

Living with advanced colorectal cancer: what can analysis of the *My Conversations* advance care planning survey tell us?

Preliminary findings from the My Conversations survey and a discussion of challenges encountered during the analytical process

Said Hussein

Introduction

- Said Hussein, second-year student at the University of Calgary (BHSc, Biomedical Sciences degree stream)
- Began as a summer student with PaCES in late May
- Spent the last 4 months working on part of **Objective E - Living with Colorectal Cancer study** primarily under the guidance of Shireen Kassam
 - Focusing on the ***My Conversations*** survey: a questionnaire exploring an individual's understanding of and satisfaction with discussions about Advance Care Planning (ACP) and Goals of Care

Defining ACP

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

Sudore RL, Lum HD, You JY, Hanson LC, Meier DE, et al. Defining Advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*. 2017, May. 53(5): 821-32.

Background - *Low engagement in cancer care?*

- Only **7%** have a GCD in ARIA (**16%** in CRC)
- Only **125 out of 11,000** have a tracking record in ARIA

Background

- Research Questions
 - Is the early palliative care pathway associated with an increase in the number of patients that report having discussed ACP elements with a healthcare provider?
 - Is early palliative care pathway implementation associated with more ACP elements being discussed earlier in the course of advanced cancer (in relation to time of death)?
 - Who are patients having ACP conversations before and after early palliative care pathway implementation?

Background

- Research Questions (continued)
 - Are patients satisfied with the ACP conversations they are having with their healthcare providers?
 - What is the total number of patients who feel heard and understood by their healthcare providers?
 - What percentage of patients think they have a GCD?
 - Do patients become more knowledgeable about what their GCD is the closer they are to death?

'Living with Colorectal Cancer' study

Observational study to gather outcome and experience data from patients with advanced colorectal cancer and their caregivers.

Objective: The primary outcome is to measure how quality of life in this population changes over time in order to understand, guide, and monitor what is necessary to improve cancer care for all Albertans

Methods: Initial and periodic PROMs and PREMs of patients and their caregivers (EQ5D5L, PPF/ESASr, Preparedness for Caregiving, ACP GCD conversations)

Duration: January 2018 to December 2020

Sample size: 200 patients between Edmonton and Calgary

Tools used

- Patient surveys
 1. Putting Patients First (PPF), ESASr, Canadian Problem Checklist
 2. My Conversations (ACP GCD conversations)
 3. EQ-5D-5L

My Conversations Tool

Completed by patients every month for the first **10** months,
then every 12 months

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**)

1a) Who did you talk with (Check (✓) all that apply)

Doctor

- ☐ Family Doctor
- ☐ Oncologist (Cancer doctor)
- ☐ Other doctor

Nurse

- ☐ Family doctor office nurse
- ☐ Cancer clinic nurse
- ☐ Home visit nurse
- ☐ Other nurse

Other healthcare provider (e.g. social worker, counselor, radiation technician etc.)

☐ _please specify _____

1b) In general, how satisfied were you with these conversations?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Not very satisfied
- ☐ Not at all satisfied

My Conversations Tool

2. How much do you feel heard and understood by your healthcare providers in the last month?

- ☐ Completely
- ☐ Quite a bit
- ☐ Moderately
- ☐ Slightly
- ☐ Not at all

A Goals of Care Designation is a medical order that guides your healthcare providers about the general focus of your care, the kinds of treatments that might be used, and where you might want that care. You might know it as a "resuscitative", "medical", or "comfort care" order that may be kept in your "green sleeve".

3. Do you have a Goals of Care Designation order?

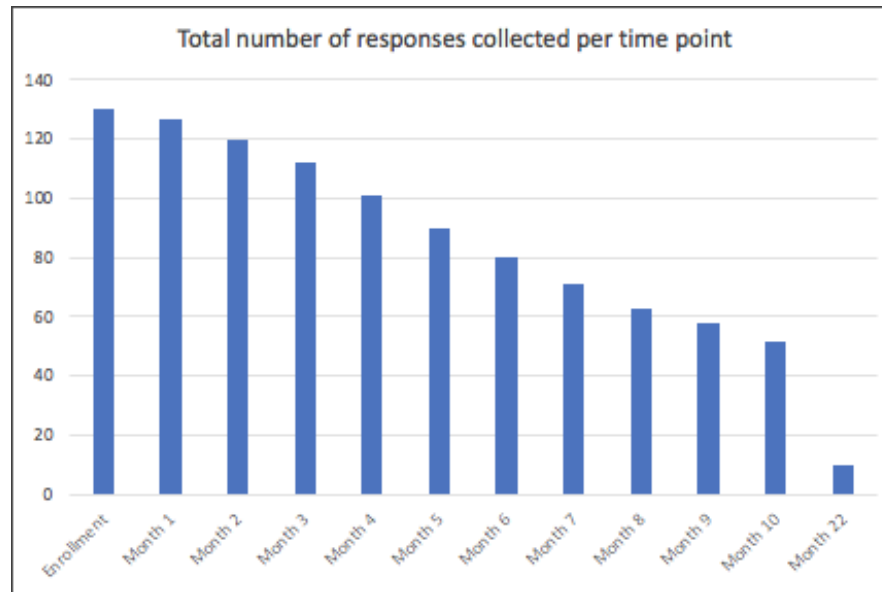
- ☐ Yes
- ☐ No
- ☐ Unsure

3a) IF YES, to the best of your knowledge, what is the focus of your Goals of Care Designation order?

