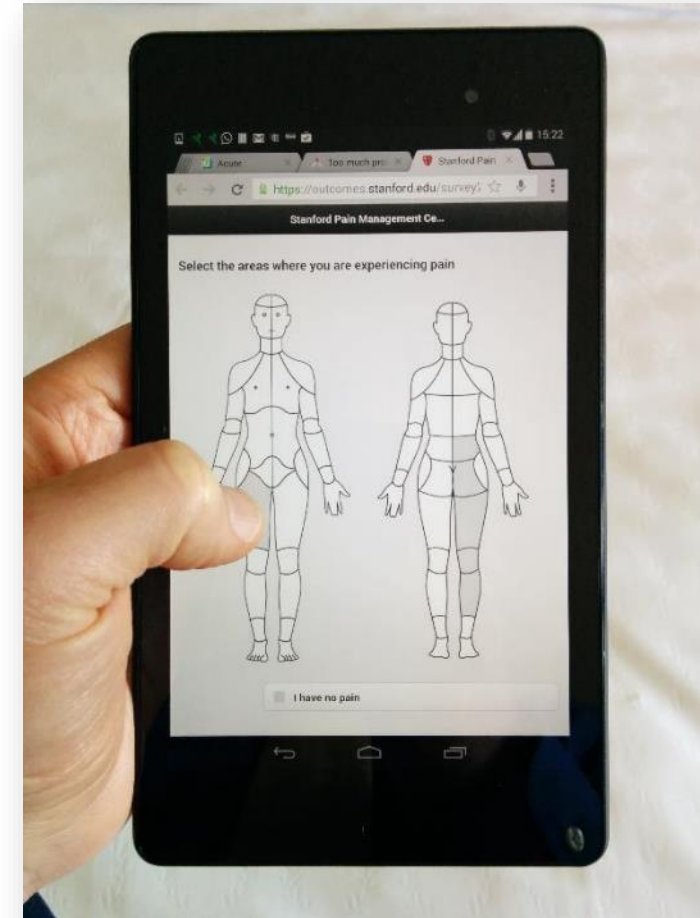
## Initial and Follow-Up Surveys




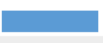

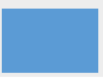












- **Initial Survey – 22 min**

- Demographics
- Prior Treatments, Pain Beliefs
- Interactive Body Map
- PROMIS 14 domain measures:
  - Pain Intensity, Pain Behavior, Pain Interference, Fatigue, Physical Function, Depression, Anxiety, Sleep Disturbance, Sleep Related Impairment, Social Functioning
- Opioid Risk Tool
- Pain Catastrophizing Questionnaire (PCS)

- **Follow up Survey – 9 min**

- Interactive Body Map
- PROMIS 14 domain measures as above
- PCS



CHOIR CAT		Legacy		Burden Reduction	
Domain	# Items CHOIR CAT v1	Instrument	# Items		
Anger	6.24 ± 1.21	Buss-Perry Aggression Questionnaire (BPAQ)	29		 78%
Anxiety	4.93 ± 0.97	Generalized Anxiety Disorder 7-item (GAD-7)	7		 30%
Depression	4.97 ± 1.07	Beck Depression Inventory II (BDI-II)	21		 76%
Fatigue	4.78 ± 0.76	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	40		 88%
Physical Function	4.11 ± 0.48	Health Assessment Questionnaire-Disability Index (HAQ-DI)	20		 79%
Pain Interference	4.19 ± 0.71	Brief Pain Inventory	7		 40%
Sleep Disturbance	4.95 ± 1.41	Sleep Disorders Questionnaire (SDQ)	12		 59%
Sleep-Related Impairment	4.54 ± 1.24	Epworth Sleepiness Scale (ESS)	8		 43%
38.7 ± 7.9		144			 73%

## Why not use **Epic** or your favorite electronic medical record (EMR)?

- Short version – you can't do it.
- Computational complexity of modern patient reported outcomes (PROs) are beyond what can be provided by traditional EMR.
- With modern PROs, software decision support, and development of learning based systems, need rapid algorithm development and frequent code revisions.
- Solution is to off-load modern PRO processing/infrastructure to a separate system
- Also allows rapid development and implementation of features

# CHOIR's ability to rapidly iterate and improve

## EMR code review/release process

- A necessity given the wide ranging critical roles of EMRs
- **Typically measured in months**



## CHOIR code review/release process

- IOM released report on April 28, 2015
- Mackey sent to group at 3:14pm
- CHOIR Provider new Core Metrics user interface live on April 30, 2015 at 7:31am



WELL-BEING Physical 96 Mental 86



ADDICTIVE BEHAVIOR Drugs No Smoking No Alcohol No



SOCIAL SUPPORT Soc Isolation 50

- **CHOIR: from concept to live beta in 40 hours**

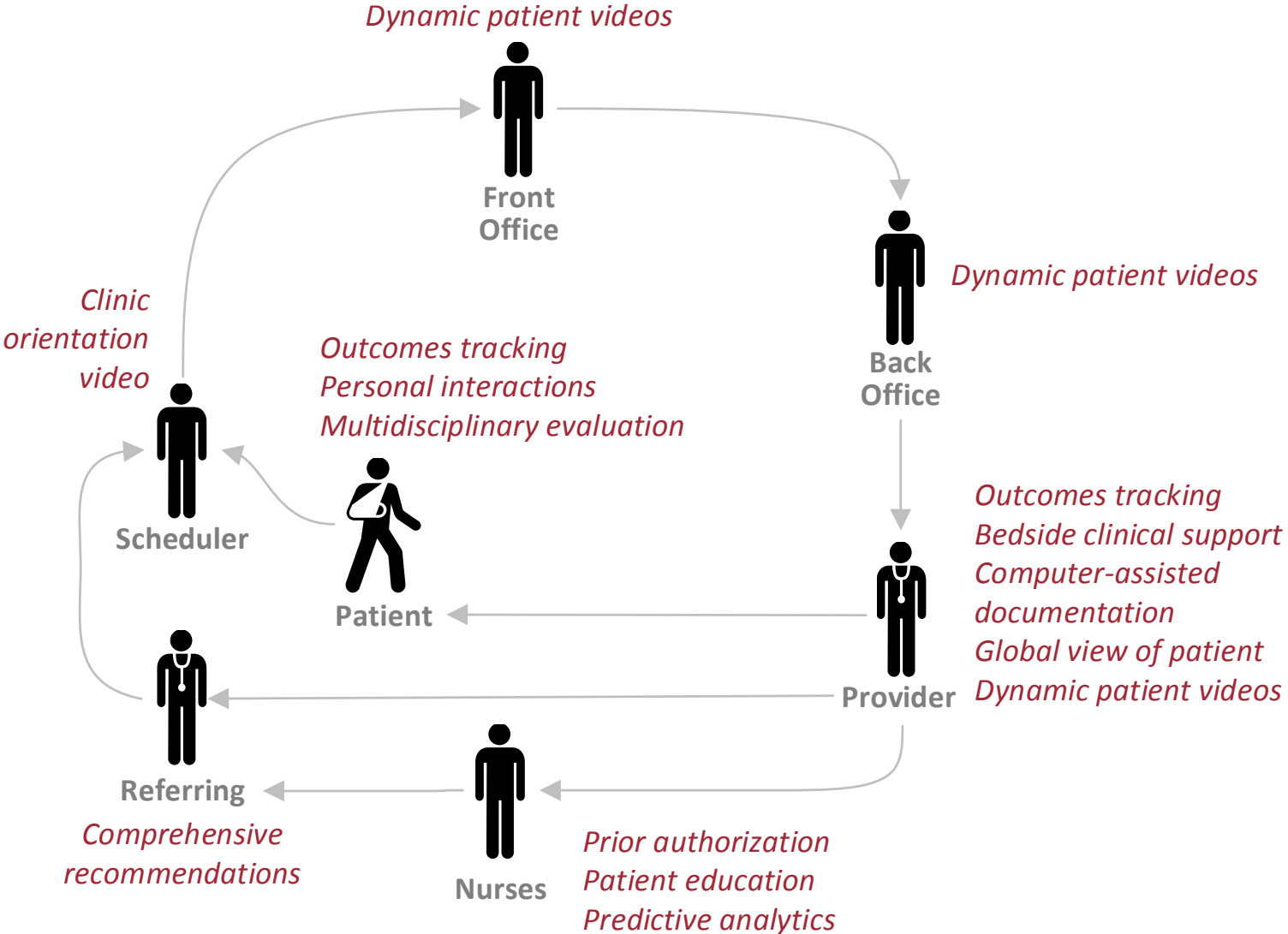
## Why not use



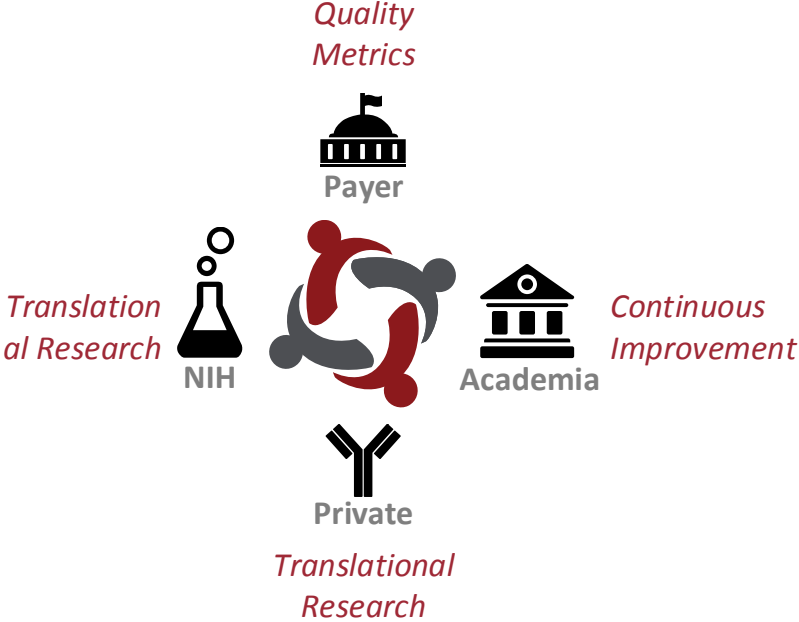
- REDCap more project centric; CHOIR is more patient centric
- Patient experience is not performant (network and engine latency for official remote service)
- Significant customization required for automated assessments based on scheduled appointments
- Significant customization required for PDF physician reports
- No streamlined user interfaces and workflows for new patient coordinators and clinic front desk
- Details of how assessments are implemented (security, sessions, restarting where left off) are more carefully thought through than REDCap (biased opinion)



# #1 Reason for clinical informatics system failure: Lack of buy in



CHOIR is designed to provide value to all stakeholders in the patient's experience

