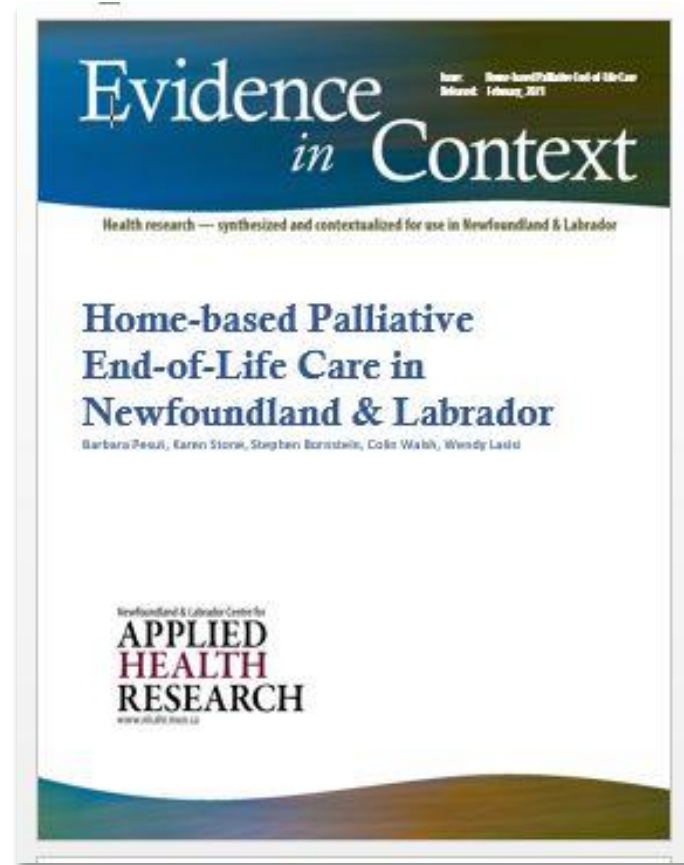




## Home-based Palliative End-of-Life Care in Newfoundland & Labrador

Barbara Pesut, Karen Stone, Stephen Bornstein, Colin Walsh, Wendy Lasisi

Newfoundland & Labrador Centre for  
**APPLIED  
HEALTH  
RESEARCH**  
[www.nlcahr.mun.ca](http://www.nlcahr.mun.ca)



# Welcome

# Home-based Palliative End-of-Life Care

## CHRSP Project Team



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Subject Matter Expert  
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NL Centre of Applied Health Research



**Stephen Bornstein, Ph.D.**  
Program Director, CHRSP  
Director, NL Centre of Applied Health  
Research, and Professor, Political Science  
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**Project Team**  
Consultants and Advisers  
Government NL  
Regional Health Authorities  
Patients and Caregivers  
Research Exchange Group on Palliative  
and End-of-Life Care

