CHOIR Collaborative Health Outcomes Information Registry

Open Source Platform for Measuring Health Outcomes and a Learning Based System

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Centers of Excellence AMERICAN PAIN SOCIETY Award Recipient 2008-2012

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- T32 DA035165
- R01DA035484

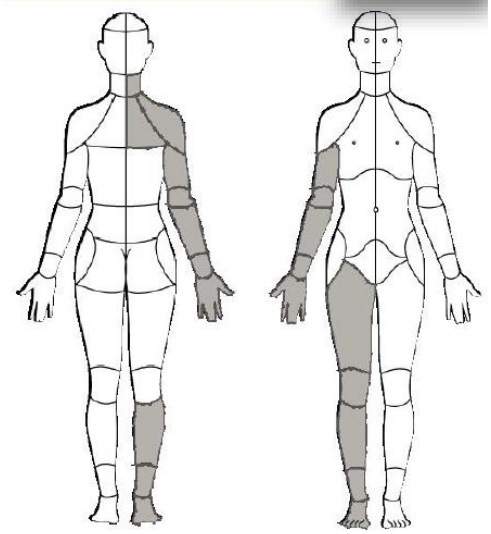
National Institutes of Diabetes and Digestive and Kidney Diseases
- U01 DK082316

Redlich Pain Research Endowment

Dodie and John Rosekrans Pain Research Endowment

No industry conflicts

Sandra with Complex Regional Pain Syndrome (CRPS)

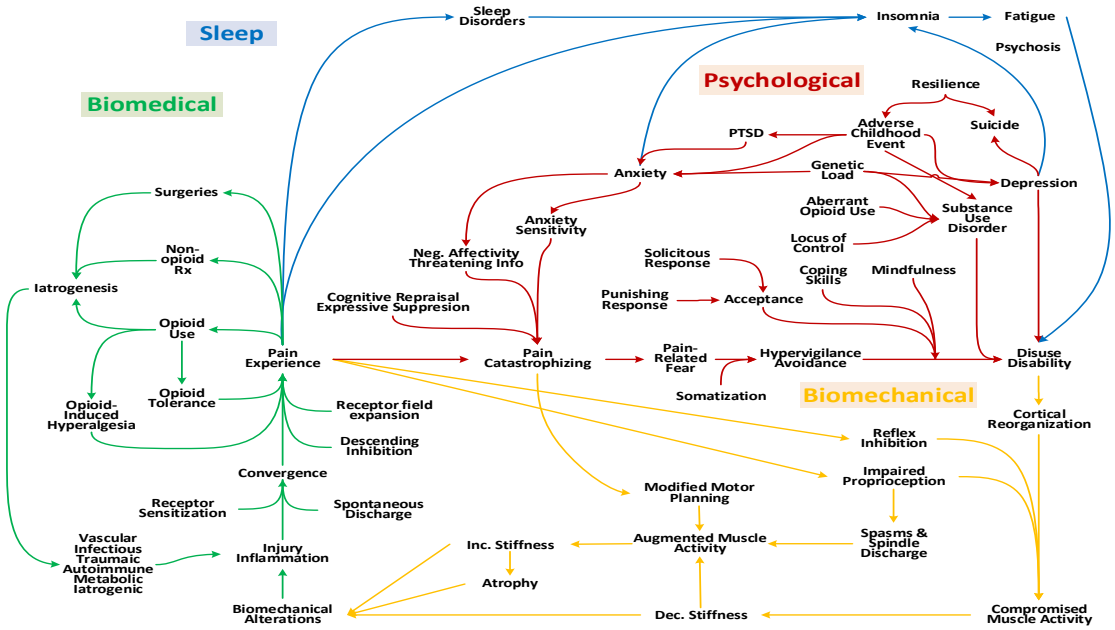


"It's that feeling, if you're digging through the bottom of a cooler, and you just get that burning sensation because your arm is so cold,"

How do you know whether you have helped Sandra or a particular patient?