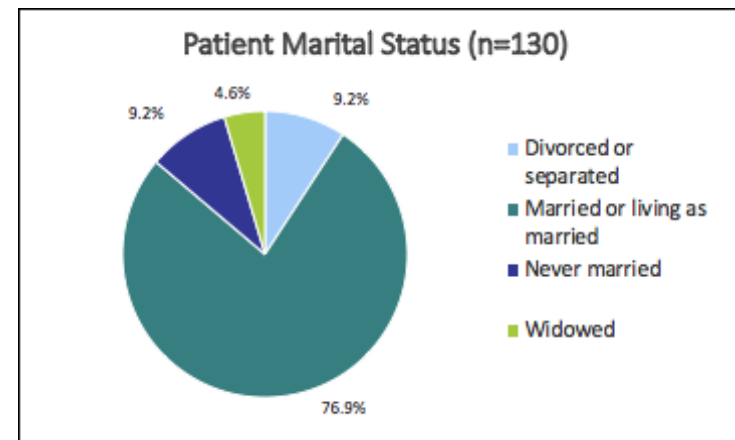
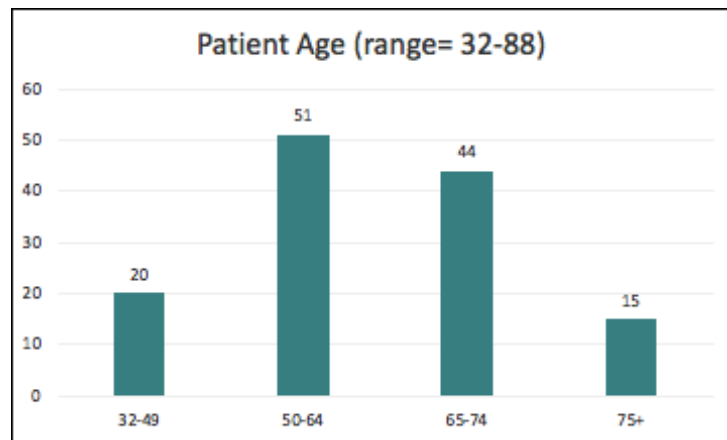
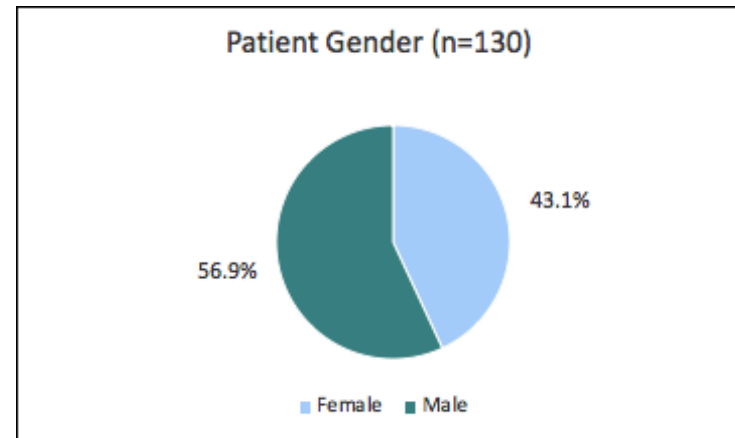
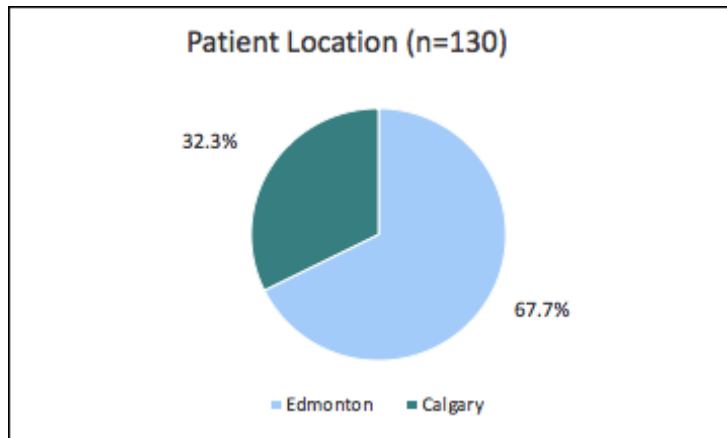
- ☐ Resuscitative care (R1, R2, R3)
- ☐ Medical care (M1 or M2)
- ☐ Comfort care (C1, C2)
- ☐ Unsure

Demographics

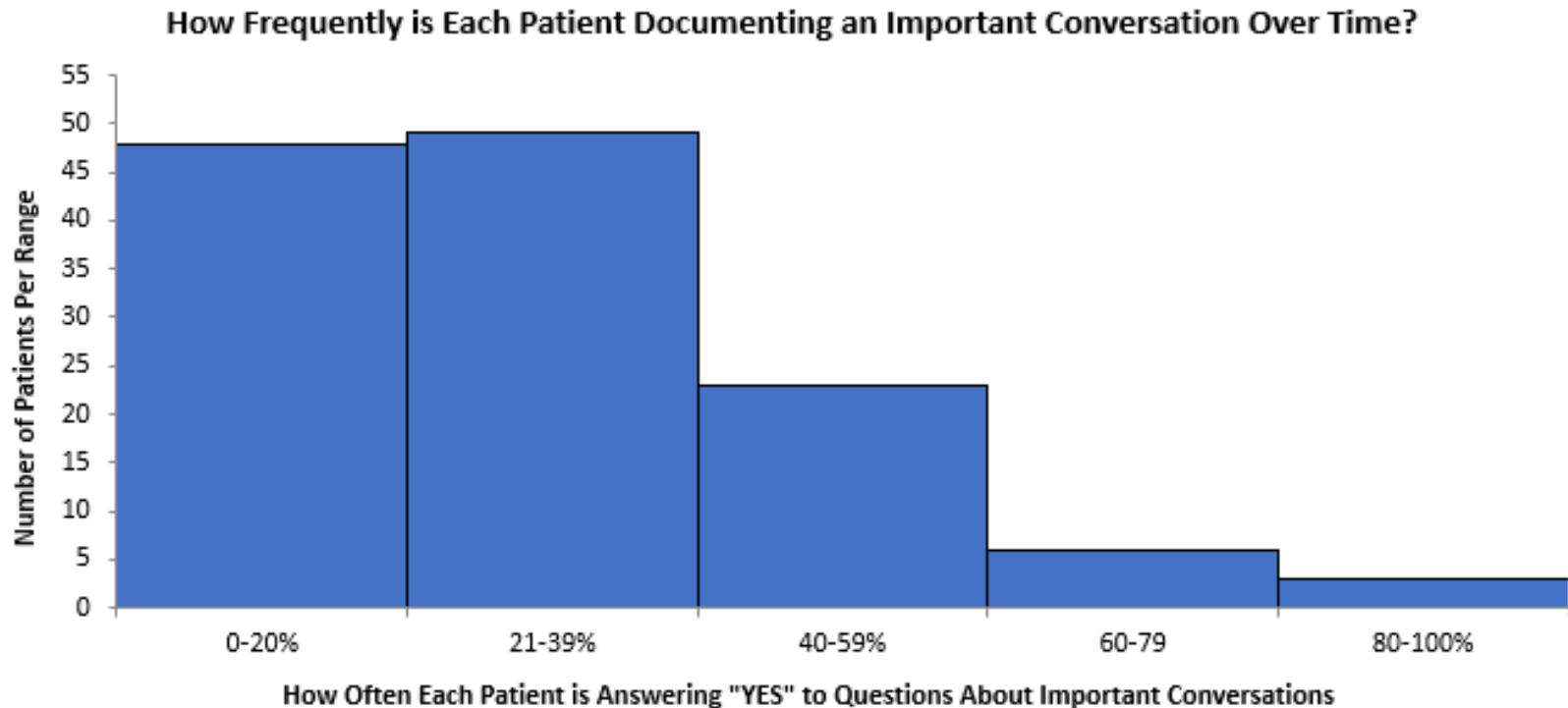
- **130** patients have provided data on an ongoing basis
 - Data collection is ongoing (ends December 2020)
 - Patients are enrolled on a rolling basis (recruitment period from January 2018 - July 2020)



