

UGANDA BUREAU OF STATISTICS



Cognitive Testing of the Washington Group General Measure of Disability

Activity Report

Population and Social Statistics Section Uganda Bureau of Statistics P.O.Box 13 Entebbe 12 January 2006

1.0 Introduction and Back ground

Uganda Bureau of Statistics (UBOS) is planning to pretest the 6 core disability questions in the fourth Uganda Demographic Health Survey early next year. The 6 questions and interviewers guide were developed by The Washington City group on Disability. Prior to carrying out the actual exercise, a cognitive testing of the 6 core disability questions was carried out from 15th to 16th December 2005 in two Districts of Masindi and Tororo. The 6 core questionas are to be included

1.1 Objectives of the cognitive testing

To illustrate:

- 1) Whether core questions are administered with relative ease;
- 2) How core questions are interpreted by respondents;
- 3) The factors considered by respondents when forming answers to core questions; and
- 4) The degree of consistency between core question responses and responses to a set of more detailed questions addressing respondent functioning in each of the domains covered by the 6 core questions.

1.2 Coverage

A total of 84 interviews was purposively selected by age, sex, education level, rural/urban, language and disability type were interviewed. The exercise was conducted in Tororo and Masindi districts because they have a diversity of the 6 local languages

2.0 Preparation for field work

2.1 Preparatory meetings

Prior to the testing, preparatory meetings were held with the National Union of Disabled Persons in Uganda (NUDIPU) and the Department of Disability and Elderly in Ministry of Gender, Labour and Social Development, to discuss modalities of conducting the cognitive exercise. Issues discussed included (but not limited) to selection of an appropriate training and venue, selection of respondents and interviewers, use of interpreters and the necessary logistics.

2.2 Staff

A total of 13 staff was involved in the exercise. These included;

- 7 interviewers- 1 per language (6 local languages) including English. They were selected based on the 6 local languages and experience with conducting household based interviews.
- 1 Community Development Worker and 1 District Rehabilitation officer were the contact persons at the districts. They were however assisted by the Community Based Rehabilitation (CBR) volunteers in the two districts, to mobilize and collect the respondents in one central location where the interviews were done.
- 3 UBOS Staff helped in the training and field preparations, 2 of which traveled with the interviewers to supervise the exercise.
- 1 staff from NUDIPU assisted in the training exercise. Her main focus was centered around "how to conduct interviews with PWD's.
- 2 other members from the Ministry of Gender Labour and Social Development were involved

in the preparatory activities.

2.3 Questionnaire finalization

Some modifications were made to the section with questions on the demographic characteristics. These included;

- question 2 on "years spent in school" was changed to "the current schooling status" i.e. to find out those who have never been to school, those who are attending school and those who have ever attended school but are now not in school.
- Question 5 on household income was excluded from the questionnaire because no reliable information can be derived from such questions. UBOS usually collects information on income through the expenditure approach.
- The last question on general health we had to include boxes to be checked for "yes/no" for each of the health conditions.

Otherwise all the other questions were left as was.

Prior to the actual field work, the questionnaire was then pretested with 4 NUDIPU Board members and UBOS staff. Pretesting the questionnaires with the NUDIPU Board members was one way of sensitizing them about the entire Cognitive testing exercise. Comments from the exercise were shared with the Washington City Group secretariat, see Appendix I.

2.3.1 Questionnaire Translation

The questionnaire was then translated to the 6 core local languages that include Luo, Luganda, Ateso/karamojo, Runyankole/Rukiga, Runyoro/Rutoro, and Lugbara. Front and Back translation was done.

2.4 Pre-visits

The NUDIPU contact persons at the districts assisted with selection of respondents. Pre-visit were undertaken in the districts

- To sensitize the district officials about the entire cognitive testing exercise and further seek collaboration to work with them.
- To discuss the selection criteria of respondents, selection of respondents and the implementation plan.
- To book the venue for the exercise
- To identify and recruit interpretators for those respondents that required the use of sign language.