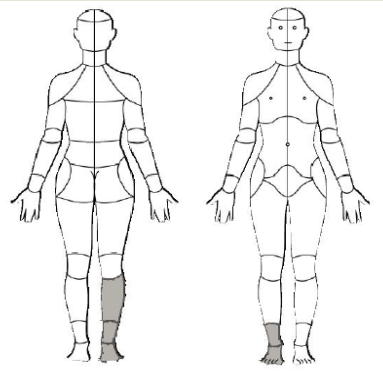


# CHOIR Provider: Clinically useful reports and tools to aid assessment and decision making

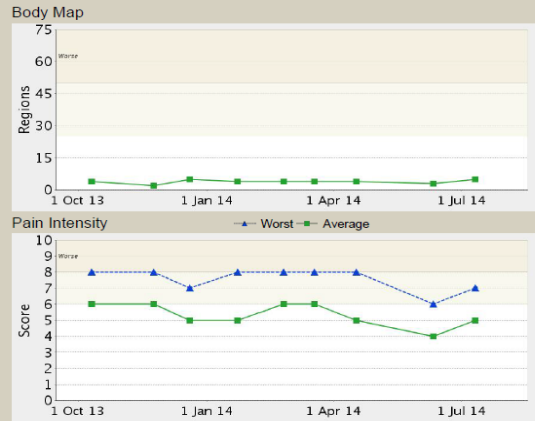


Stanford Pain Management Center Outcomes

Page 1  
Age 33  
Gender F



5 areas selected on the most recent body map



## PROMIS Outcomes Measures

Measures	Score	%ile	Category
Depression	44	27	Minimal
Anxiety	46	34	Normal
Anger	41	18	

Measures	Score	%ile	Category
Physical Function *	60	84	
Pain Interference	57	76	
Pain Behavior	59	82	

Measures	Score	%ile	Category
Fatigue	49	46	
Sleep-Related Impairment	45	31	
Sleep Disturbance	50	50	None to Slight

## CHOIR Provider

Rapid Doc

CHOIR Report

Subjectives 1

Objectives

Impression

Instructions

Conditions

Guidelines

Treatments

Experimental

## Subjective

BETA Use the EPIC SmartPhrases .CLINICCHOIRATT and .CLINICCHOIRFELLOW

MRN: [REDACTED]

Age: [REDACTED] Gender: [REDACTED]

WELL-BEING Physical 96 Mental 86 
 ADDICTIVE BEHAVIOR Drugs No Smoking No Alcohol No 
 SOCIAL SUPPORT Soc Isolation 50

### Pain Experience

**Location:** \*\*\*  
**Inciting event:** per patient, "Started suddenly as back pain preoperatively"  
**Duration:** [REDACTED]  
**Timing:** Constant  
**Pain quality:** Stabbing, Sharp, Aching Tiring, Exhausting  
**Intensity:** 5/10 on average, 8/10 at worst  
**Radiation:** \*\*\*  
**Alleviating factors:** Medications, Movement, Sitting  
**Exacerbating factors:** Bedrest and "Being too active"

## CHOIR Primary Care

Guidelines

Opioid Risk Mitigation

Opioid Tapering Guide

Pain Medication Interactions

Rapid Doc

Impression 1

Instructions 1

Major Conditions

CRPS

Total Body Pain

Orofacial Pain & Headache

Nerve Entrapments

## Opioid Risk Mitigation

Stanford Pain Clinic Opioid REMS Algorithm  
 Opioid REMS Tips Sheet  
 AAPM & APS Opioid Treatment Guidelines  
 CURES

Morphine 24 mg/day Methadone 10 mg/day

Daily Dose	Opioid
0 mcg/hr	Buprenorphine transdermal
60 mg	Codeine (Tylenol #3, #4)
0 mcg/hr	Duragesic
15 mg	Hydrocodone
0 mg	Hydromorphone (Dilaudid)

## Opioid Taper Tool

1. Current daily opioids taken

Morphine Eq 200 mg/day 50 SA 150 LA

Short-acting Medication	mg per day
Morphine	0
Hydrocodone	50
Oxycodone	0
Hydromorphone	0

Long-acting Medication	mg per day
Morphine	0
Hydrocodone	0
Oxycodone	100
Hydromorphone	0
Methadone	0

2. Program style Evenly-loaded

3. Program duration 12 weeks

Patients with significant anxiety may need longer durations: PROMIS Anxiety scale

4. Program priority Short- & Long-acting together

Early reduction of short-acting opioid is important to address opioid dependency

5. Prescription frequency Every 4 weeks

Patients with a history of aberrant behaviors may need weekly prescriptions

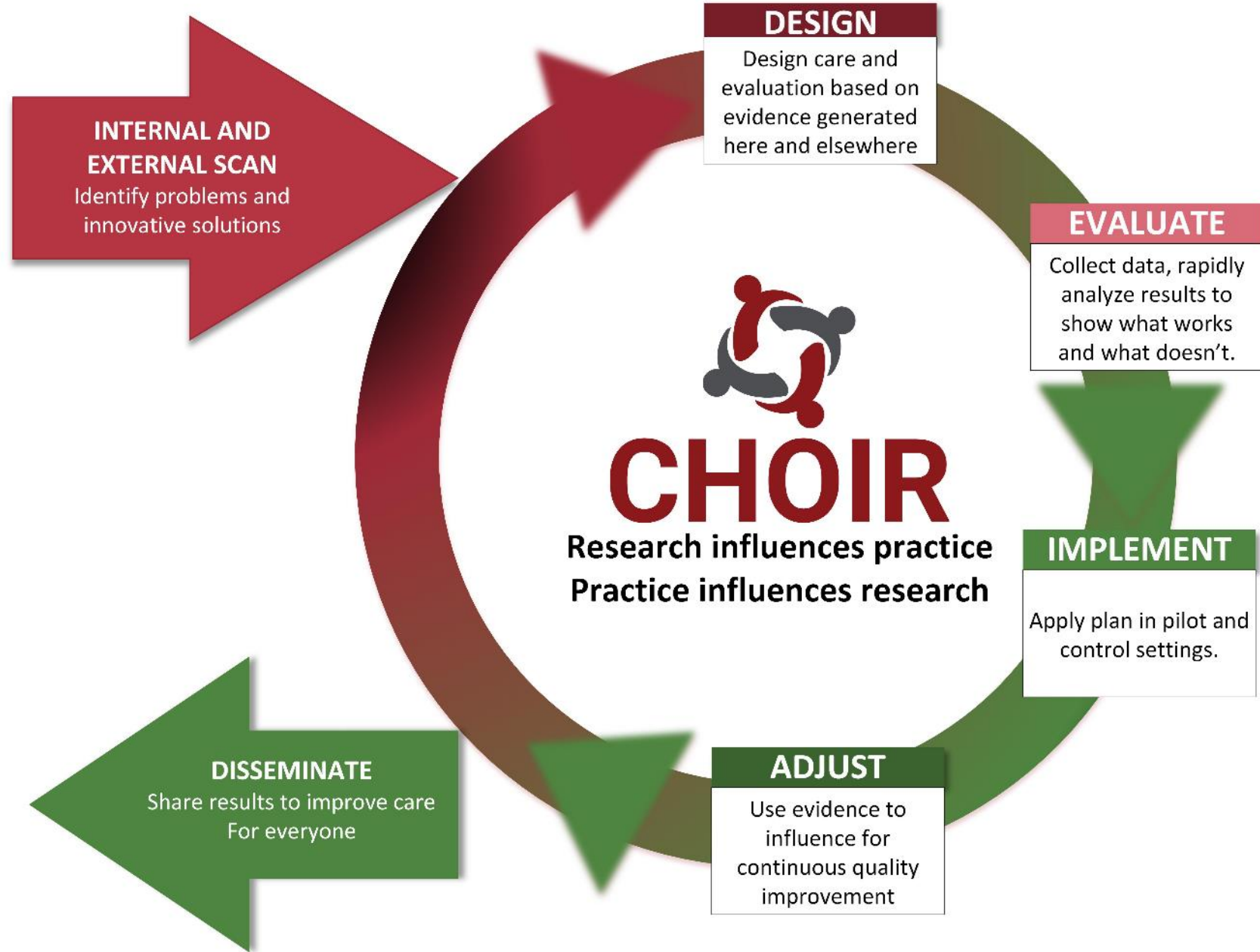
6. Preferred tapering agents

Short-acting Morphine IR  
Long-acting MS Contin

7. Incomplete Cross-tolerance 50% reduction

Morphine Eq 100 mg/day 25 SA 75 LA

# CHOIR as a Platform in Clinical Practice and Research



# CHOIR as a Platform in Pain Research and Clinical Practice

## Research

- Generation of preliminary data
- Dynamic studies of pain
- Systems studies of pain
- Comparative effectiveness
- Large simple trials/pragmatic trials

## Clinical Practice

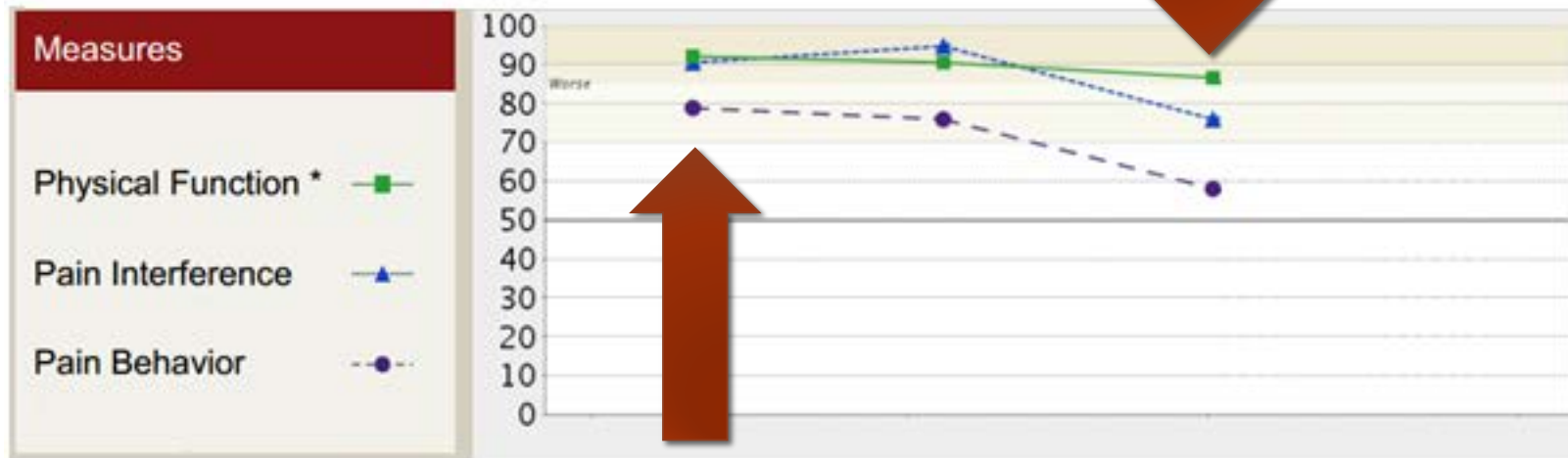
- Recording individual patient data
- Dynamic treatment of pain
- Systems treatment of pain
- Learning based systems of pain



# CHOIR: Using Dynamic Outcomes to Inform Care for Sandra



No change in Function!

