

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

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**brainXchange KTE Webinar in Partnership with Alzheimer Society of Canada (ASC) and the Canadian Consortium of Neurodegeneration in Aging (CCNA) – September 27, 2016**

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

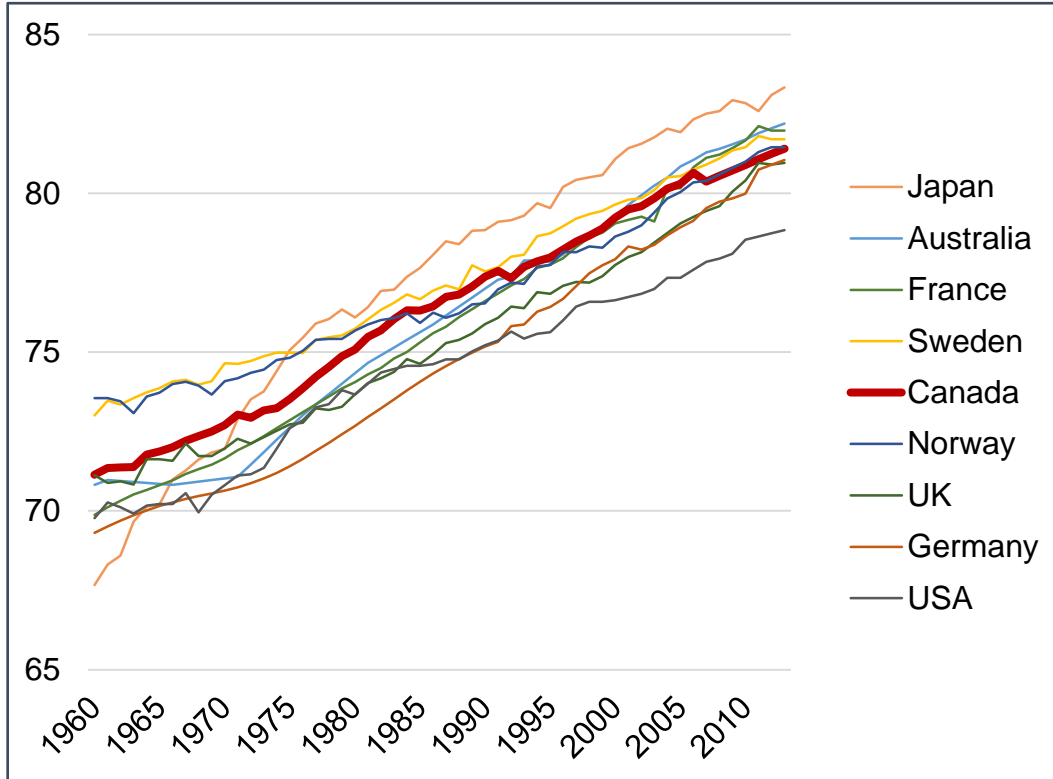
1. Getting to Know each other
2. Why is End of Life in LTC important?
3. What we know already?
4. Introducing SALTY – Seniors Adding Life to Years
5. Lessons learned already
6. Advice and Feedback

