International Society of Wheelchair Professionals I wheelchairnet.ORG

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ISWP Evidence-based Practice Working Group
Comparative Effectiveness Research Subcommittee

June 12, 2016 Meeting Recap

The ISWP Evidence-based Practice Working Group Comparative Effectiveness Research Subcommittee met in-person on Sunday, June 12th, 2016 from 09:00 a.m. to 05:00 p.m. Ireland Standard Time (IST) at Dublin, Ireland. This provides a recap.

Next Meeting: Thursday, July 7th, 2016, 10:00 a.m. U.S. Eastern Time.

Discussion:

Objectives of the meeting: What do we all want to achieve today?

- After the introductions from all the participants, the agenda was reviewed and proceeded to the meeting after no changes.
- Mary mentioned the ongoing works for the advocacy toolkit and that two countries, South Africa and Romania have been selected for this project and the goal is to collect more policy-wise data from these countries.
- Karen mentioned the possibility of using texting in mobile phones to collect data in Kenya. Deepan added that mobile phones are more reachable in India as well and would be a good source to collect data.
- Nathan stated that there is a need for a framework to understand the simple way to collect robust effective data. He also added that the best way to move forward is to start small and grow from there.

Review of the CER working group goals:

- The goal of the CER SC is to focus on creating a framework for the right people for the right country. Jon added that there are ongoing efforts from the WHO to include all the technologies and then developing the priorities to engage people similar to the GATE foundations.

- While developing the CER framework, the team discussed on including the outcome measures, inclusion of other technology, scope and mandate.

- Deepan mentioned that it should be applicable in different ways like the assistive technology and have sub-categories and also identifying the pros and cons for the domains.

- Jon added that in the wheelchair domain, we would want to persuade the government with policies. Some ways of doing so can be to compare it with other technology. For example, comparing it hearing aid.

- Karen mentioned that the goal of the CER SC goals should focus on improving the wheelchair service. The survey questions shouldn't be vague.

- Different countries have different challenges in their own aspect; difficulty in shipping is huge and the need of wheelchairs varies across the spectrum was discussed.

- Many people in Kenya are unaware of their diagnosis and the kind of wheelchair they have and so considering questions related to the region is important. They can answer questions like how far they can go with the wheelchair but not questions like what kind of wheelchair they are using.

- Jon added that simple questions such as "What is wrong with you?" and "Are you using the wheelchair?" can be important to policy makers, service providers and for the quality assurances purposes.

- Deepan suggested that we prepare the framework first, develop something similar to the EQ-5D and target on large populated countries.

- Karen suggested that the people should understand the benefits of the survey and the top level survey questions on asking the clinicians depends on what kind of data we want.

- Using the texting surveys in mobile phones have their own drawbacks like it would be difficult to interpret if the wheelchair user or the caregiver is answering the questions.

- Jon added that understanding the funding and the policy of a particular region is crucial. Also understanding the context, environmental factors and accessibility of that region are important.

- Karen suggested considering the framework to order the chairs in the country with the clinicians fitting them. The framing of the questions such as i) If you had an assessment before receiving the wheelchair? or ii) Did you receive the wheelchair without any assessment? are vital.

- Deepan mentioned that it is only the process guideline and not the domain guideline and Jon added that the environmental and personal factors are probably things to be captured in the framework.

Review of the Minimum Uniform Data Set (MUD):

- Karen presented her feedback on the minimum uniform dataset that she used in Kenya to collect data.

- The participants were disabled students from a boarding school in Kenya. The students were from both the primary and the secondary schools.

- The average age of the secondary school students is 17 and the primary school students is 11 and a half. 65 students from the secondary school and 45 students from the primary school participated in the survey.

- Two therapists and local students were also present to help.

- The minimum uniform data set (MUD) with feedbacks and comments can be found at the end of this document.

- **You can also access it in the google drive here:**
  https://drive.google.com/drive/folders/0B96jRy5C8-f7Qkh2ek1lYWd3ME0

Review of the conceptual framework:

- Karen is working on other studies to measure the distance travelled in the wheelchair. She performed these studies on 30 students for 4 mins in 4 different terrains in Kenya.

- The members discussed that the environmental and personal agreement has to be addressed within each segment and should be of different domain. Also the process for the data analysis and to identify the questions for the domains and to change the language according to the wheelchair user and then collect the data and implement them;

- Social support structure can be derived from the environmental and the personal domain.

- There were discussions on the availability of wheelchair parts locally in a particular country. When delivering a wheelchair, it should also include use extra cushion, casters and stuffs. The organization need to have facility to store this and other part is to learn from the different available parts.

- Measure the impact: The framework need not necessarily will have to measure the impact. It can also be just to collect the data.

- Suggestions on one question to identify two domains were made. For example, a question on 'Did you get the training/assessment done?' One aspect is what is assessment and the other one is how to identify the assessment. Discussion on what kind of analysis to be done to identify the two different domains were made.

- Karen mentioned that the questions should be specific, for example: Do you have trouble getting the parts?

