Data Curation for Rehabilitation Research and Related Clinical Trials

May 22, 2019
8:00am - 3:00pm
Gainesville, FL

Syllabus

Instructors/Organizers
Kenneth J. Ottenbacher, PhD, OTR
Professor & Director, Division of Rehabilitation Sciences
University of Texas Medical Branch

Shane Redman, MA
Data Project Manager
Inter-university Consortium for Political and Social Research (ICPSR)
University of Michigan

Amol Karmarkar, PhD, MPH
Associate Professor, Division of Rehabilitation Sciences
University of Texas Medical Branch

Guest Speaker
Linda Tickle-Degnen, PhD, OT, FAOTA
Professor, Occupational Therapy
Department of Occupational Therapy
Tufts University

Location
University of Florida
Clinical and Translational Research Building (CTRB)
Room 3161/3162
*Boxed lunches will be provided.

Description
What is data curation? This free workshop is for any individuals interested or actively engaged in preparing data, including clinical trial data, for sharing and reuse among those involved in rehabilitation and disability outcomes research. Data curation includes the steps taken to ensure that research data can be used by secondary users long into the future. Increasingly, federal agencies are asking researchers and projects they fund to ensure the data produced are accessible to others. This workshop will provide practical training for how to best accomplish this goal.

Workshop participants will learn how to plan, review, clean, document, and disseminate data, including clinical trials data and data containing risks of personal identifiable information disclosure. Emphasis will be placed on curation practices, and description of a work flow involved in this process, availability of resources, as well as discussion with others in the workshop. Workshop participants can expect to leave with knowledge and experience of how to
plan, assess, improve, and disseminate data for long-term preservation and access. Individuals who have collected or plan to collect their own data will benefit most from this workshop.

Please note that participants are strongly encouraged to provide their own personal laptop computer. Tablets are not suitable.

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<th>Wednesday, May 22</th>
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| **8:00 am – 8:30 am** | Welcome and Introductions / Overview of the CLDR  
Ken Ottenbacher |
| **8:30 am – 9:00 am** | Why is Data Sharing Important (even in Clinical Trials research)  
Amol Karmarkar |
| **9:00 am – 9:40 am** | Overview of ICPSR and Intro to ADDEP  
Shane Redman |
| **9:40 am – 9:50 am** | Break |
| **9:50 am – 10:35 am** | Preparing Data for Archiving (include Identifying and Protecting Confidential Data)  
Shane Redman |
| **10:35 am – 11:15 am** | Metadata and Transferring Data to a Repository  
Shane Redman |
| **11:15 am – 11:25 am** | Break |
| **11:25 am – 11:45 am** | “Why Share Research Data: PI Perspective”  
Linda Tickle-Degnen |
| **11:45 am – 12:45 pm** | Working Lunch – Instructors will divide into groups and make themselves available to discuss related topics (ex: Data Management/Curation, Analysis, and Funding Opportunities)  
Amol Karmarkar, Ken Ottenbacher, Shane Redman |
| **12:45 pm – 1:15 pm** | Panel Discussion  
Linda Tickle-Degnen, Ken Ottenbacher, Amol Karmarkar, & Shane Redman |
| **1:15 pm – 2:00 pm** | Data Consultation and Exercises – For those seeking input on data related to planned, ongoing, or completed research projects  
Shane Redman / Amol Karmarkar |
| **2:00 pm – 2:10 pm** | Break |
| **2:10 pm – 2:50 pm** | Data Consultation and Exercises continued  
Shane Redman / Amol Karmarkar |
| **2:50 pm – 3:00 pm** | Wrap-up |
| **3:00 pm** | End |