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Growing Global Leaders…
Advancing Palliative Care

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NCI's Office of International Affairs

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The Work Continues

Using the Five Practices of Leadership to Influence Provincial & National Organizations

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Texas
Loui siana
50 States info

Historical Perspective

- Cancer Care 2000
- Canadian Hospice/Palliative Care Association
- Senate Reports
- Secretariat on Palliative and End-of-Life Care
- Federal Reports
- Canadian Partnership Against Cancer


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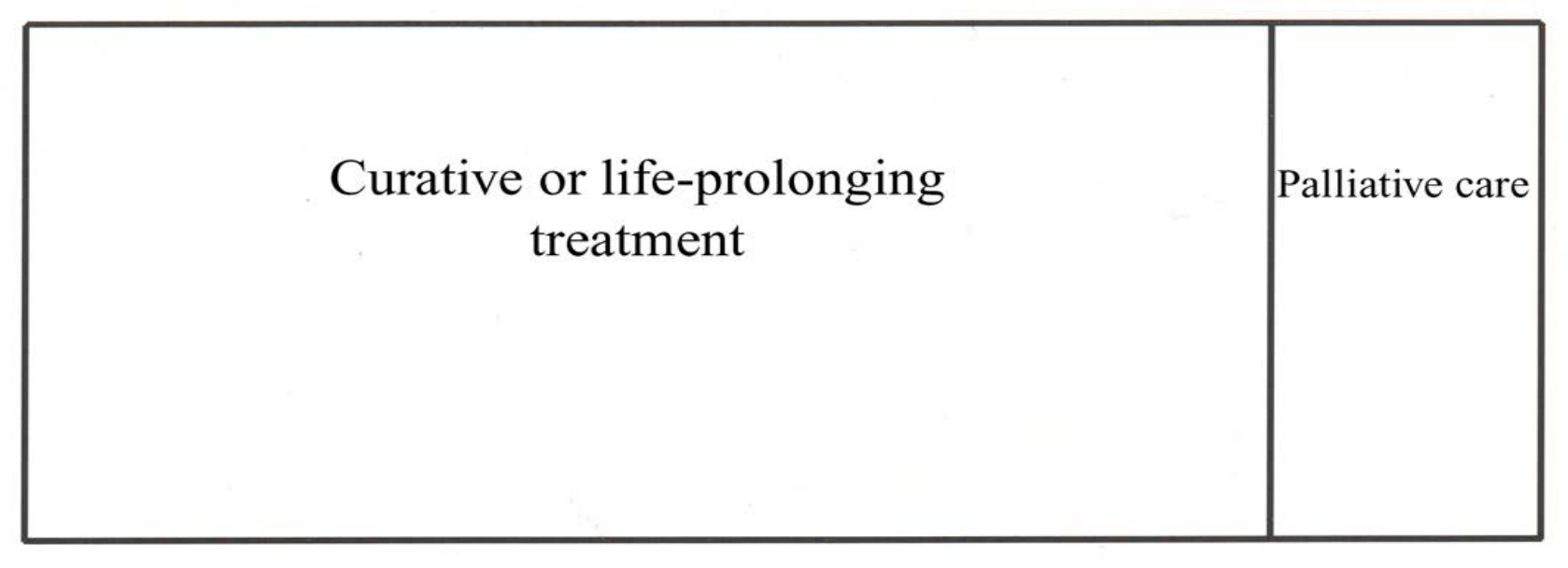
Ontario's Ministry of Health & Long-Term Care

- **End-of –Life Care Strategy (2004)**
  - **$115.5 M (US $) over 3 years**
  - **To shift care from acute care settings to appropriate alternate settings of choice**
  - **To enhance client-centered & interdisciplinary service capacity**
  - **To improve access, coordination and consistency of services and supports**