# WHERE ARE YOU LOCATED?



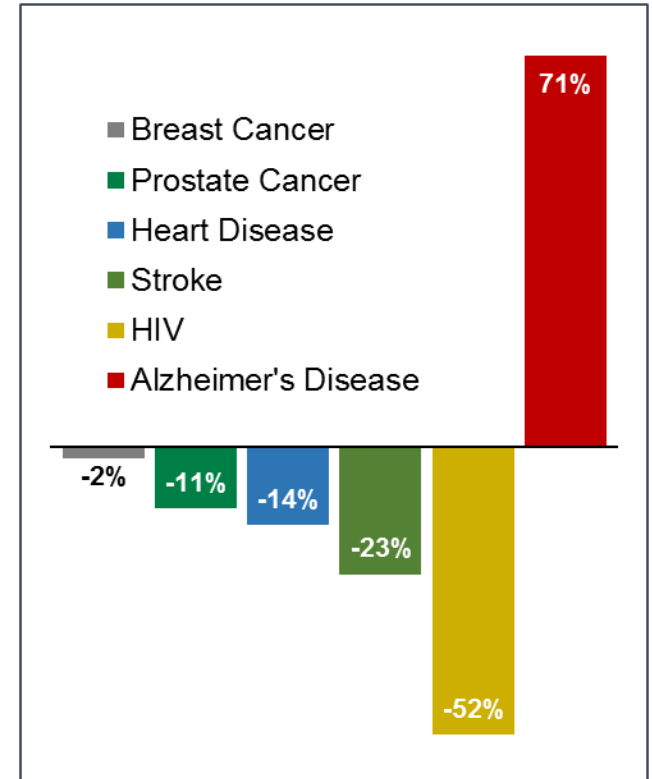
# Demographics

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](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

# Long Term Care as Late Life Care

## 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

**EoL care is challenging for NHs**

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

**Dementia is not well recognized as a terminal disease**

(van der Steen et al. 2014)