- Questions should be directly addressed to service providers rather than on Quality of Life (QOL) to include questions like 'where you able to get the parts?' or 'How hard is to get the wheelchair into your country?' An appropriate wheelchair need to be appropriate for the environment and their culture as well.

- Jon posted a question to the group on how to get the economic factors in a country. Things to consider are lots of productivity, supplier perspective and that would include the wheelchair and the on-going maintenance. We should keep in mind that the value of money changes over time.

- Users and the service: Nathan added to measure care or time. The money the society has put in and the number of hours that was put in to it can be measured.

Open Discussion:

- Nathan mentioned that addressing to the manufacturers that they can save money by selling expensive wheelchairs that can last longer than producing cheaper wheelchairs is crucial. He also added that the time horizon is of matter.

- Mary mentioned the initial return will be lower but in the long term it's going to have an impact.

- There is an ethical dilemma but cost-effectiveness would be the strongest argument.

- Some of the questions raised by Karen: How does a local organization find out about the wheelchair needed person and approach them? Who are we convincing? Stakeholders have different perspective so should we identify each stakeholders and have questions directed them?

- The conceptual framework was then reviewed and the latest version can be found here:
  https://docs.google.com/presentation/d/1pd_sKnUDc10oh7uKSyXVz26F1UYEVq7Y2k14D8fezq8/edit#slide=id.g145d81886f_0_45

Action:

1. Framework: To start to write the framework, identify and group the method and metrics and to also identify the group where each belongs to. Start putting together the primary data set and the relationship of what we want and what exists. Also identifying what tool contributes to each factor.

2. Review of the papers: Jon suggested to go back and look at the papers that have been published (journal papers) with data and then see how it fits in the framework and capture the related wheelchair framework. Grouping of already published journal papers provides us with things to write about for a start. Looking into existing data that we have access to will also help in this process.

3. MUD (Minimum Uniform Data Set): To collect the primary data, the best way to do at this point is MUD (Minimum Uniform Data Set), next steps are to complete the IRB application related to it and then looking into collecting the data through the internet globally.

4. Crowd source request: Ask for conference briefs to contribute to the data set.

5. Policy Toolkit desk review: Correspond with Padmaja and Mary to collaborate on the case study results and others.

6. Deepan to submit the **funding proposal by June 17th 2016** for the 'Research Intern' position.

7. A paper on the framework to follow tentatively by T**hursday, December 1st 2016.**

8. Next funding proposal is due by **Friday, October 21st 2016**. Funding proposal to include the in-person meeting at the ISS 2017.

9. Other possible funding options include:

- Funding options to support data center work

- Primary data collection (MUD)

- Research brief request

- Identify data sources

    - Polytrauma data

    - SCI model systems

    - ACCESS, JHPIEGO, Pitt Data

    - M&E of USAID projects

    - NGOs: HI, Motivation, UCP

Participants:

- ✓ Deepan Kamaraj, University of Pittsburgh*(co-chair)*
- ✓ Nathan Bray, Centre for Health Economics and Medicines Evaluation*(chair)*
- ✓ Karen Rispin, LeTourneau University
- ✓ Padmaja Kankipati, SMOI
- ✓ Nancy Augustine, University of Pittsburgh
- ✓ Jon Pearlman, University of Pittsburgh
- ✓ Mary Goldberg, University of Pittsburgh
- ✓ Krithika Kandavel, University of Pittsburgh

Prepared by: Krithika Kandavel

**Evidence Based Practice Working
Group Minimum Uniform Data Set**

DRAFT: Data Set (April 21, 2016)

Date:_____

Check one:

Completed by client.

Completed by someone else.

Client Name (for internal use only) _____

~~Patient~~ Year of Birth:_____

Height:_____(centimeters)

Weight:_____(kilograms)

Do not know height and/or weight (check box)

Gender:
      a. Male
      b. Female

1. ~~Diagnosis~~ Why do you use a wheelchair (check all that apply ~~one)~~

      a. Cerebral Palsy
      b. Spinal Cord Injury
      c. Stroke
      d. Amputation
      e. Brain Injury
      f. Muscular Dystrophy
      g. Polio
      h. Spina Bfida
      i. Was in accident
      j. Was injured

      k. Was born this way

      l.   Other (please describe) _____

      m. Don't know/no answer

2. What year did you receive this diagnosis?

      a. Year_____

      b. Don't know/no answer

3. What is the highest grade in school that you completed?

      a. Some Primary School

      b. Primary School

      c. Some ~~High~~ Secondary School

      d. ~~High~~ Secondary School Graduate

      e. Some ~~College~~ University

      f. ~~College~~ University Degree

      g. Advanced Degree (Masters, PhD)

      h. None

      i. Don't know/no answer

4. Can you read and write?

      a. Read

           Yes

           No

           Don't know/no answer

      b. Write

           Yes

           No

           Don't know/no answer

5. What language or languages do you speak? _____

6. What is your current occupational status? (check one)

      a. Employed Full Time (at least 40 hours per week)

      b. Employed Part Time (fewer than 30 hours per week)

c. Unemployed
d. Student
e. Don't know/no answer

~~Date of Interaction:~~_____(moved to top of questionnaire)