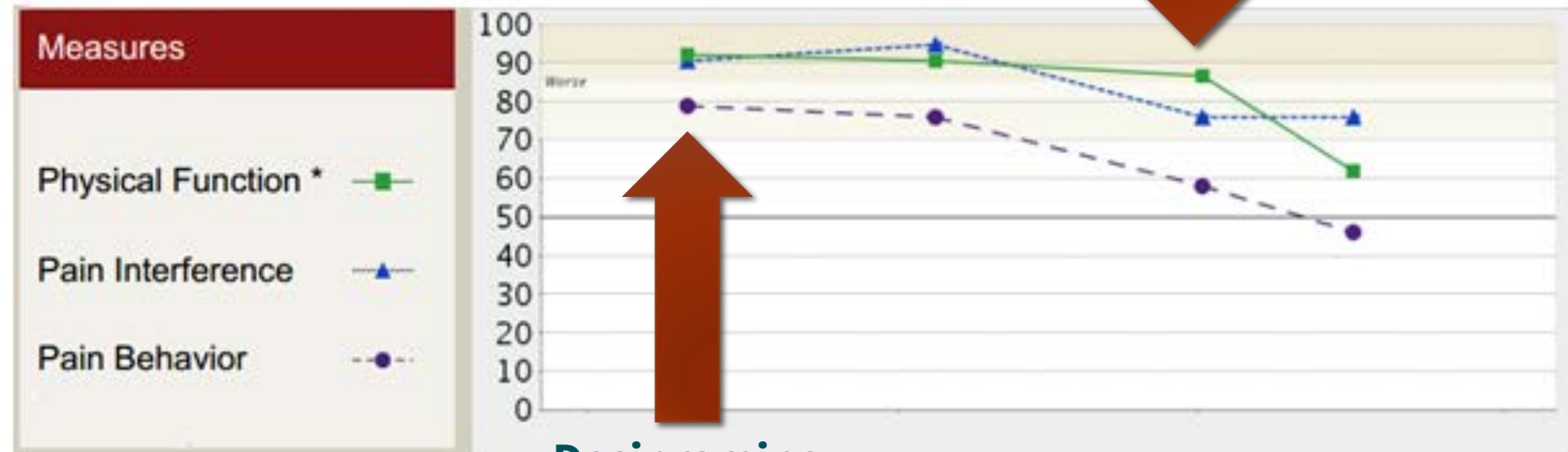


Desipramine  
Low-dose Naltrexone

# CHOIR: Using Dynamic Outcomes to Inform Care for Sandra



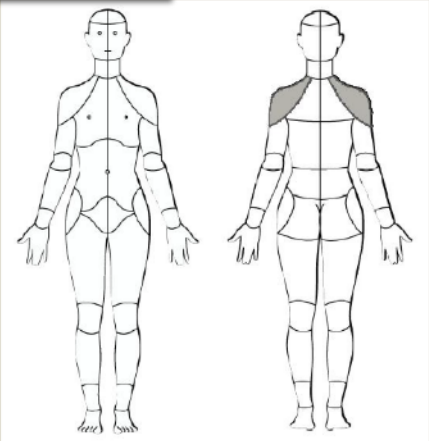
Health Education



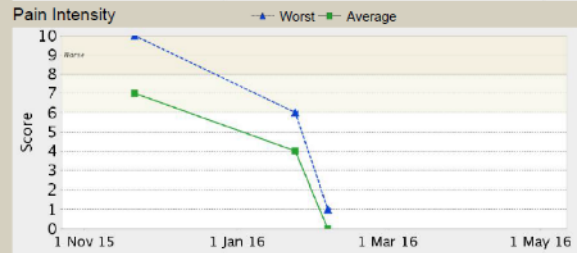
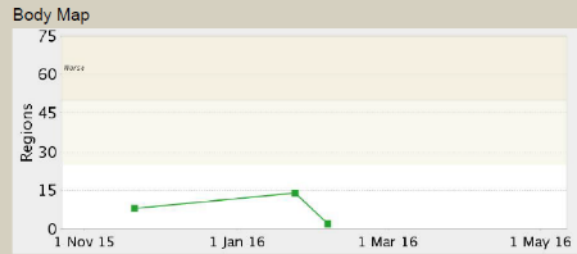
Desipramine  
Low-dose Naltrexone



Age 39  
Gender F

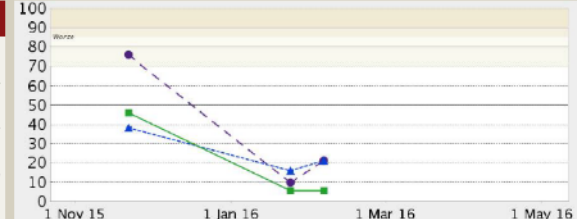


2 areas selected on the most recent body map

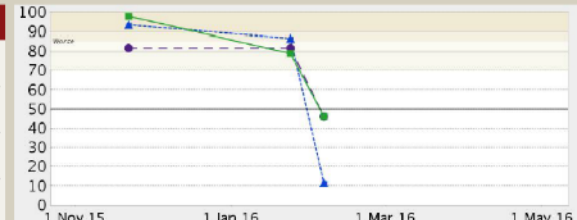


**PROMIS Outcomes Measures**

Measures	Score	%ile	Category
Depression	34	5	None/Minimal
Anxiety	42	21	Normal
Anger	42	21	



Measures	Score	%ile	Category
Physical Function *	50	50	
Pain Interference	38	12	
Pain Behavior	49	46	



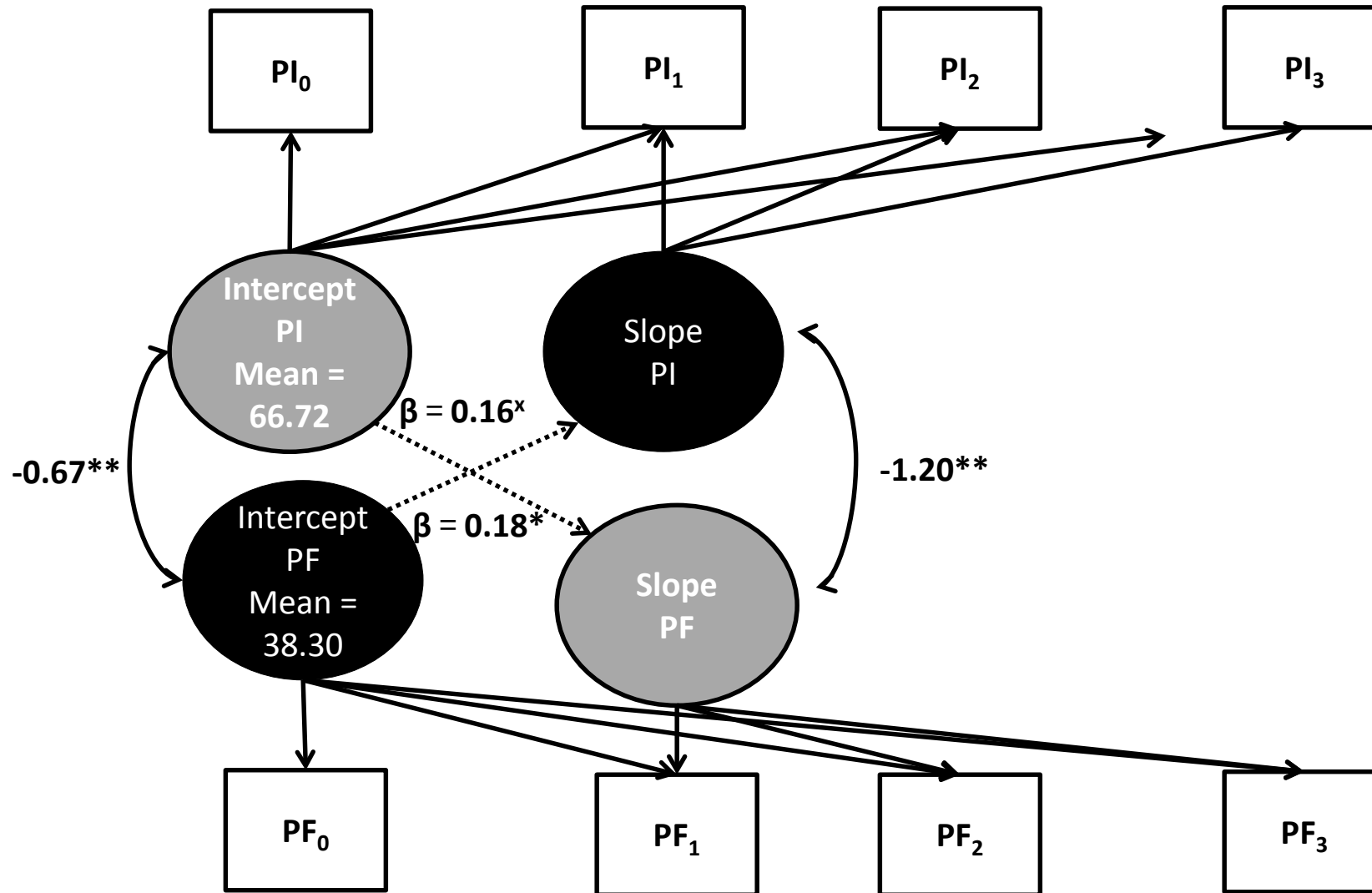
Measures	Score	%ile	Category
Fatigue	32	4	
Sleep-Related Impairment	29	2	
Sleep Disturbance	34	5	None to Slight



**painCatastrophizingScale**

22 Nov 15	24
24 Jan 16	12
06 Feb 16	2

# Physical Function and Pain Interference Only Weakly Related Over Treatment Course



# Using CHOIR to generate “research quality” clinical data

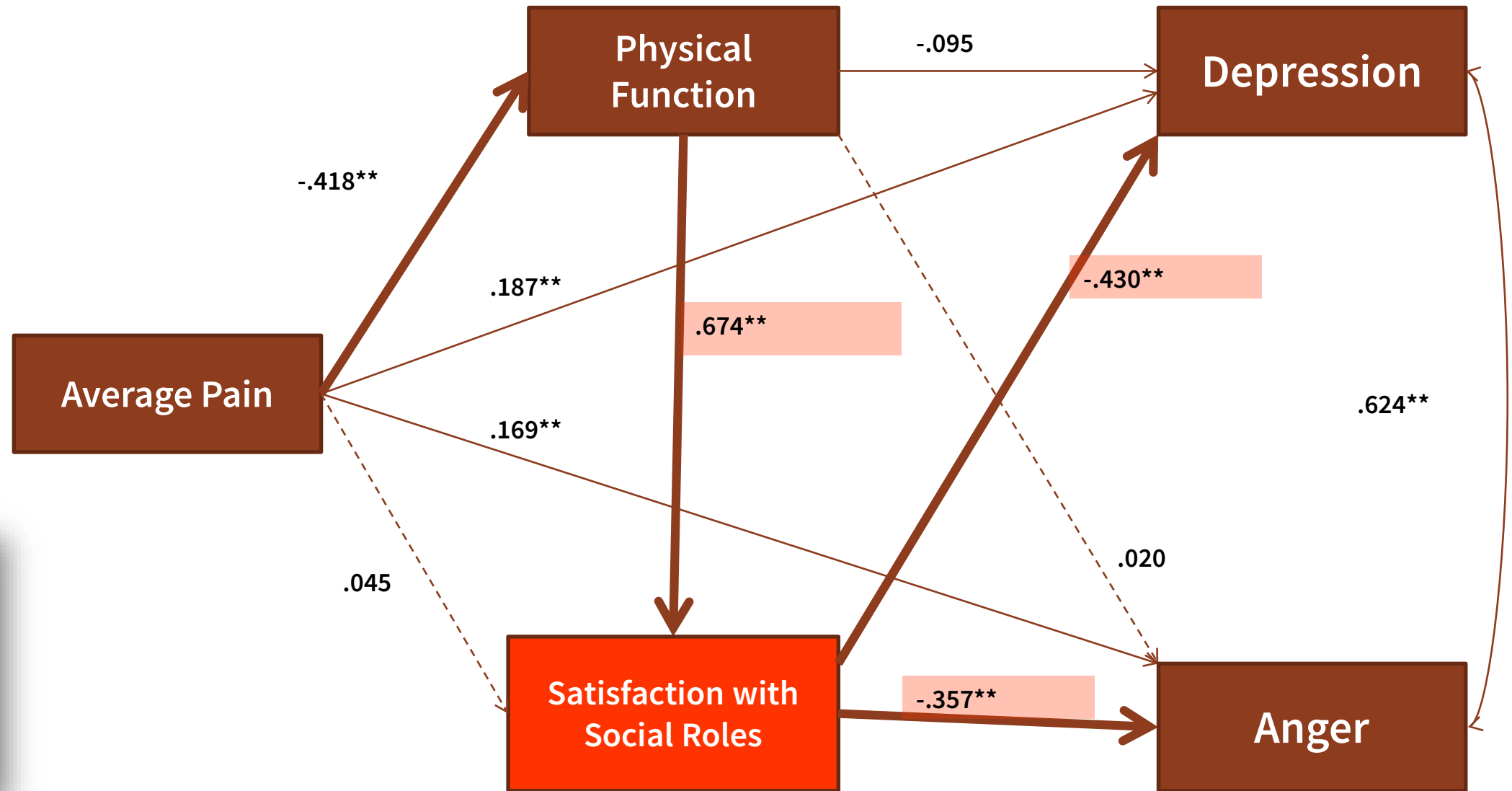
Data with equal quality  
of a clinical trial



