# INTENTIONAL IMPROVEMENT OF CARE FOR PERSONS LIVING WITH DEMENTIA: INCORPORATING THE LEARNING HEALTH SYSTEM MODEL INTO A MEMORY CLINIC

APRIL 21, 2023

#### ALEXANDRE HENRI-BHARGAVA, MDCM, MscCH, FRCPC

CLINICAL ASSOCIATE PROFESSOR OF MEDICINE (NEUROLOGY), UBC MEDICAL DIRECTOR, NEIL & SUSAN MANNING COGNITIVE HEALTH INITIATIVE NEUROLOGIST, ISLAND HEALTH

SPECIAL THANKS TO LAURA BINDER, LHS FACILITAOR, ISLAND HEALTH







#### **DISCLOSURES**

- I conduct clinical trials through the Consortium of Canadian Centres for Clinical Cognitive Research (C5R) and the Clinical Trials Unit at Island Health
  - These include trials sponsored by industry: Roche, Intelgenx, Anavex, Green Valley, Cerevel, NovoNordisk
- I have consulted for Roche, Biogen, Boehringer-Ingelheim, and Hydrocephalus Canada
- I have received grant support from CABHI, and the Neil and Susan Manning Cognitive Health Initiative
- I will not be discussing any material directly pertinent to these potential conflicts...

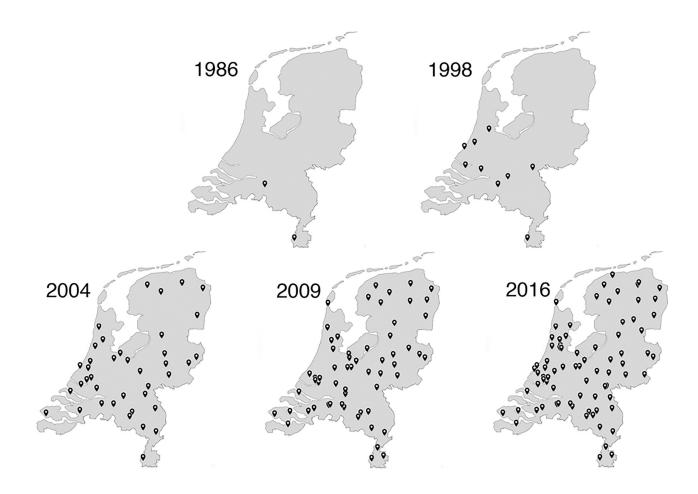
## LEARNING OBJECTIVES

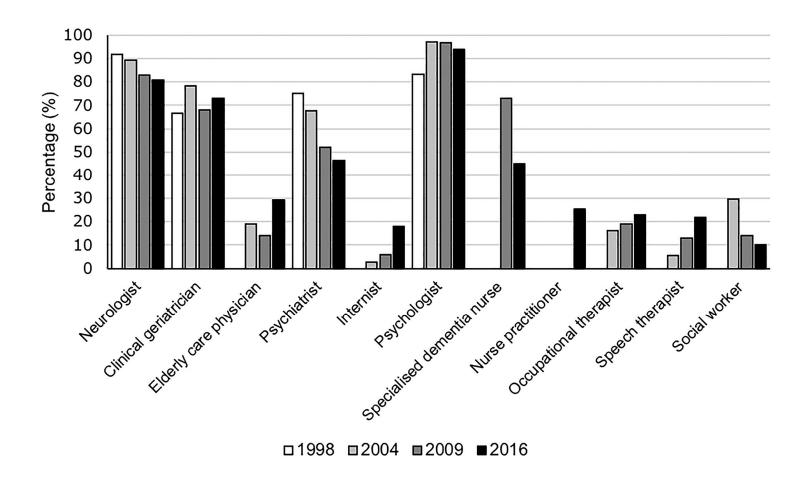
After attending this session, participants will be able to:

- 1. Discuss opportunities for improvement in outpatient care of persons living with dementia provided by the Memory Clinic model.
- 2. Explain the concept of the Learning Health System model.
- 3. Describe the applicability of the Learning Health System model into care provided by a Memory Clinic.