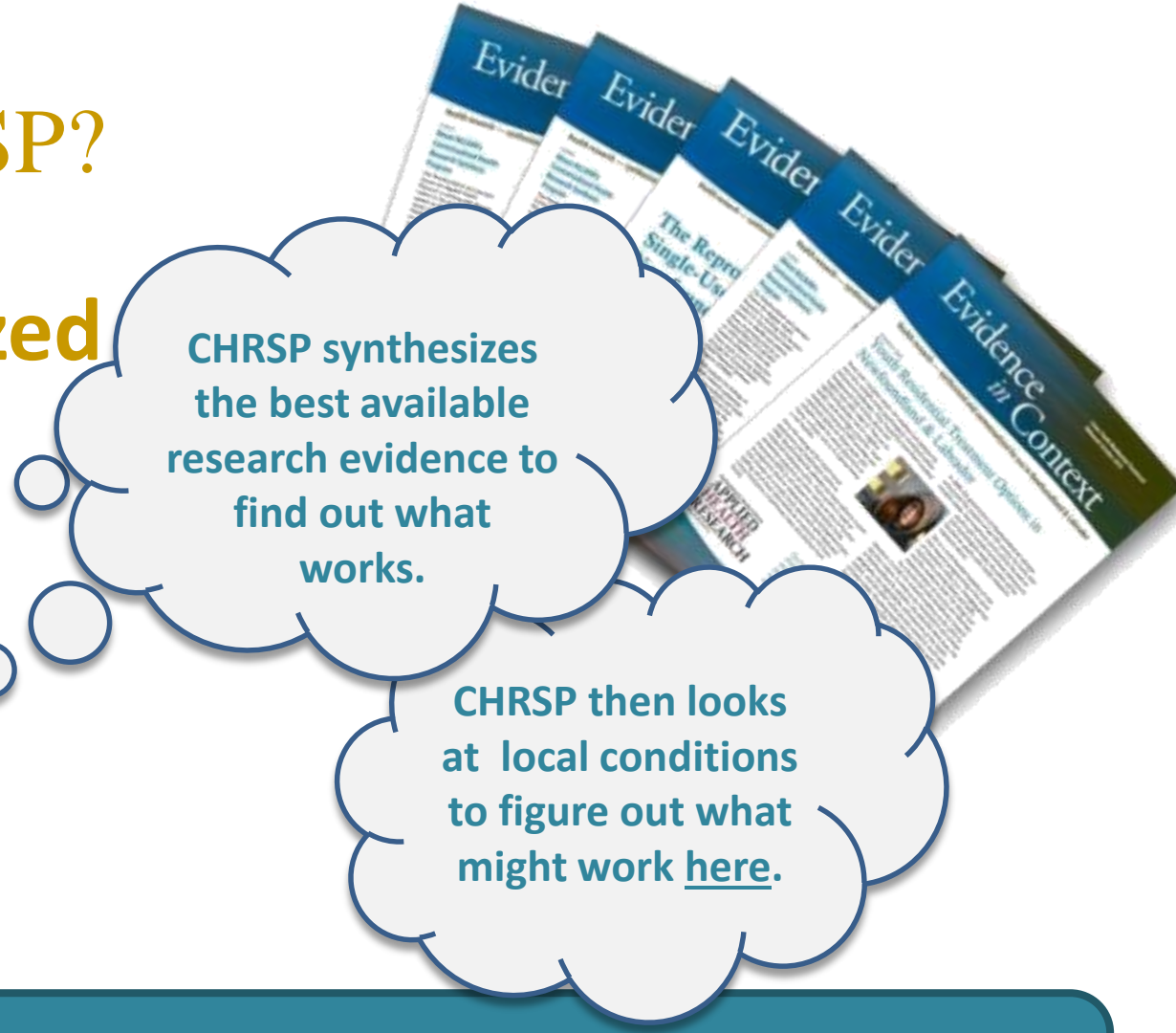
# Today's Session

## OVERVIEW

- **About CHRSP** – Stephen Bornstein
- **Background and Methods** – Colin Walsh
- **Synthesis Findings** – Barbara Pesut
- **Considerations for Decision Makers** – Colin Walsh
- **Facilitated Discussion** – Stephen Bornstein

