# SALTY – Improving End of Life Care in Long Term Care

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Scientific Lead and Co Lead Stream 4

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SENIORS- ADDING LIFE TO YEARS (SALTY)

#### **Funding Partners**

Canadian Institute of Health Research (CIHR), Michael Smith Foundation for Health Research (MSFHR), Nova Scotia Health Research Foundation (NSHRF), Alzheimer Society of Canada (ASC)

Gratefully Acknowledged

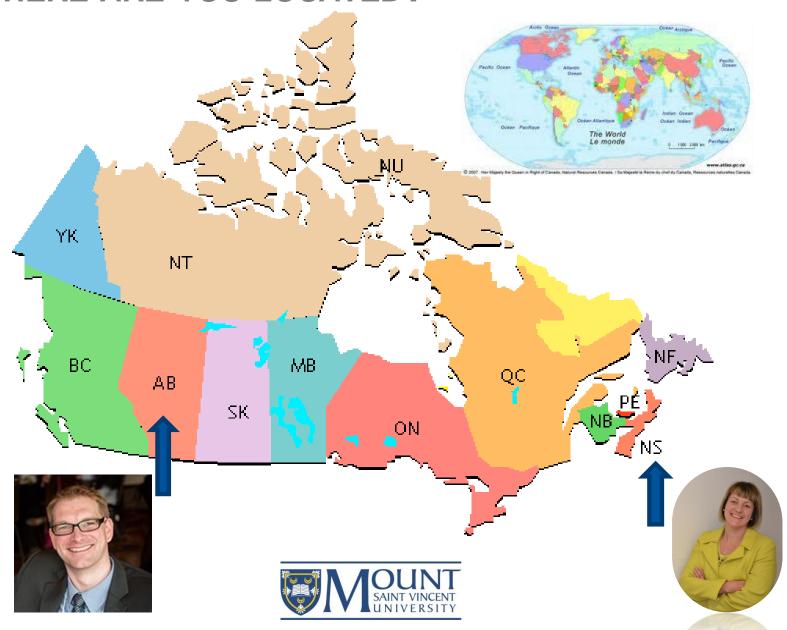


#### **OUTLINE**

- 1. Getting to Know each other
- 2. Why is End of Life in LTC important?
- 3. What we know already?
- Introducing SALTY Seniors Adding Life to Years
- 5. Lessons learned already
- 6. Advice and Feedback

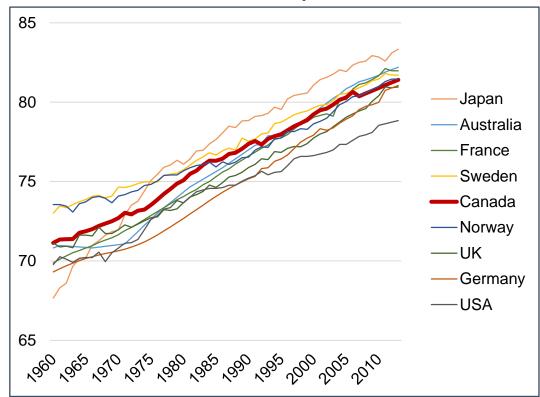


#### WHERE ARE YOU LOCATED?



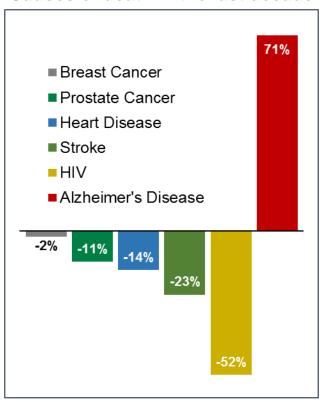
## **Demographics**

## Life expectancy in years by year of birth and selected developed countries



The World Bank (2015) (http://data.worldbank.org/indicator/SP.DYN.LE00.IN?cid=GPD\_10)

#### Causes of death in the last decade



2015 Alzheimer's Disease Facts and Figures

#### **Today** 1,519 LTC facilities

149,488 residents 90% 65+ years old



#### By 2038

Demand for LTC care expected to almost double

Canadian Institutes of Health Information (2014)

Alzheimer Society of Canada (2010)

#### Long Term Care as Late Life Care

EoL care is

challenging

for NHs

(Ersek et al. 2013;

Mitchell et al. et al. 2009)

#### LTC is late life care

- 80% of LTC residents will die in the facility
- · On average, residents die 18 months after admission

(Mitchell 2005; Temkin-Greener, 2013; Menec 2009)

Up to 90% of residents with advanced Dementia will receive care in a LTC facility

(Givens 2009)

LTC is dementia care

well recognized as a terminal disease (van der Steen et al. 2014)

Dementia is not

Difficult to determine when final stage begins

(Mitchell et al. et al. 2009)