Quality data can be used for:

- Clinical trials
  - Pilot data
  - Large simple trial designs
- Clinical decision making
- Improving quality care and monitoring
- Comparative effectiveness research

# Social satisfaction mediates pain-related emotional distress



Sturgeon, J. A., Dixon, E. A., Darnall, B. D., & Mackey, S. C. Contributions of Physical Function and Satisfaction with Social Roles to Emotional Distress in Chronic Pain: A Collaborative Health Outcomes Information Registry (CHOIR) Study. *Pain*. (2015)

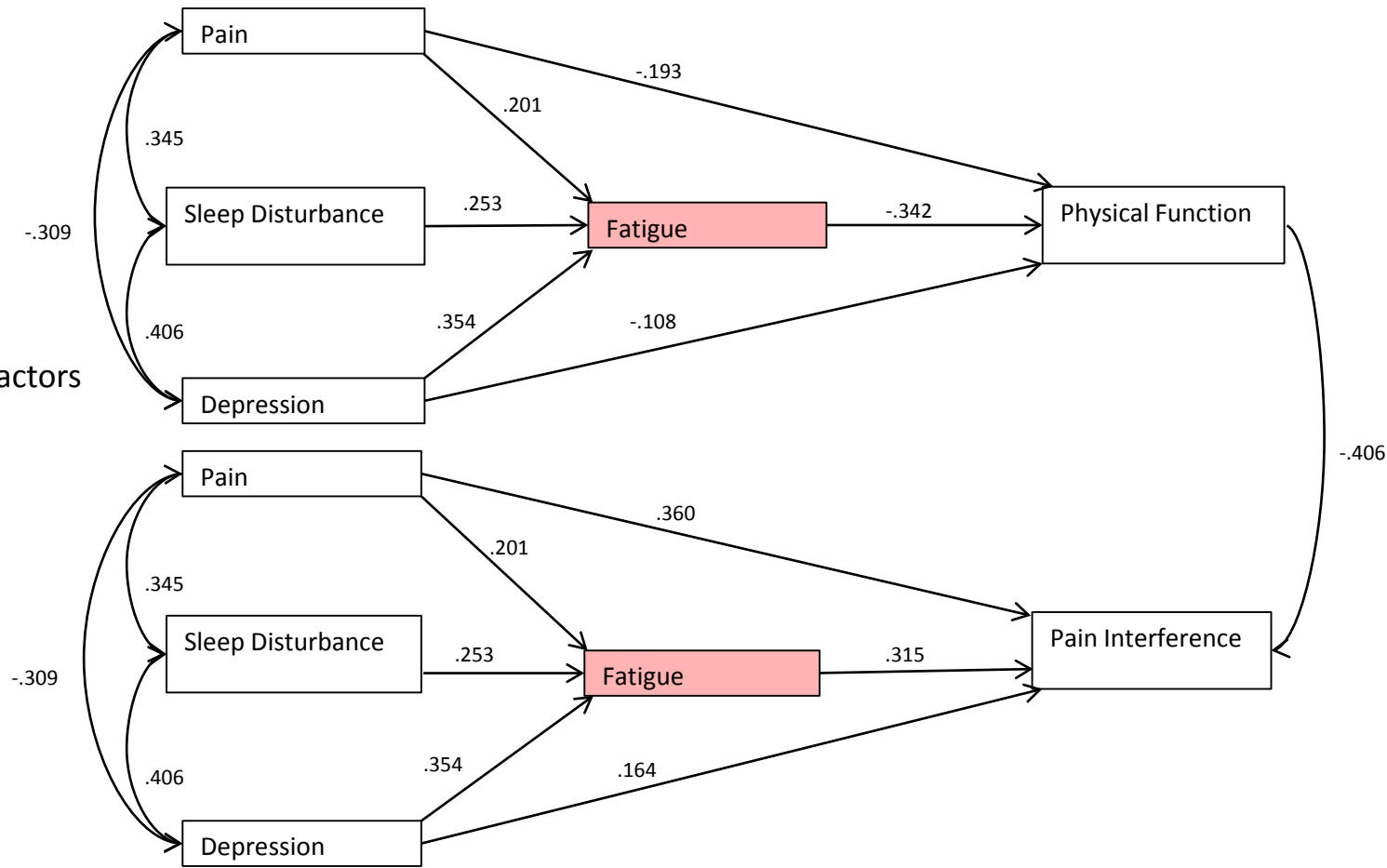


# Physical and Psychological Correlates of Fatigue and Physical Function: A Collaborative Health Outcomes Information Registry (CHOIR) Study

John A. Sturgeon, Beth D. Darnall, Ming-Chih J. Kao, and Sean C. Mackey  
Department of Anesthesiology, Perioperative and Pain Medicine, Stanford Systems Neuroscience and Pain Laboratory, Stanford University School of Medicine, Palo Alto, California.

## Fatigue is:

- Common in chronic pain
- Understudied as a target of intervention
- Likely a confluence of physical and psychological factors
- A significant barrier to physical functioning, likely mediating effects of pain on physical dysfunction



# Single Session Pain Catastrophizing Class to Reduce Pain

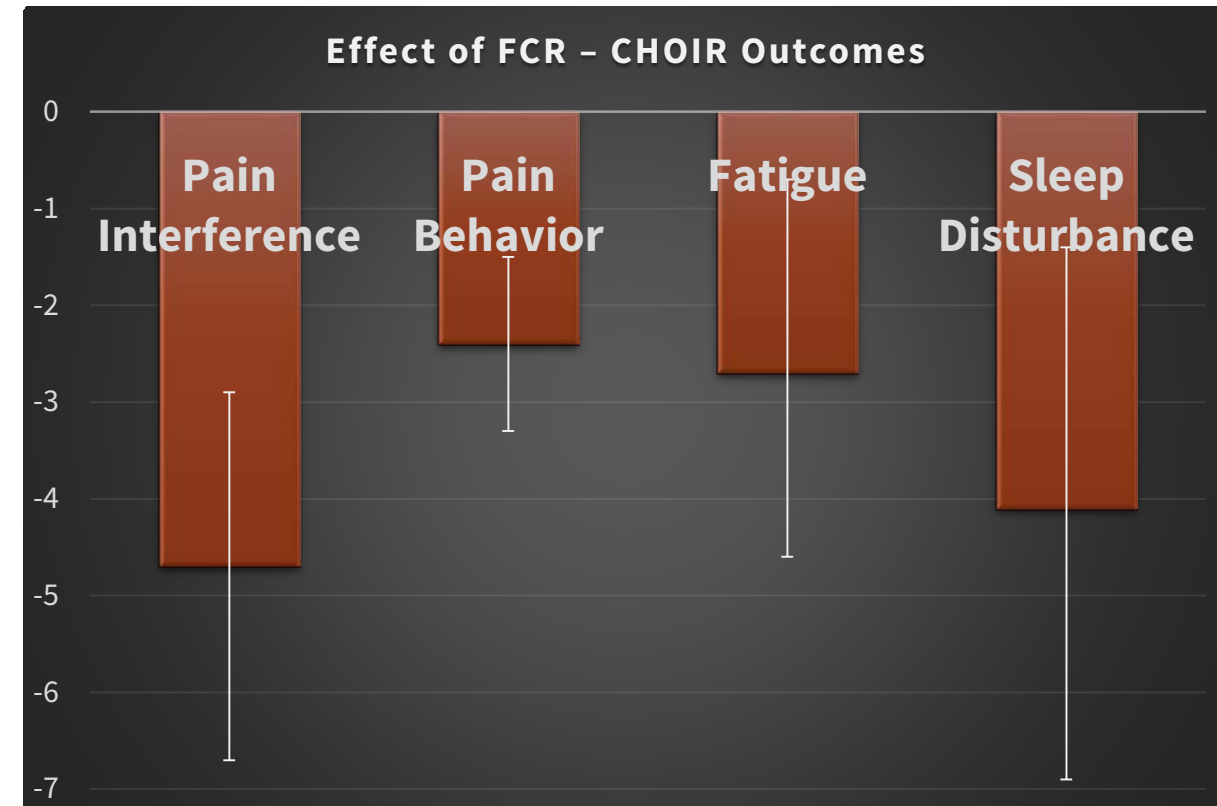
N=57 with chronic pain

Single session class

PCS = Pain Catastrophizing Scale



Time Point	PCS Mean (SD)
Baseline	26.1 (10.8)
Post-Treatment Week 2	16.5 (9.9)
Post-Treatment Week 4	13.8 (9.5)





**Pain Medicine**  
Section Editor: Spencer S. Liu

**A Pilot Cohort Study of the Determinants of Longitudinal Opioid Use After Surgery**

Ian Carroll, MD, MS,\* Peter Barelka, MD,† Charlie Kiat Meng Wang, BS,\* Bing Mei Wang, BS,\* Matthew John Gillespie, BS,\* Rebecca McCue, BA,\* Jarred W. Younger, PhD,\* Jodie Trafton, PhD,‡ Keith Humphreys, PhD,‡ Stuart B. Goodman, MD, PhD, FRCSC, FACS, FBSE,†† Fredrick Dirbas, MD,‡‡ and Sean Charles Mackey, MD, PhD\*

**Search Article**

**Factors Associated with Opioid Use in a Cohort of Patients Presenting for Surgery**

Jennifer M. Hah,<sup>1</sup> Yasamin Sharifzadeh,<sup>2</sup> Bing M. Wang,<sup>2</sup> Matthew J. Gillespie,<sup>2</sup> Stuart B. Goodman,<sup>3</sup> Sean C. Mackey,<sup>1</sup> and Ian R. Carroll<sup>1</sup>