# What is CHRSP?

- **Contextualized**
- **Health**
- **Research**
- **Synthesis**
- **Program**



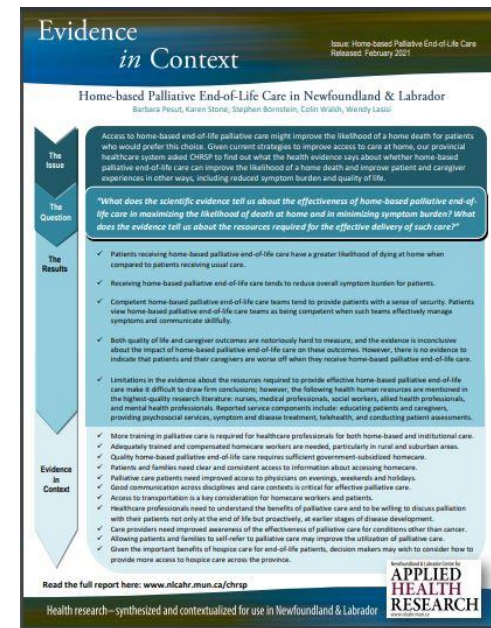
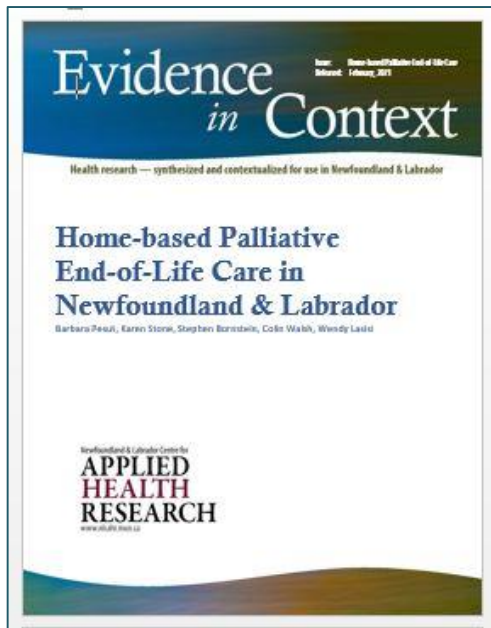
CHRSP synthesizes the best available research evidence to find out what works.

CHRSP then looks at local conditions to figure out what might work here.

Designed to support evidence-informed health policy in Newfoundland & Labrador.



# Colin Walsh: Background and Methods



# Background



Decision makers in Newfoundland and Labrador want to help people receive care in their own homes, including care at the end of life. With this in mind, health system decision makers from across the province asked CHRSP to find out more about home-based palliative end-of-life care (HPC).

# Research Question

“What does the scientific evidence tell us about the effectiveness of home-based palliative end-of-life care in maximizing the likelihood of death at home and in minimizing symptom burden?

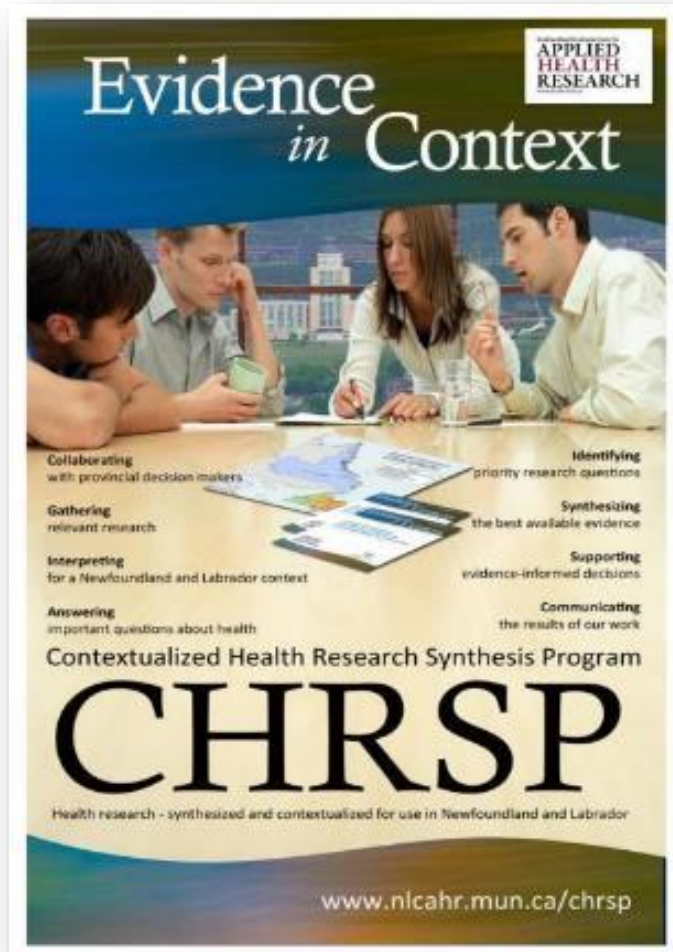
What does the evidence tell us about the resources required for the effective delivery of such care?”





