Strategic plan for CCNA

It is important to understand the seriousness of dementia—as a chronic disease related to aging, as a burden on Canadian citizens, as a financial burden on the healthcare system, and as a monumental challenge for every individual and family afflicted with the diseases that cause dementia. The proportion of the Canadian population over 65 will climb from 16% in 2016 to 23% in 2041. As this demographic evolution occurs, the concerns and problems of older persons have taken centre stage in Canada. In 2016, there were 564,000 Canadians living with dementia, and this will rise to 937,000 in the next twelve years. The annual cost to the country is now above $10.4 billion, and this will double by 2031. The World Health Organization (WHO) report on dementia, the WHO Global action plan, and the InterAcademy Partnership for Health (IAP for Health) Statement stress that each country should determine a priority research agenda, with evidence underpinning all actions. Multidisciplinary research that strikes a balance between care and cure needs to be conducted. The WHO report emphasizes that significantly more research is required to better understand the causes of dementia, and how and when lifestyle factors can influence the risk of developing it.

What is CCNA?

More than 350 clinicians and researchers throughout Canada came together to form the Canadian Consortium on Neurodegeneration in Aging (CCNA), a CIHR-funded network with collaborating partners, in 2014 with the goal of accelerating progress in research on age-related neurodegenerative diseases (NDDs).

Vision

CCNA's leading vision is to significantly reduce the burden of age-related neurodegenerative diseases (NDDs) of Canadians by accelerating the discovery, innovation, and the adoption of new knowledge. We aim to position Canada as a global leader in increasing our understanding of NDDs, working towards prevention, and improving the quality of life of those living with dementia.

Goals

CCNA's overarching goals:

- **Research**: Based on national priorities in dementia health care.

    o Shape and conduct high quality research to understand and prevent dementia as early as possible, and to improve the quality of life and care of those living with dementia while understanding the various related ethical, legal, and social issues.

- o Effectively translate significant findings in order to reach out to the public, stakeholders, and people with lived experience, and disseminate knowledge to these various audiences.

- **Synergy**:
  - o Catalyze research on dementia by being a vehicle for innovative cross-team and cross-platform interdisciplinary research; fostering synergy amongst researchers, including trainees, and dementia stakeholders who otherwise might remain in their silos.
  - o Consolidate the network and expand on synergies built since the beginning of Phase I.
  - o Synergize dementia research expertise in ways that cannot be achieved through traditional funding means.

- **Talent**:
  - o Capitalize on our wide network of Canadian research expertise to support young researchers and clinician-scientists (trainees or junior researchers) to provide opportunities for integration in interdisciplinary research and decisional roles, and to develop a network of their own to support the growth of their career.

- **Inclusion**:
  - o Change the Canadian dementia research landscape by increasing the consideration of sex and gender along with stigma and social inclusion in research, by engaging people with lived experience in the research process and decisions, and by developing a better understanding of questions related to the cognitive health and healthcare of Indigenous populations.
  - o Grow in our understanding of equity, diversity and inclusion considerations in research and in training and capacity building.

Long-term aspirations

Our long-range aspirations are built on the foundation of CCNA deliverables.

- Conceive and develop personalized therapy based on the emerging characterization of subgroups.

- New, effective and multimodal interventions/therapeutic approaches that alter the course of NDDs and that improve the health and well-being of persons with lived experience.

- Evidence-based and effective risk-reduction strategies capable of being implemented and taken up by the Canadian public.

- Paradigm shift leading towards evidence-based clinical best practices, with universal and equitable policies for dementia healthcare for all Canadians.

- Obtain adequate and sustained funding that supports Canadian dementia research through CCNA.

- Contribute scientific leadership for a fully-funded National Dementia Strategy research component that is multifaceted and informed by research output from CCNA that prevents and treats NDDs and supports persons and families with NDDs.

Deliverables

CCNA's organizational deliverables:

- A unique and diverse dataset of more than a thousand deeply-phenotyped participants with various forms and severity of neurodegenerative disease that will dramatically boost the advancement of our understanding of dementias with implications for Canadian and worldwide populations.

- Fostering teams with the multi-disciplinary expertise necessary to analyze this "big data" cohort, using innovative approaches including AI and machine learning.

- Significant and high-quality scientific advances (publications, presentations, etc.) across CCNA's wide scope of research.

- New and innovative prevention and life improvement tools/strategies.

- Knowledge translation products for CCNA's significant scientific advances.

