Cultural Advisory Panel

October 15, 2010/1200-1330

Questions for focus group:

1. **Acceptability of C-TOCv2: any better? What barriers to willingness to take the test?**

2. **Usability of C-TOCv2: What barriers to it being used by people in your community? What types of assistance may they require? Who would they like to provide assistance?**

3. **What problems do you see from the test takers' perspective, e.g. understanding, motivation, experience of test-taking? Consider people form your community.**

4. **Test instructions and practice: for each test, are instructions presented in a clear way? Are practice trials helpful? How could each be improved further?**

5. **Distractions and interruptions: there are many type of distractions and interruptions that can occur in the home which may disrupt progression through C-TOC. Can you think of some? Imagine an interruption lasting several minutes? What types of informative cues would you find useful for resuming progress?**

FD: Fariyal Dhirani, South-East Asian Community
CJ: Dr. Claudia Jacova
GR: Gita Rafiee, Iranian Community
RH: Dr. Ging-Yuek Robin Hsiung
KK: Kamaljit Kaur, South-East Asian Community
MN: Dr. Marina Niks, CHCP Research and Project Manager
NS: Norma Sanchez, Latin-American Community
SS: Sayuri Sugawara, Japanese Community
VL: Vivian Lam, Chinese Community
PJ: Patricia Juvic, Cultural Advisor Group Coordinator
MB: Matthew Brenner, UBC Computer Science Graduate Student

FD: In my community yes, most definitely, as I said early about the Ismaili group that I am involved with, we had some sessions on awareness, dementia, the rise in dementia, increase in numbers and we are very aware of seeking help using both medical and complementary medicines or treatments, yes I can see them open to taking the test.

CJ: May I ask you to expand? And I would like to hear from everyone – if you think about a paper and pencil test versus a computer based test would the computer be acceptable to seniors in your community?

FD: Right, so, our community is quite diverse technically and educationally, age wise, those who are in their 80's I would say no, they are not familiar with computer use, they do have language problems, so no, but those who are in their 70s I can see them being open to taking test. As I was saying quality improvement program, playing WII. We have started a computer class, but not many people have signed up yet.

GR: I can see this test can be a great start in my community, perhaps we can work on the younger generation and teach them how to use it, give them information about this test, so the younger generation can bring it back to their parents, they [parents] usually live in their [children's] home. They are not in society, not working, the younger people can bring it home to them…they certainly can help.

CJ: So you're seeing the generation of adult children as the medium, provide education and be the ambassadors…

GR: They are living in isolation and don't know what's out there

CJ: If an adult child was to bring her mother the test and say I will help you, will they take it?

GR: They listen to their kids because they brought them to Canada, they are sponsoring their parents to come to Canada, so they listen. I asked myself, if I asked my mom, would she do it? And yes she would do that.

CJ: My mom would say no! *laughter*

GR: It does depend on the individual person and culture, maybe not for the whole Iranian population, but in general, because they are sponsored by their kids and living in their kids' home.

RH.: It may be disease specific too – Alzheimer Disease, frontal lobe, both deny. Even a frontal patient can do it, but will refuse to do it, because of their disease.

KK: I found that it's not very difficult for them to understand the task, but a lot don't know English and the instructions will be hard…is it possible to incorporate some kind of flash or some instructions more graphically given, so a person doesn't need the language.

CJ: This is a big problem for us. That can be done and some test can be kept entirely nonverbal, however, there is one area of concern, language in itself is an

area that can become affected first, a telltale sign of what to do. We can design a nonverbal test battery with no English required, but will we get to the problems we need to measure? We can go to what you are saying but it will have limited coverage. I take your point, we may need to think of different versions of this test. One full, and one with limited validity, applicability, but more accessibility.

MN: If it's the language you can translate it, but it's applicability in another sense, like radish is something they won't recognize even if you put the word in Japanese.

CJ: We originally thought we would limit ourselves to English, take in participant concerns, and once culturally somewhat ok, then attempt translations. It is done for the MOCHA, which is a paper and pencil test. This would be a little more difficult not in principle impossible, language abilities are not a final concern, not ultimately a concern because we can translate it.

KK: I work with these two groups and we are talking off and on about this tool and they are not comfortable taking the test at home, but maybe at the community centre or temple, with peer support, for encouragement and to support each other to take the test.

