

ISWP Evidence-based Practice Working Group

December 7th, 2017 Meeting Recap

The ISWP Evidence-based Practice Working Group met by conference call on Thursday, December 7th, 2017 from 9:00 a.m. to 10:00 a.m. U. S. Eastern Time. This provides a recap.

Next Meeting: Thursday, February 1st, 2018, 9:00 a.m. U.S. Eastern Daylight Time

Link to Meeting Recording: <https://iswp.adobeconnect.com/pyc6sys55vg5/>

Discussion: (action items in bold/underline)

1. Minutes of October 5, 2017 were approved.

2. Minimum Uniform data set status and next steps:

Evidence-based Practice WG members have access to the minimum data set tools, which were finalized in April 2017. These include: Two questionnaire versions (short version, 25 questions; long version, 36 questions); interview guides and Excel workbooks.

Here is the link to the MUD package in the google folder:

<https://drive.google.com/drive/folders/0By9K14wVjdJGNmdCY1hfeG9Dck0>

As per the September 2017 Data Collection SC call agreement – we are waiting to revise the paper questionnaires based on the following feedback:

- May 2017 short version questionnaire used by Karen Rispin, LeTourneau University, in Kenya (n=95).
- UCP/Google project long version questionnaire used in Indonesia pilot (n=150).
- University of Washington – Mark Hrniss' colleague (update: received December 15, 2017)
- Padmaja Kankipati's use in her clinic, SMOI, as opportunity permitted.

As a next step, we will need to reach consensus on incorporating changes from these sources:

- LeTourneau University, Kenya (n=95). Changes to 11 questions
- UCP/Google project, Indonesia pilot (n=150)
- University of Washington
- SMOI

We hope to distribute the finalized questionnaires and tools at January 2018 USAID meeting in Bangalore, India. We need to finalize by December 18th, 2017 to have materials ready for January 15, 2018 meeting.

As a recap, the short questionnaire version (25 questions) of the minimum data set used in Kenya, May 2017 with Primary school students (n=31) where volunteers administered the questionnaire and Secondary school students (n=64) where students completed questionnaire themselves; volunteers noted when students said they had difficulty completing a question. For the primary students, the data was shared in an excel workbook and for the secondary students, it was shared in a paper questionnaire.

The most frequently mentioned difficult questions are listed below:

Question	Number of Times Mentioned as Difficult
Q5: Service provider name	32
Q17: Mobility aids used (5-part question)	30
Q17a. Which mobility aids do you currently use?	27
Q3. Client Town	19
Q6: Service provider location	16
Q8: Purpose of visit	16
Q2: Client ID	16

Q2, Client ID: change to say: Client ID (service provider to fill in after survey is completed)

Q3, Client Town:

- The group asked the purpose of knowing this information.
- Mark asked if it's a demographic question or to know the primary use of the wheelchair use. If it's a demographic question, then Mark suggested that it could be replaced with where are you living now?
- Johan suggested that he would be interested to know if they are living in rural or urban setting or what town/district are you living in now? He also added that it depends on what we will be doing with the information. He said there are more than one place with the same town name that we should keep it in mind.
- Tricia suggested that we can also consider to add the district.
- Johan added that if the service provider can provide the Client ID number then they may as well answer 3,5 and 6 as well. We could group them and include 'To be completed in conjunction with a Service Provider'.

- Johan added if Client's Town or Client's ID will make it easier to understand.
- Tricia added that all the questions 2,3,5 and 6 can be indicated if should be filled out by the service provider.

Q4, Service Provider Name and Q6 (Service Provider) Location

- Tricia added it should be changed based on who will be filling them out, service provider or client itself.