### MEMORY CLINICS

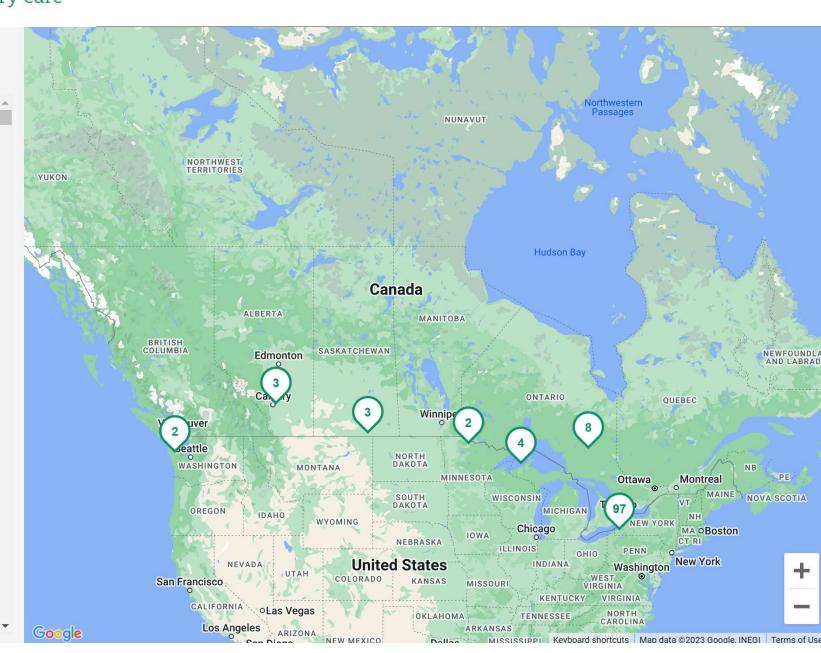
- Established in the 1980's with the following objectives:
  - 1. To forestall deterioration in dementia by early diagnosis and treatment.
  - 2. To identify and treat disorders other than dementia that might be contributing to the patient's problems.
  - 3. To evaluate new therapeutic agents in the treatment of dementia.
  - To reassure people who are worried that they might be losing their memory, when no morbid deficits are found.
    - (Fraser M. In: Arie T, ed. Recent advances in psychogeriatrics, 1992)
- Have proliferated widely since then, particularly in developed countries







#### 119 LOCATIONS FOUND



## CHARACTERISTICS OF IDEAL MEMORY CLINIC

Easy to access (geography, referral process, waitlist)

Comprehensive, timely diagnosis using up-to-date methods

- Interdisciplinary assessment
- Access to up-to-date technology

Referral and therapy across spectrum of cognitive decline

- Cost-effective pharmacological therapies
- Nonpharmacological treatments
- Care partner / family support
- Seamless integration with community resources

Provide follow-up as appropriate (esp. with fewer GPs)

Provide access to research opportunities for patients

#### CHALLENGES TO MEMORY CLINIC MODEL

- Lack of evidence that they actually work!
- More concentrated in academic centres
- More specialist-led clinics
- Lack of trained personnel across all disciplines
- Lack of centralized / co-ordinated model across a jurisdiction (cf. cancer care)
- Type of care provided is quite variable across clinics
- Mission of clinic depends upon the funder...

#### **OUR MEMORY CLINICS**

- Specialist Memory Clinic, Royal Jubilee Hospital, Victoria
  - Embedded within Seniors' Outpatient Clinic
  - Neurologist, geriatricians, geriatric psychiatrists, NP
  - NUA, OT, RN, SW, rapid access to PT, NCA, pharmacist
- Primary Care Memory Clinics, Victoria, Nanaimo
  - Part of MINT Clinic network
  - GPs, NUA, OT, RN, SW
  - Access to specialists...



