

CHCP Newsletter Submission by Dr. Claudia Jacova:

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The ideas that make up a research project often present as vague shapes whose contours come into focus only when the journey is underway. The researcher is aware of their importance but struggles to cast them into clear methodological terms. When at UBC we first began to think about developing C-TOC (Cognitive Testing on Computer), a computer-based tool to support the screening and triaging of people referred to memory, dementia or Alzheimer clinics, we only had a general sense that it should be culturally fair. This notion became stronger as we envisioned making C-TOC available for clinical purposes on the internet. Who would explain and mediate between the tool and its users, as diverse as the Canadian population itself? No one! C-TOC needed to be self-explanatory and self-evident to seniors from a multitude of cultural groups.

We knew we had just set ourselves a high standard. We also knew from the literature that an accepted method for developing cross-culturally valid tests is to obtain iterative feedback from a multicultural advisory panel. But our cognitive science, neurology and computer science team had no experience in creating such a panel and articulating a methodology for eliciting the needed feedback. The task fell to me as a cognitive scientist and principal investigator of the project to identify the right collaborators. I spent long hours conversing with experts in instrument development, knowledge translation in dementia, population health, and neuroethics. A name came up, not from UBC, not from Simon Fraser University: Dr. Marina Niks, researcher and project manager at the Douglas College CHCP. I met Marina in November 2009, and then again in January 2010, along with her Nursing colleagues Kymberley Bontinen and Patricia Juvik.

It only took these two meetings to feel certain that the three women researchers, under Marina's leadership, were serious about collaborating with us; had an excellent understanding of the goals of our C-TOC project; understood our need for community-based cultural input better than we did; and knew the communities we needed to hear from. And more: we chose the target communities, assigned to Kymberley and Patricia the lead on identifying suitable advisors from these communities, decided on the methodology for consulting our future advisors, and sealed it all with scheduling dates for the consultations with the panel, and designating the CHCP boardroom as the location for the meetings. I recall the drive back from the visit at Douglas College CHCP where I saw my vague notions of cultural validation grow into meaningful, concrete and focused ideas. I recall announcing at our weekly UBC-based Alzheimer research unit meeting that the 'cultural advisory panel for C-TOC is going to become a reality!'

Then suddenly it was May, and our first panel meeting was fast approaching. Many things had moved forward. At DC CHCP Kymberley and Patricia had quietly worked away at recruiting advisors into the panel, and working out logistics for the consultation meeting. At UBC we had just finalized our C-TOC prototype. Suddenly we had real people willing to interact with, and evaluate our tool! But we had not worked on the questions to ask of our advisors. I spent a few stormy days creating a questionnaire for completion while interacting with the tool, and was relieved that Marina took on articulating the broader questions for the focus group. We arrived early and in numbers, with my colleague and co-investigator Dr. Robin Hsiung, a graduate student, Matthew Brehmer, and an undergraduate student, Hyunsoo Lee, both from UBC Computer Science. Perhaps because I am a woman, I was highly aware of my surroundings: the liveliness of CHCP, with another meeting proceeding parallel to ours; the light pouring into the boardroom, the linen-covered tables set for the caterers, fresh flowers, and warm smiles from our DC collaborators.

In my routine academic life I do not often interact with the community, and when I do it is to educate the public. But in this particular community interaction I had to be the learner. When our advisors began to examine the C-TOC tasks, I second-guessed the rationale for C-TOC, the task content, the merits of the tool in the same way I second-guessed my PhD dissertation at the university defence. I felt all the excitement and anxiety of someone whose work is being judged. Had I even made the goals clear? Would they survive this scrutiny? Should I have chosen different paradigms? Was my questionnaire comprehensible? Every time I saw a frown, a new round of second-guessing began. By the time we reconvened in the boardroom, I was ready to destroy my work, whereas the advisors were doing their job, each judging the work constructively from the unique perspective of his/her cultural group. Marina facilitated a round of discussions that brought to light the key issues in further developing C-TOC: Who is the tool really for? Can we reduce the tool's demands on education and computer literacy? What do people really want to know before they would take C-TOC? What is the best setting for people to take C-TOC? What message do we leave the prospective test-taker with? We could not have hoped for better directions to inform our further development of C-TOC. There is now more work than ever for the UBC team, but it has just become more meaningful, more feasible, and more real. Thank you, Marina, Kymberley, and Patricia! Thank you, panel members! See you all in October.