Demographics

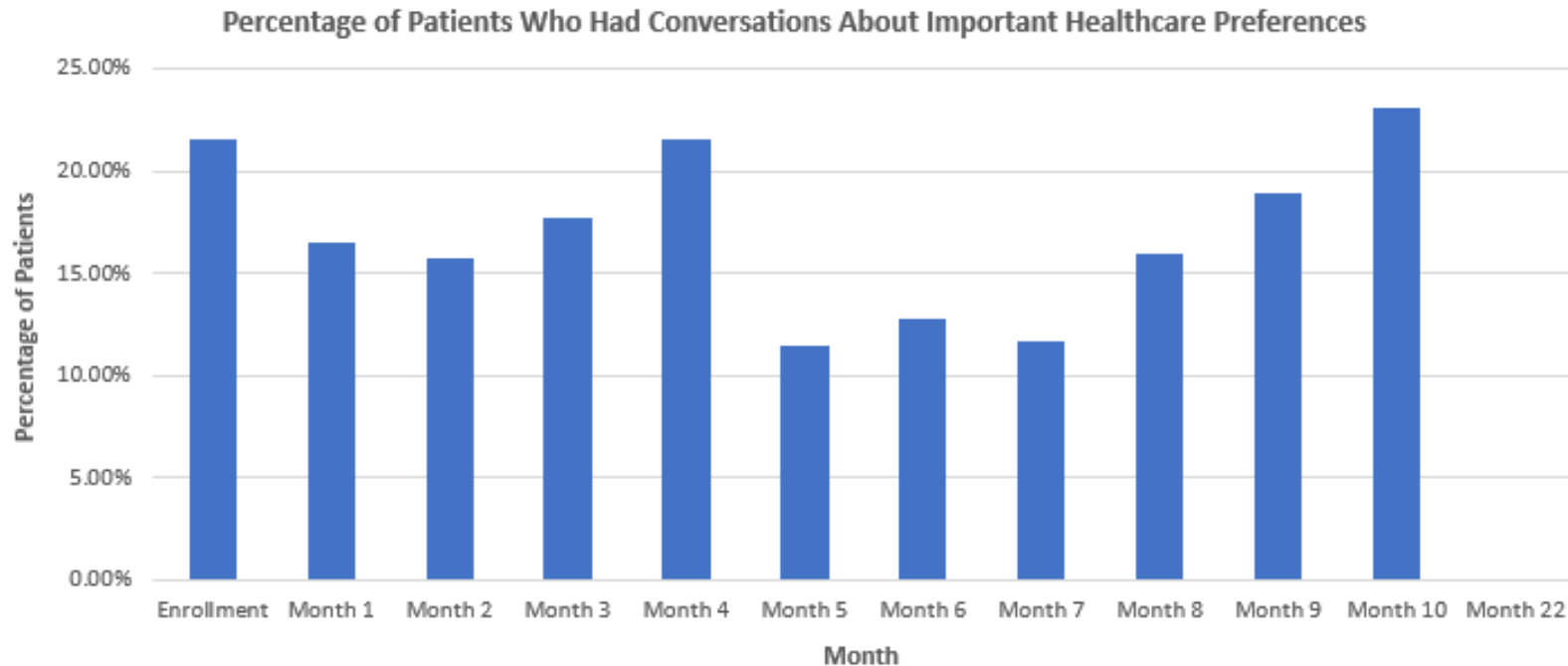


Frequency Distribution



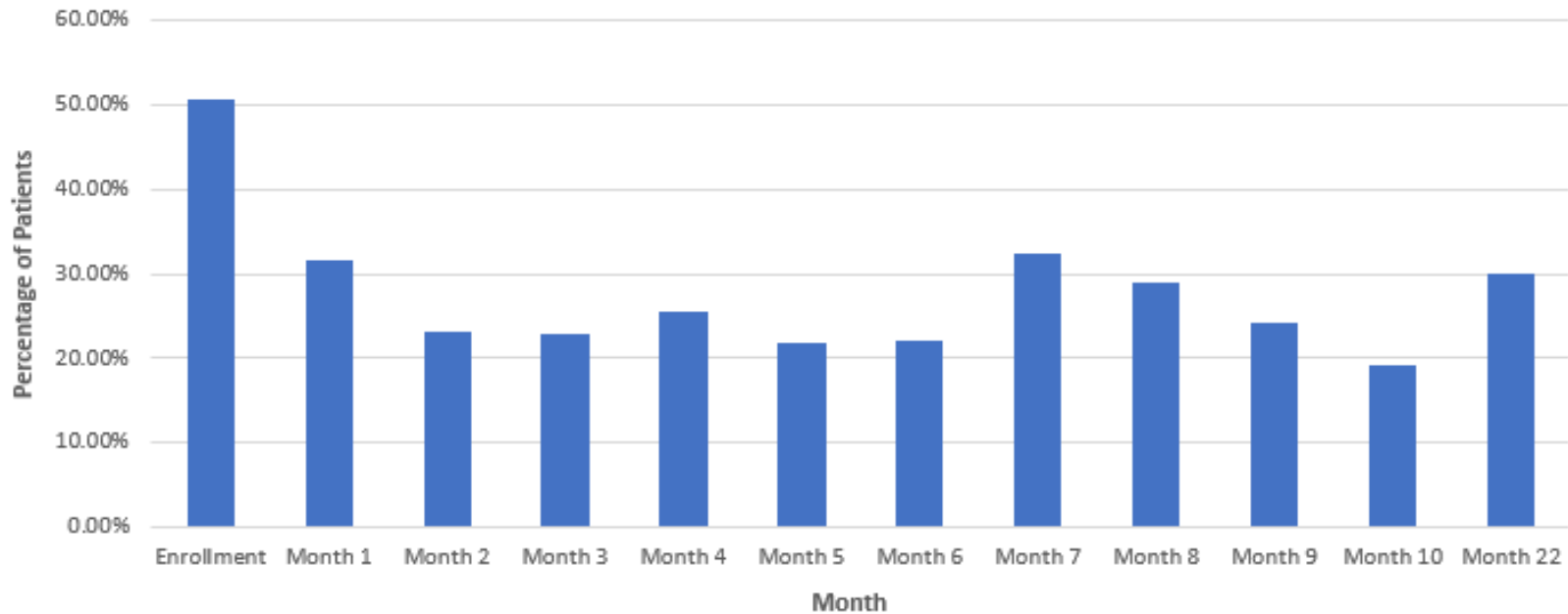
- ☐ Asked you what is important to you as you consider your healthcare preferences (such as your values, wishes, goals, or spiritual beliefs)
- ☐ Talked to you about your prognosis (life expectancy, predicted course or outlook of your illness)
- ☐ Given you the opportunity to express your fears or to 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](#))

