

MINING CCNA GOLD: A COMPASS-ND WORKSHOP FOR CCNA TRAINEES - EXECUTIVE SUMMARY

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About the CCNA Training and Capacity Building Program

The mission of the Training and Capacity Building Program (T & CB) is to provide the next generation of neurodegenerative disease researchers with opportunities for interdisciplinary collaboration, networking, mentorship, and professional development. There are currently 180+ CCNA trainees in postsecondary institutions across Canada.

Introduction

The Mining CCNA Gold workshop was organized as a response to what we heard from trainees responding to a 2020 survey on the impacts of the COVID-19 pandemic on CCNA trainees. Survey results demonstrated that COVID-19 health and safety restrictions posed a significant disruption to the research activities of graduate students and postdoctoral researchers across Canada. Half of the respondents felt that lack of access to research facilities, datasets and in-person data collection would significantly delay the progress of their graduate program and/or training. The CCNA Training and Capacity Building Program responded by moving its programming online, providing funding for collaborative research projects and, responding to the need for educational/training sessions like the COMPASS-ND Workshop. As Dr. Howard Chertkow, CCNA Scientific Director, said CCNA trainees have demonstrated to other trainees that the COMPASS-ND is a tremendous resource that is just beginning to yield its treasure. This workshop demonstrated that trainees can get in on the ground floor and start digging into the data to make an impact on the science of neurodegeneration in aging.

Presentation Summaries

The Mining CCNA Gold workshop consisted of 10 presentations followed by a Question & Answer session with speakers. Five presentations featured the contributions of trainees, along with their supervisors, to new and exciting findings emerging from the COMPASS study.

The presentations are summarized as follows and are in order as they were presented in the workshop:

1. *Overview of the COMPASS-ND cohort. The Largest Canadian Study in Dementia*, Dr. Howard Chertkow and Randi Pilon

The workshop began with an overview of the COMPASS-ND, the COMPrehensive ASSESSment of Neurodegeneration and Dementia cohort study. The presentation was divided into two parts. Part 1: A summary of the major goals of the study and key components of the study including recruitment criteria, study parameters (both longitudinal and cross-sectional), recruitment sites, demographic overview, screening and clinical assessment parameters. Part 2 of the presentation covered what data is available, protected projects, and how to make a data access request.

2. *The Gold-bearing Cave of LORIS*, Dr. Alan Evans, Charlie Henri-Bellemare, Zia Mohades, and Samir Das
LORIS is the national neuroinformatics framework for COMPASS-ND data and for other large-scale clinical projects across Canada. The LORIS team gave an overview of the types of CCNA data available on LORIS, including behavioural/clinical, biospecimens, imaging, and genetic/epigenetic data. The presentation also included a detailed overview on what data is available for access and how to access it.
3. *Indigenous Data Governance and Engagement in COMPASS-ND*, Dr. Jennifer Walker
Dr. Walker presented on the important topic of Indigenous data sovereignty. That is, the responsibility to involve Indigenous nations in the collection of data, as well as how the information is used and protected. The COMPASS-ND study does include Indigenous identifiers, although not enough at this point to include in an analysis. Dr. Walker encouraged everyone to think about Indigenous rights and expectations when it comes to data collected about Indigenous people. If you're going to include Indigenous identifiers, you need to include meaningful and respectful engagement of Indigenous peoples.
4. *Team 8: Lewy Bodies Diseases: Data Mining*, Dr. Richard Camicioli and *High Resolution Diffusion Tensor Imaging of the Hippocampus Shows Differences Between Parkinson's Disease and Healthy Controls*, Alexa Budd
Dr. Camicioli's talk focused on data mining that can be applied to the Lewy Body Disease spectrum with a specific focus on imaging data. Dr. Camicioli's presentation highlight the unique features of the COMPASS-ND study that allowed for collection of a broad range of imaging data on the Lewy Body spectrum. Dr. Camicioli was followed by trainee Alexa Budd, presenting on a specific example using locally acquired imaging from 54 patients with Lewy Body Disease spectrum. Alexa described how high resolution diffusion tensor imaging was used to explore hippocampal differences between patients with Parkinson's disease and healthy controls. In addition to the local data, fifteen controls were taken from COMPASS-ND. Looking at data locally may help identify future directions for the CCNA sample. This presentation was the first of five joint trainee-supervisor presentations on studies using COMPASS-ND data.
5. *Validation of the COMPASS-ND Neuropsychological Battery: Findings from the Second Data Release*, Dr. Natalie Phillips and Dr. Jennifer Fogarty
Dr. Fogarty gave an overview of the COMPASS-ND neuropsychological test battery used in screening and neuropsychology visits. Highlighting the unique nature of the COMPASS-ND study, the tests were chosen to be sensitive to a wide range of diagnostic groups. Detailed descriptions of the neuropsychological tests are available in the workshop recording. Dr. Phillips gave an overview of the raw neuropsychological data that has been released to date and reviewed characteristics of the data including Control, Subjective Cognitive Decline, Mild Cognitive Impairment, and Alzheimer Disease groups. The MCI participants had an amnesic profile, plus impairments in other cognitive areas. Sex, test scores, age, and education level are available in the dataset.
6. *Investigating Sensory Impairment in the COMPASS-ND Dataset: Trainee Challenges and Opportunities*, Zoe Papadatos, Sana Rehan, and Nicole Grant
CCNA trainees Zoe Papadatos, Sana Rehan, and Nicole Grant presented on lessons learned from working with COMPASS-ND data. Their research is working toward defining the relationship between sensory health, cognition including structural and functional integrity of the brain, and