# Evidence in Context Method

- Assemble a team
- Synthesize the evidence
- Contextualize the evidence
- Considerations for Decision Makers
- Report in various formats



# What did we look for?

- Systematic reviews, meta-analyses
- High-quality primary studies
- Population: adults receiving palliative care at home and/or their caregivers
- Comparator: palliative care in an institution
- Outcomes: the likelihood of death at home, symptom burden, quality of life



# Evidence Rating System

Measures the strength of the body of evidence

- Quality of systematic reviews
- Number of systematic reviews
- Consistency of research findings
- Number of underlying primary research studies

Body of Evidence	Synthesis Finding		
	Favouring	No Effect	Conflicting or Against
Very strong	✓✓✓	✓✓✓	✗
Strong	✓✓	✓✓	✗
Moderate	✓	✓	✗
Weak or Very Weak	~	~	✗

# What did we find?

6 Systematic Reviews:	Methodological Quality (AMSTAR)
Cochrane Review by Gomes 2013	High Quality
Cochrane Review by Shepperd 2016	
Costa 2016	Moderate Quality
Luckett 2013	
Miranda 2019	
Sarmiento 2016	

# What did we find?

6 Recent Primary Studies:	Methodological Quality (Downs & Black)
Abe 2019	Good Quality
Tanuseputro 2018	
Wang 2019	
Kjellstadli 2018	
Nagaviroj 2017	Fair Quality
Tan 2019	

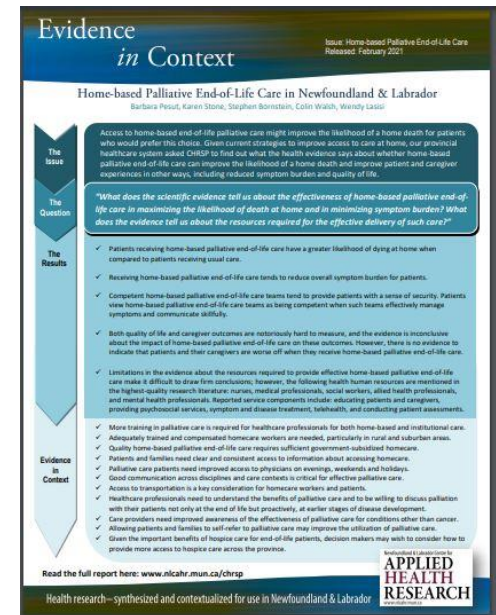
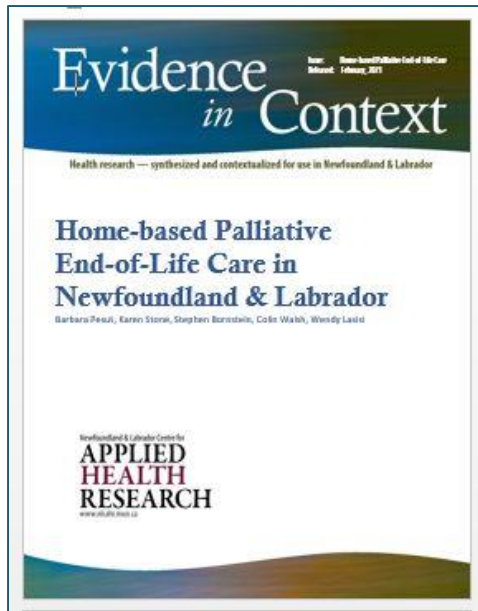


# Limitations of the Evidence



- Definitions of the comparator – “Usual Care” – are highly variable
- Multiple challenges locating evidence about the *resources* required for effective HPC

# Barbara Pesut: Synthesis Findings



# Key Message #1

The available research evidence indicates that patients receiving home-based palliative end-of-life care have a greater likelihood of dying at home when compared to patients receiving usual care.



## Key Message #2

The available research evidence suggests that receiving home-based palliative end-of-life care tends to reduce overall symptom burden for patients.



## Key Message #3

Competent home-based palliative end-of-life care teams tend to provide patients with a sense of security. Patients view home-based palliative end-of-life care teams as being competent when such teams manage symptoms effectively and communicate skillfully.





## Key Message #4

Quality of life and caregiver outcomes are notoriously hard to measure.

The evidence is inconclusive about the impact of home-based palliative end-of-life care on these outcomes.

We found no evidence to indicate that patients and their caregivers are worse off when they receive home-based palliative end-of-life care.



# Key Message #5

Limitations of the evidence about the resources required for effective HPC care make it difficult to draw firm conclusions.

**Health human resources**  
most often mentioned:

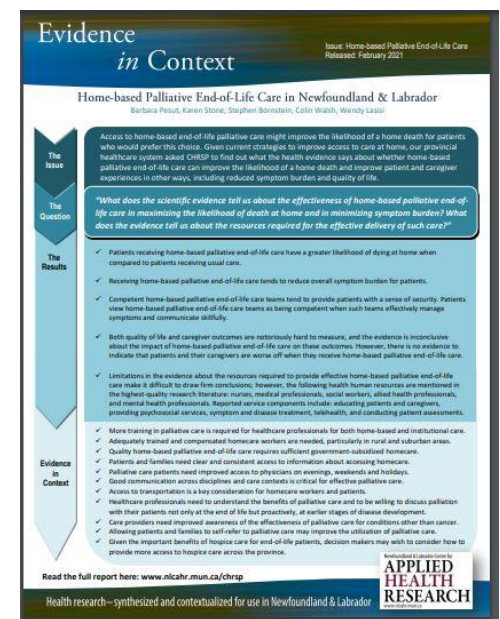
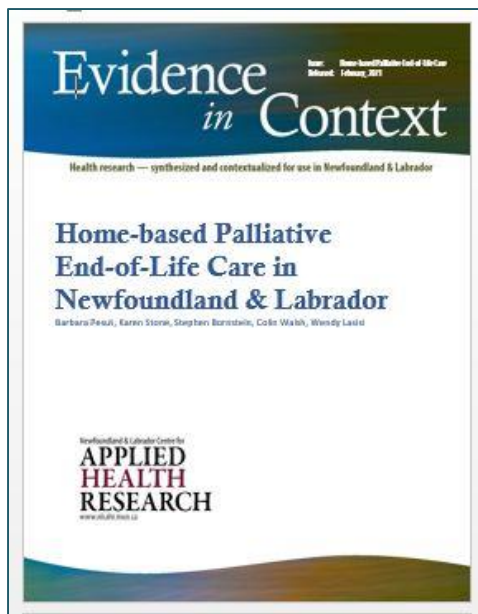
- nurses
- medical professionals
- social workers
- allied health professionals
- mental health professionals

**Service components**  
most often mentioned:

- educating patients and caregivers
- psychosocial services
- symptom and disease treatment
- telehealth



# Colin Walsh: Considerations for Decision Makers



# Training

Healthcare professionals need adequate training in palliative care—  
for both home-based and institutional care



Decision  
↑  
Context  
↑  
Evidence

# Home Support

More adequately-trained and compensated homecare workers are needed, particularly in rural and suburban areas.