Analysis – Question 1

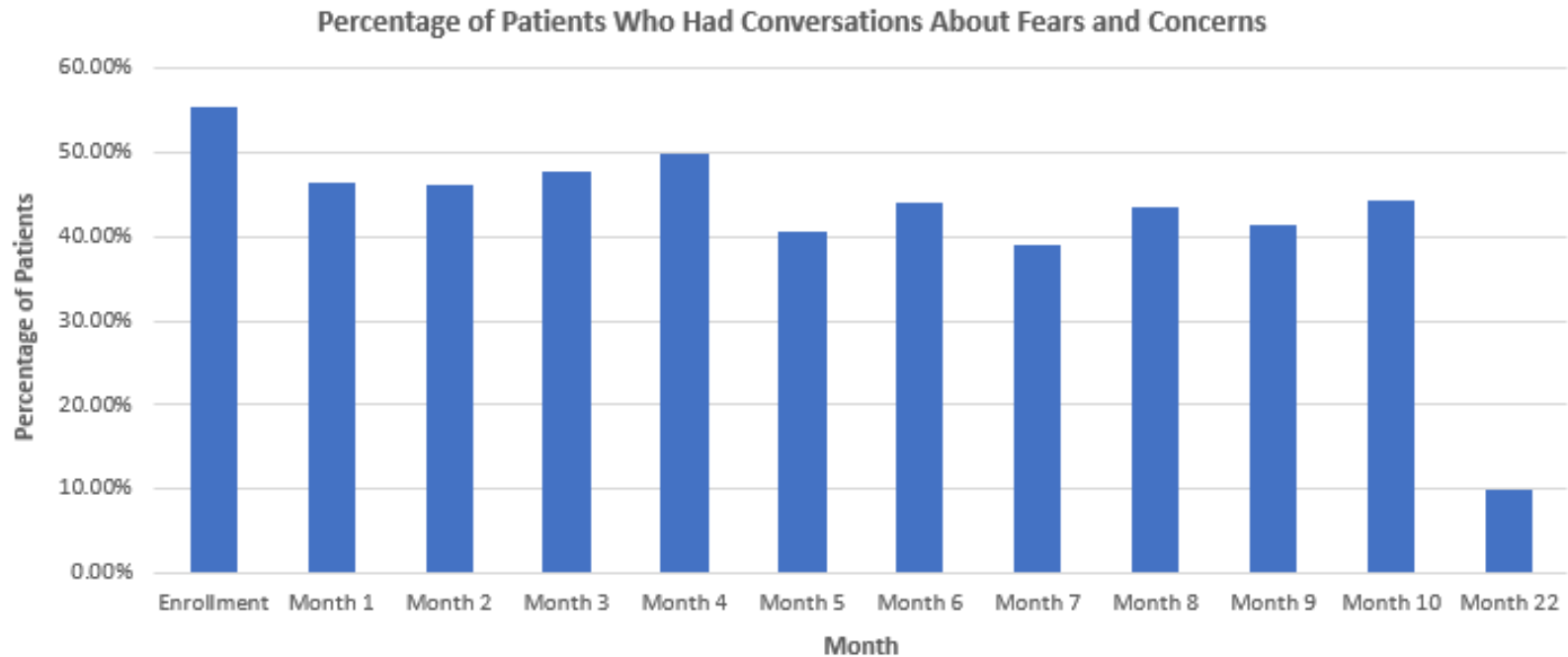


Analysis

Percentage of Patients Who Had Conversations About Prognosis

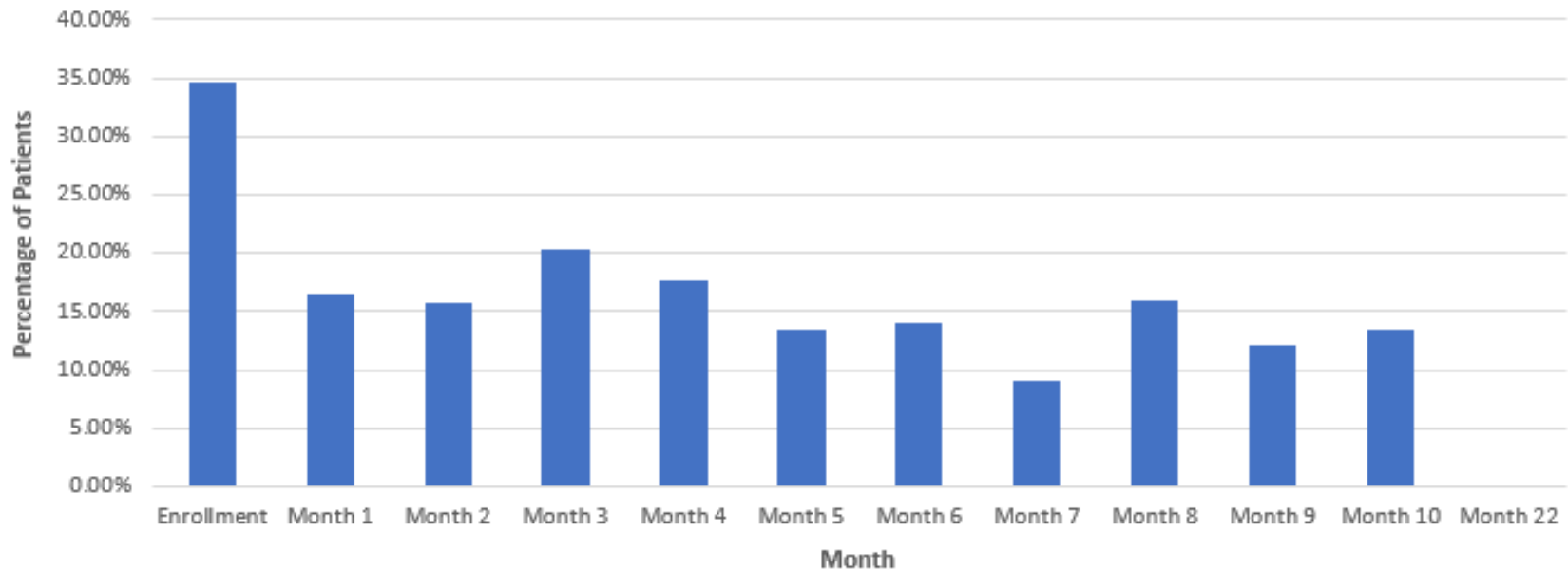


Analysis



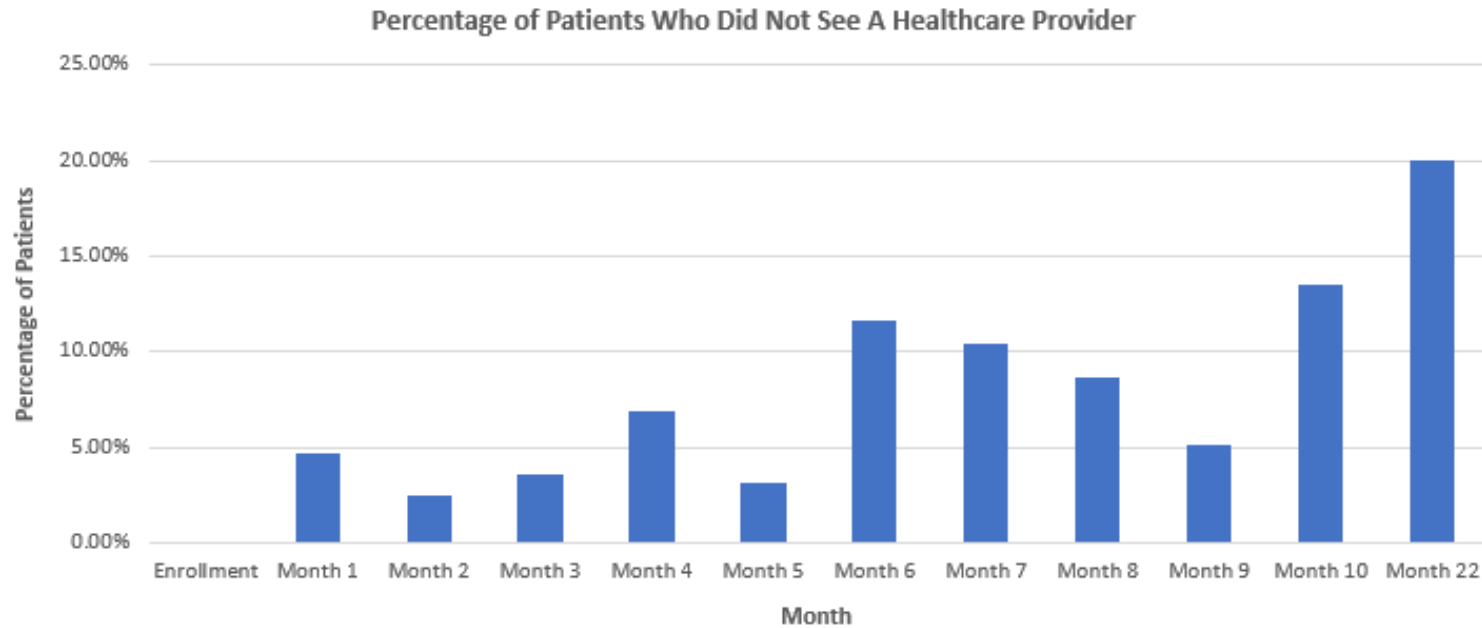
Analysis

Percentage of Patients Who Had Conversations About Treatments They Prefer/Don't Prefer If Very Sick or at End of Life