Cancer Care Ontario

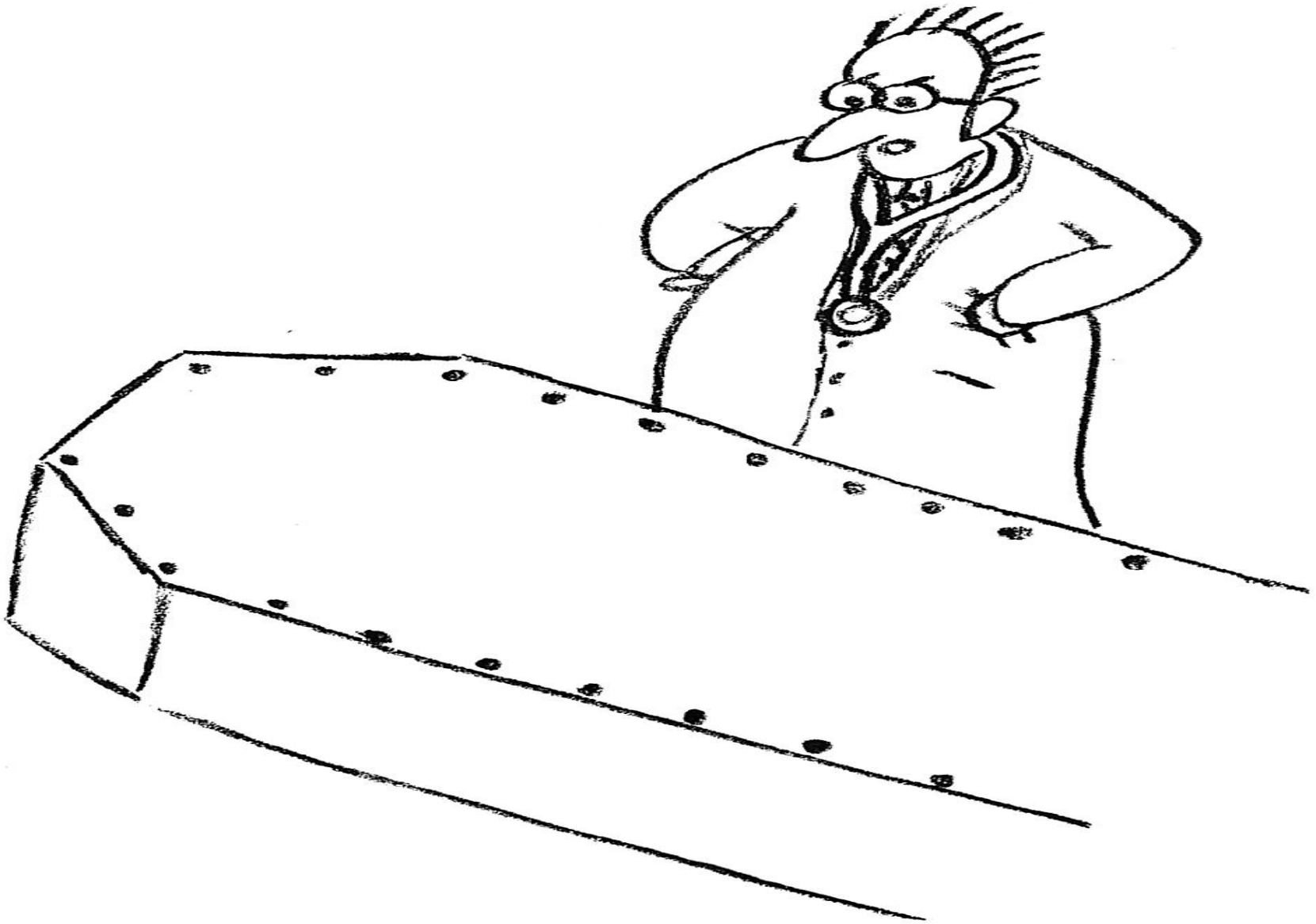
- Provincial Government's chief cancer advisor
- Directs nearly $700 Million
- Mandate to develop an integrated cancer system with coordinated cancer services
- Works with regional providers to plan and improve services
- Ontario Cancer Plan: Palliative Care a priority

Traditional' Model of Care'



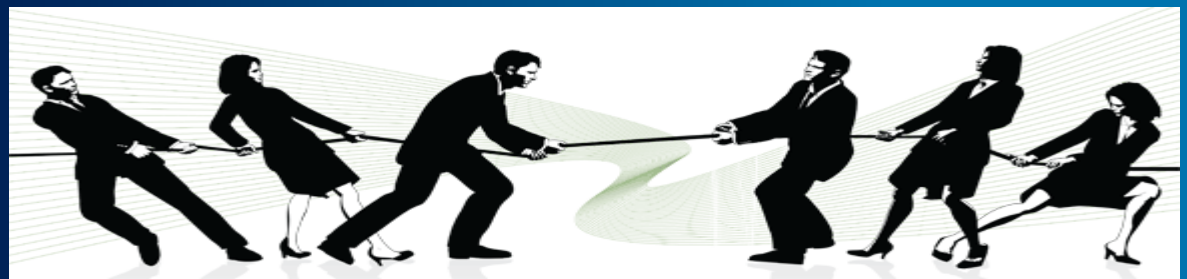
Adapted from Cancer Pain Relief and Palliative Care. Technical Report Series 804. Geneva: World Health Organization, 1990

But we have a promising new phase II drug...