# Characterizing Presurgical Factors that Predict Chronic Pain or Opioid Use



**Pain Medicine**  
Pain Medicine 2014; 15: 954-964  
Wiley Periodicals, Inc.

**Self-Loathing Aspects of Depression Reduce Postoperative Opioid Cessation Rate**

Jennifer M. Hah, MD, MS,\* Sean Mackey, MD, PhD,\* Peter L. Barelka, MD,‡‡ Charlie K. M. Wang, BS,§ Bing M. Wang, BA,§ Matthew J. Gillespie, BS,§ Rebecca McCue, BA,§ Jarred W. Younger, PhD,‡ Jodie Trafton, PhD,‡ Keith Humphreys, PhD,‡ Stuart B. Goodman, MD, PhD, FRCSC, FACS, FBSE,†† Fredrick M. Dirbas, MD,‡‡ Peter C. Schmidt, MD,‡ and Ian R. Carroll, MD, MS\*

**Pain Medicine**  
Pain Medicine 2015; 16: 2386-2396  
Wiley Periodicals, Inc.

**ACUTE & PERIOPERATIVE PAIN SECTION**

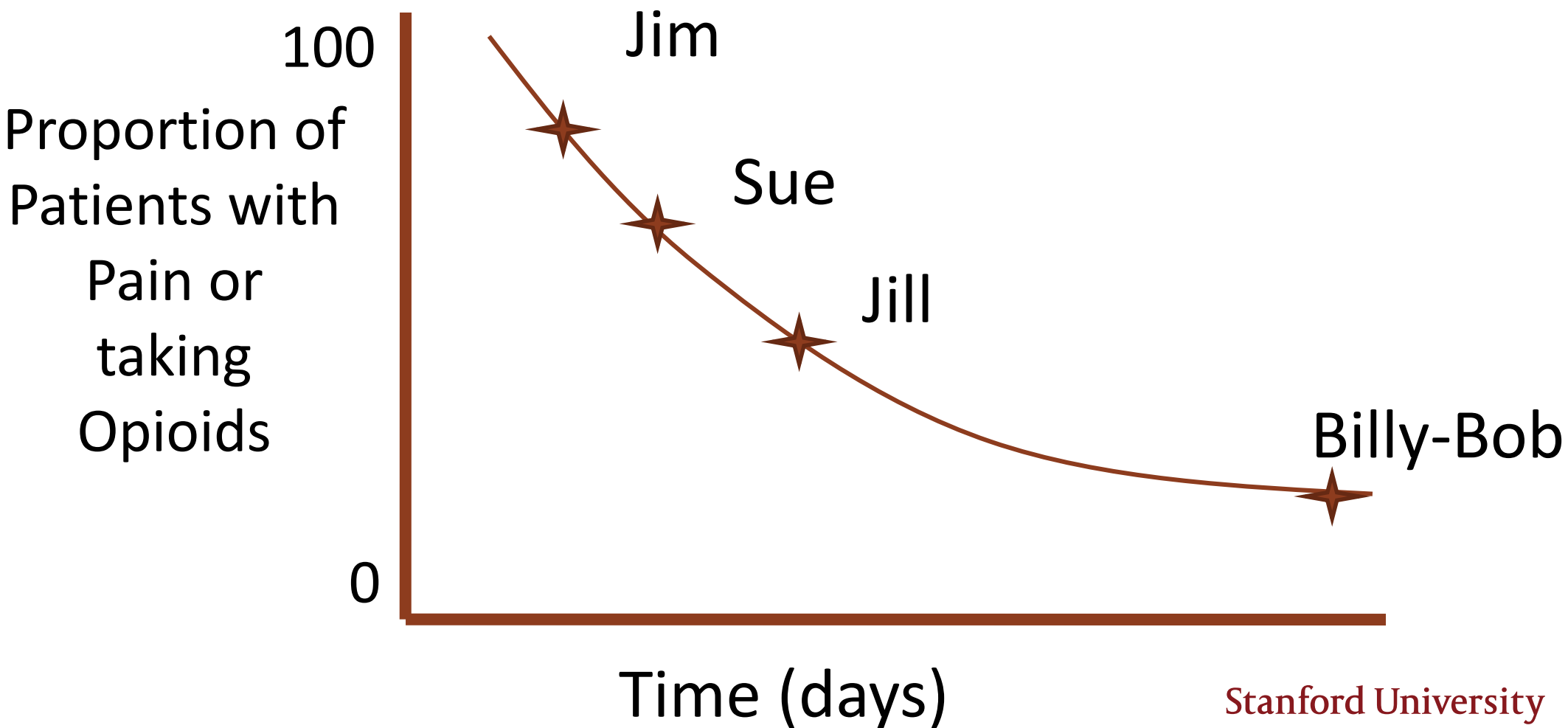
**Original Research Articles**

**Pain Duration and Resolution following Surgery: An Inception Cohort Study**

Ian R. Carroll, MD, MS,\*† Peter L. Barelka, MD,\*† Jennifer M. Hah, MD, MS,\*† Bing M. Wang,‡ Charlie K. M. Wang, BS,‡ Matthew J. Gillespie, BS,‡ Rebecca McCue, BA,‡ Jarred W. Younger, PhD,\* Stuart B. Goodman, MD, PhD, FRCSC, FACS, FBSE,†† Fredrick M. Dirbas, MD,‡‡ and Sean C. Mackey, MD, PhD\*

measured pain and opioid use after patients reported the cessation to opioid and pain. The primary determinants reported, and surgery in C...

Imagine four patients whose pain or opioid use resolves...



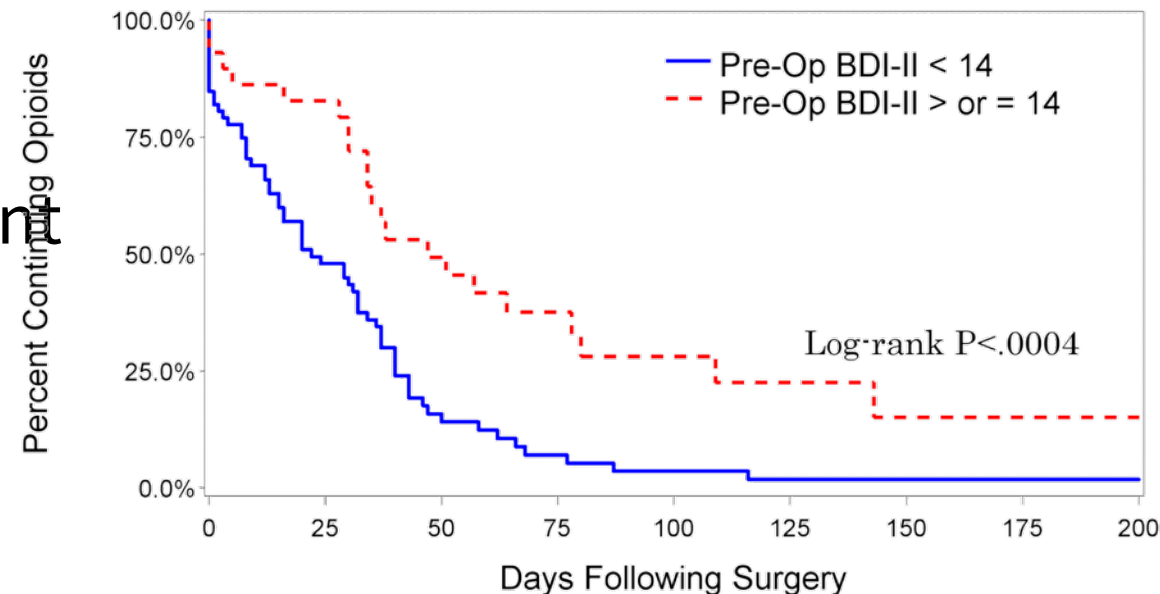
# Factors Predicting Prolonged Opioid Use After Surgery

## Reduction in rate of opioid cessation

Preoperative opioid use: 73% reduction

Self-perceived risk of addiction: 53% reduction

Beck Depression Inventory, each 10-point increase: 42% reduction

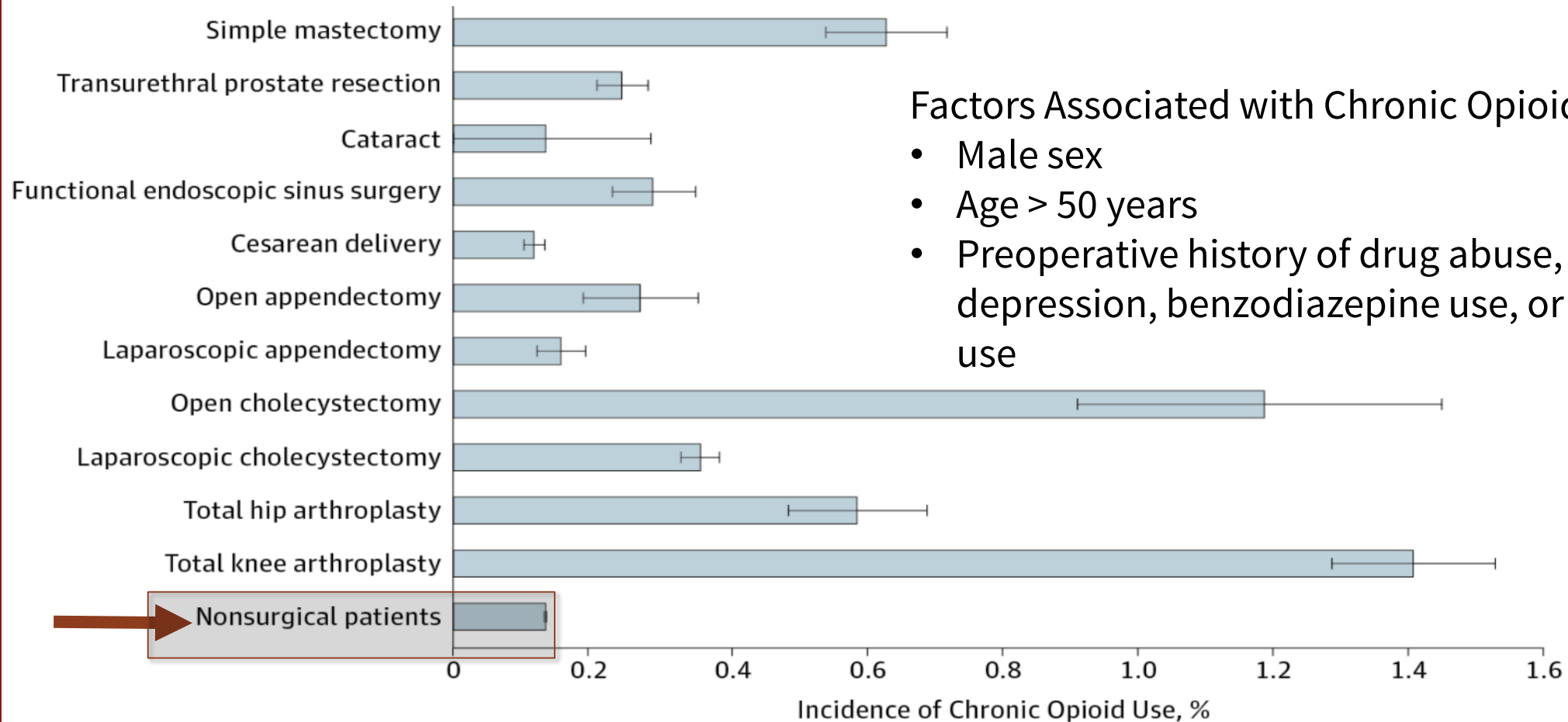


Carroll I, Barelka P, Wang C, Wang B, Gillespie M, McCue R, Younger J, Trafton J, Humphreys K, Goodman S, Dirbas F, Whyte R, Donington J, Cannon W, Mackey S, *A pilot cohort study of the determinants of longitudinal opioid use after surgery.* *Anesth Analg*, 2012

