

Can we achieve *early & systematic* use of Palliative Care supports and positively impact patient-family and health care system outcomes?

Yes, but....

PaCES

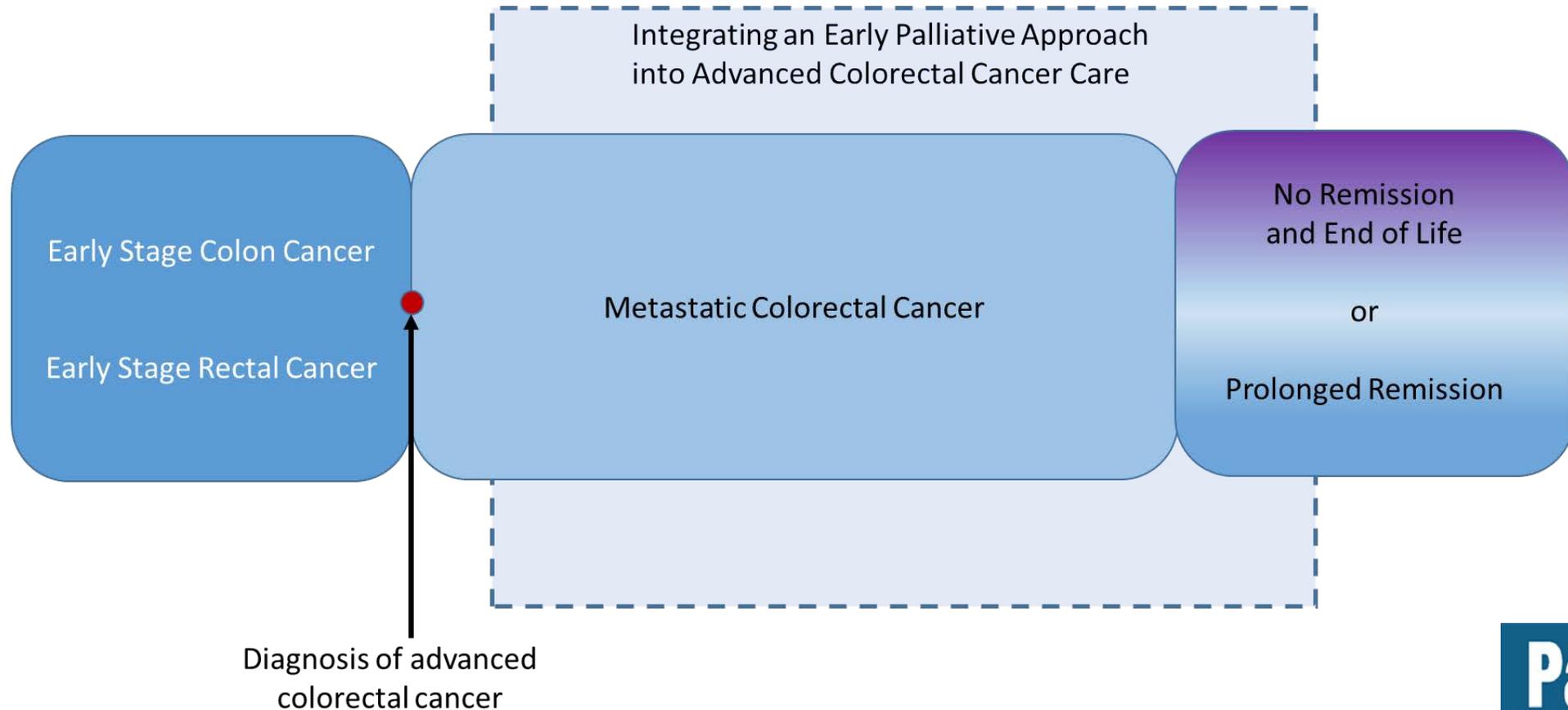
PALLIATIVE CARE EARLY AND SYSTEMATIC

Objectives:

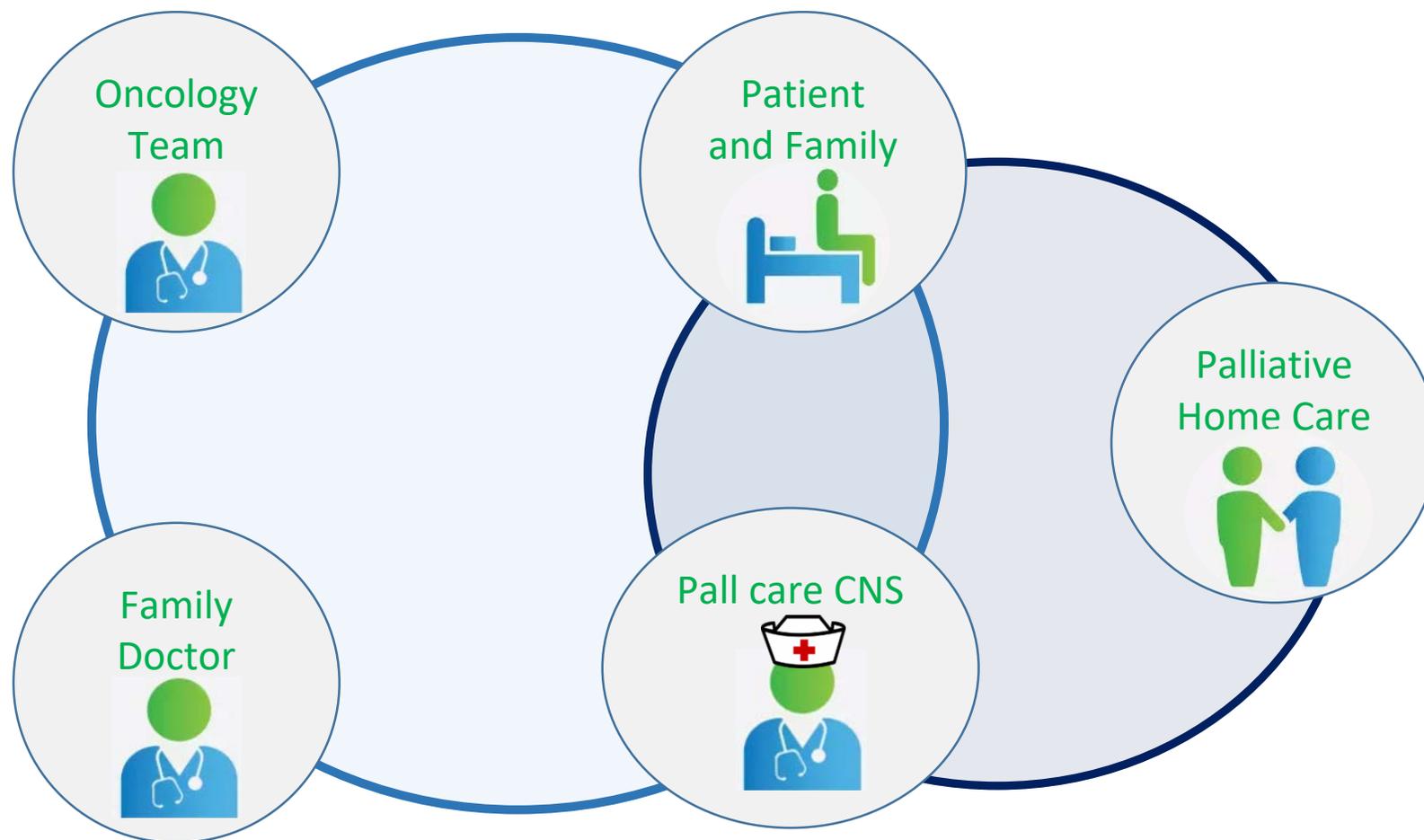
1. To share the experiences of PaCES first year, barriers and facilitators encountered in the pilot to date;
2. To discuss attitudinal and cultural shifts: Letter to the Editor, “Can Studies on Early Palliative Care be Harmful to Patient Well Being?”

What do we mean by *early*?

A palliative approach to care that occurs concurrently with cancer treatment



Routine Early referral to PC nurse specialist



CNS Referrals: January 2019 – January 2020



58 Referrals

20 Deaths (6 home, 8 hospice, 6 hospital)

35 current (28 as case manager, 7 as consultant)



Average survival from referral: 25 weeks
(baseline 2 months)

Early Palliative care Elements



This is Susan...



Susan's 4 Elements:

Illness Understanding/Coping

- **HISTORY** of dramatic survival 2017 informs Susan's hopes and expectations;
- Worries about mother witnessing "inevitable suffering"

Symptoms/Function

- Pain is tolerable but has deeper meaning
- **History** of dying friend

HISTORY

ACP/Decision Making

- **HISTORY**
- Father's death, hidden illness
- Disturbing GCD discussion
- Friend's death in hospital informs Susan's desire to die at home
- Survival experience informs Susan's decision re: Lonsurt

Care Coordination

- Rural roots, "how things are done," health care and social community **HISTORY**
- Rural PCS as Susan's needs become greater

“Why would I plant a tree in my garden if I didn’t expect to see it grow?”

Emerging experience: from patients

I wish you (PC) had been introduced to us at the very beginning

I was afraid to ask 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.