7. What is the purpose for the visit? (Check all that apply)
   a. Assessment
   b. Ordering
   c. Maintenance
   d. Repair
   e. Education
   f. Follow-up
   g. Fitting and delivery
   h. Health check
   i. Assistance with wheelchair
   j. Participate in research study
   k. Other (describe)_____

8. Physical Function Ability:
Suggest phrasing differently; e.g., How would you travel a distance of 25 feet? Also, need to express 25 feet in some other way; many don't understand. Terms unilateral/bilateral wouldn't be understood.

   a. I can walk at least 25 feet without support.
      Yes   No   DK/No Answer
   b. I need unilateral support (e.g., can used with one hand/arm) to walk 25 feet but do not need bilateral support (e.g., walker or crutches using both hands/arms)
       Yes   No   DK/No Answer

   c. I need bilateral support (e.g., walker or crutches) to walk 25 feet.
          Yes   No   DK/No Answer
   d. I cannot walk 25 feet even if I use supports (e.g., you use a wheelchair and do not walk using your legs.)

10

Yes   No   DK/No Answer
e. I need support only if I am traveling more than 25 feet.
Yes   No   DK/No Answer

9. Is your upper body affected by your inability to self propel a manual wheelchair?
   a. My upper body is not disabled
   b. My upper body is somewhat disabled.
   c. My upper body is very disabled.
   d. Don't know/no answer

Consider moving Questions #10 and 11 ahead of Question #9, Physical Function Ability

10. What is the primary mobility aid you currently use indoors? *Please check ~~only one~~ all that apply.*
   a. Manual wheelchair
   b. Power wheelchair
   c. Cane/crutch/walker
   d. ~~Orthotic/Prosthetic~~ Braces
   e. Artificial leg
   f. Board with wheels
   g. Other (describe)_____

11. What is the primary mobility aid you currently use when you are outside? *Please check ~~only one~~ all that apply.*
   a. Manual wheelchair
   b. Power wheelchair
   c. Cane/crutch/walker
   d. ~~Orthotic/Prosthetic~~ Braces
   e. Artificial leg
   f. Board with wheels
   g. Other (describe)_____

12. What is the Manufacturer name, if known? _____

13. What is the Model/Make, if known? _____

14. What is the serial number, if known? _____

Often clinician has to help with wheelchair manufacturer, make/model and serial number information.

15. *(For each mobility aid person uses)* How long have you been using this mobility aid?
> a. Less than one year
> b. 1 to 3 years
> c. 4 to 5 years
> d. More than 5 years
> ~~e. 1 to 3 months~~
> ~~b.   4 to 6 months~~
> ~~c   7 to 9 months~~
> ~~d.   10 to 12 months~~
> ~~e   1 to 3 years~~
> ~~f.   4 to 6 years~~
> ~~g   7 to 9 years~~
> ~~h   10+ years~~

16. How many hours per day do you use your mobility aid?
> a. 1 hour or less
> b. 2 to 4 hours
> c. 5 to 8 hours
> d. 9 to 12 hours
> e. 13+ hours

Same comment as previous question. May need to ask for each mobility aid.

17. Where did you receive the mobility aid?
> a. NGO
> b. Manufacturer
> c. Hospital
> d. Research Study
> e. Self paid
> f. Government
> g. Business/Donation
> h. School
> i. Charitable clinic
> j. Government clinic

k. Other (describe) _____

18. Did you or your family contribute any money to purchasing the chair?
        a. Yes
        b. No
        c. Don't Know/No Answer

19a. ~~If selecting manual or power wheelchair what type of cushion are you using?,~~ What sort of padding or cushion do you sit on?
        a. Foam
        b. Air
        c. Gel
        d. Honeycomb
        e. Custom
        f. Other (please describe) _____
        g. No cushion

19b. Is your cushion or padding removable?
        a. Yes
        b. No
        c. Don't know

19c. Is your cushion or padding waterproof?
        a. Yes
        b. No
        c. Don't know

20a. Does your back support (backrest) have padding?
        a. Yes
        b. No
        c. Don't know

20b.   ~~If selecting manual or power wheelchair,~~ What type of back support (backrest) are you using?

        a. Sling (made of soft fabric and can be folded)
        b. Rigid (made with a hard plastic shell)
        ~~c.   Custom fit~~
        d. Other (please describe) _____
        e. None

21. In what settings do you use this wheelchair~~/scooter~~? *Please check all that apply*

        a. Home
        b. School
        c. Sports
        d. Leisure activities
        e. Other public places outside your home
        f. Work
        g. Transportation
        h. Outdoors on rough surfaces

22a. Do you have an assistant helping you at home?

        a. Yes
        b. No
        c. Don't know/no answer

22b. Do you have an assistant helping you when you go outside?

        a. Yes
        b. No
        c. Don't know/no answer

Prepared by: Nancy Augustine