# Many surgeries associated with increased risk of chronic opioid use in opioid naïve patients



641,941 patients undergoing one of 11 surgeries



Factors Associated with Chronic Opioid Use:

- Male sex
- Age > 50 years
- Preoperative history of drug abuse, alcohol abuse, depression, benzodiazepine use, or antidepressant use

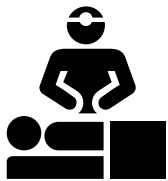


Pain Medicine

Section Editor: Spencer S. Liu

# A Pilot Cohort Study of the Determinants of Longitudinal Opioid Use After Surgery

Ian Carroll, MD, MS,\* Peter Barelka, MD,† Charlie Kiat Meng Wang, BS,\* Bing Mei Wang, BS,\*  
Matthew John Gillespie, BS,\* Rebecca McCue, BA,\* Jarred W. Younger, PhD,\* Jodie Trafton, PhD,‡  
Keith Humphreys, PhD,¶ Stuart B. Goodman, MD, PhD, FRCSC, FACS, FBSE,†† Fredrick Dirbas, MD,‡‡  
Richard I. Whyte, MD, MBA,§ Jessica S. Donington, MD,§ Walter B. Cannon, MD,§  
and Sean Charles Mackey, MD, PhD\*



# CHOIR | Peri-Op

Optimal Pre-habilitation for Surgery

## Characterizing Presurgical Factors that Predict Chronic Pain or Opioid Use

### Research Article Factors Associated with Opioid Use in a Cohort of Patients Presenting for Surgery

Jennifer M. Hah,<sup>1</sup> Yasamin Sharifzadeh,<sup>2</sup> Bing M. Wang,<sup>2</sup> Matthew J. Gillespie,<sup>2</sup>  
Stuart B. Goodman,<sup>3</sup> Sean C. Mackey,<sup>1</sup> and Ian R. Carroll<sup>1</sup>

Hindawi Publishing Corporation  
Pain Research and Treatment  
Volume 2015, Article ID 829696, 8 pages

Pain Medicine  
Pain Medicine 2015; 16: 2386-2396  
Wiley Periodicals, Inc.

### ACUTE & PERIOPERATIVE PAIN SECTION

#### Original Research Articles Pain Duration and Resolution following Surgery: An Inception Cohort Study

Ian R. Carroll, MD, MS,\*†  
Jennifer M. Hah, MD, MS,\*†  
Charlie K. M. Wang, BS,‡  
Matthew J. Gillespie, BS,‡  
Jarred W. Younger, PhD,\*  
Keith Humphreys, PhD,§  
Stuart B. Goodman, MD, PhD, FRCSC, FACS,  
Fredrick M. Dirbas, MD,‡††  
and Sean C. Mackey, MD, PhD\*

measured pain and opioid use after surgery in a cohort of patients reported the cessation to opioid cessation. The primary determinants reported, and surgery in C...

Pain Medicine  
Pain Medicine 2014; 15: 954-964  
Wiley Periodicals, Inc.

### Self-Loathing Aspects of Depression Reduce Postoperative Opioid Cessation Rate

Jennifer M. Hah, MD, MS,\* Sean Mackey, MD, PhD,\*  
Peter L. Barelka, MD,‡† Charlie K. M. Wang, BS,§  
Bing M. Wang, BA,§ Matthew J. Gillespie, BS,§  
Rebecca McCue, BA,§ Jarred W. Younger, PhD,‡  
Jodie Trafton, PhD,¶ Keith Humphreys, PhD,¶  
Stuart B. Goodman, MD, PhD, FRCSC, FACS, FBSE,\*\*  
Fredrick M. Dirbas, MD,‡†† Peter C. Schmidt, MD,‡  
and Ian R. Carroll, MD, MS\*





## Estimating hospital Length of Stay (LOS)

- LOS is the main driver of in-hospital healthcare cost
- Heritage Foundation
  - \$3M cash prize
  - *Outcome variable*: total hospital + ED LOS over the next year for individual patients
  - *Predictor variables*: comprehensive administrative dataset
  - Contest ran for 2 years, 2011-13



## Results

- While there are clear leaders in the final leaderboard, no single variable proved to be the main driver
- General opinion:
  - Even the best performing model was unsatisfactory
  - No small subset of administrative variables percolated as the main driver
- Our opinion:
  - This data is plagued by high-dimensionality, epidemiologic concerns, and inherent problems with administrative data (3 of the 6 Vs of Big Data)

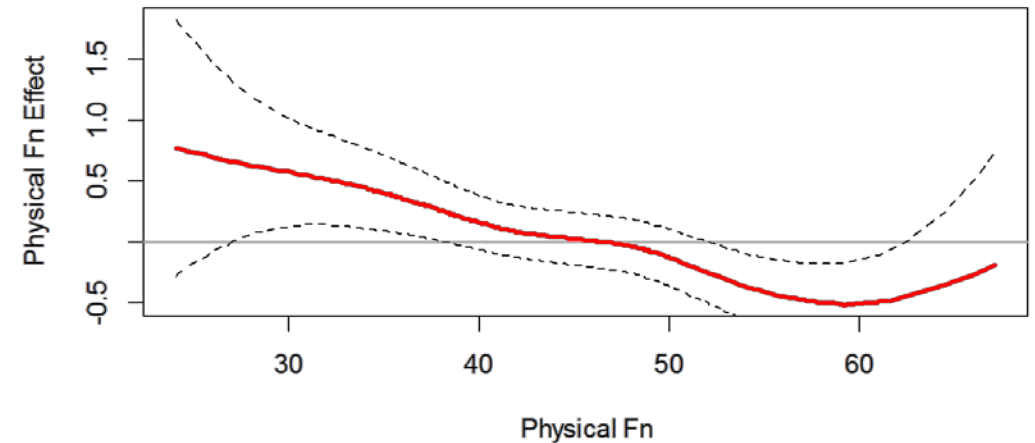
## Peri-Operative CHOIR: Predicting LOS

- Of the 2,073 patients seen at APEC, 991 have LOS at least 1 day
- Incorporated into **generalized additive model** and **quantile regression**
  - Race and ethnicity
  - Pre-op PROMIS measurements

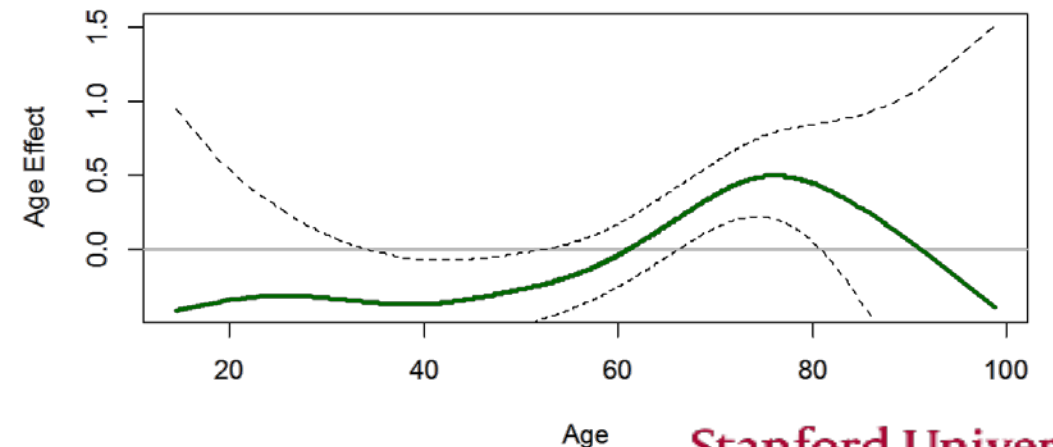
### Result

- Age, Gender, & Physical Function together significant
- LOS linearly increases as a function of worsening Physical Function effect despite adjusting for Age
- LOS significantly increases when Age is above 60

Physical Fn effect on LOS



Age effect on LOS



Test Patient13 Height: 5' 6" DOB 05/05/1975 Age 40  
 MRN 10013-1 Weight: 175 lbs Gender M

**Contact number**

Best contact phone number to reach you before surgery? 555-1234  
 If this is not your phone, please indicate whose phone number it is My brothers

**Pre-Anesthesia Questionnaire**

Anesthesia Pre-op Clinic visit in the last 12 months No  
 Have had surgery at Stanford Yes

**Past Surgeries**

Type of operation Appendix removed  
 Year of surgery 1992  
 Anesthetic given: General anesthesia Yes  
 Problems or side effects? Yes  
 Explain Nausea and dizziness when i woke up  
 Type of operation Broken ankle  
 Year of surgery 2001  
 Anesthetic given: General anesthesia Yes  
 Problems or side effects? Yes  
 Explain same as before

**Health Conditions**

Allergic to foods  
 Type of reaction I get hives if I eat strawberries  
 Corticosteroid use in last 6 months No  
 Personal or family history of anesthesia complications No  
 Past medical history / Problems not already documented in EMR High blood pressure  
 Review of symptoms palpitations or irregular heart beats, ankle swelling, difficulty walking, acid reflex symptoms  
 Acute illness in last 2 weeks Yes  
 cold  
 No hospitalization in the past 6 month

**Smoking, Alcohol and Drugs**

Smoked 1 pack(s) per day 12 years Quit 2006  
 Do drink alcohol. More than 10 drinks per week. Every day. 3 drinks per day  
 Have not used recreational drugs in the last 5 years

**Questions**

Questions for the anesthesiologist No

**Pain Intensity: 0=No Pain, 10=Worst Pain Imaginable**

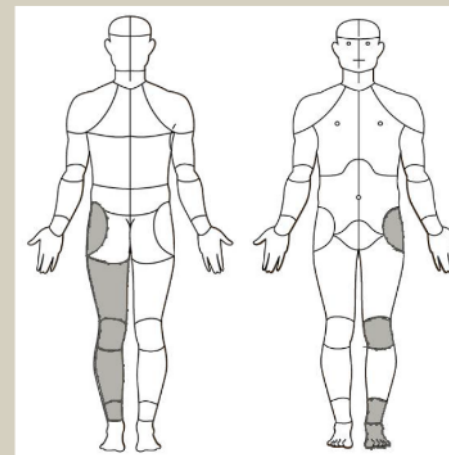
Worst	Average	Now	Least
6	2	3	1



Test Patient13 Height: 5' 6" DOB 05/05/1975 Age 40  
 MRN 10013-1 Weight: 175 lbs Gender M