Two Solitudes

- Oncology
  - Curative therapies
  - Clinical trials, scientific basis
  - “high-tech” therapies
  - “Cancer can be beaten”
  - Optimists
- Palliative Care
  - Grass-roots movement
  - Dissatisfaction with modern medicine’s way of caring for terminally ill patient
  - An alternative system of whole person care



Factors that support/impede change/innovation spread

- External context
- Readiness for change
- Characteristics of the innovation
- Organizational communication, influence and linkages
- Dissemination & assimilation processes
- Organizational culture

BMC Hlth Services Research 2009, 9:245

Readiness for Change

- More than 25,000 people in Ontario die with cancer each year
- 80-85% of people seen by palliative teams have cancer
- Patients experience significant physical, psychological, social & spiritual distress & suffering as a result of a cancer diagnosis
- Wide variations in access & quality across the province


MODEL
THE WAY

Activities

- Travelled to each region
- Met with regional teams with Vice presidents of the cancer centers

CCO Board Report

Recommendations following regional site visits:

- **Stable funding for:**
  - **Physicians**
  - **Advanced practice nurses**
- **Development & implementation of provincial standards and guidelines**
- **Appointment of regional leadership**
- **Enhance data collection on palliative services**

CCO's Palliative Care Program

Principles for strategy development:

- **Consistent with CCO strategy**
- **Consistent with, and complementary to, provincial EOL strategy**
- **Embraces Canadian Hospice Palliative Care Association's Principles and Norms of Practice**
- **Maximizes opportunities for collaboration & synergy with other activities of the health care system.**

Key issues

- Need for a comprehensive understanding of the barriers and opportunities to moving forward
  - Fundamental culture change required
  - Impact on virtually all players in cancer system, not just palliative care teams
- Need for information/data

Activities

- Established Regional Palliative Care leaders

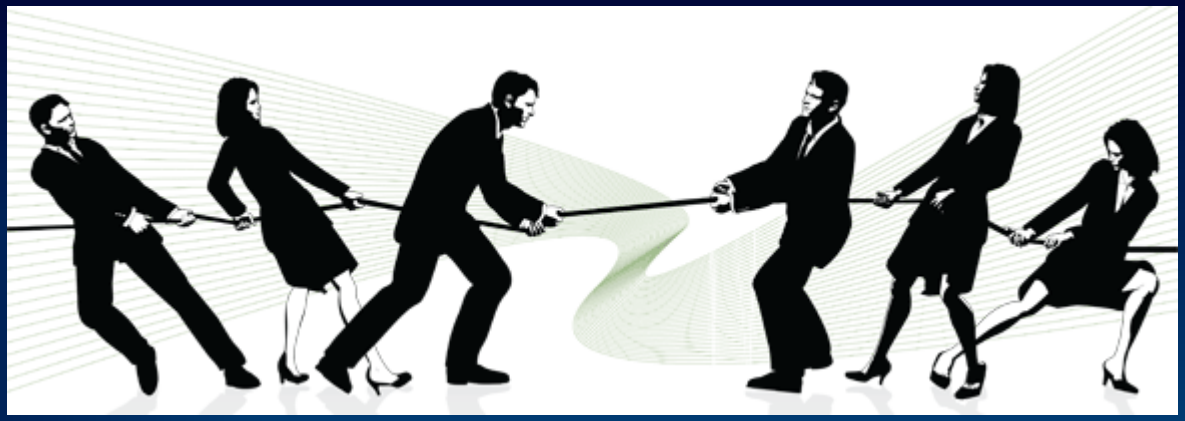
  stipends (enabler)
- Mandated that Regional PC leads sit at executive tables of each Regional Cancer Program

Inspire a Shared Vision

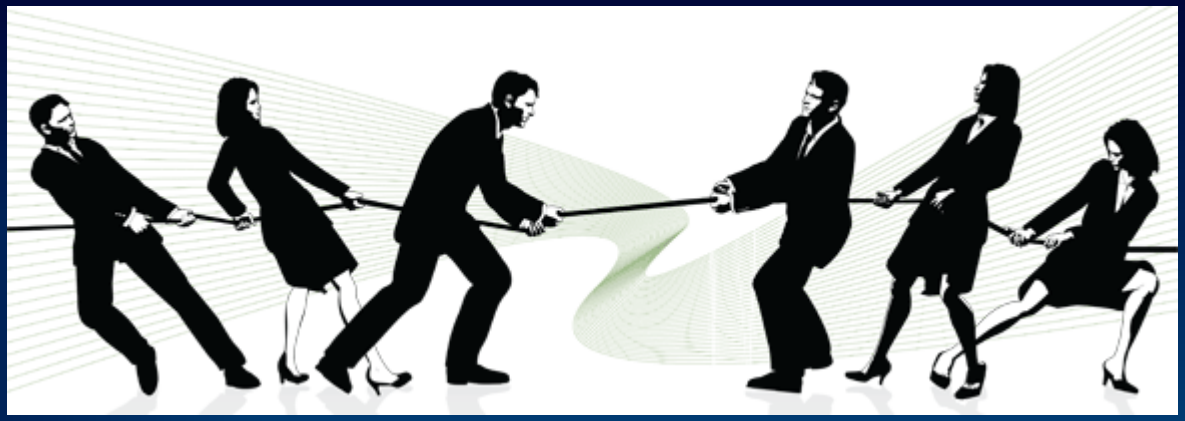
Palliative Care Vision

Every person living in Ontario, when faced with a cancer diagnosis, should have the opportunity to live life fully, to receive optimal symptom management, to be supported with dignity and respect throughout the course of his/her illness, and in the face of incurable disease, each person should have the opportunity to live and die in a setting of his/her choice.


