SENIORS – ADDING ***LIFE*** TO YEARS (SALTY)

SALTY PROJECT OVERVIEW

A 4-year Research Project Across Four Canadian Provinces

Carole Estabrooks

Professor & Canada Research Chair (Tier 1) in Knowledge Translation, University of Alberta

brainXchange with ASC and CCNA

April 9th, 2019

SALTY PROJECT TEAM

Salty Project Leads

Dr. Janice Keefe: Scientific Lead , Mount Saint Vincent University

Dr. Carole Estabrooks: Scientific Co-Lead, University of Alberta

Heather Cook: Knowledge User Lead, Seniors Advocate BC

Dr. Leah MacDonald: Clinical Lead, Vancouver Island Health Authority

Heather Fifield: Resident & Family Lead, Bridgewater, NS

ESTABLISHED RESEARCH TEAMS

i PANEL
INITIATIVE FOR A PALLIATIVE APPROACH IN NURSING: EVIDENCE & LEADERSHIP

TREC
Translating Research in Elder Care

Advice Seeking Networks
IN LONG TERM CARE

SALTY
Seniors-Adding Life to Years

RCRHS
Réseau canadien sur les ressources humaines en santé

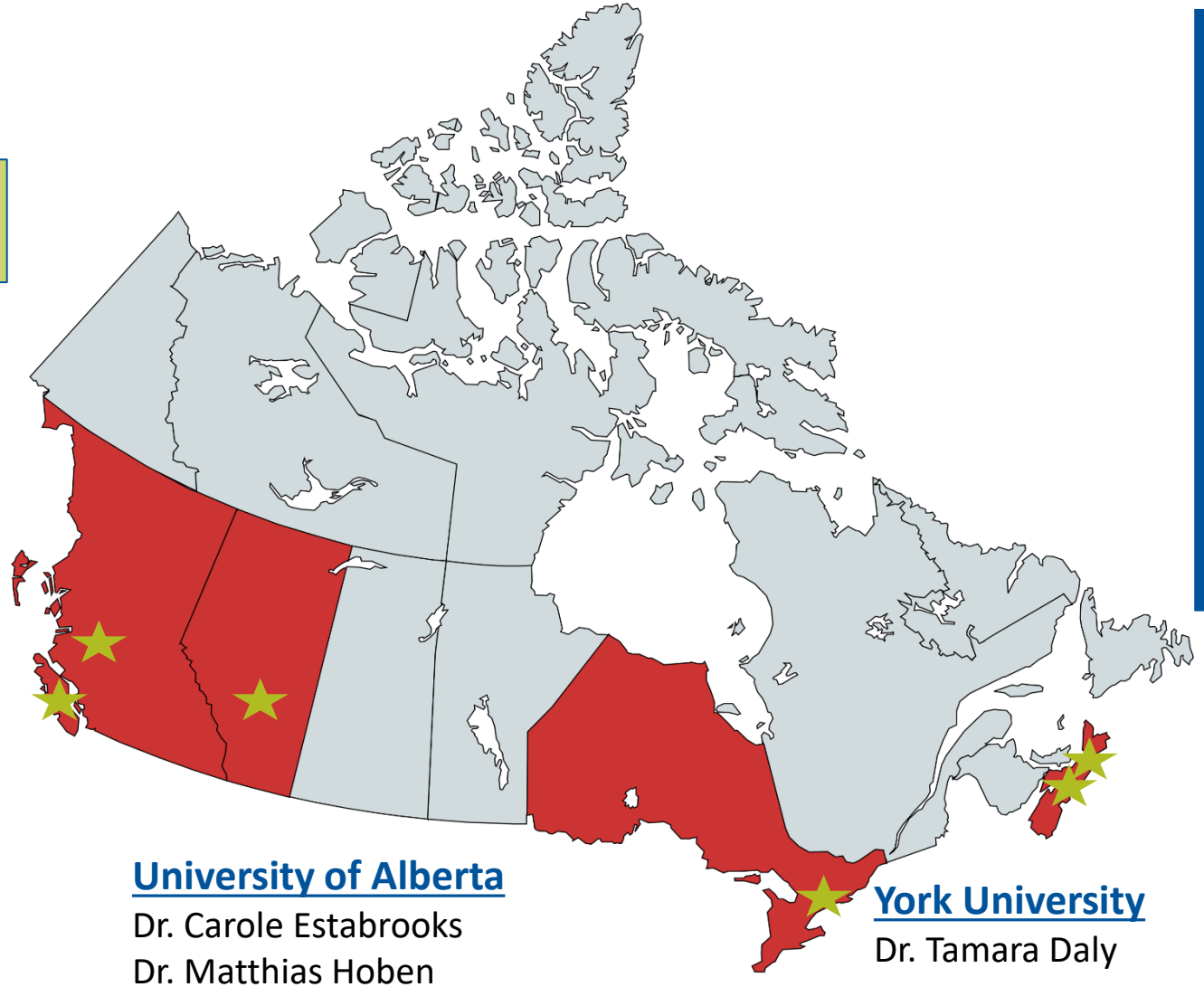
CHHRN
Canadian Health Human Resources Network

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

Care and Construction Project - NS

SALTY TEAM ACROSS CANADA

★ **Lead Sites and Investigators**



23 Academic Researchers
- 13 Universities
- 3 Canada Research Chairs
- 2 CIHR Chairs

11 Knowledge Users
- Facility, regional and provincial

14 Collaborators
- Decision makers, resident, family, staff and volunteers

17 Trainees

CIHR and 3 Funding Partners

Interior Health, BC
Dr. Dee Taylor
Heather Cook

University of Victoria
Dr. Kelli Stajduhar
Dr. Denise Cloutier
Dr. Leah MacDonald