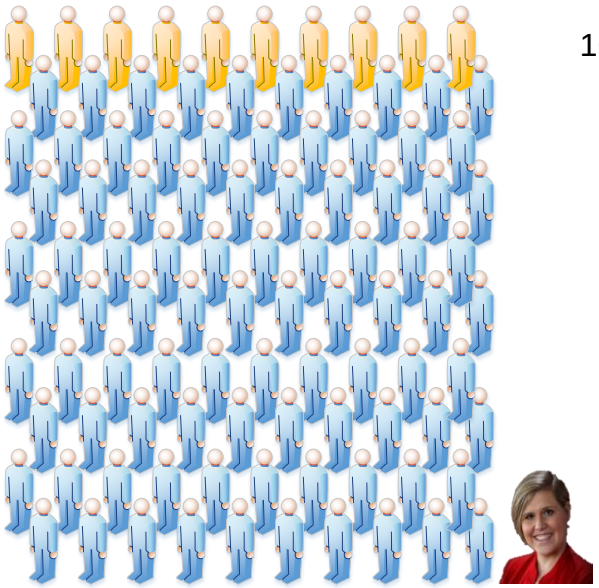
How do you know when a certain treatment is better than another for a specific patient?

The Systems Challenge of Pain



From Ming Kao

The Problem with Randomized Controlled Trials and Chronic Pain



10% of persons with chronic pain qualify for clinical trials

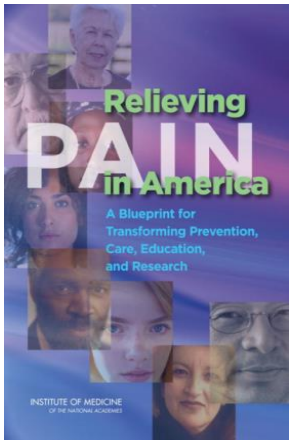
90% do not qualify!!!

Experiences With Pain – Institute of Medicine Report

- Affects 100 Million Americans
- Indirect/direct medical expenses
  US $560-$630 Billion/year
- Pain can become a disease

IOM Finding 2-2. More consistent data on pain are needed.

Bottom line: We need better data!!



INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Institute of Medicine – Relieving Pain In America 2011

Institute of Medicine:
Need for Patient Registries and Learning Health Systems

"There is a need for greater development and use of **patient outcome registries** that can support point-of-care treatment decision making, as well as for aggregation of large numbers of patients to enable assessment of the safety and effectiveness of therapies.

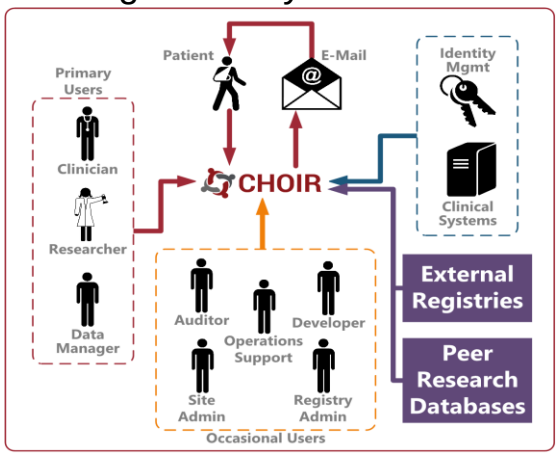
"We seek the development of a **learning health system** in which science, informatics, incentives and culture are aligned for continuous improvement and innovation – with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral byproduct of the delivery experience"

CHOIR

Collaborative Health Outcomes Information Registry

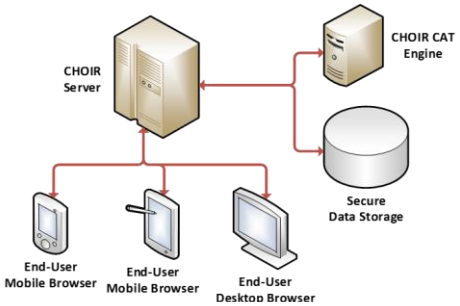
- Open source, open standard, highly flexible, and **free** health and treatment registry and platform for a learning health system