TURN
TO CLEAR
VISION
QUARTERS ONLY



Challenge the Process

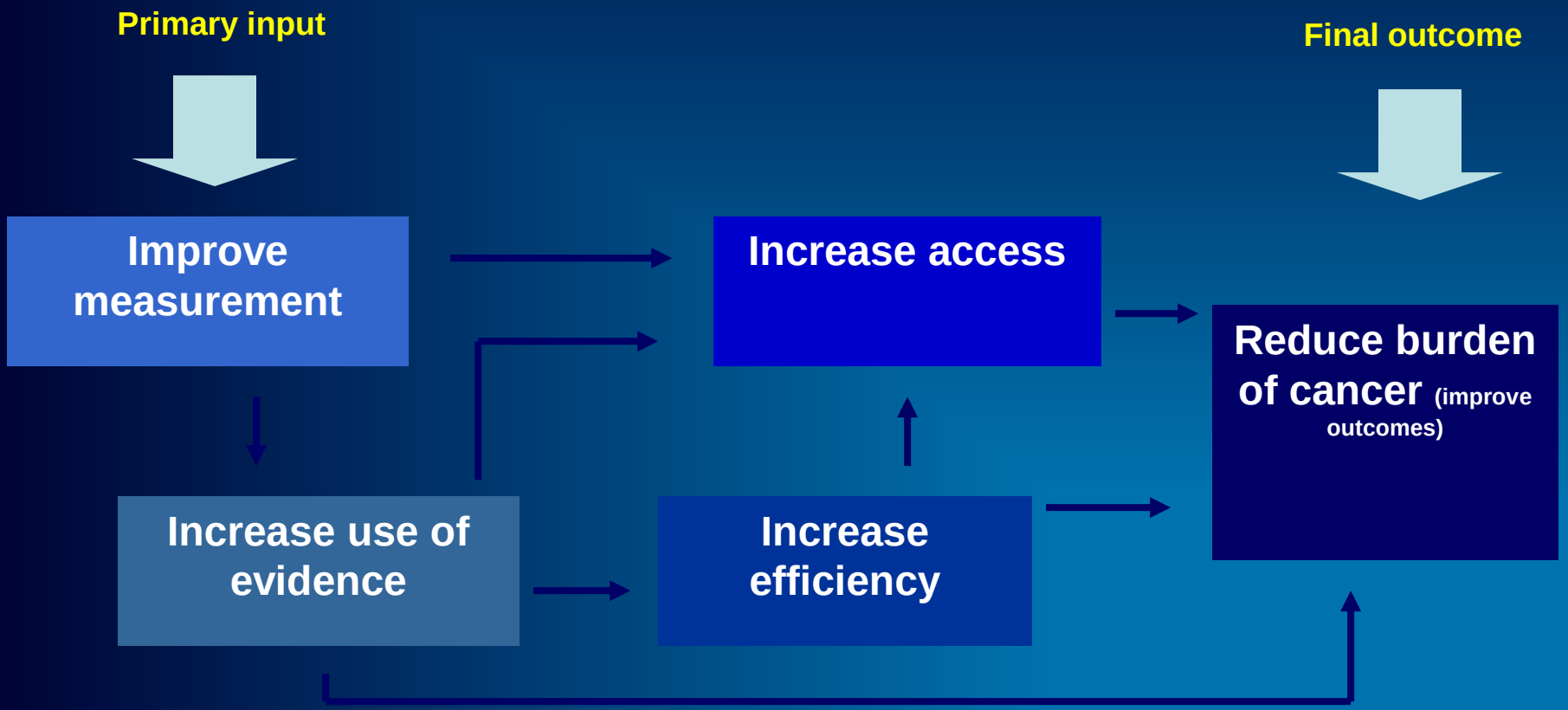


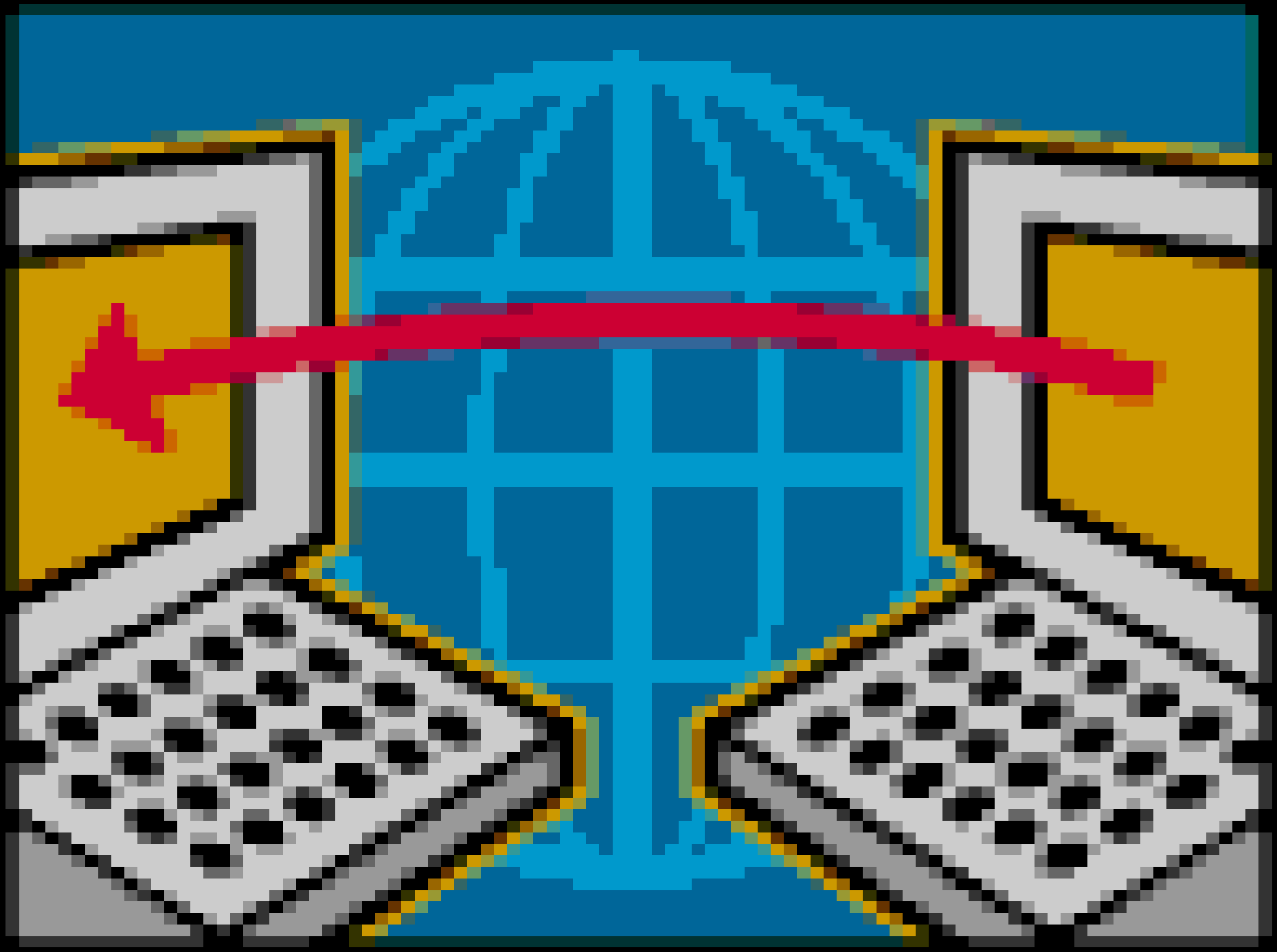
Challenge the Process

Issues Identified

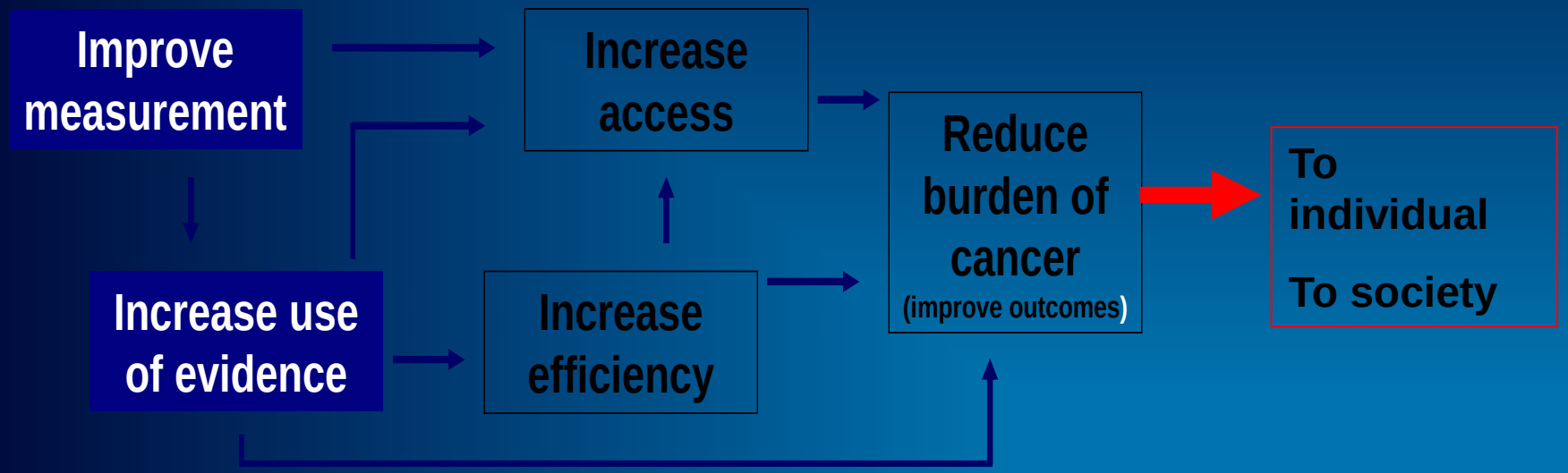
- Lack of coordination of services
- Inadequate resources
- Inconsistent symptom management
- Few assessment tools
- Little evidence-based practice
- Under-utilization of expert resources
- Variable knowledge