Decision  
↑  
Context  
↑  
Evidence



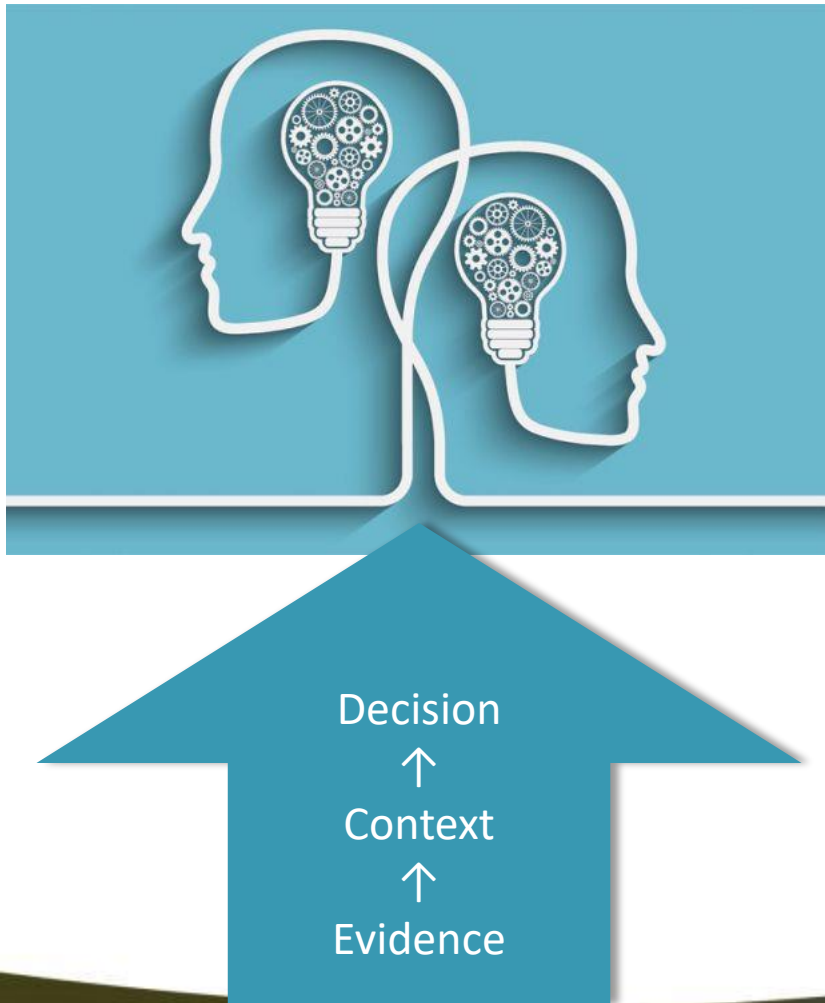
# Subsidized Support Hours

Quality patient care at the end of life requires sufficient government-subsidized homecare of all types, including palliative care.



