

**ISWP Evidence-based Practice Working Group  
October 8, 2015 Conference Call**

The ISWP Evidence-based Practice Working Group met by conference call on Thursday, October 8, 2015 from 10:00 a.m. to 11:00 a.m. U. S. Eastern Time. Participants' list follows. This provides a recap.

**Next Call: *Thursday, November 5, 2015, 10:00 a.m. U.S. Eastern Time.***

**Link to Meeting Recording: <https://iswp.adobeconnect.com/p49w22008h6/>**

**Action Items**

1. The Working Group identified three projects/areas of interest, described in the recap below:
  - a. Uniform data set, housed in a central database
  - b. Country/region specific wheelchair sector data, also housed in a central database
  - c. Comparative effectiveness research

Rich Schein and Padmaja Kankipati to request Working Group members' project preference and request other contacts not on the Working Group who could be recruited to help.

2. Nancy Augustine to forward ISWP Training Working Group's analysis of internet connectivity to inform the group about ability to connect to online services in certain regions.

**Discussion:** A copy of the meeting presentation is attached.

1. ***Uniform Data Set:***
  - a. ***ISWP 2015 Survey:*** Rich Schein reviewed results of an early 2015 ISWP survey among members (39 respondents) regarding data their organizations currently collect, their willingness to share de-identified data with ISWP and fields that could comprise a uniform/minimum data set.



Among the roughly 50% of respondents who said they might contribute data, most indicated the need for confidentiality and privacy, as well as IRB requirements and limited time available for data entry and administration.

- b. ***World Vision Database:*** World Vision has created a database for collecting information about its initiative to provide training, wheelchair service provisioning and social inclusion in El Salvador, Kenya, Nicaragua, Romania and India. Rich Schein described the database and presented a comparison of data fields identified in the ISWP survey with ACCESS project data fields. As expected, the ACCESS project collects much more information.
- c. ***Country/Region-specific Data:*** Eric Wunderlich also recommended data be collected which could help other ISWP working groups – Advocacy, Training and Standards – related to:
  - Level of need
  - Services/training received
  - Quality of life
  - Economic impact
  - Condition of wheelchair
  - Access to follow-up/ongoing services for maintenance, repair, and other support
- d. ***NIH Minimum Data Set:*** Mark Harniss suggested the group review NIH's minimum data set:  
<https://www.nlm.nih.gov/cde/glossary.html#cdedefinition>. The structure encompasses universal, domain specific, required and core elements. Thirty common data elements are related to wheelchairs.
- e. ***WHO DAS, QOL and other Sources:*** Group agreed it would be worthwhile to consider WHO's disability outcome measure tools: Disability Assessment Schedule (DAS) and Quality of Life (QOL), and Lee Kirby's Wheelchair Skills Training (WST).
- f. ***Questions from the Working Group:*** In addition to considerations outlined during the August 27 call, Working Group members indicated the following questions should be addressed:
  - How can users enter information?
  - Will the database work offline?
  - How can organizations provide data from previously conducted studies?

## 2. ***Comparative Effectiveness Research (CER):***

For those who are unfamiliar with CER, it is designed to inform health-care decisions by providing evidence on the effectiveness, benefits, and harms of different treatment options. The evidence is generated from research studies that compare drugs, medical devices, tests, surgeries, or ways to deliver health care.

There are two ways this evidence is found:

- Researchers look at all of the available evidence about the benefits and harms of each choice for different groups of people from existing clinical trials, clinical studies, and other research.
- Researchers conduct studies that generate new evidence of effectiveness or comparative effectiveness of a test, treatment, procedure, or health-care service.

Comparative effectiveness research requires the development, expansion, and use of a variety of data sources and methods to conduct timely and relevant research and disseminate the results in a form that is quickly usable by clinicians, patients, policymakers, and health plans and other payers.

There are typically seven steps involved in conducting this research and in ensuring continued development of the research infrastructure to sustain and advance these efforts:

1. Identify new and emerging clinical interventions.
2. Review and synthesize current medical research.
3. Identify gaps between existing medical research and the needs of clinical practice.
4. Promote and generate new scientific evidence and analytic tools.
5. Train and develop clinical researchers.
6. Translate and disseminate research findings to diverse stakeholders.
7. Reach out to stakeholders via a citizens' forum.

Group agreed the CER is definitely one of the routes and/or subcommittees that should be formed, as there is limited research to date on CER in the wheeled mobility & seating area.

3. ***Data Centre:*** Padmaja Kankipati described the concept of a data centre -- a central repository for housing research, communications informing the sector what is available and giving members the opportunity to analyze data for publishing papers. Group agreed this is a significant endeavor and decided to put it lower on the list of priorities.

## **Participants:**

- ✓ Johan Borg, Propempo  
Nathan Bray, Centre for Health Economics and Medicines Evaluation
- ✓ Mark Harniss, University of Washington
- ✓ Astrid Jenkinson, Motivation UK
- ✓ Padmaja Kankipati, SMOI, Co-Chair
- ✓ Lee Kirby, Dalhousie University
- ✓ Eric Wunderlich, LDS Charities  
Molly Schengel, Free Wheelchair Mission
- ✓ Kavi Bhalla, Johns Hopkins University
- ✓ Karen Rispin, LeTourneau University  
Jon Pearlman, University of Pittsburgh
- ✓ Rich Schein, University of Pittsburgh, Co-Chair  
Deepan Kamaraj, University of Pittsburgh
- ✓ Nancy Augustine, University of Pittsburgh

Prepared by: Nancy Augustine, Rich Schein, and Padmaja Kankipati