### ORIGINAL RESEARCH

# Listening to Trainee Concerns and Suggestions During COVID-19: a Report from the Canadian Consortium on Neurodegeneration in Aging (CCNA)

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#### **ABSTRACT**

#### **Background**

The COVID-19 pandemic has caused significant disruption to research activities across Canada. The Training and Capacity Building (T&CB) Program of the Canadian Consortium on Neurodegeneration in Aging (CCNA) conducted a survey between May 11<sup>th</sup>, 2020 and May 19<sup>th</sup>, 2020 to identify the challenges faced by CCNA trainees because of the pandemic and how to best support trainees in response to those challenges.

#### Methods

Graduate students and postdoctoral researchers working under the supervision of CCNA investigators (n=113) were invited to complete a web-based survey of 13 questions. Trainees were asked questions about the impact of COVID-19 on their research activities, degree progression, funding status, and suggestions for support from the T&CB Program during the COVID-19 pandemic.

#### Results

A total of 41 trainees responded to the survey (response rate: 36.3%); 83% of respondents reported that they experienced changes to their research activities as a result of COVID-19, and 50% anticipated that their degree completion would be delayed. Respondents requested information from the T&CB Program on funding for non-COVID-19 projects, alternative datasets, and short educational workshops.

#### Conclusion

The majority of CCNA trainees surveyed experienced significant changes to their research activities as a result of the COVID-19 pandemic. The T&CB Program responded by switching to online programming and facilitating remote

research. Further engagement with trainees is needed to ensure continued progress of research in age-related neurodegenerative disease in Canada post-pandemic.

**Key words:** COVID-19, trainees, students, research, neuro-degenerative, survey

#### INTRODUCTION

The COVID-19 pandemic has changed the way many of us live and work. There have been significant changes to research activities and funding, which have affected the work of many graduate students and post-doctoral researchers. (1,2) The Canadian Consortium on Neurodegeneration in Aging (CCNA) is comprised of 19 research teams across Canada investigating age-related neurodegenerative disease, including dementia, and focusing on prevention, treatment, and quality of life for persons living with a clinical diagnosis. (3) Currently, 167 trainees including graduate students and postdoctoral researchers contribute to the work of the consortium. The CCNA Training and Capacity Building (T&CB) program has a mandate to support the next generation of researchers and their efforts in developing increasingly effective approaches to understanding and combating agerelated neurodegenerative conditions. Given the significant disruption and uncertainty caused by COVID-19, the T&CB Program wanted to hear from CCNA trainees about how they were managing during this challenging time. A survey was conducted between May 11th, 2020 and May 20th, 2020 to identify the challenges and barriers that CCNA trainees experienced because of the pandemic, and to learn how the T&CB Program can best support trainees in response to those challenges.

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#### **METHODS**

CCNA trainees were invited to complete a web-based survey. The T&CB Program defines a CCNA trainee as a graduate student (Master's or PhD) registered full-time or part-time in a Canadian post-secondary institution. Graduate students must be supervised by a CCNA investigator and engaged in CCNA-related work. Post-doctoral researchers are also recognized as CCNA trainees if they are associated with a Canadian post-secondary institution (registered as a student and/or holding an appointment as an employee). They must be working under the mentorship of a CCNA investigator and engaged in CCNA-related work. For the purposes of this survey, we added additional trainee categories including MD/PhD students and early-career investigator (first five years). Early-career investigator was added to capture CCNA trainees who may have recently transitioned to academic employment.

Invitations to complete the survey were sent on May 11<sup>th</sup>, 2020. The survey closed on May 20<sup>th</sup>, 2020. Two reminders were sent: the first on May 14<sup>th</sup> and a final reminder on May 19<sup>th</sup>. A multi-pronged approach was used to reach trainees who were affiliated with the CCNA at the time the survey was launched in May 2020 (n=113). In addition to contacting trainees directly, CCNA Investigator members (n=338) and members of the CCNA Research Executive Committee (n=16) were contacted to encourage their trainees to complete the survey.