A donor-initiated collaboration between Island Health, Victoria Hospitals Foundations, UVic, and UBC, to improve diagnostic and treatment opportunities for patients with dementia and related disorders.

#### TIMES COLONIST

Home > Local News

#### Oak Bay couple touched by dementia donate \$2.5M to new program

A research project to improve dementia diagnosis and treatment began with a \$2.5-million offer from an Oak Bay couple looking for answers.

Cindy E. Harnett Oct 5, 2017 10:44 AM











Neil Manning announced a pledge of \$2.5 million Thursday at Royal Jubilee Hospital as part of the Neil and Susan Manning Cognitive Health Initiative. | DARREN STONE









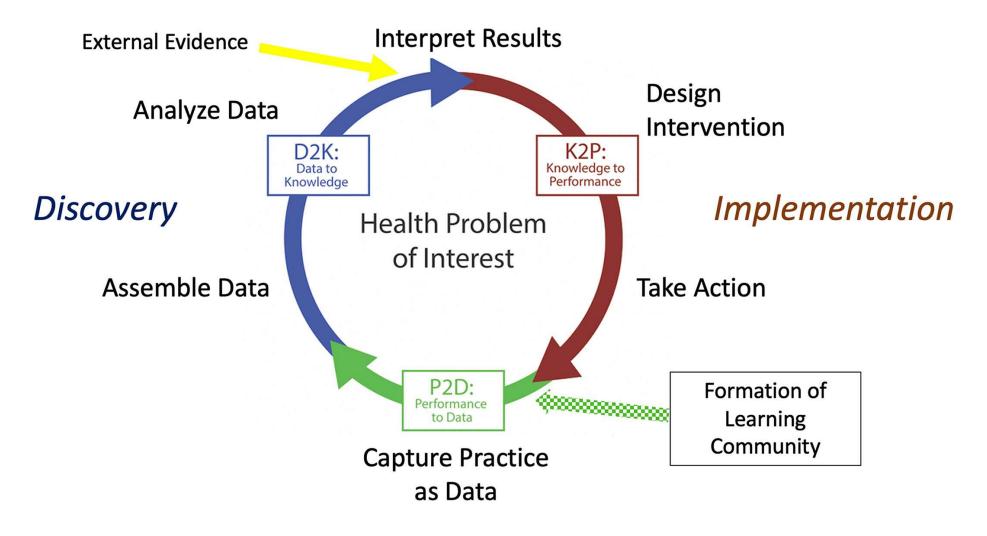
#### LEARNING HEALTH SYSTEM

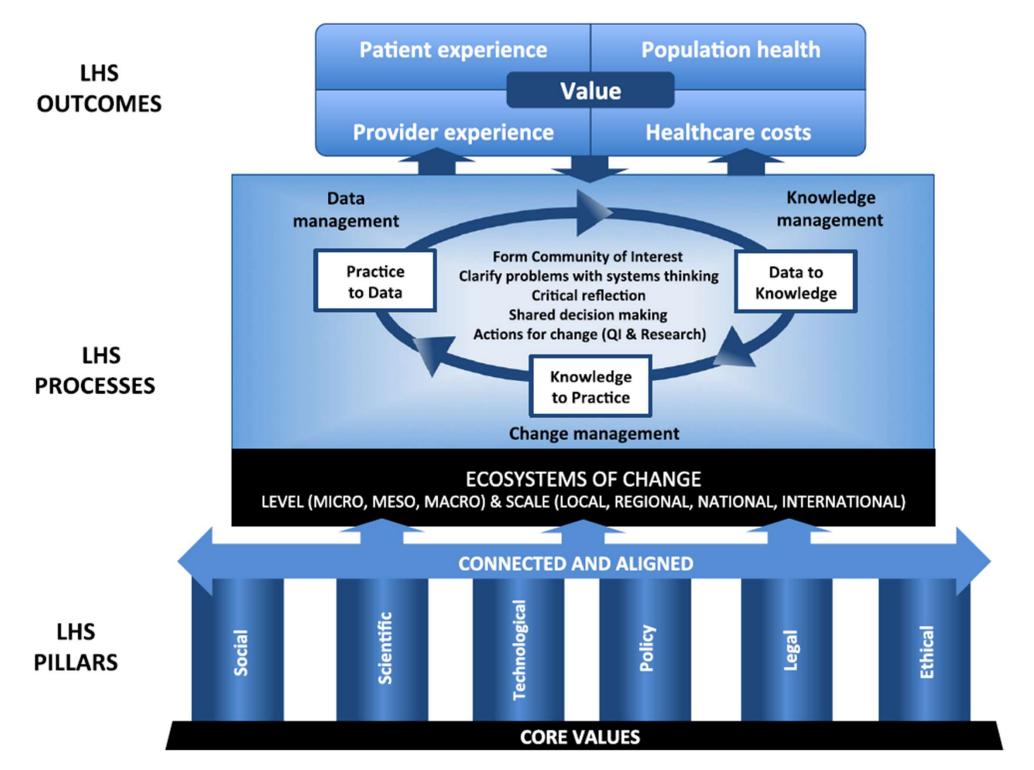


"A system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families as active participants in all elements, and new knowledge is captured as an integral byproduct of the care experience."

Committee on the Learning Health Care System in Americalnstitute of Medicine, 2013

