

The Quebec Alzheimer Plan The Never-Ending Cycle from Practice to Research to Policy and Back

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Disclosure

- ◆ Chair, Quebec Ministry of Health Task Force on Alzheimer's Disease
- ◆ Advisor to Ministry of Health on implementation of the recommendations
- ◆ Consultant/speaker: Pfizer, Novartis, Merck

Context

- ◆ “Perhaps the 21st century's most serious health challenge”; “dementia...a critical public health priority” (WHO 2012)
- ◆ The Rising Tide AD Society of Canada
- ◆ One baby boomer in five will develop Alzheimer's Disease in his or her lifetime
 - Although evidence that incidence may be declining.
- ◆ A complex, chronic disease with a massive impact on the health care system
 - 2001-2006, acute hospitalizations among people with AD rose by 26%, compared to 1% for those in the same age group without AD
- ◆ It has major human, social and societal impacts.
- ◆ It is misunderstood, underestimated, and underfunded
 - CIHR grants for Alzheimer's research amounted to only 15% of grants for cancer research and 29% of grants for research on heart disease.
- ◆ To prepare for:
 - ↑ ↑ ↑ number of new cases each year
 - Disease-modifying drugs

Mandat

- ◆ Décision visionnaire du Ministre/collaboration du MSSS/respect de l'indépendance des travaux du comité
- ◆ Proposer au Ministre de la Santé et Services sociaux un plan d'action national sur la maladie Alzheimer et les maladies apparentées de la prévention à la fin de vie y inclus l'agenda de recherche



**Meeting the Challenge of
Alzheimer's Disease and
Related Disorders**

**A Vision Focused on the
Individual, Humanism, and
Excellence**

**REPORT OF THE COMMITTEE OF EXPERTS FOR
THE DEVELOPMENT OF AN ACTION PLAN ON
ALZHEIMER'S DISEASE AND RELATED
DISORDERS
HOWARD BERGMAN, M.D., CHAIR**

May 2009

Québec 

Practice to Research to Policy

In Preparing the Qc AD plan

- ◆ Evidence-Practice-Emerging Solutions
 - Composition of the committee
 - Researchers, managers, clinicians, patient representatives
 - Engagement more widely with stakeholder groups and with decision makers

Members of the Committee of Experts on Alzheimer's Disease

Committee Members

Howard Bergman, Chair

Marcel Arcand

Céline Bureau

Howard Chertkow

Francine Ducharme

Yves Joanette

Paule Lebel

Martine Lecoeur

Claire Pagé

Nicole Poirier

Jean-François Trudel

Philippe Voyer

Sub-Committees Members

Sylvie Belleville

Barbra Gold

Paul Lysy

Fadi Massoud

Alain Robillard

Lucie Tremblay

Support Group

Pierre Bouchard

Isabelle Lussier

Elizabeth Iacono

Seven priority actions

24 recommendations

1. Raise awareness, inform and mobilize.
2. **Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers.**
3. In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities.
4. Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity and comfort.
5. Treat family/informal caregivers as partners who need support.
6. Develop and support training programs.
7. Mobilize all members of the university, public and private sectors, for an unprecedented research effort.

Provide access to personalized, coordinated services: Objectives

- ◆ Ensure rapid access to assessment and management of the disease following a comprehensive process including:
 - Pharmacological, psychological, social and environmental approaches
- ◆ Innovative ways to negotiate services; faster and easier access to a varied and flexible range of services in the community and specialized services nearby:
 - Develop a lasting relationship of trust between the person with Alzheimer's/family and a professional assigned to the patient as soon as the diagnosis is made

Provide access to personalized coordinated services

- ◆ Implementation of a service structure based on the chronic-care model and the collaborative-practice model, introduced gradually, starting in Family Medicine Groups (GMFs) and CR (Cliniques Réseaux)
- ◆ **The primary care physician and the nurse clinician responsible for continuity of patient care**
 - partnership with each patient and his or her family for the process of assessment, diagnosis, treatment, monitoring, and follow-up
 - The nurse clinician plays the role of Alzheimer's nurse care navigator.
 - approximately 10 to 15 patients with AD per MD = 100-150 per FMG with 10 MDs

Provide access to personalized, coordinated services

- ◆ Fast, easy, flexible access to specific, specialized resources as the disease progresses
 - Memory Clinics
 - Secondary and tertiary care
 - Behavior and Psychological Systems of Dementia teams
 - Psychosocial resources
 - Alzheimer's Support Centres (ASC)
 - Home care programs
 - Optimal hospital stay and transitions