**Multiple clinical** complications associated with **Dementia** 

(Mitchell et al. et al. 2009)

Residents receive interventions which are inconsistent with an optimal end of life care approach

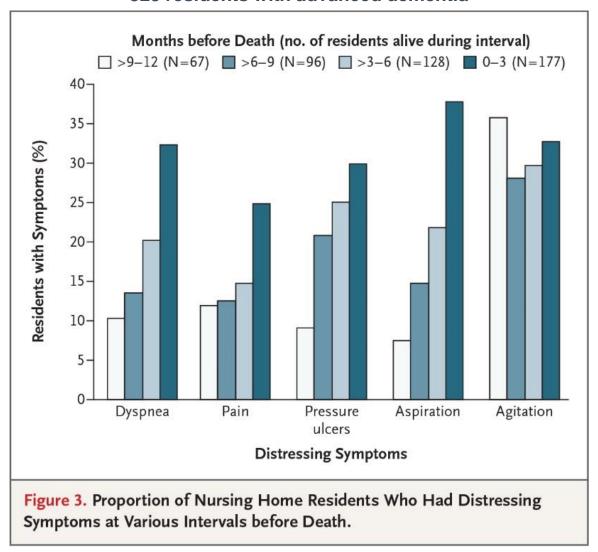


Unnecessary suffering

(Ersek et al. 2013; Mitchell et al. et al. 2009)

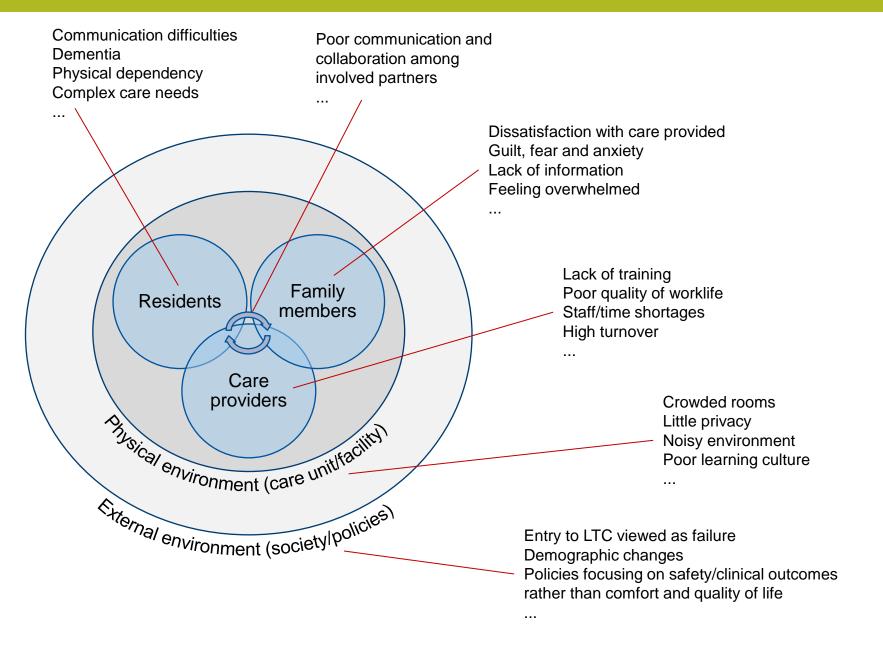
#### **End of Life with Dementia**

#### Burdensome symptoms at the EoL of 323 residents with advanced dementia



Mitchell et al., The Clinical Course of Advanced Dementia. NEJM. 2009: 361(16).

#### **Previous Research**



Care and Construction Project - NS



Re-imagining
Long-term
Residential Care:
An International
Study of Promising
Practices









#### PROJECT FACTS



9 academic researchers from 11 universities



- 10 diverse disciplines
  - nursing, health services, medicine, social work, management, geography, sociology, gerontology, political economy
- 3 Research Chairs
  - 1 Canada Research Chair Tier I; and 2 CIHR Research Chairs Gender and Work
- 9 trainees and more to come
- 22 knowledge users
  - clinicians, decision makers,
  - > representatives of family, persons with dementia, staff, volunteers
- Work focused in four provinces ON, BC, AB, NS
  - > Facility level, regional level, provincial level
- Research design includes both cross sectional and longitudinal and multiple methods
- 4 funding partners
  - ➤ CIHR, MSFHR, NSHRF and Alzheimer Society of Canada

