PALLIATIVE CARE EARLY AND SYSTEMATIC (PACES)

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

30th Annual Palliative Education and Research Day
Oct 21, 2019

30th Annual Palliative Education and Research Day

Faculty/Presenter Disclosure

Faculty: Sharon Watanabe

Relationships with financial interests:

Grants/Research Support: CIHR, Alberta Health, MSI Foundation

Speakers Bureau/Honoraria: Pallium

Consulting Fees: None

Patents: None

Other: University of Alberta, Alberta Health Services

30th Annual Palliative Education and Research Day

Faculty/Presenter Disclosure

Faculty: Aynharan Sinnarajah

Relationships with financial interests:

Grants/Research Support: CIHR, Alberta Health, Canadian Frailty Network, MSI Foundation, University of Calgary

Speakers Bureau/Honoraria: None

Consulting Fees: None

Patents: None

Other: University of Calgary, Alberta Health Services

Disclosure of Financial Support

This program has not received financial support from commercial entities.

This program has received in-kind support from the Provincial Palliative and End-of-Life Care portfolio and the Chief Medical Information office.

<u>Potential for conflict(s) of interest</u>:

- **Presenting on behalf of Palliative & End of Life Care programs (Edmonton and Calgary Zones), Alberta Health Services; University of Calgary; University of Alberta**
- **No potential conflict(s) of interest**

Mitigating Potential Bias

- **Not applicable**

Your stories

- Discuss with your neighbour (2 minutes each):
  - Briefly describe a situation where a patient first received palliative care late in the course of illness. What were the consequences, if any, of the late referral?
- Share selected observations (2 minutes total)

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Objectives

1. Describe the details of the first ever Alberta early palliative care pathway developed for patients with advanced colorectal cancer.

2. List key steps taken to develop the pathway including stakeholder engagement and alignment with existing AHS initiatives

3. Summarize early findings of implementation of the early palliative care pathway in Calgary, as well as existing resources at the Cross Cancer Institute.

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Agenda

- Background
  - PaCES
  - Change Management
  - Local Context
- Identifying Problems
- **Solutions**
- Implementation Process
- Experience So Far
- Lessons Learned and Conclusion

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In the beginning…..

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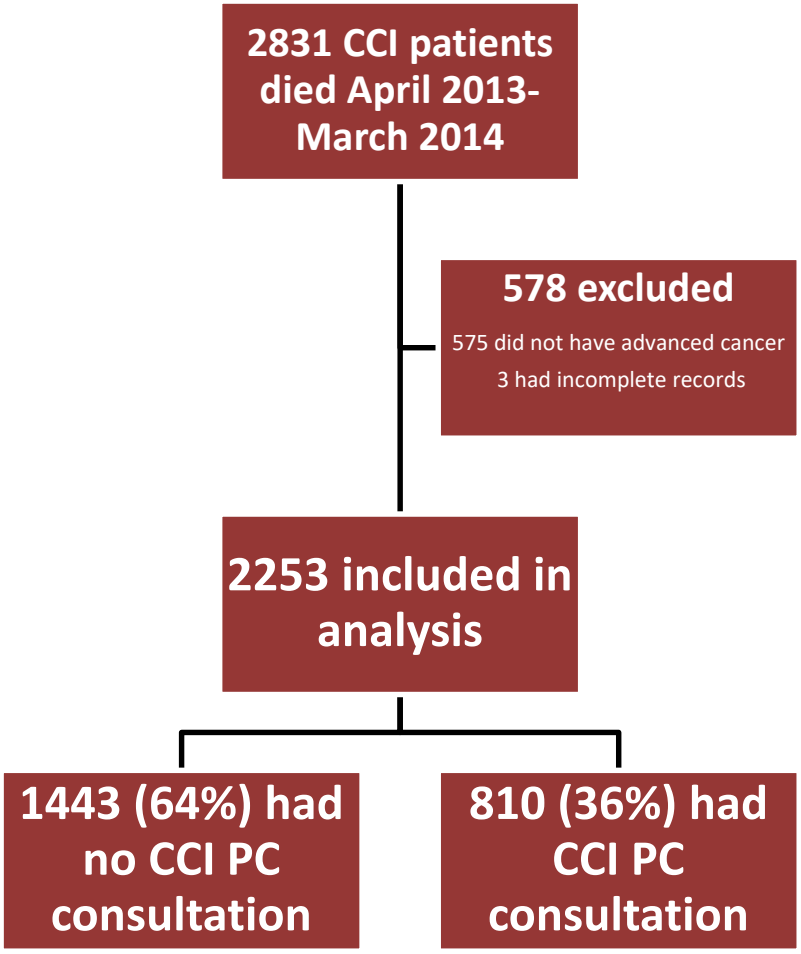
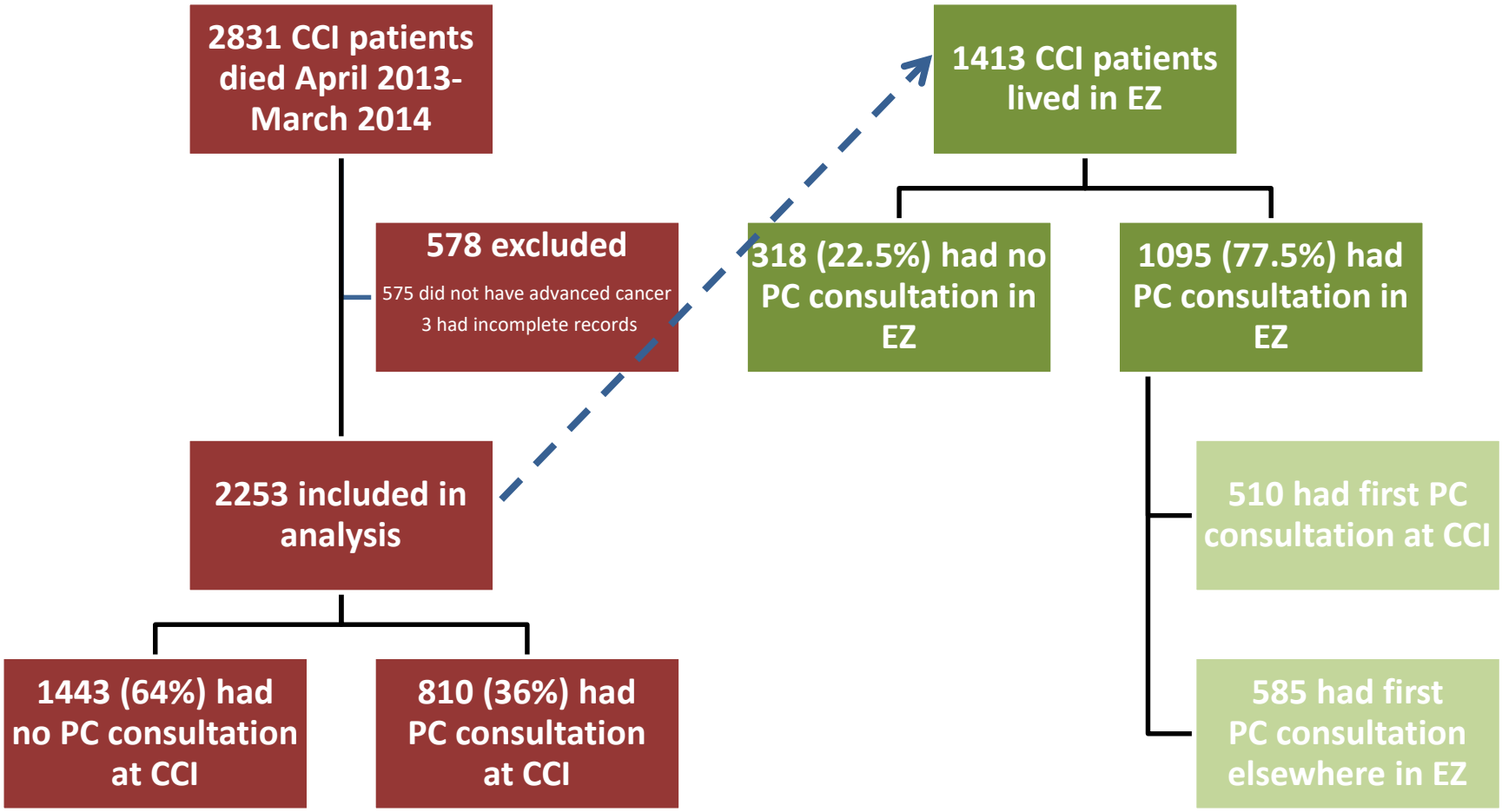
<40% of patients with advanced cancer had PC consultation at CCI



>75% had PC consultation when other sites were included



PC consultation occurred relatively late

Setting	Median (IQR) interval, months		
	Advanced cancer diagnosis to death	Advanced cancer diagnosis to first PC consultation	First PC consultation to death
CCI	10 (4 – 21)	4.5 (1 – 15)	2 (1 – 5)
EZPCP	9 (3.8 – 21)	4.4 (1.1 – 15)	2.1 (0.9 – 4.6)

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PaCES: Palliative Care Early and Systematic

- Early palliative care pathway (processes and resources) for Albertans with ***advanced colorectal cancer*** (initially, as proof of principal)

MISSION

*"To provide **early** and ongoing access to coordinated, comprehensive and compassionate palliative care to improve quality of life for Albertans with advanced cancer."*

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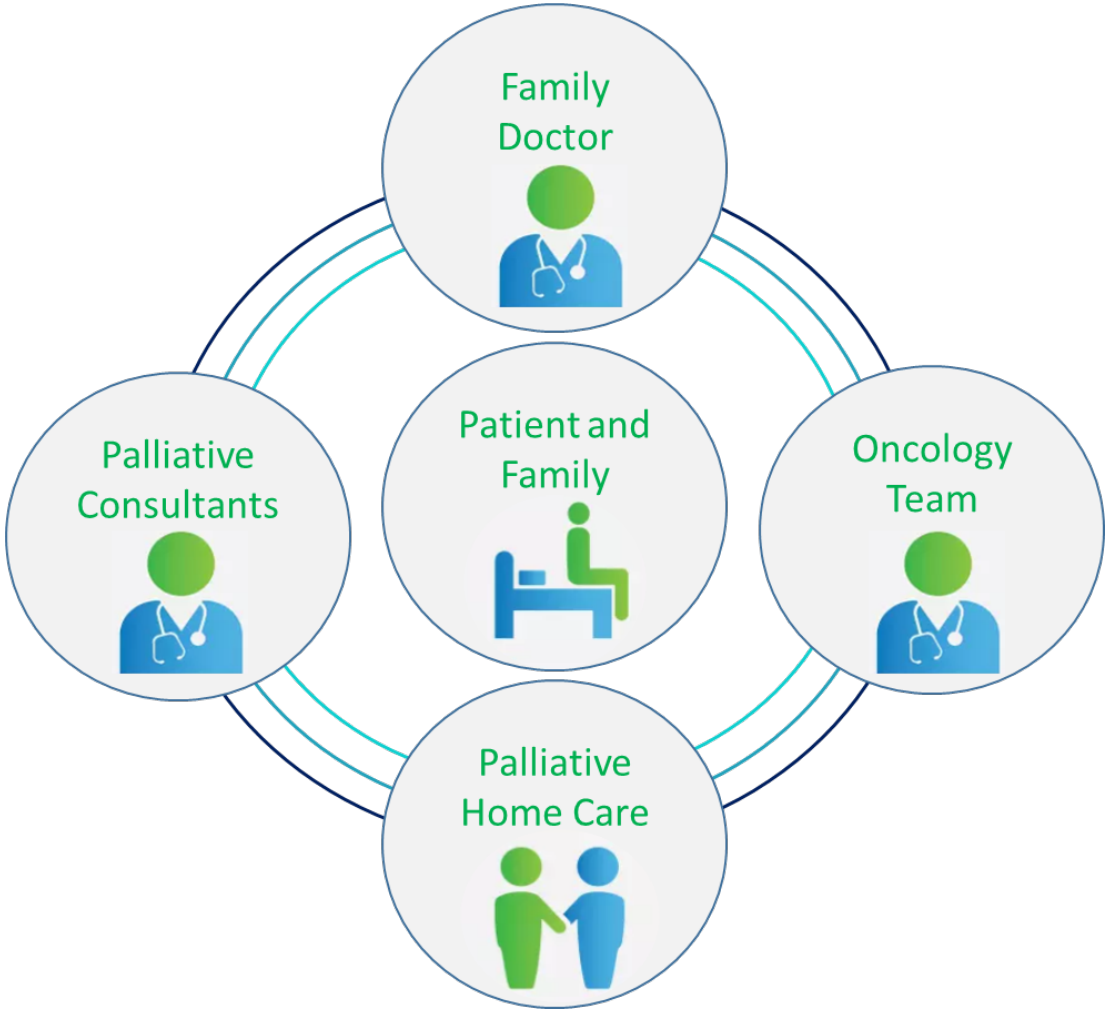
Vision: Improving quality of life for Albertans with advanced cancer



