

ISWP Evidence-based Practice Working Group

February 1st, 2018 Meeting Recap

The ISWP Evidence-based Practice Working Group met by conference call on Thursday, February 1st, 2018 from 10:00 a.m. to 11:00 a.m. U. S. Eastern Time. This provides a recap.

Next Meeting: Thursday, April 5th, 2018, 10:00 a.m. U.S. Eastern Daylight Time

Link to Meeting Recording: <https://iswp.adobeconnect.com/p94q8rv7sbzr/>

Action Item:

Working Group members who were not able to participate on call are asked to review presentation and meeting recap and provide feedback on Questions 20-24 **by Monday, February 19, 2018.**

Discussion:

1. Minutes of December 7th, 2017 were approved.

2. Minimum Uniform Data set (MUD):

a. Changes made based on input to date: ISWP received feedback during the December 7th, 2017 Evidence-based Practice WG call, as well as from the University of Washington, University of Pittsburgh biostatistician and Google User's Voice project from MIT. Based on the feedback, we have made the following changes:

- Client and Wheelchair Clinic Information
 - Added instruction requesting section be completed by service provider, with client input
 - Added request for complete address for client and for wheelchair clinic, including town and district
 - Added name of person at wheelchair clinic who helped with the section or the survey
- Q8: "Why are you here today?"
 - Added "I am here for a health check."

- Removed: “I am here for WC maintenance or repair” and “I need general help with my wheelchair.”
- Changed “Do Not Know/No Answer” to “Not Sure”
- Q9: Changed to “Age (approximate age)” and “Do Not Know/No Answer” to “Not Sure”
- Q10: Simplified options for gender to “Male”, “Female”, and “No Answer”
- Q11: Added “Vocational training” to education list
- Q13: Provided list of possible people with whom client could live, suggesting to check all that apply

| | |
|----------------------------------|--|
| Parents or parents | Child or children |
| Sister or sisters | Other family members, such as grandparent, aunt, uncle, cousin |
| Brothers or brothers | Friends or other people who are not related |
| Husband, wife, spouse or partner | Live alone |

- Questionnaire long version: Moved questions regarding manufacturer, model and serial number of client’s assistive devices and cushion/postural support to end for service provider to complete.

b. Consensus needed on some questions

The group then discussed and reached consensus on the following questions:

Q8. Why are you here today?

I have a wheelchair that does not meet my needs. Chandra mentioned if its already on the WHO 8 steps referral form, it should be left as is. Eric added that we need to have potential answers that fit with the thinking of people who would come to the service provider: to get a wheelchair, for some type of follow-up (maintenance, repair, adjustment), for training, for health check, for study.

I am here to participate in a research study. Karen Reyes mentioned that during the Google wheelchair user’s voice pilot in Indonesia, they had users indicating that they wanted to participate in a research study. She suggested keeping it as is. Another option is to create two

subcategories under “research study”: research about wheelchairs and research about something else.

Q11. What is the highest level of education you completed?

Eric mentioned that the original question and answers are okay. Chandra added that in other countries, ‘Home-schooling’ means something different as in children are home but not necessarily being educated. She mentioned that simpler is better. The group agreed to keep the question without changes.

Q14. About how long have you needed a mobility aid?

The recommendation is to change to ‘About how long have you needed something to help you walk or move, such as a wheelchair or walker?’ The group agreed with the changes.

Q15. Why do you need a mobility aid or aids?

The recommendation is to change to ‘Why do you need help to walk or move?’. The group agrees with the changes.

Q17. Check the box below the statement that best describes how much difficulty you have walking a long distance (100 meters):

17. Check the box below the statement that best describes how much difficulty you have walking a long distance (100 meters):

| No Difficulty | Some Difficulty | A lot of Difficulty | Severe Difficulty/ Cannot walk 100 meters |
|--------------------------|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

↩

EBP Working Group suggestion: Consider using Washington Group’s Short Set of Questions on Disability as it pertains to walking. Link: <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/The-Washington-Group-Short-Set-of-Questions-on-Disability.pdf>. Question: “Do you have difficulty walking or climbing steps?” Responses: “No-no difficulty.” “Yes-some difficulty.” “Yes-a lot of difficulty.” “Cannot do at all.”