Q8, Purpose of Visit:

- Johan asked if this will be only filled out by people using or receiving wheelchair.
- The group suggested to highlight (bold and underline), 'primary purpose or most important'.
- Tricia suggested that we re-visit the options, maybe we have Wheelchair repair or a repair/ routine follow-up covered in all the blocks and maybe be straight forward with the others, getting first wheelchair, wheelchair is broken, wheelchair does not meet any needs, need help with my wheelchair, health check and research study.
- Mark added that we can take out 'I need general help..' option can be more specific, the group agrees that it overlaps with the does not meet my needs.
- Karen added that 'I am here to get my wc' is confusing so maybe changed to I am here to get a wc or first wc?
- The agreed list is I am here to get my first wc or a wc, my wc is broken, I have a wc that does not meet my needs, I am here for Maintenance or repair or routine follow-up, I am here for a health check and here to participate in a research study.

Q17, Mobility Aids Used

- Johan suggested pictures of all the products from different mobility rather than description, and instead of having the table, the respondents can choose from the charts and then fill out how, where they will use it, etc. Only experts will be able to answer some of the products.
- Mark suggested to replace the 'Current Mobility - Aids' with 'Current Assistive List/Needs'. He added that it's too complicated for a client to fill it by their own.
- Johan asked why Rollator is under manual wheelchair as it should be under the walking products. He added that the 'Crank system' is confusing.
- Johan suggested that sometimes the date you need are the client's seldom use, frequency is important than the importance of use.

- Tricia and Johan added that the chart with mobility device pictures and then numbers/smileys for each question would be helpful.

Q18, Difficulty Walking and Q19, Difficulty Pushing Wheelchair

- Johan suggested to use the Washington group's question on walking., link: <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/The-Washington-Group-Short-Set-of-Questions-on-Disability.pdf>
- He also suggested difficulty in walking 100 meters can be an option because 1 kilometer is a long distance.
- Mark added that if this one from the WHO DAS questionnaire then we keep it as it is. He added that it's a question for ISWP's internal group to either keep or simplify the existing questions if it's taken from WHO DAS or other validated survey.

Q22, Where Wheelchair is Currently Used

- Johan asked if it's our interest to know if they use the wheelchair in the options mentioned or if its captured in other questions. Mark added it captures a more of the context of the use.
- Tricia added that it could be taken from the FMA, the options could be At Home, At School, At Work, From one place to another or stowing or sitting in a vehicle?
- Mark added that 'I use it between work to school' can be an option.
- Johan is interested to know how difficult it is to use wc in the various options (work, home, etc.), he added that if they don't use it in a place then we don't know why, this question only captures the current and we wouldn't know what is the purpose.
- Mark added Transportation should be broken being in a bus or car in a wheelchair and actually using the wheelchair for transportation (getting from one place to another).
- Johan added that 'All the places outside home' in the place of Other public places outside homes.

Q24, agreement with wheelchair statements.

- Change to Yes, mostly/ Yes, somewhat, No, not at all and Do not know

Q25, Satisfaction with Current Wheelchair

- Johan asked if these questions are from the Quest, link: http://www.midss.org/sites/default/files/questeng.scoring_sheetpdf_0.pdf
- He added to have labels for all the options above the number.

- Mark added three comments for this question, does it map to another question in a survey? What is the rationale for shortening? If you want to shorten it then, Very Satisfied, Quite Satisfied and Not satisfied at all are his suggestions.
- Mark and Johan added if we could use the options from the Quest (bottom of the page).

4. Data Center Move: Studies available in the data center are from Mexico (Teleton), Indonesia (UCP), Kenya and Philippines (Jhpiego), 7 countries (World Vision ACCESS Project) and Kenya (Minimum Data Set, Le Tourneau). Dalhousie University completed secondary analysis of Jhpiego data; ready for publication.

We will be migrating the data center into a more accessible web-based center through ADDEP (Archive of Data on Disability to Enable Policy and Research) and ICPSR (Inter-University Consortium for Political and Social Research) consortium. 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](#). 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. The ADDEP team was positive about potentially using the archive which is more publically available and accessible. Tricia Karg of Pitt is exploring further.

Participants:

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