**PROMIS Physical Function**

Does your health now limit you in doing two hours of physical labor? Somewhat  
 How much do physical health problems now limit your usual physical activities (such as walking or climbing stairs)? Quite a lot  
 Are you able to do chores such as vacuuming or yard work? With some difficulty  
 Does your health now limit you in walking more than a mile? Quite a lot



9 areas selected on the most recent body map

PROMIS Outcomes Measures	Score	%ile	Category
Physical Function *	62	88	
Pain Interference	61	86	
Depression	46	34	None/Minimal
Anxiety	53	62	Mild
Anger	48	42	
Fatigue	42	21	
Sleep Disturbance	31	3	None to Slight

\* Scores and percentiles have been inverted

Research Paper

**PAIN**<sup>®</sup>

September 2016 Volume 157 Number 9

# **Pediatric-Collaborative Health Outcomes Information Registry (Peds-CHOIR): a learning health system to guide pediatric pain research and treatment**

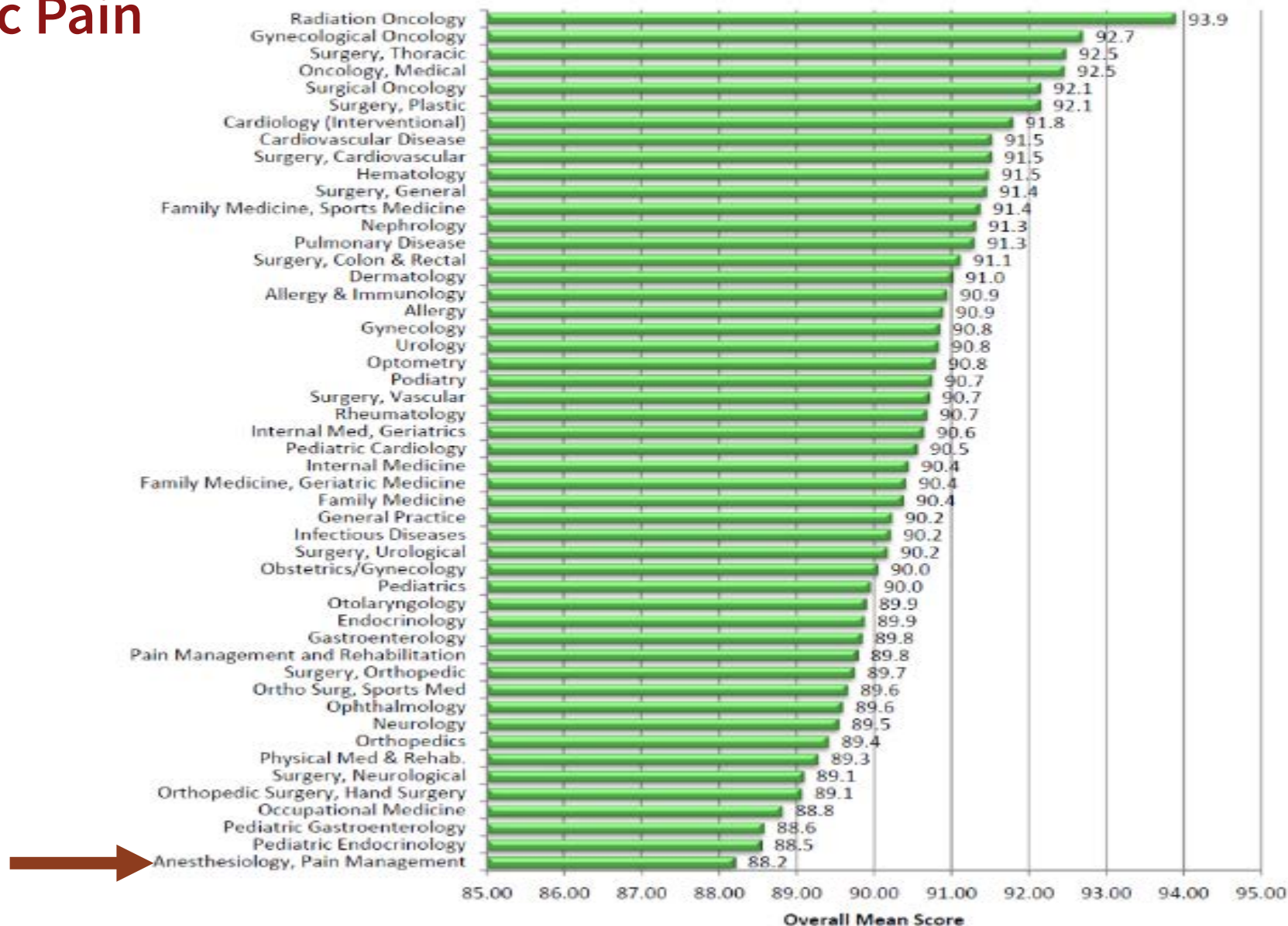
Rashmi P. Bhandari<sup>a,\*</sup>, Amanda B. Feinstein<sup>a</sup>, Samantha E. Huestis<sup>a</sup>, Elliot J. Krane<sup>a</sup>, Ashley L. Dunn<sup>a</sup>, Lindsey L. Cohen<sup>b</sup>, Ming C. Kao<sup>a</sup>, Beth D. Darnall<sup>a</sup>, Sean C. Mackey<sup>a</sup>

# Press-Ganey Patient Satisfaction and the Challenges of Chronic Pain



## Medical Practice Satisfaction by Specialty

Based on 4,274,639 surveys received from 17,685 sites nationwide between 1/1/2012 - 12/31/2012.  
Only includes specialties used by 50+ facilities with 5,000+ patients. Only the "Included sample" is included in this





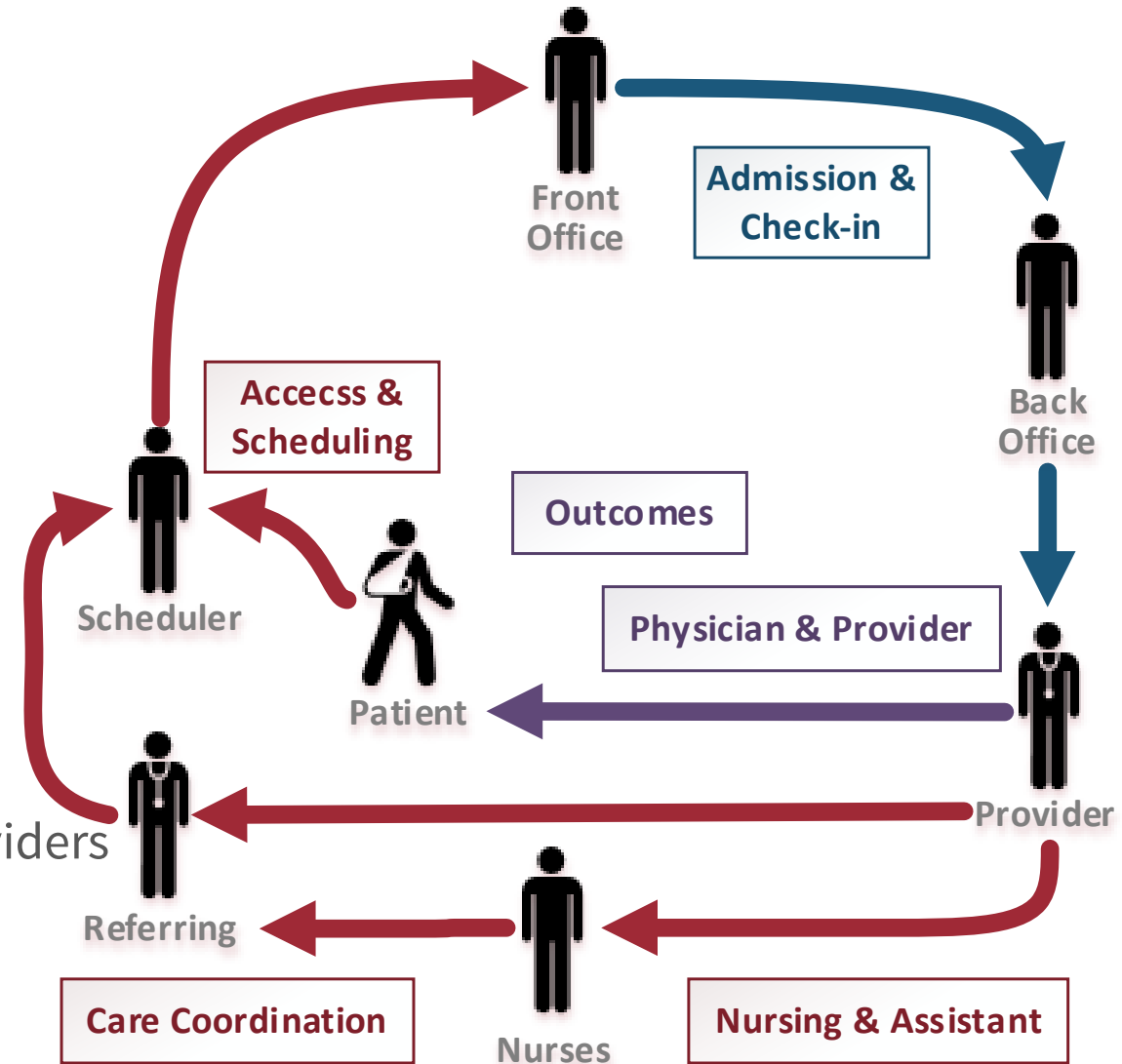
# System To Enhance Patient eXperience (STEPx)

## An unmet need

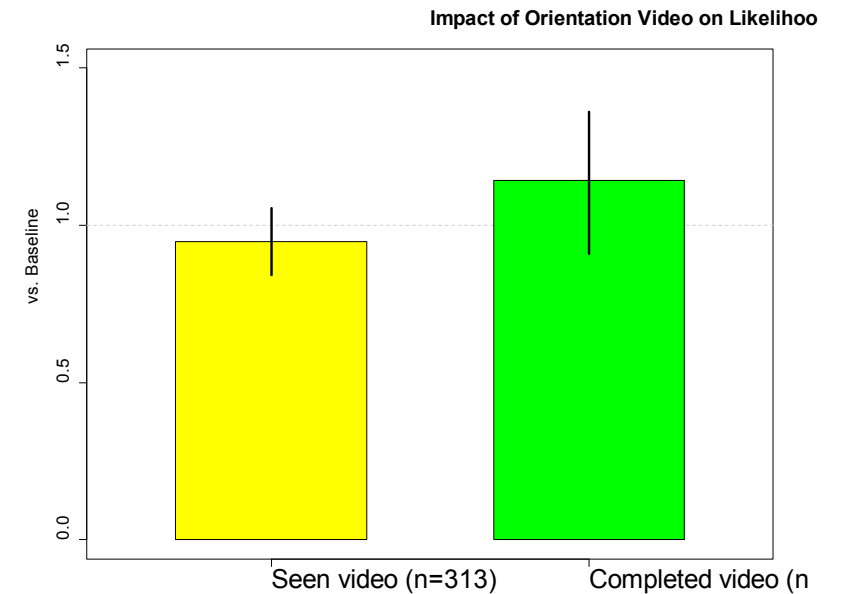
- Comprehensive capture of patient experience touchpoints
- Concise item stems
- Actionable results
- Integrated into CHOIR
- Open source and free