University of Alberta
Dr. Carole Estabrooks
Dr. Matthias Hoben

York University
Dr. Tamara Daly

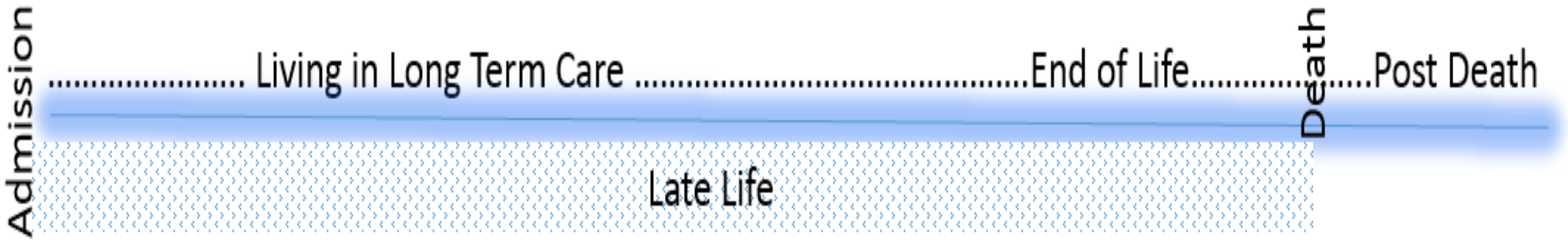
University of Ottawa
Dr. Ivy Bourgeault

St. Francis Xavier University
Dr. Katie Aubrecht

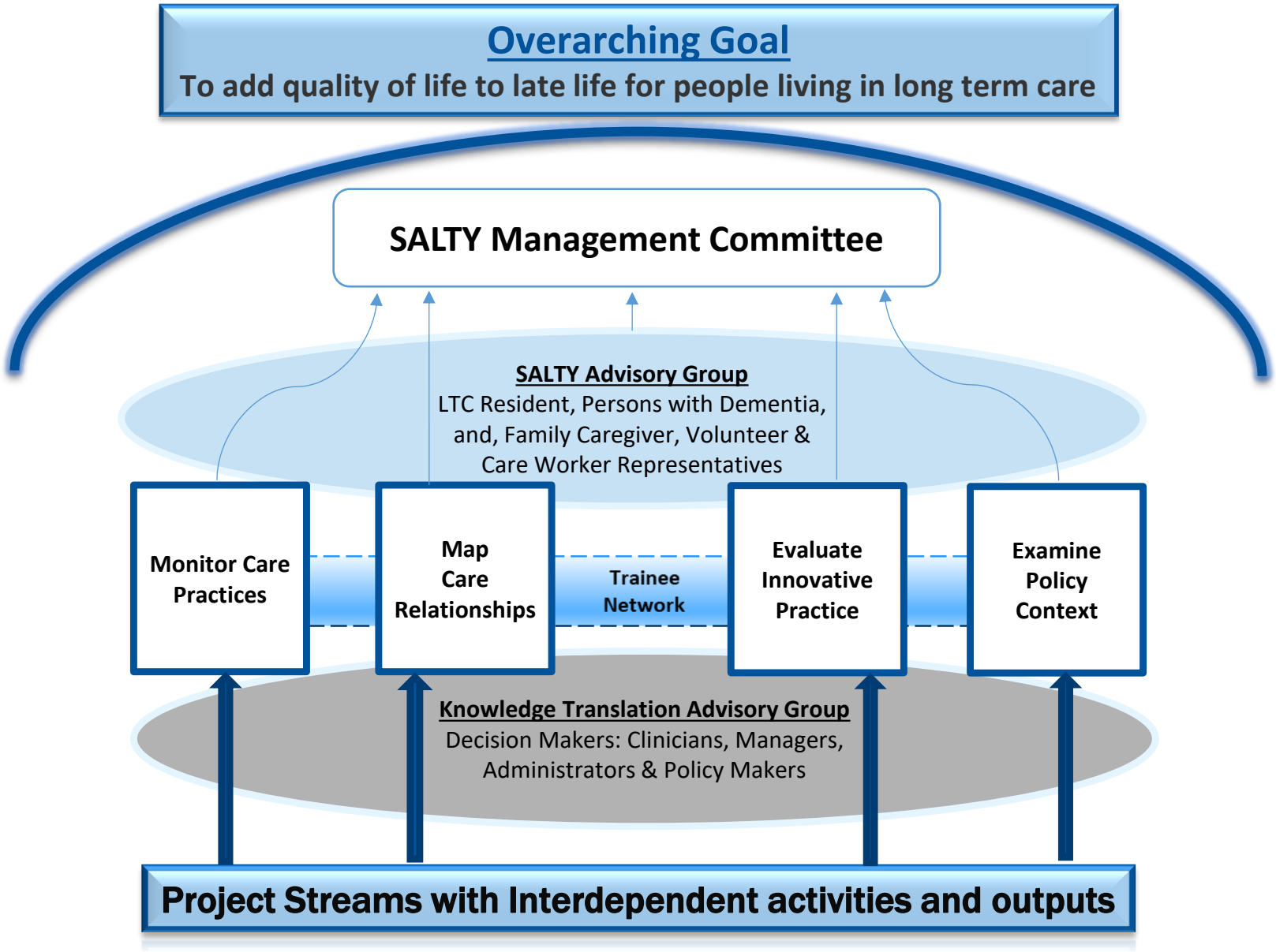
Mount Saint Vincent University
Dr. Janice Keefe

SALTY PROJECT GOAL

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



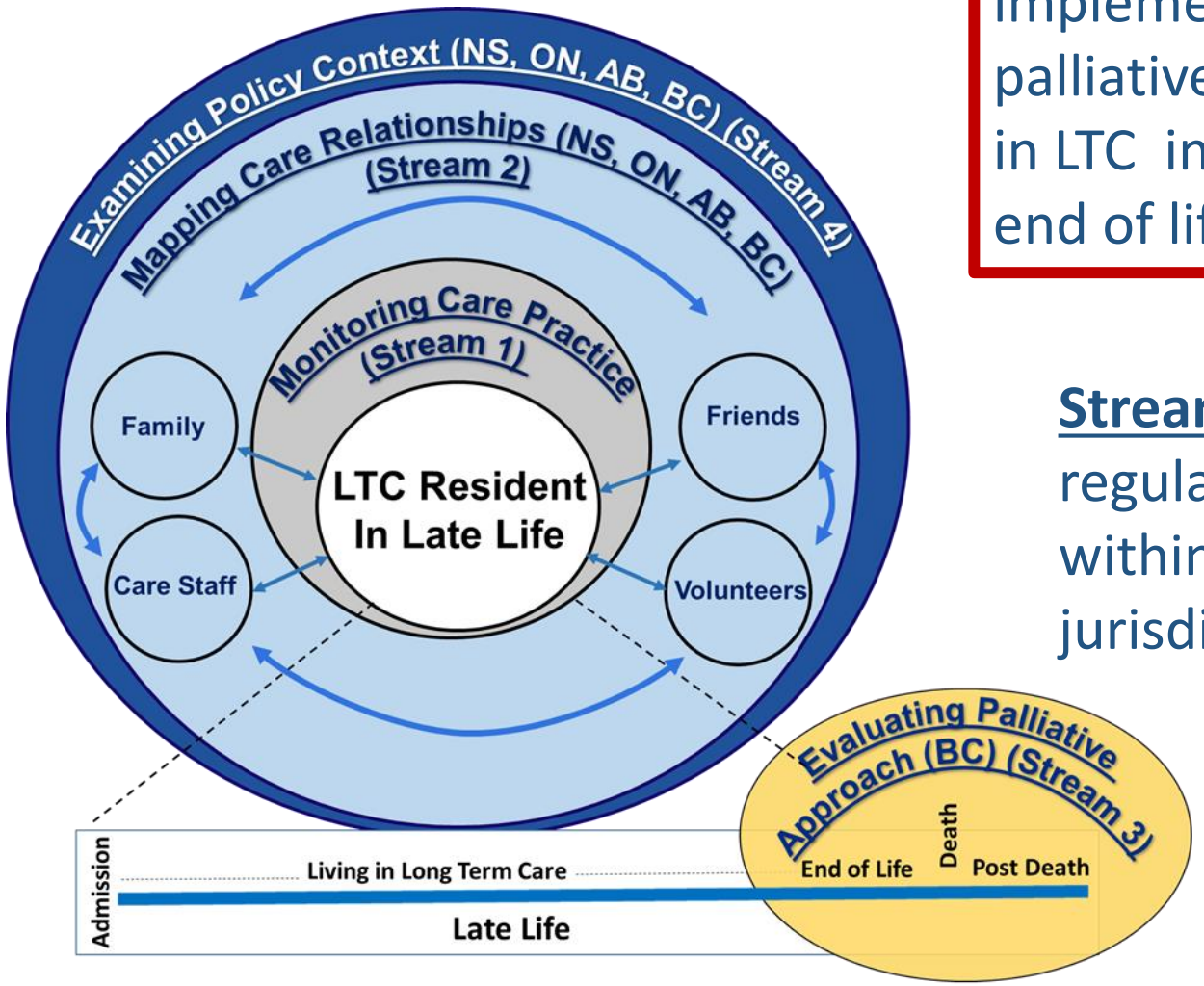
SALTY iKT MODEL



SALTY RESEARCH STREAMS

Stream 1: Developing appropriate measures from RAI-MDS 2.0 data to monitor quality of care during late life/end of life.

Stream 2: Identifying promising approaches to care + work, and analyzing how they enhance quality care + care relationships.



Stream 3: Evaluating the implementation of a palliative approach to care in LTC in BC for improving end of life outcomes.

Stream 4: Examining the regulatory environment within the different jurisdictions.

ACKNOWLEDGEMENTS AND CONTACT INFORMATION

CONTACT

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SALTYltc

The authors acknowledge the Seniors – Adding *Life* to Years (SALTY) team for its contributions to this study. This research is funded through a Late Life Issues grant from the Canadian Institutes of Health Research (#145401) in partnership with the Michael Smith Foundation for Health Research, Nova Scotia Health Research Foundation and the Alzheimer Society of Canada.

SENIORS – ADDING *LIFE* TO YEARS (SALTY)

Integrated Palliative Approach to Care in Residential Care (iPAC-RC)
Stream 3 – Evaluating a Quality Improvement Project

Kelli Stajduhar, RN, PhD, FCAHS

University of Victoria

brainXchange

April 9, 2019

Team Members:

Denise Cloutier, PhD

Leah MacDonald, MD

Carren Dujela, MA

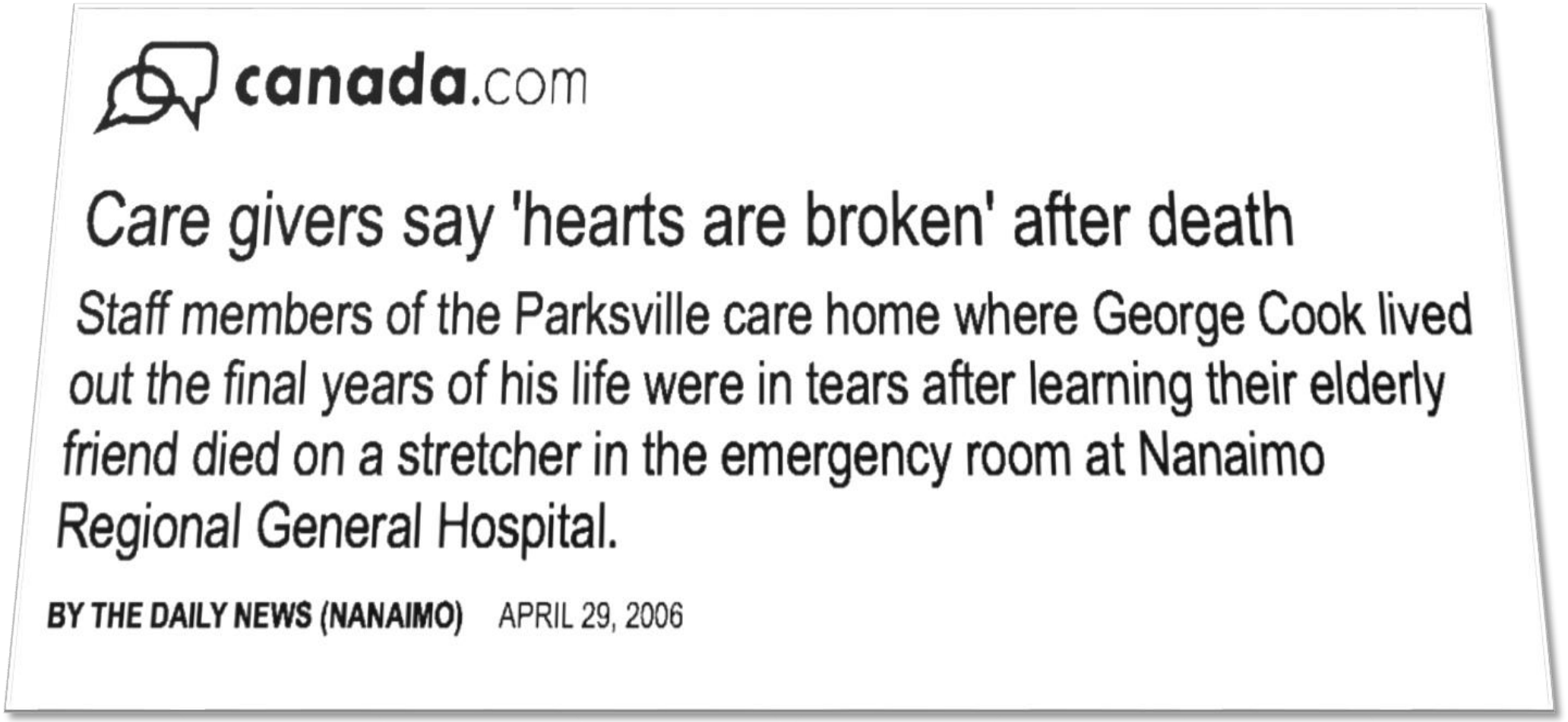
Della Roberts, RN, MSN, CHPCN (C)

Kaitlyn Roland, PhD

SALTY

Seniors-Adding Life to Years

Background



canada.com

Care givers say 'hearts are broken' after death

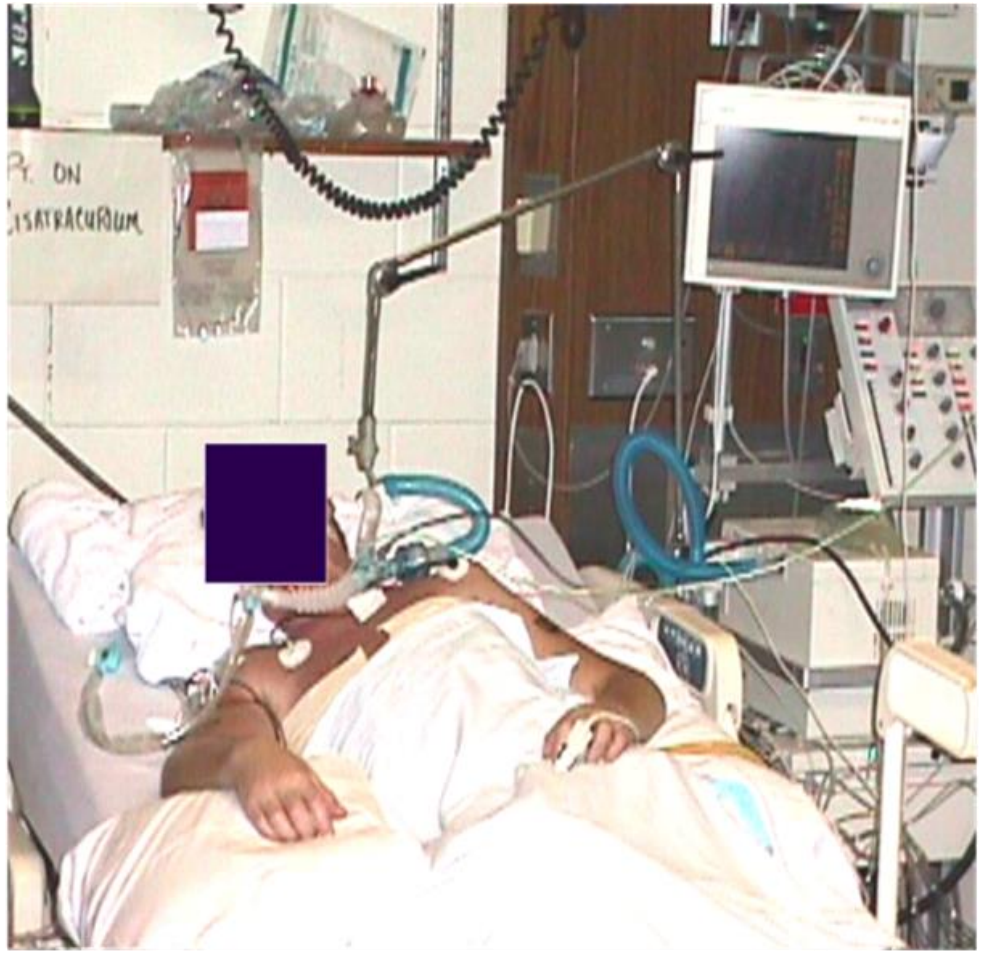
Staff members of the Parksville care home where George Cook lived out the final years of his life were in tears after learning their elderly friend died on a stretcher in the emergency room at Nanaimo Regional General Hospital.

BY THE DAILY NEWS (NANAIMO) APRIL 29, 2006

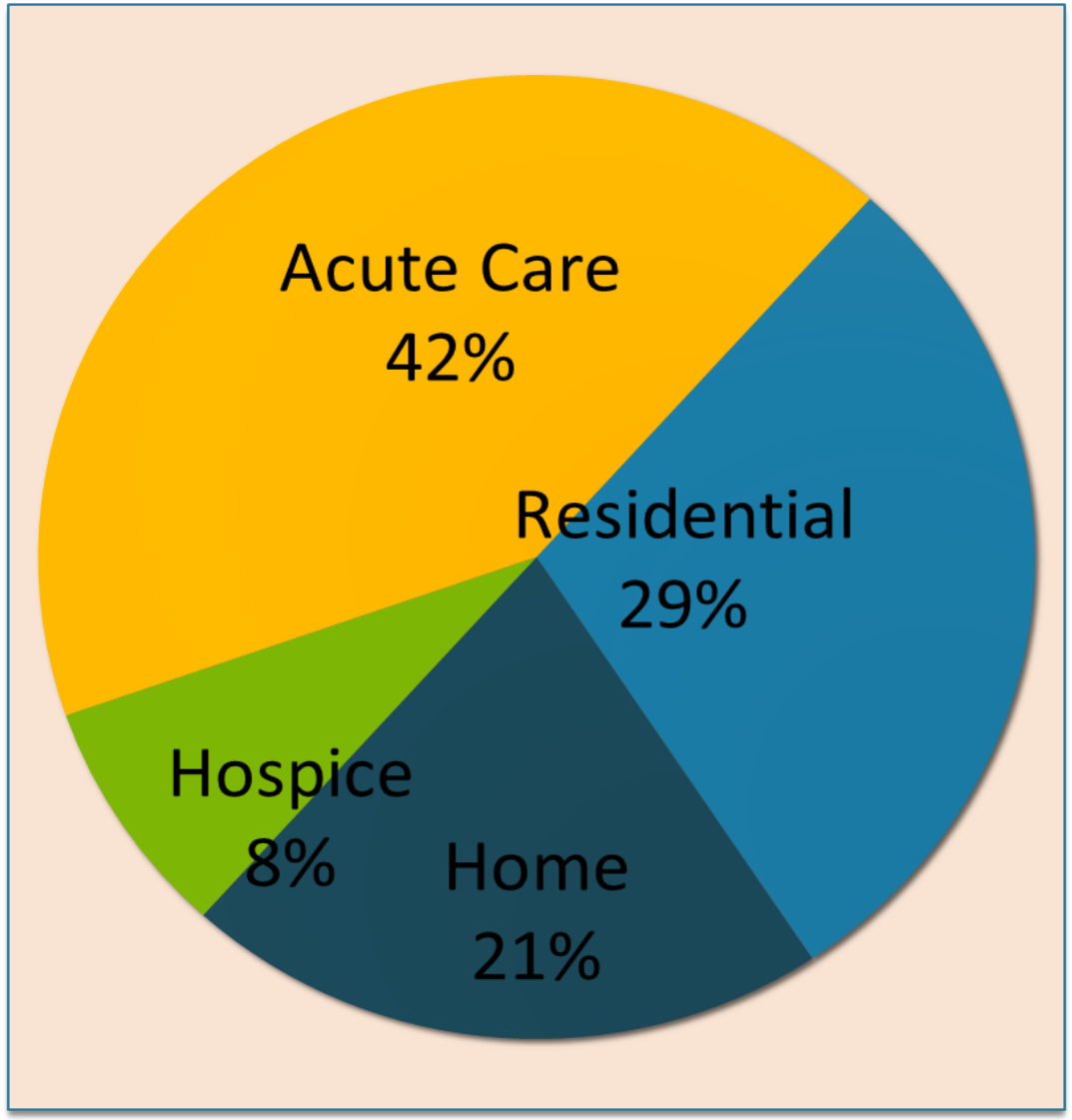
Consequences of Dying in Acute Care

"Intensification of care" at the end of life associated with:

- Worse quality of life of person in final days
- Worse quality of death
- Increase stress, anxiety and post traumatic stress disorder in family members
- Greater costs of care



Where Do People Die?