2.5 Training

A one-day non-residential training exercise was conducted at UBOS in Entebbe, lunch and tea were provided. The training was facilitated by UBOS staff and an officer from NUDIPU who worked as an external facilitator during the training. The training utilized the documents received from the city group including the following;

1. A summary of the implementation protocol,

2. The Cognitive testing interview guide with emphasis on the interviewer instructions, All these included comments on the pretest from the WCG .

2.6 Field work

Travel logistics to upcountry districts was provided by UBOS i.e. a vehicle with a driver and fuel. A total of four interviewers worked in Masindi while 3 worked in Tororo District. The interviews were conducted in the two Districts on the 15th and 16th December 2005.

The interviewers were provided with the necessary questionnaires and other materials.

All respondents were cooperative and the exercise was a success. A snack, transport refund for the PWD and his/her assistant were provided. Arrangements were made such that the respondents arrived at the venue for interviews in the morning. The venues had separate rooms for each respondent to be interviewed in privacy.

Each interviewer was expected to carry out at least 7 interviews per day using the selected language questionnaires. Each interview took approximately 30 to 40 minutes and starting at 9:30 am to 6 pm daily.

2.6.2 Observations and findings in the field

- i) In Tororo district, selecting respondents who specifically have self care problems was difficult. Children (especially less than 12 years of age) were particularly difficult to have them involved in the exercise. The respondents were mainly adults and literate.
- ii) In Masindi, one of the respondents refused to be interviewed probably because of this mental condition. We however encountered a person with a mental problem who consistently replied' I don't know' to almost all the questions.
- iii) The interviewers felt that questions pertaining to activity limitation under hearing, cognitive and lower mobility needed a skip to the next question on 'what activities are you thinking about?' if the respondent replied that they had no activities that they can not do in the first question.
- iv) The WG recommended that the Interviewer should have discussions with the supervisor right after the end of each interview. This was not possible due to the fact that the respondents felt that information they were giving was not kept confidential. Discussions were held at the end of the day, instead.

3.0 Data entry Process

The data was entered using CSpro 2.6 and it was exported into the Ms Excel spread sheet that the WG provided. This activity took 3 working days by two Data entrants.

List of Staff who participated

Trainers

Helen Nviiri UBOS
 Pamela Kakande UBOS
 Helen Asamo NUDIPU

UBOS Supervisors/District Team Leaders

- 1. Pamela Kakande
- 2. Johnstone Galande

District Supervisors

- 1. Community Development worker Masindi
- 2. District Rehabilitation Officer, Tororo

Interviewers

Byawaka Peter Luganda
 Otim Moses Ateso
 Andama Dora Lugbara
 Benson Ogwang Luo

5. Musimenta Theophilus Runyankole/Rukiga6. Assimwe Rose Runyoro/Rutoro

7. Asaba Bernard English

Translators

S.No	Language	Front translator	Back Translator
1.	Luganda	Mr. Augustine Wassago	Mr. Kakande James
2.	Luo	Mr. Olobo-Layanga	Sr. Akello
3.	Lugbara	Ms. Andama Dora	Mr. Andama Joseph
4.	Ateso	Ms. Atiro Margaret	Mr. Okello Patrick
5.	Runyankole/Rukiga	Mr. Twesigye Bylon	Mr. Rugyema Godfrey
6.	Runyoro/Rutoro	Ms. Judith Nyangoma	Ms. Rose Asimwe

Appendix I

Comments from the Pretest Exercise for NUDIPU Board Members and UBOS Staff

A pretest was conducted among 4 NUDIPU Board Members and selected UBOS staff before setting off for field work. Below is the report of findings which was sent to the WCG secretariat for comments.

 Instead of asking for "how many years in all did you spend studying in school, college or university?" we suggest asking for 'what is your highest education attainment? Primary, secondary, tertiary, university".

This is related to how school is considered in each cultural setting. If this is the way school is referred to in Kenya, that is fine. However, we will need a definition of what is meant by each term so that we can use the measure correctly.