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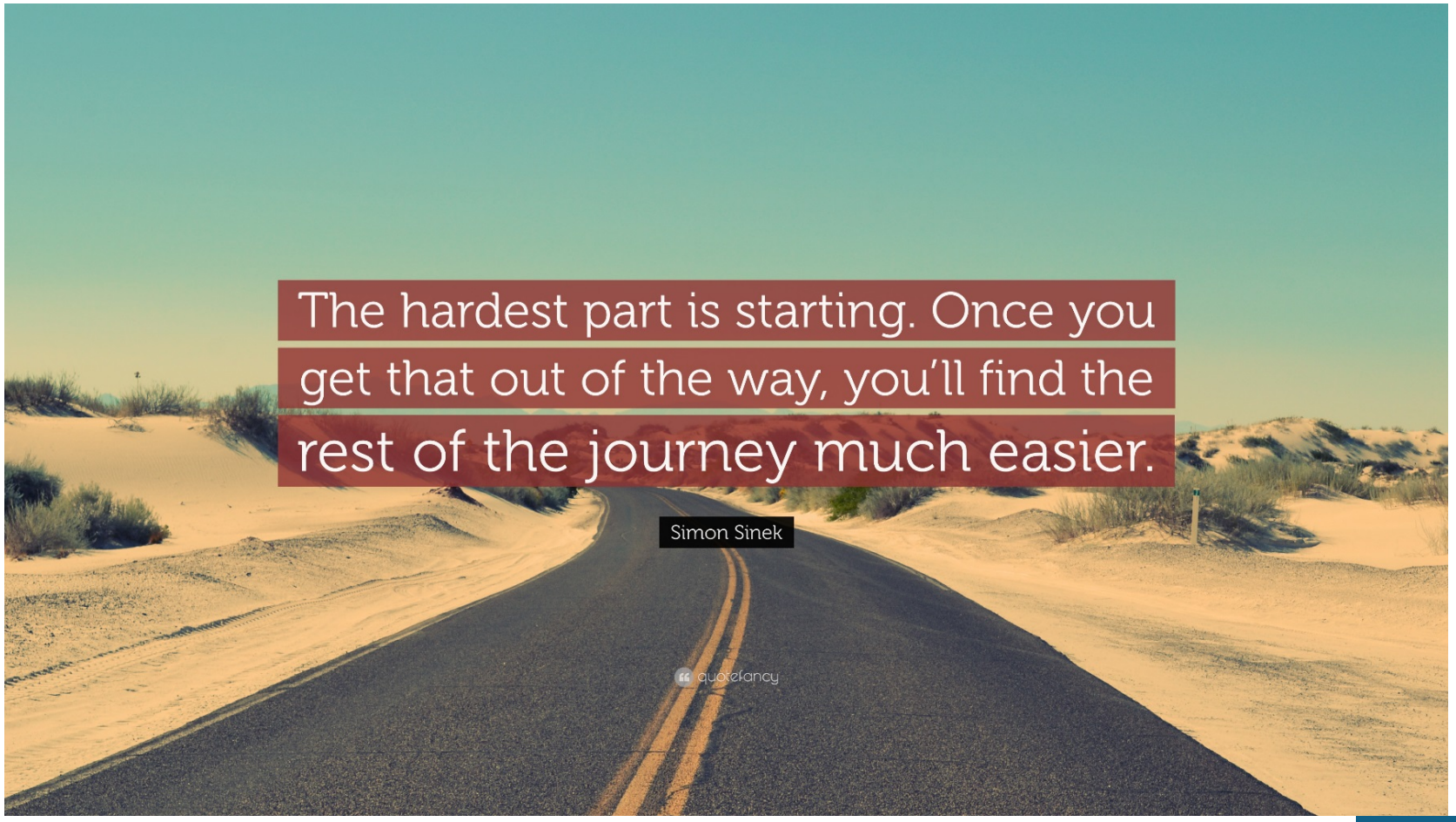
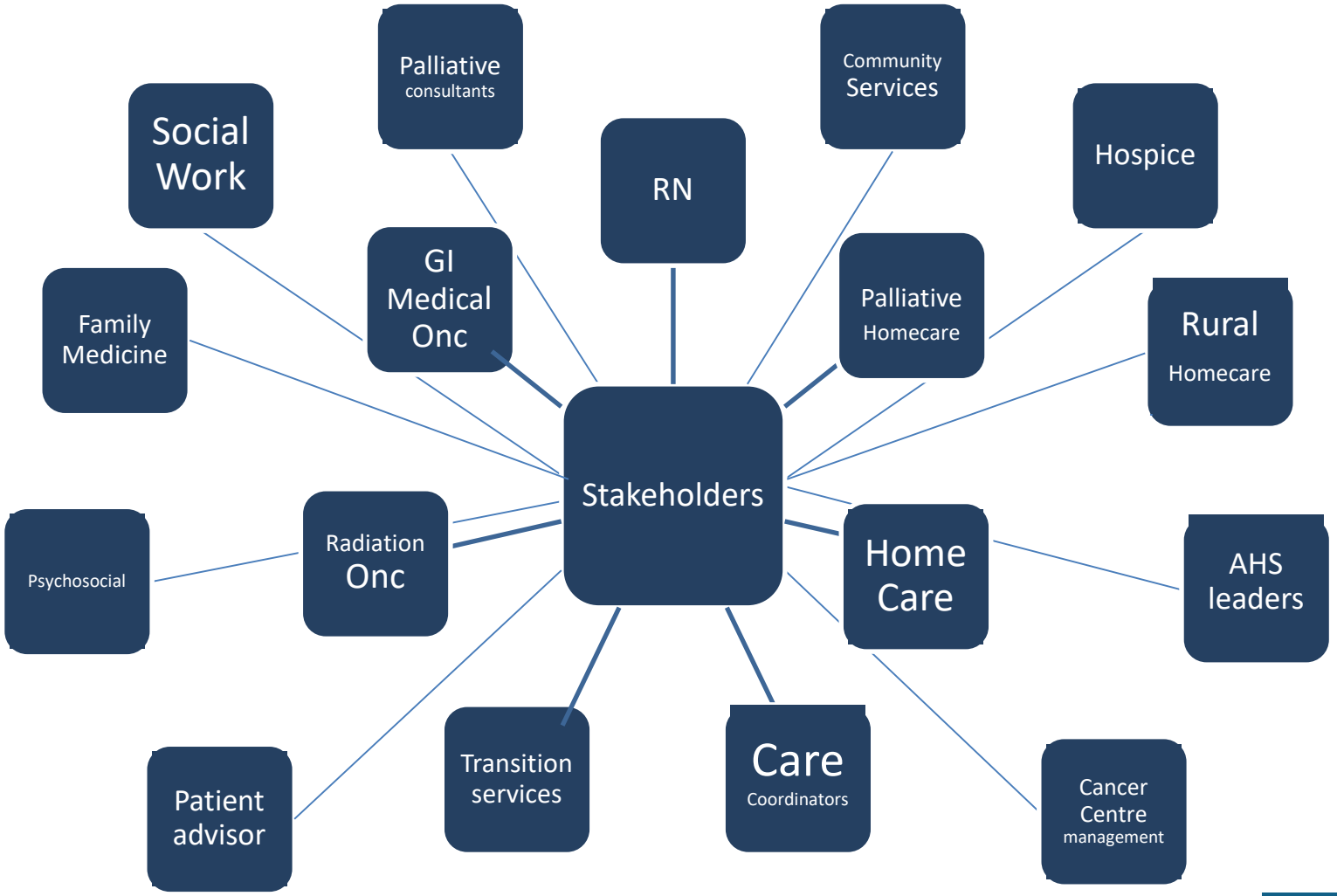
PaCES: Starting the Journey



Stakeholder



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The Problem

- 60% patients with advanced GI cancers have late PC <3 months from death or no PC referral
- Late or no PC is associated with lower patient quality of life and higher caregiver distress
- Late or no PC associated with death in hospital for 50% of patients *vs.* 25% receiving earlier PC

*Temel NEJM 2010 ; Zimmerman Lancet 2014; Cheung Cancer 2015

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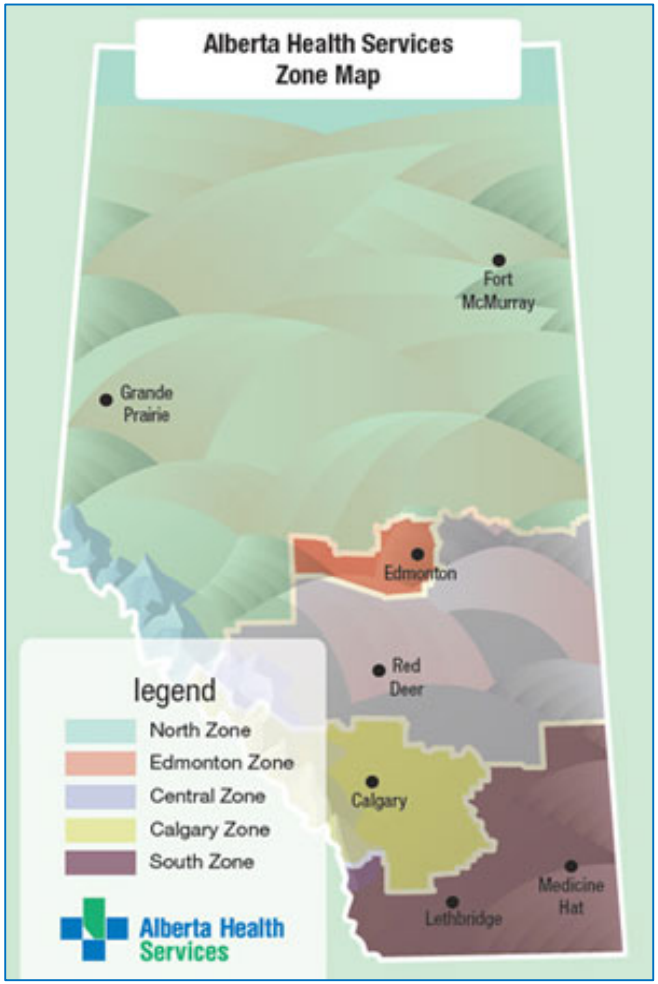
PaCES: Health Resource Study



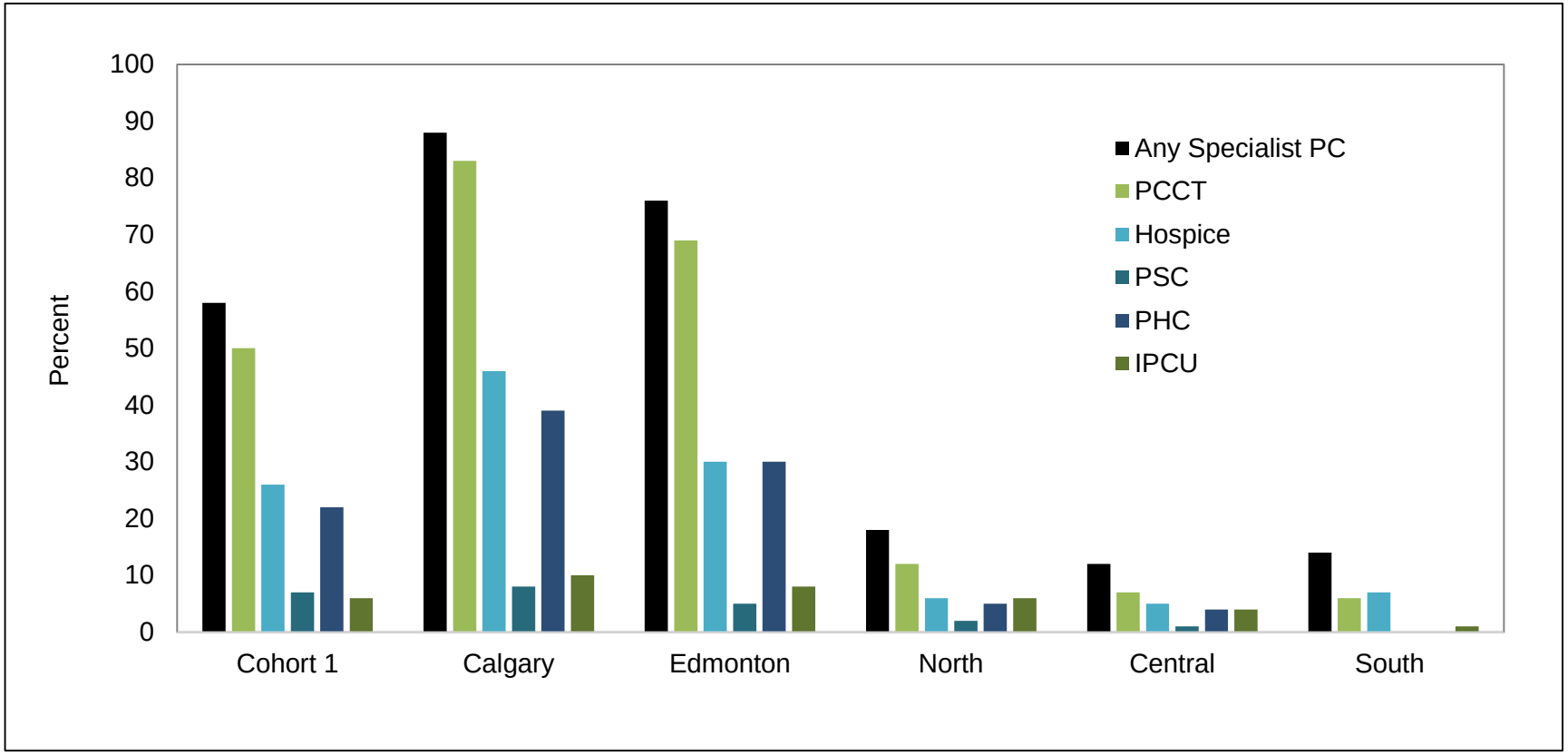
Who: Colorectal cancer patients
What: Timing of palliative care (PC) access
Where: All AHS Zones
When: Deceased Jan 2011- Dec 2015
Why: Examine association with aggressive EOL care

Table: Median duration (days) from first specialist PC access to death.

