

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

Shireen Kassam¹, Crystal Beaumont⁴, Jessica Simon^{1,2,3}, Patricia Biondo¹, Sharon Watanabe^{2,4}, Madalene Earp¹, Patricia Tang^{1,2}, Marc Kerba^{1,2}, Aynharan Sinnarajah^{1,2,3}

1. Department of Oncology, University of Calgary; 2. Alberta Health Services; 3. Department of Family Medicine, University of Calgary, Alberta, Canada; 4. Department of Oncology, University of Alberta

STUDY OVERVIEW

Observational Study of patients recruited in two tertiary cancer centres in Alberta, Canada

Gather experience of patients living with advanced colorectal cancer

OBJECTIVE

Measure how the quality of life changes over time for patients living with advanced colorectal cancer

METHODS

Initial and periodic PREMs (Patient reported experience measures) and PROMs (Patient reported outcome measures) of patients

Putting Patients First (PPF)

Includes the Edmonton Symptom Assessment System Revised (ESAS-r), the Canadian Problem Checklist and an “at peace” question

My Conversations

Explores the patient’s understanding of and satisfaction with discussions about Advance Care Planning and Goals of Care

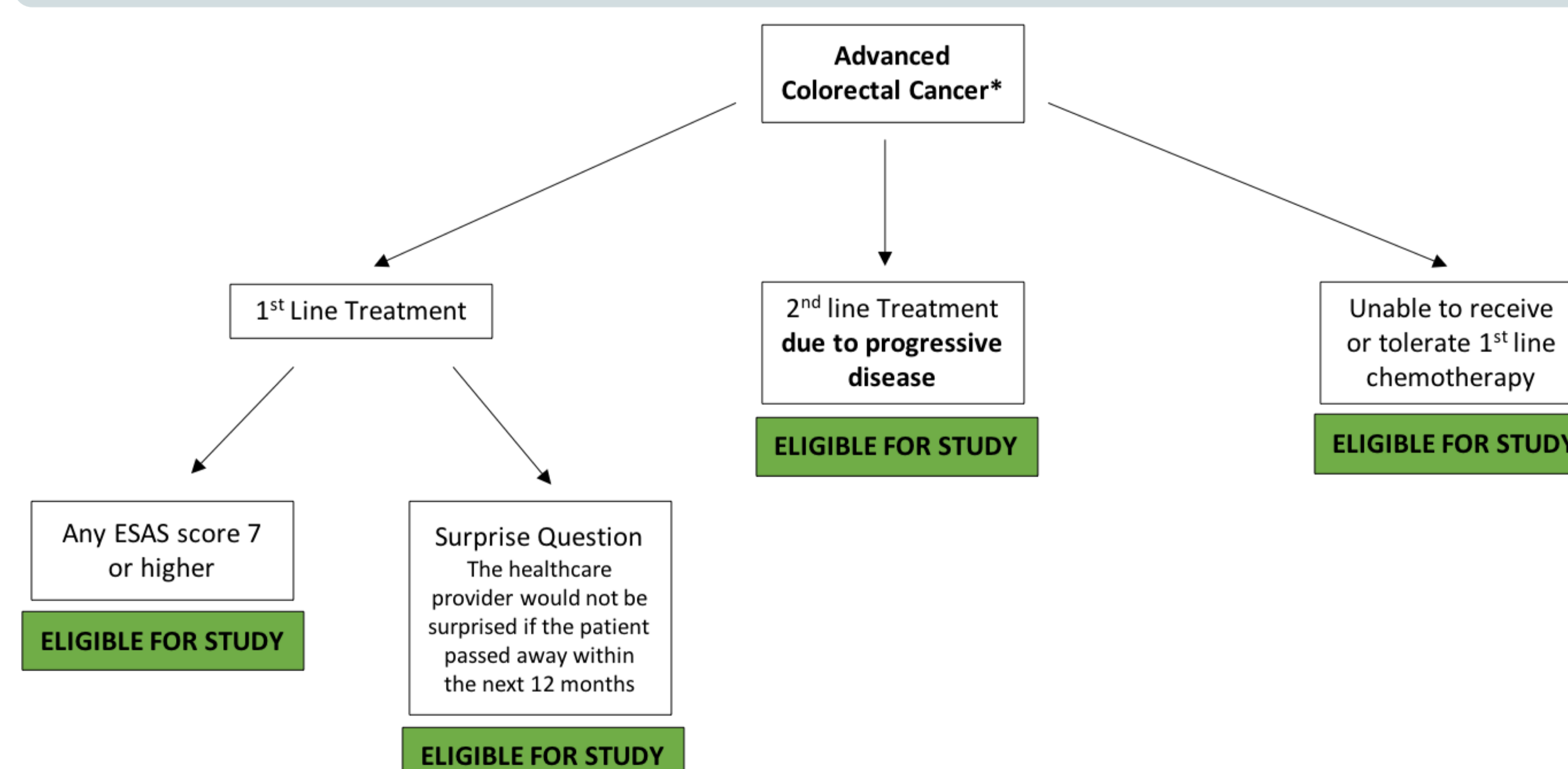
EQ-5D-5L

Measures health-related quality of life

DURATION

January 2018 to December 2020