**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

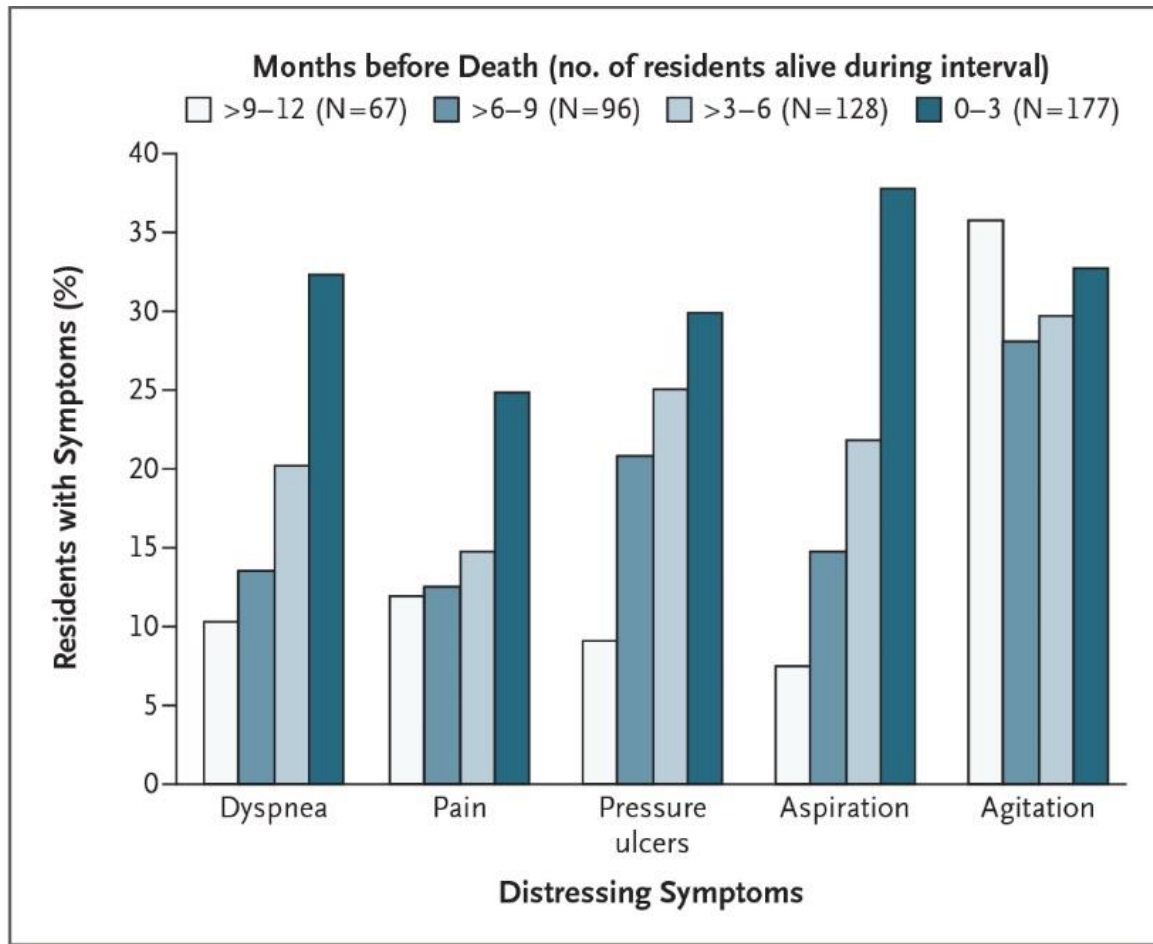


Unnecessary suffering

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

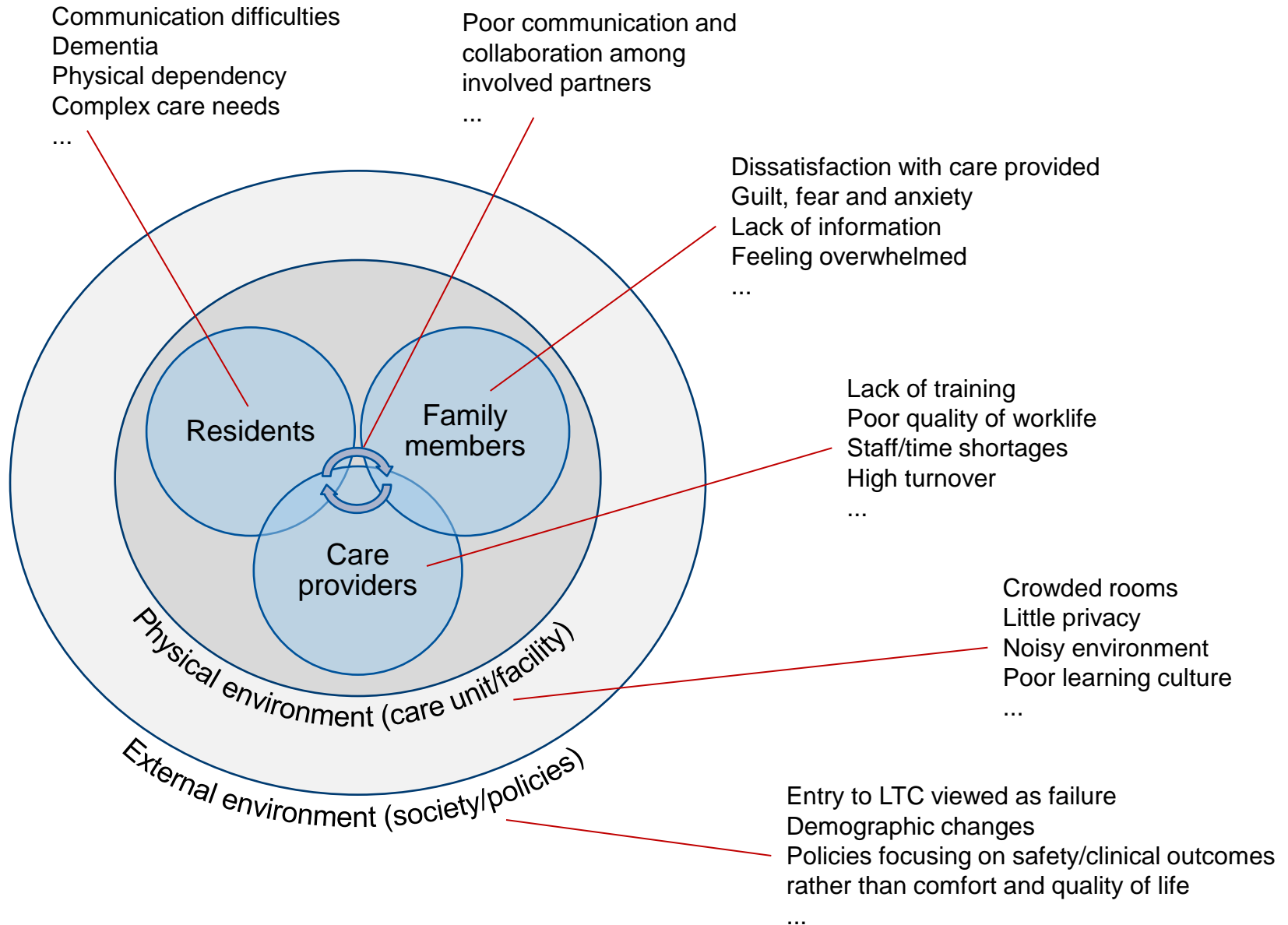
# End of Life with Dementia

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



**Figure 3.** Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

# Previous Research





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

**SALTY**  
Seniors- Adding Life to Years





# PROJECT FACTS

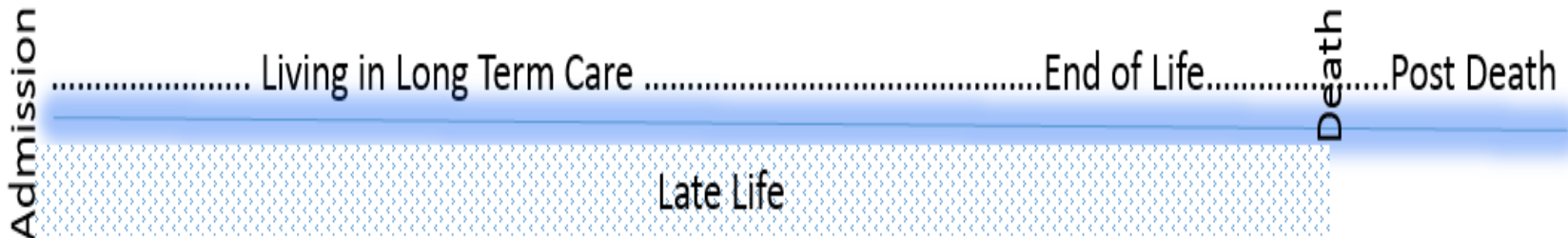
**SALTY**  
Seniors- Adding Life to Years



- 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, Work & Health
- 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.