Region of residence at death (AHS Zone)	Median PC duration (days)	Range (days)
All Zones	51.0	0-3220
Calgary	56.0	0-2346
Edmonton	46.5	0-1782
North	40.5	0-1285
Central	29.5	0-1239
South	42.0	1-2155

On average, patients in this cohort are **first** accessing palliative care services 51 days before death → varies by zone

Palliative Care Services Used



- Most patients in Calgary (88%) and Edmonton (76%) Zone accessed PC
- Few patients in Central (12%), North (18%), South (14%) accessed PC
- Availability of PC services differ by zone

Select factors related to having aggressive end-of-life indicators (N=3337)

Factor	≥1 EOL indicator	P
Timing of palliative care		
None	2.15 (1.66-2.77)	***
< 3 months from death	1.53 (1.24-1.89)	***
≥3 months from death	ref	
Region of residence at death		
Calgary (Z2)	ref	
Edmonton (Z4)	1.35 (1.11-1.65)	**
South (Z1)	0.48 (0.31-0.73)	***
Central (Z3)	0.93 (0.61-1.43)	
North (Z5)	1.92 (1.20-3.08)	**
Urban		
Urban	ref	
Rural	2.25 (1.57-3.23)	***
Duration of disease (any CRC)		
1-6 mo	2.26 (1.63-3.13)	***
6-12 mo	1.97 (1.40-2.77)	***
12-24 mo	1.33 (0.98-1.82)	
24-60 mo	1.08 (0.81-1.45)	
> 60 mo	ref	
Age at death (years)		
<60	3.25 (2.52-4.19)	***
61-70	1.85 (1.47-2.34)	***
71-80	1.43 (1.16-1.78)	**
>80	ref	

Patients who received no palliative care are 2.15 times more likely to experience aggressive EOL care

Zone is an important predictor of whether a patient experiences aggressive end of life care

(even after adjusting for other variables in the model)

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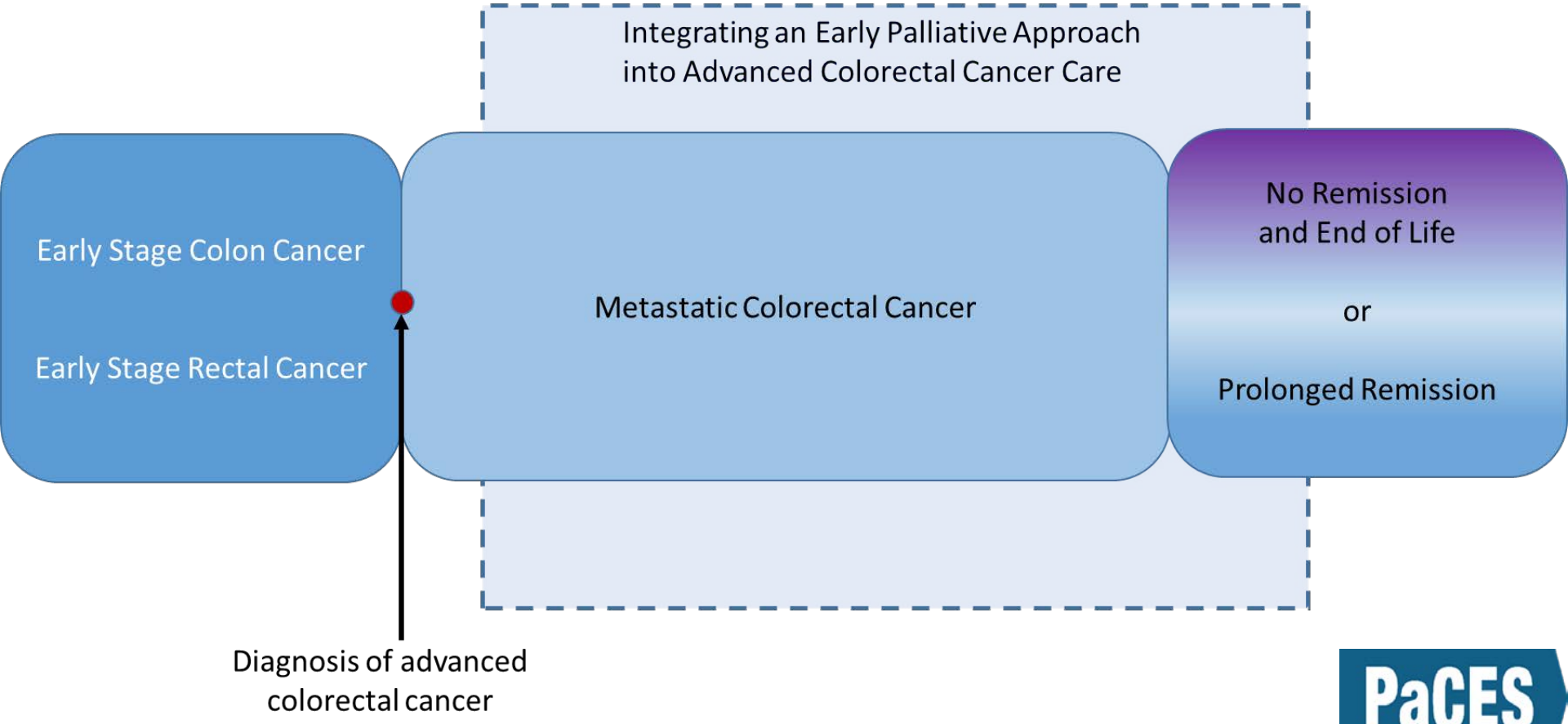
What do we mean by *early*?

A palliative approach to care that occurs concurrently with cancer treatment



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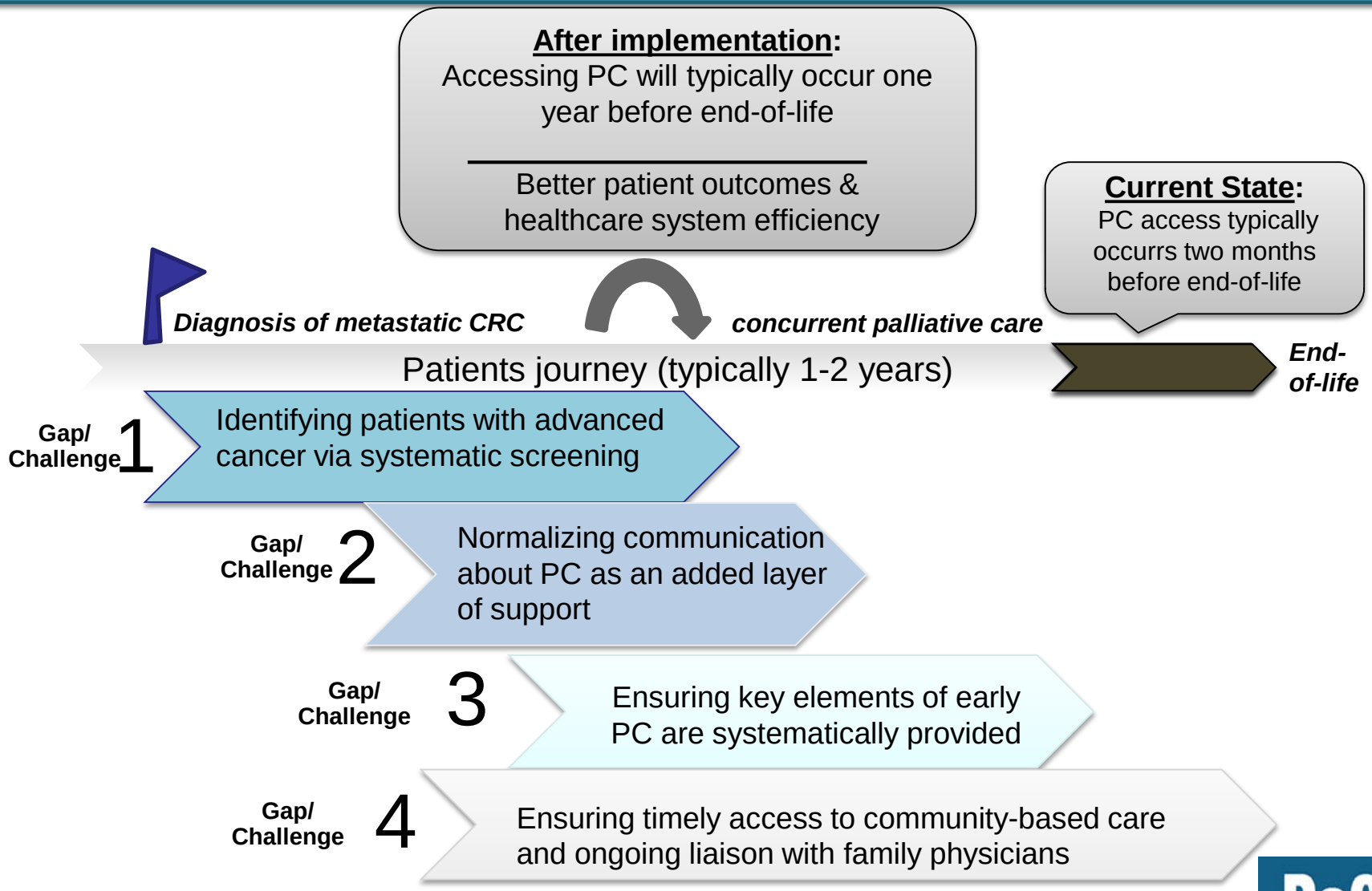
Easy to say, harder to do in practice



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Why is early PC hard to achieve?

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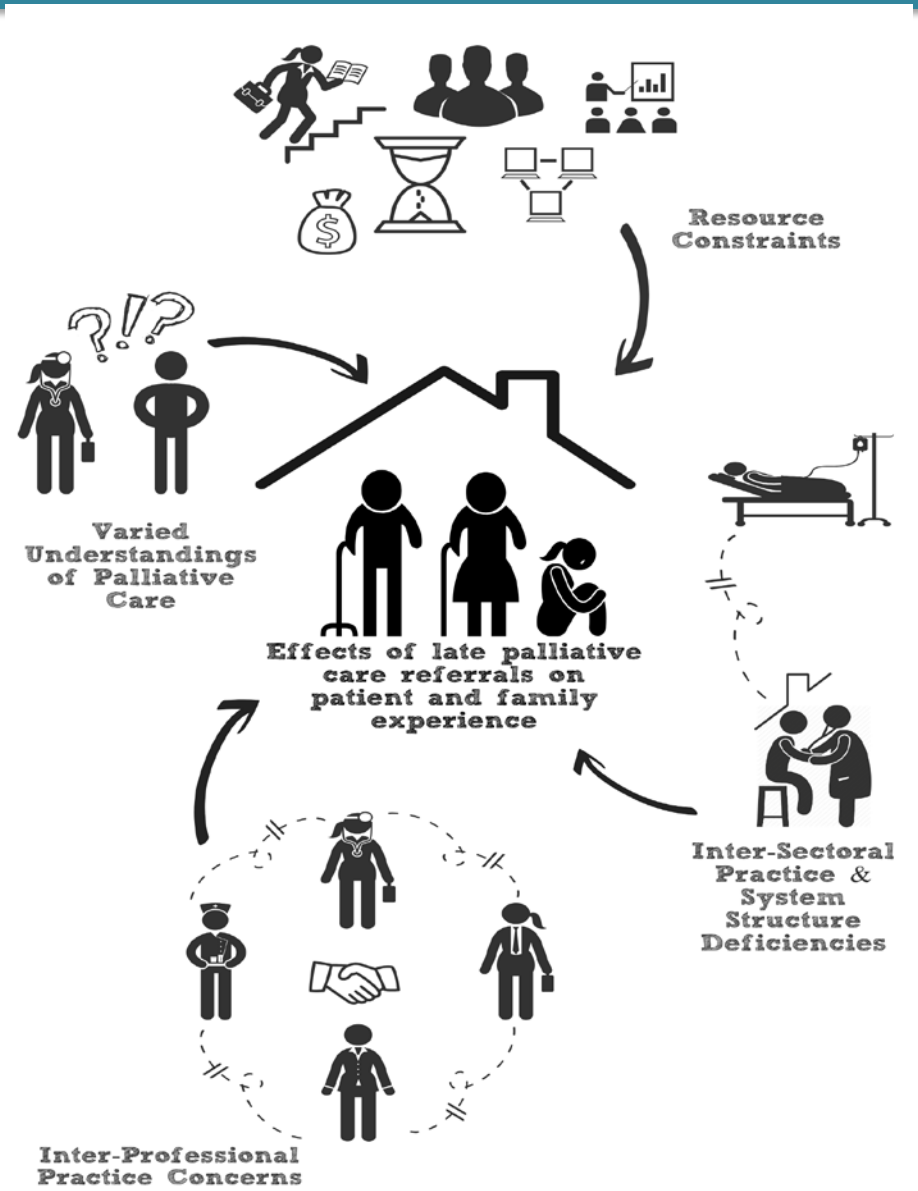
Barriers

Barriers faced by oncology clinicians in referring patients to PC, working with PC and addressing PC needs in cancer clinics



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Identifying the Problems

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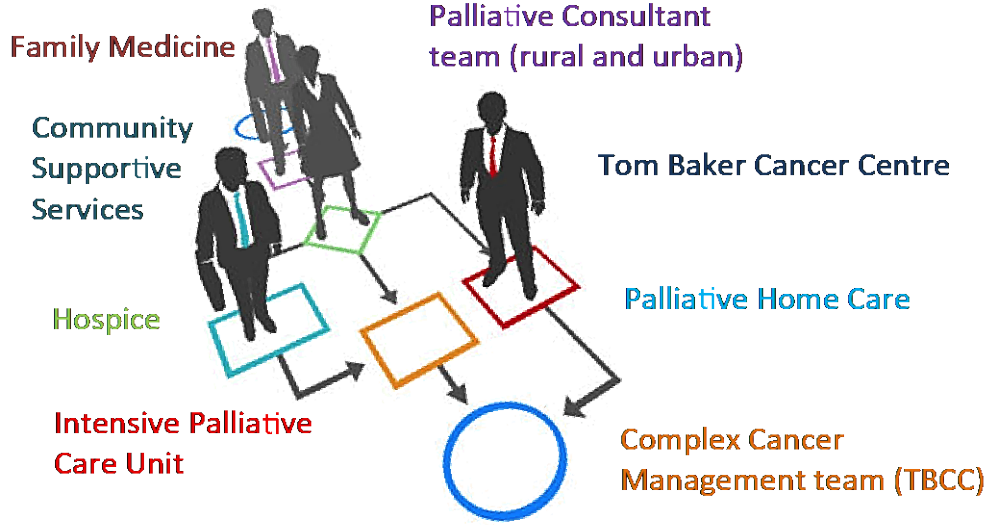
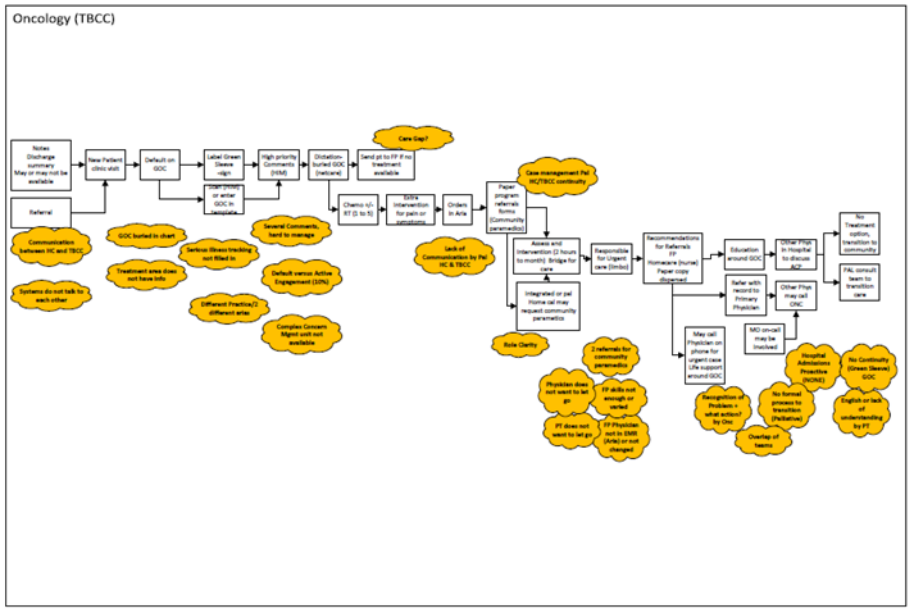
Processes mapped across the continuum