Implementation

- ◆ Ministerial decision with budget after ministerial study of the Qc AD plan recommendations
 - Strategic ministerial team for implementation
 - Included HB, clinician-researcher and author of the Plan as advisor
 - Mobilisation of clinical milieu
- ◆ Priority: Primary care
 - 15 implementation projects to then scale-up
 - Primary care linked to memory clinics and teams for behaviour symptoms

Practice to Research to Policy

In preparing implementation

- ◆ What is out there
 - The good, the bad and the ugly
- ◆ What are the emerging solutions
- ◆ What are the key elements for successful implementation in the GMF's

**PORTRAIT DES INTERVENTIONS MISES EN PLACE AU SEIN DES GROUPES DE MÉDECINE DE FAMILLE
POUR LES PATIENTS AVEC DES TROUBLES COGNITIFS LIÉS AU VIEILLISSEMENT (TCV)
(LA MALADIE D'ALZHEIMER ET LES MALADIES APPARENTÉES)**

Isabelle Vedel, MD, PhD
Michèle Monette, erg, MSc
Liette Lapointe, PhD

Étude réalisée à la demande du ministère de la Santé et des Services sociaux (MSSS)
dans le cadre de l'implantation du plan d'action ministériel

Février 2012

The quick and dirty study

not that quick and not that dirty

◆ 11 GMF's in diverse regions

- Qualitative
- Interviews with clinicians
- Review of documentation

◆ Result

- key elements necessary for the optimal organisation of services for patients and caregivers
- strategic elements for successful implementation
- potential barriers

Implementation

- ◆ Based on the recommendations in the Qc AD Plan, on the «not so quick and not so dirty» study, on consultations with specialists involved in memory clinics and teams for «BPSD», as well as with caregiver organisations
 - Ministry decision on how to roll out 15 implementation (not demonstration or pilot) projects with the objective of scaling up progressively around the province, based on lessons learned
- ◆ Independent peer reviewed evaluation
 - What does the government want to know
 - Does it work or not
 - Or rather
 - Having made the policy decision, what lessons can be learned from the initial implementation projects in order to better understand the essential elements for improvement and scaling-up

Practice to Research to Policy

In evaluating implementation

-
- ◆ A collaborative care model in primary health care for persons with Alzheimer's disease/related disorders and with other chronic diseases
 - Quebec and Ontario interdisciplinary team
 - Mainly Qc-Ont research team
 - Qc-Ont Partners Council chaired by David Levine
 - Canadian Partners Council chaired by Lillian Bayne
 - International Advisory Council
 - UK, France, Switzerland, USA, China, PAHO