# IMPORTANT CONSIDERATIONS

Gender

Dementia



Under-  
represented  
Voices


# 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

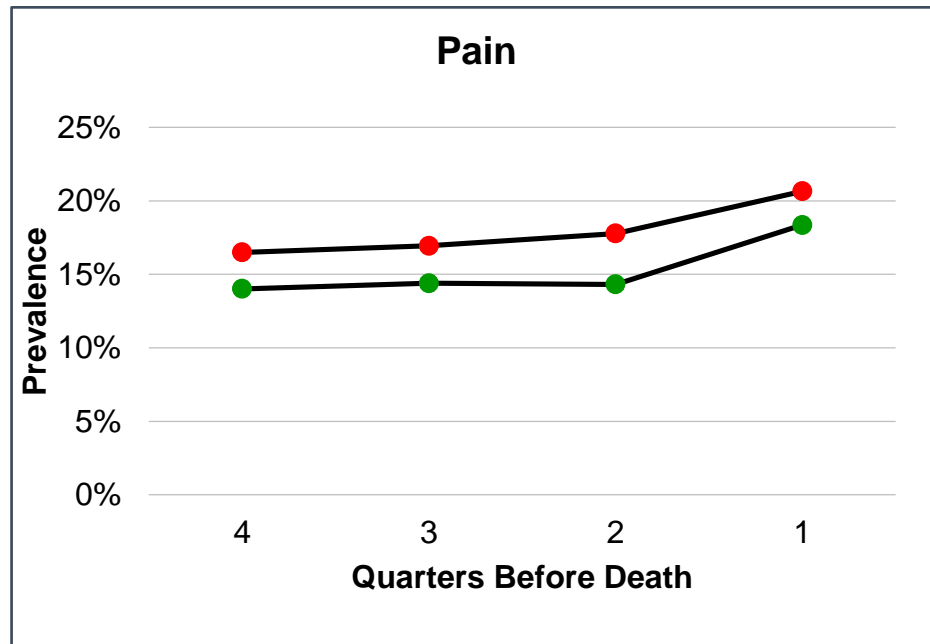
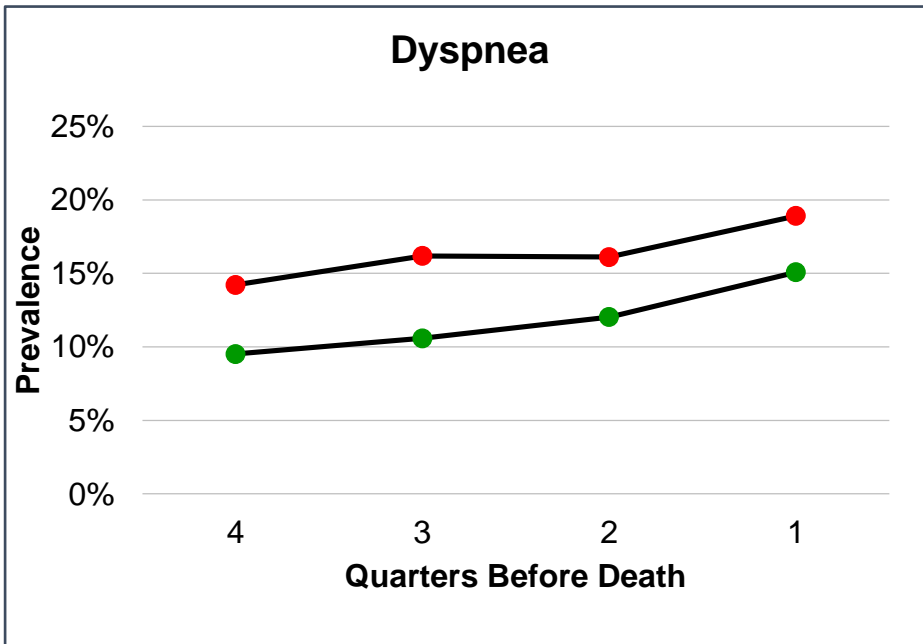


Inter  
dependent  
activities and  
outputs

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**  
( $P_{\text{Ctxt}} < .0001$ ;  $P_{\text{time}} < .0001$ )

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)



- Use RAI-MDS 2.0 data to develop set of quality indicators that will be used to monitor care in the year prior to death
  - 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, Aubrecht)



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 implementation of the QI Project, Vancouver Island, BC
  - Assess the impact of the implementation project
  - Assess indicators of quality of care at the end of life pre and post implementation
  - Identify process for successful implementation in Island Health and influencing contextual factors (facilitators, barriers and lessons learned for scaling up to other facilities)