101 “pain points” or gaps identified

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7 Problem statements

- Transitions
- Shared Definition
- Role Clarity
- Visible Patient Journey
- Goals of Care Practice
- Varied PC Skills
- Fragmented Communication

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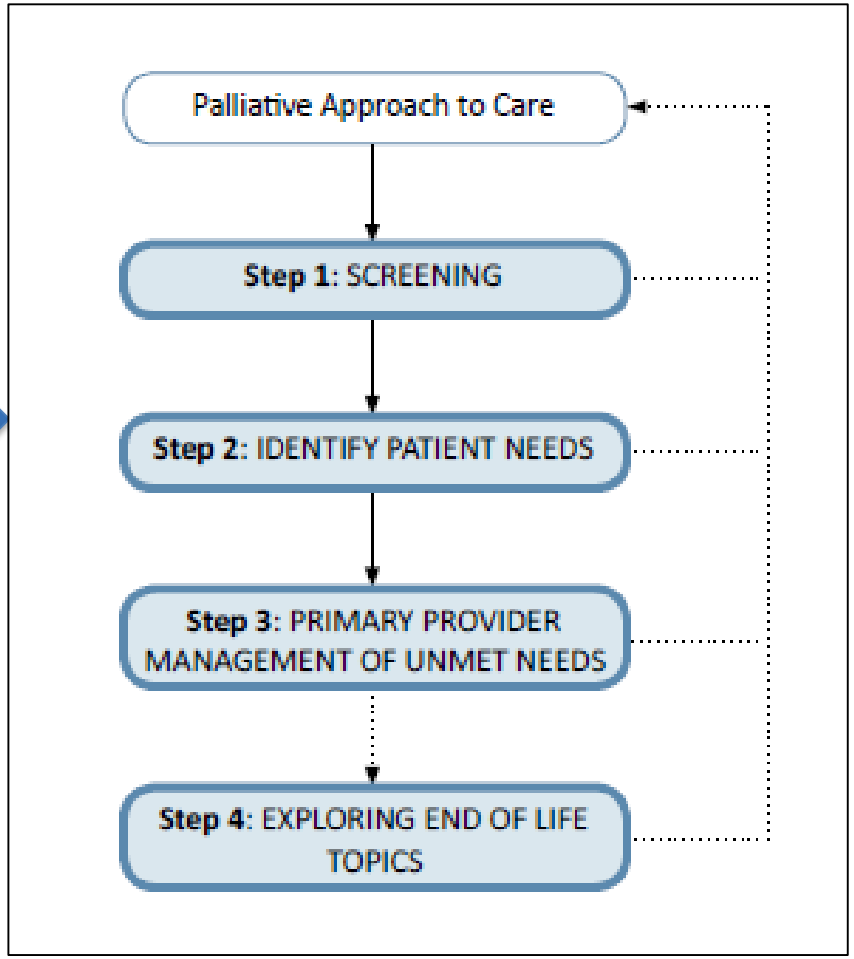
Plenty of solutions

37 pages of proposed solutions or 700 individual comments



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Solutions

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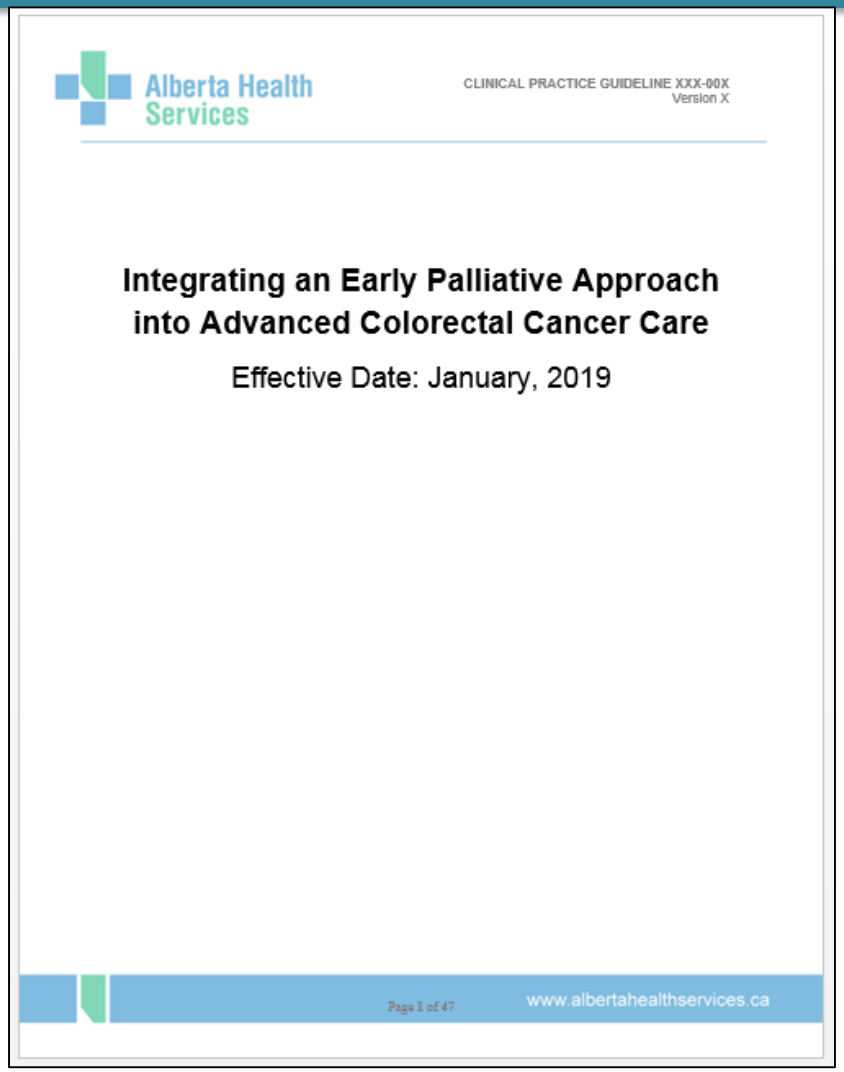
Guideline & Pathway



Alberta Health Services

CLINICAL PRACTICE GUIDELINE XXX-00X
Version X

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

Effective Date: January, 2019

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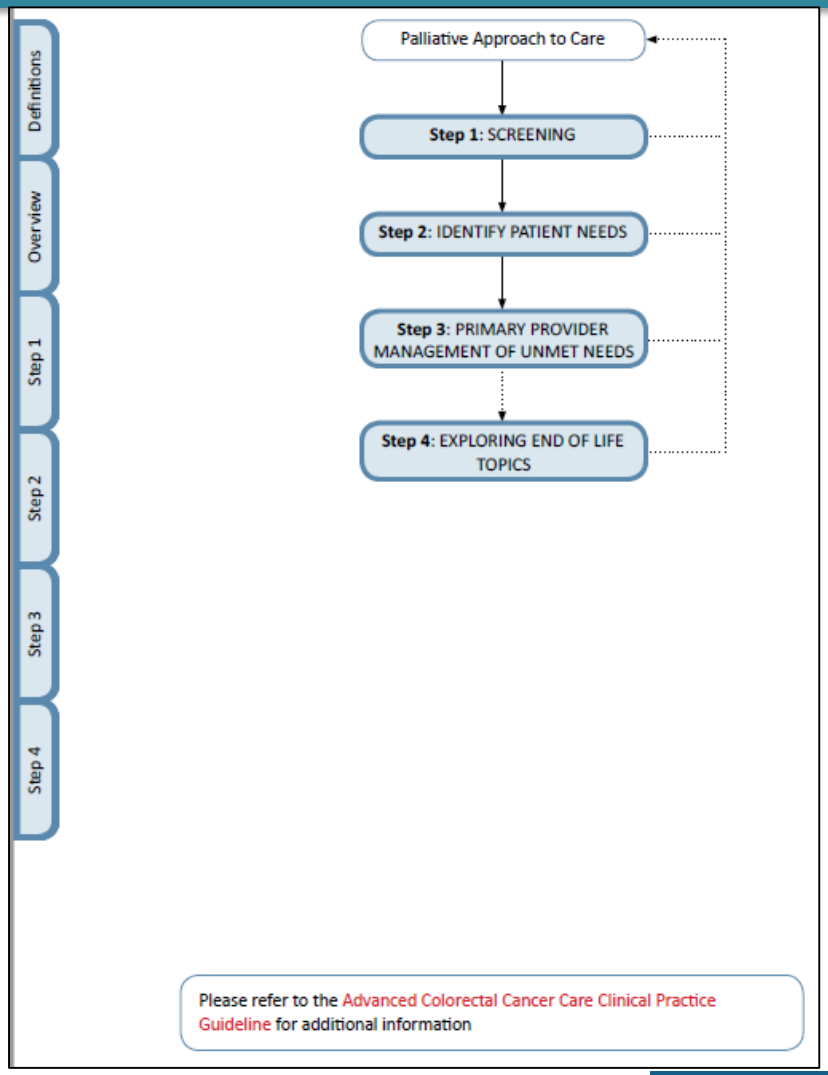

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Essential Components of an Early Palliative Approach to Care

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www.ahs.ca/GURU

Information located under “Gastrointestinal” and “Palliative & Supportive Care”

▼ Palliative & Supportive Care

- Metastatic Colorectal Cancer: Early Palliative Approach
  - Interactive Care Pathway
  - Referral Based Services for Advanced Cancer Care
  - Local Tips for Providers
  - Advanced Cancer Shared Care Letters
    - Sample Physician Letter
    - Sample Patient Letter
  - Introducing Palliative Care: Tips for Health Care Professionals

Symptom Management Summaries

- Anxiety
- Depression
- Oral Care
- Tenesmus
- Sleep Disturbance

Additional Resources

- ASCO Anxiety and Depression Guideline
- ASCO Fatigue Guideline
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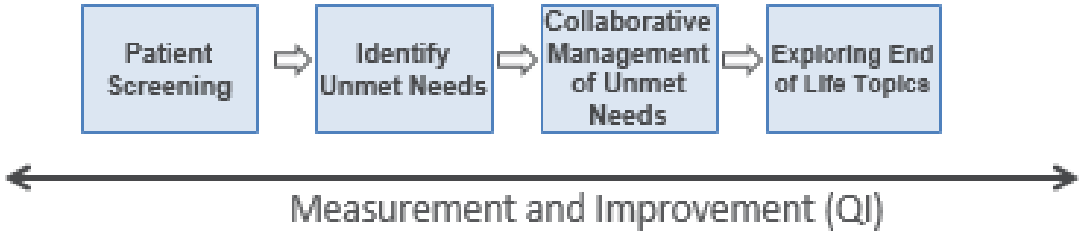
What's there? 1. Interactive care pathway

Step 1: Screen using Patient reported outcome Dashboard

Step 2: Identify Patient Needs

Step 3: Primary Provider Management of Unmet Needs

Step 4: Exploring End of Life Topics



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Step 1: Screen using PRO Dashboard

Comments	Qstr Entry Date	Previous PPF Symptom Complexity	Home Care (PPF)	Palliative Home Care (db)	Request for Goals of Care (PPF)	GCD Order (ARIA)	Goals of Care Date (ARIA)	Weight Change(%)
6 weeks f/u as per appt slip...pt aware....ss	2018-Dec-31	L	N		N	M1	03/10/2016	0.18%
f/u as per appt slip..pt aware...zg	2019-Jan-14	L		Y				-9.17%
f/u as per appt slip.mailed..zg	2019-Jan-14	M	Y	Y	N	M1	16/02/2016	-2.04%
f/u as per appt slip..pt aware...zg	2019-Jan-15	L	N					7.83%

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Step 2: Identify needs

Component	Assessment Tool
Illness comprehension and coping	Canadian Problem Checklist (CPC)
	Edmonton Symptom Assessment System- Revised: anxiety and depression scales (ESAS-r)
	Serious Illness Care Program (SICP)
Symptoms and functional status	ESAS-r
	CPC
	Eastern Cooperative Oncology Group (ECOG)
	Palliative Performance Scale (PPS)
Advance care planning and patient's preferred method of decision making	ACP GCD Tracking Record
	CPC
	SICP
Coordination of care	PPF

Putting Patients First

APPENDIX 1: PUTTING PATIENTS FIRST PAGE 1 (ESAS-R)

Alberta Health Services

Patient Label

Talking About What Matters To You
Putting Patients First

Your answers will help us understand how you have felt since your last visit, and how you feel today. Knowing this will help us care for you. If you cannot or do not wish to fill out this form for any reason please let us know.

Note: Please make sure to fill out both sides of the form

A member of your healthcare team will go over the form with you and talk to you about what concerns you the most today. If we are not able to talk about all of your concerns today, we will decide the next steps together.