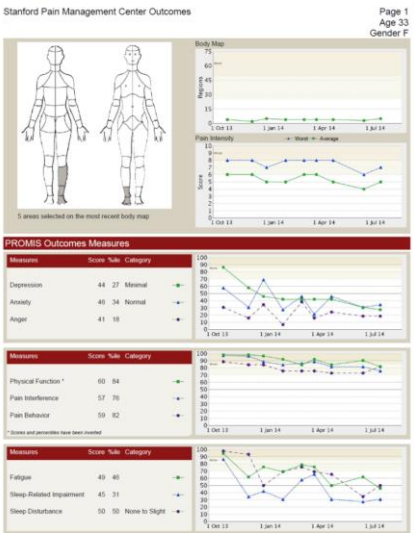
- Point of care decision making
- Comparative effectiveness research
- Longitudinal outcomes research
- Large simple trial designs
- Software based decision making



CHOIR: Data Capture System Features

- Easy to use data entry for patients, staff and clinicians
- Clinical workflow support e.g. notify patient of survey URL prior to clinical appointment
- Data import support for automated data entry (e.g. EMR) for medications and other treatments, medical conditions, costs, etc.
- Point of care reporting to support clinical decision making

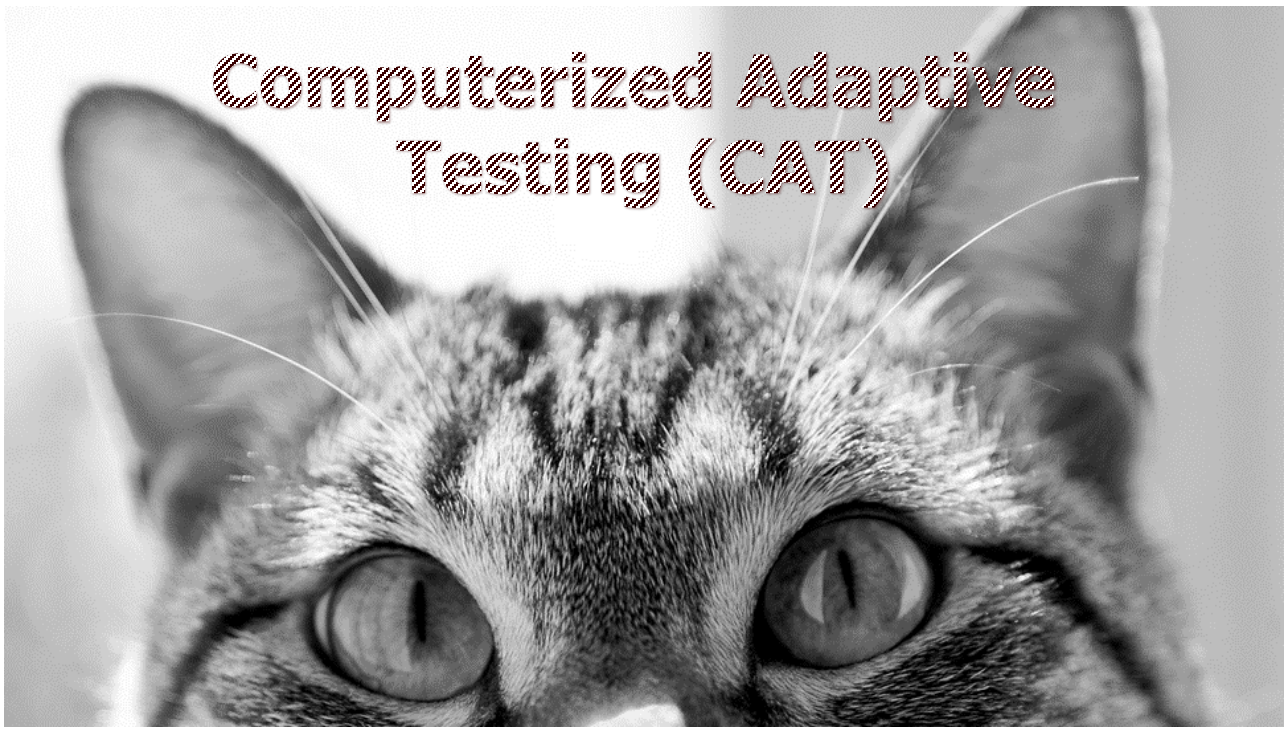




PROMIS®

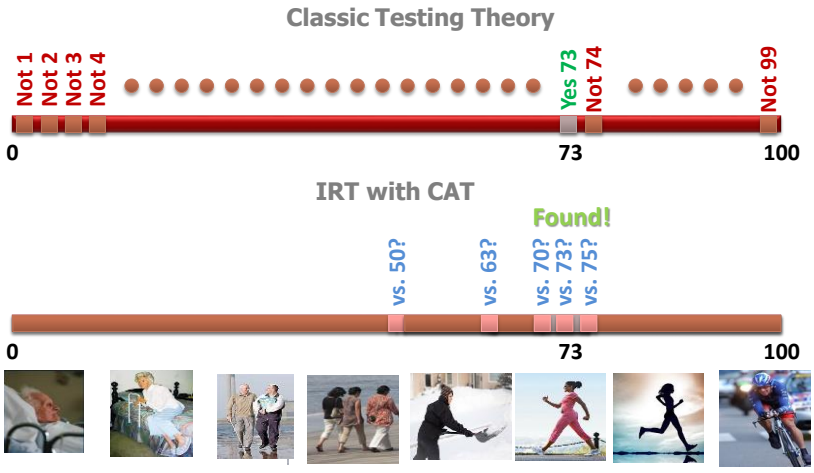
Dynamic Tools to Measure Health Outcomes from the Patient Perspective

- Physical Health
- Social Health
- Mental Health
- Global Health



Computerized Adaptive Testing (CAT) Applied to Health Care

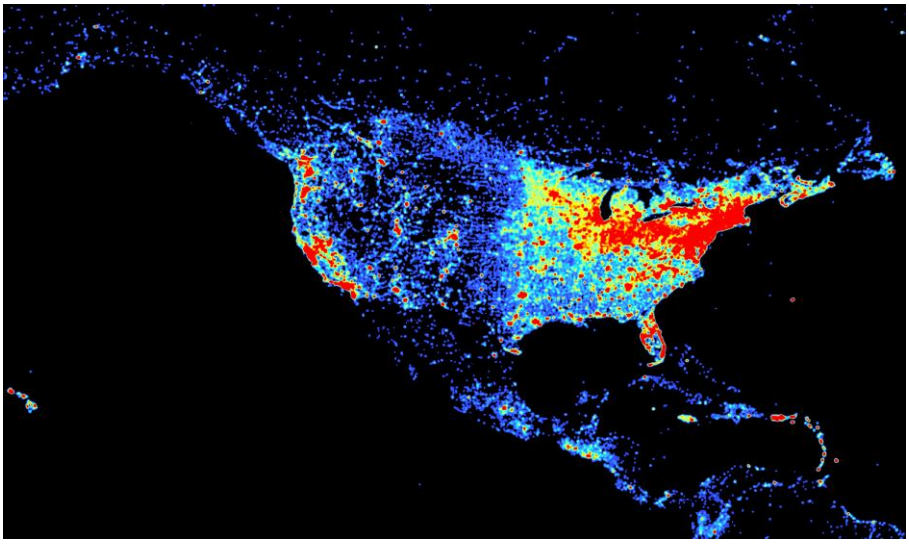
Suppose our subject score is **73** on a 1 to 100 scale of **Physical Function**



PROMIS Metric: Comparability to the US Population

T Score

- Mean = 50
- SD = 10



https://dhs.stanford.edu/spatial-humanities/comparing-population-density-and-wikipedia-density-on-gis-day/

