

NIH Pain Consortium: The Stanford and NIH Pain Registry

Richard A. Denisco, M.D., M.P.H.

National Institute on Drug Abuse

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Background

- Explosion in number of treatments for chronic pain management
- Unclear which treatments are effective & safe and for which patient and at what cost.
- PCORI has announced \$68 million for comparative effectiveness research

A Pain Registry may help to address these issues and may set the stage for comparative effectiveness research.

Stanford and NIH Pain Registry

- **Contract Site:** Stanford University
- **PI:** Sean Mackey, M.D.
- **Framework:** Free, Open Source, centralized registry for tracking chronic pain sufferers and their self-reported outcomes over time.
- **Primary data in Registry:**
 - Patient identifiers, demographics
 - Diagnostics
 - Treatment plan
 - Self-reported patient outcomes (PROMIS measures)

Overall goal for the **Stanford and NIH Pain Registry**

- **Develop, test and implement an open source, open standard and free National Pain Registry.**
- This registry will be used to collect outcomes data that will be used for:
 - *(1) outcomes research,*
 - *(2) comparative effectiveness research, and*
 - *(3) point of care decision making on large numbers of patients suffering from chronic pain.*

Outcome Measures for **Stanford and NIH Pain Registry**

- Number of health providers who have contributed data to the national registry
- Cumulative number of patients in the national registry
- Number of sites actively using the research database software
- Percentage of sites using the research database software who also contribute data to registry

Summary

- **Initial results are promising**
- **Patient data started with 6 CAT PROMIS domains:**
 - *PROMIS Pain Intensity*
 - *PROMIS Pain Interference*
 - *PROMIS Physical Function Bank*
 - *PROMIS Fatigue Bank*
 - *PROMIS Depression Bank*
 - *PROMIS Anxiety Bank*
- **Next steps**
 - *Expand survey bank to capture further domains.*
 - *Improving GUI.*
 - *Developing a body map.*
 - *Integrate treatment info.*
- **Integrated smoothly into clinic using web and iPad devices**
- **Expand to other academic medical centers.**

Thank You!