The survey consisted of 13 questions, including multiple choice and short answer responses. The survey was reviewed by the T&CB Program Lead during the survey period (2019–2021), three CCNA-affiliated investigators, the Chair of the CCNA Trainee Society Executive Committee, and one individual external to the CCNA. Section 1 of the survey was devoted to questions on the effects of COVID-19 on trainee research activities and graduate programs. Section 2 was devoted to questions about trainee preferences for T&CB Program activities (e.g., What type of activities

would trainees like to see organized for this year's CCNA Science Day?). Questions in Section 2 were to help guide future T&CB programming and have been excluded from this report. Respondents were routed to different questions in the survey based on the answers they provided. Thus, not all questions have the same number of respondents. The number of respondents for each question is indicated below each corresponding figure or table. In addition, the exact questions asked in the survey are described in the caption of each corresponding figure or table.

#### RESULTS

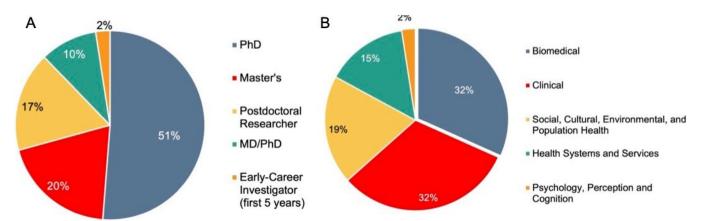
#### **Trainee Profile**

A total of 41 trainees responded to survey (response rate: 36.3%). Half of the respondents were doctoral students (51%). An almost equal number self-identified as Master's students (20%) or postdoctoral researchers (17%) and a smaller percentage identified themselves as MD/PhDs (10%). Only one respondent identified as an early-career investigator (Figure 1A).

Trainees were asked about the primary focus of their research. A third of respondents focused on biomedical research (32%) and a third focused on clinical research (32%). Nineteen per cent of respondents focused on social, cultural, environmental, and population health research, 15% on health services research, and 2% on psychology, perception, and cognition (Figure 1B).

## Impact of COVID-19 on Research Activities and Degree Progression

Trainees were asked how their research activities have been affected by COVID-19 restrictions. The vast majority (83%) of respondents indicated they had experienced changes to their research activities as a result of COVID-19. Respondents who indicated that their research activities had been affected



<sup>a</sup>For a definition of each category, survey respondents were directed to The Canadian Institutes of Health Research Glossary of Funding-Related Terms: https://cihr-irsc.gc.ca/e/34190.html#r7.

FIGURE 1<sup>a</sup>. A) What is your level of study or training? B) Please indicate the primary focus of your research. (Number of Respondents, n = 41)

were routed to a follow-up question asking them how their research was affected by COVID-19. Participants could select more than one option from a list of items describing different types of barriers to engaging in research activities due to COVID-19 restrictions.

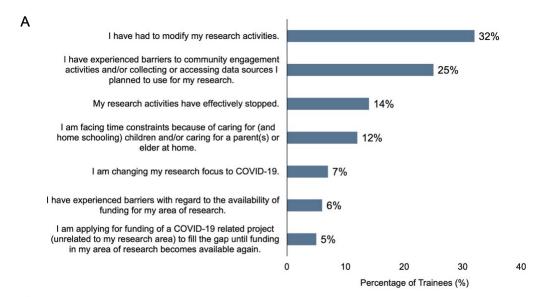
Specifically, 32% had to modify their research activities, 25% experienced barriers to community engagement and/or data collection, 12% faced time constraints because of the need to balance research duties with caring for children or elderly parents, 7% changed their research focus to COVID-19, and 6% experienced barriers related to funding. Importantly, 14% of trainees had their research activities stopped altogether, and 5% applied for funding for COVID-19–related projects to fill the gap until their regular research activities could resume (Figure 2A).