psychosocial factors. Each trainee gave an overview of research questions they are exploring for their graduate program using the sensory and psychosocial data. The presentation concluded with recommendations from Sana, Nicole and Zoe for trainees who want to work with COMPASS data and LORIS.

7. *Get the spin on the COMPASS-ND Magnetic Resonance Imaging Data*, Dr. Simon Duchesne and Dr. Mahsa Dadar
Dr. Duchesne gave an overview of the imaging platform and explained why MRI was selected for the COMPASS study. One unique aspect of the imaging in COMPASS-ND is that a cross-platform protocol was used to harmonize MRI machines across vendors. All scans have been reviewed by board certified radiologists. Dr. Dadar, and former CCNA trainee, presented work that she did for her PhD thesis in which she developed a fully automated tool that segmented white matter hyperintensities (lesions in the brain that show up as areas of increased brightness in an MRI scan) from the structural MRI.
8. *Discovering sex and gender variables in COMPASS-ND*, Dr. Gillian Einstein
Although there is no direct sex and gender data yet from COMPASS, Dr. Einstein gave an overview of the importance of research into sex and gender, key challenges of doing sex and gender research, the misconception that sex and gender only tells you about women's health, and dispelling the myth that sex and gender science is not its own discipline. Dr. Einstein concluded with important approaches that can be taken to look at sex and gender and reporting requirements when submitting a publication for review by the CCNA Publications and Data Access Committee (PDAC).
9. *Does hearing loss or biological sex modulate the efficacy of exercise and cognitive training on dual-task performance in older adults with mild cognitive impairment?* Dr. Karen Li, Niroshica Mohanathas, and Berkley Petersen
The research presented focussed on the benefits of cognitive enrichment through training intervention designs. For example, seated brain training has been shown to improve standing balance and mobility in older adults with mild cognitive impairment. Trainees Niroshica Mohanathas and Berkley Petersen presented a collaborative project between CCNA Teams 12 and 17. This project received funding from the Training Program's 2020 Interdisciplinary Trainee Research Innovation Challenge (iTRIC) and from the Women, Sex, Gender and Dementia Program. The project looked at whether cognitive and/or physical training can improve dual task walking in older adults with hearing loss. Data from the COMPASS-ND study and SYNERGIC trials were used. Niro and Berkley highlight challenges when working with two different databases, and tips and tricks on how to successfully navigate the challenges.
10. *Dual-task gait and mild behavioral impairment: The interface between non-cognitive dementia markers*, Dr. Zahinoor Ismail and Dylan Guan
This presentation looked at non-cognitive markers of dementia, including gait deficits and mild behavioural impairment. The study described looked at whether there is an association between mild behavioural impairment and dual task walking in older adults without dementia. Dylan emphasized that the COMPASS-ND study is rich with data and that staying organized is key to a successful analysis. This study shows a relationship between MBI and gait deficits.