Stanford Pain Management Center

- Interdisciplinary, coordinated comprehensive approach to pain management
- Use of validated outcomes assuring optimal patient assessment and care
- Over 14,000 patient visits (2014)
- 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

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Stanford Pain Management Center: Integrated Comprehensive Model of Care

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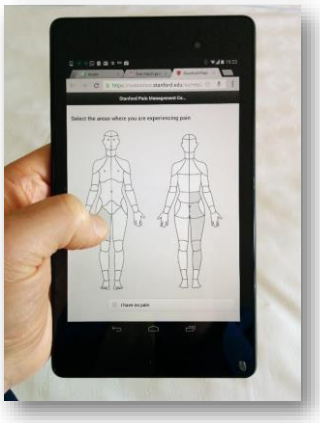
CHOIR Collaborative Health Outcomes Information Registry

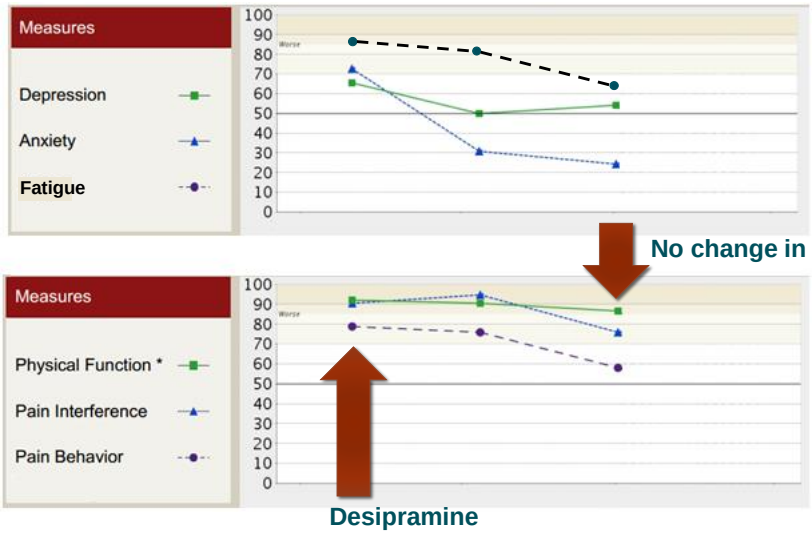
Initial and Follow-Up Surveys



- **Initial Survey – 22 min**
  - Demographics
  - Prior Treatments, Pain Beliefs
  - Interactive Body Map
  - PROMIS 9 domain measures:
    - Pain Intensity, Pain Behavior, Pain Interference, Fatigue, Physical Function, Depression, Anxiety, Sleep Disturbance, Sleep Related Impairment
  - Pain Catastrophizing Questionnaire (PCS)
- **Follow up Survey – 9 min**
  - Interactive Body Map
  - PROMIS 9 domain measures as above
  - PCS

NIH PROMIS		Legacy		Burden Reduction
Domain	# Items CHOIR CAT v1	Instrument	# Items	
Anger	6.24 ± 1.21	Buss-Perry Aggression Questionnaire (BPAQ)	29	88%
Anxiety	4.93 ± 0.97	Generalized Anxiety Disorder 7-item (GAD-7)	7	30%
Depression	4.97 ± 1.07	Patient Health Questionnaire (PHQ-9)	9	45%
Fatigue	4.78 ± 0.76	Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)	40	88%
Physical Function	4.11 ± 0.48	Health Assessment Quesionnaire-Disability Index (HAQ-DI)	20	79%
Pain Interference	4.19 ± 0.71	Brief Pain Inventory	7	40%
Pain Behavior	4.06 ± 0.45	N.A.		
Sleep Disturbance	4.95 ± 1.41	Sleep Disorders Quesionnaire (SDQ)	12	59%
Sleep-Related Impairment	4.54 ± 1.24	Epworth Sleepiness Scale (ESS)	8	43%
Overall	38.7 ± 7.9		132	71%

