

# Introducing Person-Centered Outcome Tools at the National Institutes of Health

**Thursday, April 3, 2014**

8:30 a.m. to 12:30 p.m.  
Building 10, Masur Auditorium  
NIH Clinical Center

## Agenda

**Objective:** To provide introductory information on the National Institutes of Health (NIH)-funded tools, the Patient-Reported Outcomes Measurement Information System (PROMIS®), the NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox), and the Quality of Life in Neurological Disorders (Neuro-QOL).

**8:00 a.m. Registration and Check-in**

**8:30 a.m. Welcome and Introduction**  
*Susana Serrate-Sztein, M.D.*  
Project Officer, PROMIS

**8:35 a.m. Opening Remarks: NIH Investment in Improved Assessment Tools and a Platform for Clinical Research and Care at the Clinical Center and Intramural Programs**  
*James Anderson, M.D., Ph.D.*  
Director, Division of Program Coordination, Planning, and Strategic Initiatives

*Stephen Katz, M.D., Ph.D.*  
Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases

*Josephine Briggs, M.D.*  
Director, National Center for Complementary and Alternative Medicine

*Richard Hodes, M.D.*  
Director, National Institute on Aging

*Story Landis, Ph.D.*  
Director, National Institute of Neurological Disorders and Stroke

**9:00 a.m. Overview of New Person-Centered Outcome Tools: What Tools Were Created and How Do They Compare to Legacy Tools?**

*Richard Gershon, Ph.D.*  
Associate Professor, Medical Social Sciences, Northwestern University

**10:30 a.m. Break**

- 10:40 a.m. Overview of Tools To Assess Adult and Pediatric Pain**  
*Karon Cook, Ph.D.*  
Research Associate Professor, Medical Social Sciences, Northwestern University
- 11:10 a.m. Intramural Early Adoption of New Patient-Centered Outcome Tools and Technology**  
*Margaret Bevans, Ph.D., R.N., AOCN*  
Clinical Nurse Scientist, Clinical Center
- 11:30 a.m. Overview of Assessment Center as a Data Collection Platform**  
*Nan Rothrock, Ph.D.*  
Research Associate Professor, Medical Social Sciences, Northwestern University
- Description and Demonstration of Assessment Center on Campus**  
*Nan Rothrock, Ph.D.*  
Research Associate Professor, Medical Social Sciences, Northwestern University
- Technical Support for Assessment Center on Campus**  
*Yang Fann, Ph.D.*  
Director, Intramural IT and Bioinformatics Program, National Institute of Neurological Disorders and Stroke
- 12:15 p.m. Questions and Answers**
- 12:30 p.m. Adjourn**

# Training on Person-Centered Outcome Tools at the National Institutes of Health

**Thursday, April 3, 2014**

1:30 p.m. to 4:30 p.m.

Building 12A, Room B51

NIH Center for Information Technology

## Agenda

**Objective:** To provide hands-on training for the National Institutes of Health (NIH) versions of the Patient-Reported Outcomes Measurement Information System (PROMIS®), the NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox), and the Quality of Life in Neurological Disorders (Neuro-QOL).

**1:00 p.m. Registration and Check-in**

**1:30 p.m. Logging in on Campus and Accessing the Assessment Center**

*Bagus Adiyanto*

Software Engineer, National Institute of Neurological Disorders and Stroke

**Setting up a Study in Assessment Center and Launching for Data Collection**

*Monica Prudencio*

Informatics Project Manager, Northwestern University

**3:00 p.m. Break**

**3:15 p.m. Pulling a Launched Study Into Assessment Center and Collecting Data**

*Bagus Adiyanto*

Software Engineer, National Institute of Neurological Disorders and Stroke

**Training Review and Support Resources**

*Bagus Adiyanto*

Software Engineer, National Institute of Neurological Disorders and Stroke

**4:00 p.m. Questions and Answers**

**4:30 p.m. Adjourn**