

**Palliative Care**  
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National Consensus

**L'importance des**  
**soins palliatifs** | Forger  
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Elements of Integrated and Coordinated Palliative Care

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## Disclosure

- I have no Conflicts of Interest

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## Acknowledgements

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**What are the essential elements of an integrated and coordinated palliative care program that will help improve access to quality palliative care in Canada?**

## The Issue

- The WHO's definition of **palliative care**:

*'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'*

- This has implications for health systems:
  1. Palliative care needs to be included in the **continuum of care**, provided alongside potential curative treatments
  2. All should have access to **essential, safe, affordable & effective** palliative care services

## The Issue

- Despite two decades & a growing evidence base of integrating palliative care into regular care, the majority of Canadians don't have access to the benefits of a **regional, comprehensive, coordinated & integrated** palliative care program
  - Palliative care in Canada is viewed as **suboptimal, fragmented & uncoordinated**; patients aren't always able to realise their **preferences for care** & place of death; **crisis management** occurs
- What the public expect from a universal health care model needs to be taken into account
- A **population health approach** to planning is required – acknowledging the importance of **communities**

## The Issue

### STAKEHOLDERS

- 4 key groups need to work together to **effect change & improve** the quality of palliative care:
  - 1. Governmental organizations**
  - 2. Nongovernmental organizations**
  - 3. Professional healthcare organizations**
  - 4. Public engagement**

## Contents

- What Canadians consider as essential elements in palliative care
- What the literature tells us about integrated care
- Integrated care in palliative care
- Implications

# What Canadians consider as essential elements in palliative care

- Ipsos Public Affairs survey -
  - Respondents were presented with **27 elements** which could be included in a **national palliative health care program**
  - Respondents were presented with a list of **15 additional elements** which could apply to a **palliative home care program**



## Most Essential Elements: National Palliative Care Program Facility

|                               | Rank | Agree | Disagree | Don't know |
|-------------------------------|------|-------|----------|------------|
| Pain management               | 1    | 92%   | 2%       | 6%         |
| Personal hygiene              | 2    | 92%   | 2%       | 5%         |
| Specialized nursing care      | 3    | 91%   | 3%       | 6%         |
| Medications                   | 4    | 91%   | 3%       | 6%         |
| Meals                         | 5    | 91%   | 3%       | 6%         |
| Specialized physician         | 6    | 90%   | 3%       | 6%         |
| Individual to coordinate care | 7    | 88%   | 4%       | 7%         |

MOST ESSENTIAL

## Other Essential Elements: Palliative Care Program

|                                                        | Rank | Agree | Disagree | Don't know |
|--------------------------------------------------------|------|-------|----------|------------|
| Specialized personal support workers                   | 8    | 86%   | 4%       | 9%         |
| Dedicated palliative care unit in health care facility | 9    | 86%   | 5%       | 8%         |
| Psychological counselling                              | 10   | 85%   | 6%       | 8%         |
| Nutrition management                                   | 11   | 83%   | 7%       | 9%         |
| Minimum nurse : patient ratio                          | 12   | 82%   | 9%       | 9%         |
| Social workers to explain services                     | 13   | 82%   | 9%       | 9%         |
| Beds for overnight stay                                | 14   | 82%   | 10%      | 8%         |

OTHER ESSENTIAL

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## Attitudes Towards Palliative Care Program

|                                                                                              | Rank | Agree | Disagree | Don't know |
|----------------------------------------------------------------------------------------------|------|-------|----------|------------|
| Close family & friends important to the patient should be able to visit at any time          | 1    | 91%   | 4%       | 4%         |
| The public health system should cover the costs of palliative care so that all can access    | 2    | 89%   | 4%       | 6%         |
| The environment & furniture should provide a home-like setting                               | 3    | 85%   | 7%       | 7%         |
| Patients should have the ability to practice cultural traditions in palliative care settings | 4    | 76%   | 13%      | 12%        |

