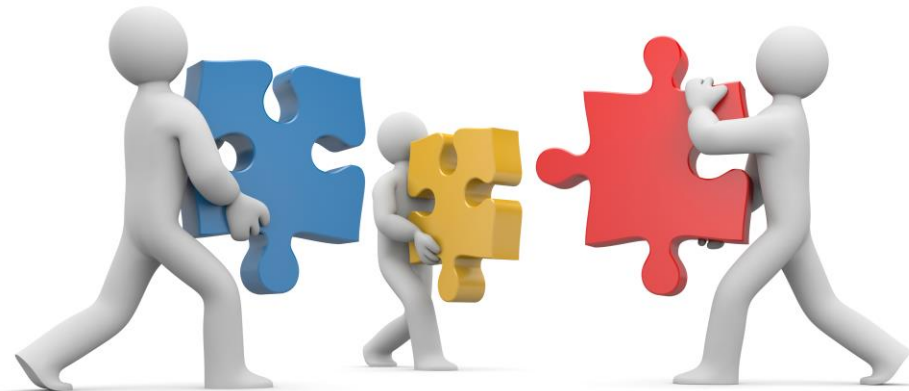


Collaboration is vital: meaningful engagement of patient and family advisors in the development of an early palliative care pathway



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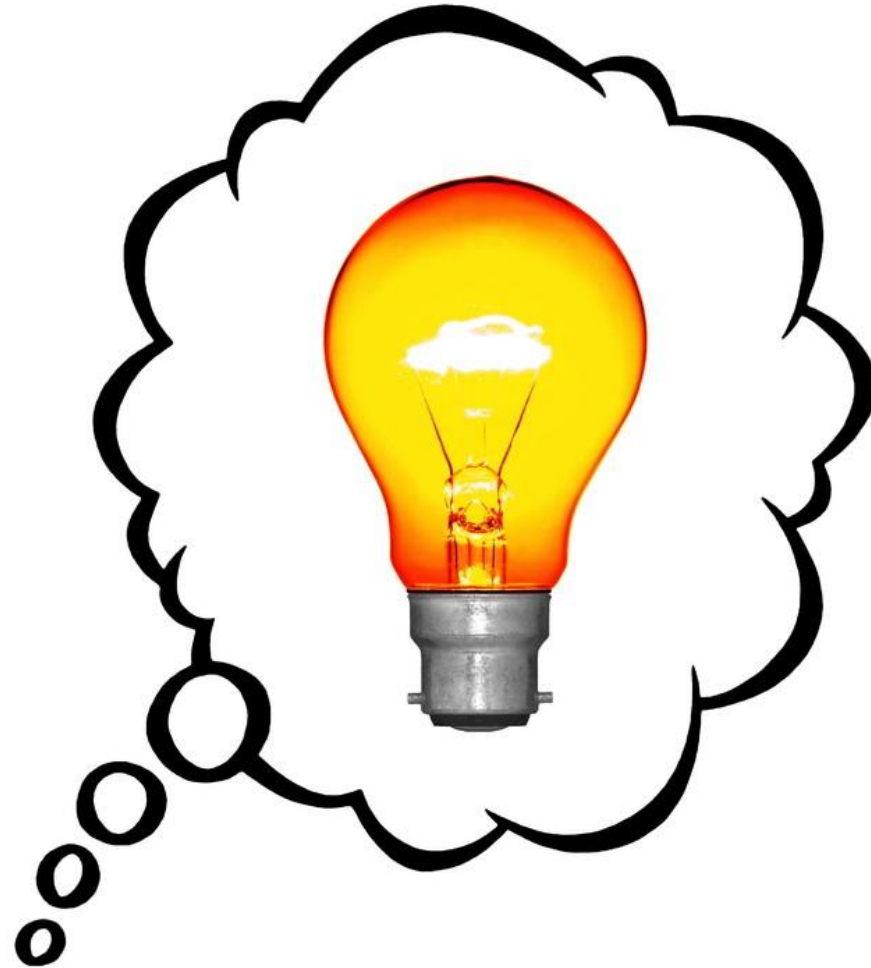
Disclosures

- ▶ Nicole McKenzie is a family advisor with the Patient and Family Advisory Network for Cancer Care in Alberta. She has no financial or commercial interests to declare.

Becoming an Advisor



What does “Palliative Care” mean to you?





“The FMC parking lot will continue to be a place of despair”

Patient Partner quote from the Alberta Cancer Foundation project investigating transitions to palliative care

EARLY Palliative Care

- ▶ **What?** Consultative visit by specialist palliative care provider and/or palliative homecare service ≥ 3 months before death
- ▶ **When?** May be used concurrently with cancer-focused treatments, soon after diagnosis of advanced cancer
- ▶ **Why?**
 - ▶ Improves patient quality of life
 - ▶ Reduces caregiver distress
 - ▶ Leads to fewer aggressive, costly and inappropriate end of life interventions

*“I can’t imagine trying to design a study about **patient** outcomes in cancer care without **patients** and families who have experienced cancer guiding us in what to ask and how to ask it”*

*“Also our colleagues may ignore the need to improve our care processes but they can’t ignore the powerful stories of our **patient** advisors!”*