Decision  
↑  
Context  
↑  
Evidence

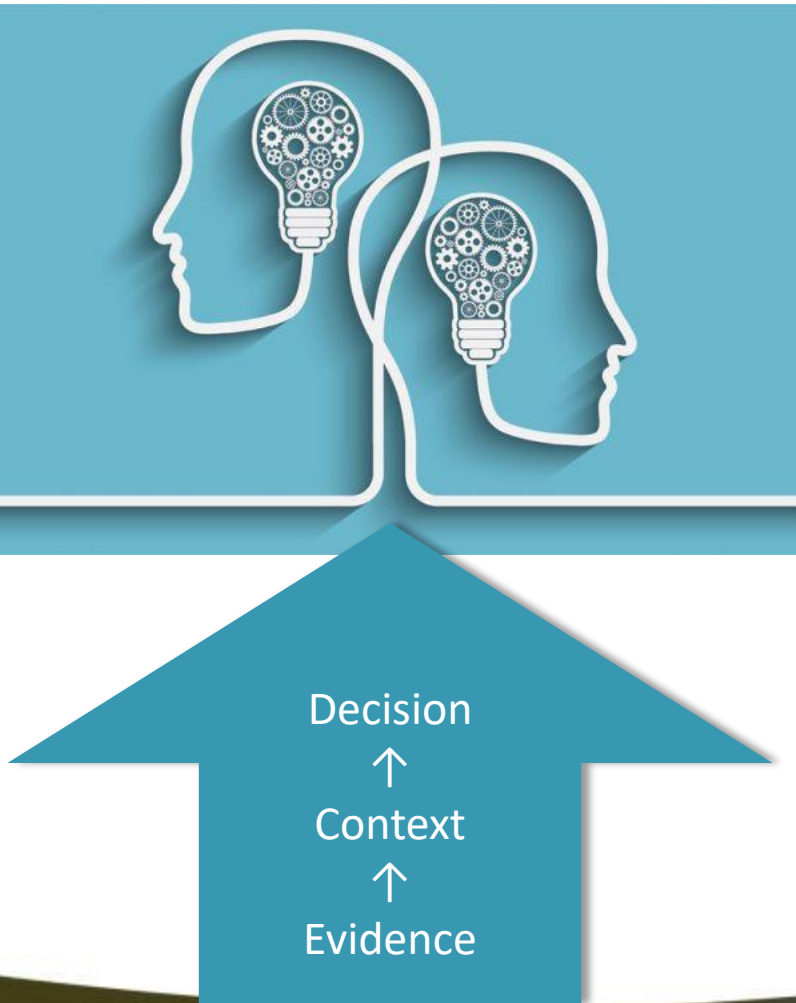
# Information for families



Patients and their families need clear and consistent access to information about what homecare is available to them and how they can access it.

# Access to Physicians

Palliative care patients need improved access to physicians on evenings, weekends and holidays.



# Communication & Knowledge Sharing

Communication and knowledge-sharing is critical for effective palliative care.

- Across RHAs
- Sharing patient information
- Connecting across disciplines and care contexts



Decision  
↑  
Context  
↑  
Evidence

# Transportation Issues

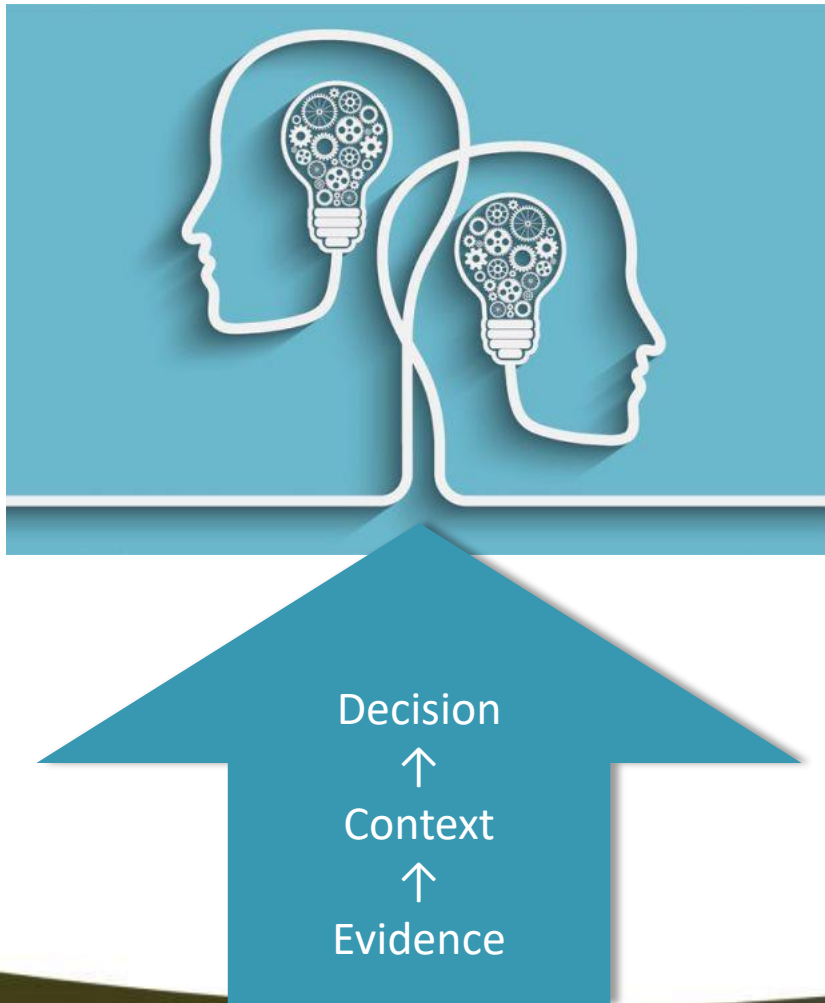
Access to public transportation, or to publicly-subsidized transportation for homecare workers and their patients, especially outside the province's principal cities, is a key consideration