Analysis

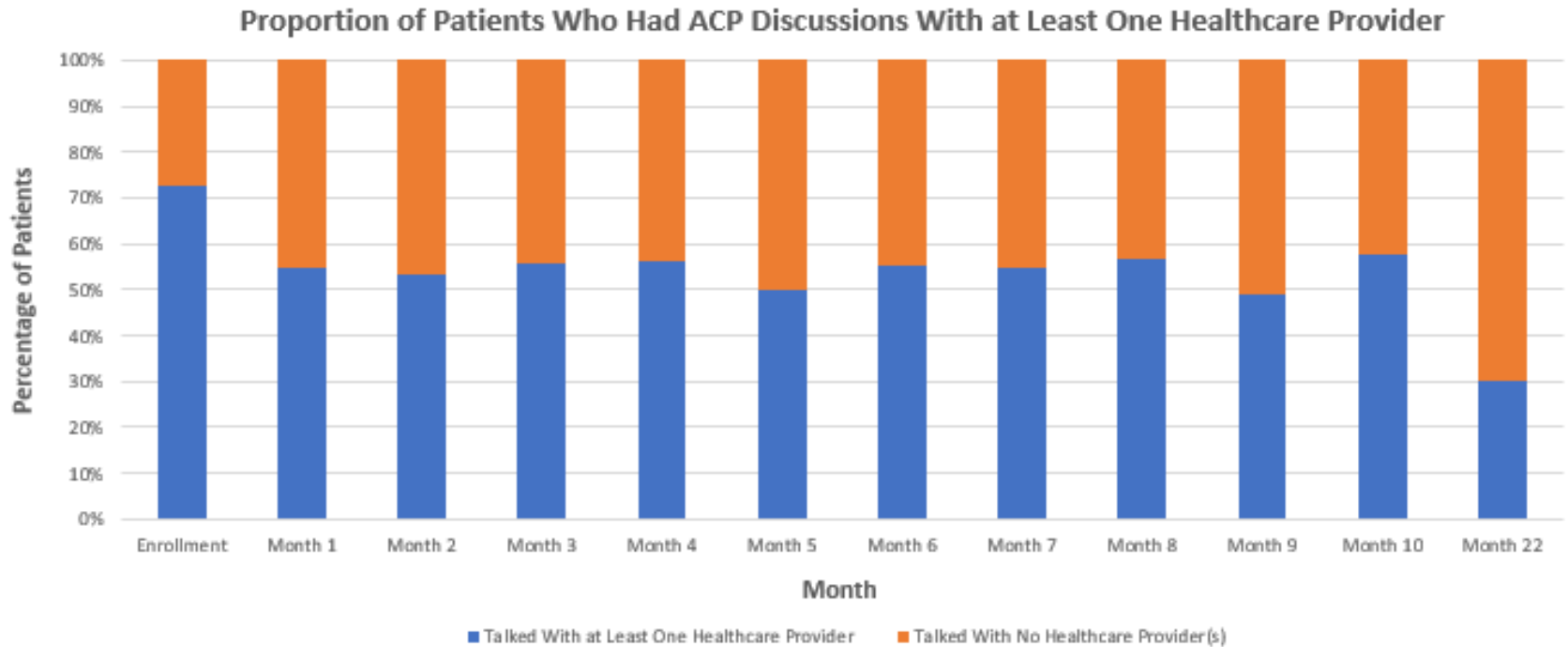
- Overall, **7%** of patients (9/130) reported never having “important (ACP) conversations” with their healthcare provider



Analysis

- **0 out of 130** patients had conversations about important healthcare preferences at every time point
- **3%** of patients (4/130) had conversations about prognosis at every time point
- **8%** of patients (10/130) patients had conversations about their fears and concerns at every time point
- **1 out of 130** patients had conversations about treatments they prefer / don't prefer if very sick or at end of life at every time point

Analysis



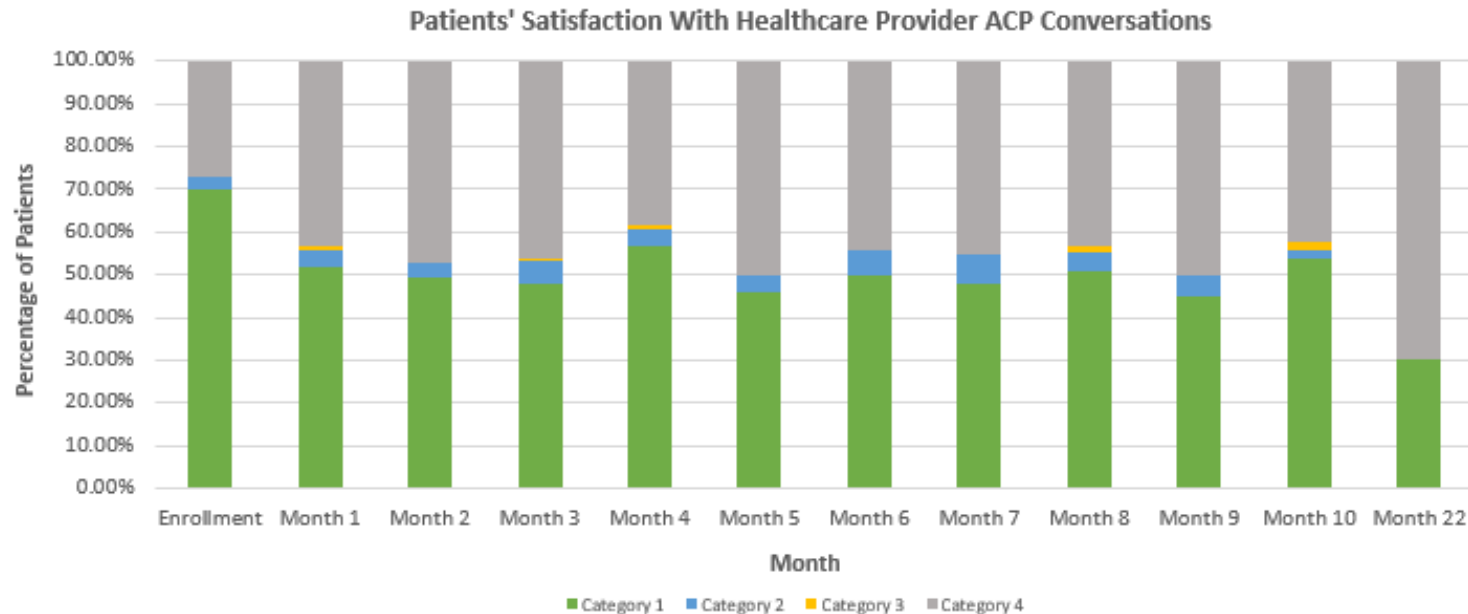
Analysis – Chi-squared Test (Question 1)

For patients who have **at least 1 important conversation between Enrollment and Month 3**, is there a significant difference in numbers between Calgary patients and Edmonton patients?