↩

Google User’s Voice Project added more specific distances: “<100 m, 100-499 m, 500-999 m, 1-5 km, >5 km, do not know.” Most people were traveling less than one kilometer. Based on feedback from the researchers, in the end, they broke this out into two questions. Have you had difficulty moving a long distance such as a kilometer? If, yes how much difficulty.

Univ. of Washington comment: “If this question is from WHO-DAS questionnaire, then keep as is.” ISWP comment: “WHO DAS Short Version question references “Walking a long distance, such as a kilometer (or equivalent).” Response options: “No difficulty.” “Mild difficulty.” “Moderate difficulty.” “Severe difficulty.” “Extreme difficulty or cannot do.”

Karen mentioned that in Indonesia, people used references and including more options for distance were easier for them to respond. Chandra and Karen agreed the question is useful as is. Eric suggested the scale be consistent with other questions in the survey so not to confuse people (Q19, difficulty pushing wheelchair, has a scale).

Q18: Matrix question related to mobility aids and use.

18.-The table below includes a list of common things to help you walk or move, like wheelchairs, braces and walkers.--Please think about all of the things you own to help you walk or move and how you use them.--Please provide answers for each item you use regularly in the table below.--If you do not own a specific item listed, or you own it but do not use it on a regular basis, please leave the row blank...

| Items to help you walk or move | Put a check in this column if you currently own this item | Put a check in this column if you use this item indoors | Put a check in this column if you use this item outside | Put a check in this column if you have used this item for more than one year | In a typical week, how many days do you use this item? (Put a number between 1 and 7.) | In a typical week, how many hours each day do you use this item? (Put a number between 1 and 24.) |
|--|---|---|---|--|--|---|
| Manual wheelchair | | | | | | |
| Manual wheelchair for active use | | | | | | |
| Manual wheelchair, assistant controlled | | | | | | |
| Manual wheelchair, lever-propelled | | | | | | |
| Manual wheelchair, power-assisted | | | | | | |
| Manual wheelchair for sports or recreation | | | | | | |
| Electrically powered wheelchair | | | | | | |
| Scooter | | | | | | |
| Cycle (Bicycle, Quadricycle, Tricycle, Handbike) | | | | | | |
| Walking Stick or Cane | | | | | | |
| Crutch or Crutches | | | | | | |
| Walker or Walking Frame | | | | | | |
| Rollator | | | | | | |
| Club-foot Brace or Braces | | | | | | |
| Lower limb orthoses | | | | | | |
| Artificial limb or limbs | | | | | | |

Q18 considerations:

Eric mentioned that the ‘things they own’ might be different in some context, as in they might have access to them but might not necessarily own them or own them and not use them. (Follow-up note: Jon Pearlman suggested keeping the column labeled as “currently own” instead of changing to “currently use.” If the client indicates he/she does not use the item anywhere (indoors/outside columns) or at any time (days/hours columns), it could be determined that the person owns the item but has abandoned it. Jon explained abandonment information is very useful.

Eric suggested simplifying the categories further. Chandra suggested not listing items that clients might not be able to receive. Based on the group’s feedback, the revised list would be:

- Manual wheelchair
- Electrically powered wheelchair

- Board with wheels (*Note: In place of Scooter*)
- Hand-powered cycle (*Note: In place of Cycle-Bicycle, Quadricycle, Tricycle, Handbike*)
- Walking Stick or Cane
- Crutch or Crutches
- Walker or Walking Frame
- Brace or Braces
- Artificial limb or limbs
- Other (*Note: will include lines below for client to describe*)

Karen commented that ‘Scooter’ was a term not known in Indonesia. Chandra mentioned that if the person is with a board of wheels on it, that could be called a scooter. Rollator would be removed from the list.

Q19. How much difficulty do you have pushing your current wheelchair?

Questions for Current Wheelchair Users

For the next few questions, think about your current wheelchair. If you are getting a new wheelchair at your visit today, think about the wheelchair you have used up until this visit.

Univ. of Pittsburgh question: Do we need to specify which wheelchair (if they have more than one) they should be thinking about when answering the questions?

19. → How much difficulty do you have pushing your current wheelchair? (Check one)

Univ. of Pittsburgh comment: Reworked formatting for question. It's often easier for respondents to understand if the Likert options are horizontally displayed and if you anchor the ends of the scale with descriptions.

| No Difficulty | Mild Difficulty | Moderate Difficulty | Severe Difficulty | Extreme Difficulty |
|---|-----------------|---------------------|-------------------|----------------------------------|
| I can push my own wheelchair without any problems | | | | I cannot push my own wheelchair. |

If same responses as WHO-DAS, keep. Otherwise, change to same responses as Q17. ISWP note: None, Mild, Moderate, Severe and Extreme are the WHO-DAS 2.0 options. "Cannot do" is not part of the "Extreme" option.

The group suggested making the scales in Q17 and Q19 consistent.

Members to provide to feedback on Questions 20,21,22,23 and 24 **by Monday, February 19, 2018**. Goal is to finalize data set by February 28 so it can be used in Phase 2 of the Google User’s Voice Project.

3. Data Center Move: ISWP is moving studies from the Pitt Health Sciences Research Data Center to the Center for Large Data Research & Data Sharing in Rehabilitation (CLDR), Archive of Data on Disability to Enable Policy and Research (ADDEP).

The Center for Large Data Research and Data Sharing in Rehabilitation (CLDR), part of the MR3 Network at the University of Texas, has an initiative to advance research on disability called [ADDEP](#). ADDEP’s goal is to bring together existing disability data already available at ICPSR with newly acquired data from rehabilitation medicine and related areas. Users can deposit and find data through ADDEP’s web-based tools. ADDEP is hosted by [Inter-university Consortium for Political and Social Research \(ICPSR\)](#), the largest social science data archive in the world and part of the University of Michigan's [Institute for Social Research](#). The ADDEP team was positive about potentially using the archive which is more publicly available and accessible.

The curation of available studies is in process. It takes 15-20 days to review/curate data for one study. The first studies should be available in late March 2018. In the meantime, data for studies listed in the “Studies Available” column can be obtained through Pitt:

| Studies Available | Studies Pending |
|---------------------------------|--|
| Mexico (Teleton) | Indonesia (Google WC User’s Voice Project) |
| Indonesia (UCP) | 7 countries (World Vision ACCESS Project) |
| Kenya and Philippines (Jhpiego) | Kenya (Minimum Data Set, LeTourneau) |

CLDR also funds pilot projects to perform secondary analysis of data on ADDEP. USAID is a sponsor, and University of Pittsburgh library system is a member. **Nancy** to provide ADDEP/CLDR funding options for the group.

4. 2018 Calls: 2018 calls will be held bimonthly, on the first Thursday at 10:00 a.m. U.S. Eastern Time: April 5; June 7; August 2; October 4; and December 6.

Participants:



Johan Borg, Lund University

Nathan Bray, Centre for Health Economics and Medicines Evaluation

Molly Broderson, Free Wheelchair Mission

Mark Harniss, University of Washington

✓ Kristi Haycock, LDS Charities

Maria Toro Hernandez, Universidad CES

Astrid Jenkinson, Motivation UK

Padmaja Kankipati, SMOI, Chair

✓ Karen Reyes, UCP Wheels for Humanity

✓ Karen Rispin, LeTourneau University

✓ Chandra Whestine, World Vision

✓ Eric Wunderlich, LDS Charities

Deepan Kamaraj, University of Pittsburgh

✓ Tricia Karg, University of Pittsburgh

Alexandra Miles, University of Pittsburgh

Jon Pearlman, University of Pittsburgh

✓ Nancy Augustine, University of Pittsburgh

✓ Krithika Kandavel, University of Pittsburgh

Prepared by Nancy Augustine and Krithika Kandavel