- When starting each section there is need to put some introductory notes to the section
 On 5a: The respondent needs to be reminded that the activities being asked about are in
 relation to the difficulty. Most people will answer the question by telling you what is on their
 mind at that time or what they are planning to do, which is often off the subject under
 discussion.
 - That may be the case, but we want to see what it measures. If there is a problem with the question it will come out. If we keep reminding them of how we mean the question, we will not learn how they are interpreting the question. I would recommend against making this change.
- See qn 6 under vision and hearing, qn 7 under cognitive and lower mobility, qn4 under self care and communication): A time element is necessary for example add the word 'now', because for a people without that particular difficulty, all of them replied with reference to the future and not now. Others say it depends on the prevailing situation. Others say the responses options are so limiting, we could think of adding more response options that capture the time aspect. I appreciate that you want to make changes that satisfy your assessment of the questions. However, this is the way everyone is testing the questions and if you change things for your purposes we cannot compare them to the others. If it is a problem that we don't have a time element in the question, we will find that out by the way people answer.
- Qn 9: Given the instruction in brackets for example [without your glasses] it looks like all
 questions in 9 apply to a person who wears glasses. First to find out if this person has difficulty
 without glasses and second to find out if he has difficulty with glasses worn. Or is it that the
 first part applies for only those without glasses and the second part for those who wear glasses.
 If the latter is the case then the instruction in brackets should change to [those who do not
 wear glasses] This comment applies to Vision, hearing,
 - I am out of town so I don't have the questions with me. We are only asking about difficulty with glasses if they use them. Too many people have trouble without their glasses and we don't want to capture all of them. I will look at that instruction next Monday when I am back in the office, but if it is there it may be an error.

We want people to respond whether they use glasses or not. If the question worded as it is creates problems then we will have to change it ,but only after the test.

Vision

• Should a person who is clearly blind be asked all these questions? If not at question number does the interviewer stop asking questions related to vision?

It is hard to make assumptions about what another person can see or what they will answer. Even

people who use a white cane have some sight. It is best to ask the question and see what kind of response you get. If repondents don't like being asked they will tell you.

• Despite the simple English used in the core question, instead of the last option of 'can not do at all' can't we use 'can not see at all'

I think lit is reasonable to say can't see at all or can't hear at all.

• On 9: when issues of being short or long-sighted come in, should this person be categorized as with 'some difficulty' or with 'a lot of difficulty'?

The person has to tell you how much difficulty they experience. If they say they are shortsighted, you need to refocus them on the question and indicate that you need to know how much difficulty that creates for them.

Hearing

 Should a person who is clearly mute be asked all these questions? If not at question number does the interviewer stop asking questions related to hearing?

Fisrt of all being mute can be associated with other things than hearing. My son does not speak because he is retarded. If you are asking about the interviewing process for someone who cannot speak, it is possible that you may have to use a proxy respondent. Certainly the question must be asked since you don't know for certain what is the cause of the muteness.

- On 9: is hearing in this case with reference to 'not hearing because of an accent', or hearing with understanding of what is said or just hearing the sound of a person speaking?'
- I am not sure what you are referring to here. Those sound like the extended questions which we are using to try to see what we are capturing with the general question. Hearing is the ability to hear sound whether it is music or voice or clapping sounds. The more specific questions refer to different conditions for being able to hear. Issues about an accent or understanding what is said is part of communication and not necessarily related only to hearing.
- On 10: Most of the respondents answered that it depends on the accent of the person speaking so it can be included in the question or in the training. A response option for sometimes can be included for those who do not miss words everyday and not every week. Are persons who miss words due to reasons (such as lack of concentration, pace of the person speaking) and due to a hearing difficulty also our concern or they should be ignored and recorded as never.

Persons answers should be accepted and not prejudged by what you think is going on. If you feel that some of these things are happening you can attach notes to the answers that express your impressions. We are not getting into the why of a response, only the response itself. If respondents make tese comments when they answer the question, you can include their comments as well, that all contributes to our understanding.

Cognitive

- Qn 3: An option for rarely was called for as some respondents found that the present response
 options are not suitable to their situation.
- This should be a comment accompanying the responses. However, we are testing the responses that we have given to be used.
- Qn 8: the response options yes/no are too extreme and therefore require an option for 'some times'.
- If you are talking about the supplemental questions you can also make a comment however
 at this point we are not changing any of the language in order that everyone test the same
 thing.

Lower mobility

- Given that most of the population lives in the rural areas where walking is the main means of transport it would be necessary to add climbing or walking up a steep terrain or climbing a hill in the core question because there are few buildings where one has to climb steps. In addition most of the responses got are "...It depends on the terrain".
- That is important for us to note, but at this point the questions are being tested for this kind of thing don't change yet.
- Qn3 seems very similar to the core question so the respondent always thinks you have asked the same question twice. There is therefore need to move it closer to the core question.

- We are also not moving questions. You can tell them sometimes things seem to be repeated, but that is done for a reason. You can certainly indicate prior to actually asking the questions that the respondents are participating in a test and that it may turn out that there are problems with the questions, such as some seem to be repetitive, and that this is exactly what we are trying to understand and fix.
- A definition for walking is needed giving reference to distance and surface.
- We want the respondent to define walking in their circumstances, whatever walking means to them. So if they live in rural areas and walk on dirt roads, that is their circumstance. If they live in the city and walk on sidewalks, that is fine. We cannot start introducing environment here and certainly start standardizing. Eventually when we develop the extended sets we may also be able to introduce environmental questions such as the kind of surface they walk on most of the time.
- Qn 11c does standing include with some support such as leaning or using an equipment
- That is one of the supplemental questions it should reflect however they stand normally. However, I wouldn't consider leaning actually standing.

Self care

 Qn 5d: In the case of Uganda the gender and poverty aspect of this question is biased because ladies do not put on stockings in Uganda. Its only men in formal employment and students who put on socks. Can't we instead use 'putting on shoes'

Absolutely – these need to be culturally relevant

Communication

- Should a person who is deaf and dumb be asked these questions? Because this person will keep answering with reference to if he is communicating in sign language.
- If he or she communicates in whatever way, yes. We don't care how they communicate, but the fact that they are able to communicate in some way.
- On 5: How do we handle persons who respond and that it depends on whether the subject is technical or in a different language or in sign language.
- Not sure what you mean here. If the language is different, it is still communication.
- On 8: the degree of shyness varies from person to person so why don't we make the response options as No / somewhat shy / very shy.

Sorry – we can't chang concepts and wording at this stage. We wouldn't be able to compare.

General health

- Qn 2: why don't we add an option for disease based conditions especially chronic conditions given the HIV/AIDS prevalence?
- If you want to add that at the end for your own use, that is fine. As we indicated, you can add your own questions to this protocol
- The definitions for some of the health conditions is needed.
- I had forgotten that there were health conditions there I will try tofind definitions for you.

Other comments;

- Under interviewer debriefing, qn 3 there is need to clarify who or what category of people should be recorded.
- As I said, I don't have the questionnaire here. I will have to check that on Monday.
- Issues of the wider environment have not come out in this cognitive testing.
- No, that is for the extended set. However, if respondents say something about the environment, you can record those comments and give them to use as well.

Appendix II

TIME TABLE for Cognitive Testing 2005 (12th December 2005)

Time	TOPIC	FACILITATOR
Morning 9am	Registration of Participants Introductions. Administrative Arrangements Introduction to the Cognitive testing - Objectives of the survey, - Role of the interviewers, - Importance of Results.	Pst Population
	Field ProceduresGeneral Procedures of Conducting an Interview with a PWD	NUDIPU
Afternoon	 General question-by-question explanation Questionnaire 	Pst Population and St
	Mock/actual Interviews, for the Questionnaire Discussion of experiences from the interviews Arrangements for next day's travel	Pst Population and St

Training will start at 8:30 and end at 5:00 pm with a 10 minutes tea break (10:30 - 10:40) and a lunch break of one hour between 1:00 and 2:00 p.m.