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

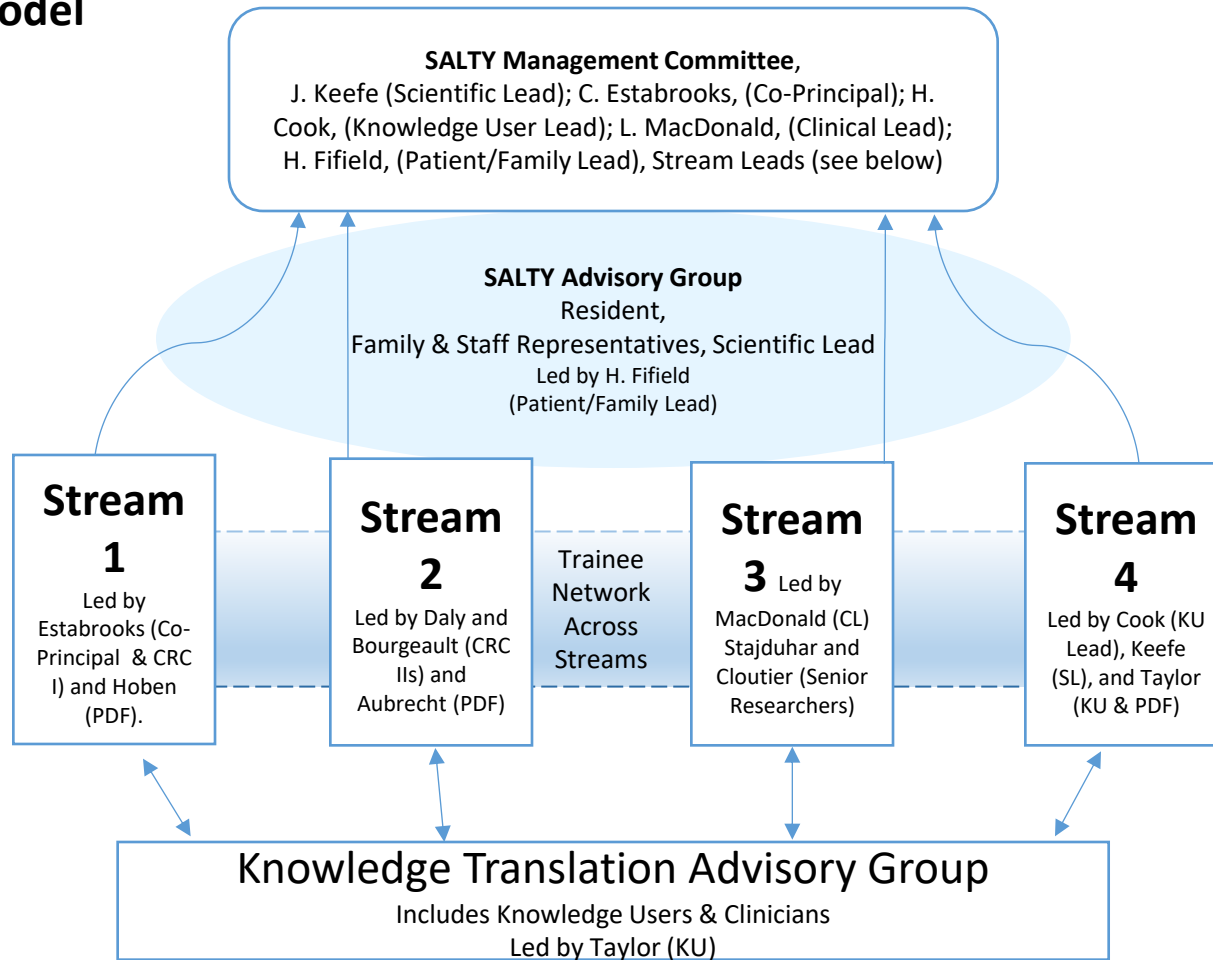


- content analysis of policies to assess how they can support or limit application of end of life practice
  - Identify relevant policies – literature, KI interviews
  - Analyze policies re facilitators and barriers
  - Develop alternative approaches