CHOIR: Using Dynamic Outcomes to Inform Care for Sandra



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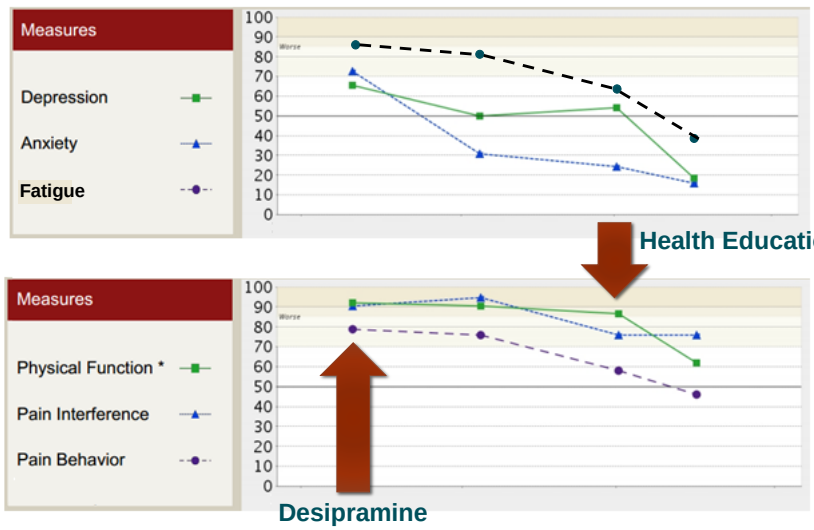
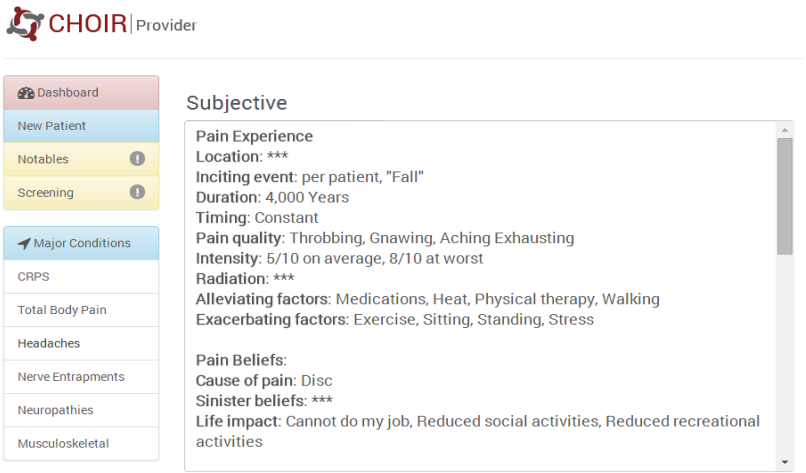