#### WHAT IS OUR AIM?

## To add quality of life to late life for people living in residential long term care.



Late Life

Living in Long Term Care End of Life Post Death

#### **IMPORTANT CONSIDERATIONS**

Gender









under ted

## FOUR INTER-RELATED STREAMS OF WORK TO ACHIEVE OUR COLLECTIVE AIM

Stream 1 - Monitor Care Practices

Stream 2 - Map Care Relationships

Stream 3 – Evaluate Innovative Practice

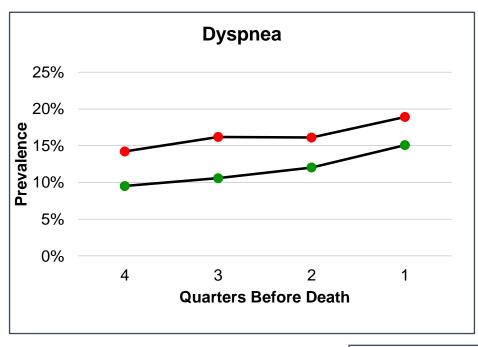
Stream 4 – Examine Policy Context

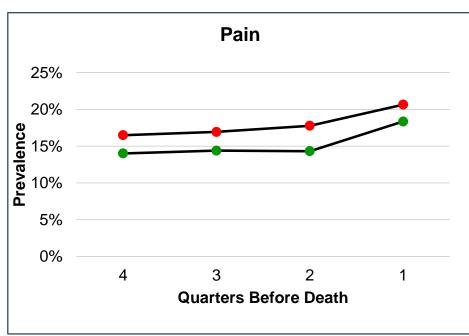
Inter dependent activities and outputs

To add quality of life to late life for people living in residential long term care.

### Symptoms of End of Life at Home

Dyspnea & pain symptoms, last 12 months of life among residents with dementia (RAI-MDS 2.0 data from 3,647 residents in 36 TREC 1.0 facilities in AB, SK, MB, 2008-2012)



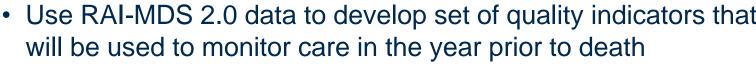


Green = more favorable context
Red = less favorable context
(P<sub>Ctxt</sub><.0001; P<sub>time</sub><.0001)

Estabrooks et al., Dying in a nursing home: Treatable symptom burden and its link to modifiable features of work context. JAMDA 2009: 16(6), 515-520.

#### **OUR APPROACH**

#### Stream 1 – Monitor Care Practices (Leads: Estabrooks, Hobin)



- Rank symptoms and practices based on multiple sources
- Analyze sub-sample of deceased residents
- Validate with CIHI data
- Panel discussions with stakeholders

#### Stream 2 – Map Care Relations (Leads: Daly, Bourgeault,





longitudinal research to map the social and relational dimensions of quality of life and quality of care

- Scoping review and key informants to identify best practice for relational care
- Case studies in four provinces
- Transfer of approaches across jurisdictions

#### **OUR APPROACH**

## Stream 3 – Evaluate Innovative Practice (Leads: Stajduhar, Cloutier, MacDonald)



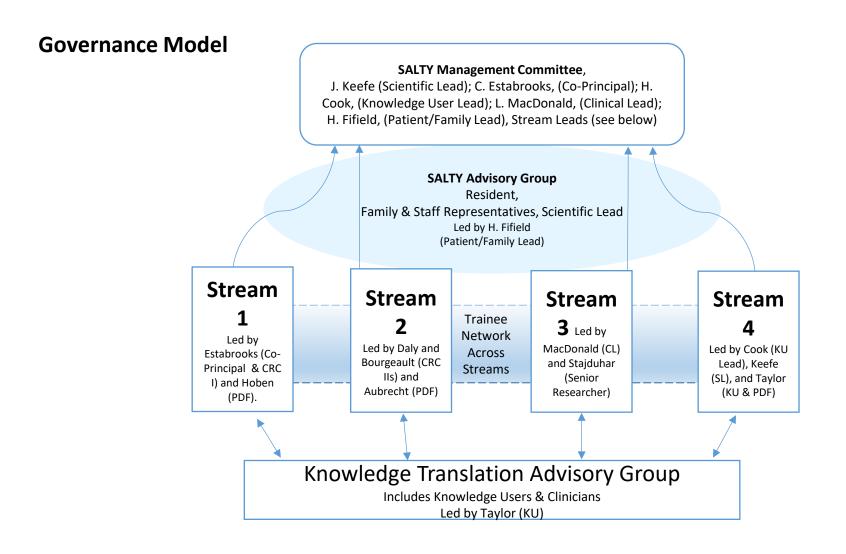
- evaluate the Gold Standard Framework, end of life program, that has been implemented in BC
  - Base line data from participating facilities
  - Implement GSF
  - Assess process for successful implementation with BC and across jurisdictions