- Recruitment, training and integration of a network of highly qualified personnel.

- New collaborations within and outside the network.

- Leveraged funding and partnership development to support high quality research in order to ensure long-term viability of CCNA and its ability to respond to Canada's dementia health care needs.

- Creating and sustaining a vehicle for interdisciplinary collaboration and cross-fertilization amongst dementia researchers from widespread disciplines.

CCNA's Phase II strategic research priorities

1. Understand the real-life heterogeneity of Alzheimer disease subgroups

Background

There is well-documented heterogeneity in Alzheimer disease (AD) at the clinical, imaging, genetic, and pathological levels of analysis. We believe that this heterogeneity reflects the presence of underappreciated mechanistic subgroups which, in turn, explain the past failure of so many medications tested as disease modifying therapies for AD. CCNA will advance our understanding of heterogeneity, which will facilitate the future of personalized treatment.

Priorities

- Directly study NDD individuals with multi-morbidity and mixed dementias in order to understand common mechanisms and shared pathologies.

- Understand the neuropathological and multi-factorial mechanisms that contribute to NDDs heterogeneity and expression.

- Understand the contributions of sex and gender in the expression of these diseases.

2. Allow earlier diagnosis

Background

We stand on the threshold of effective early diagnosis of NDDs, but have yet to determine the who, when, and how of implementing biochemical, clinical, and imaging diagnosis in a way that is acceptable and leads to improved treatment and better quality of life.

Priorities

- Develop an understanding of biomarker and clinical combinations to identify subgroups of neurodegenerative diseases before symptoms are florid by leveraging information from large data sets and through state-of-the-art computational modelling methods.

- Understand the ethical legal and social implications of early diagnosis, and how best to transmit the new evidence from biomarkers to patients and their physicians.

3. Develop new treatment and interventions

Background

Treatment instituted for individuals in the early stages of NDD could be far more effective. Such treatments could be molecular/pharmaceutical, and address underlying disease states as well as difficult emerging behaviours. Treatment can also be based on cognitive training, interventions to address psychosocial and lifestyle factors, and education, in an effort to mitigate factors that contribute to cognitive and functional decline in NDD.

Priorities

- Develop personalized therapy according to subgroups.

- Support scientific discovery-based research programs.

- Accelerate the application of research into clinical settings.

- Provide a critical link between pre-clinical science research programs in neurodegenerative diseases and clinical populations.

- Investigate treatments beyond a narrow biomarker target approach to address age-related mechanisms and their impact.

- Improve medical, psychosocial, and health care interventions for persons at risk of cognitive and functional decline (e.g., subjective or mild cognitive impairment, anxiety/depression, multi-morbidity, and frailty).

4. Develop prevention strategies

Background

The most effective, and cost-effective, approach to reducing the burden of dementia and NDDs undoubtedly lies in the realm of prevention, and over two dozen prevention strategies have early phase or population-study based evidence for efficacy. It is imperative to move towards concrete evidence-based approaches for prevention that can be effective in the population at risk.

Priorities

- Develop and disseminate evidence-based psychoeducational programs to reduce dementia risk and increase positive health behaviours.

- Develop evidence-based combination prevention strategies that will reduce dementia risk and/or slow disease progression.

5. Innovate with novel life improvement tools/strategies

Background

There are a multitude of advances and interventions that could be implemented to improve the quality of life of persons living with dementia. Research is needed to develop and validate these approaches, which do not require the discovery of new molecules or breakthroughs in treatment in order to be effective.

Priorities

- Hearing, vision, and communication support.

- Interventions that address the functional needs of individuals with NDD and their families (e.g., driving cessation protocols).

- Reduced multi-morbidity and management of frailty.

- Develop strategies for reducing age- and dementia-related stigma and social inclusion.

- Culturally appropriate and collaboratively developed healthcare strategies for Indigenous populations.

6. Optimize health care delivery

Background

Canada's single payer healthcare system offers a unique opportunity to evaluate and compare different provincial dementia programs, and develop best practices for the healthcare system. This is particularly important in the setting of delivery to rural and Indigenous populations, and research at the health care delivery level is vitally important.

Priorities

- Identification of service delivery challenges.
- Optimization of health care delivery across different provincial systems.
- Optimization of health care delivery for rural and Indigenous communities.
- Optimization of integrated health care delivery for older adults with NDD and associated co-morbidities (e.g., frailty, sensory loss, mental health concerns).

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