Data from Vital Statistics for Island Health, 2014

Quality Improvement in Long Term Care

PROJECT GOALS

1. Embed a resident-centered palliative approach to care in 4 long term care facilities.

2. Improve the dying experience

    - support residents dying in place
    - improve the experience of team members in caring for the dying, and
    - reduce ER visits and hospitalization for residents

Integrating a Palliative Approach to Care in Residential Care (iPAC-RC) Evaluation Goals

1. Assess the impact of the IEOL project (the QI project) from the perspective of administrators, clinicians, direct care workers and family members.
   - Influence of Tools
   - Organizational Context

2. Identify the process for successful implementation of the IEOL project and highlight lessons learned for scaling up elsewhere.
   - Shifting practice
   - Staffing realities/impacts

SALTY
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What were the QI “interventions”?

- Support
  - Learning Essentials Approaches to Palliative Care (LEAP-core)(2 days)
  - Link Nurses
  - Palliative Rounds
- Tools
  - Infographic Poster
  - Early Identification Tool
  - Communication Guide
  - Guide for Goals of Care
  - Letter to Physicians

Early Identification Tool

A PALLIATIVE APPROACH TO CARE

There are often signs that a resident's health is declining and they are at higher risk of dying. Being attuned to these signs allows health care providers to better inform and guide residents and their families in this final season of their life. **What factors support the care team's impression that the resident is at risk of dying in the coming months?**

Early Identification Tool

CHECK ALL THE FACTORS THAT ARE RELEVENT FOR THE RESIDENT

- ☐ Progressive weight loss (greater than 10% in 6 months)
- ☐ Progressive, irreversible functional decline
- ☐ Resident or family asking for comfort measures only, treatment withdrawal or limitation
- ☐ Unplanned transfers to Emergency Department or hospital admissions
- ☐ Extreme frailty (e.g. persistent pressure ulcers, recurrent infections, delirium, persistent swallowing difficulties, falls)
- ☐ Advanced dementia or other neurological disease (e.g. unable to dress, walk or eat without help, incontinence, unable to communicate verbally, eating and drinking less, swallowing difficulties, recurrent UTI, aspiration pneumonia)
- ☐ Advanced cancer diagnosis
- ☐ Severe heart disease (e.g. breathlessness or chest pain at rest or with minimal exertion)
- ☐ Severe respiratory disease (e.g. breathless at rest or with minimal exertion, on oxygen therapy, recurrent hospitalizations)
- ☐ Advanced illness of any cause with progressive function decline or poorly controlled symptoms

☐ Resident **NOT "identified"** at this time,
to be reviewed on this date: _____

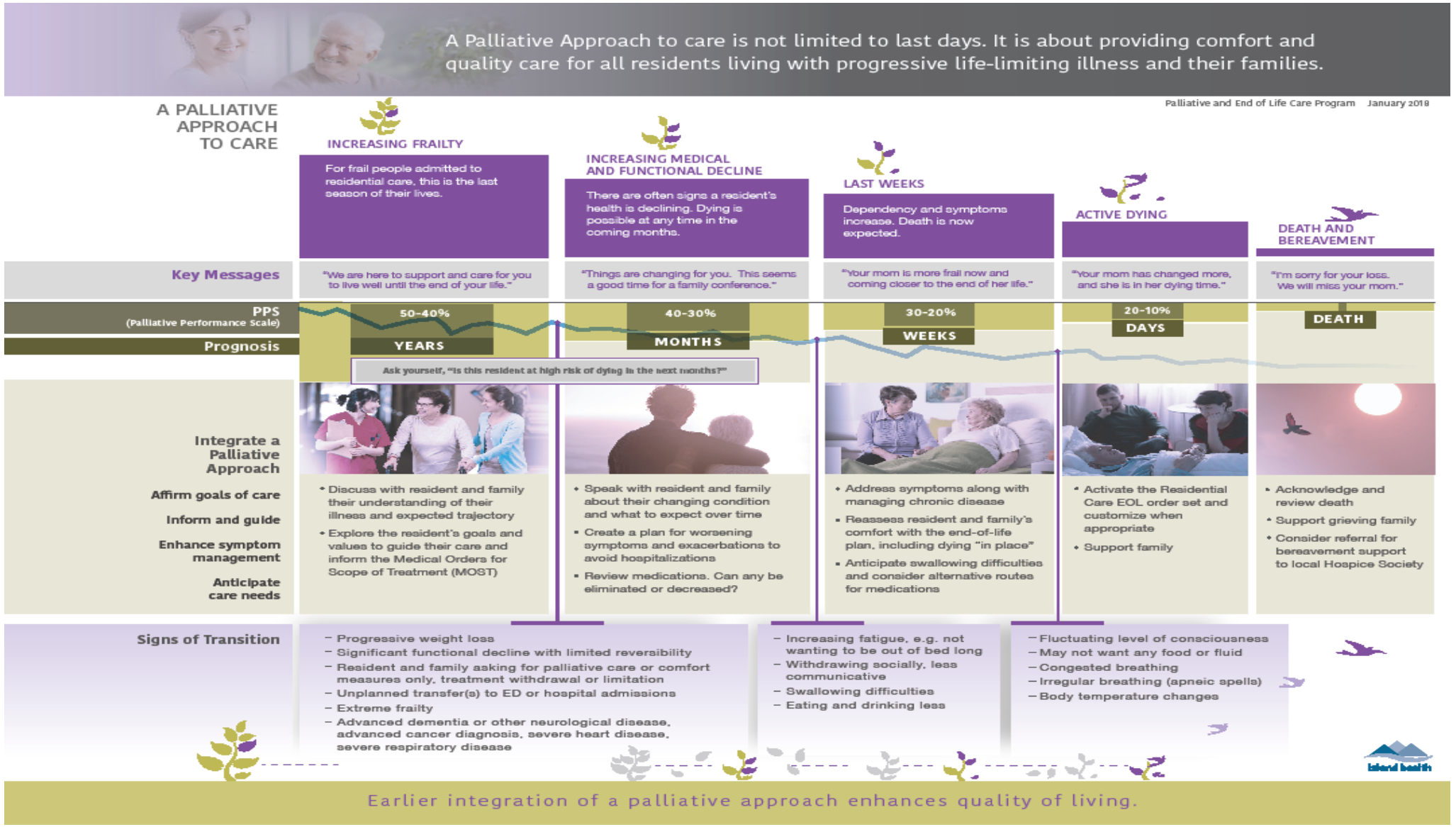
☐ Resident **"identified"** at this time,
date of Identification: _____

Signature: _____

Criteria adapted from Supportive and Palliative Care Indicators Tool (SPICT™) www.spict.org.uk and The Gold Standards Framework Proactive Identification Guidance (PIG) 2016 v56 © The Gold Standards Framework Centre in End of Life Care www.goldstandardsframework.org.uk/PIG

Inland Health

Infographic Poster



Communication Guide

For Nurses and Social Workers

CONVERSATION GUIDE for RESIDENTIAL CARE TEAM

A resident's increasing frailty has been identified and the early identification tool for a palliative approach to care has been completed.

CONVERSATION - LISTENING MORE THAN TALKING
Elements of conversation often take place over many small conversations and do not need to happen in one long session.

STEPS	DESCRIPTION	SCRIPT QUESTIONS / Sample Statements
1 INITIATE discussion	**Contact** the resident and/or family **Ask** permission for discussing change **Gather information** from the team about the specific changes identified **Plan** what you will say to the resident and/or family	**Q:** I would like to talk with you about the changes in your mom's health. Is that OK? **Q:** Have you been noticing change? What changes have you been noticing?
2 ASK the resident and family	**Ask** the resident and/or family what their thoughts are about the resident's current status **Ask** the resident and/or family about what is important to them	**Q:** What do you understand about what is happening for your mom, with her illness? **Q:** What is most important to your mom now? What is most important to you?
3 TELL share information about changes	**Ask** permission to share information **Share information** on current status; include changes staff have seen, the increasing frailty, and that more change could happen at any time **Give information** in a straightforward way **Use words** the resident and family will understand Use "I **wish**...", "I **worry**...", "I **wonder**..." strategy	**Q:** Is it okay if I tell you the changes the care team has been seeing? As you noticed, your mom is sleeping more and doesn't go to activities. She is also eating less and has lost 5 pounds over the last 2 months. She is more irritable and is in more pain when moving. These changes are all part of what we expect as someone becomes more frail and ... ... they become less able to fight off a cold or infection. ... they are moving toward the end of life. ... life is getting shorter. ... I **wish** things were different. I **worry** time is getting shorter. I **wonder** if we could talk about how we can provide care for your mom at this time.

