# Summary of Activities Undertaken under Initiative #9B – Research Coalition

## Initiative #9B: Research Coalition
## Ontario's Strategy for Alzheimer Disease and Related Dementias

**2005**

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## OVERVIEW OF REPORT

The following report provides an overview of the activities undertaken under Initiative #9B – Research Coalition of Ontario's Strategy for Alzheimer Disease and Related Dementias. The first part of the report summarizes the main activities undertaken as part of the implementation of this initiative and the second part of the report provides a description of the individuals who expressed an interest in being part of the Research Coalition.

### Part I: Implementation of Initiative #9B – Research Coalition

The Research Coalition was formed as part of Initiative #9B of Ontario's Strategy for Alzheimer Disease and Related Dementia. The mandate of the coalition was to plan, co-ordinate and monitor collaborative multidisciplinary research on Alzheimer Disease and related dementias (ADRD), to promote ADRD research, and be an advisory resource to the provincial government around research issues. In November 2001, in an effort to monitor the extent to which collaborative multidisciplinary ADRD related research was being pursued in Ontario, an invitation was extended to a multidisciplinary list of individuals to become members of the research coalition. Soon after, a Nominations Committee was formed to establish a Steering Committee to move this initiative forward. In September 2002, a Research Coalition Steering Committee was formed with members from diverse academic and methodological backgrounds and regional representation. The Ontario Seniors' Secretariat and Ontario Ministry of Health and Long-Term Care were represented on the committee.[1]

The Research Coalition Steering Committee ratified a Strategic Directions document in June 2003.[2] One of the goals of the Research Coalition was to identify and promote Ontario's priority research agenda for ADRD by seeking input from researchers and the lay public. Activities carried out under Initiative #9B, and in particular information about ADRD research obtained in the development of the research coalition, led to the development of a comprehensive process to investigate research priorities and research capacity-building opportunities for ADRD research in Ontario. In October 2003, the Research Coalition issued a Request for Proposals to select a consultant to undertake this project under the management of the Alzheimer Society of Ontario (ASO) and in collaboration with the Ontario Seniors' Secretariat. The Research Coalition Steering Committee was disbanded and from the pool of researchers identified through the Research Coalition an Advisory Group[3] was constituted to support the ASO in launching the ADRD Research Priority Setting initiative. The major objective of this process was to generate a "Report on Capacity" (for ADRD research) and a "Call to Action Report" that will advise the provincial government about a strategic direction for ADRD research in Ontario including recommendations for advancing research priorities and enhancing and sustaining research capacity in Ontario. The process of identifying research priorities included input form researchers, clinicians, persons with early dementia and their caregivers, and research funding bodies.[4]

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[1] The Ontario Research Coalition Steering Committee Membership: Mary C. Tierney, Ph.D., (Chair), Luis Fornazzari, M.D., (Vice Chair), Michel Bedard, Ph.D., Michael Borrie, M.D., Larry Chambers, Ph.D., Heather Keller, Ph.D., Carol McWilliam, Ph.D., J.B. Orange, Ph.D., Ex-Officio: Angie Szuch (Ontario Seniors' Secretariat), Elizabeth Esteves (Ontario Seniors' Secretariat), and Susan King (Ministry of Health and Long-Term Care).

[2] This document, *"The Path Forward: A Strategic Direction for the Ontario Research Coalition on Alzheimer Disease and Related Dementias – 2002-2004"* was released on June 16, 2003 and is available on the Alzheimer Society of Ontario website: www.alzheimerontario.org.

[3] Advisory Group Membership: Michael Borrie, M.D., Larry Chambers, Ph.D., Lorna de Witt, Sherry Dupuis, Ph.D., Nathan Herrmann, M.D., Robert Hopkins, Ph.D., Raymond Pong, Ph.D., Parminder Raina, Ph.D., Peter St. George-Hyslop (alternate: Howard Mount, Ph.D., and Ekaterina Rogaeva, Ph.D.,), Irene Turpie, M.D., Ex-officio: Elizabeth Esteves (Ontario Seniors' Secretariat), Angie Szuch (Ontario Seniors' Secretariat) and Michael Klejman (Ministry of Health and Long-Term Care).

[4] This process was undertaken by æstima research and completed in July 2005.

## Part II: Description of Research Coalition Members

One hundred and four (104) individuals expressed an interest in being members of the Research Coalition of Ontario's Alzheimer Strategy. The following is a description of the members in terms of their professional affiliation, regional distribution, position/discipline, current research interests, and identified research priorities for ADRD research.