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## Most Essential Elements of a Palliative Home Care Program

|                                                   | Rank | Agree | Disagree | Don't know |
|---------------------------------------------------|------|-------|----------|------------|
| 24/7 access to specialist nurse                   | 1    | 91%   | 2%       | 7%         |
| Daily assistance with care giving                 | 2    | 91%   | 3%       | 6%         |
| Access to equipment as needed                     | 3    | 91%   | 3%       | 7%         |
| Panic alerts/buttons for patients when left alone | 4    | 91%   | 3%       | 6%         |
| Education & information for caregivers            | 5    | 91%   | 2%       | 7%         |
| Someone in the system to coordinate care          | 6    | 91%   | 2%       | 7%         |
| Single access point for help                      | 7    | 90%   | 3%       | 7%         |

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## Other Essential Elements of a Palliative Home Care Program

|                                                         | Rank | Agree | Disagree | Don't know |
|---------------------------------------------------------|------|-------|----------|------------|
| On-call access to specialist doctor                     | 8    | 89%   | 3%       | 7%         |
| Respite services for caregivers as needed               | 9    | 87%   | 3%       | 9%         |
| Social worker/ care providers providing weekly checks   | 10   | 86%   | 5%       | 8%         |
| In home chart accessible to all                         | 11   | 85%   | 4%       | 10%        |
| Financial support for caregivers who take time off work | 12   | 83%   | 9%       | 9%         |
| Renovation funding                                      | 13   | 80%   | 11%      | 9%         |

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## Attitudes Towards Palliative Home Care

|                                                                                                    | Rank | Agree | Disagree | Don't know |
|----------------------------------------------------------------------------------------------------|------|-------|----------|------------|
| Patients should have the right to receive care in their own home at the end of life                | 1    | 90%   | 4%       | 6%         |
| The public health system should cover the costs of palliative care so all can access it as needed  | 2    | 86%   | 6%       | 6%         |
| Access to all types of palliative home care services should be available in rural locations        | 3    | 86%   | 6%       | 8%         |
| Palliative care should be provided in a person's home as much as possible                          | 4    | 86%   | 6%       | 7%         |
| Palliative home care services should be provided as frequently in rural locations as urban centres | 5    | 85%   | 7%       | 7%         |

## What the literature tells us about integrated care

- Integrated care is an **important framework** to **enhance quality of care, efficiency**, and **patient satisfaction** in health & social care systems
- Aim:  
To address fragmentation in patient services, and enable better coordinated and more continuous care
- **But what is integrated care...? First let's consider...**



## The Tower of Babel



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## What the literature tells us about integrated care

- A recent review of the literature reveals some **175 definitions & concepts** of what is meant by integration & integrated care
- The WHO's definition of **integrated healthcare services**:

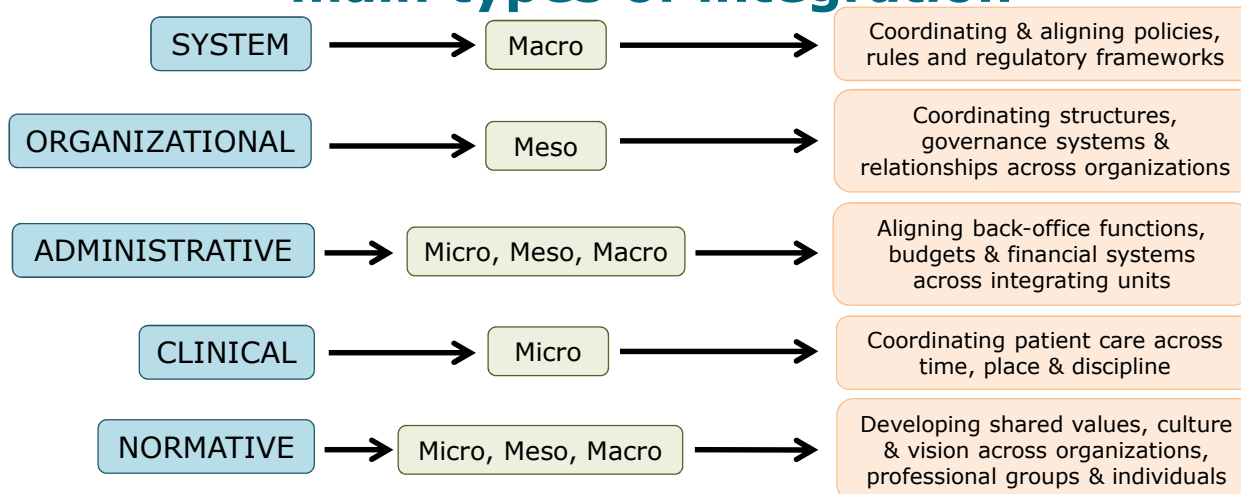
*'The management & delivery of health services so that clients receive a continuum of preventative & curative services, according to their needs over time and across different levels of the health system'*

