

# **Feasibility of collecting survey-based patient reported outcome measures (PROMs) from patients living with advanced cancer: Emerging findings from the Living with Colorectal Cancer study**

Kassam S, Beaumont C, Simon J, Biondo P, Watanabe S, Earp MA, Sinnarajah A

## **Interim Results**

30th Annual Palliative Education & Research Day  
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PALLIATIVE CARE EARLY AND SYSTEMATIC

## Presenter Disclosure

**Faculty:** Shireen Kassam

### **Relationships with financial interests:**

**Grants/Research Support:** CIHR and Alberta Health

**Speakers Bureau/Honoraria:** None

**Consulting Fees:** None

**Patents:** None

**Other:** Employee of University of Calgary

## Disclosure of Financial Support

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Potential for conflict(s) of interest: None



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## Mitigating Potential Bias

Not Applicable



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Living with Colorectal Cancer:  
Patient and Caregiver Experience



Patient Data



Feasibility of  
collecting PROMs

# Study Overview

## Objective:

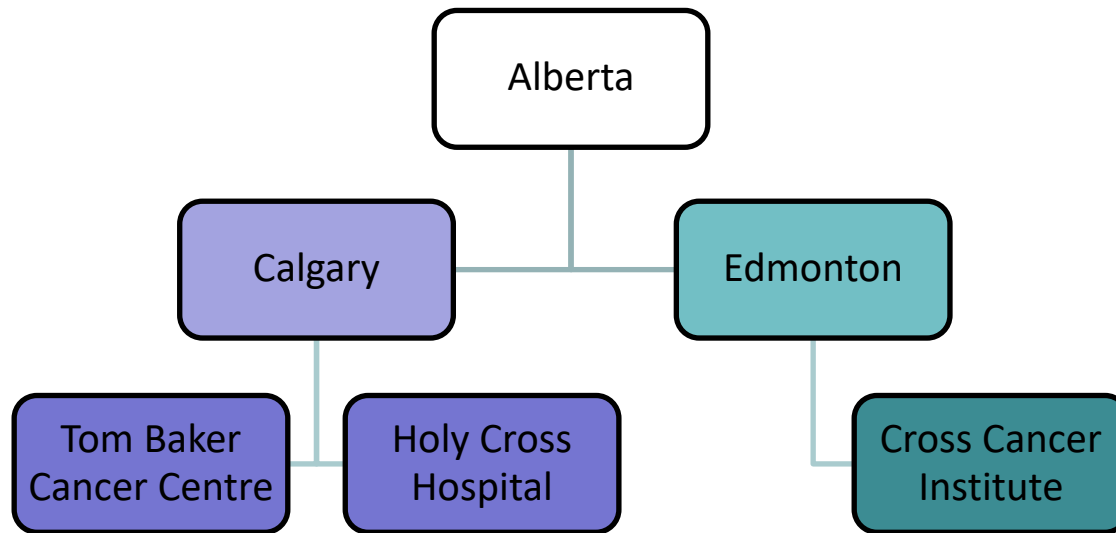
- Measure how quality of life in this population changes over time
- Before and after the Palliative Care Early and Systematic (PaCES) pathway is implemented

