Name of Organizer: Keith Lohse

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Title of Symposium: All data big and small: Information architecture, data sharing, and informatics in rehabilitation science

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Description of submitted symposium (please limit to 2000 characters): This symposium will introduce the audience to the importance of data integration in rehabilitation science and explore several recent methods for integrating data across trials at both the individual patient level and the group level. Focusing on the SCOAR database and two recent attempts to integrate individual patient data, we will demonstrate how to use these resources to conduct (1) advanced bibliographic searches such as searching by sample size, outcome measures, and/or different patient strata, (2) bottom-up or data driven searches that were previously impossible in the clinical trial literature, (3) exploratory meta-analyses of all trials published in the recent history of the field, and (4) evidence-based power-analyses that will allow researchers to see the historical range of effect-sizes for different interventions given at different doses, given at different times, and for different patient demographics. Although "big data" approaches to analyzing rehabilitation are very important, it is also tremendously important to consider the information architecture for the field more broadly (what, when, and how do we measure different variables even in the smallest studies?). By carefully scrutinizing the information architecture in stroke rehabilitation, we can design a system that will allow our data to grow from independent pockets of small-to-medium data into properly "big" data that will afford new insights and greater precision than we have ever had in rehabilitation science. Although the focus of this symposium will be stroke, we think that many of these issues are applicable to other areas of neurorehabilitation.

Length of time required for symposium?: 90 minutes

Additional Presenters (Limited to 4 additional presenters, list full name and email address) Please Note: Any Non-member speakers must receive prior approval from the Program Chair.: 1. Sydney Schaefer (sydney.schaefer@usu.edu) 2. Kathryn Hayward (kathryn.hayward@ubc.ca) 3. Julie Bernhardt (j.bernhardt@unimelb.edu.au)

What is the role of each presenter?: Keith will introduce the Centralized Open-Access Rehabilitation database for Stroke (SCOAR) and current barriers to data integration. SCOAR contains data from 215 RCTs representing 12,786 patients; all of this information has been translated from an unstructured format (i.e., multiple and various independent research articles and supplements) into a structured information architecture. SCOAR lays the foundation for a "living" database. Sydney will present clinically relevant analyses from SCOAR, including those related to dose and timing of rehabilitation interventions. Analyses focus on the Fugl-Meyer Assessment and gait speed measures, the most common CDEs for functional outcomes in SCOAR for the upper extremity and lower extremity. These analyses can inform clinical practice and clinical trial design by making the most current evidence readily available for dosing and sample size decisions. Kathryn will discuss data integration at the individual patient-level, focusing on biomarkers of impairment and recovery in severe stroke, based on data from published trials. These data summarize our current knowledge of the relationship between neurological

structure and function in severe stroke. These findings provide key indicators that are specific to the group of individuals with severe upper limb impairment. Julie will discuss the importance large scale data integration as an emerging frontier for rehabilitation science, addressing the current lack (and necessity) CDEs across trials and the severe limitations this lack of CDEs puts on hypothesis generation and data exploration. From recent multinational RCTs, there is a strong argument for consistent CDEs for participant demographics, study methodology, and clinical outcomes. Although previous arguments have been made on the adoption of CDEs, this talk will focus on CDEs specific to therapy and new methods to encourage the adoption of these CDEs in clinical trials.

Objective 1: Discuss the current benefits and barriers/challenges to integration of data across rehabilitation and recovery trials, both at the group and individual patient level.

Objective 2: Interact with the freely available SCOAR database and feel competent using SCOAR for exploratory meta-analysis and power-analysis.

Objective 3: Understand the positive impact that data sharing and integration across trials can have to advance the field of rehabilitation and recovery.