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