Decision  
↑  
Context  
↑  
Evidence

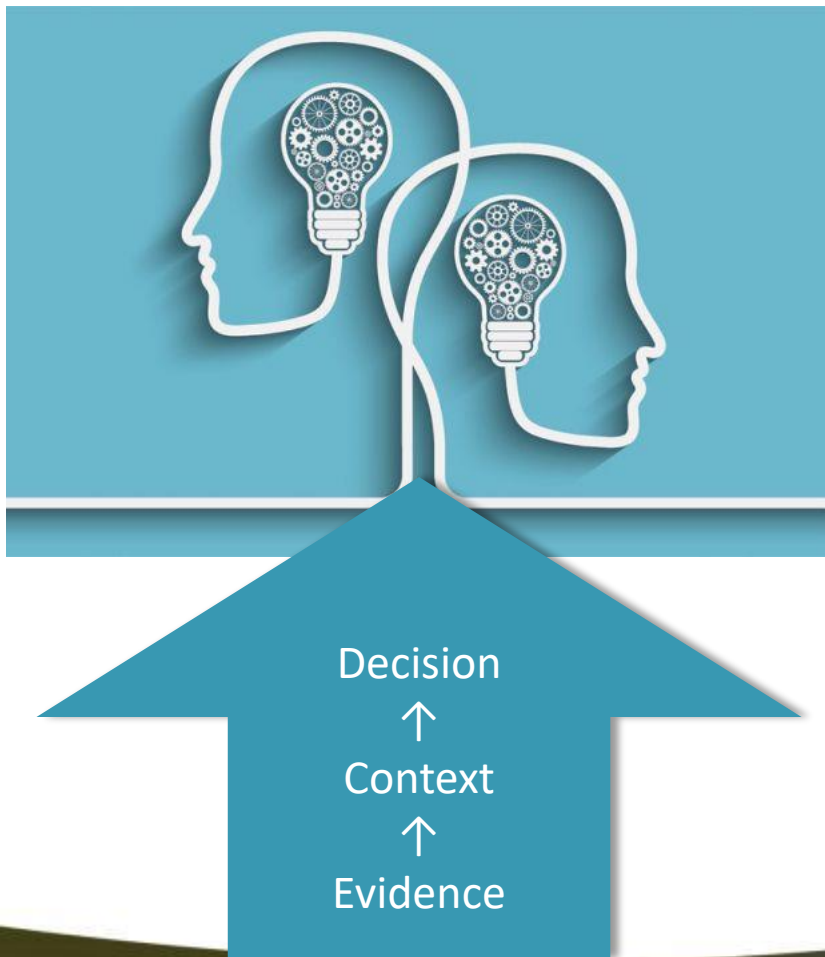


# Understanding Palliative Care



Healthcare professionals need to better understand the benefits of palliative care and to be willing to discuss palliation with their patients, not only at the end of life but proactively, at earlier stages of disease development.

# Patients with a variety of health conditions



Physicians and other care providers need improved awareness of the effectiveness of palliative care for patients with conditions other than cancer.

# Self-referral

Allowing patients and their families to self-refer may improve patient access to care in cases where physicians are reluctant to discuss palliation with their patients.



Decision  
↑  
Context  
↑  
Evidence

# The Hospice Option

Given the benefits of hospice care for end-of-life patients, decision makers may wish to consider how to provide more access to hospice care across the province.



Decision  
↑  
Context  
↑  
Evidence

# Questions/ Discussion





Evidence  
*in* Context

Health research —  
synthesized & contextualized for  
use in Newfoundland & Labrador.

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