What We Heard - 10 Key Recommendations and Challenges

Many of the observations about the challenges of accessing and working with data came from CCNA trainees working on the ground with COMPASS-ND data. Trainees were praised for the ingenuity and creativity demonstrated while working with a dataset that is not yet complete. For example, trainees talked about the challenges related to harmonizing data between two studies, COMPASS-ND and the SYNERGIC Trial, how to stay organized and solve for challenges. Real-time discussion and exchange of new ideas took place and the workshop was an opportunity to talk about new and exciting findings. In discussing these new findings, potential collaborations between teams and investigators emerged. The trainees benefited from very clear instructions about how to apply for LORIS access to COMPASS-ND data. The Training and Capacity Building Program will take all the interest and feedback we received on the workshop and look at how we can include a similar session for the 2022 Science Day. Given the success of this session, the Training Program will plan a second COMPASS-ND workshop in the near future.

1. Recommendation (Zoe, Sana, & Nicole): Once a trainee has a research question and methodology for a study, and the project has been approved by the CCNA, select the variables you need in order to build a separate data file. Because the COMPASS dataset is quite extensive, copying and pasting the variables of interest into your own dataset file facilitates organization.
2. Recommendation (Zoe, Sana, & Nicole): When choosing the variables to build your own dataset, the first piece of information you will need is participant IDs and diagnostic grouping. Participants grouping is reassessed after each clinic visit and evolution of diagnosis has its own file. Pay special attention to choosing one of two final diagnoses; either COMPASS-ND's or the physician's diagnosis.
3. Recommendation (Zoe, Sana, & Nicole): Building familiarity with your data and keeping track of your participants is challenging. The COMPASS-ND is updated frequently with more participants, so you will need to regularly update your dataset. Additionally, longitudinal data adds variables to keep track of.
4. Recommendation/Challenge (Zoe, Sana, & Nicole): Building a comprehensive data dictionary that succinctly and accurately describes all the variables available in the dataset is challenging. The development of a comprehensive and detailed data dictionary by the CCNA would be helpful to trainees working with COMPASS-ND data.
5. Recommendation (Zoe, Sana, & Nicole): The LORIS data query tool can be challenging to use if you don't know exactly what you're looking for; do some background research before diving in.
6. "Tricks and Tips" from Nicole, Sana, and Zoe:
 - i. Collaborate with your lab mates to keep yourself organized and informed.
 - ii. Document all decisions that are made within the lab as a group; e.g., use common Excel files to track exclusions, quality control decisions, or missing data.
 - iii. Learn a common programming language like R. This will allow you to systematize your workflow and document questions and analysis scripts. It encourages consistency across projects and lab members.
7. Challenges and Recommendations (Niro and Berkley): Niro and Berkley noted the following inconsistencies when working with two datasets (COMPASS-ND and SYNERGIC):

- i. Lack of standardized test administration between COMPASS-ND and SYNERGIC; e.g., COMPASS-ND records how long it takes participants to complete a dual task, but Synergic does not.
- ii. Lack of harmonization of data between the two studies used. Data entry and double data entry is used in COMPASS-ND; unclear if similar methods are used in the SYNERGIC trial.
- iii. Communication across sites. Some sites are quick to respond to queries while other sites were much slower. Moreover, who to contact for help is not always clear.
- iv. The use of terms like sex and gender in LORIS. Gender classified as male or female making it unknown as to whether an individual's gender identification differed from their identified sex.

Other Challenges included the following:

- i. Delays in gaining access to full SYNERGIC data, which took six to eight months,
 - ii. Trainees were asked to contribute to double data entry in LORIS in order to ensure the readiness of participant data relevant to their study.
8. Tips and Tricks (Dylan Guan): Create your own data dictionary for your data files. This will be helpful if working with different groups of variables/data files.
 9. The LORIS platform will be launching a Data Query Tool (DQT), which will allow users to search for and filter data relevant to them. Following the launch of the DQT, LORIS will offer training workshops.
 10. The LORIS platform includes a Data Dictionary, which contains all the fields entered in LORIS with a short description.