#### Stream 4 - Examine Policy Context (Leads: Cook, Keefe, Taylor)



- content analysis of policies to assess how they can support or limit application of end of life practice
  - Identify relevant policies literature, KI interviews
  - Analyze policies re facilitators and barriers
  - Develop alternative approaches

#### PROJECT GOVERNANCE



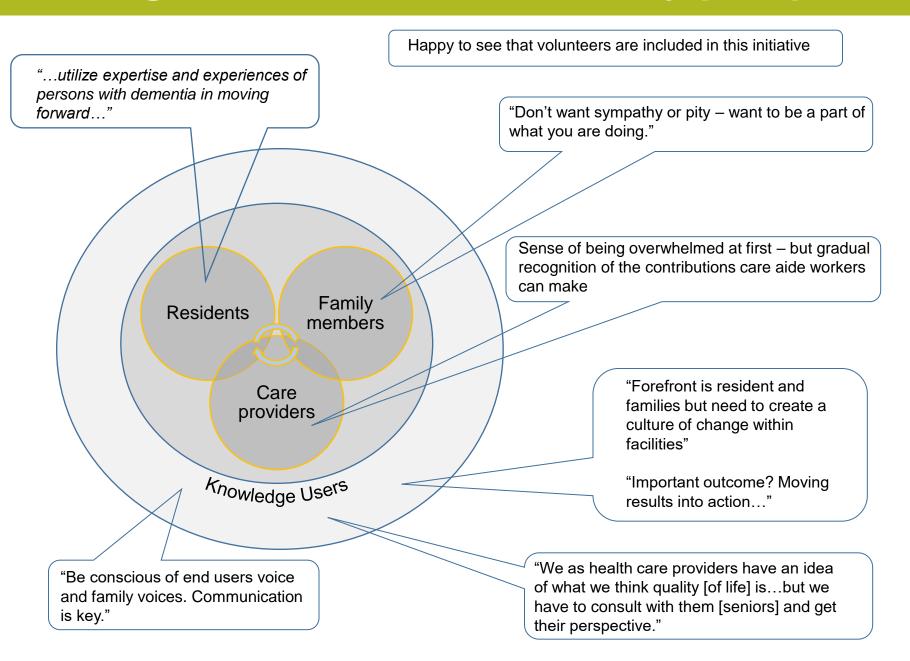
#### TRAINING AND MENTORSHIP

# PROVIDE RICH, INTEGRATED TRAINING ENVIROMENT FOR EMERGING SCHOLARS – interdisciplinary, applied health interactions.

Support the development of emerging scholars interested in advancing both the science of late life care for LTC residents and application in this sector.



## Hearing from the Resident/Family perspective



### SIGNIFICANT MILESTONES/OUTPUTS

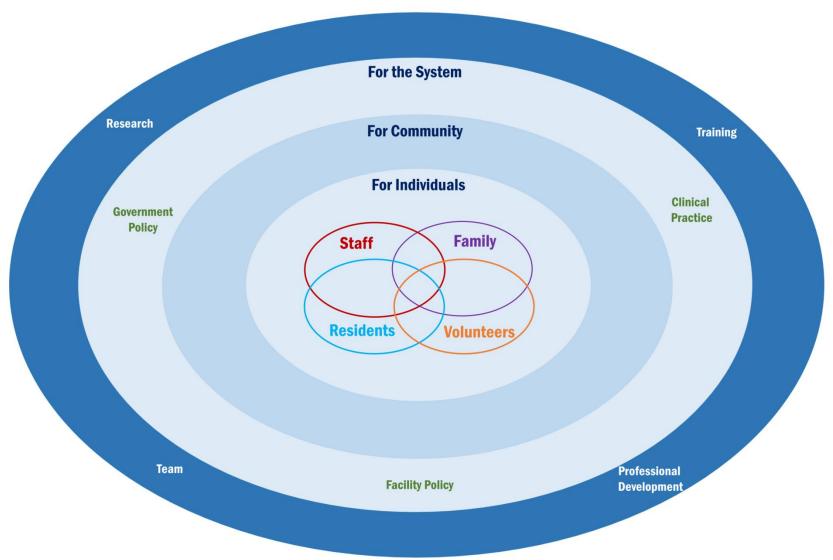
2016-2017	2017-2018	2018-2019	2019-2020
Project governance and management	STR 1-validated indicators	STR 2-case studies complete	STR 4-policy workshops
Team meeting (Halifax)	STR 3-GSF evaluation complete  Provincial Sector Engagement Workshops	Team meeting (Ottawa)	At least 10 publications  Video and other KT products

SALTY ADVISORY GROUP KT ADVISORY GROUP

### **SALTY....SO WHAT?**

#### AIM: To add quality of life to late life for people living in residential long term care.

SALTY: What difference can we make...



#### **Advice / Questions/ Comments**



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Discover, Connect, Engage.







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