

WORKING TOGETHER TO END DEMENTIA

POST-EVENT: OCTOBER 19-30, 2020
CONSULTATION AND WORKSHOPS - DESCRIPTIONS AND BIOS

CIHR-IA Consultation: DRS Phase II consultation: Stakeholder consultation towards the development of the CIHR Dementia Research Strategy Phase II

The current CIHR Dementia Research Strategy (DRS) is comprised of a national and international component. It aims to create new scientific knowledge and enable its translation into improved health and wellness for people living with dementia, their families and caregivers. Furthermore, it contributes to ensuring collaborative Canadian participation and leadership in world-class research that is aligned with a coordinated, global agenda to address the complex challenges of dementia. CIHR and the Institute of Aging are now moving toward the development of the Phase II of the strategy. We are seeking input from the research community and partners involved in dementia research. This consultation is a first in an upcoming series of consultations that will involve all stakeholders, including people living with dementia and their caregivers, to identify specific needs and immediate and future research priorities.



Facilitator: Dr. Jane Rylett was appointed as Scientific Director of the CIHR Institute of Aging in 2019. She is also Distinguished University Professor at the University of Western Ontario and a Scientist in the Molecular Medicine Research Laboratories at Robarts Research Institute. Trained in Canada, England and Germany as a cellular and molecular neuroscientist, her laboratory studies the consequences of age-related changes in brain and neurodegenerative diseases. Dr. Rylett is recognized internationally for contributions to the field of cholinergic neurobiology and Alzheimer disease. Research in her laboratory focuses on mechanisms regulating chemical communication in the nervous system in health, normal aging and disease and the impact on cognitive function. She has served as Chair of the Institute Advisory Board for the CIHR Institute of Aging, on Boards of for international endeavours for Alzheimer Disease research. She served as leader of the Canadian Consortium on Neurodegeneration in Aging (CCNA) Theme 1 – Prevention until 2019. She was also appointed as an inaugural College Chair of the CIHR College of Reviewers in 2016 and held the position of Executive Vice-Chair. Dr. Rylett is a Fellow of the Canadian Academy of Health Sciences.

NOTE: This session has not been recorded

LORIS workshop #1- Data dissemination: Data query tool, data access, data release and sftp

This first workshop presented by the CCNA LORIS developers will introduce users to the different modules in LORIS that are required for data dissemination. During this workshop there will be a particular highlight on the requirements to get access to the data and a practice session to get used to the DQT.

DQT: Following the approval to access the data, the Data Query Tool (DQT) can be used to extract the relevant data. This module provides a graphical frontend for scientists to query and extract arbitrary data from a LORIS instance without backend SQL access.

Data Access: The new Data Access module was designed to facilitate the process of both requesting and granting access to data. This process is now entirely integrated within LORIS. The data managers can easily view all data access requests in a single admin panel. Researchers requesting data for their studies can directly fill in the data access request form on LORIS rather than doing so via email. As a result, the data access process is more efficient for CCNA researchers, data managers and central staff.

Data Release: The Data Release Module can be used to easily distribute packaged data releases of your study. Users can download customized subsets of data from this module. Scaling and transferring solutions were implemented for researchers downloading large datasets. In addition, an sftp server is used to securely transfer files over a remote system to users based on permission.



Facilitator: *Zia Mohades is a data manager at CCNA. He holds a master in bioinformatics, and has been working at MCIN (McGill Centre for Integrative Neuroscience) since for almost 11 years as a developer and project manager.*



Facilitator: *Jessica Callegaro has a Bachelor degree of Arts & Science from McGill University in Cognitive Science with a minor in Computer Science. She has been working at MCIN with the CCNA-LORIS team as a software developer for the past 2 years.*



Facilitator: *Rolando Acosta, MSc. is a software and Machine Learning engineer. He is passionate by Medical Sciences and Biology and has been working a MCIN for almost a year.*

Integrating sex and gender in aging and neurodegeneration research: Examples from micro- to macro-data

Continuing last year's successful Scientific Day workshop on including sex and gender in your research, this year we offer a perspective of sex and gender research in an APOE4 animal model dealing with molecular aspects of aging and in big data sets dealing with multiple biological and life factors as risks for AD.

The session will include the following presentations:

- Introducing Sex and Gender: The challenges and benefits of bringing them together (Einstein)
- Studying sex and sex-linked factors in an APOE4 animal model of AD (Galea)
- Factoring sex into aging and neurodegeneration research: Examples with large data bases (Dixon)

We invite you to bring your questions about how to incorporate sex and gender into your own research, research you would like to do, and reading other people's research. Come prepared for brainstorming!



Facilitator: *Gillian Einstein is The Wilfred and Joyce Posluns Chair in Women's Brain Health and Aging, Professor of Psychology at the University of Toronto and Guest Professor of Gender and Health at Linköping University in Linköping, Sweden. She is an Adjunct Scientist at Women's College Research Institute and at the Rotman Research Institute in Toronto. She is a board member of the International Gender Medicine Society, Chair of the Canadian Institutes of Health's Institute of Gender and Health Advisory Board, and Founder of the Canadian Organization of Gender and Sex (COGS) Research. She is Lead of the Women, Sex, Gender, and Dementia cross-cutting program of the Canadian Consortium on Neurodegeneration and Aging. She has served as a temporary advisor for the World Health Organization on Female Genital Circumcision/mutilation/cutting (FGC) and has numerous honours such as: Named one of 20 Canadian Brain Research Stars, Brain Canada; The May Cohen Lecture in Women's Health; Invited Member, CIHR College of Reviewers; Lawrence & Nancy Golden Memorial Lectureship in Mind-Body Medicine. She has also been recognized and profiled as a Leader in Women's Health in Ontario by the Ontario Women's Health Network and as a feminist voice in Psychology; Profiled in Psychology's Feminist Voices. Her research is funded by the Canadian Institutes of Health Research, the Alzheimer's Society Canada, and the Ontario Brain Institute. Her broader interests encompass memory, the long term effects of hormone treatment, and the bridge between our scientific understanding of the nervous system and larger concerns having to do with self, identity, feminism, and the nature of science. She has published on Alzheimer disease, vision, sex differences, Female Genital Cutting, and estrogens' effects on aging, pain, sleep, memory and mood. Her current research is on the effects of ovarian removal on women's memory and brains. She is also interested in cognition in trans-individuals and how different cultures shape the nervous system. The overarching question of this research is: How do both sex and gender mediate women's brain health?*



Facilitator: *Liisa Galea is a Professor in the Department of Psychology and Djavad Mowafaghian Centre for Brain Health, Director of the Graduate Program in Neuroscience, Lead of Women's Health Research Cluster, and a Scientific Advisor at Women's Health Research Institute at the University of British Columbia. Her research goal is to improve brain health for women and men by examining the influence of sex and sex hormones on normal and diseased brain states such as depression and Alzheimer's disease. She was the first researcher world-wide to develop preclinical models of postpartum depression and was one of the first to study the long-term effects of motherhood on the brain. Dr. Galea obtained her Ph.D. in Neuroscience from Western University and was a postdoctoral fellow at the Rockefeller University. She is a Distinguished University Scholar, is a twice winner of the NSERC (Natural Sciences and Engineering Research Council of Canada)-Discovery Accelerator Supplement, received the Michael Smith Senior Scholar Award, Cattell Sabbatical Award, and the Vancouver YWCA Women of Distinction award. Liisa was recognized as a Fellow at International Behavioral Neuroscience Society (IBNS). She has an H index of 69 (Google) and over 160 scientific papers in peer-reviewed journals. Dr. Galea is the chief editor of FiN (Frontiers in Neuroendocrinology IF: 9.059), past section editor for eNeuro and Neuroscience, and serves/served on the editorial boards of Endocrinology, Hormones and Behavior, and Neuroscience. Dr. Galea served on peer review panels for National Institute of Health (US), Canadian Institutes for Health Research (CIHR), Wellcome Trust (UK) and NSERC. She has secured over \$7M as PI. She is a President-Elect of the Organization for the Study of Sex Differences (OSSD), and serves on numerous committees (Canadian*

Association for Neuroscience: Advocacy, EDI, Society for Behavioral Neuroendocrinology, IBNS) and advisory boards (e.g. Institute for Gender and Health CIHR, Women's Brain Project).



Facilitator: Roger A Dixon is Professor of Psychology (Science) and member of the Neuroscience and Mental Health Institute at the University of Alberta. He is Co-Lead of CCNA Team 9 (Biomarkers of Aging and Neurodegeneration). Recent recognitions include: (1) Canada Research Chair in Cognitive Aging (Tier 1); (2) Baltes Award for Distinguished Career Research in Aging (American Psychological Association); (3) Two NIH MERIT Awards. His research interests include applications of data-driven neuroinformatics and multi-omics technologies to discovery, validation and classification of multi-modal biomarker predictors of heterogeneity in (1) dynamic individualized trajectories of decline and (2) subtypes of neurodegenerative disease.

Tailoring messages for your KT audience

Do you have research findings that you want to share beyond traditional scientific publications and presentations?

The CCNA KTE program can help! In this interactive workshop you can learn how to tailor messages for different audiences - and then practice doing this with your own research findings. You will receive feedback from the KTE Team and your peers.



Facilitator: Inbal Itzhak is a certified Knowledge Translation (KT) Specialist with a PhD in Communication Sciences and Disorders. Inbal is the Knowledge Translation and Exchange Specialist at CCNA. She is experienced in knowledge translation capacity building and project planning, as well as stakeholder engagement and partnership development.



Facilitator: Carrie McAiney is an Associate Professor in the School of Public Health and Health Systems at the University of Waterloo, Schlegel Research Chair in Dementia at the Schlegel-UW Research Institute for Aging, and Scientific Director of the Murray Alzheimer Research and Education Program. Carrie also serves as the KTE Co-Lead for the CCNA, and is a co-principal investigator on CCNA's Team 19 - Research on the Organization of Health Services for Alzheimer's (ROSA). As a health services researcher, Carrie works collaboratively with persons living with dementia, family care partners, providers and organizations to evaluate the impact and implementation of interventions and approaches that aim to enhance care and support for individuals living with dementia and their family members, and to improve the quality of work life for dementia care staff.

Neuropsychological function in persons with SCD, MCI, and AD: Overview of findings from the COMPASS-ND second data release

The COMPASS-ND study of the Canadian Consortium for Neurodegeneration in Aging (CCNA) is the largest observational study of dementia in Canada. It is aimed at understanding the disease mechanisms and diagnostic profiles of neurodegenerative illnesses. To date, 1140 Canadians who are living with, or who are at risk for developing, dementia have been tested, including those with subjective cognitive decline (SCD), mild cognitive impairment (MCI), Alzheimer's disease (AD), vascular dementia and MCI, mixed

dementia, fronto-temporal lobar dementia, and Parkinson's disease/Lewy body dementia. Research diagnoses are based on an initial clinical screening exam. Participants then complete an independent battery of neurocognitive tests designed to provide data for the research consortium, a clinical visit with a physician, an MRI scan and bloodwork.

The neuropsychological test battery assesses a broad range of cognitive function (e.g., episodic learning and memory, executive function, attention/concentration, language, processing speed, visual spatial abilities, reaction time, etc.). To date, of the 1080 enrolled participants, data for the first 200 have been verified and released. This webinar will report the initial results of the demographic and cognitive data from participants from the Second Data Release (DR2, March 2020). Specifically, we will present data from participants with study diagnoses of:

- SCD (n=56; 43 women, 13 men, mean age = 70.0 years; mean education = 17.0 years),
- MCI (n=104; 46 women, 58 men, mean age = 71.4 years; mean education = 15.7 years),
- MCI-V (n=64; 23 women, 41 men, mean age = 77.3 years; mean education = 15.3 years),

and AD (n=48; 16 women, 32 men, mean age = 74.6 years; mean education = 15.3 years).

We will: 1) describe the groups according to the above-noted cognitive domains, 2) disaggregate the data by sex, 3) present the frequency with which MCI participants show amnesic and/or single or multi-domain impairments, and 4) will report whether the MCI and V-MCI participants differ in their neuropsychological profiles. Time permitting, we will also examine the relationships between certain neuroanatomical measures (e.g., hippocampal volume) and memory performance.

Our goal will be to 1) familiarize webinar participants with the cognitive measures available, 2) the key cognitive findings from the Second Data Release, and 3) to encourage CCNA members to avail themselves of these data.



Facilitator: *Dr. Jennifer Fogarty is a clinical neuropsychologist who is also the neuropsychology platform leader COMPASS-ND. Dr. Fogarty is also an assistant professor in the Faculty of Medicine at Western University. Dr. Fogarty provides clinical consultation to geriatricians and neurologists in the Aging Brain and Memory Clinic at Parkwood Institute.*



Facilitator: *Dr. Natalie Phillips (Ph.D., Clinical Psychology, Dalhousie, 1996) is a Professor in the Department of Psychology, Concordia University, and holds the Concordia University Research Chair (Tier 1) in Sensory-Cognitive Health in Aging and Dementia. Dr. Phillips examines the neuropsychology of healthy aging and Alzheimer disease. She studies the relationship between our senses and our cognitive abilities and language processing in older adults, including those who are bilingual. Dr. Phillips is one of the principal developers of the Montreal Cognitive Assessment (MoCA), a cognitive screening instrument used around the world for the assessment of mild cognitive impairment. She is the Associate Scientific Director of the Canadian Consortium on Neurodegeneration in Aging (CCNA, <http://ccna-ccnv.ca/en/>), which is Canada's national research consortium on dementia. She is the one of the organizing neuropsychologists for the COMPASS-ND study, and she is founding leader of CCNA Team 17 (<http://ccna-ccnv.ca/en/research/theme-3/>), which examines issues of sensory health and cognitive function in person with dementia.*

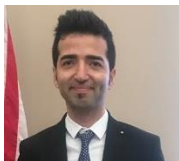
LORIS workshop #2- Quality control: Statistics

This second workshop presented by CCNA LORIS developers will introduce users to the different steps in the quality control process. LORIS contains multiple modules to facilitate quality control, including the Behavioural QC module.

Behavioural QC Module: This module acts as a centralized place for users to navigate the unfinished data and what steps remain to complete the data entry. The Feedback Module is also an integral component of Behavioural QC, where users can enter additional information to accompany the data in cases where a task may have been interrupted, discontinued, not administered, incorrectly administered, or incomplete.

Statistics: The Statistics Module contains multiple tools to give a large statistical overview of the progression of the study in four domains: demographics, behavioural data, imaging data, and recruitment data. In each of these categories, the module includes a general statistical summary, as well as the ability to filter for more specific results.

Study Tracker: This module serves as a study management tool that is used to monitor visit registration for participants in the study and data entry across all visits. This allows users to easily follow the participant's status across multiple visits. This is particularly useful for study coordinators who can use this graphical overview of their participants' progression to help manage their deadlines.