$$P = 0.46$$

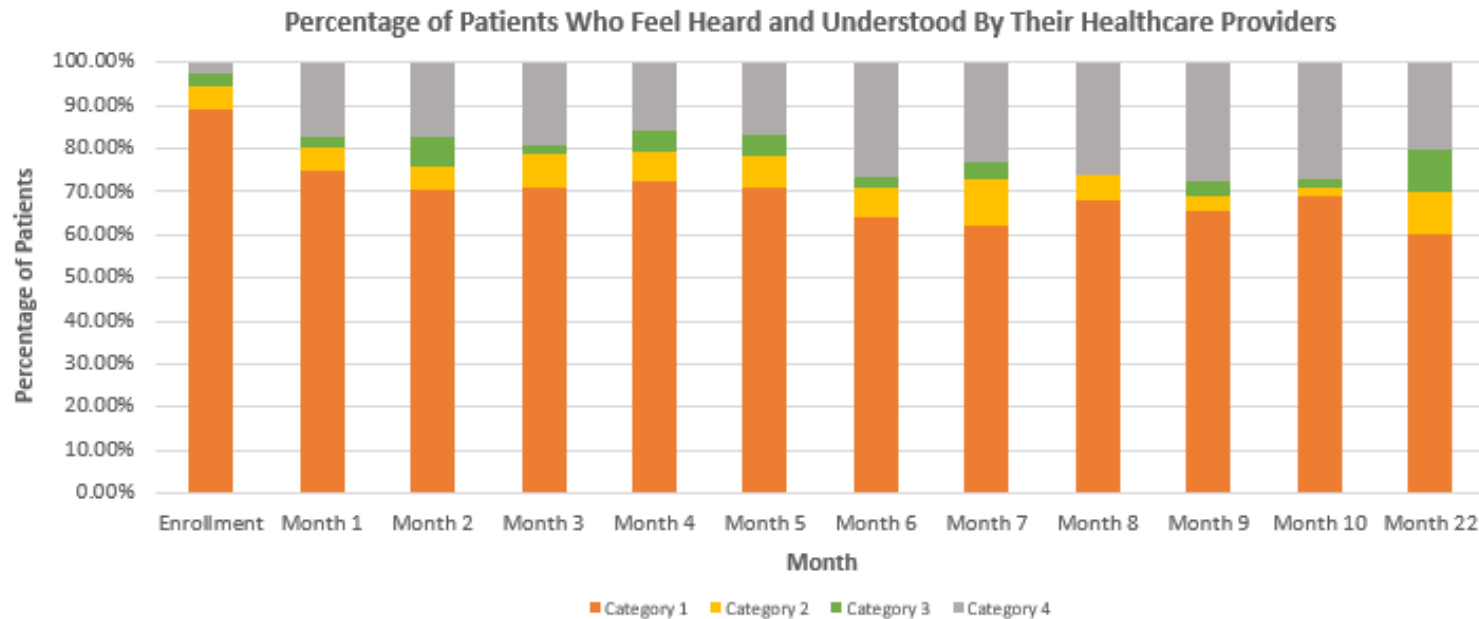
There is no significant difference between
Calgary and Edmonton patients

Analysis



- ☐ Completely
- ☐ Quite a bit
- ☐ Moderately
- ☐ Slightly
- ☐ Not at all

Analysis – Question 2



Legend	
■	Category 1 (i.e. completely, quite a bit)
■	Category 2 (i.e. moderately)
■	Category 3 (i.e. slightly, not at all)
■	Category 4 (i.e. no response provided that month)

Analysis – Question 3

A Goals of Care Designation is a medical order that guides your healthcare providers about the general focus of your care, the kinds of treatments that might be used, and where you might want that care. You might know it as a "resuscitative", "medical", or "comfort care" order that may be kept in your "green sleeve".

3. Do you have a Goals of Care Designation order?

- ☐ Yes
- ☐ No
- ☐ Unsure

3a) IF YES, to the best of your knowledge,
what is the focus of your Goals of Care Designation order?

- ☐ Resuscitative care (R1, R2, R3)
- ☐ Medical care (M1 or M2)
- ☐ Comfort care (C1, C2)
- ☐ Unsure

Legend	
3	Yes
2	No
1	Unsure
0	Incomplete
	Off-Study

Heat Map Analysis

Patient ID	Enrollment	1	2	3	4	5	6	7	8	9	10	22
1001P	3	1	3	3	3	3	1	3	0	0	1	
1002P	2	3	3	3	3	3	3	3	3	3	3	
1003P	2	1	3	1	1	2	2	2	2	2	2	2
1004P	3	3	3	3	3							
1005P	3	2	3	2	0							
1006P	3	3	3	3	3	3	3	1	3	3		
1007P	3	3	3	3	3	0	3	3	0			
1008P	3	0										
1009P	2	2	2	2	2	2	2	2	2	2	2	2
1010P	3	0	0									
1011P	3	3	2	3	3	3	3	3	3	0		
1012P	3	3	3	3	3	3	0	3	3			
1013P	2	3	3	3	3	3						
1014P	1	3	3	3	3	3						
1015P	3	3	3	3	3	3						
1017P	2	2	2									
1018P	3											
1021P	2	2	2	2	2	2	2	2	2	2	2	3
1023P	2	2	2	2	2	2	2	2	2	2	2	2
1024P	1	0	0	0	1	1	1	0	1	1		
1025P	2	2	2	2	2	2	2	2	2	2	3	3
1028P	1	1	1	1	1	1	1	2	2	0	1	
1030P	2	2	0	1	0	0	2	1	2	0	2	
1031P	3	3	3	0	0							
1032P	1	1	1	3	1	1	1	1	1	3	2	
1033P	1	0	0									
1034P	1	0										
1035P	2	2	2	2	2	2	2	3	3	0	3	
1036P	3	3	3	0	0							
1037P	3	3	3	2	2	2						
1038P	3	0	0									
1039P	3	3	3	3	3	3	3	3	3			
1040P	3	1	1	0	1	1	3	3	0	3	3	
1041P	1	0	0									
1042P	2	2	0	2	3	0	2	2	2	2	2	2
1043P	2	2	2	2	2	3	3	0				
1044P	2	0										
1047P	1	1	1	1	1	1	1	0	1			
1048P	1	1	2	0								
1055P	1	0	0									
1056P	1	3	3	0		3	3	3	3	3		
1063P	3											