Date *(yyyy-Mon-dd)*	Completed by: ☐ Patient ☐ Family ☐ Assisted by family/health professional

Please answer the yes/no questions:

1. Have you been to Emergency and/or been admitted to hospital since your last visit? ☐ Yes ☐ No
2. Have your medications changed since your last visit? (e.g. stopped, started, dose change) ☐ Yes ☐ No
3. Have you had a fall since your last visit? ☐ Yes ☐ No
4. Would you like information on Goals of Care or advance care planning (green sleeve)? ☐ Yes ☐ No
5. Are you receiving home care services? ☐ Yes ☐ No
6. Have you used tobacco in the past year? ☐ Yes ☐ No In the past 30 days? ☐ Yes ☐ No

Please circle the number that best describes how you feel **NOW**

0 means you do not have that symptom, 10 means it is at its worst

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
No tiredness *(Tiredness=lack of energy)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
No drowsiness *(Drowsiness=feeling sleepy)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
No nausea	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
No lack of appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible lack of appetite
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
No depression *(Depression=feeling sad)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
No anxiety *(Anxiety=feeling nervous)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Best well-being *(Well-being=how you feel overall)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible wellbeing
No _____ Other problem *(e.g. constipation)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible _____

Continue on back side ➜

APPENDIX 1: PUTTING PATIENTS FIRST PAGE 2 (CPC)

What concerns have you had since your **last visit**? Check any boxes that have concerned you.

Emotional
- ☐ Fears/Worries
- ☐ Sadness
- ☐ Frustration/Anger
- ☐ Changes in appearance
- ☐ Intimacy/Sexuality
- ☐ Thoughts of ending my life

Social/Family/Spiritual
- ☐ Feeling alone
- ☐ Feeling like a burden to others
- ☐ Worry about friends/family
- ☐ Support with children/partner
- ☐ Meaning/Purpose of life
- ☐ Faith

Practical
- ☐ Work/School
- ☐ Finances
- ☐ Getting to and from appointments
- ☐ Home Care
- ☐ Accommodation
- ☐ Quitting tobacco
- ☐ Drug costs
- ☐ Health insurance
- ☐ How much alcohol you drink

Physical
- ☐ Fever/Chills
- ☐ Bleeding/Bruising
- ☐ Cough
- ☐ Headaches
- ☐ Concentration/Memory
- ☐ Vision or hearing changes
- ☐ Numbness/Tingling
- ☐ Sensitivity to cold
- ☐ Changes to skin/nails
- ☐ Bladder problems
- ☐ Lymphedema/Swelling
- ☐ Range of motion
- ☐ Strength
- ☐ Speech difficulties
- ☐ Sleep

Mobility
- ☐ Dizziness
- ☐ Walking/Mobility
- ☐ Trouble with daily activities (e.g. bathing, dressing)

Nutrition
- ☐ Weight gain (amount) _____
- ☐ Weight loss (amount) _____
- ☐ Special diet _____
- ☐ Difficulty swallowing
- ☐ Mouth sores
- ☐ Taste changes
- ☐ Heartburn/Indigestion
- ☐ Vomiting
- ☐ Diarrhea
- ☐ Constipation

Informational
- ☐ Understanding my illness and/or treatment
- ☐ Talking with my health care team
- ☐ Making treatment decisions
- ☐ Knowing about available resources
- ☐ Taking medications as prescribed

Other Concerns: _____

Thank you for filling out the form. The rest of the form will be completed by your healthcare professional

To be filled out by a health care professional only - Screening Intervention Documentation

Review of Form:

☐ Patient declined to fill out form ☐ Language barrier ☐ Other _____

☐ Form reviewed through conversation with patient
If form not reviewed why: ☐ Patient declined discussion ☐ Other: _____

Is patient at falls risk? ☐ Yes ☐ No

☐ Patient Priority Concern Identified ☐ Patient indicated no concerns

Specify ONE priority concern (either ESAS or CPC):

ESAS: ☐ Pain ☐ Drowsiness ☐ Appetite ☐ Depression ☐ Well-being
☐ Tiredness ☐ Nausea ☐ Shortness of breath ☐ Anxiety ☐ Other

CPC: ☐ Emotional ☐ Practical ☐ Mobility ☐ Social/Family/Spiritual
☐ Nutrition ☐ Physical ☐ Informational ☐ Other _____

Specific area indicated under the CPC domain: _____

Actions taken:

☐ Provided information/Education ☐ Offered Tobacco Cessation Advice ☐ Prescription provided
☐ Provided emotional support ☐ Referral suggested but patient declined ☐ No further action required

Referrals:

☐ Social Work ☐ Palliative Care ☐ Fatigue ☐ Tobacco Clinic ☐ Dyspnea/Respiratory
☐ Psychology ☐ Nutrition ☐ Home Care ☐ OT/Physio/Speech ☐ CO Navigation
☐ Spiritual Care ☐ Pharmacy ☐ Pain Clinic ☐ Other _____

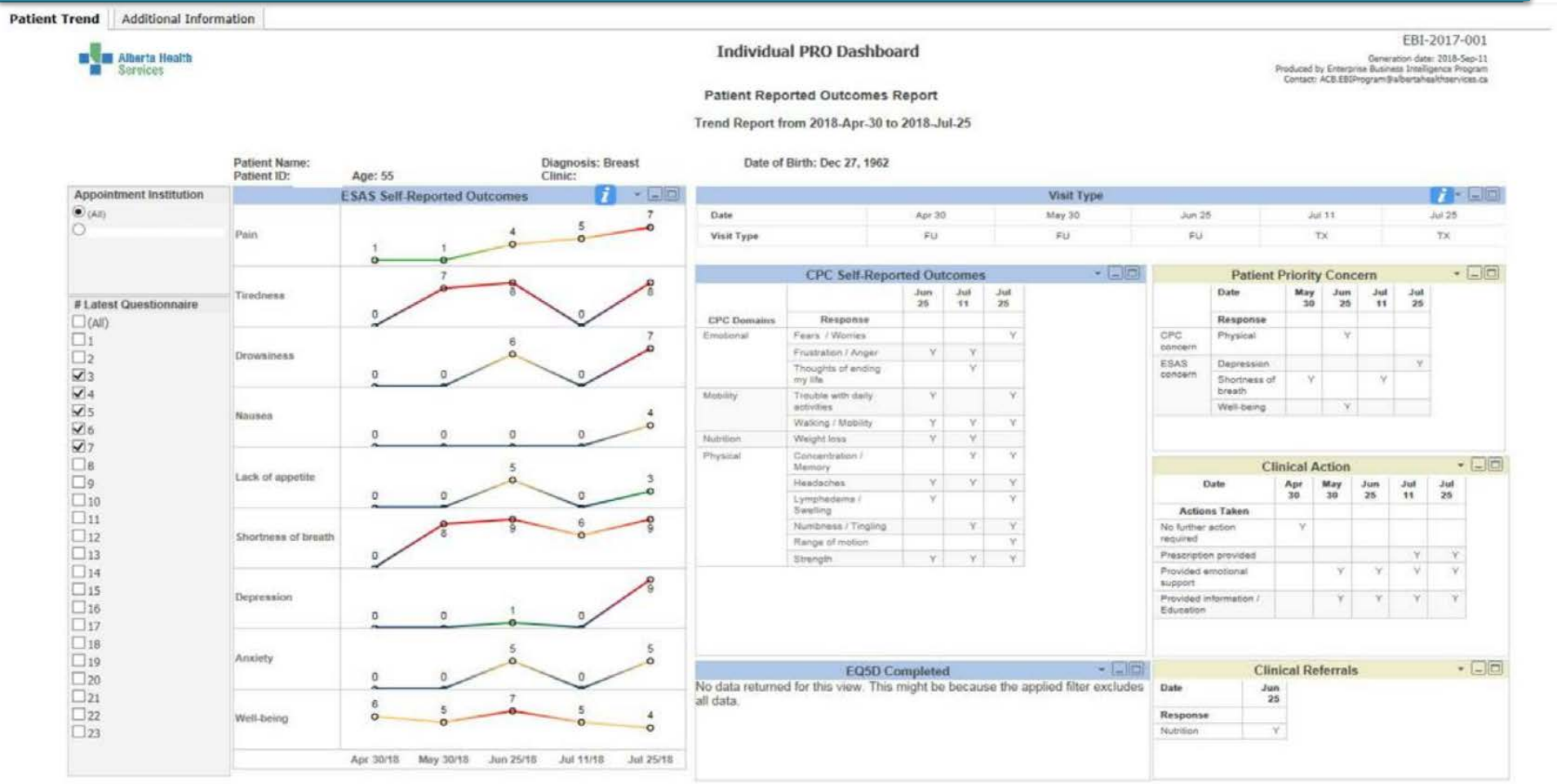
Further details on action taken:

_____

☐ See progress notes/nursing documentation for further information

Reviewed By *(Name of Health Care Professional)*	Signature *(of Health Care Professional)*	Date *(yyyy-Mon-dd)*

PRO dashboard: Trending data



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Step 3: Managing Unmet Needs

▼ Palliative & Supportive Care

- Metastatic Colorectal Cancer: Early Palliative Approach
  - Interactive Care Pathway
  - Referral Based Services for Advanced Cancer Care
  - Local Tips for Providers
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    - Sample Physician Letter
    - Sample Patient Letter
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Symptom Management Summaries

- Anxiety
- Depression
- Oral Care
- Tenesmus
- Sleep Disturbance

Additional Resources

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Step 3: Local Tips – Calgary Zone

★ Provincial Content

Contents

PALLIATIVE CARE EARLY AND SYSTEMATIC

Step 3: Referrals Service Descriptions

Service	Description	Contact Information
2.1 Palliative Home Care	Provides in-home care, support, and comfort to people coming to the end of their lives and their families with a focus on managing symptom issues, providing emotional and psychological support. Works with clients with a progressive, life limiting illness. Provides 24 / 7 support to the patient and the family. ***Note: Rural areas do NOT have a separate Palliative Home Care program; they have Integrated Home Care with mixed caseloads and Palliative Care Consult support**	ROUTINE REFERRAL: Alberta Referral Directory - Search by Edmonton OR Calgary Accessible in these cities through Community Care Access (for clinicians or patient self-referral: **Edmonton:** : 780-496-1300 : 780-496-8438 **Calgary:** : 403-943-1920 **OR** 1-888-943-1920 : 403-943-1602

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Step 3: Introducing Palliative Care

Contents

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Step 3: Coordination of Care

Shared Care Letter

Alberta Health Services

Physician
Advanced Cancer – Shared Care
SAMPLE LETTER ONLY

Re: Advanced Cancer Shared Care

Dear Dr. _____,

Your patient [Aria: Insert name] is in treatment at our Cancer Centre for an advanced, incurable, colorectal cancer. This requires a **collaborative effort and a palliative approach to care.** We will work closely with you to coordinate care, improve quality of life and symptom management. We appreciate your ongoing management of non-cancer related problems, while the Cancer Centre will focus on issues related to cancer and its treatment. This document outlines **relevant information for you as their primary care provider related to:**

- Potential signs and symptoms of cancer related emergencies
- Other palliative supportive measures
- Contact information for the GI oncology team

Please refer to the latest consultation note for prognosis specific to your patient (will be sent separately). If no prognosis is noted or you have further questions, please contact us. All Cancer Centre consult and progress notes, imaging, and lab work are available in NetCare. At any time if you have any concerns or are in need of more information, please contact the medical oncologist.

COLLABORATIVE CARE

We have asked the patient to make a follow up appointment with you and your team. Maintaining a close relationship is important for emotional support, advance care planning and follow-up of non-cancer related health issues. Studies suggest that active involvement with family physicians, psychological and emotional services, and connections within the community improve patient and family outcomes. We ask that non-cancer related concerns and issues including medications be managed by your team. Symptoms can also be co-managed together. To optimize shared care, please communicate to us any significant changes or updates.

Care Component	Cancer Care Team	Family Medicine Team
Chemotherapy and chemotherapy related concerns	•	
Organizing investigations related to cancer treatment	•	
Symptoms (i.e. pain, anxiety, depression, sleep disturbances, constipation, psychosocial)	•	•
Advance Care Planning	•	•
Patient and Family concerns	•	•
Legal/financial concerns (e.g. POA)	•	•
Accessing community resources	•	•
Non-cancer comorbidities		•

Please note patients with pre-existing:

- **Diabetes** may require changes to their medications due to changes in oral intake, weight loss, and concurrent antiemetic medications.
- **Anti-hypertensives** may require adjustments, especially if they lose weight.

It is advised to avoid becoming pregnant or fathering a child while receiving chemotherapy. An adequate method of contraception should be used for both men and women. The combination of a barrier method and the contraceptive pill would give the best protection.

MONITORING FOR COMPLICATIONS

Chemotherapy side effects will have been reviewed in previous letters prior to initiation of treatment.

- **Fever** (temperature over **38°C for one hour or 38.3°C once) while on chemotherapy**, may indicate life threatening febrile neutropenia. Direct patient to Emergency Room.

Attention Reception Staff: Please ensure this is given to the family physician. After it is reviewed and completed, please fax back to Tom Baker Cancer Centre @ 403-283-1651

Shared Care Information Exchange

We are sharing the care of this advanced colorectal patient. To foster collaborative care, we would like to provide you the opportunity to ask any questions and individualize this patient's care plan.

Please confirm your clinic is the patient's current medical home:

☐ Yes ☐ No (if No, no further comments are required)

☐ Please confirm you are managing **non-cancer** related concerns and medication refills:

Comments: _____

Please provide clinic contact information stamp, if the medical oncologist needs to contact you:

Do you feel comfortable in participating in the palliative approach to care for our patient?

Approach to Care	Yes	No	Comments
Symptom Management: (E.g. opioids if required)			
Psychosocial: (E.g. family distress)- are SW access and other supports available?			
Advance Care Planning- do you have a Goals of Care Form (Green Sleeve) on file? (please fax copy if so)			

Non urgent questions you would like answered: _____

Please fax this letter to: 403-283-1651.