# Study Overview

## What:

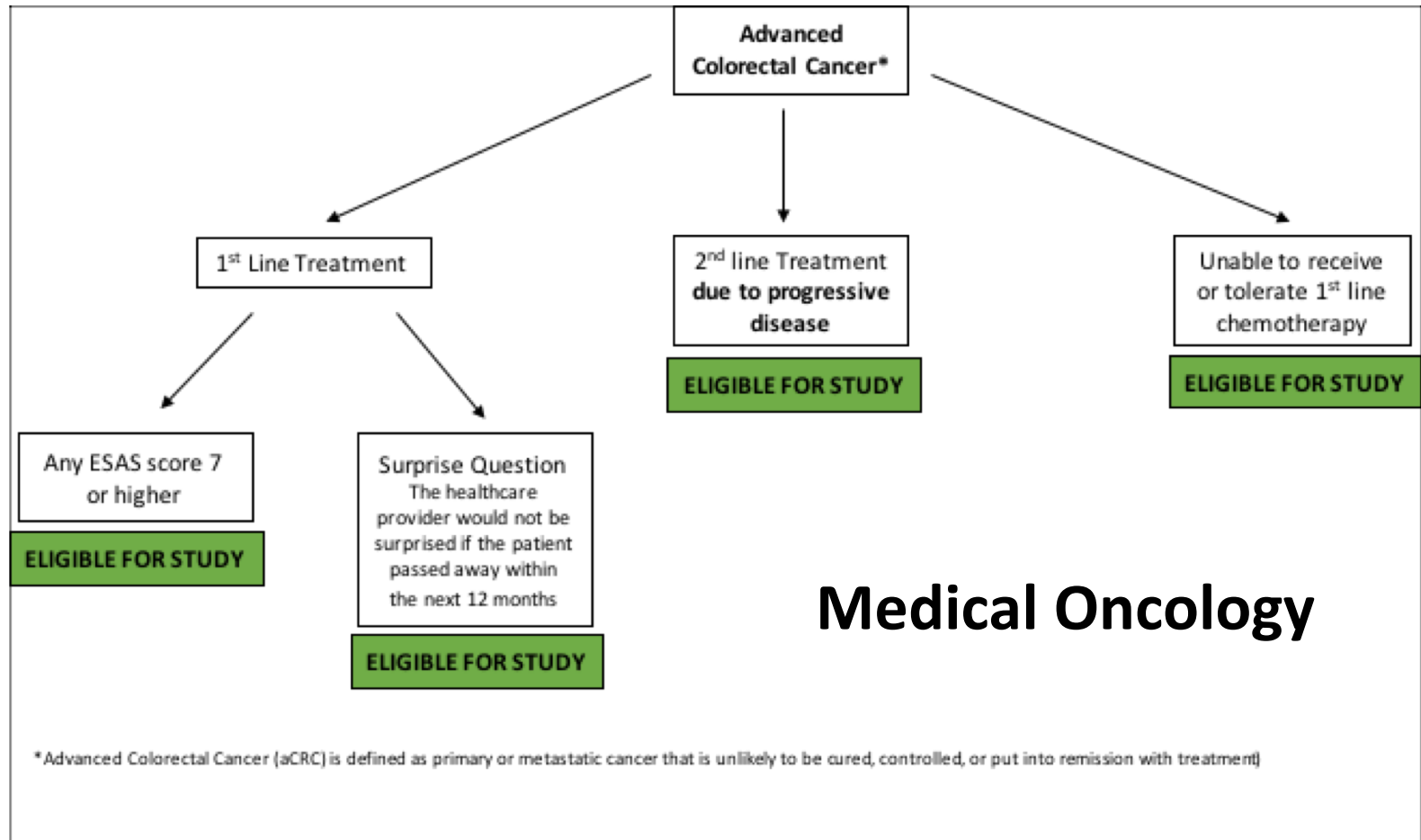
- Observational study
- Gather experience of **patients** with advanced colorectal cancer and their caregivers

## Where:



# Study Overview

## Who:



# Study Overview

**Duration :**



## Types of participation

### Full

- Patients complete surveys monthly

### Partial

- Patients complete one set of surveys at enrollment only
- Following enrollment, study staff has access to the patient's medical record but patients are not required to complete any further surveys

# Study Overview

## Methods:

- Initial and periodic PROMs and PREMs
  - PROM: capture a patient's perception of **their health**
  - PREM: capture a patient's perception of **their experience with health care or a service**

Please check the box that best describes how you feel **NOW**.

**I feel at peace.**

- ☐ 1. Not at all  
☐ 2. A little bit  
☐ 3. A moderate amount  
☐ 4. Quite a bit  
☐ 5. Completely

What concerns have you had **in the last month**? 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)

**Other Concerns:** \_\_\_\_\_

**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



Too

## MY CONVERSATIONS

### Living with Colorectal Cancer: Patient and Caregiver Experience

My  
Car

<b>Subject ID</b> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<b>Date form completed</b> ____/____/____ Y Y Y Y M M D D
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Some people talk with their healthcare providers (e.g. doctors, nurses, etc.) about their illness, healthcare preferences, and planning for the future.

