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ISWP Evidence-based Practice Working Group

December 1st, 2016 Meeting Recap

The ISWP Evidence-based Practice Working Group met by conference call on Thursday, December 1st, 2016 from 09:00 a.m. to 10:00 a.m. U. S. Eastern Time. This provides a recap.

Next Meeting: Thursday, January 5th, 2017, 09:00 a.m. U.S. Eastern Time.

Link to Meeting Recording: <https://iswp.adobeconnect.com/p695938lr56/>

Discussion (action items in bold/underline)

The following are the updates from the various activities of the working group:

1. African Journal of Disability (AJOD): Deadline is extended to December 15th 2016. ISWP has 8-9 articles so far and welcomes more articles for the special issue which will be published in Spring 2017.

2. Data Collection:

a. Minimum data set

Nancy started the update mentioning that ISWP had a good discussion on the previous data collection subcommittee call on November 17th. Based on the feedback, ISWP developed some objectives, and draft of three surveys organizations can use to collect data. Some of the information from the WHO WSTP Basic Wheelchair Assessment Form and the Follow-up Form has been incorporated into the surveys. Also included are data points that other organization are able to collect and willing to share. The group identified the minimum data along with additional optional data and also prepared three draft surveys:

i. Demographic survey: Collected at the initial visit and would include.

- Location, age, gender, education and living situation.
- Purpose of visit (new/replacement wheelchair or other reasons).
- Recommend collecting information on the person's diagnosis or reason for mobility aids used.
- Types of mobility aid(s) used.

ii. New/replacement wheelchair assessment survey: Collected during the assessment phase and would include.

- Current wheelchair users: Whether wheelchair meets needs, if it's safe/durable and whether cushion provides proper cushion relief. These aspects were taken from the WHO assessment forms.





- For both current and new wheelchair users:

- Ability to move/walk a given distance, if they are able to propel the wheelchair with their upper body ability, need for assistance inside and outside.
- Where wheelchair will be used.
- Anticipated funding/support for wheelchair.

iii. Follow-up survey: Collected when client returns for maintenance, repairs or routine follow-up. This would include

- Demographic information – For example we would want to know if their living situation/education/employment situation had changed as a result of having a wheelchair.
- Purpose of visit.
- Wheelchair source/funding.
- Wheelchair user satisfaction.
- Wheelchair and cushion check.
- Fitting check.
- Client comments – an open area for clients to provide comments on the wheelchair.

Data Collection subcommittee feedback:

- This is a lot of data to collect even with the minimum data. ISWP would invite organizations to collect data for their own purposes and share the data for the data repository.
- Capture data on all 8 WHO basic steps for wheelchair service provision. , ISWP decided to start with assessment and follow-up step for now just to see how it works.
- Consider alternatives to paper surveys, such as open data kit or SMS. Could be a challenge to complete the forms and enter data for people working in the field.

Johan mentioned a tool called KOBO, developed by Harvard University, which is free to use. He also added he had used EPI-INFO which worked well for his work.

Next steps:

- **Krithika Kandavel** to explore the open data kit options (such as mobile or SMS) to facilitate data entry in less-resourced settings.
- **Nancy Augustine** to incorporate the subcommittee's feedback in the survey versions for review on the December 15th data collection subcommittee call.

Karen Rispin mentioned her work in Kenya does not fit the 8 steps because it is not a normal fitting and provision flow. Even where organizations are following the 8 steps, there is limited time for clinicians to collect data and resistance from adding more tasks. The surveys would be a tool, but ISWP would be happy to take the data in other formats based on what organizations currently provide; e.g., Excel. Karen suggested two pieces: 1) an initial form that can be filled



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out; or 2) an online spreadsheet that can be uploaded or added to the existing dataset.

Goal is for subcommittee to reach consensus on minimum data in the next one or two Subcommittee calls.

Karen Rispin offered to test the tool in Kenya next year. Maria Toro Hernandez will look into it as it might be useful for her work too.

b. Country data collection in Romania and Kenya

ISWP is working to establish a contract between the university and Motivation Romania. Padmaja added that Norah Keitany is interested in the project for Kenya. Padmaja shared materials related to the project and expects to receive a timeline and budget soon.

c. Country data reporting proposed format: <http://wheelchairnet.org/content/iswp-wiki>

ISWP team developed a wiki format to present the data that the group will collect. The data can be navigated either by clicking on the country in the map or by using a drop-down menu in the top right corner of the map to select a particular country. This is a dynamic platform and will be regularly updated. Feedback from the group is welcome. Karen Rispin sent ISWP a mapping tool she learned of through another organization. ISWP will be contacting them.

3. Data Center: Next steps and timing

The data center is established with a shared drive in a virtual desktop in which data will be stored as an excel file for a start and eventually a sequel database. (The database will require us to clean up and format the data, which will be a future step.) The first step is to collect different projects and create different project folders that will have read-only materials (raw data), description of the data, data dictionaries and any references, as well as instruments that was used to collect the data. Users will contact ISWP to gain access to the data center, which will require them to get a Pitt sponsored e-mail account, complete online trainings (about the security and privacy of the data) and establish a data use agreement (for organizations contributing data) and a user folder with the requested data will be set up for them to work with. Through the virtual desktop, users will have access to the statistical packages and Microsoft excel and word where data analysis can be performed. The raw data has to stay in the shared folder whereas the analysis can be exported or downloaded to the computer.

Tricia will start working on the Pitt studies conducted in Mexico, Indonesia and India as ISWP already has access. She is working to establish a data user agreement with the JHIPEGO study. Evidence-based Practice Working Group members are requested to let ISWP know of potential students for the data center.

Karen Rispin mentioned her interest to share some of her data sets. Tricia to connect with Karen to work on the data user agreement.

4. Comparative Effectiveness Research Subcommittee

a. Intern Status

ISWP is in the process of recruiting another intern for the spring 2017 semester as the project scope did not meet the previous intern's classwork requirements.

b. Item for African Journal of Disability

The group is drafting a brief article highlighting the needs of a research framework. Nathan Bray and Deepan Kamaraj to forward to the CER Subcommittee for input/approval.

Participants

- ✓ Johan Borg, Lund University
Nathan Bray, Centre for Health Economics and Medicines Evaluation
Mark Harniss, University of Washington
- ✓ Maria Toro Hernandez, Universidad CES
Astrid Jenkinson, Motivation UK
- ✓ Padmaja Kankipati, SMOI, Co-Chair
Karen Reyes, UCP Wheels for Humanity
Eric Wunderlich, LDS Charities
Chandra Whestine, World Vision
- ✓ Tricia Karg, University of Pittsburgh
Alexandra Miles, University of Pittsburgh
Molly Broderson, 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
- ✓ Krithika Kandavel, University of Pittsburgh
- ✓ Nancy Augustine, University of Pittsburgh

Prepared by Krithika Kandavel