Patient ID	Enrollment	1	2	3	4	5	6	7	8	9	10	22
3001P	1	2	2	2	2	2	2	3	3	3	3	3
3004P	2	3	3	3	3	3	3	3	3	3	3	3
3005P	1	2	2	1	2	2	0	2	3	0		
3006P	2	2	3	2	2	2	2	2	2	2	2	2
3007P	3	3	3	3	3	0	3	3	3	3	3	3
3008P	3	3	3	3	3	0						
3009P	3	3	3	3	3	3	3	3	3	3	3	3
3011P	3	3	3									
3012P	2	2	2	2	2	2	2	2	2			
3015P	2	2	3	3	3	3	3	3	3			
3018P	2	2	2	2	2	2	2	1	2	2	2	1
3019P	2											
3020P	3	1	1	2	3	2	2	2	2	2	2	2
3021P	3	2	3	3	3	3	3	3	3	3	3	3
3023P	2	2	2	2	2	2	2	2	2	2	2	2
3024P	2	2	2	2	2	3	2	3	3	3		
3025P	1	1	2	1	2	1	1	1	1	2	3	
3026P	3	3	2	3	3	3	3	3	3	3	3	3
3027P	2	2	2	2	2	2	2	2	2	2	2	2
3028P	1	0	2	2	3	0	3	1	1	1	2	1
3029P	3	3	3	3	3	0						
3030P	2	2	2	2	2	2	2	2	2	2	2	2
3034P	2	0	1	2	0		2	2	2	2	2	2
3035P	2	1	0	2	2							
3038P	3	0	2	2	2	2						
3040P	3	3	3	3								
3042P	2	3	0	3	3							
3043P	2	1	2	1	1	1	1	1	1	1	1	1
3044P	3	3	3	3	3	0	0					
3046P	2	2	2	2	3	3	3	3	3	3	3	3
3047P	1	1	3	0	3							
3048P	2	2	2	2	2	2	2	2	3	3	3	3
3049P	3	3	1	0	3	3	2	2	3	2	2	2
3050P	2	3	3	3	3	3	3	3	3	3	3	3
3051P	3	3	3	3	3	3	0	3	3	3	3	3
3052P	1	1	1	1	1	1	1	1	1	1	2	2
3054P	3	3	3	3	3	3	3	3	3	3		
3055P	2	2	2	2	3	3	3	3				
3056P	1	0	0	0								
3057P	1	2	1	1	3	1	1	1	1	1	1	3
3060P	3											
3061P	3	3	3	3	3	3	3	3	3	0		
3063P	2	2	2	2	2	2	2	2	2	2		
3064P	3	3	3	3								
3065P	2	2	2	3	2	3	3	3	3	3	3	3
3067P	1	3	3	1	3	3	3	3	3	3	1	3

Patient ID	Enrollment	1	2	3	4	5	6	7	8	9	10	22
3068P	3	3	2	3	2	3	1	0	1	0		
3070P	2	1	1	1	1	1	1	1	1	1	1	1
3071P	2	2	3	2	3	3	0	3	3	0	3	
3072P	2	3	3									
3073P	3	3	3	3	3	3						
3074P	1	2	3	1	2	2						
3075P	2	1	2	2	2	2	0	0	2	3	3	
3076P	1	1	1	1	1	1	2	1	1	3	3	3
3077P	2	2	2	2	2	2	2	2	2	2	2	2
3080P	3											
3083P	3	3	3	0	3	3	3	0				
3085P	3	0										
3086P	1	2	2	2	2	2	2	2	2	2	2	2
3088P	2	2	2	2	2	2	2	2	2	2	2	2
3090P	2	3	2	2	2	2	3	2	0			
3091P	3	2	2	2	2	3	3	3	1	1	1	1
3092P	3	3	3	3	3	0						
3093P	1	3	3	0								
3095P	2	0										
3096P	3	3	3									
3101P	1	1	1	1	1	1	1	1	1	1	2	3
3103P	2	2	2	2	2	2	0	2	2	2	2	2
3106P	3	3	3	3	2	3	3	3	0			
3108P	2	3	0									
3109P	3	3	0	3	3	3	3	3	3	3	3	3
3111P	1	2	2	1	1	1	1	1	2	1	1	
3113P	3	3	3	3	3	3	3	3	3	3	3	3
3114P	1	1	2	3	3							
3115P	2	1	0									
3117P	3	0										
3118P	1	1	1	1	1	2	2	2				
3119P	2	2	2	2	2	2	2	2	2	2	2	2
3120P	3	3	3	3	3	3	0					
3122P	3	3	3	3	3	3	3	3	3			
3123P	3	3	3	3	3	3	3	3				
3124P	3	3	0									
3125P	1	1	1	1	1	1	1	1	1	3		
3127P	2	2	2	2	2	2	2					
3128P	2	2										
3129P	3	3	3	3	3							
3130P	2	0	3	1								
3133P	3	3	3									
3135P	3	3	3									

Analysis – Question 3

A Goals of Care Designation is a medical order that guides your healthcare providers about the general focus of your care, the kinds of treatments that might be used, and where you might want that care. You might know it as a "resuscitative", "medical", or "comfort care" order that may be kept in your "green sleeve".

3. Do you have a Goals of Care Designation order?

- ☐ Yes
- ☐ No
- ☐ Unsure

3a) IF YES, to the best of your knowledge,
what is the focus of your Goals of Care Designation order?

- ☐ Resuscitative care (R1, R2, R3)
- ☐ Medical care (M1 or M2)
- ☐ Comfort care (C1, C2)
- ☐ Unsure

Explore:
**Do patient responses to these
questions change over time?**

Analysis – Question 3

Do patient responses change over time?

- Overall, **29%** of patients (37/130) responded to Q3 with a “YES” at Enrollment and remained consistent with that answer throughout



- Overall, **15%** of patients (20/130) responded to Q3 with a “NO” at Enrollment and remained consistent with that answer throughout

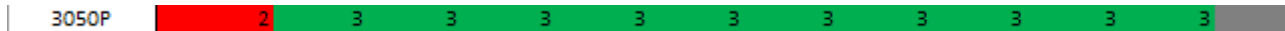


- Overall, **56%** of patients (73/130) changed their response to Q3 at least once; furthermore, within this category, **75%** of patients (55/73) changed their response to Q3 two or more times



Analysis

- Overall, **13%** of patients (17/130) responded with a “NO/UNSURE/INCOMPLETE” response to Q3 at Enrollment, and then later changed their response to “YES” and remained consistent in that “YES” response



- When patients changed their response from “NO/UNSURE/INCOMPLETE” to “YES” for Q3, on average, the change was reported at **month 3**
- There was **one** case of a patient responding initially with a “YES” to Q3, then changing to “NO/UNSURE/INCOMPLETE” and remaining consistent with that response