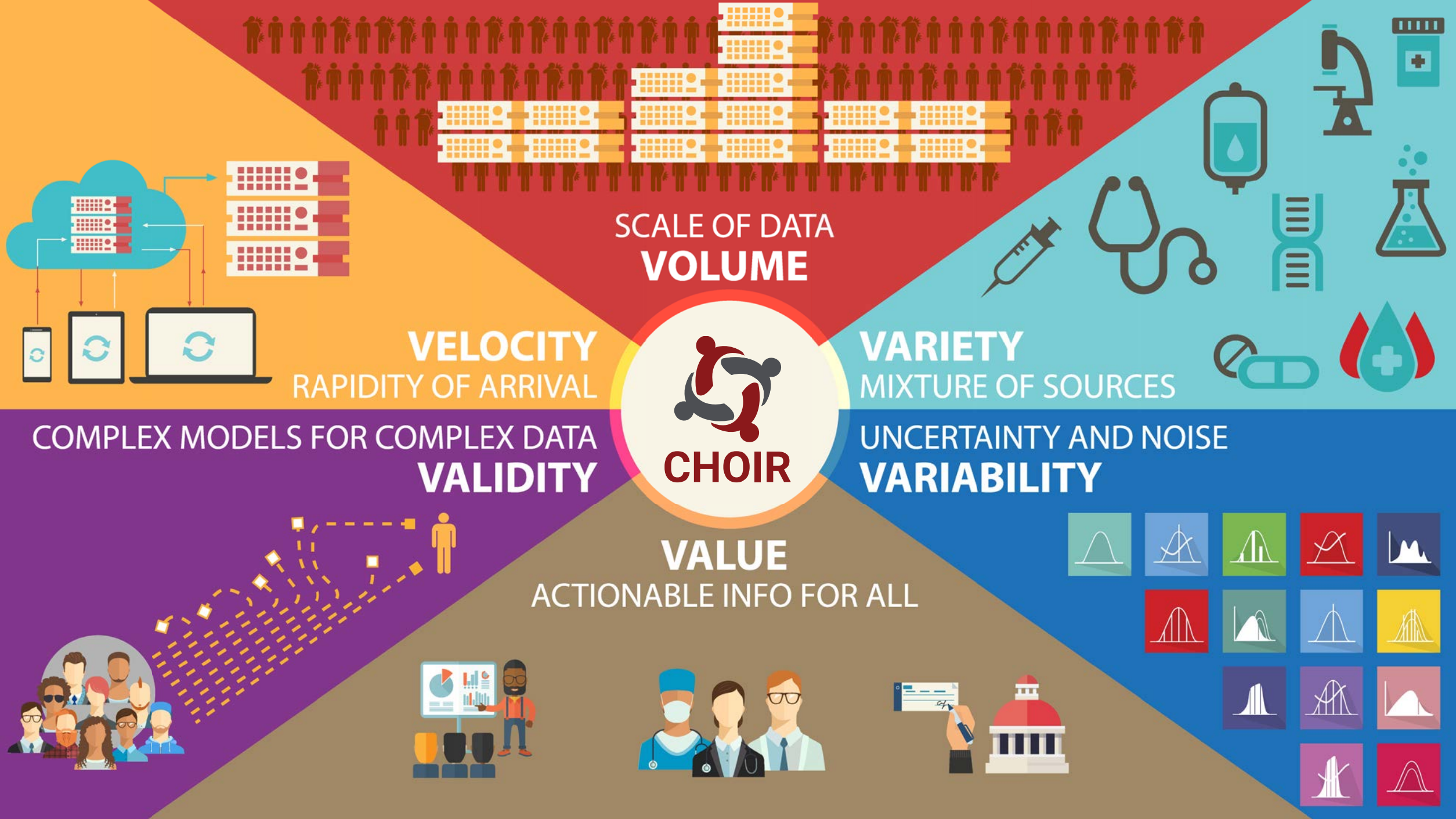
Covers, and extends, all the domains of existing patient satisfaction surveys, including:

- Press Ganey
- Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)
- TOPS

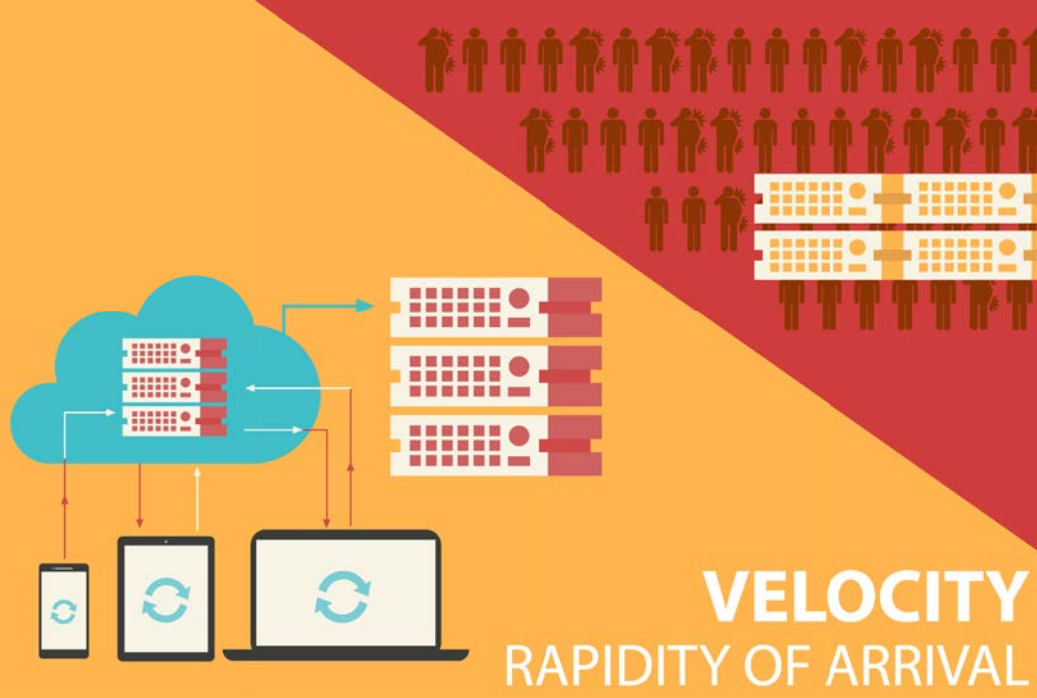


# Pain Clinic orientation video improves patient satisfaction



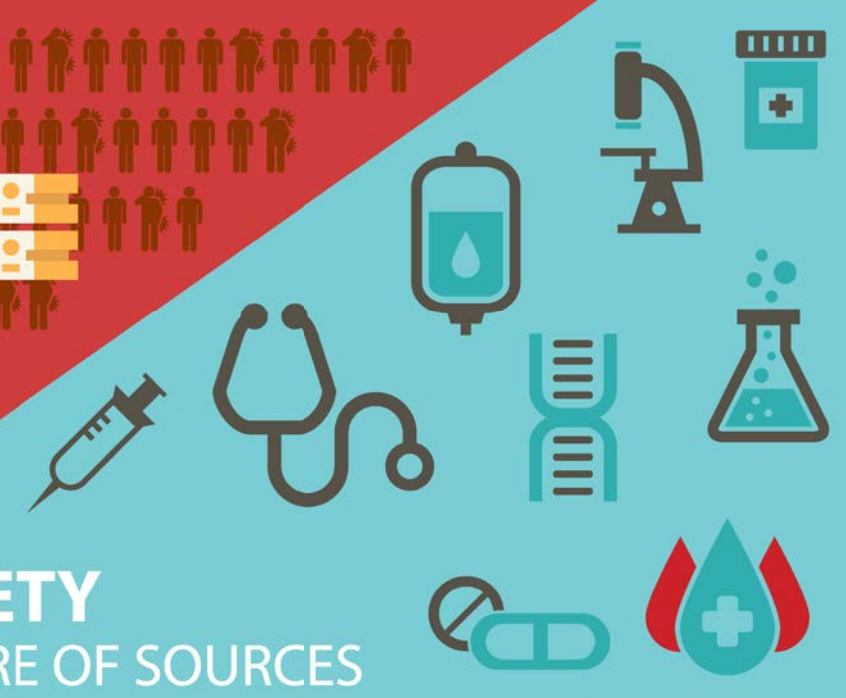


SCALE OF DATA  
**VOLUME**



**VELOCITY**  
RAPIDITY OF ARRIVAL

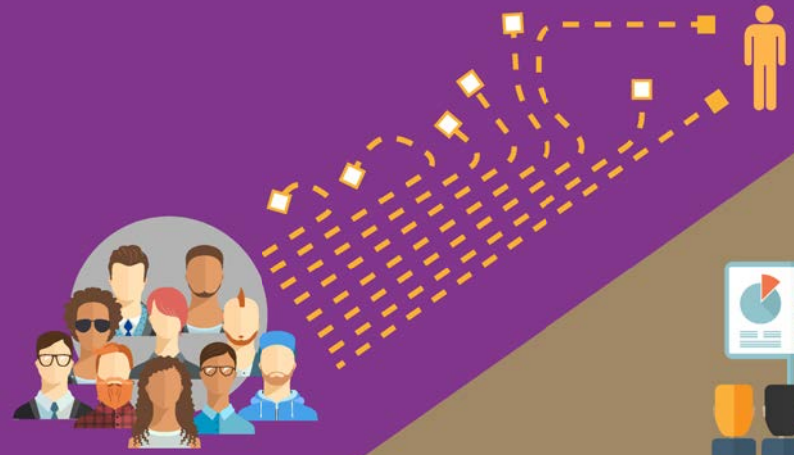
**VARIETY**  
MIXTURE OF SOURCES



UNCERTAINTY AND NOISE  
**VARIABILITY**



COMPLEX MODELS FOR COMPLEX DATA  
**VALIDITY**



**VALUE**  
ACTIONABLE INFO FOR ALL



**CHOIR**



# CHOIR

Information

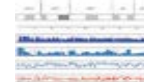
Bedside

Bytes

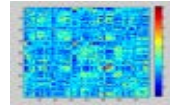
Bench

Bedside

1,000,000,000  
Billions



Whole Genome Seq

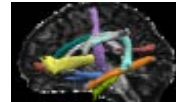


Resting State

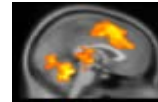


SNP typing

1,000,000  
Millions



Tractography



Activity

Metabolomics



Volumetry



Transcriptomics



Microbiomics



Quantified Self

Experiential  
Sampling

1,000  
Thousands



Documentation



Labs &  
Diagnostics



Psychometrics



Immunomics



1  
Individuals



- Implemented in multiple clinics and academic sites nationally and internationally
- Genetics: Stanford GenePool
- National pain data repository across sites with governance
- Software based decision support
- Mobile device integration for daily experiential sampling.
- Quantitative sensory testing
- Adaptive randomization for pragmatic trials
- Open source (free) licensing with minimal restrictions







- NIH Pain Consortium
- Redlich Pain Research Endowment
- Stanford Center for Clinical Informatics



- Michael Halaas
- Susan Weber
- Garrick Olson
- Teresa Pacht



- Northwestern/PROMIS
- Karon Cook, PhD



- Stanford Systems Neuroscience and Pain Lab (SNAPL)
- All our collaborators!!!!!!



<http://CHOIR.Stanford.edu>