CJ: So it would be peers, whereas in your

GR: Peers is great for my community too

NS: Ah, certain peers

GR: Peers with good knowledge, for example, a nurse from that culture to help them, not needing to know that nurse, but the nurse knowing the language.

KK: Trust, psychological, may relate. Grandchildren are supportive, but not in all, they may want to help, but then they are trying to use their own judgment, and not a safe option. The Dr. can pass the word to every patient - start a campaign, Dr.'s can pass the information about the test. Encourage seniors who need to take the test to go in for it. Of course community centers, ISS of BC, MOSAIC, supportive and pass word around. Arrange for an awareness workshop – useful because it creates dialogue and they start thinking about what can and should be done.

NS: I would like to speak form my community perspective, but I am also cross cultural and some that might not be represented here, like Afghan, where level of illiteracy is vey high. First of all, some of my evaluation of each 1 of the parts might not be accurate from the very beginning, high education, high literacy, computer skills. For example, lab instruments, you may not know, musical instruments might have never seen a trumpet or saxophone. Using a puzzle as a

toy, somebody might stop and think, is this a toy? Iffy, confusing to a senior, gloves, sports – so common, in some countries and some they may never see this. My community is extremely diverse, seniors communicate with family via email, some never saw a computer, the diversity is huge, I do know as we age, more and more educated become senior, you need high level of language and computer skills. And in term so who can administer, I would use MOCHA, MMSE, takes help from somebody who understand how to administer the test. Maybe this test could be done by someone, not peers, there is no confidentiality as the communities are sometimes very small not confidential – but family member, group facilitators, like those running seniors groups, neighborhood houses.

CJ: As I listen, it will not be the case that one solution will meet all needs, interesting, peers, children, no children, no peers – group facilitators – different ideas resonate from different people helps me know that we are going to have to be flexible in the application of this tool when it is mature enough for that. I take your earlier points as well about the pictures, Afghan for example, it can be addressed to some extent, it may not be the greatest difficulty, we have some universal things we encounter, when you start choosing a picture, it is never culturally unbiased. Rose, you tell me roses don't grow in Afghanistan, I take your points very well, how aware I am and how difficult it is to do this.

NS: If I am administering, line between alphabet letters, if I had to do that with Chinese community, they may have a hard time. How do other communities do this without an alphabet or number system?

FD: Once the test is developed, you can just apply different language, if they have literacy in their own language and then apply software, I think it is feasible, it is a good tool, and can be used. There is Chinese language computer software etc… I receive emails in different languages. I think if we focus on the tool, we can overcome the language problem. And the tool, looking at MMSE MOCHA, those are different aspects we are testing of the brain function, the symbols, pictures, are important to differentiate functions.

CJ: Gives one a score, it needs to be looked up – don't receive extensive information on language – coverage is minimal in a test like that. We want more coverage, we are trying not to have people waiting 2 years, so something more in depth, but at the same time culturally fair. But I agree, language doesn't concern me so much, translate, the bigger concern is computer literacy, because that cannot be overcome. For that we have people from CS dept, who need to make the greatest effort possible to design an interface that is easy as can be. Who knows about the future, we have iPads now, all of this may have a solution

FD: What we are looking at is the tool

NS: The tool is good and thorough, it's amazing.

CJ: Matt will focus on this. It needs to be done so that it is easiest possible… perhaps we can reach those who have minimal experience

NS: I am imagining some people that suffer from depression and severe anxiety. If I had to take a break, what do I do?

CJ: It is in the help menu, but not functional, it is in our thoughts, but does not have a body. But what your saying is that when you want to take a break you wouldn't automatically turn to help menu.

NS: Even if I need a bathroom break. Good for people to approach this test knowing that they should eat if they are hungry, factors that make it hard to concentrate.

CJ: if you need to take a break, you wouldn't dream of clicking the help button.

NS: Yes, also when you go into the program and reach options…there is nothing that says click here to continue.

CJ: it is immature, that won't stay like that

SS: People in my community probably will use the test if Dr. recommend or suggest. The setting maybe at office, not at home, some facility, if family member around, he may ask specific questions to solve the problem, so maybe a nurse to help to translate. Also the computer; most living independently at home don't have a computer. Also, if you want computerized test, may try one item, and then try to take it again. Get familiar with the test. Get better as you go along, maybe not only one time, more of a practice session. Length is better this time, senior can concentrate maybe 30 minutes, I know you haven't decided on length yet, but maybe shorter.