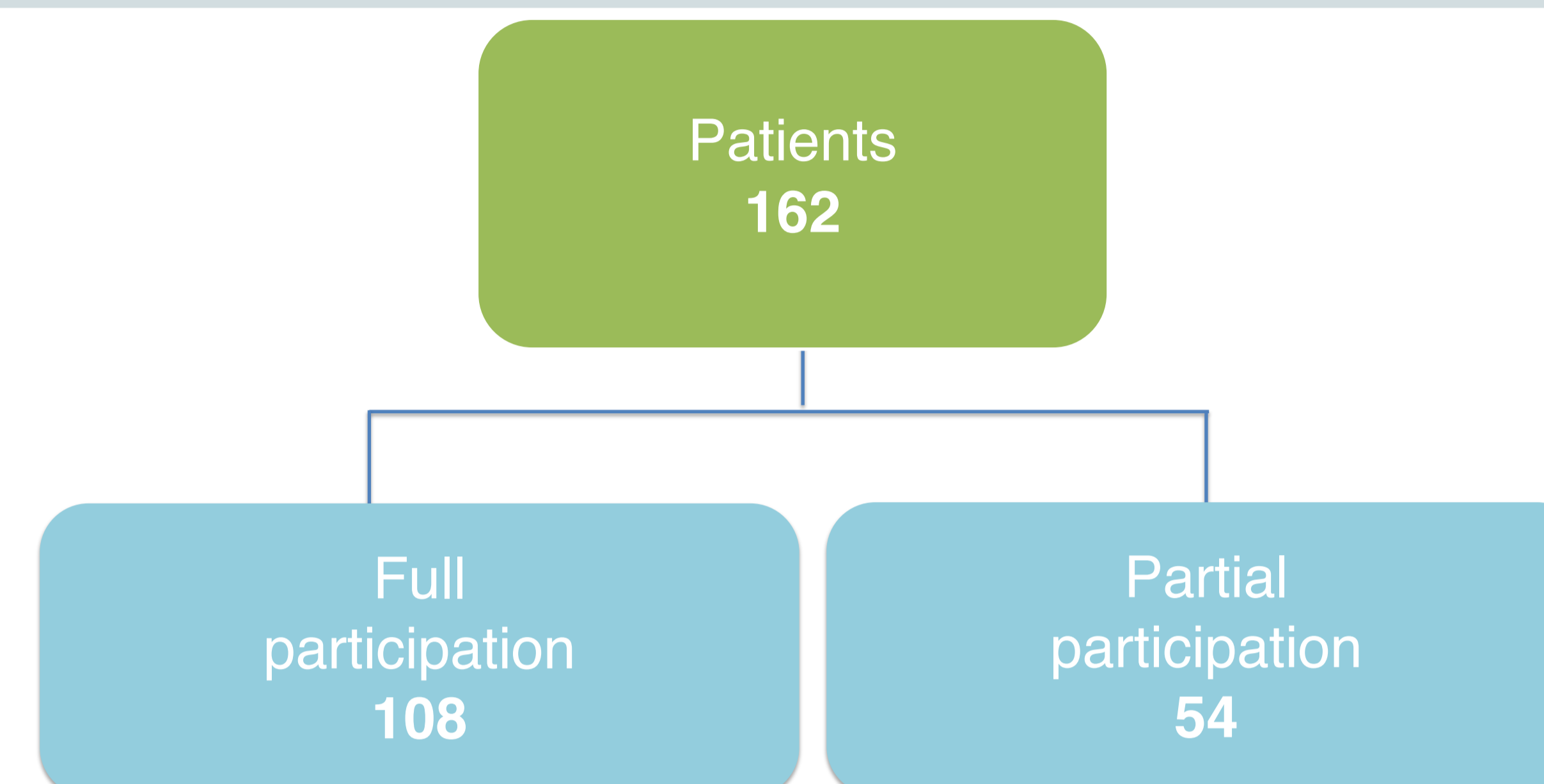
ELIGIBILITY



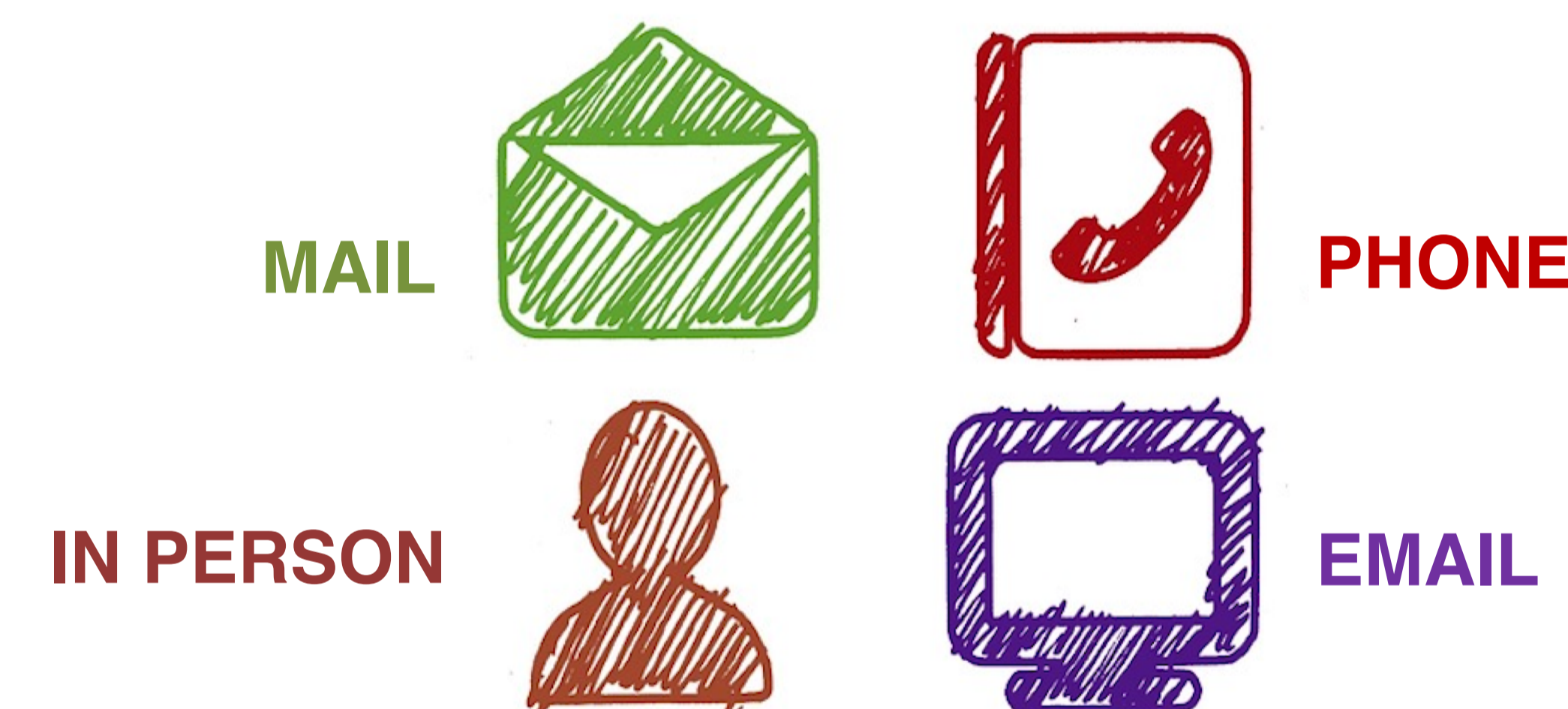
*Advanced Colorectal Cancer (aCRC) is defined as primary or metastatic cancer that is unlikely to be cured, controlled, or put into remission with treatment

RECRUITMENT

FROM JANUARY 2018 TO AUGUST 2019



METHODS OF PARTICIPATION



Mail	In Person /Phone	Email
5	34	69

KEY LEARNINGS

SUCCESSES

- Patient engagement**
 - Face-to-face contact appreciated
 - Patients eager to provide experiences
- Multiple methods for survey completion**
 - Allows patients to participate in a manner most practical for their lifestyle
 - Did not impact PROMs collection