### *Affiliation*

The majority of the Research Coalition members are affiliated with academic or health care (hospitals, rehabilitation) centers (See Table 1). Those affiliated with academic centers represent a variety of faculties (departments), including psychology, medicine (anatomy and cell biology, neurology, geriatric medicine, psychiatry), communication sciences & disorders, epidemiology and biostatistics, nutrition, and nursing.

**Table 1: Affiliations of the Research Coalition Members**

| Affiliation | Percent (Number) |
|---|---|
| University | 50.0% (52) |
| Health Care Centre | 48.1% (50) |
| Mental Health Care Centre | 13.5% (14) |
| Long-Term Care | 2.9% (3) |
| Regional Geriatric Program/Regional Psychiatry Program | 1.9% (2) |
| Community Agency (e.g., COTA, Caregiver Network Inc, CCAC) | 4.8% (5) |
| Alzheimer Society of Ontario (Regional Chapters) | 7.7% (8) |
| Government (Ministry of Health and Long-Term Care, Ontario Senior Secretariat) | 1.9% (2) |

* Percentages do not add to 100% because some members provided more than one affiliation

### *Location*

The majority of Research Coalition members are located in Toronto, with fewer members distributed in other regions across the province (see Table 2).

**Table 2: Distribution of Research Coalition Members across the Province (N = 104)**

| Region | Percent (Number) |
|---|---|
| Central East | 8.7% (9) |
| Central South | 12.5% (13) |
| Central West | 6.7% (7) |
| East | 8.7% (9) |
| North | 3.8% (4) |
| Southwest | 11.5% (12) |
| Toronto | 48.1% (50) |

### *Position/Discipline*

Information about Research Coalition members' professional position and discipline were extrapolated from available information on their suffix and title (this information was available for 74 members). For example, if a member had MD listed as their suffix, and Professor as their title, they were categorized as both a physician and a professor. It should be emphasized that this provides a general sense of the membership, but is not precise. While some information was available about members' titles (e.g., "professor") information about discipline may have been missing (for members who were listed as 'Ph.D.').

Coalition members represent clinicians (physicians, nurses, psychogeriatric resource consultants), academics, and administrators (chairs/directors/managers; see Table 3).

**Table 3: Position/discipline of Research Coalition (N = 74)**

| Position/discipline | Percent (Number) |
|---|---|
| Physician | 28.3% (21) |
| Psychologist* | 5.4% (4) |
| Researcher | 8.1% (6) |
| Nurse | 9.5% (7) |
| Psychogeriatric Resource Consultant | 9.5% (7) |
| Professor** | 29.7% (22) |
| Chair/Director/Manager | 33.8% (25) |
| Student/post-doc fellow | 4.1% (3) |
| Policy and Planning | 2.7% (2) |
| Community Services Manager/Coordinator | 5.4% (4) |
| Other*** | 2.8% (2) |

[1] Percentages do not add to 100% because some members were categorized in more than one position/discipline
* including neuropsychologists
** including assistant, associate, and full professors
*** "Other" includes: occupational therapist, professional engineer

### *Research Interests*

The current research interests and research priorities of the coalition members were categorized using the *Model of Four Themes* developed by the Canadian Institutes of Health Research (CIHR). These themes are as follows:

1. ***Biomedical***: research related to understanding ADRD including aetiology, mechanisms (physiological and molecular), development of markers (biochemical or neuroimaging), risk factors (including genetic), cure, prevention, and development of early diagnositic tools.
2. ***Clinical***: research related to assessment and treatment of ADRD, including studies of drug and non-drug interventions.
3. ***Health Services and Health Systems:*** research related to health care delivery including community services, caregiver needs, advocacy issues, and access to care.
4. ***Health of Populations, Societal and Cultural Dimensions of Health and Environment Influences on Health:*** research related to the assessment of population health, determinants, and distribution of ADRD.

Fifty-five members reported their current research interests, 19 of whom were conducting research categorized in more than one of the CIHR themes. Five members reported that they were not currently conducting research. Table 4 summarizes the current research interests of the coalition members. The majority of members are conducting clinical research, with the lowest proportion of members of conducting population health research.