CJ: Something that is on our mind. That is an interesting notion to have a mini version to get people to practice first. I have to say I did look over your shoulder and thought wow this is going really well.

VL: I saying that on behalf of Chinese community, most of the Chinese community people will listen to what the physician recommend, they will take his test, I really think this has benefit for mild cognitive impaired people, especially I am seeing more younger age 50-60 that have symptoms of mild cognitive impairment, most of them really want to know do they have dementia, what's wrong with them, they would like to take the test. I also agree with what the majority says about language issue, pictures, computer issues, those things…I think this time it is easier to do this, I am still wondering even if possible with mild cognitive impairment that they are able to do such a complicated process. I come across a lot of mil even simple tasks they have difficulty to perform, some area I can see there a problem with me I have a problem doing this, some area with

complicated steps, I need longer time to understand it and then do it. Also, with the translation part, I also agree with those things, at this stage most of the senior are illiterate, but 10 years there will be a big change. Second generation can assist, with their help, the second generation caregivers don't have problem helping parents to do this test. I look forward to see it as simple as possible with visual and verbal instructions to help this test go better. Even in the early stage of dementia with verbal and visual stimulation they can do it. I would think this is a really really good test in future, especially people having more and more awareness of their illness – the mild cognitively impaired people right now really know they have something wrong, and there s such a wait list.

CJ: I think when we constructed this test what we had in mind; the person was not in full-blown moderate dementia. Where it would not take too much clinical skill, we are talking about those who get concerned over fairly minor symptoms, but can be a concern and need to be picked up – we had mild cognitive impairment in mind – this test is too hard. This is the level of functioning we are - early mild cognitive impairment stage, that where we start and maybe we have to make it simpler.

RH: The other thought was, adaptive response. If they are doing really well, make harder and harder questions, if they are already failing, then make it simpler – this is in thought

CJ: We haven't given the test to a lot of people, test responders – where we can calibrate the level of difficulty, so that the person is relatively comfortable but working to their maximum potential

NS: The test gets more complex and difficult as you go toward the end, the time when people are tired, so they may understand the test but

CJ: Test ordering

NS: Reason for this order?

CJ: No, we can reorder.

NS: Even instructions are more complex as you get to the end.

GR: When I reflect, I can see people think physician are god, if this is prescribed by physician they will do it, if the goal is to shorten wait time, work with family physician

NS: working in mental health and with immigrants and refugees, the first complaint is "my memory is failing" and this can be due to trauma, fatigue, stress etc…they may be computer literate – do we encourage them to take the test?

CJ: We can't give them a rate, in the office it is different when the GP is there, maybe we can think of ways to give people feedback, it would be irresponsible of us to tell them they have done poorly, to give impersonally, have to be clinical. With depression, the expectations must be clear.

RH: It will help me decide how bad a patient is, with feedback received from a Nurse Practitioner or GP, then decide how to treat this person - has depression, or specific dementia, then specific treatment.

CJ: Not to leave a person hanging, but

RH: Irresponsible

CJ: There is a test for Alzheimer Disease online, I won't say the name of the test, but if you do badly "impaired" shows on screen. Still require clinical, not a diagnosis, just a tool to be evaluated within the context of the person's life.

NS: From a clinical setting perspective, this test is great, saving the anxiety of waiting 6 months – 2 years.

PJ: On test instructions and practice, from your communities, Sayuri and Kamaljit, practice, graphics, instructions, practice time?

SS: Too small, calculation of numbers, too tiny, hand mobility may have problem.

VL: With misplaced objects – too small to see, bigger and more colourful

PJ: The actual visual?

GR: Some of the colours were too bright to see. I don't know which colour is best to choose.

CJ: Not always used, but red, blue, and yellow, not always used, but those are the three colours, there is a prevalence of colour blindness

GR: Contrast too

KK- Yes, the chocolate bar in the forest, brown against green

CJ: Part is size, part is contrast, we may not retain the forest scene – upon careful review visibility and contrast can be remediated.