Guide for Goals of Care

Today's Date: _____

Guide for Goals of Care Plan

(following identification of resident for palliative approach to care)

DOMAINS OF CARE	GOALS	ACTIONS
Early Identification	Ensure coordinated team-based support is initiated when resident is identified as in greater need of a palliative approach to care	☐ Complete "Early Identification Tool" ☐ Notify MRP if resident is identified (send form letter if used by this facility) ☐ Communicate to care team that resident has been identified
Information Sharing and Being a Guide to Family	Ensure that the family/ resident have opportunity to discuss the anticipated illness course and the benefits of a palliative approach to care to inform their care plan	☐ Choose a care team member to speak with family/resident about changes the care team has noted ☐ Document wishes and concerns on the Advance Care Planning Notes and Conversation Form (or equivalent) kept in Greensleeve of a resident's chart ☐ Encourage family to make an appointment with the resident's doctor to discuss anticipated illness course, prognosis and MOST ☐ Consider a family meeting with care team and MRP ☐ Provide ongoing check-ins with family
Confirming Goals of Care	Ensure that care provided is in keeping with resident's wishes and values, and is medically appropriate	☐ Revisit "Medical Orders for Scope of Treatment" (MOST) ☐ If MOST designation appears inconsistent with condition notify MRP and encourage family to make an appointment to revisit MOST

Letter to Physicians

INSERT residential care facility's letterhead here

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please respond by fax to [insert facility's fax number here]

Regarding your patient _____ **Date** _____

Dear Dr. _____ ☐ **Attachment included**

Your patient has been identified as being at a higher risk of dying in the next months:

- ☐ Progressive **weight loss** (> 10% over 6 months) _____ (lbs or kgs)
- ☐ Progressive, irreversible **functional decline**
- ☐ **Resident or family asking for comfort measures only**, treatment withdrawal or limitation
- ☐ **Unplanned transfers** to Emergency Department or hospital admissions
- ☐ **Extreme frailty** (e.g. persistent pressure ulcers, recurrent infections, delirium, persistent swallowing difficulties, falls)
- ☐ **Advanced dementia** or other **neurological disease** (e.g. unable to dress, walk or eat without help, incontinence, unable to communicate verbally, eating and drinking less, swallowing difficulties, recurrent UTI, aspiration pneumonia)
- ☐ **Advanced cancer diagnosis**
- ☐ **Severe heart disease** (e.g. breathlessness or chest pain at rest or with minimal exertion)
- ☐ **Severe respiratory disease (**e.g. breathless at rest or with minimal exertion, on oxygen therapy, recurrent hospitalizations)
- ☐ **Advanced** _____ with progressive functional decline or poorly controlled symptoms

Above criteria are adapted from the Supportive and Palliative Care Indicators Tool (SPICT™) www.spict.org.uk and The Gold Standards Framework Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care www.goldstandardsframework.org.uk/PIG

☐ **MOST** on file Date: _____ ☐ No **MOST** on file

Your patient, their family and the care team would appreciate your assessment and input.

Care Team Lead Name/Signature: _____

PHYSICIAN'S RESPONSE

- ☐ I will visit the facility to review my patient's situation in the coming week
- ☐ My Office Assistant will follow-up and book a meeting with the family at my office
- ☐ Comment:

_____

Sites

- Urban, owned & operated site, 72 beds
- Urban, affiliate site, 217 beds
- Rural, affiliate site, 160 beds
- Rural, owned & operated site, 90 beds
- Semi-rural *control*, owned & operated, previously affiliate site, 75 beds

Data Collection

Start of Quality Improvement Project (January 2016)

- Phase 1 collection (17-20 months post-implementation, June-Sep 2017)
  - *Focus groups*: 8 with care staff (RN/LPN/Care Aide) (n=33); 4 with family members (n=30)
  - *Interviews*: 22 key informants
  - *Surveys*: Clinician (65 Care Aides; 41 RN/LPN); Bereaved family member (n=40)
- Control Site collection
  - *Focus groups*: 2 with care staff (RN/LPN, Care Aide) (n=13)
  - *Interviews*: 4 key informants
  - *Surveys*: Clinician (62 Care Aides; 17 RN/LPN)

End of Quality Improvement Project (December 2018)

- Phase 2 (6 months post-project completion, May 2018)
  - *Focus groups*: 9 with care staff and management (RN/LPN/Care Aide/DOC/Care Leader) (n=53)
  - *Interviews*: 11 key informants
- *Chart audits* of residents deceased Dec 4 2016 – Nov 20 2017, n=234
  - Does not include control site deaths, received at UVic July 2018

Evaluating QI "interventions"

- Case study descriptions of care context in each of the 4 sites and control
- Site specific report of:
  - Perceptions/awareness of project by staff
  - Evaluation of toolkit
    - Poster – little mention T1, beneficial to improve understanding of palliative approach (mostly staff, sometimes families); variable visibility at T2
    - Early ID - useful
    - Communication Guide – use for staff communicate with families
    - Guide for Goals of Care – not useful and no longer used T2
    - Letter to Dr – helpful for staff organization, but no response from Dr.
  - Support strategies: palliative rounds, education, link nurses
    - Education - Lack of awareness and opportunity for care aids
    - Palliative rounds - viewed as beneficial, but 2 sites we no long having them… why? How can we support sustainability?
    - Link nurses – need clear expectations of roles and responsibilities
- Outcomes
  - Lack of communication was the most substantial issue and where the greatest change can happen
  - Giving staff the tools to ask the right questions about a resident's (and/or his/her family) goals and listen increased confidence and comfort with PAC
  - Increased comfort with language (i.e. saying "death") shifted culture of care because it shifted how they approached care

Shifting Practice in LTC to a Palliative Approach

Adopt

- The Learning Essentials Approaches to Palliative Care" ("LEAP") LTC 2-day session

"[there is] a lack of understanding around the language and definition about what is a palliative approach? You know, so often you'll hear ah, clinicians talking about palliative care as final days and hours, so I think that was a gap in terms of education."

- Create awareness of a PAC

"a palliative approach generally isn't taken in residential care and often planning for these patients is reactive rather than proactive, and so these patients end up with unnecessary transitions at EOL"

- Identified need of LTC staff for conversation strategies

"a lot of it grew from those initial education sessions when you saw where the interest was in conversation strategies"

- Identified need for visual, accessible source of PAC info (i.e. Infographic poster developed)

Adapt

- Early Identification Tool
- Guide for Goals of Care Plan
- The Letter to Physicians
- The Conversation Guide

Embed

- Link nurses identified strategies to help sites embed tools into current practice
- Palliative Rounds
  - site specific development and format

"the palliative supportive rounds bring people together to talk about what went well, what didn't go so well, how things can be improved next time what it felt like emotionally to care for these patients, both the good and the bad."

- Tool uptake
  - Infographic: public education, visibility, conversation starter
  - Early ID: change in approach to care, conversation with families
  - Conversation guide: shift in communication, comfort and shift in practice

Staffing Realities/Impacts

Themes

- Baseline knowledge of PC models

  "her understanding of PAC was different than mine… it was difficulty for me to engage her in a conversation because we were at completely different starting point."

- Training opportunities and attendance

  "lack of educational opportunities for every level from the health care aide up."