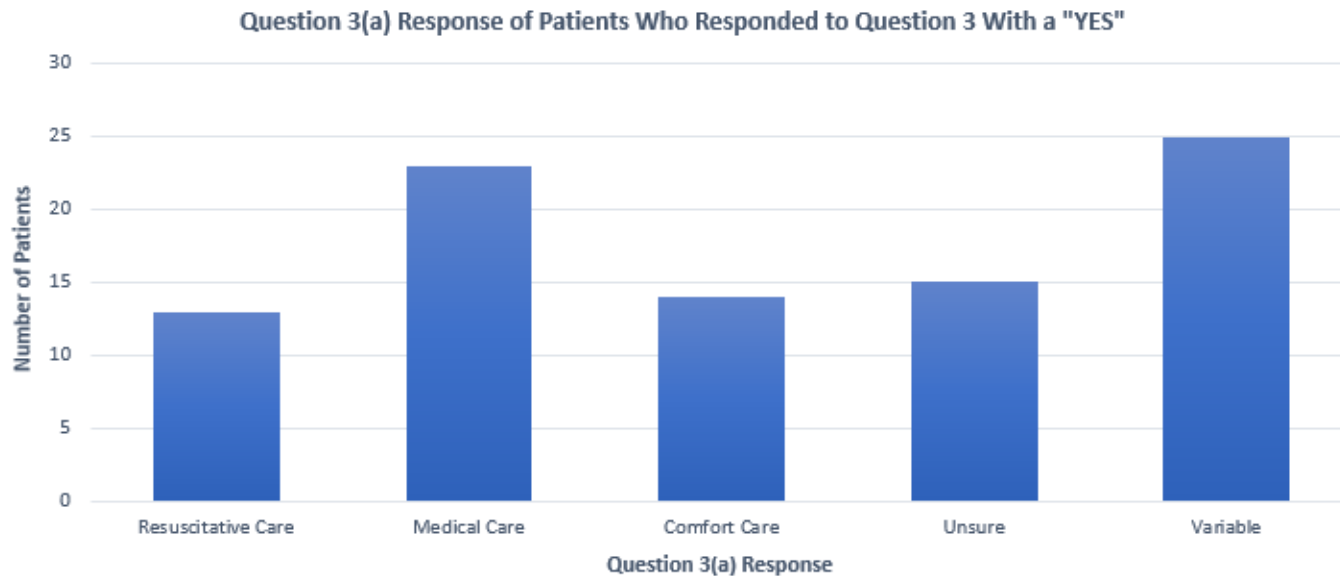


Analysis

- **52%** of patients (67/130) changed their response to question 3 (*do you have a GCD?*) while on follow-up
- **30%** of patients (39/130) changed their response to question 3(a) (*what is the focus of your GCD order?*) while on follow-up
- Overall, **33%** of patients (43/130) remained consistent in their responses over the course of their follow-up period for both questions 3 and 3(a) of the *My Conversations* survey
- Overall, **35%** of patients (45/130) changed their response to question 3 to “Unsure” at least once while on follow-up

Analysis

- **69%** of patients (90/130) reported having a GCD;
 - **90%** of those patients (81/90) also provided a response to question 3(a) (*what is the focus of your GCD order?*)



My Conversations - Question 1

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**)

1a) Who did you talk with (Check (✓) all that apply)

Doctor

- ☐ Family Doctor
- ☐ Oncologist (Cancer doctor)
- ☐ Other doctor

Nurse

- ☐ Family doctor office nurse
- ☐ Cancer clinic nurse
- ☐ Home visit nurse
- ☐ Other nurse

Other healthcare provider (e.g. social worker, counselor, radiation technician etc.)

☐ _please specify _____

1b) In general, how satisfied were you with these conversations?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Not very satisfied
- ☐ Not at all satisfied

Overall Trends – Question 1

- On average, only **17%** of patients per month reported having conversations with their healthcare provider(s) about important healthcare preferences
- On average, **54%** of patients per month reported having ACP discussions with at least one healthcare provider
- On average, **50%** of patients per month reported feeling “satisfied” or “very satisfied” with the ACP conversations they had with their healthcare provider(s)

My Conversations – Question 2

2. How much do you feel heard and understood by your healthcare providers in the last month?

- ☐ Completely
- ☐ Quite a bit
- ☐ Moderately
- ☐ Slightly
- ☐ Not at all

Overall Trends – Question 2

- On average, **70%** of patients per month reported feeling “quite a bit” or “completely” heard and understood by their healthcare provider(s)
- On average, **4%** of patients per month reported feeling only “slightly” or “not at all” heard and understood by their healthcare provider(s)

My Conversations – Question 3

A Goals of Care Designation is a medical order that guides your healthcare providers about the general focus of your care, the kinds of treatments that might be used, and where you might want that care. You might know it as a "resuscitative", "medical", or "comfort care" order that may be kept in your "green sleeve".

3. Do you have a Goals of Care Designation order?

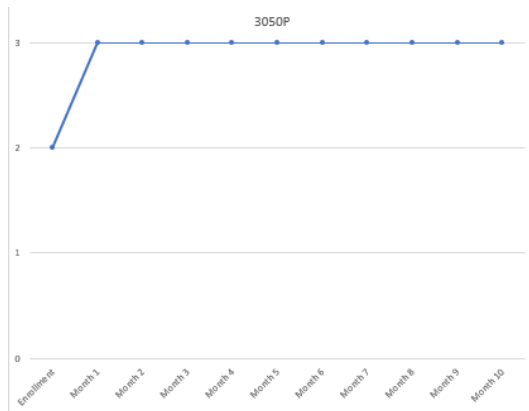
- ☐ Yes
- ☐ No
- ☐ Unsure

**3a) IF YES, to the best of your knowledge,
what is the focus of your Goals of Care Designation order?**

- ☐ Resuscitative care (R1, R2, R3)
- ☐ Medical care (M1 or M2)
- ☐ Comfort care (C1, C2)
- ☐ Unsure

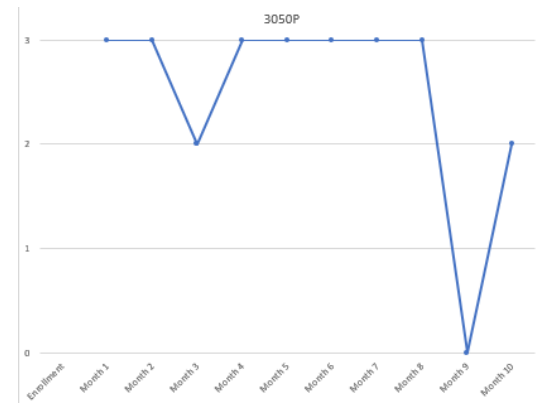
Overall Trends – Question 3

- **56%** of patients (73/130) changed their response to Q3 at least once, with many changing back and forth continuously
- While patients may have known they had a GCD order, many patients were unsure of what their GCD order's focus was



Legend - Q3	
Yes	3
No	2
Unsure	1
Incomplete	Blank

Legend - Q3 (a)	
Resuscitative	3
Medical	2
Comfort	1
Unsure	0
Incomplete	Blank



Limitations of Data

- All data is from patient-reported responses only
 - This is both a limitation and a strength
- There are some gaps in the data (patients sometimes miss time points due to illness, vacation, etc.)
- Not all patients are seen every 4 weeks
 - If they do not have an appointment or see a healthcare provider that month, this would explain why they did not have any important conversations at that time point

Comparison to Literature

Why are “important conversations” so critical?

- Being asked about preferences for care in the event of a life-threatening illness was highly important to patients with a serious illness
- Prognostic disclosure occurs infrequently among patients with serious illness, even though patients ranked these discussions as being highly important to them
- Satisfaction with end-of-life treatment and communication increases with the number of elements discussed

You, J. J., Dodek, P., Lamontagne, F., Downar, J., Sinuff, T., Jiang, X., Day, A. G., Heyland, D. K., & ACCEPT Study Team and the Canadian Researchers at the End of Life Network (CARENET) (2014). What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne, 186(18), E679–E687. <https://doi-org.ezproxy.lib.ucalgary.ca/10.1503/cmaj.140673>

Comparison to Literature

Future considerations and the *My Conversations* survey

- An SICP cluster randomized clinical trial demonstrated that a communication quality-improvement intervention resulted in significant improvements in key conversation indicators
- This intervention led to a significant increase in the mean number of documented discussions per patient, indicating that the initiation of serious illness communication earlier may prompt more discussions over time

Paladino J, Bernacki R, Neville BA, et al. Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients With Life-Limiting Cancer: A Cluster Randomized Clinical Trial of the Serious Illness Care Program. *JAMA Oncol.* 2019;5(6):801-809. doi:10.1001/jamaoncol.2019.0292

Comparison to Literature

More conversations

proportion of patients with a documented discussion before death



Better conversations



Earlier conversations



More accessible EMR documentation of conversations



Analysis Still to Come

- **Control versus Implementation period**
 - Implementation of the pathway in Calgary began in January 2019 and included referral to a Clinical Nurse Specialist
 - Compare patient responses during the control period (January 2018 - January 2019) versus the implementation period (January 2019 - December 2020)

Thank You

Questions / Comments