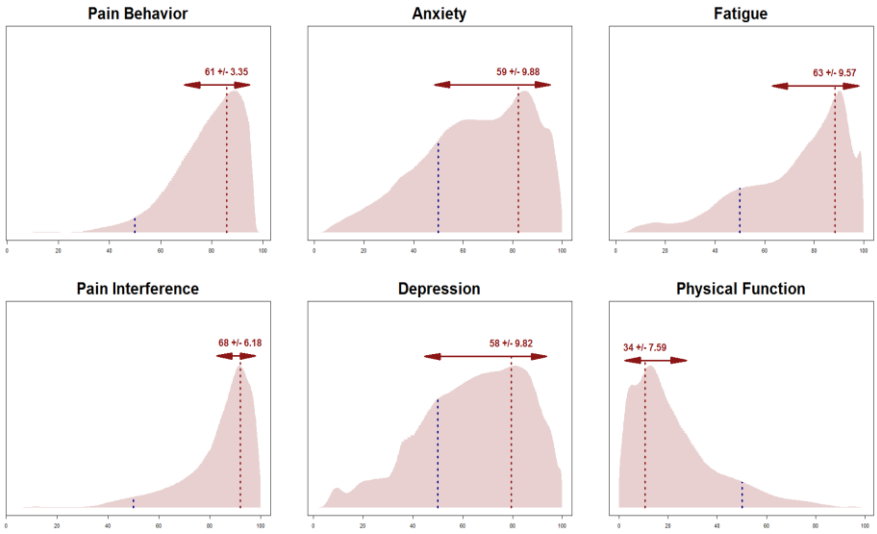
Clinical Practice

CHOIR Provider: Computer-Assisted Documentation

80-90% of clinical note automatically pulled from CHOIR input
Condition specific calculators



Patient characteristics: Stanford Pain Management Center



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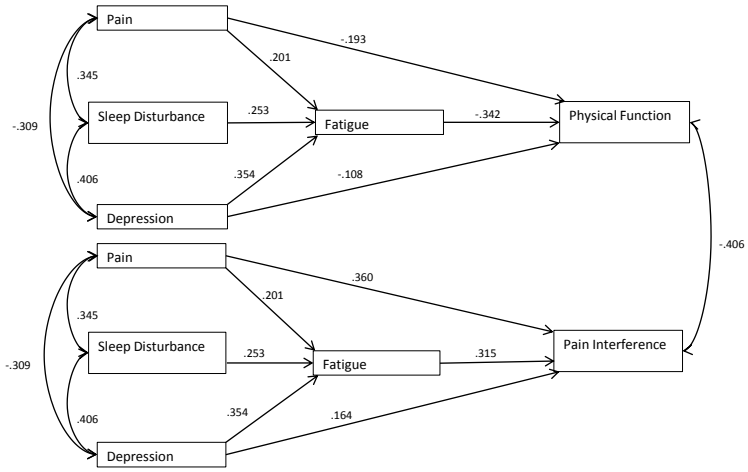
Physical and Psychological Correlates of Fatigue and Physical Function: A CHOIR Study



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

Sturgeon, Darnall, Kao, & Mackey (In Press).

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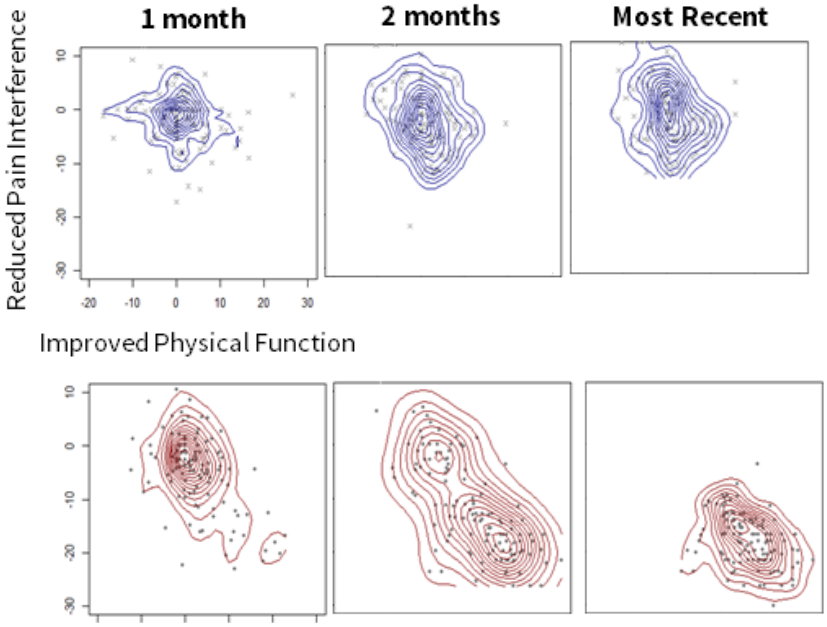
Dynamics of Patients' Response to Treatment

Non-Responders

Responders



CHOIR Collaborative Health Outcomes Information Registry — 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)