Facilitator: *Zia Mohades is a data manager at CCNA. He holds a master in bioinformatics, and has been working at MCIN (McGill Centre for Integrative Neuroscience) since for almost 11 years as a developer and project manager.*



Facilitator: *Pierre Pac Soo, Bsc. Maths and Computer Science, is a Software developer.*



Facilitator: *Camille Beaudoin is a Software developer with an interest in the intersection of computer science and neuroscience.*

What researchers who want to be entrepreneurs need to know about adoption and commercialization

As a researcher with an innovative idea, product, or program, have you wondered:

- Is my research ready for adoption by target users and settings?
- How do I take my work out of the lab and into the commercial sector?
- What are intellectual property considerations?
- How do I develop a business model?
- How can I access other funding sources/growth opportunities to scale my idea?

This interactive workshop will provide a high-level overview of key things to consider if you are thinking about taking your research into the innovation space. Participants will also have an opportunity to exchange their own experiences with moving research and innovation into consumer and care settings.

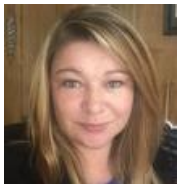


Facilitator: Shusmita Rashid is a Senior Knowledge Mobilization and Implementation Specialist at the Centre for Aging and Brain Health Innovation. She engages researchers, innovators and end users to facilitate the acceleration of innovations and works closely with organizations to strategically address barriers and enhance organizational culture for the adoption of innovations. Shusmita holds an MPH from the University of Manchester and a BSc. from the University of Toronto and has over eight years of experience using Implementation Science and Knowledge Translation to design, implement, and evaluate evidence and theory-based programs and innovations.

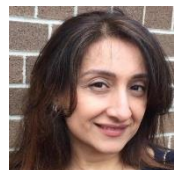
Working with national and international collaborators such as the Public Health Agency of Canada, Canadian Institutes of Health Research, World Health Organization and UNICEF, Shusmita has provided technical assistance on 16 large-scale healthcare research projects and coached over 25 organizations on implementing research and innovation in real world settings. In her previous role as Research Manager of the Team for Implementation, Evaluation, and Sustainability, Knowledge Translation Program at the Li Ka Shing Knowledge Institute, Shusmita co-developed the Practicing Knowledge Translation course. She has delivered 14 in-person workshops and 25 online coaching webinars on applied KT to over 800 participants in 5 countries (Canada, USA, Australia, Ethiopia and Uganda). She is an invited guest lecturer at University of Toronto's Institute of Health Policy, Management and Evaluation. Most recently, she developed the curriculum for CABHI's Spark U Curriculum, a learning collaborative to help early stage innovators advance in their journey from innovation development to commercialization to planning for sustainability.

I tried remote methods for my research but it didn't work – a trouble-shooting session to crowdsource solutions

A follow-up to the webinar "from 0 to 100 in remote dementia research" where we discuss real world challenges posed by the necessity for remote methods due to the pandemic. We won't have all of the answers, but hopefully the crowd will be able to provide some collective wisdom.



Facilitator: *Dr. O'Connell is a Professor in the Graduate Program in Clinical Psychology at the University of Saskatchewan. She practices in the interdisciplinary diagnostic memory clinic, the Rural and Remote Memory Clinic. She co-leads Team 15 in the Canadian Consortium on Neurodegeneration in Aging where she leads the newly developed Rural and Remote Memory Clinic-interventions (RRMCI) for Saskatchewan residents. The RRMCI involves a suite of behavioral and psychological interventions tailored to persons with cognitive impairment or dementia and their caregivers. All interventions are provided by Telehealth or internet videoconferencing to ensure accessibility for rural families. During COVID her team has used their skills in remote delivery of interventions to help numerous older adults access the internet to maintain social connections, they support a local aging group in moving all of their group programming online, and they are offering their support to any families wishing to access the Alzheimer Society of SK on-line supports. Finally, Team 15 is working to create the interdisciplinary RRMC in a virtual format, the vRRMC. She is also a psychometrician, with a particular interest in measurement equivalence, which includes data for equivalency of in-person and remotely delivered cognitive assessments. Dr. O'Connell gave a webinar on how to move your dementia research to a remote format, and the current workshop is a follow-up to this webinar.*



Facilitator: *Shirin Vellani is a Nurse Practitioner, who has experience working in a variety of specialized geriatric services programs. She is a PhD candidate in a collaborative PhD program in Nursing Science and Aging, Palliative, and Supportive Care at the University of Toronto. Her research focuses on engaging older adults and their care partners with early*

stage dementia in advance care planning utilising virtual platform. She is also working as a RA for her PhD supervisor, Dr. Kathy McGilton at the Toronto Rehabilitation Institute and as a TA at the University of Toronto.