CHALLENGES

- Burden on healthcare providers**
 - Clinic flow: room occupied while Research Assistant recruits and enrolls patients
- Maintaining long-term contact with patients**
 - Patients withdraw when they become too sick to participate

TYPES OF PARTICIPATION

FULL

Patients complete surveys at enrollment, then periodically until end of study

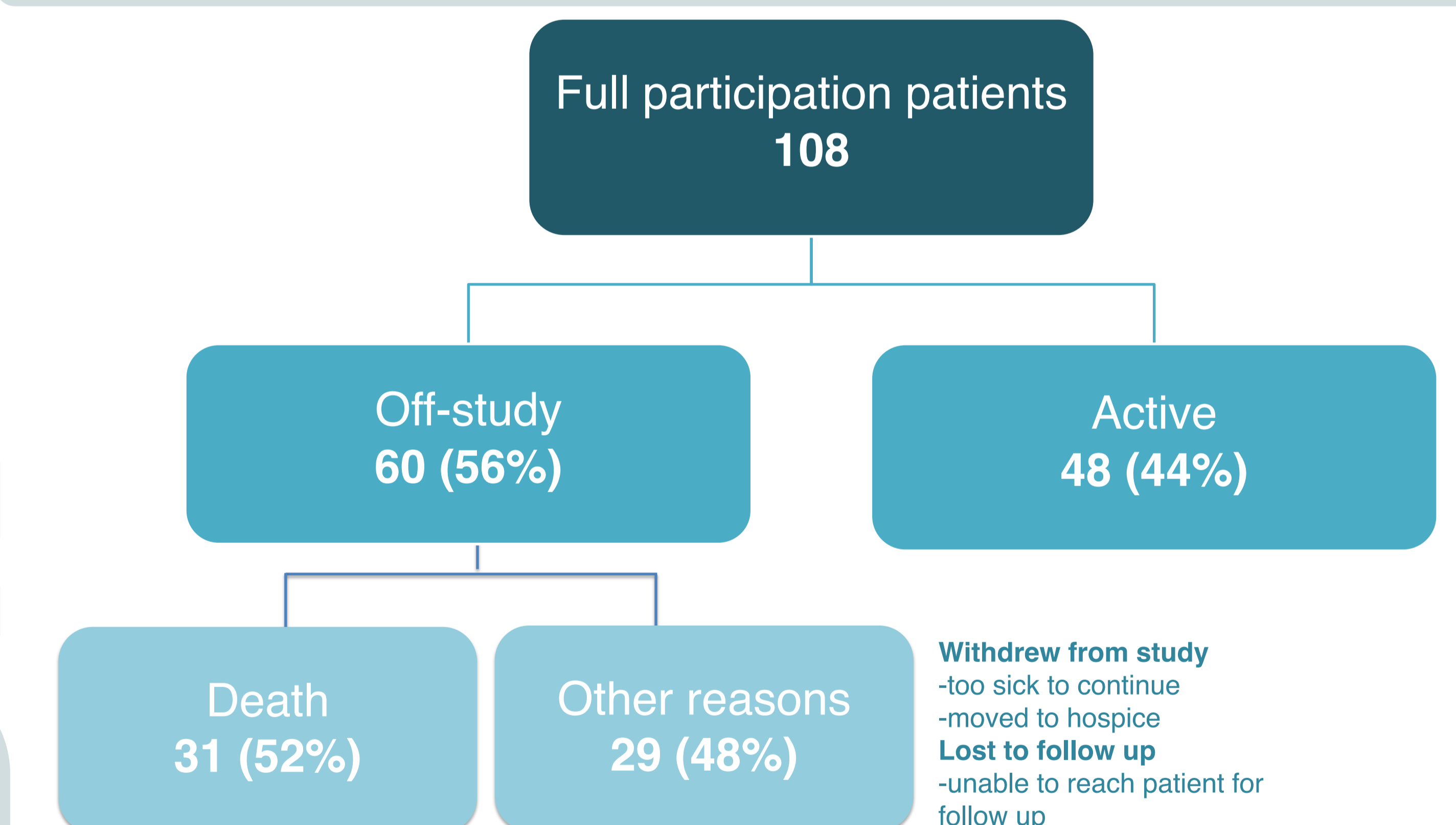
PARTIAL

Patients complete surveys at enrollment and grant researchers permission to access their medical records, but are not required to complete any further surveys

DEMOGRAPHICS

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

INTERIM RESULTS



CONCLUSION

It is challenging but possible to engage and retain patients with advanced cancer in research focused on PROMs. Offering flexible modes of participation assists with patient engagement.