

## ISWP Evidence-based Practice Working Group

### November 3rd, 2016 Meeting Recap

The ISWP Evidence-based Practice Working Group met by conference call on Thursday, November 3rd, 2016 from 09:00 a.m. to 10:00 a.m. U. S. Eastern Time. This provides a recap.

**Next Meeting:** Thursday, December 1st, 2016, 09:00 a.m. U.S. Eastern Time.

**Link to Meeting Recording:** <https://iswp.adobeconnect.com/p3dzsul2buf/>

**Discussion** (action items in bold/underline)

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

#### 1. Data Collection:

##### a. Country data collection in Romania and Kenya

Country data collection in Romania is successful work in progress with some questions from Motivation Romania that is being addressed. In Kenya, the group is working to identify an in-country consultant to be able to conduct interviews with the various organizations who are working in the field of service provision to focus on the data variables from the data matrix. Chandra is helping the group in getting two people who might be interested in the project. The group hopes to finalize the consultant and get work started soon. The back-up country would be the Philippines as ISWP now has an affiliate program tied up with them and there is an overlap in the needs assessment and the country data collection efforts. Motivation Romania provided an updated timeline and the group can expect to see a report in February 2017. The group will be posted on more updates on this.

**Action:** Karen to connect the group with some contact personnel in Bethany Kids in Kenya who might be interested in the project.

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

ISWP team developed a wiki format to present the data that the group has been collecting. 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 dynamic and will be regularly updated. The group talked about formats where people can contribute data but it would still need to be reviewed before its posted for consistency, accuracy and reliability. ISWP team to re-group and talk about populating some information to see how it looks before the next meeting. Feedbacks from the group are welcome.

**Action:** ISWP will hope to gather maximum information from one country and try to populate data to test the case.

### c. Minimum data set

PJ mentioned that the group had a good meeting previously with lots of feedback on the questionnaire. The recap from the meeting will be shared with the group. There are some aspects that need to be addressed. For example, one of the questions asks the client/caregiver to provide an answer for the purpose of their visit and one of the feedbacks was that the question sequence will vary depending on the response, that is if the person visits to be assessed or fitted then they will have a different sequence of questions when compared to a person who will be visiting to receive a wheelchair or visiting for other purposes. The group is also finalizing on another question about the ability of the person to move and how this can be recorded or asked.

Karen Rispin questioned the group on what the result was as the group had previously discussed on gathering information specially to wheelchairs or everything. Nancy mentioned that the group agreed that the person can use different mobility aid and they wished to capture all of them.

Karen also asked the group if the questionnaire will then focus on collecting information from the wheelchair users or persons using prosthetics and orthotics or other devices without a wheelchair. PJ added if this questionnaire will be primarily used by the wheelchair service provider. Karen agreed that this was her understanding too but the questions on other devices makes her think otherwise. She suggested that we can focus on the wheelchair users and include the other device question because that will be interesting to know.

Nancy mentioned we will reach consensus on the questionnaire and work on the excel too to see how difficult or easy it is to collect the data. PJ mentioned that there is a thought to include an instruction manual to guide the interviewer on the questions. Nancy added that the group is also looking to focus on the core questions that can be collected.

## 2. Data Center: Next steps and timing

Nancy introduced Tricia Karg from University of Pittsburgh to the group who will be helping ISWP with the data center. The data center will be set up with a help of a group that runs a data center service where all the data will be stored in their server. It will provide access to users outside the university to pull up the data, analyze and aggregate them and write papers and use the data however they see fit. ISWP team will have a meeting with the data center group in 2 weeks. They will be able to download the analysis. Instructions on how the study should be cited if used will also be included. Any data that ISWP receives from outside subjects to a data user agreement with that party which will mention also that ISWP will offer the shared data to people outside the university.

As a first step, some of the IRB approved data will be uploaded to the data center just so the internal team understands how this works and the process. It's a virtual desktop with a data

dictionary. The team intends to develop quick reference guide to anyone who is willing to contribute data and is interested to access the data. After the data center training on November 14<sup>th</sup>, the team will draft a timeline to roll this out.

Trish added that with respect to the users, it works in a group model where there is permission control through groups and not individually. There is also no limit to the number of users in the group. All users need to have a sponsored Pitt account and complete at least one hour of privacy training before using the dataset. There will also be information on how to use and cite the data.

Right now, the group is looking for de-identified data. At first, it will be individual dataset and later we can work to combine the data. Karen added it will be useful to indicate how we would want some of the fields like the age, disability and gender to be entered so that it's easier to find the categories. Nancy added that this is where the excel tool can be used. Trish mentioned that general guidelines for those who have existing datasets to format to helps them in formatting or combining the data will be useful too.

Karen added that there are two part of the data. One is more than a typical demographic since it includes disability and wheelchair type and the other is the data collection tool like the FMA. There can be some kind of grouping the datasets to the data collection tool that it used. It will be useful to see data from different sites for a particular data collection tool (for example: MUD, WHO-QOL, FMA, etc)

Karen Reyes mentioned that for the google project, they are working to identify some of those parts where what kind of tools and questions were similar so they can aggregate them and try to identify what instrument they can use. Nancy mentioned to Karen to keep the group posted on what tools they are looking to use. Karen added that she will share the tools once it has been identified.

### **3. Comparative Effectiveness Research Subcommittee**

#### **a. Intern Status**

ISWP is in the process of looking out for another intern as the previous intern's project scope did not meet her requirements. Nancy intends that the intern might start in Spring 2017.

#### **b. Item for African Journal of Disability**

The group will work on focus a case study that highlights the needs of a research framework instead of a manuscript for the AJOD submission. Nathan and Deepan are working on this.

## 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