**1. In the last month, has a healthcare provider talked with you about the following?**  
(Check (√) all that apply)

- ☐ Asked you what is important to you as you consider your healthcare preferences (such as your values, wishes, goals, or spiritual beliefs)
- ☐ Talked to you about your prognosis (life expectancy, predicted course or outlook of your illness)
- ☐ Given you the opportunity to express your fears or to discuss what concerns you
- ☐ Asked you about treatments you prefer to have or not have if you were to be very sick or at the end of life
- ☐ I had contact with a healthcare provider in the last month but I had none of these conversations (**Go to question 2**)
- ☐ I did not have contact with a healthcare provider in the last month (**Go to question 3**)

## Tools used

### EQ-5D-5L-

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.  
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health  
you can imagine

100  
95  
90  
85  
80  
75  
70  
65  
60  
55  
50  
45  
40  
35  
30  
25  
20  
15  
10  
5  
0

I)

The worst health  
you can imagine

## Methods of participation

MAIL



PHONE



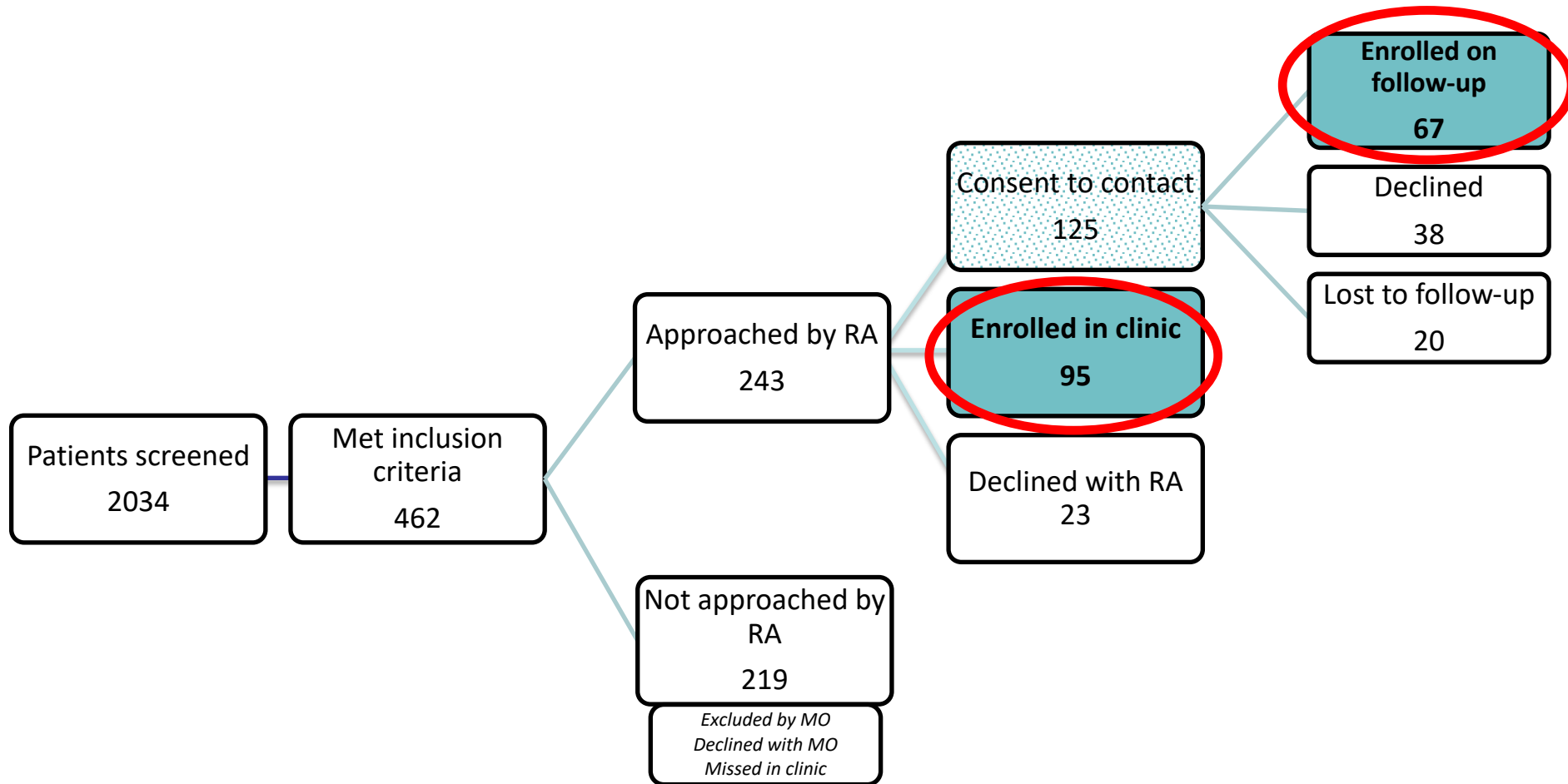
IN PERSON



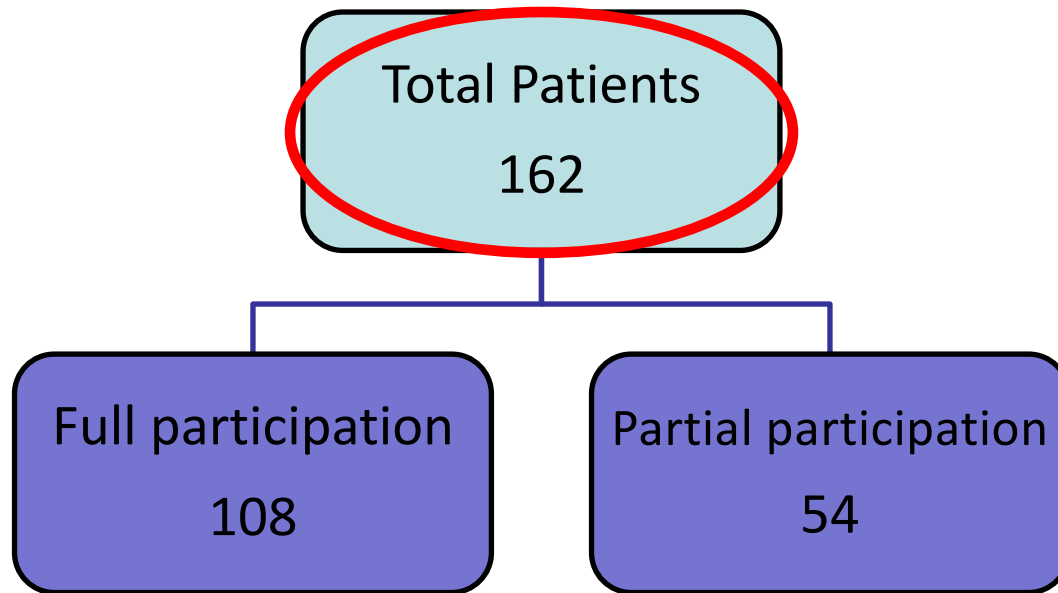
E-MAIL



# Screening & Recruitment



## Screening & Recruitment



as of August 2019

## Demographics\*

Full Participants	Median age (Range)	Female	Male	Reported speaking a language other than English
108	64 (32-88)	46 (43%)	62 (57%)	21%