Dr. Jessica Simon, PaCES Principal Investigator



Patient and Family Advisor Priorities

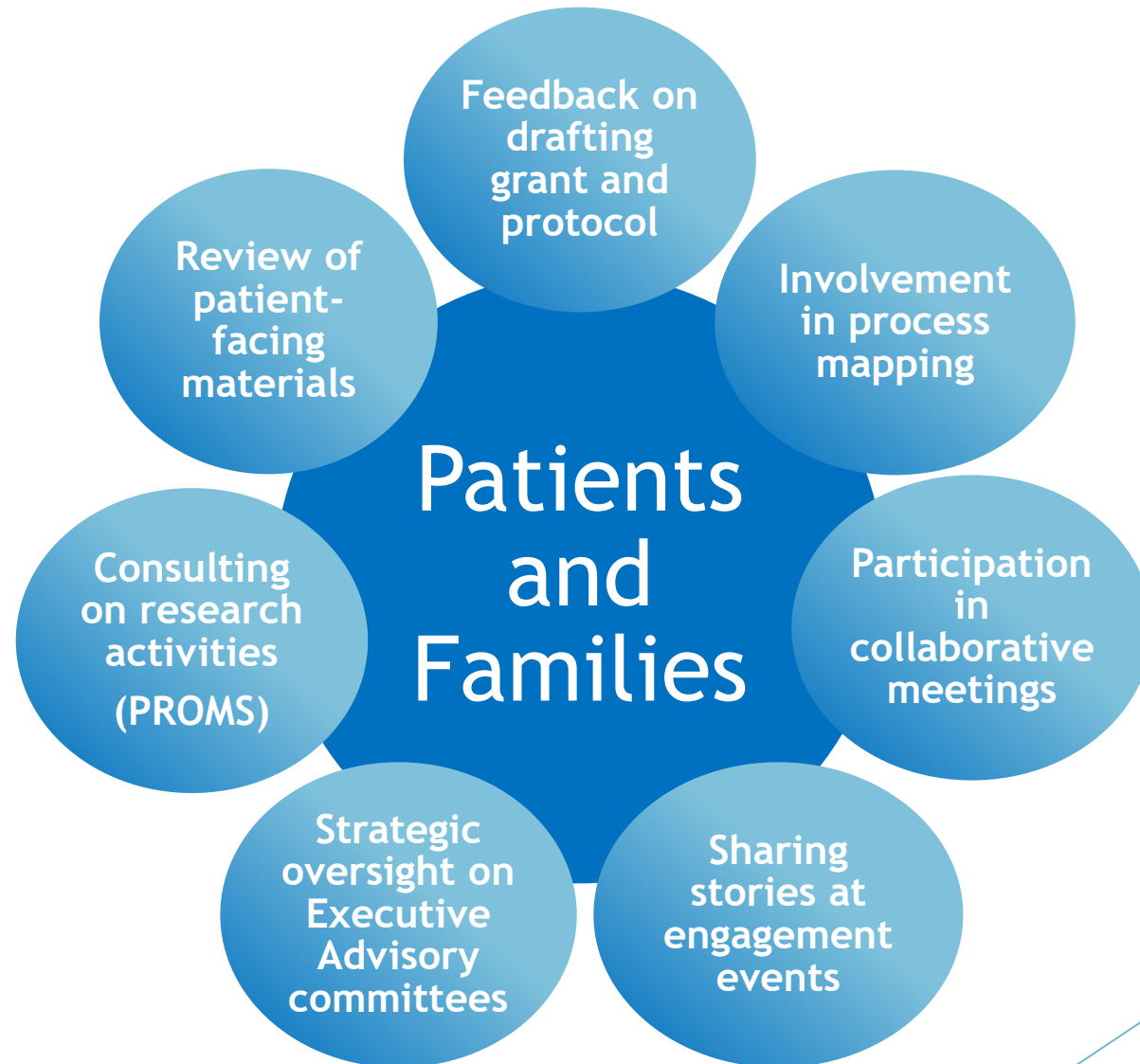
- ▶ To improve the transition to palliative care, we need:
 - ▶ A sense of continuity in care
 - ▶ Opportunities to discuss preferences for future care
 - ▶ Prompt access to specialized palliative care when needed



Palliative Care Early and Systematic (PaCES) Objectives

- ▶ Measure current use of services in AB for advanced colorectal cancer patients
- ▶ Assess barriers and facilitators to clinicians to provide palliative care concurrent to treatment
- ▶ Assess patient and family preferences on how early palliative care can be delivered in rural AB
- ▶ Develop an evidence-informed PaCES pathway for colorectal cancer in AB
- ▶ Evaluate the proposed pathway in Calgary (with Edmonton as control site) following pre-implementation data collection

PaCES Advisor Engagement Activities



Practical approaches to meaningful patient and family engagement



- ▶ Engage **early** and engage **often**
- ▶ Be **flexible**, **transparent** and **reasonable** with your “asks”
- ▶ Demonstrate a **genuine interest** in receiving feedback
- ▶ Involve advisors **throughout** the research process
- ▶ Show **compassion** - advisors are re-living difficult experiences
- ▶ Be **patient** - advisors are often NOT health care professionals
- ▶ Practice ongoing **communication** and **appreciation**

QUESTIONS?



THANK YOU!