KK: Clicking of the mouse, recognize the object, but sometimes you have to click twice. Is this done on purpose or…

CJ: We forgot to explain that the one time that you didn't need to click was during the picture-pair test, we made it worse – because I saw you clicking. I had already observed that – we wanted it easier, standard time, but because people are in the clicking mode it isn't working well. It is difficult to strike a balance between an automatic transition and the need to click.

FD: I found clicking and dropping the letters a bit frustrating.

CJ: Too small?

FD: Click and then try to move, and then move to position and then you would lose it – not very smooth for me.

CJ: We are still working with a façade not the real program, still just powerpoint, and not showing you the horse, just the donkey – these particular thinking

VL: You will find better in the 3rd section, no stress! *laughter*

CJ: And you will!

GR: No sound, so quiet, we are using just the visual – was that on purpose?

CJ: The idea is that someone in Prince Rupert may only have a simple computer, no speaker, what do we do? We can offer the enriched auditory environment.

GR: Can we add something people can hear to let them know? Clapping, nice soft music?

RH: Instructions yes, but not part of the test.

CJ: We can also have audio for mouse click, clapping, encouraging music

NS: The music will have to be optional, for me it's noise when I am trying to concentrate

CJ: So an option, select, some component or not, display a screen, and this is what you might hear if you want or turn off feature

GR: Do they see the correct prompt – if they don't do it right?

CJ: It will show try again – a prerequisite to carrying out the cognitive test

GR: Disappointing…

CJ: Yes, discontinuation rule, won't have you continue if you get a certain number incorrect – 4-5 consecutive failures, then discontinuation of the test and go on to the next one without saying anything

MB: On point 4, it was overhauled considerably since last time. Learning by doing, rather than a long list of instructions. Does learning by doing work? Will people in your community prefer this? There are other options like audio, watching it being done, a movie? What can we do?

FD or GR? Not sure: Watching a small video or movie is a good option For example, this is what you need to do, like click and drag, then leave it there and click again. Maybe throughout the test, on each page you should be able to see that, I know of the senior they might do 2-3 correctly but by 4 they forget and can't go back.

CJ: Option to show instruction again, regardless of where you are in the test

GR: Are you testing memory by instruction and not being able to go back?

CJ: No, at this point, goal is not clutter screen- too much material, balance between instructions always there and having the screen relatively clean with one main focus. Here is this button that button – I was told by a colleague that the one thing you need to do is reduce the clutter, people will get lost – I weight this with the very appropriate comments you are making – we can't clutter, but need to give options, visible, but not distracting

MB: Pause, break, help button, administered over web, inside of a web browser with all of those buttons as well, the end product is the whole screen, something to consider when wanting to put more objects on there

VL: I like the examples, so people know better before they do it

CJ: We followed one patient, a very intelligent patient, who said when she read the instruction she felt mounting anxiety because she didn't know what she was going to see. Pairing the words with the visual. We took that seriously, again there are many ways to learn, animated demo is another way, I don't know what would work better, maybe all are needed?

VL: I would like to know if it is better to give a clear picture to the patient and family who will assist, beforehand to do the test to increase their confidence, reduce stress, I think that is better. So they have some pictures of what they are about to do.

NS: It would be good for somebody administering the test to have the instructions. If patient has instructions, does it not change the validity of the test if

I have the knowledge of everything I am suppose to do? Do you understand? It is kind of tricky, how to make the test valid when you already know the answer.

CJ: I think what Vivian has said is to give a demonstration of what people are going to actually do, match symbols, numbers. I can show you what to do. However there is a relationship between the way you deliver the instruction and the way the test is performed. It will take fine-tuning in terms of validation because we want to validate these against existing tools, do we want 100% correlation or partial correlations? Does the test discriminate between one diagnosis and the next, that is validity for us.

NS: Like MMSE, create biases with instructions.

GR: Going back to your questions, no matter which culture, every person is different, some people are strong when they see, when they hear, can we combine all these ways of learning?