  "they are so hungry for the education but they're just trying to do the basics in care"

- Cultural perspectives

  "cultural attitudes towards death and dying"

- Staff turnover influences a team-approach to care and practice innovation

  "barriers would be that there's high staff turn-over so that we educate and support… because there is a very staff turn-over, would start all over again." "the constant staff churn"

- Staff contracts and continuity of care

  "staff having multiple jobs you know often time people's focus is getting out of here as quick as they can because they've got another job to go to and you know that sort of thing sometimes the focus isn't as much on the task at hand maybe as much as it should be…"

Organizational Context

Facilitators and barriers to implementing a new PAC in LTC

- ❑ Organizational readiness as a factor for implementation
- ❑ Adequate implementation time is needed for successful uptake and acceptance
- ❑ Site leadership support and engagement facilitated successful implementation
- ❑ Sustainability
- ❑ Continuity of care

ACKNOWLEDGEMENTS AND CONTACT INFORMATION

CONTACT

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SALTY Seniors-Adding *Life* to Years

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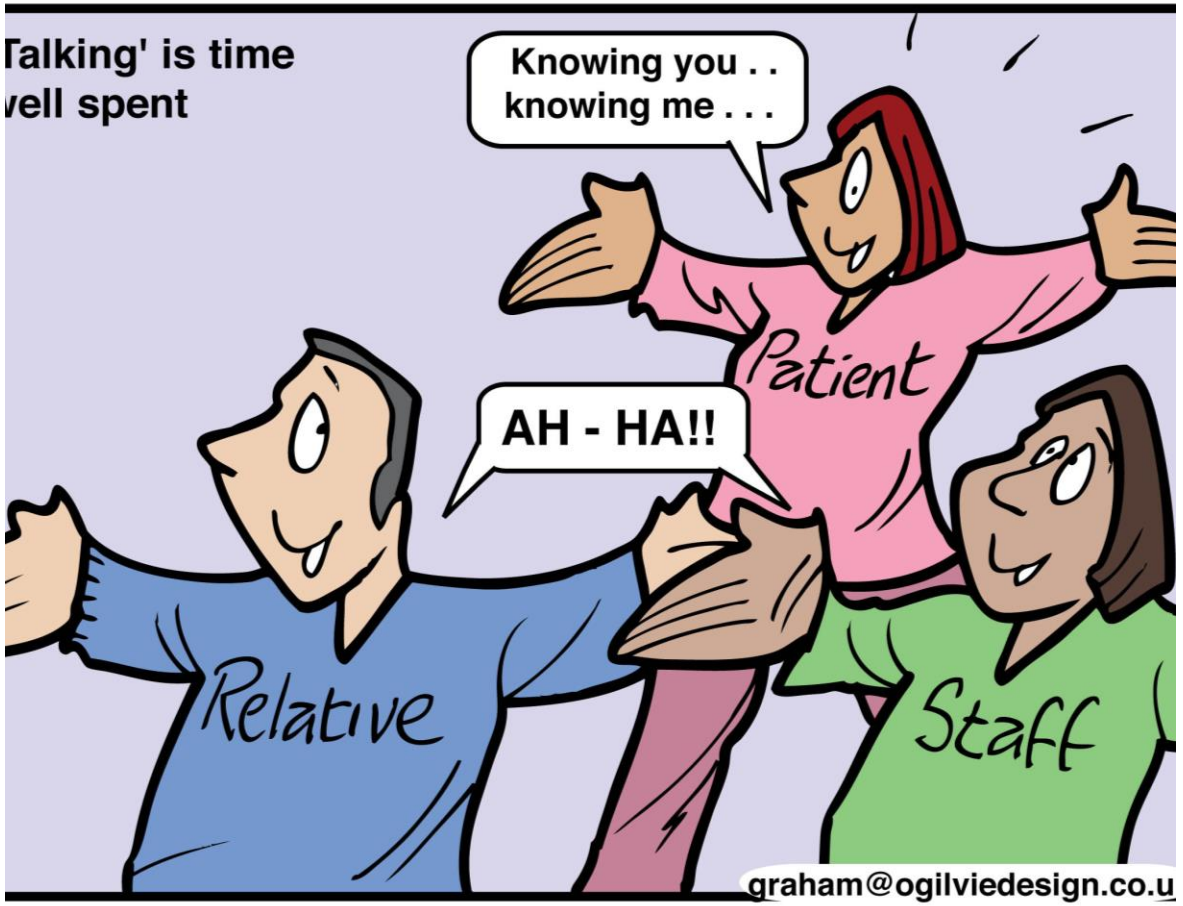
CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

MICHAEL SMITH FOUNDATION FOR HEALTH RESEARCH
Discover. Connect. Engage.

NOVA SCOTIA Health Research FOUNDATION

Alzheimer Society CANADA

Questions?



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SENIORS – ADDING *LIFE* TO YEARS (SALTY)

Stream 1: Prioritize & Monitor Resident Outcomes Near the End of Life

Matthias Hoben

Faculty of Nursing, University of Alberta

brainXchange webinar

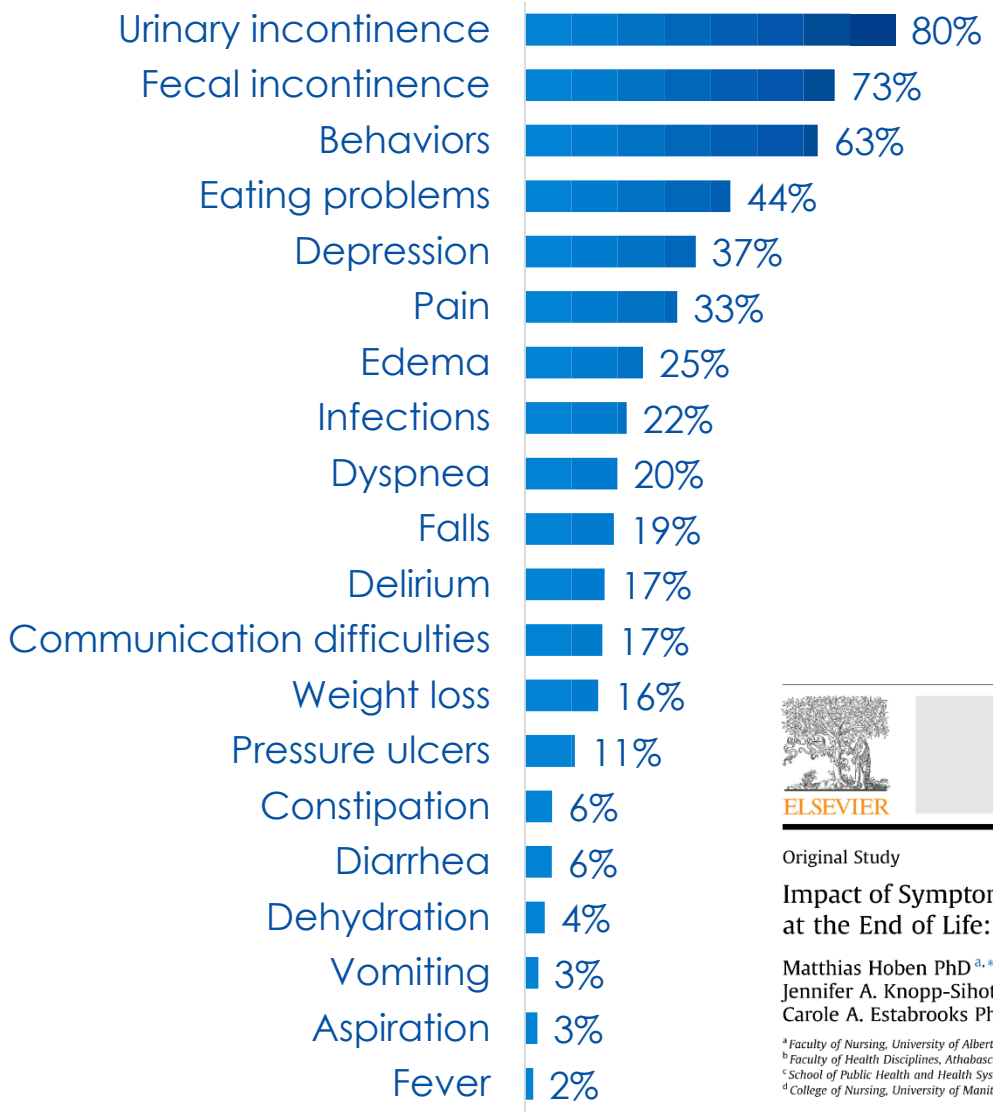
April 9, 2019

TREC
Translating Research in Elder Care

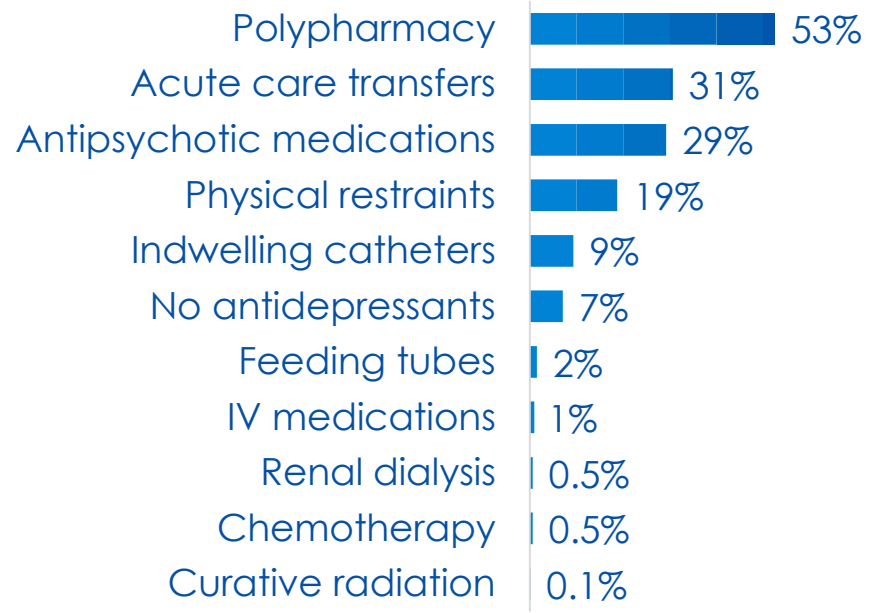
SALTY
Seniors-Adding Life to Years

Burdensome symptoms and potentially inappropriate care are common at the end of life in nursing home residents