 - ◆ Other ongoing studies and KTE programs

Practice to Research to Policy

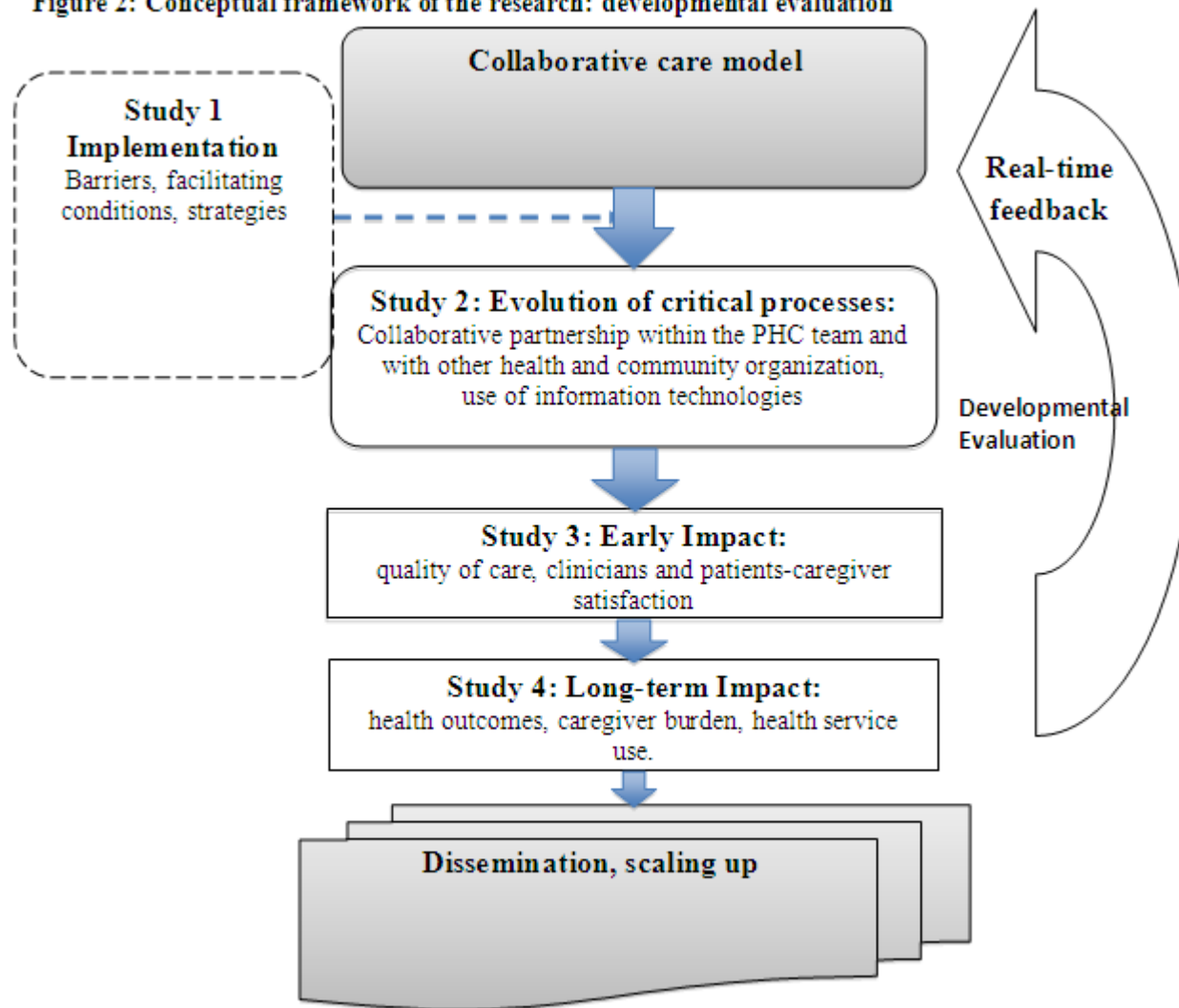
In evaluating and enabling implementation

A collaborative care model in primary health care for persons with Alzheimer's disease/related disorders and with other chronic diseases

- ◆ Produce rapid and pertinent results for stakeholders (patients-caregivers-citizens, decision makers, managers and clinicians), in order to refine the collCM for persons with ADR+ CD, maximizing its effectiveness and its efficacy;
 - Refine essential structures and processes necessary for maximizing impact of the collCM
 - Identify key strategies for implementation and dissemination necessary for uptake and sustainability of the collCM
- ◆ Systematically evaluate the long-term impact of the refined collCM;
- ◆ Facilitate knowledge exchange and effective linkages to facilitate the adaptation, dissemination and sustainability of the collCM in the two provinces and in Canada.