MB: The more options the better

GR: Yes, fair for everybody

FD: Learning by doing, practice time is good

CJ: In addition to that we can give an option to watch someone do test, multiple ways of learning, still keep the validity. We take those to our patients. Representative of part of the population, but they will tell us what works for them. They haven't seen v2 yet, so we don't know. If they and you say why don't you put a video, then, we will have judges there too and utilize your suggestions with the people who will ultimately need to do the test. Needing a break, running out of energy, bathroom, they can happen, but interruptions that might take place, that might be more mentally taxing, like someone might need something at home and then pick up where you left off what types of interruptions do you forsee, what types of cues when they come back after the disruptions is over?

GR: Physical noise

NS: Training, make sure you will have no interruptions, unplug the phone, turn on, answering machine, prevent those things, do the test when nobody is home
CJ: Prevention – going back to interruptions, depends on where

MN: If they were taken with a group and facilitator, the time is protected, but if in GP office, isolated space with computer, I haven't seen that.

CJ: Might be a loud conversation

MN: Libraries, computers have a set amount of time

GR: Physical environment – biggest barrier, head phones to hear computer and block out environmental noise?

MB: At clinic, to shut out distractions, but at home not all will have them

CJ: There are patients with mild cognitive impairment that have difficulty controlling their attention, and the social and physical environment will be a distraction, Matt's biggest worry is not something unforeseen, but the patients' themselves, like seeing a bird out the window and following, how would that play out, what would work to bring that person back?

GR: I can see that at the bottom 'are you still there?' That helped me to concentrate. Some of those prompts? Voice that says, "hello are you there?" *laughter*

MB or MN?: Once sitting back down, can't remember where you are at, what information does someone need to get back into the mindset before the interruptions.

FD: The testing is in different blocks, now you have completed 'this this this', now you can progress onto this. Summarize, onto the next – I know this is a tool and not a teaching kind of thing, but still.

PJ: Prompts are good to keep people, 2 more tests to go etc…Here's what I've done so far

MB: Imagine half way through. Say you are constructing square puzzles, and at half way are pulled away, can't remember how many lines you've moved etc… how do we move on from that?

GR: One question back? If I interrupt, option to go one step back

CJ: one question back, you do not consider that for scoring, regardless of where you were, resume scoring from item that was not finished

NS: I am interrupted, did not click break, are you still there, then what?

MB: There might be several circumstances, 30 seconds, 3 minutes to hours, where different messages are generated, discount the whole test and start again after too much time. But at 30 sec, 3 min, what do you count, not count.

NS: Maybe if I remember. Maybe I will need to go back to the beginning of that portion of the test.

GR: I am wondering if we can add this distraction piece to the whole testing, if the person is success even though he was distracted, then maybe he has better memory, can you use this for the testing

CJ: Measure how well he can do that, interruption and come back to original task, there are neuro-physical paradigms that use this deliberately. It is a very difficult situation and a task interruption is a real work even that could measure that – to measure how much or little time instruction, help, support a person needs.

GR: There is not way to limit all these distractions, maybe add it in the scoring – she can score 5 more points?

CJ: Not only an accident, something that can be exploited. In neuro-psychological testing, there's a tester, a room, not real world performance at all – executive control portion of attention as we do in everyday life. We can introduce this component.

GR: Not my idea, when I was brand new to Canada and wrote the TOEFL for language barrier, when I finished test, I said to the tester, it was not fair, I had anxiety, there was noise, couldn't do as well – she said this is part of the test. We are testing you if in the real world, you are going to be a nurse where there is a lot of noise and distraction, can you speak in English with all these distractions?

NS: Remember, the rose, there is time already scheduled, for example in the MMSE, you mention 3 words, remember 5 min later, now its in this test, a interruption that is a long time will it be valid?

CJ: No, it is a matter of the amount of time – a few minutes fine, ½ hours not fine, definitely out of the window of validity. Test nestled around 3 memory tasks, extremely vulnerable to invalidation, because if someone is absent there is no way that that's valid, we can think about eliminating a memory test and having some free tests. That we are aware of.

NS: Different from MMSE, words, now have image too, adds the visual part

CJ: Did do on purpose, association of quality verbal-visual package together. May be too easy for people who have mild problems. If we have too many people performing at perfect level, we will have to make it harder, just add very similar alternatives. I have to think.

NS: Still testing that part too, beyond culture

CJ: Validity of content is still unknown – we thought first design it.

MN: Normally it is done first mainstream, then cultural group. This one, from the beginning with cultural input, but that means there is not set validity that you are testing against.