# PROJECT GOVERNANCE

## Governance Model





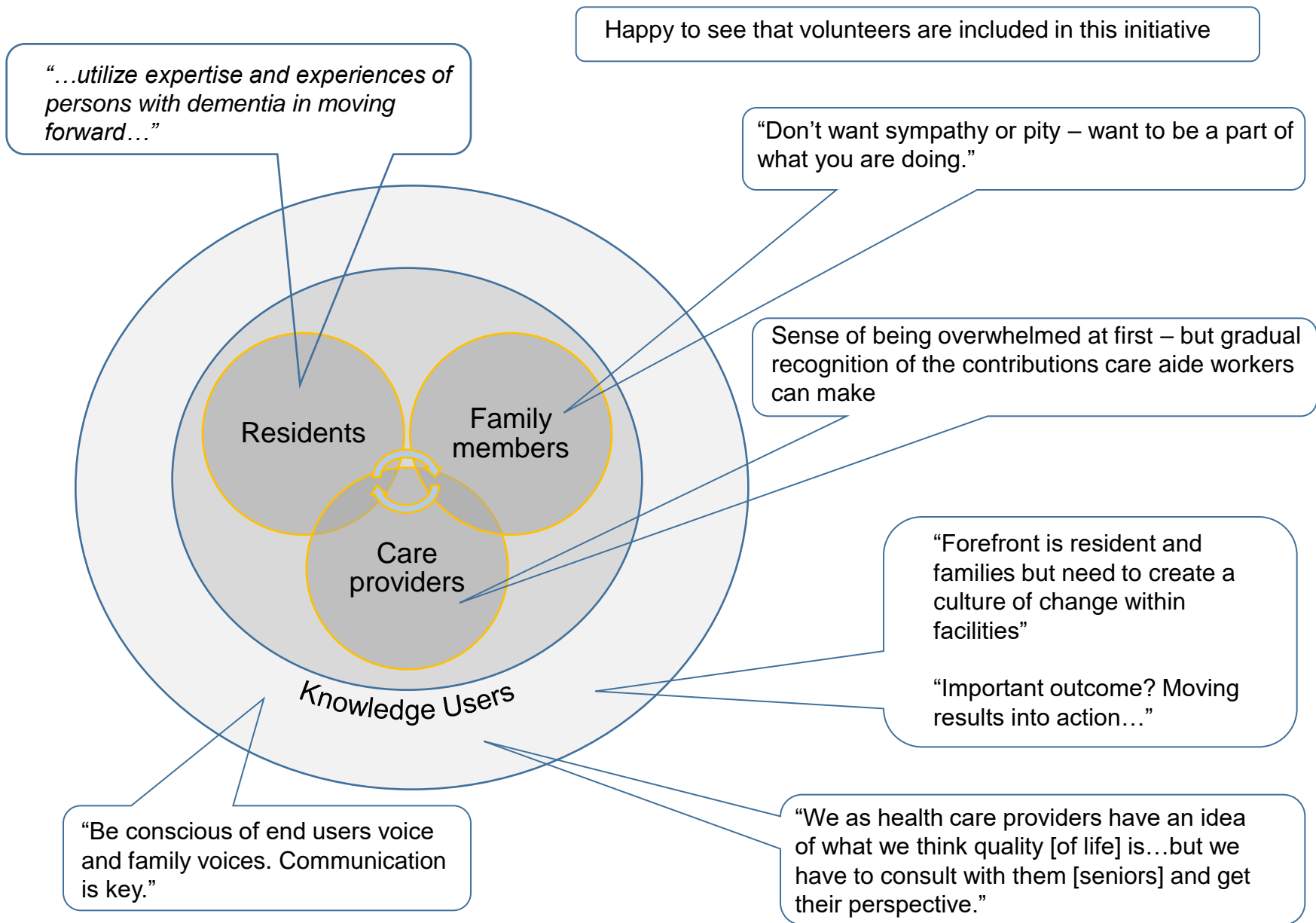
# TRAINING AND MENTORSHIP

**PROVIDE RICH, INTEGRATED TRAINING ENVIRONMENT 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



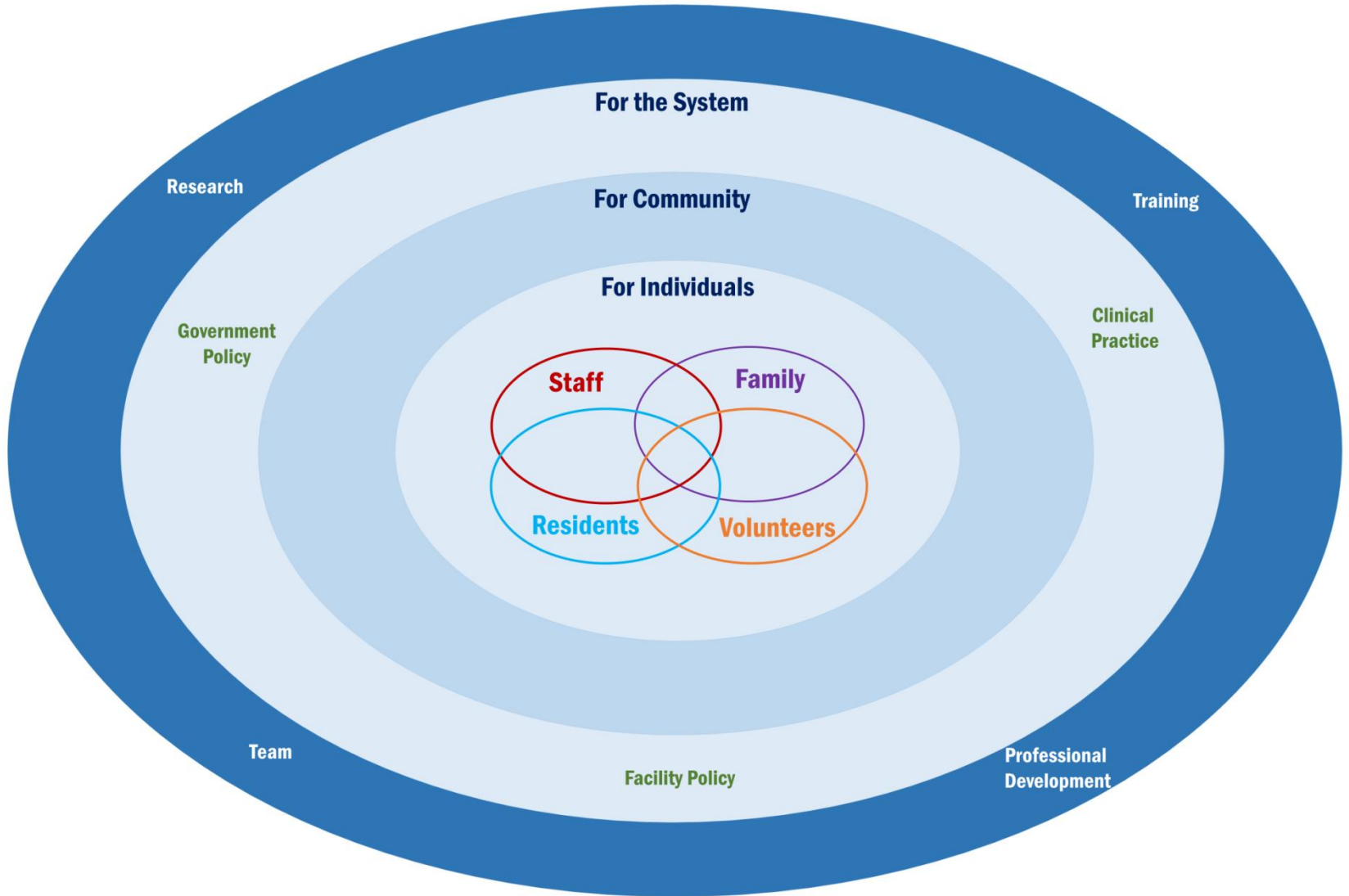
# SIGNIFICANT MILESTONES/OUTPUTS

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

# 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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**Alzheimer Society**  
CANADA