Non-urgent messages for the oncologist can be left at:
[Aria Sig Block]

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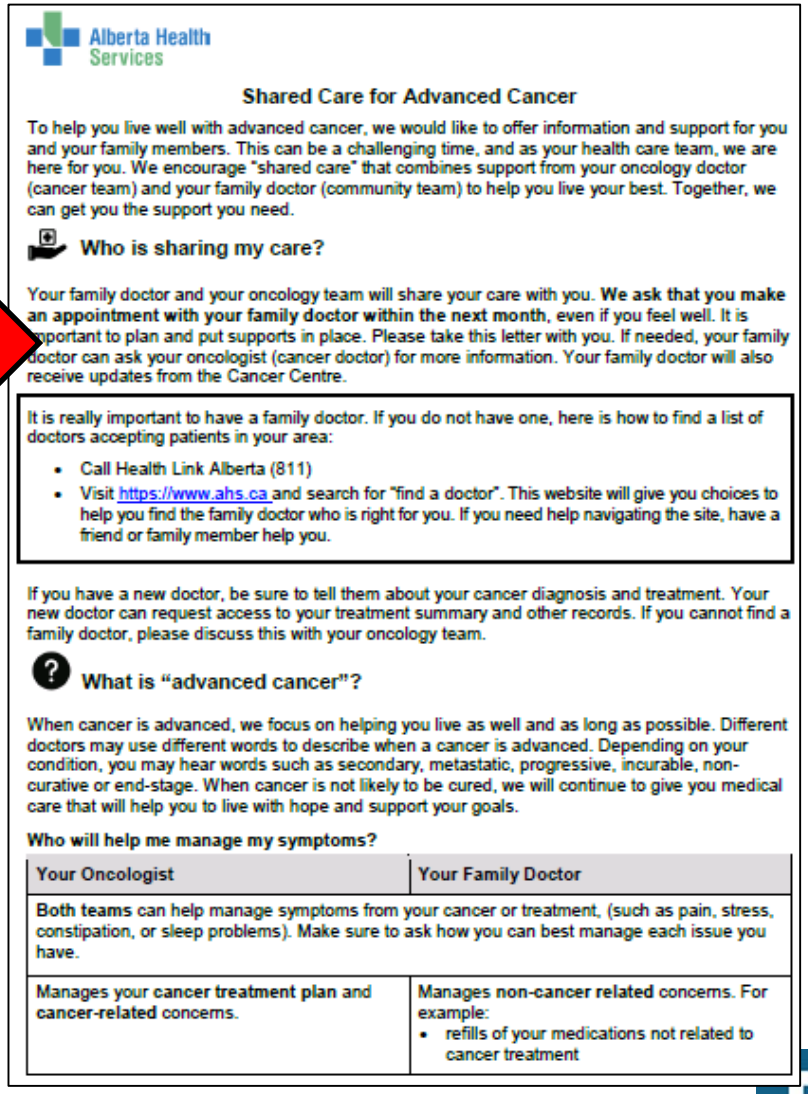
Step 3: Shared Care Patient Handout

Advice to see Family physician



Alberta Health Services

Shared Care for Advanced Cancer

To help you live well with advanced cancer, we would like to offer information and support for you and your family members. This can be a challenging time, and as your health care team, we are here for you. We encourage "shared care" that combines support from your oncology doctor (cancer team) and your family doctor (community team) to help you live your best. Together, we can get you the support you need.

Who is sharing my care?

Your family doctor and your oncology team will share your care with you. **We ask that you make an appointment with your family doctor within the next month**, even if you feel well. It is important to plan and put supports in place. Please take this letter with you. If needed, your family doctor can ask your oncologist (cancer doctor) for more information. Your family doctor will also receive updates from the Cancer Centre.

It is really important to have a family doctor. If you do not have one, here is how to find a list of doctors accepting patients in your area:

- Call Health Link Alberta (811)
- Visit https://www.ahs.ca and search for "find a doctor". This website will give you choices to help you find the family doctor who is right for you. If you need help navigating the site, have a friend or family member help you.

If you have a new doctor, be sure to tell them about your cancer diagnosis and treatment. Your new doctor can request access to your treatment summary and other records. If you cannot find a family doctor, please discuss this with your oncology team.

What is "advanced cancer"?

When cancer is advanced, we focus on helping you live as well and as long as possible. Different doctors may use different words to describe when a cancer is advanced. Depending on your condition, you may hear words such as secondary, metastatic, progressive, incurable, non-curative or end-stage. When cancer is not likely to be cured, we will continue to give you medical care that will help you to live with hope and support your goals.

Who will help me manage my symptoms?

Your Oncologist	Your Family Doctor
Both teams can help manage symptoms from your cancer or treatment, (such as pain, stress, constipation, or sleep problems). Make sure to ask how you can best manage each issue you have.	
Manages your **cancer treatment plan** and **cancer-related** concerns.	Manages **non-cancer related** concerns. For example: • refills of your medications not related to cancer treatment

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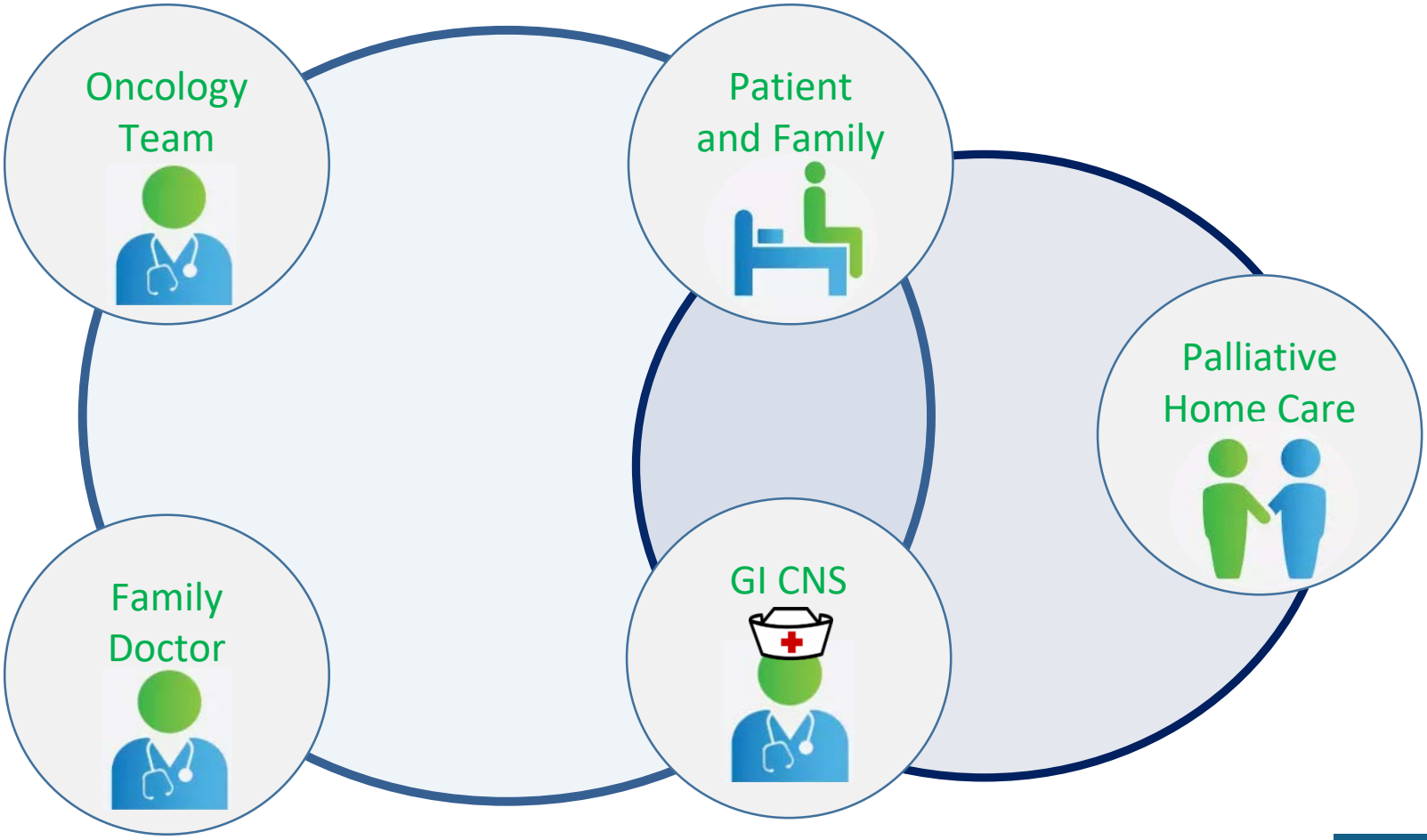
Routine referral to PC nurse specialist



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Integrated & Palliative HC memo

Clients do not have to have personal care needs to be eligible for home care services.

Early referrals can:

1. Establish a relationship
2. Access to home care professional services e.g. OT
3. Help clients and families navigate community care services
4. Assist with advance care planning conversations
5. Support clients and families in contemplating & sharing end of life planning.

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Implementation in Calgary

We are all human…change is hard.

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Implementation Process

Pre Planning
- Learning from similar projects
- Input from front line staff and operations

Pilot
- Pilot in two oncology clinics
- Test and implement proposed changes

Refine
- Learn from pilot
- Refine process

Scale and Spread
- Implement refined process in remaining 6 GI clinics
- Phased change

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How’s it going so far?

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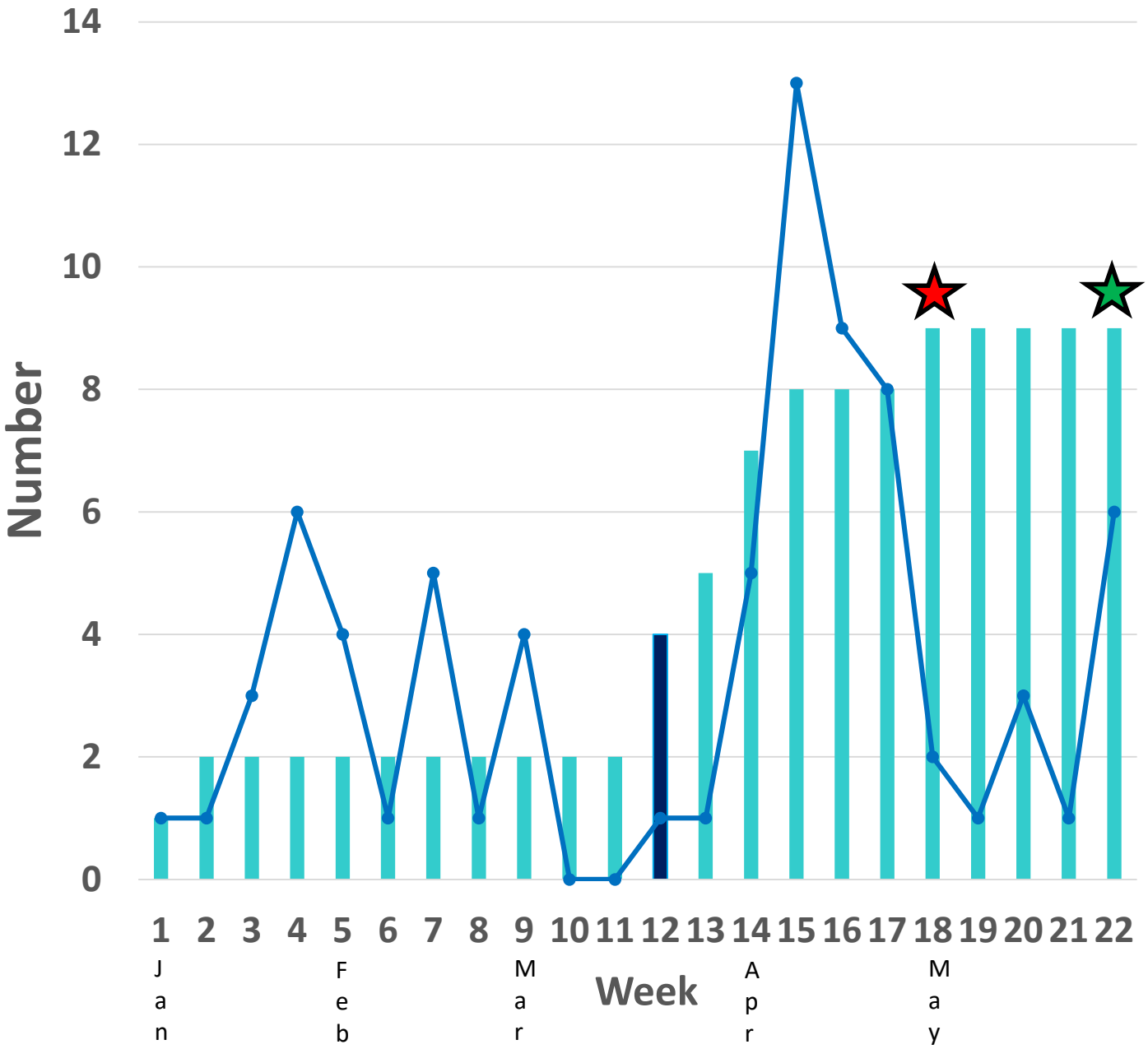
Advanced Cancer Shared Care Letter Orders



Number of MO active

Number of Letters Ordered

Camille stopped clinic visits

Jan started clinic visits

Total letters ordered= 76

Total fax backs= 39

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Successes

- Correcting family physician
- GCD sent in by community providers
- Supports available through PCN
- Opportunity to ask MO questions e.g. prognosis
- Desire to engage in shared care of patient

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Challenges

- Highlighting incorrect providers
  - Getting provider information updated
- Remember to sign for scanning and address questions asked on returned coversheet
- Screening and Ordering
  - Busy clinics, other opportunities?

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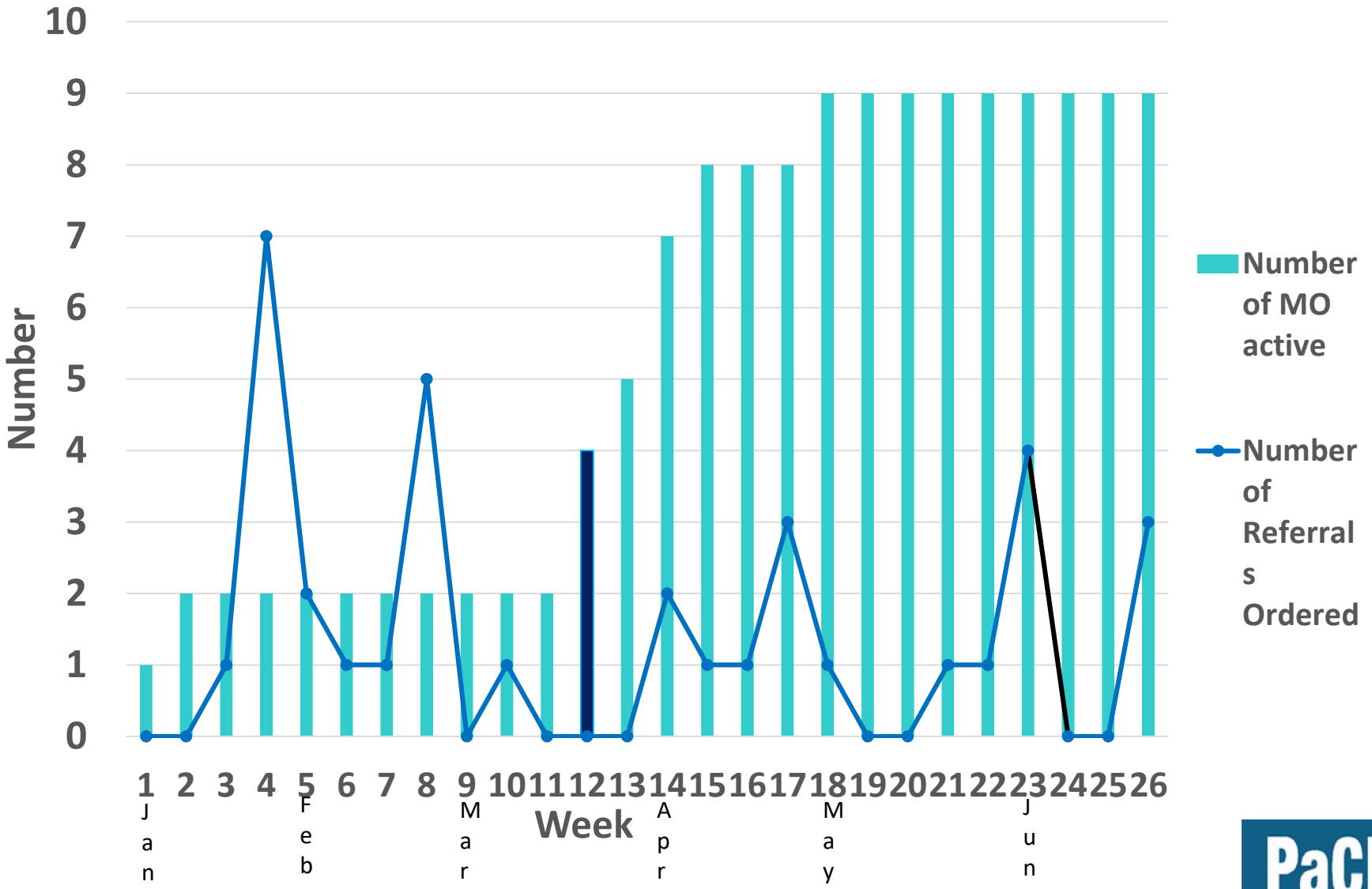
Palliative Care Referrals



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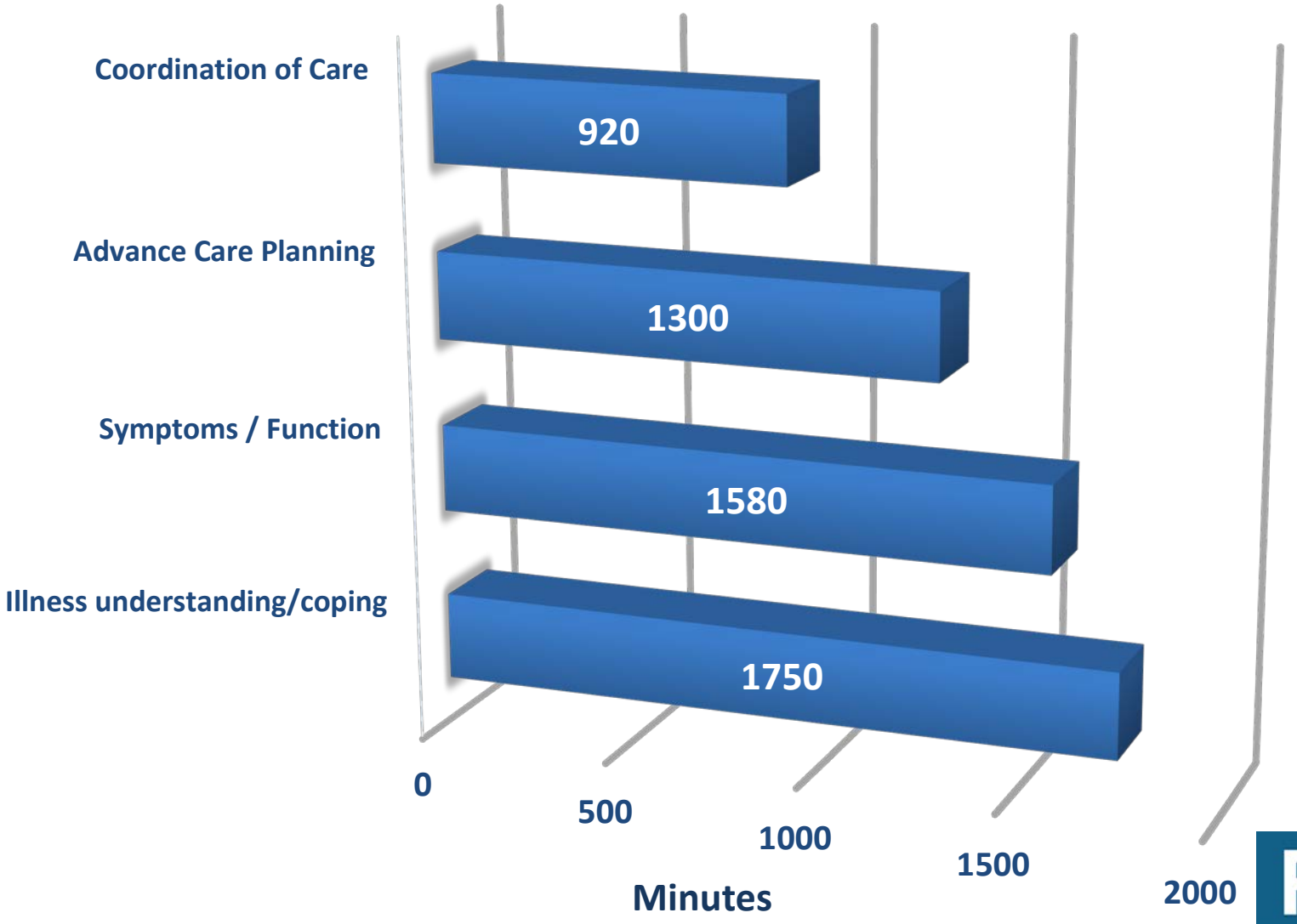
Palliative Care Elements



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PC Nurse Specialist – Emerging Experience

Patients have be overwhelmingly grateful for PC support:

- "I wish you [PC] had been introduced to us at the very beginning."
- "No one has asked me about time and the quality of my life before."
- "I was afraid to ask about what was coming, but it helps to have it out in the open. I feel like I don't have to push those thoughts away all the time."

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Community Provider Feedback

“The take home message for me is that it is important to start palliative care early and to educate patients and family that palliative care does not mean end of life care.”

“More willing to contact/collaborate with oncologists”
(FP Strengthening Linkages Workshop)

“I appreciated discussing what W went through in hospital before his dying. It meant that his family could come here for help without having to repeat all of the details.”

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What else?

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Evaluation: Living with Colorectal Cancer Study

- Observational study
- Interrupted time series with control
  - Palliative care referral
  - Patient reported outcomes (ESAS, EQ5D)
  - Caregiver preparedness
  - Advance care planning conversations
  - Financial impact
  - Health service resource utilization

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Living With Colorectal Cancer Study

	Calgary	Edmonton
Patients	56	118
Caregivers	28	44
as of Aug 31, 2019		

Interim Results: Workshop by Shireen Kassam

Enrollment ONGOING at CCI

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Wrapping up

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UNIVERSITY OF CALGARY

About PaCES
Our Team +
Our Stakeholders

Learn more about PaCES activities

- Measuring current healthcare use
- Engaging oncology clinicians
- Understanding the rural patient experience
- Developing our early palliative care pathway
- Evaluating our early palliative care pathway

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CLICK HERE for the early palliative care guideline and pathway!

"I will be forever grateful for the many acts of kindness, both big and small —that reassured both of us that we weren't alone, that others cared, and that her life was honoured and respected to its end."

(PaCES Patient/Family Advisor, on her mother's journey with cancer)

Vision:

Improving quality of life for Albertans with advanced cancer

Mission:

To provide early and ongoing access to coordinated, comprehensive and compassionate palliative care to improve quality of life for Albertans with advanced cancer

What is PaCES?

The Palliative Care Early and Systematic (PaCES) Project is a province-wide team of researchers and knowledge end-users

Palliative Care Services at CCI

- Pain and Symptom Control
  - For patients under the care of the CCI with inadequately controlled symptoms
  - Outpatient, multidisciplinary, inpatient, telehealth
- Community Liaison
  - For advanced cancer patients being discharged from care at the CCI
- Referral from any MD or NP

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Take home points

Integrate palliative care earlier

Palliative Care is an added layer of support (not just for dying!)

Supports you can use: **www.ahs.ca/GURU**

Attend to 4 Elements

Enhance Shared Care

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[Aria Sig Block]

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Continuing the journey……

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Next steps

- Palliative Education Day
  - Options for dyad training
- Non tumour-specific Advanced Cancer Shared Care letter (patient, provider)
- Local Tips – Other Zones (Provincial Pall Care Tumor group – S Watanabe: **WG members**)
- Keep recruiting for Living with CRC
- Application to expand to all GI & Lung cancers; Active intervention in Red Deer & Calgary

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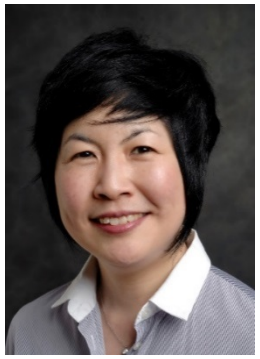
PALLIATIVE CARE EARLY AND SYSTEMATIC

PaCES Core Team


P. Tang


S. Watanabe

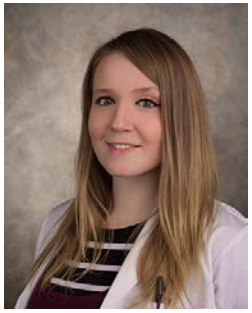

J.Simon


S. Kassam


M. Earp


A. Tan


P. Biondo


C. Beaumont


M. Kerba


J. Vandale


A. Sinnarajah

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Let us know what you're thinking

Sharon.Watanabe2@ahs.ca

Ayn.Sinnarajah@ahs.ca

Thank you!

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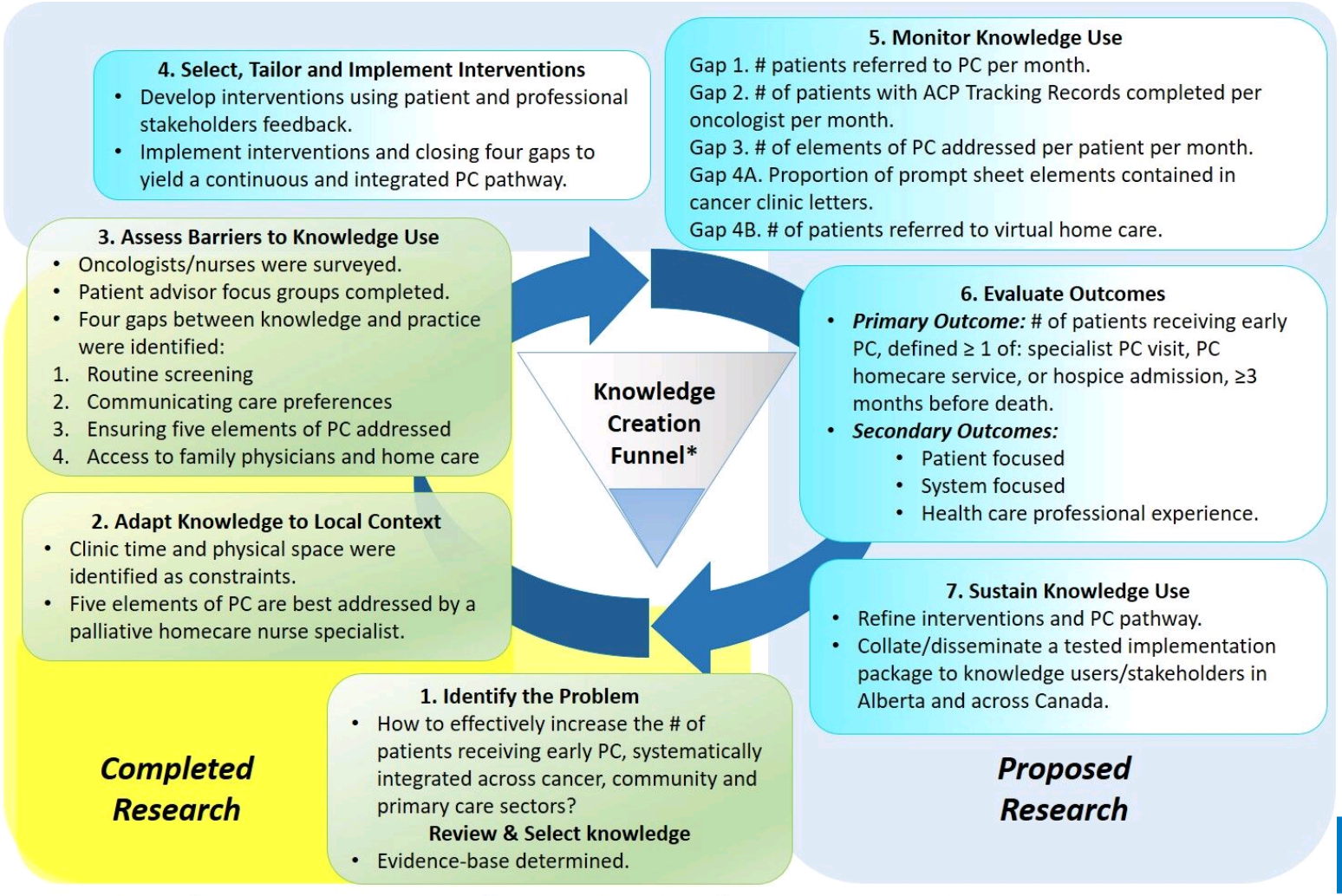
APPENDIX

Knowledge Translation Framework



*Our tested implementation package (how to effectively implement, monitor and sustain the pathway) will be new knowledge created.