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## Common taxonomy– used to identify the main types of integration



## Intensity of integration



## Expression of integration

- **Lack of evidence** about which integrative types are best suited to a particular setting
- It is widely accepted that:
  - “**One size of integrated care does not suit all**”
- Consider the context (care setting)
- Guided by objectives, stakeholders, availability of resources & scale of initiative

## Integrated Care in Palliative Care

- The WHO's definition of palliative care has implications for health systems:
  - They need to include palliative care in the continuum of care linking to **prevention, early detection** and **treatment programs**
  - It is **not** just an optional extra
  - Needs to be provided **alongside** potentially curative treatments
  - Needs to be provided in accordance with the principles of **universal health coverage**
- Most Canadians' views on essential elements & attitudes of a palliative care program resonate with the WHO

## Integrated Care in Palliative Care

- Integrated palliative care needs to be addressed at different levels:
  - Treatment guidelines
  - Interdisciplinary collaboration
  - Supportive role of informal caregivers
  - Community care
  - Institutional care
- Context shapes service - communities play an **increasingly significant role** in their own health & social care
- **Compassionate communities**
  - a public health approach to end of life care
  - enabling all to live well within own community to the end of life

## Integrated Palliative Care (IPC)

- EU research project **InSUP-C**: international research team aim to find the best way to deliver care to people at the end of life
  - Defined **IPC** as:
 

*'Bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid & unpaid'*
  - Via expert consensus created a taxonomy for IPC initiatives applicable across diseases, healthcare sectors & systems
  - A substantive step towards how we **define & understand IPC**

## Taxonomy Categories for IPC

### 1. TYPE OF INITIATIVE

Guidelines, pathway, model

### 2. LEVEL OF CARE

Primary, Secondary, Tertiary

### 3. SECTOR

Inpatient, homecare

### 4. TIME FRAME OF INTERVENTION

Early integration, concurrent, end of life

### 5. FOCUS OF INTERVENTION

Treating function, advising/consulting, training

### 6. COLLABORATION

Network, protocols, team, case management

### 7. KEY CONTACT

Non-palliative & palliative care specialists, GPs

#### • Benefits

- Template to classify schemes & initiatives in other areas
- Toolkit for policy makers & professional caregivers to enhance IPC knowledge
- Facilitator for future development & cooperation of IPC

## Implications

- Governmental organizations, nongovernmental organizations, & professional healthcare organizations must **work together** to effect change & the quality of an integrated palliative care program
- Most Canadians:
  - expect federal government to develop & implement national standards for palliative care supporting integration into the **Canada Health Act**
  - agree that the public health system should **cover the costs** of palliative care
  - views resonate with the WHO on palliative care - promoting the action national health systems need to provide palliative care in accordance with the **principles of universal health coverage**
  - have clear preferences as to what comprises the **essential elements** of quality palliative care

## Implications

- Canadians feel:
  - that patients at the end of life should have the **right to receive quality palliative care** whether it is in a facility or their home
  - that rural communities should have **access to quality palliative care**
- Palliative care needs to be **included in the continuum of care** linking to **early integration**, concurrent with regular treatment as well as at the end stages of advanced illness
- Elements that comprise quality palliative care are required to be **embedded** in an **integrated, coordinated system of care**
- Integrated palliative care is shaped by **context** involving considerations on project goals, stakeholders involved, existing arrangements, availability of resources & the scale of the initiative

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## Elements of Integrated and Coordinated Palliative Care

### Questions