**Table 4: Current Research Interests (N = 55)**

| CIHR Theme | Percent (Number) |
|---|---|
| Biomedical | 23.6% (13) |
| Clinical | 69.1% (38) |
| Health Systems and Services | 32.7% (18) |
| Population Health | 9.1% (5) |

[1] Percentages do not add to 100% because some members had research interests in more than one theme.

The following are some examples of specific research interests within each of the themes.

**Biomedical:**

- *"Posterior cortical atrophy"*
- *"Neuroimaging techniques used in Mild Cognitive Impairment to predict which individuals are more likely to progress to AD."*
- *"Mechanisms of brain cell death in animal models of Alzheimer Disease to test the effects of two potentially inter-related therapeutics (nerve growth factor supplementation and specific cholinergic agonist replacement).*
- *"Use of mouse models to better understand the pathological events which underlie neurodegenerative diseases; the role of copper in the development of Alzheimer disease pathologies."*
- *"Determination of neuroanatomical regions associated with apathy in Alzheimer's Disease patients."*
- *"Role of diet and type 2 diabetes as a risk factor for non-vascular dementia including AD."*

**Clinical:**

- *"End-of-life decision-making; hydration issues in end stage dementia."*
- *"Treatment of behavioral disturbance and/or depression in dementia."*
- *"Clinical drug trials."*
- *"Development of computerized cognitive devices to assist people with dementia complete activities of daily living with less dependence on a caregiver."*
- *"The use of the Confusion Assessment Method, a screening tool for Delirium, as an appropriate tool for the severely cognitively impaired population."*

**Health Systems and Services:**

- *"Caregiver stress experienced by caregivers of patients with dementia."*
- *"Systems issues"*
- *"Dementia Networks in Ontario"*
- *"Care for the elderly across the health continuum with an emphasis on the quality of life of older adults and their family caregivers."*
- *"To determine a standardized method within our community for determining eligibility for LTC."*

**Population Health:**

- *"Analyses of the Canadian Study of Health and Aging."*
- *"Health promotion."*
- *"Population health; epidemiology."*
- *"Health and aging in seniors."*

### *Research Priorities for ADRD Research*

Coalition members' were asked to identify priorities for ADRD research. Their responses were categorized using the *Model of Four Themes* developed by the CIHR. Forty-nine members identified research priorities, 14 of whom identified research priorities categorized in more than one of the CIHR themes. Table 5 summarizes the research priorities for ADRD research identified by coalition members. The majority of members (59%) identified clinical research as a priority, with health systems and services research identified as a priority by the next highest proportion of members (43%). Only one member identified population health research as a priority.

**Table 5: Research Priorities for ADRD Research (N = 49)**

| CIHR Theme | Percent (Number) |
|---|---|
| Biomedical | 24.5% (12) |
| Clinical | 59.2% (29) |
| Health Systems and Services | 42.9% (21) |
| Population Health | 2.0% (1) |

[1] Percentages do not add to 100% because some members identified research priorities in more than one theme.

The following are some examples of research priorities identified by coalition members.

**Biomedical:**

- *"Find a cause and cure for ADRD"*
- *"Genetics of AD; Vaccine; secretase inhibitors; stem cell research"*
- "*Immune system involvement and regulation of cell damage responses should be a high priority."*
- *"Basic science and descriptive studies addressing the pathogenesis and etiology of Alzheimer's disease."*
- *"Early detection of persons at risk for development of AD."*

**Clinical:**

- *"Management of behavioral problems in the severely demented; sexual disinhibition and treatment in t he demented elderly; people who grow old with schizophrenia and develop dementia."*
- *"Mild cognitive impairment; moderate and severe AD; particularly ways of assessment and treatment."*
- *"Pharmacological areas"*
- *"Development, use, and acceptance of technology that assist people with dementia to live better."*
- *Developing tools to screen for driving safety in primary care; developing tools to screen for cognitive impairment."*

**Health Systems and Services:**

- *"Caregiving for families with relatives with dementia; long-term care facility research (staff education, quality of life issues for residents, improving transitions between E.R. and LCTF for resident, family and staff)."*
- *"Needs of informal caregivers and/or significant others to individuals with dementia; ethno-cultural considerations in creating supportive environments for dementia."*
- *"Determining the best designs for dementia care facilities."*
- *"Reasons behind 'Urgent' placements to long-term care facilities from the community and hospitals (and if there is a trend for prevention of such situation)".*
- *"Service provision; case management for individuals with dementia and their caregivers."*

**Population Health:**

- *"Dementia in our native populations."*

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