\* Full Participants only



Mail	In Person /Phone	Email
5	34	69

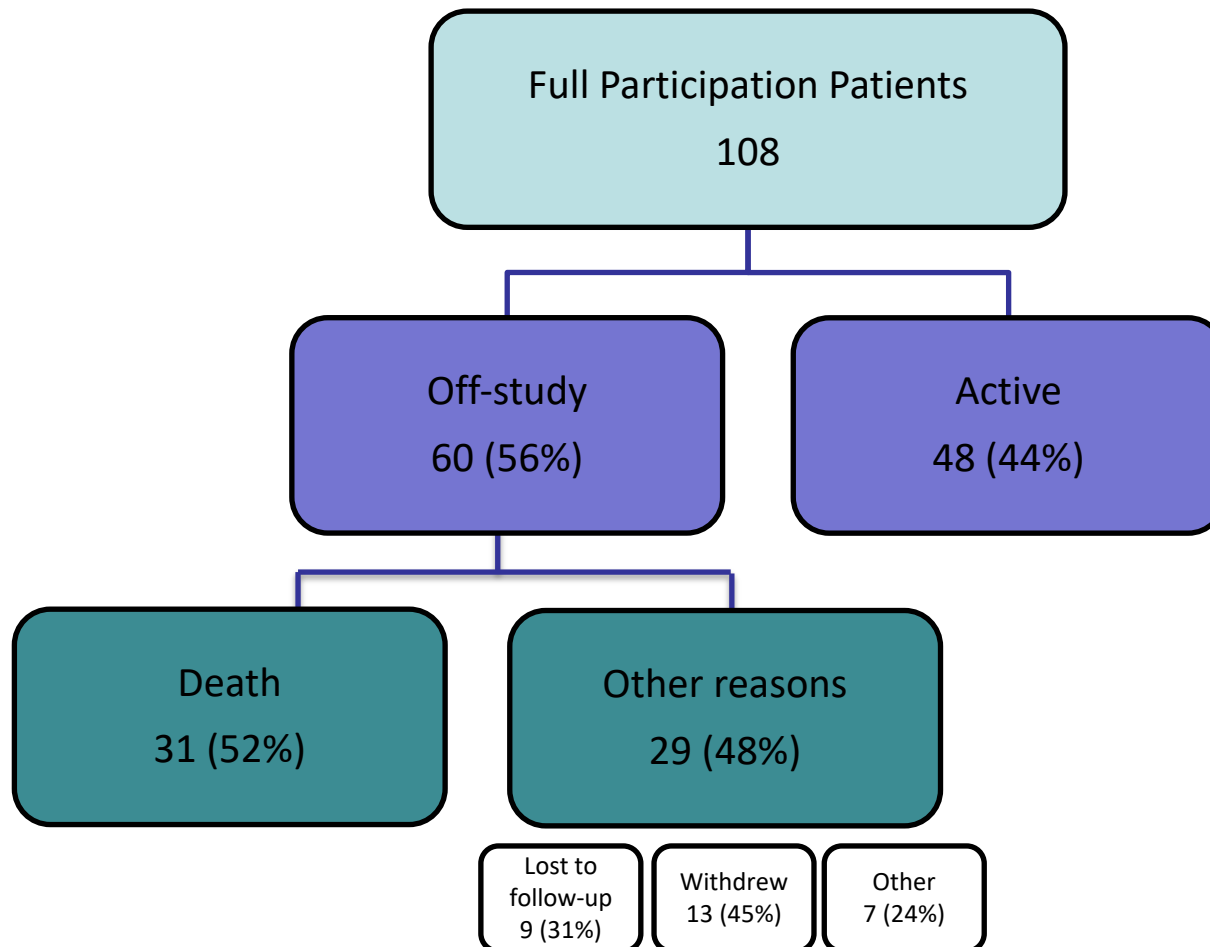
## Non-English speaking patients

### 12 eligible patients identified\*

- 11 declined
  - 3 too sick/ in hospice on follow-up
  - 1 deceased on follow-up
  - 4 no longer interested in participating
  - 2 not interested in participating because surveys must be done in person/ via mail (no online option)
  - 1 off all treatment and moved to another country
- 1 enrolled (Cantonese speaking, Edmonton)

\*Arabic, Tagalog (x4), Spanish, Cantonese (x2), Vietnamese (x2), Russian (x2)

## Off-study rates





## Off-study statistics\*

Days between enrollment date and off-study date:

- 40- 569 days (range)
- 186 days (median)

**1** MONTH

**6** MONTHS

**19** MONTHS

\*Full participation patients only

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## Missing Data

Reasons for missing data (surveys that are not completed):

- Too sick or in hospital
- Death
- Lost to follow-up
- Patient requests to stop follow-up surveys
- Vacation
- Other
  - -patient forgot, technical difficulties etc.

$$\frac{120}{906} = 15\%$$

So what is the feasibility of collecting survey-based patient reported outcome measures (PROMs) from patients living with advanced cancer?



It is challenging but possible to engage and retain patients with advanced cancer in research focused on PROs.



Offering flexible modes of participation assists with patient engagement.

# Key Learnings

## SUCCESSES

### 1. Patient engagement

- Face-to-face contact appreciated
- Patients eager to provide experiences

### 2. Multiple methods for survey completion

- Allows patients to participate in a manner most practical for their lifestyle
- Did not impact PROMs collection

## CHALLENGES

### 1. Burden on healthcare providers

- Clinic flow: room occupied while Research Assistant recruits and enrolls patients

### 2. Maintaining long-term contact with patients

- Patients withdraw when they become too sick to participate

## Next Steps

Determine the time between patients going off-study and actual date of death

## Future Considerations

*“It is interesting to think about my responses to the survey questions every month but it is pretty structured. I would love to tell my story from the beginning, starting with when and how I was diagnosed so you can get the full picture of my experience.”*

*-Patient A*

Some patients expressed a desire to provide more details about their experience

- Consider a qualitative survey/ data collection method
  - *Dr. Maria Santana’s companion study*

## Future Considerations

### Explore other ways to engage non-English speaking patients

- Currently, patients must complete surveys via mail only (no online versions of the surveys in other languages)



*“I’m happy to fill out these surveys every month and let you know how things are going with me. I hope this will help someone else in the future.”*

*-Patient B*

*“It’s nice that I can do the surveys during my chemo treatment but can also do them with you over the phone if I’m not coming to the Cancer Centre that month.”*

*-Patient C*

# Thank You

## Questions / Comments?



CIHR IRSC



Canadian Institutes of Health Research  
Instituts de recherche en santé du Canada

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