In a second follow-up question, respondents were given the chance to expand on their answers with open-ended text responses to the above by describing how they have modified their research activities (Table 1). Trainees were also asked to rate the severity of the changes experienced on a scale of 1 (not severe) to 5 (severe). Slightly more than half of the trainees rated the severity of the changes they experienced as 4 or 5 (53%). Forty-four per cent rated the severity of the changes they experienced as 2 or 3, while 3% rated the severity of the changes as 1 (not severe) (Figure 2B).

Trainees were asked if COVID-19 has changed anything regarding the completion of their program. Half the respondents anticipated that the completion of their degree or postdoctoral fellowship would be delayed (50%). Slightly less than half of the trainees reported they were on track to complete their program on time (47%). In contrast, 3% of trainees anticipated that the completion of their program would be accelerated (Figure 3).

#### **Impact of COVID-19 on Funding Sources**

Trainees were asked if they lost a source of income or employment due to COVID-19. The majority of trainees (79%) of trainees answered "No", 18% answered "Yes", and 3% preferred not to answer (Figure 4). In a follow-up question, trainees were asked if their current research funding



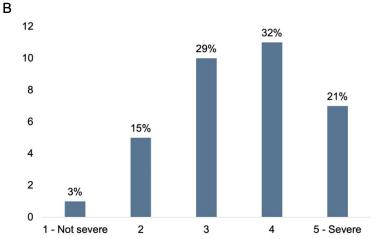


FIGURE 2. A) How have your research activities been affected? B) Please rate the severity of changes you have experienced. (Number of Respondents, n = 34)

had a time limit. Sixty-five per cent of trainees answered the question. Of those, 63% answered "No" and 37% answered "Yes" (Figure 5).

## Suggestions for the CCNA Training and Capacity Building (T&CB) Program

To help inform the T&CB Program about trainee needs during COVID-19, the survey asked if there any specific training-related topics about which trainees would like more information. Most trainees requested more information about funding for non-COVID-19 research (80%), followed by availability of alternative datasets (63%) and short educational workshops (63%). Five per cent of respondents asked for more information on other topics (Table 2).

Trainees were asked if there were specific topics or research questions they believed should be tackled by CCNA researchers and investigators in relation to the impact of COVID-19 on older adults living with or affected by

neurodegenerative conditions. Trainees were invited to list up to three research questions or topics (Table 3). They suggested several research projects including access to information, safety of patient assessments, mental health of older adults, research priorities after COVID-19, inclusion of COVID-19—related variables in future studies, as well as impact of COVID-19 on geriatric care, older adults in marginalized communities, and on caregivers. The questions suggested by the trainees are shown in full in Table 3.

#### **DISCUSSION**

The goal of the COVID-19 Training and Capacity Building (T&CB) program survey was to learn about the impact of the pandemic on the research activities of CCNA trainees. At the time the survey was launched in May 2020, health-care research institutions across Canada were under significant financial strain related to COVID-19. In a letter to the federal

TABLE 1.

Responses grouped by theme on how CCNA trainees modified their research activities in response to COVID-19 disruptions (Number of Respondents, n = 34)

Theme	Impact on CCNA Trainee Research Activities	Trainee Response
Lockdown of research institutes.	This led to the cessation of all research activities, lack of access to equipment, lack of access of existing data and loss of past progress.	Trainees responded to this by reducing the scope of their research, changing the research topic, shifting to remote analysis of existing data and focusing on literature reviews and/or manuscript writing.
Suspension of non-urgent patient assessments.	This affected follow-up of participants in longitudinal studies and prevented delivery of therapeutic interventions to elderly participants in-person or at home.	Trainees responded by shifting to virtual assessments and delivery of interventions or recruiting different participants other than those originally targeted.
Community organizations moved to prioritize client safety per public health guidelines.	Data collection planned by community partners was halted and research activities conducted in community settings had to be suspended.	Trainees responded to these disruptions by adapting their research protocols or revising their timelines for community engagement
Degree completion timelines	The disruptions caused by the pandemic interfered with the usual degree completion timelines (graduate degrees or postdoctoral fellowships)	Trainees had to modify their projects in order to finish their degrees on time.

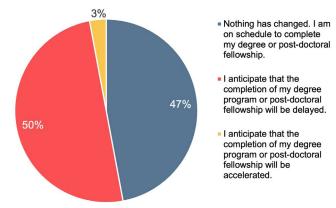


FIGURE 3. Has anything changed regarding the completion of your graduate training program? (Number of Respondents, n = 34)

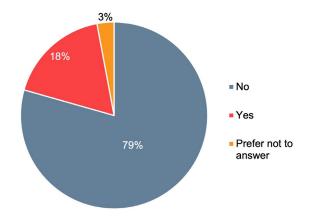


FIGURE 4. Have you lost of source of income or employment due to COVID-19? (Number of Respondents, n = 34)

government in late April 2020, HealthCareCAN estimated that hospital-based research institutes incurred over \$600 million in unfunded costs since the start of the pandemic in March. (4) There were concerns that funding for research in other areas—including neurodegenerative disease—would be affected, given the need to fund COVID-19–related projects. (2)

In addition to funding concerns, the present survey found that the main barriers trainees experienced were related to COVID-19 restrictions, such that trainees were locked out of laboratory spaces and unable to access encrypted online databases because university campuses were under lockdown, and prevented from conducting in-person data collection due to health and safety concerns. Trainees also reported having to modify the scope of their research in order to complete their degrees on time. Trainees also experienced time constraints as a result of having to balance research duties with child care or caring for elderly parents while working remotely.

The survey data in the present report show that, in the short-term, the COVID-19 pandemic has had a significant impact on research in age-related neurodegenerative diseases in Canada. Like CCNA trainees, the T&CB Program has had to pivot quickly to respond to the impact of the pandemic. The present survey was a tool used to capture data on barriers so we could discern how to best help our trainees. We responded by moving in-person programming online and by continuing to support trainee research in age-related neurodegenerative disease through a research award program conducted remotely. The Interdisciplinary Trainee Research Innovation Challenge (iTRIC)(5) program was launched in July 2020 and it will continue for a second year in 2021. This is a collaborative program that allows CCNA trainees to form interdisciplinary teams to work on projects beyond their discipline-specific boundaries.

Aside from the challenges caused by the pandemic, the present survey also highlights how the pandemic has generated interest in new areas of research in aging. In response to the survey, CCNA trainees suggested numerous research questions related to the impact of COVID-19 in older adults with neurodegenerative disease which they believe should be tackled by the CCNA in future.

Our survey does have limitations. It was conducted during the first wave of the pandemic when research facilities across

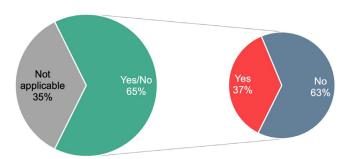


FIGURE 5. Does your current research funding have a time limit that might be exceeded? (Number of Respondents, n = 34)

Canada were under the initial lockdown, so we did not assess the impact of subsequent periodic lockdowns on our trainees and their research activities. Our survey was focused on broadly identifying the challenges experienced by our trainees at the onset of pandemic; therefore, we did not collect data on the specifics of some of these challenges. For example, 12% of trainees faced time constraints due to having to care for family members at home. It was not specified whether this was due to childcare or the need to care for elderly family members. Future follow-up surveys could be more focused on specific challenges faced by trainees (e.g., childcare, periodic lockdowns, trainee mental health). This is particularly relevant given the duration of the pandemic which could not be predicted at the time of our initial survey in May 2020.

The T&CB program will continue to use this data to look at how it can facilitate the continued success of CCNA trainees and maintain the level of creativity and innovation we have come to expect of CCNA trainees despite the challenges caused by the pandemic.

#### **CONCLUSION**

The CCNA Training and Capacity Building (T&CB) survey found that trainees working on age-related neurodegenerative disease research experienced significant disruptions to their research activities as a result of the COVID-19 pandemic. This included lack of access to data, suspension of data collection, limited community engagement, and modifications to the scope of research. The T&CB moved to support trainees by shifting its programming fully online, and launching a new collaborative and remote research award program. The T&CB will continue engaging with CCNA trainees to ensure their success and to ensure continued progress in age-related neurodegenerative disease research in Canada in the post-pandemic period.

TABLE 2.

Is there anything specific you would like more information about? (Number of Respondents, n = 31)

Торіс	Count (n)	% of Respondents to the Question <sup>a</sup>
Funding sources to support training and/or research in areas not related to COVID-19.	24	80
Alternative data sets for conducting your research.	19	63
Short educational/training workshops on particular topics.	19	63
Other topics <sup>b</sup>	5	17

aThe total count does not add up to 31 and the % total does not add up to 100 because respondents were allowed to select more than one topic.
 bOther topics included: ethics of online data collections, remote access of administrative data, foundational topics in neuroscience, ongoing CCNA projects that trainees can collaborate on, literature reviews and manuscript writing workshops.

#### OSMAN: IMPACT OF COVID-19 ON CCNA TRAINEES

#### TABLE 3.

Are there specific topics or research questions you believe should be addressed by CCNA trainees and investigators in relation to the impact of COVID-19 on older persons living with or affected by neurodegenerative conditions?<sup>a</sup>

Theme	Research Questions/Topics Suggested by CCNA Trainees	
Access to information	How to ensure older adults with neurodegenerative conditions access latest information on the pandemic?	
Safety of participant assessments	How to safely assess older adults participating in research studies during (and after) the pandemic. How willing are older adults to participate in research in the current conditions? How can technology be used to facilitate the participation of older adults with dementia in research studies from the safety of their homes/care facilities? How can perceptual and cognitive function assessments be modified to allow participants to complete them virtually?	
Research priorities after COVID-19	How will COVID-19 shift priorities in aging research?	
Mental health and cognitive well-being of older adults.	What is the impact of social distancing on stress and depression among older adults? How to provide emotional support during (and after) the pandemic without compromising patient safety? How does COVID-19 affect sensory impairments in older adults with dementia (both minor and extensive neurocognitive impairment)? How does COVID-19 affect neurodegenerative conditions in infected vs non-infected patients (acceleration, no effect, etc.). Does infection accelerate neurodegeneration or increase susceptibility?	
Inclusion of COVID-19 related variables in neuroimaging and machine learning studies on dementia.	What are the most widely used COVID-19-related variables among clinicians and researchers? Which databases investigate COVID-19 related variables (COMPASS-ND, others)?	
Impact of COVID-19 on caregivers	What is the impact of pandemic-related stressors and sense of helplessness on non-paid caregivers of older adults (e.g. spouses/partners, children, community members, etc.)? and how to address this?	
Impact of COVID-19 on geriatric care What is the impact of restrictions on access to non-urgent care e.g. did it lead to delayed diagnoses?  Relationship between frailty and COVID-19 mortality / morbidity.  Neurological manifestations of COVID-19 in infected patients.  Lifespan effects of COVID-19 on brain aging in infected patients.  How to encourage and assist older adults to exercise at home while having access to limited equipment?  The relationship between socioeconomic effects of the COVID-19 (e.g. on income, education, employment) and future progression to dementia.		
Marginalized and vulnerable communities	What is the impact of COVID-19 on older adults with dementia from marginalized and vulnerable communities including but not limited to: Indigenous communities. Northern and remote communities. Rural, racialized, LGBTQ+, low SES and other vulnerable communities.	

<sup>&</sup>lt;sup>a</sup>Respondents were invited to list up to three questions or topics; responses have been grouped by theme.

#### **Key Points**

- 1. The COVID-19 pandemic has caused significant disruption to research activities across Canada.
- 83% of CCNA trainee respondents experienced major changes to their research including lack of access to data sources due to lockdowns, suspension of communitybased data collection, and the need to balance between research and caregiver duties after shifting to remote work.
- 3. 14% of respondents had their research activities stopped and 6% experienced barriers to funding as a result of

- COVID-19. 50% of the respondents anticipated that their degree completion would be delayed
- 4. The CCNA Training and Capacity Building Program shifted its programming fully online and launched a new collaborative and remote research award program to support trainees.

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#### CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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