Cancer System Strategy Map





Strategy for Quality Improvement In Palliative Cancer Care



Reduce Burden of Cancer

To the Individual:

- **early detection & management of symptoms**
- **Smoother “transitions” & improved continuity of care between sites**
- **Improved quality of life**
- **Improved satisfaction with care**
- **Live and die in setting of choice**

Reduce Burden of Cancer

To Society:

- **Decreased acute care hospital days**
- **Decreased emergency room visits**
- **Decreased ICU days and deaths**
- **Decreased use of ineffective treatments**

Characteristics of Innovations with Successful Spread

- Simple
- Clinically useful
- Evidence-based
- Address a deficiency & have an impact on quality of care & patient satisfaction
- Potential to impact cost

Palliative Care Integration Project (PCIP)

- Use of common assessment tools:
  - ESAS & PPS
- Development & Implementation of:
  - Symptom Management Guidelines
    - Pain, Dyspnea, Nausea/vomiting, Constipation, Delirium
  - Collaborative Care Plans
    - Stable, Transitional, End-of-Life

Edmonton Symptom Assessment Scale (ESAS)

Date of Completion:_____Time: _____

Please circle the number that best describes:

0 1 2 3 4 5 6 7 8 9 10

No pain — Worst possible pain

0 1 2 3 4 5 6 7 8 9 10

Not tired — Worst possible tiredness

0 1 2 3 4 5 6 7 8 9 10

Not nauseated — Worst possible nausea

0 1 2 3 4 5 6 7 8 9 10

Not depressed — Worst possible depression

0 1 2 3 4 5 6 7 8 9 10

Not anxious — Worst possible anxiety

0 1 2 3 4 5 6 7 8 9 10

Not drowsy — Worst possible drowsiness

0 1 2 3 4 5 6 7 8 9 10

Best appetite — Worst possible appetite

0 1 2 3 4 5 6 7 8 9 10

Best feeling of well being — Worst possible feeling of well being

0 1 2 3 4 5 6 7 8 9 10

No shortness of breath — Worst possible shortness of breath

0 1 2 3 4 5 6 7 8 9 10

Other problem

ESAS completed by:

☐ Patient ☐ Health professional

☐ Family ☐ Assisted by family or health professional

version date: December 11, 2002

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

PCIP Results

- Symptom documentation increased
- Acute Care deaths decreased: 65 – 59.6%
- Acute Care LOS/person yr decreased 22.69 – 22.26

Dudgeon, et al. JPSM

Enable Others to Act

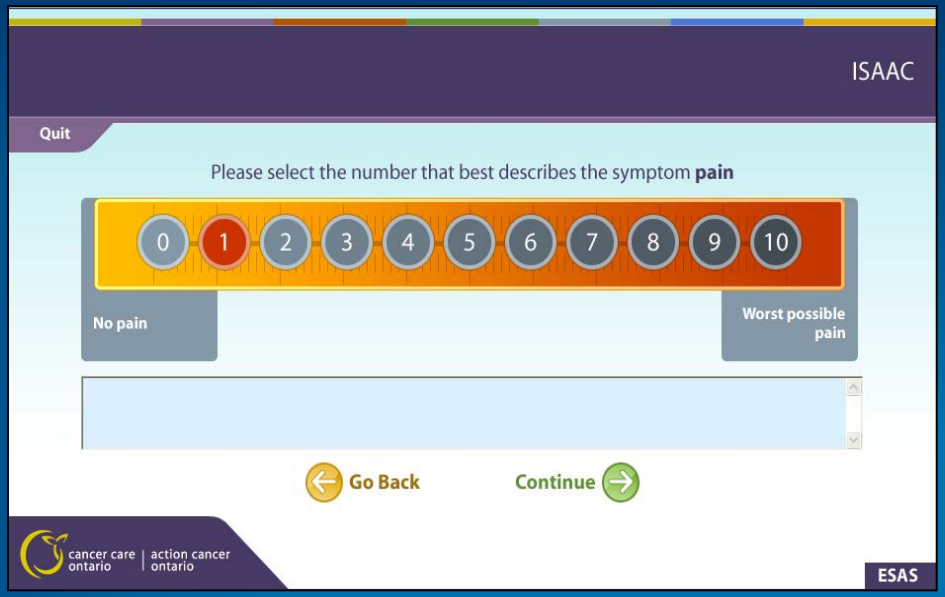
Provincial Palliative Care Integration Project