Burdensome Symptoms



Potentially Inappropriate Care



JAMDA 17 (2016) 155–161

ELSEVIER

JAMDA

journal homepage: www.jamda.com

Original Study

Impact of Symptoms and Care Practices on Nursing Home Residents at the End of Life: A Rating by Front-line Care Providers

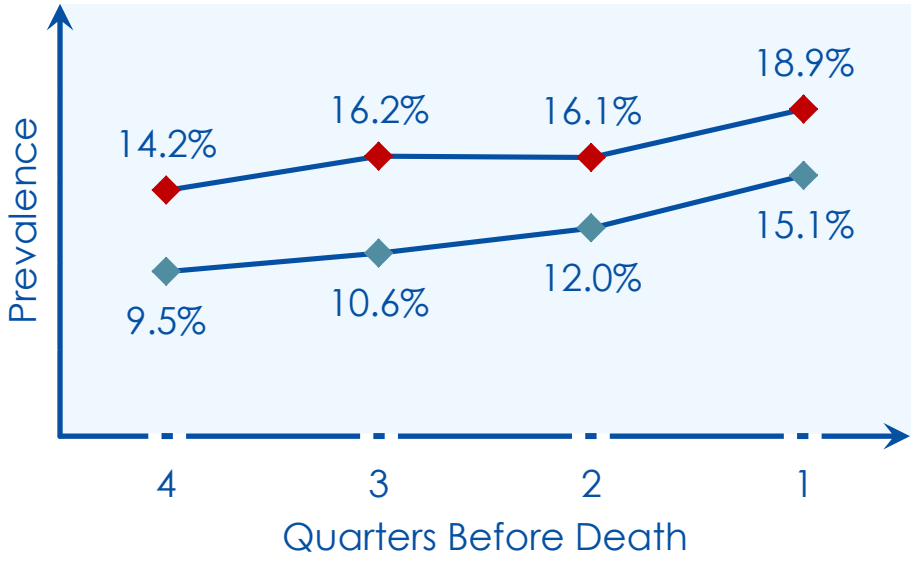
Matthias Hoben PhD [a,*], Stephanie A. Chamberlain MA [a], Jennifer A. Knopp-Sihota PhD [a,b], Jeffrey W. Poss PhD [c], Genevieve N. Thompson PhD [d], Carole A. Estabrooks PhD [a]

[a] Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada
[b] Faculty of Health Disciplines, Athabasca University, Edmonton, Alberta, Canada
[c] School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, Canada
[d] College of Nursing, University of Manitoba, Winnipeg, Manitoba, Canada

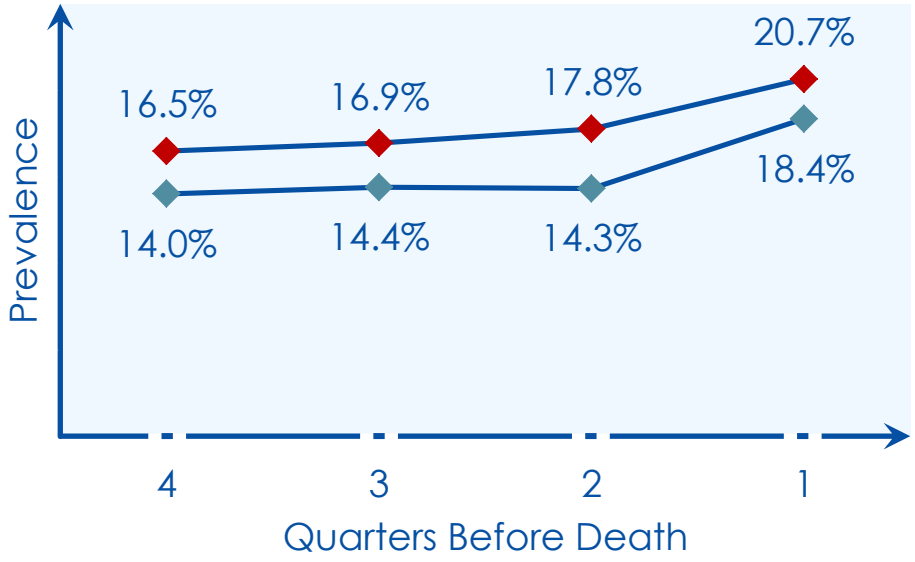
*Last assessments of N=6007 residents deceased between 2007 and 2011 in 30 Western Canadian nursing homes

Symptom burden increases towards the end of life but is lower in facilities with more favorable work environments

Dyspnea



Pain



JAMDA 16 (2015) 515–520

JAMDA

journal homepage: www.jamda.com

Original Study

Dying in a Nursing Home: Treatable Symptom Burden and its Link to Modifiable Features of Work Context

Carole A. Estabrooks PhD [a,*], Matthias Hoben PhD [a], Jeffrey W. Poss PhD [b], Stephanie A. Chamberlain MA [a], Genevieve N. Thompson PhD [c], James L. Silvius MD [d], Peter G. Norton MD [e]

[a] Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada
[b] School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, Canada
[c] College of Nursing, University of Manitoba, Winnipeg, Manitoba, Canada
[d] Division of Geriatric Medicine, Department of Medicine, University of Calgary, Calgary, Alberta, Canada
[e] Department of Family Medicine, University of Calgary, Calgary, Alberta, Canada

- Less favorable work context
- More favorable work context

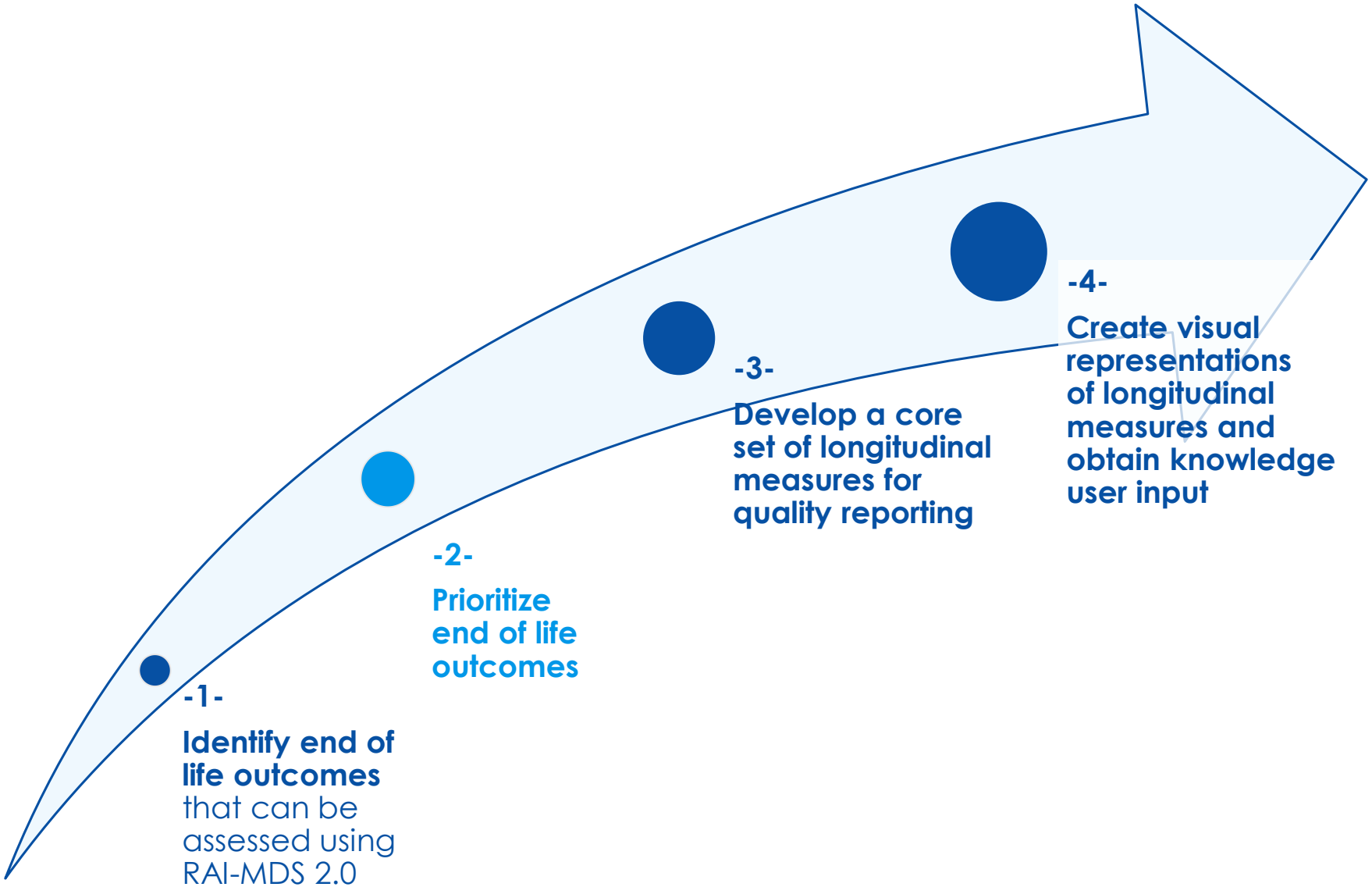
($P_{Context}$<0.0001; P_{time}<0.0001)