Facilitator: Katherine McGilton, PhD, RN, FAAN is Senior Scientist and Research Division Head with KITE, Toronto Rehabilitation Institute-University Health Network. Dr. McGilton is a Professor at the University of Toronto's Lawrence S Bloomberg Faculty of Nursing and is currently the co-lead of the Quality of Life Theme for the Canadian Consortium on Neurodegeneration in Aging (CCNA). She has spearheaded the International Consortium of Professional Nurses in Long-Term Care Facilities (LTCF) founded in 2011 – focused on building capacity to contribute to interdisciplinary research, practice, education and policy in LTCF. Dr McGilton's research interests in LTCH have focused on staffing, job satisfaction of personal support workers and regulated nurses, leadership, and implementation of evidence informed practices. Dr McGilton's research also focuses on care of persons with cognitive impairment, particularly in identifying interventions and models of care delivery that improve outcomes.

The CCNA Advisory group of People with Lived Experience of Dementia: Discussing opportunities for engagement in CCNA research

The Engagement of People with Lived Experience of Dementia is the CCNA's newest program, developed in Phase II. It has just brought together an Advisory Group of people with lived experience of dementia (i.e., people living with dementia and friends, family and caregivers/care partners). The Advisory Group members come from across Canada and, while they all have lived experience of dementia, their backgrounds and experiences are varied. The Advisory Group will be a valuable resource for the CCNA; CCNA researchers are enthusiastic about opportunities for engagement and the Advisory Group members are keen to be engaged in CCNA research.

In the first part of this workshop, a researcher and a member of Patient Council from the Can-SOLVE CKD Network will co-present, describing and sharing insights from some of the engagement work within their kidney research network comprised of 120 researchers across Canada and 18 research projects spanning basic science, clinical and population health research. In the second part of the workshop, you will be split into smaller groups (composed of CCNA researchers, trainees and Advisory Group members) to discuss opportunities for engaging the Advisory Group in CCNA research.



Facilitator: Dr. Bethell is an Affiliate Scientist at KITE, Toronto Rehabilitation Institute, University Health Network. As an epidemiologist and health services researcher, she is interested in using large health administrative and survey datasets for research and reporting on health outcomes. To date, her work in this area has been focused on topics related to mental health, injuries and prescription medication use and how these issues influence health across the life course. She is also developing work in the area of social connectedness and health, and in particular, how these social factors influence brain health and cognitive outcomes. She is also interested in patient engagement in research, particularly research related to dementia.



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Guest: *Marisa Battistella is a pharmacy clinician scientist and member of the Can-SOLVE CKD Network. Her research program focuses on translational studies that address unmet clinical needs across the entire spectrum of pharmacotherapy care in chronic kidney disease patients, from pre-prescribing (using genomics to guide the selection of drugs) to deprescribing (tapering, stopping, discontinuing or withdrawing drugs), with the goal of managing polypharmacy (use of multiple medications) and improving patient outcomes.*



Guest: *Arlene Desjarlais joined the Can-SOLVE CKD Network as a patient partner after the loss of her husband, Glen, to chronic kidney disease. In her role as patient partner, Arlene has participated in many research groups such as the Indigenous Peoples’ Engagement and Research Council (IPERC), the KidneyPro Working Group, and the Knowledge Translation Community of Practice. Arlene has found purpose and passion in her role as a patient partner in research and, through her work, hopes to contribute to advancing knowledge and an eventual cure for CKD.*