- Based on a successful & proven palliative care integration initiative from the South East Local Health Integration Network region
- Implementation in all 14 regions starting September 2006
- Funded by Ministry of Health and Long-Term Care and Cancer Care Ontario (CCO)
- The project consisted of:
  - Quality improvement framework
  - Multidisciplinary education
  - Cross sectoral collaboration
  - Common, evidence-based tools
  - Formal evaluation
- Will result in a system with integrated care across care sites & improved patient related outcomes

Dissemination Processes

- Learning sessions on quality improvement
  - Rapid cycles of Plan-Do-Study-Act (PDSA)
- IHI's Collaborative Model for Achieving Breakthrough Improvement
  - Weekly teleconferences between PIC & RIC's
  - Monthly teleconferences MD leads
- Provincial collaborative meetings

Computerized Symptom Screening



ISAAC Tracks Symptoms Over Time

Patient: Rollins, Jack Health Card: 4164439012 Chart Number: TB4431719

	Sep 23/ 06	Oct 19/ 06	Nov 28/ 06	Dec 10/ 06	Jan 12/ 07	Feb 04/ 07	Feb 24/ 07	Mar 06/ 07	Mar 28/ 07	May 16/ 07
Pain	0	3	0	0	7	5	3	1	1	1
Tiredness	3	6	7	4	8	8	3	4	6	6
Nausea	0	4	0	0	0	0	0	0	0	0
Depression	0	0	3	0	4	4	5	5	0	5
Anxiety	3	6	3	0	7	7	8	4	0	0
Drowsiness	0	0	0	0	0	3	0	4	7	9
Appetite	5	8	7	3	5	8	7	6	9	10
Wellbeing	2	8	8	2	8	8	9	5	3	3
Shortness of Breath	0	4	2	0	7	4	8	2	2	1

FOR STAFF USE ONLY

PPS _____ Date _____

P ☐

C ☐

U ☐

Edmonton Symptom Assessment System (ESAS)

✓	Accessible at the clinic via a touch-screen kiosk, or from home via the internet
✓	Tracks symptoms over time and across care settings
✓	Puts patients in control of their own symptom assessment
✓	Results available to clinicians no matter where the patient completes the tool – in clinic, at home, or at another cancer centre
✓	Clinicians are notified by e-mail when the score exceeds certain parameters

To Achieve Screening Aims

- Examination of roles, reorganization of workflow & responsibilities, change booking times
- Involvement & education of all team members
- Engagement of clinical champions – “pull”
- Development of Symptom Guides & algorithms

Evidenced Based Tools to Guide Care

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Cancer Care Ontario's Symptom Management Guides-to-Practice: Pain

Preamble

Ontario Cancer Symptom Management Collaborative

An initiative of Cancer Care Ontario, the Ontario Cancer Symptom Management Collaborative (OCSMC) was undertaken as a joint initiative of the Palliative Care, Psychosocial Oncology and Nursing Oncology Programs. The overall goal of the OCSMC is to promote a model of care enabling earlier identification, communication and documentation of symptoms, optimal symptom management and coordinated palliative care.

The OCSMC employs common assessment and care management tools, including the Edmonton Symptom Assessment System (ESAS) screening tool to allow patients to routinely report on any symptoms they are experiencing. Symptom Management Guides-to-Practice were developed to assist health care professionals in the assessment and appropriate management of a patient's cancer-related symptoms. In addition to the symptom specific Guides-to-Practice, quick-reference Pocket Guides and Algorithms were created. Additionally, for a comprehensive management plan for patients with advanced disease, please refer to the Palliative Care Collaborative Care Plans.

Objective

The objective of this initiative was to produce Guides-to-Practice for management of patients with cancer-related symptoms. These documents are clinical tools designed to assist health care practitioners in providing appropriate patient care and are not intended to serve as standards of care.

Target Population

The target population consists of adult patients who require symptom management related to cancer. It is outside the scope of these Guides-to-Practice to address in detail the management of patients experiencing acute adverse effects secondary to systemic or radiation therapy. Please visit the Program in Evidence-Based Care for guidelines related to these topics.