*Last four assessments of N=3647 residents deceased between 2007 and 2011 in 30 Western Canadian nursing homes

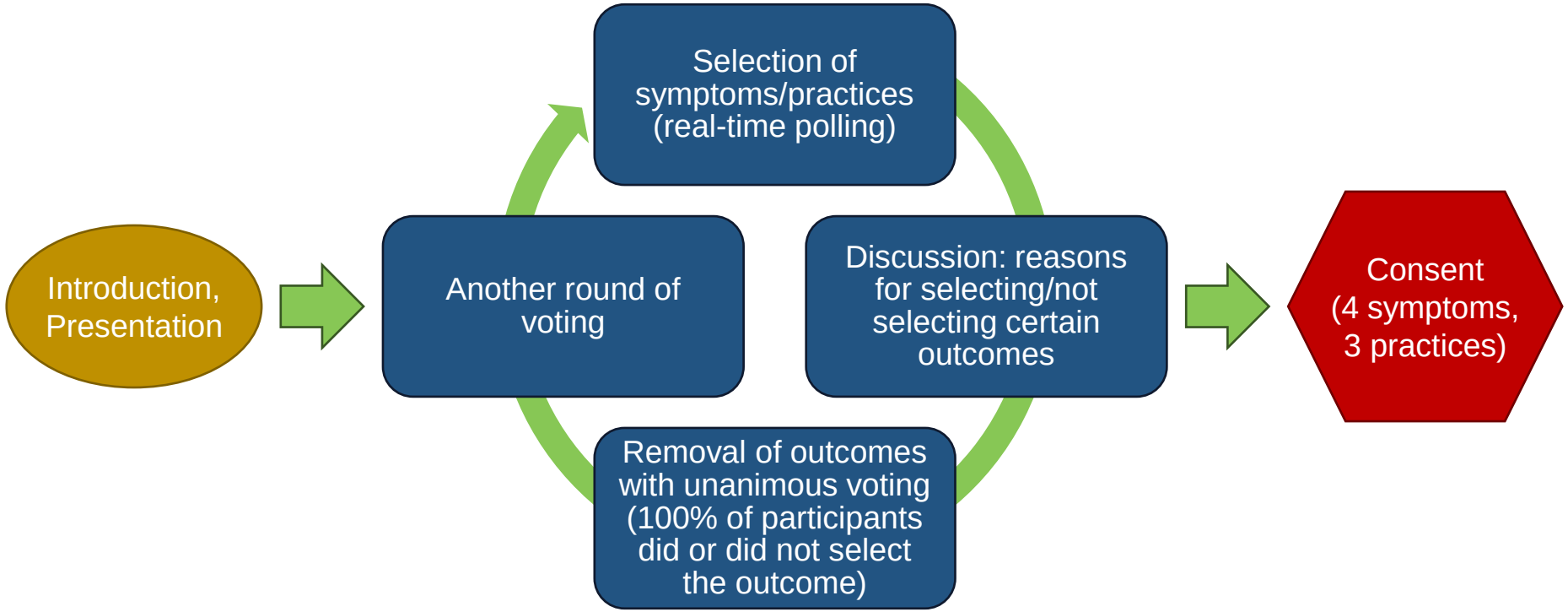
stream 1 aims to identify burdensome symptoms and potentially inappropriate care

➲ *If we can't measure it, we can't improve it*

Project steps



Web-based Delphi panels with LTC policy/decision makers



Delphi panels

Outcomes selected by both groups

- Pain
- Depressive symptoms
- Poly-pharmacy

Outcomes selected by policy makers only

- Shortness of breath
- Infections
- Acute care transfers
- No use of anti-depressants

Outcomes selected only by Advisory Group members

- Responsive behaviours
- Communi-cation diff.
- Use of anti-psychotics
- Use of phys. restraints

What have we done so far?

Spoken to …

- government and health authority stakeholders
- TREC/SALTY advisory board members
- care staff

However, want to include residents' perspectives

Action Project Method

It's all about goals …

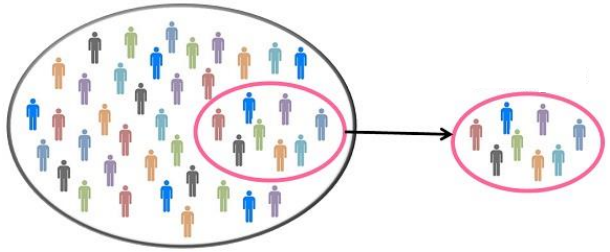
- People work towards goals within a social context
- Actions are goal directed
- Projects: sets of goal directed actions linked over time
- Joint Projects: goal directed actions between two or more socially related people

Why to use the Action Project Method?

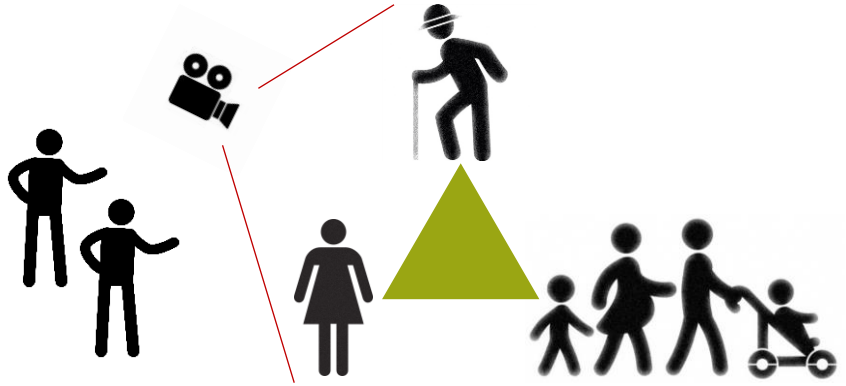
Ideal method for our research purpose

- Living in a nursing home involves projects related to symptoms and care *(e.g., increase happiness through actions that will reduce pain or increase social interactions)*
- Situates residents' experiences within larger social context (e.g., family, friends, caregivers)
- Allows for differences in residents' and their partners' experiences/perspectives

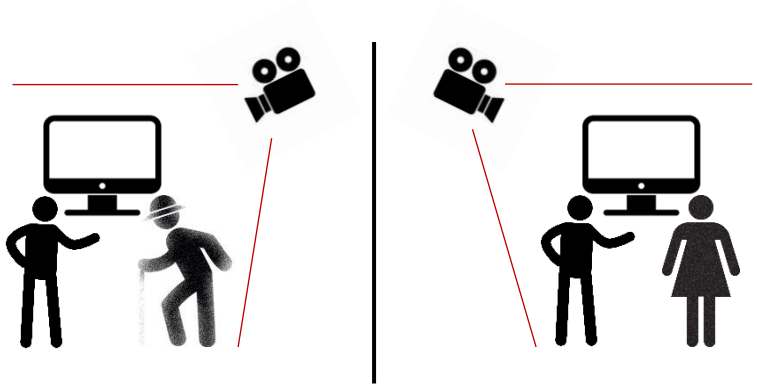
How it works …



Select participants



Dyadic self-guided conversation about symptoms/care



Video recall interview

Analyze data at both dyadic and individual level, compose narratives, present to participants, adjust as needed

What we have done so far

- 5 dyadic interviews and 3 individual interviews
  - Individual interviews unexpected, but show importance of autonomy and agency (control) for some residents
- Various projects, such as creating a positive environment, maintaining physical/emotional intimacy, advocating for needs, and dealing with mortality
- Participant profiles
  - Situate residents within their environment and context
- Dyadic and individual narratives
  - We will be presenting the stories to the participants in the coming weeks

Challenges

- Vulnerable groups
  - Participants are often dealing with physical or cognitive difficulties
  - Never know what to expect with partner that participants choose
  - Must work to develop trust with participants
- Location
  - Hard to find places for interview
  - Participants often have roommates
  - Staff is nearby, difficult if participants are sharing negative experiences about staff
- Technology
  - This method is dependent on technology, so travelling to different locations increases likelihood of issues

Next steps

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