

**ISWP Evidence-based Practice Working Group
Country Data Subcommittee**

February 18, 2016 Meeting Recap

The ISWP Evidence-based Practice Working Group Country Data Subcommittee met by conference call on Thursday, February 18, 2016 from 9:00 a.m. to 10:00 a.m. U. S. Eastern Time. This provides a recap.

Link to Meeting Recording: <https://iswp.adobeconnect.com/p1nyh88to00/>

Next Meeting: Thursday, March 17, 2016, 10:00 a.m. U.S. Eastern Time.

Discussion (action items in bold/underline)

1. ***Subcommittee Update:*** Astrid Jenkinson, Motivation UK, is on maternity leave. Joining the Subcommittee are: Maria Toro Hernandez, Universidad CES, and recent University of Pittsburgh PhD graduate; Rachel Gartz, University of Pittsburgh graduate in rehab science who is working with ISWP, and Erin Higgins, University of Pittsburgh undergraduate student in computer engineering.
2. ***Collaboration with Other Working Groups:*** Goal is to reduce overlap among groups collecting the same information.
 - a. Regarding Advocacy WG, **Nancy Augustine** to: a) provide list of data points Advocacy Working Group is planning to collect; and b) learn whether there is due date for survey being conducted among Advocacy WG members regarding a priority for collecting data.
 - b. Regarding Comparative Effectiveness Research Subcommittee, **Nancy Augustine** to invite Comparative Effectiveness Research subcommittee representative(s) to the March 17 Country Data Subcommittee call for further clarification on the subcommittee's request to gather outcome measures data over past 20 years related to clinical outcomes such as mobility, quality of life, posture, and seating for manual and power wheelchairs.



3. **Data List:** Subcommittee suggested starting with data that is low-hanging fruit. Comparative Effectiveness Research Subcommittee's request would be put on hold for now. Maria Toro Hernandez suggested adding data related to local research:
 - a. Local research groups: Individuals involved in academia, research and technology involved in wheelchair research.
 - b. Research papers/studies published for research done in the country.

Updated list is attached.

4. **Focus Countries:** Subcommittee to determine criteria for selecting pilot countries. Nancy Augustine suggested aligning efforts with Advocacy Working Group and ISWP affiliate network being developed. Nancy Augustine to talk with Jon Pearlman about status of countries to be selected for affiliate network. (2/19 follow-up: Since the affiliate plan still is being developed, Jon suggests the Country Data Subcommittee proceed with identifying target countries. An approach could be for subcommittee members to propose countries then score based on weighted criteria, including:
 - Strong partner in country
 - Country size
 - Number or some measure of stakeholders who could use data
 - Whether country ties into another Working Group project [e.g., Advocacy is considering Romania, South Africa and Thailand]
 - Other criteria the subcommittee suggests)

Subcommittee acknowledged it will be important to have someone both in country and in U.S. to support data collection. Maria suggested that U.S. liaison be bilingual.

5. **Data Presentation:** Erin Higgins presented options for gathering and reporting data via a map and a list. There were some questions about ability to see small countries; a zoom feature would be available. No consensus was reached on this call; data aggregation and presentation would be part of the test phase. Subcommittee agreed the wiki/application should be available to ISWP members as a value-added benefit of membership.

6. ***Funding Proposal:*** The subcommittee is submitting a funding proposal to the Advisory Board to test a protocol for gathering key wheelchair sector information by country. Approach: 1) Develop protocol, encompassing steps to be taken effectively and reliably to collect data; 2) verify reliability of data/information collected from web sources versus data collected by an in-country data collector; and 3) identify barriers to compiling/collecting data. Amount requested: \$20,000 for six-month pilot.

Participants

- ✓ Maria Toro Hernandez, Universidad CES
- Astrid Jenkinson, Motivation UK (Chair)
- ✓ Padmaja Kankipati, SMOI
- ✓ Eric Wunderlich, LDS Charities
- ✓ Nancy Augustine, University of Pittsburgh
- ✓ Rachel Gartz, University of Pittsburgh
- ✓ Erin Higgins, University of Pittsburgh

Prepared by: Nancy Augustine