#### LEARNING HEALTH SYSTEM



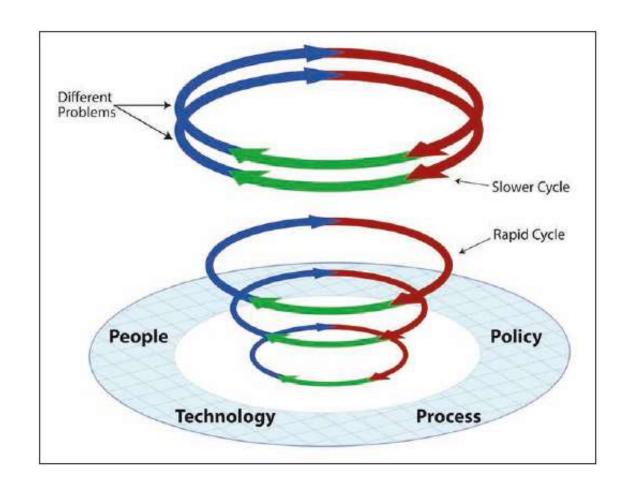


Menear M. et al., Health Research Policy and Systems, 2019

## LEARNING HEALTH SYSTEM

Common infrastructure can support multiple LHS cycles

(Friedman, 2017)



## ADVANTAGES OF THE LHS APPROACH



Improve the patient experience and outcomes



Improve system value and decrease costs



Promote evidence, research and innovation to inform practice and decision making



Reduce practice variations

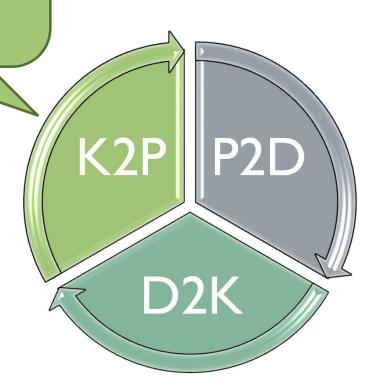


Increase workforce satisfaction

## EXAMPLE: IMPLEMENTATION OF A PSYCHOEDUCATIONAL PROGRAM FOR MCI

- Mild Cognitive Impairment / Mild Neurocognitive Disorder
  - A syndrome that defines a person with objectively-validated subjective cognitive complains that do not impair their day-to-day function (vs. dementia)
  - May be a prodromal state of dementia
  - Patients often have retained insight and actively seek help
- Pre-LHS state: locally-developed psychoeducational course scheduled for updating
  - Problem: no data on outcomes for this course
  - Problem: COVID pandemic can this course be administered online?