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Symptom Management Pocket Guides:

NAUSEA & VOMITING

August 2010

Encourage the Heart

Symptom Assessment Highlights

- **Since the inception of ISAAC in January 2007:**
  - **Over 1.4 million ESAS screens in ISAAC**
  - **Over 1 million unique patients have completed at least one ESAS screen**
  - **A steady increase in the monthly number of ESAS screens and patients using ESAS**
- **In July 2012:**
  - **52% of cancer patients seen at an RCC were screened at least once**
  - **Half of the RCCs had screening rates above the provincial target of 70%**

Patients who complete ESAS value this approach to symptom assessment

93%	• Thought ESAS was important to complete as it helps health care providers know how they are feeling
92%	• Agreed that their health care providers took into consideration ESAS symptom ratings in developing a care plan
91%	• Agreed that their physical symptoms have been controlled to a comfortable level
87%	• Agreed that their care team responded to their feelings of anxiety or depression

Survey of 3,320 patients from 14 Regional Cancer Centres in 2012

Culture Change

- Patient-centered
- Standardized objective measure
- Measurement focuses quality improvement
- Opportunity for research
- Determine best practices
- Opportunity for evaluation of concordance with guidelines

The cancer journey

Better cancer services every step of the way

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Ontario
Cancer Care Ontario
Action Cancer Ontario

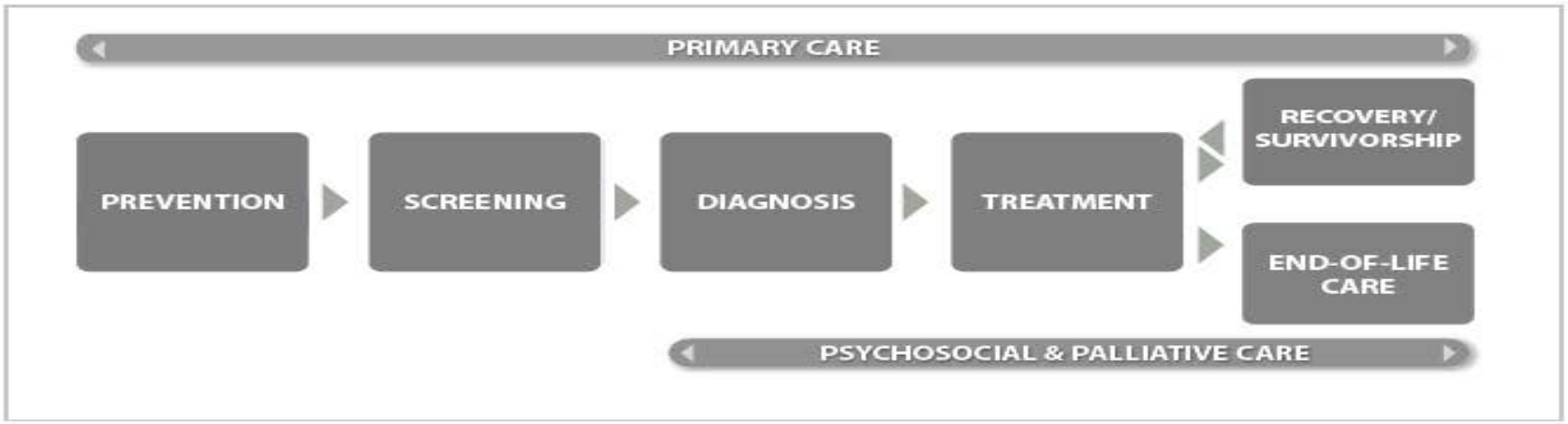
By Patient Journey

The cancer patient journey is a way to think about the phases or steps that a cancer patient may experience, from diagnosis to recovery or end of life. Because more than half of all cancers can be prevented and screening for cancer is an important way to improve outcomes, we also include these components in the cancer journey. Looking at cancer in this way, we can study the entire cancer system through the patient lens and identify any gaps or bottlenecks along the way.

IN MY WORDS

A Circle of Care needs to be developed so that all community partners who will participate with these patients connect and communicate for a seamless delivery of service.

Anonymous



Click the graphic above to explore the CSQI through the patient journey.

Senior Scientific Leader for Person-centred Perspective

Take Home Messages

- Identify your circle of influence
  - Learn what is important
  - Speak “their” language
- Know the organizational culture
- Seize the opportunities
- If the elephant isn’t moving – play with the horses for awhile

Conclusions

- Progress is possible
- Persistence is necessary
- Attention to “process” is important
- REAL collaboration is necessary
- Everything takes more time than you think!!!!

You Make a Difference


Never give up.
Never surrender.
Never stop learning.
Never stop changing.

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Gandhi…

You need to be the change you want to see in the world…