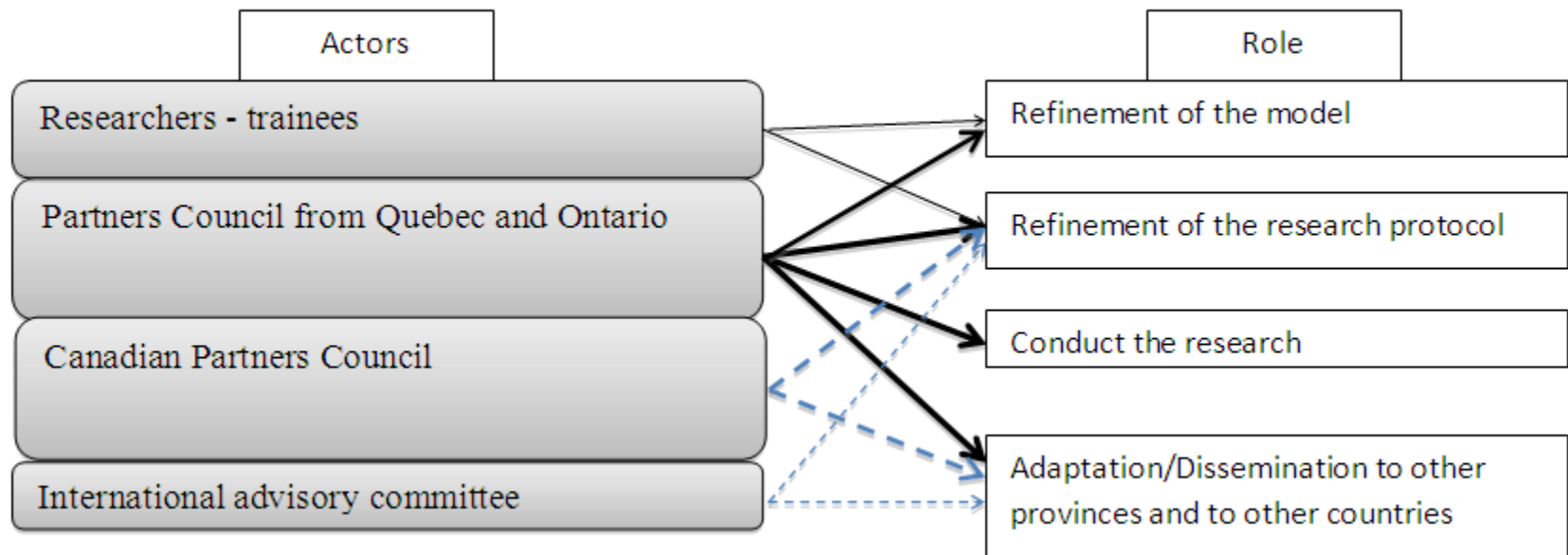
Developmental Evaluation

Figure 2: Conceptual framework of the research: developmental evaluation



Participatory Research Approach

Figure 1: Governance structure



The Never-Ending Cycle from Practice to Research to Policy and Back and finally

- ◆ Basis for an ongoing Canadian and international research and policy network bringing together decision-makers (ministry), managers, clinicians, patients and caregivers and researchers

Critical role of research in change

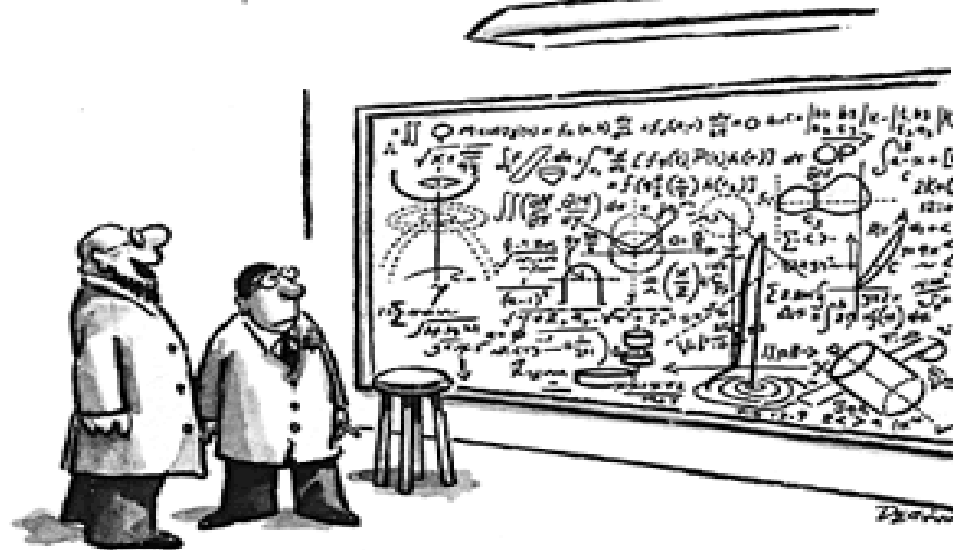
- ◆ Understand the health and functional status, trajectory and costs of the target population
- ◆ Understand the context
 - the emerging solutions
- ◆ Understand why change is necessary
- ◆ Understand attitudes and expectations of clinicians, managers, decision-makers, patients and families
- ◆ Evaluative research
- ◆ Synthesising evidence

Approach and methodologies

- ◆ Be sure to understand the question and therefore the objectives of the research
- ◆ Use quantitative and qualitative methodologies
- ◆ Participatory research
- ◆ Developmental evaluation
- ◆ Look for essential elements applied in diverse settings
 - Rather than the holy grail one-size-fits-all model

The Never-Ending Cycle from Practice to Research to Policy and Back will it ever end.....

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"Hey, no problem!"

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