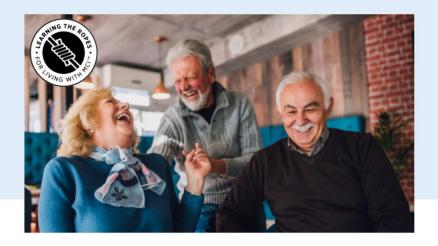
I. Lit. review: "Learning the Ropes for MCI" course



## Learning the Ropes for Living with MCI®

Less than a minute read

Learning the Ropes for Living with MCI® is a program that supports people living with mild cognitive impairment (MCI) and their partners in care.

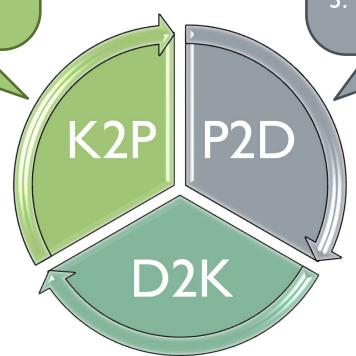


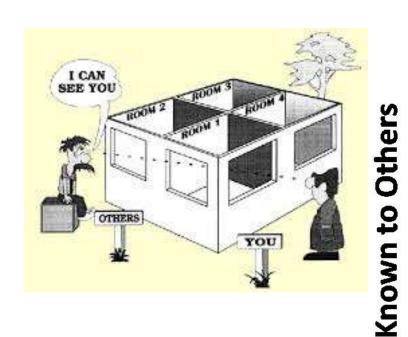
I. Lit. review: "Learning the Ropes for MCI" course

2. Consultation with patient partners, OTs, LHS community – adapt to local context

LTR Local Implementation

- I. Selection of outcome measures, including PDOs
- 2. Pre- and post data coll.
- 3. Ql, not research





**Known to self** 

Not known to self

Open area or Arena

**Blind spot** 

Not known to Others

Hidden area or façade

Unknown

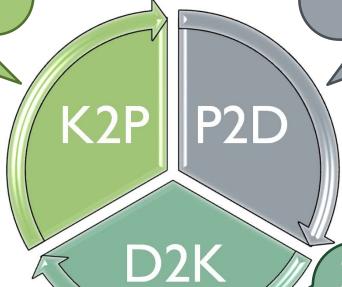
The Johari Window Model

I. Lit. review: "Learning the Ropes for MCI" course

2. Consultation with patient partners, OTs, LHS community – adapt to local context

LTR Local Implementation

- I. Selection of outcome measures, including PDOs
- 2. Pre- and post data coll.
- 3. Ql, not research



Open:

Satisfaction, QoL on par w other LTR courses Blind:

Huge need for caregiver support

Hidden:
Could not
compare w prev

Blind:
Online not as good as thought

 Lit. review: "Learning the Ropes for MCI" course

2. Consultation with patient partners, OTs, LHS community – adapt to local context

LTR Local Implementation

- I. Selection of outcome measures, including PDOs
- 2. Pre- and post data coll.
- 3. Ql, not research

K2P P2D

D2K

I. Continue to offer LTR

- Funding & logistics?
- 2. Favour in-person over virtual groups
- 3. Tailor content based on feedback

Open:

Satisfaction, QoL on par w other LTR courses

Blind:

Huge need for caregiver support

Hidden:
Could not

compare w prev

Blind:

Online not as good as thought

I. Lit. review: "Learning the Ropes for MCI" course

2. Consultation with patient partners, OTs, LHS community - adapt to

cal context

K2P P2D

D2K

MCI Caregiver support group

LTR Local Implementation

- I. Selection of outcome measures, including PDOs
- 2. Pre- and post data coll.
- 3. QI, not research

D2K

Continue to offer LTR

- Funding & logistics?
- Favour in-person over virtual groups
- 3. Tailor content based on feedback

Open:

LTR courses

Hidden:

Could not

Blind:

Blind:

Online not as good as thought

Huge need for

caregiver support

Satisfaction, OoL

on par w other

compare w prev

### **ANOTHER EXAMPLE**

- Modernizing cognitive assessment
- Dual-task gait analysis proposed as easy, useful measure



I. Literature identifies dualtask cost as marker of cognitive deterioration

2. Paradigm for local implementation developed

DTG Local Implementation

I. "Easy" but time consuming

2. Clinicians feel no new knowledge added

K2P P2D
D2K

I. Maybe DTG not ready for clinical implementation

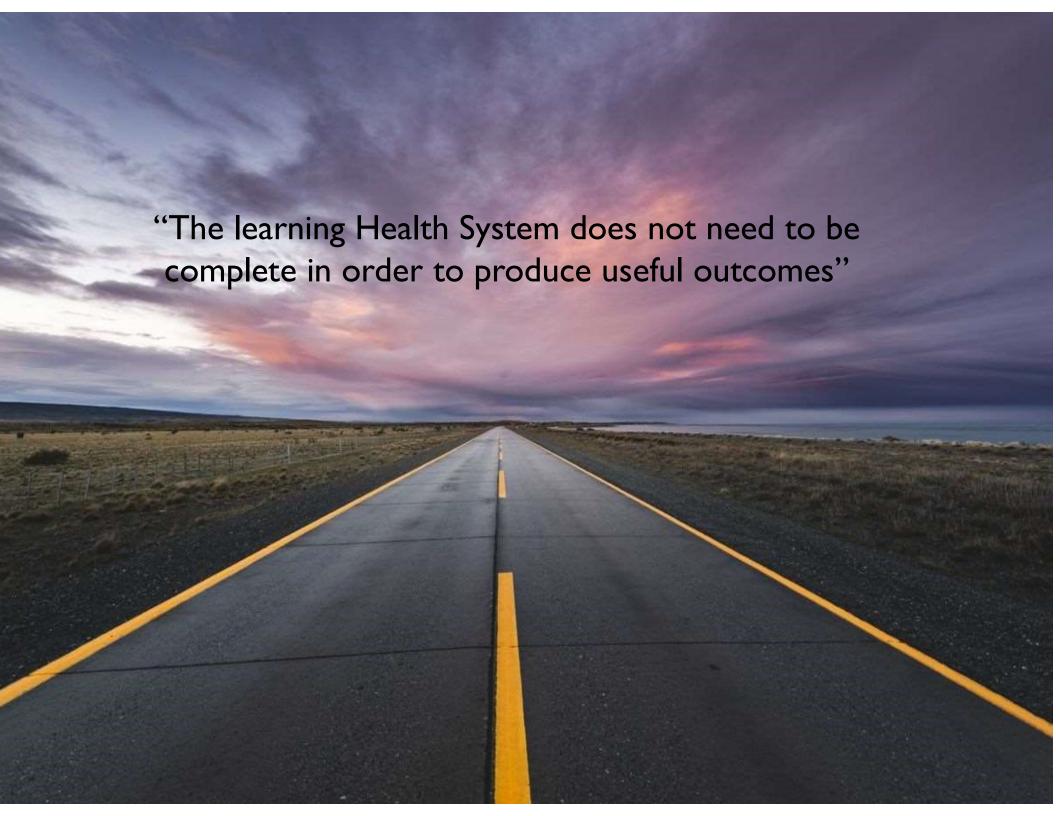
2. Liaise with university school of exercise science-> plan more in-depth research study

#### **FACILITATORS**

- Philanthropy to ignite the flame + ongoing support
- Buy-in from Health Authority
  - Funding clinical positions with time protected for LHS activities
- Novel position: Learning Health System Facilitator
  - Blends education, professional practice, administration, and research
  - Flexibility is the key
- Communication with stakeholders and making them part of the CoL

#### **CHALLENGES**

- Carve out time and funding for LHS activities beyond direct clinical care
  - Requires huge mind-shift for health funders
- Prioritize potential problems to be approached through LHS model
- Data systems... big and small
  - And integration into other existing data structures
- Integrate into "usual" clinical operations and structures
- Keep patient needs at the centre at all times recruit patient partners



## THANK YOU FOR YOUR ATTENTION!

