Video 6:

I wanted to talk a little bit about data collection methodology - some of the things that we do in the WG that apply to any data collection anywhere. We think that these are good methods that can be used by anybody and should be used when you’re designing data collection tools around the world. There are a number of things that we do - first of all, we realised that we developed questions in English, it’s our working language, but our focus is always international so we have to keep that in mind when we’re designing questions. The first thing we do is cognitive testing. That involves really understanding how other people interpret the questions that were asking. Asking a question is only one part of the process the other part is getting an answer that meets the needs of that question - something that we expect to get. So we have to try and determine if different respondents interpret the question the same way and give consistent responses. We look at patterns of interpretation among different responses and we’re always aware of different or out of scope patterns. For example, if we ask “does your child have difficulty eating?” we expect some response that indicates that the child has no difficulty putting food on the spoon and putting that food in his/her mouth. Some parents we found said yes my child has difficulty eating because the child never eats his green beans, never eats his vegetables. That’s not what we’re looking for, that’s what we call out of scope. A parent is answering based on their child’s wilfulness and their own frustrations. That’s an error in data collection and we want to make sure those errors are small as possible. That’s why we do cognitive testing to find different patterns of interpretation that we can later verify in a larger field test. What we do before the field test though is because we have an international perspective we have these questionnaire translated into different languages for where the field test is going to be conducted. They have to take great care when we do translations because words mean different things in different languages. We’re not interested in the literal translation – word for word of what we’ve written in English – but we want to make sure that the question we ask in English is feasible, reasonable, in the language that it’s being asked. Sometimes you have to use different words to get the same concept. It’s the concept that’s important. So not a literal translation but a translation that captures the same construct, the same concept. Once the questionnaire is translated then we cognitively test it again in that country. So that we can found out if people in that country, in that language, in that culture understand the question the same way. Amongst themselves and also in relation to the English translation. Remember, we’re looking cross-national comparability. Once we have the questionnaire that’s cognitively tested and we think that we have reliable data from it, we’ll go into the field. We’ll do a much larger random sample of the population. I forgot to say that cognitive testing really only involved 20-25 people that come in for interviews on their thought process in answering questions. When we go to the field we do a random sample of maybe 1000 people - far more representative- we only administer the questionnaire and get their responses to find how the questionnaire works in a population. With cognitive testing and field testing results we can determine whether or not the questionnaire is good enough to go into the field for a large survey data collection. The other important element in data preparation, data collection is enumerator training. I always say that if I were the only one who was going out to collect data there would be no problem - I know what I need to do and I collect data from everybody. If you do a census there are thousands of enumerators who go into the field. A survey can have 10s or 100s of enumerators. Each one of those people brings their own baggage along, their own attitudes, their own feelings and we really can’t allow that kind of variability in our data collection. Data collections are based at the end of the day on good data and statistics. We’re trying to find the truth in the questions we ask in the answers we get. And we try to reduce the amount of variability every step along the way. The more people we have asking questions the more variability that is possible but if we train enumerators well enough we can reduce that to a minimum. We want enumerators to first of all have neutral attitudes about disability and we’ll train them about how to approach and speak to people who have different functional limitations, different impairments. We want them to understand the importance of avoiding discriminatory words; we don’t use the word disability we want to train them to respect that. We want to train them to understand how to deal with all situations and how to deliver the questions uniformly. Part of that means that the questionnaire that they’re given to deliver is delivered word for word, they don’t change any questions, any wording. They ask the questions that are there and offer the response categories that are provided for them. No adjustments, no changes in the wording. Another thing that’s important is that they don’t record their observations; they ask the question regardless of the situation they’re presented with. For example, if you’re interviewing a person who’s in a wheelchair and the question your supposed to ask is “do you have difficulty walking?” you can’t just assume that because the person is in a wheelchair that they have difficulty walking, some people in wheelchairs have no difficulty walking some have a lot of difficulty or can’t walk at all. It’s not your job to make that judgement – 7ou ask the question even if it seems unreasonable and you record the answer that’s given. Another example might be if you’re interviewing somebody who is obviously blind and you’re asking them a question “do you have difficulty seeing?” That person may answer ‘no, I have no difficulty’, and that’s happened before, I have seen that. Somebody who is blind and they have no difficulty - they have no difficulty because it’s not a function that they’re familiar with, so it’s not a difficulty for them. What do you do? You don’t record what you observe, you record what they say. It’s always possible to annotate in your notes that this person is blind or you believe this person is blind – it’s something for the supervisor to deal with later but as an enumerator your job is to record what the respondent tells you, that’s what you’re supposed to do. I mentioned a little bit about attitudes earlier, and one of the things that we try to do with our questionnaires is to avoid stigmatising language and actually one of the stigmatising words is disability. We don’t introduce our questionnaires as a disability survey or a disability module. These questions about difficulties that anybody has doing basic actions or common activities. So that’s what we talk about and we don’t say for exmap0le something like “now I’m going to ask you some questions about disability” – that’s not what we do, it’s not written in the questionnaire and you should never assume that when you’re doing this survey. Use the questions, use the wording that’s presented on the questionnaire and it’s not your job to ad-lib anywhere along the way. A few words about methodological issues in questionnaire design. It’s important when we talk about these questions that we don’t use a screener beforehand. We’re not interested in asking about disability before we ask about difficulty functioning so we never have that kind of question in front. You shouldn’t ever change the wording in the questions that were talking about. We have to maintain the same wording in order to maintain comparability cross-nationally. That’s not to say that adaptations aren’t possible, for example, I did training in Bangladesh not too long ago and the hearing question reads “do you have difficulty hearing even when using a hearing aid?” in Bangladesh hearing aids are not only not common they’re non-existent. If they don’t exist in the country then it seems unreasonable to add that to the question. So for the Bangladeshi survey that was conducted they just used the question do you have difficulty hearing? Another example is in the Maldives, or maybe Seychelles, an island country that was very flat, they didn’t have stairs anywhere. So asking a question “do you have difficulty walking or climbing stairs?” seemed unreasonable. Now it’s possible either to drop the stairs part of the question or maybe adapt it in a way … “do you have difficulty stepping onto a box?”, that’s something that most people can relate to. So those kinds of adaptions are possible where they’re not changing the concept of the question, they’re changing the wording slightly but maintaining the concept – that’s the most important part. The other thing that should never be changed are the response categories. For two reasons – one is that we want to be able to maintain the ability to measure the continuum of functioning through the responses that we offer. We would never substitute those with a dichotomous yes/no response. You lose a lot of information there and we would also lose the ability to create the kinds of data that we need when we analyse and that cross-country comparability. Now all of that said it is possible to add questions to these modules. We admit that we don’t cover every single domain of functioning so if there are important domains, if there are important areas of functioning that you feel are missing, it’s always possible to add new questions to fulfil the module as your programme or project deems. The one thing we would ask though is that you test those new questions, cognitively, before you put them out into the field.