Stakeholder Groups

Clinical areas:

- Oncology (Medical, Radiation etc), Palliative Care, Home Care, Family Physicians

Roles:

- Patient / Family advisors
- Front line clinicians
- Health System leaders / managers: Provincial, Regional, Local
- Researchers
- Knowledge Translation / Implementation experts
- Data Analytics
- Quality and Safety
- Education (Patient, Health Care provider)

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Pain Points- A Sampling

- Pt cannot find a Family Physician to work with Homecare/PC Consult team
- Duplicative referrals put in to prevent gap
- ER visits unnecessary but may be only place to go
- Family Physician with no capacity for home visits
- Not resourced for virtual remote care (e.g. rural)
- All Physician notes not avail (variety of systems involved, multiple services)
- Cross coverage of providers, who to go to for what?
- Role clarity
- Definition of Palliative care- different between providers and between providers and patients
- PC Consultants feel that there is an overall lateness to the referrals received (often when patient is in crisis)
- Barriers to giving and getting information (system issues)

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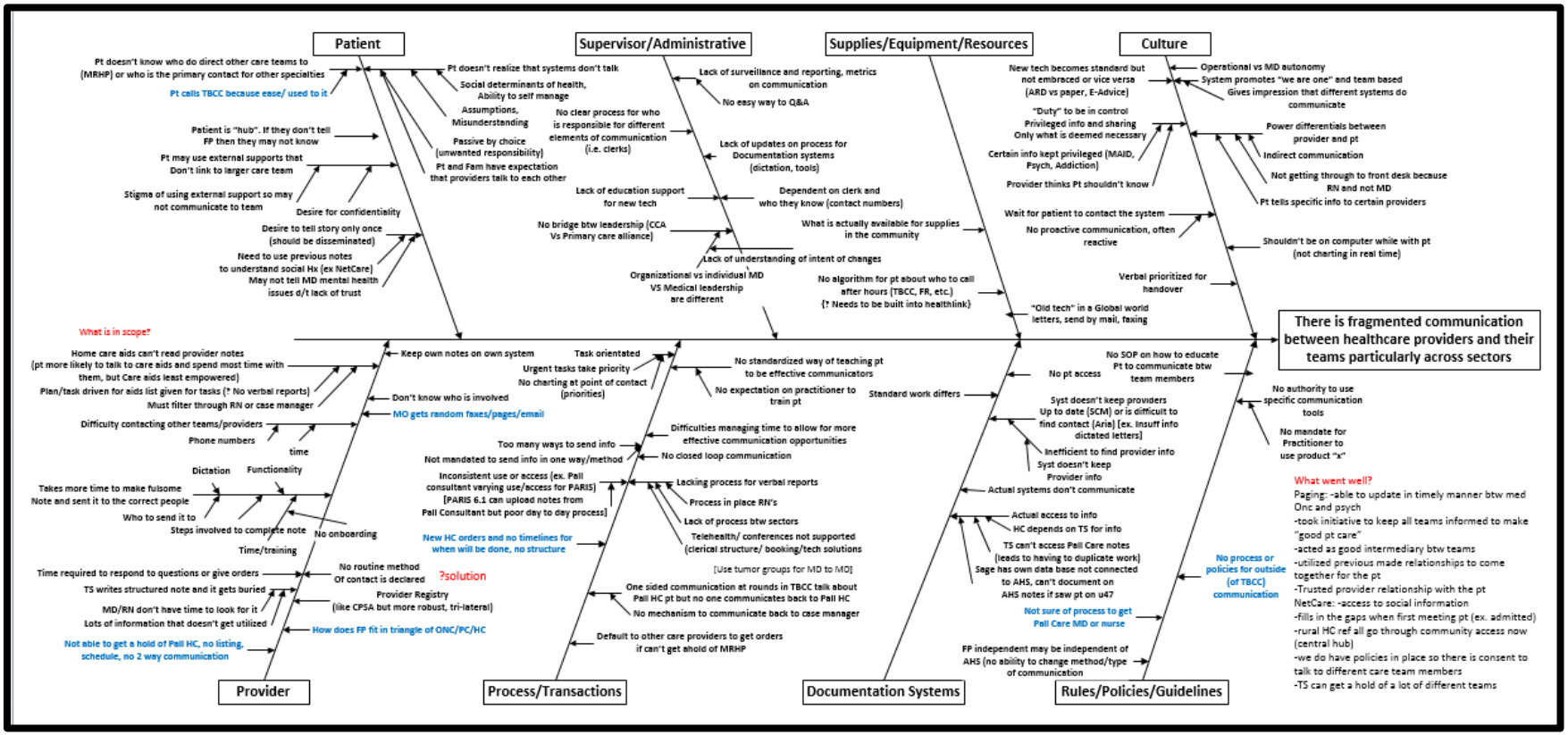
Fishbone Analysis – Why?



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Problem Statements

Transitions: No formal transition process for patients with advanced cancer to be discharged that are “No Further Recall” (NFR) to community service providers and Family Physicians creates a care gap for the patient.

Role: It is not clear among health care providers (HCP), patients and their caregivers who is responsible for each aspect of patient care.

Definition: There is no shared definition of palliative care in the eyes of HCPs and patients and no common knowledge of the palliative care services available.

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Problem Statements

Communication: There is fragmented communication between healthcare providers and their teams particularly across sectors.

Patient journey: There is a lack of visibility of the patient's schedule and resources being used by that patient to various healthcare providers.

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Problem Statements

Standard Goals of Care: While a standard policy/procedure exists for the use of Goals of Care designation, the practice is varied and there are gaps in its application.

Skill Gap: Healthcare providers have varied skills in relation to providing a palliative care approach which leads to gaps in the patient experience and late referrals to palliative care services.

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Solutions

TBCC change projects	Palliative care change projects	Knowledge/resources change projects
"Healthcare provider education" • Healthcare provider local training and education (grand rounds, simulation, courses, CME) • Communication technique- how to introduce pall care	"Healthcare provider education" • Healthcare provider local training and education (grand rounds, simulation, courses, CME)	"Healthcare provider resources" • Standard access to materials/ educational content (sharepoint, G-Drive, Websites) • Local Tips for providers • Symptom Summary tip sheets
"Referral process" • Create Standard Practice to consult pall care (business rules) • Palliative cluster elements of Patient Reported Outcomes (PRO) dashboard • "Concurrent" Chemo/Palliative treatment when on 2nd line chemo (like RT/Chemo concurrent tx)	"Referral process" • Change criteria to allow "well patient" access to home care services **Urban/rural Calgary zone • Palliative cluster elements of PRO dashboard	"Patient resources" • Definition of pall care- changing patient facing material **Provincial AND **Local • Normalizing pall care in CancerControl Alberta education material
"Transitions" • Dictation business rules (For MO), information sent to FP • Transition services- assessing process and addressing gaps • Transition package for non-curative (*shared care letters)	"Communication" • Home Care to fax/cc notes to Cancer Centre • Creation of business rules/guidelines for communication (Pall Care)	
Leadership surveillance and f/u with metrics/ audits (Local, cancer centre)	Leadership surveillance and f/u with metrics/audits (Local, cancer centre)	

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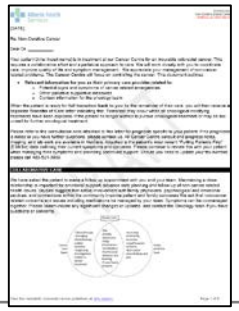
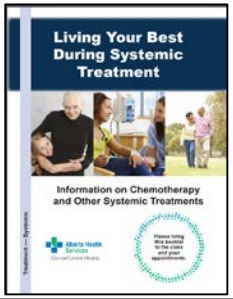
Resources to Support Implementation

Alberta Health Services

UNIVERSITY OF ALBERTA

UNIVERSITY OF CALGARY

Tools and Resources	Local Tips for Providers	Referral Based Services Available		Palliative GI CNS
Education	PaCES PALLIATIVE CARE EARLY AND SYSTEMATIC Pathway Clinical Document		PaCES PALLIATIVE CARE EARLY AND SYSTEMATIC Palliative Scripts	
System Integration	Patient Screening ⇨ Identify Unmet Needs ⇨ Collaborative Management of Unmet Needs ⇨ Exploring End of Life Topics			

Measurement and Improvement (QI)

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Alberta Health Services

Available at:

- www.ahs.ca/GURU
- **SharePoint** under “Advanced Cancer” tab
- **G Drive** under “Palliative Care (Colorectal) Resources PACES”

Provider Resources

- Local Tips
- Symptom summaries
- Referral based service descriptions

Oncology Team

Family Doctor

Provider Skill Development

- Palliative Care introduction scripts

Patient Resources

- Definition of palliative care in “Living Your Best”
- Using existing Advanced Cancer materials with transitions of care

Patient and Family

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Symptom Management Tip Sheets

▼ Palliative & Supportive Care

Symptom Management Summaries

- Anxiety
- Depression
- Oral Care
- Tenesmus
- Sleep Disturbance

Additional Resources

- ASCO Anxiety and Depression Guideline
- ASCO Fatigue Guideline
- CAPO Pan-Canadian Sleep Disturbances Guideline

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Care Coordination Letters

Alberta Health Services

PHYSICIAN
Non-Curative Transfer of Care
SAMPLE LETTER ONLY

[DATE]

Re: Non-Curative Transfer of Care

Dear Dr. _____,

Your patient [Aria: Insert name] has an incurable Colorectal cancer. All oncological treatment options have been explored at our Cancer Centre. No further disease modifying treatment is recommended and **no further follow up** will be provided by their oncology treatment team. This letter is to inform you of your patient's transfer of the care back to the community. The **consult note attached** summarizes your patient's treatments and illness course to date. All Cancer Centre letters, imaging, and lab work are also available in NetCare. Also attached is the patient's most recent "Putting Patients First" (**ESAS-r**) data outlining their current symptoms and concerns. You may find it helpful to review this with your patient when managing their symptoms and providing continued support.
This document outlines:

- **Relevant information for you as their primary care provider related to patients with colorectal cancers including:**
  - Monitoring for complications and oncological emergencies
  - Referrals for symptom control
  - Other palliative supportive measures
  - Contact information for the oncology team

MONITORING FOR COMPLICATIONS

Your patient may be at higher risk for bleeding or obstruction.

Tumor Bleeding or Obstructions:

- Acute and/or large volume bleeds may be managed urgently with radiological intervention or surgery if clinically appropriate. In advanced GI malignancies, bleeding, luminal narrowing, and pain can be controlled with radiotherapy. Depending on prognosis and patient preferences, community focused symptomatic management with support of palliative home care may also be appropriate.

- The prevalence of malignant bowel obstruction is estimated to be as high as 10-29% of those with colon cancer. Signs of obstruction may include persistent nausea, vomiting, constipation, abdominal distention and abdominal pain. Prior to a complete bowel obstruction, the patient may have overflow diarrhea in addition to the above symptoms. We recommend to:
  - Obtain X-ray of the abdomen. Assess if there is a transition point. If no transition, then assess for other contributing factors such as constipation, excessive antidiarrheal usage or other medications that may cause reduced peristaltic function
  - If on x-ray there is a **transition point**:
    - Consider referral to Gastroenterology (access referrals through Alberta Referral Directory) for endoscopic stenting or consideration of surgical intervention. Surgical intervention may not be required in a patient with an asymptomatic (or minimally symptomatic) primary colorectal cancer or clearly incurable metastatic disease
    - Consider referral to Radiation Oncology (see "Referrals" section) to relieve or prevent worsening obstruction
  - If symptoms are severe send patient to the Emergency Department
  - Consider medical management. See "malignant bowel obstruction" tip sheet, accessible via XXXXX link. Palliative consultation can advise on medical management.

View the palliative care pathway guidelines at: aihs.ca/guru

Page 1 of 4

DRAFT

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[Aria Sig Block]

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CCA Advanced Cancer Shared Care Letter (Patient):

- Pre print (DATA group) stocked in cabinets in OPD
  - Also available on SharePoint and G Drive

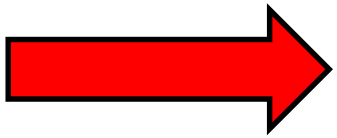
- Ordered by MO. Consider entering ordering when:
  - Prepping for clinic
  - When reviewing PaCES Dashboard data
  - In clinic

- Usual process will be to give patient letter on next OPD visit. Can give day of while in clinic per clinician discretion (e.g. patient needs to obtain Family MD).

- When GI clerk preps chart, letter is placed on top of blue flag for clinician to give to patient.

Information on how to get a family physician.

If your patient does not have one, you should give this letter the day of in clinic.



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Templated Shared Care Letter for Family Physician:

- Templated letter in ARIA

- Clerk processes order
  - Combines letter with MO Signature Block (defines how you preferred to be contacted). Block can be changed by contacting ARIA.

- Clerk to send letter via internal ARIA fax
  - MO can add additional information and send themselves via correspondence window

- Family MD faxes back the cover sheet
  - MO acts on as needed
  - **Signs/initials** and sends for scanning into chart (HIM)

PaCES Sub-projects

- PaCES Rural
- PaCES Family Physician / SUPPORT-FM
- PaCES Oncology Provider
- PaCES Health Resource Study
- PaCES Living with Cancer Study
- PaCES Pathway
- PaCES Implementation
- PaCES Serious Illness Conversation Program

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PALLIATIVE CARE EARLY AND SYSTEMATIC