I'll see you but you can't use the "P" word

We should just get sent to you when we're diagnosed instead of being asked if we want PC

But I don't need home care yet

No one has asked me about time and the quality of my life before

Emerging experience: from practitioners

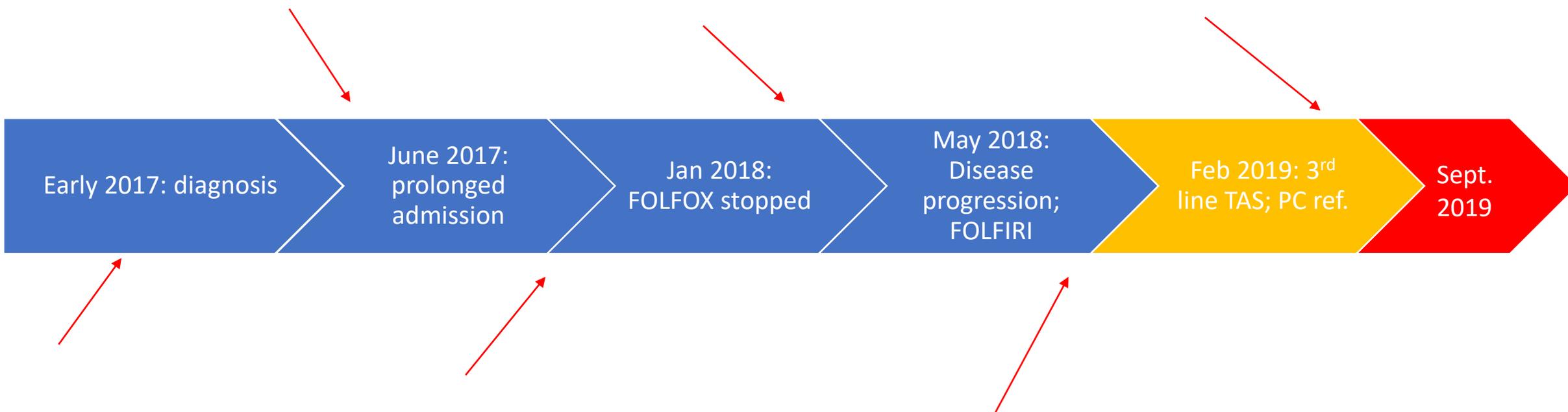
No, he's not palliative yet.

But what are we doing for her? I'd like to get her off my list.

He's still getting treatment. We'll send him when we stop chemotherapy.

You would devastate her!

Susan's journey:



Essential learnings:

- PRESENCE
- LANGUAGE
- ONGOING CONVERSATION
- CULTURAL SHIFT



Can Studies on Early Palliative Care Be Harmful to Patient Well Being?

Licia Touzet, MD,¹ Xavier Dhalluin, MD,² Arnaud Scherpereel, MD, PhD,^{2,3}
Chloé Prod'homme, MD,^{1,5} Alexis Cortot, MD, PhD,^{2,6} and Vincent Gamblin, MD⁴
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"There's no easy way I can tell you this, so I'm sending you to someone who can."

The Way Forward 2015: language and lexicon

Integrated palliative approach to care/community-integrated palliative care - Care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services.

The Way Forward 2015: language and lexicon

2. Establish a Common Language

Words are important. An integrated palliative approach to care is still new and not well understood. For many people – including many healthcare providers – the word “palliative” is associated with the last days or weeks of life. How does an integrated palliative approach differ from palliative care? To ensure a common understanding across the country, we need a common language and clearly defined terms. The words we use must embody dignity, compassion and empathy, as well as respect for different cultural attitudes towards dying.

As part of *The Way Forward* initiative, we assembled a Lexicon of Terms related to an integrated palliative approach to care that can form the basis for more discussion about a common language. To have that language adopted and used, we must engage people and organizations across the country in an ongoing process to identify the right words and integrate them into education and practice. A number of provinces and organizations have already started this work. We must also be quick to address any misperceptions about what the words mean.

EPC Harmful?

J Palliat Med. 2019 May;22(5):508-516. doi: 10.1089/jpm.2018.0338. Epub 2019 Jan 11.

Understanding the Barriers to Introducing Early Palliative Care for Patients with Advanced Cancer: A Qualitative Study.

Sarraden-Eck A^{1,2}, Beale S^{1,3}, Trojan J⁴, Capodano G⁵, Mancini J⁶.

Results: The findings suggest that referral to PCSs shortly after the diagnosis of advanced cancer increases the terminological barriers, induces avoidance patterns, and makes early disclosure of poor prognosis harder for oncologists. This situation is attributable to the widespread idea that palliative care means terminal care. In addition, the fact that the EPC concept is poorly understood increases the confusion between EPC and supportive care. **Conclusion:** Defining the EPC concept more clearly and explaining to health professionals and patients what EPC consists of and what role it is intended to play, and the potential benefits of palliative care services could help to overcome the wording barriers rooted in the traditional picture of palliative care. In addition, training French oncologists how to disclose "bad news" could help them cope with the emotional issues involved in referring patients to specialized palliative care.

Actual footage of a PC specialist in the TBCC:

