



# Survivorship Needs for Individuals Living with Advanced and Metastatic Cancer

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# Overview



- ✓ Survivor Experience: Bethany Ross
- ✓ Background
- ✓ NIH portfolio analysis
- ✓ Stakeholder meeting
- ✓ Next steps

# Survivor Experience: Bethany Ross

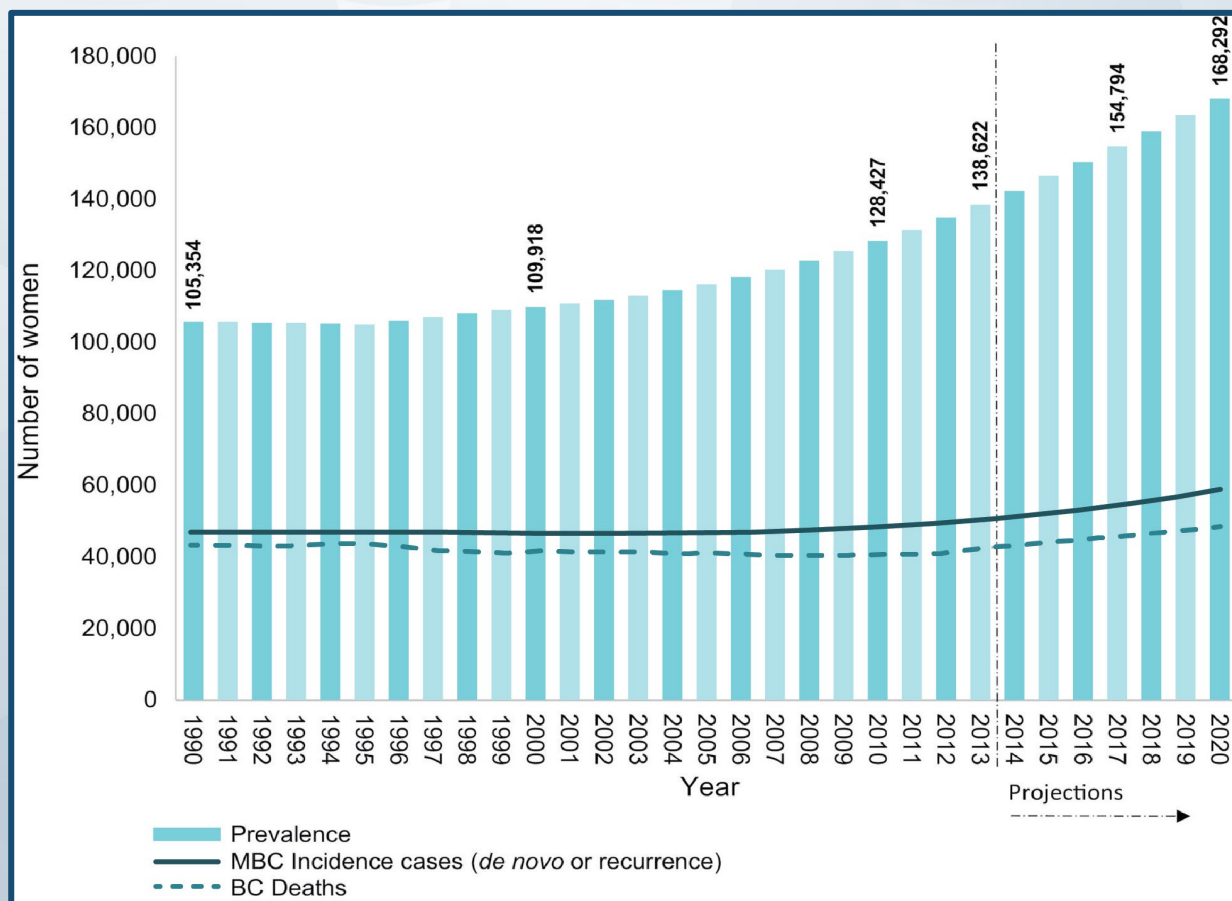


# Updated NCI Survivor Definition

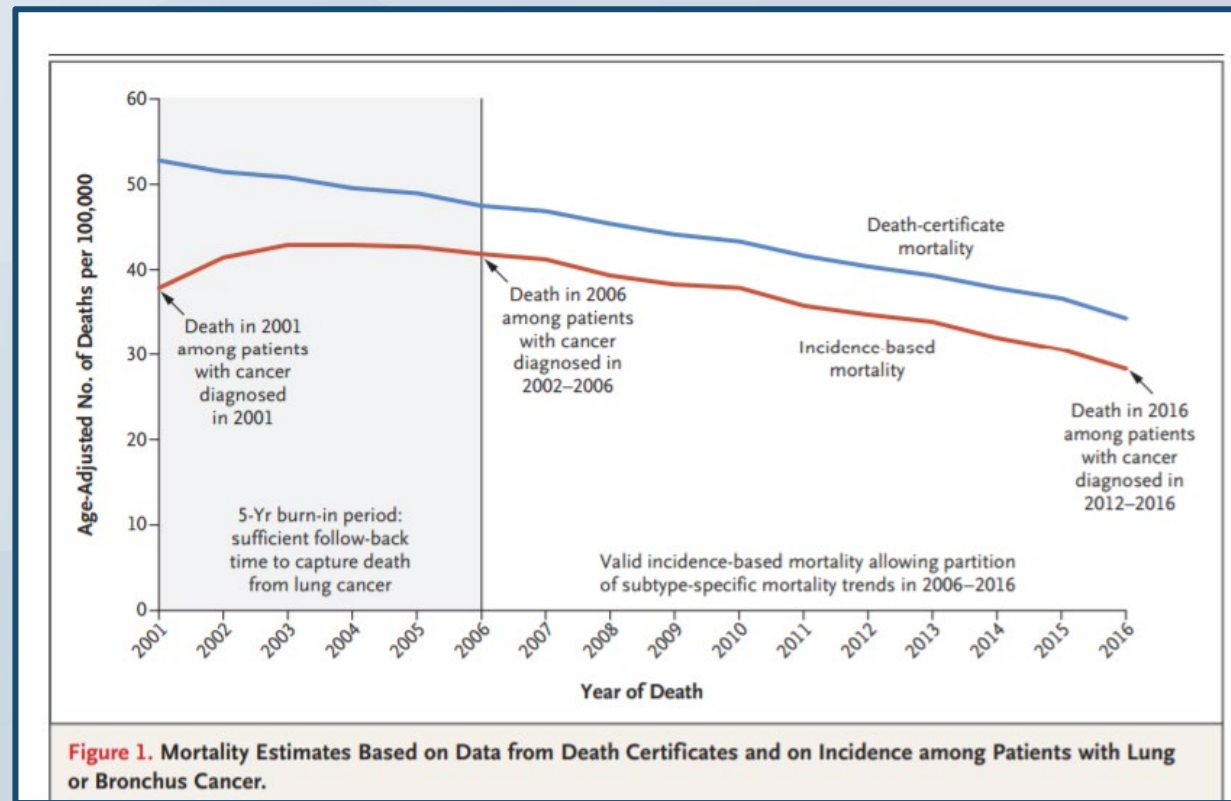
**Cancer Survivor:** An individual is considered a cancer survivor from the time of diagnosis, through the balance of life.

- There are many types of survivors, including those **living with cancer** and those **free of cancer**.
- This definition is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

# Growing Population of Advanced and Metastatic Cancer Survivors



**Increasing prevalence of metastatic breast cancer survivors**  
*Mariotto et al., 2017, CEBP*



**Decreasing mortality of lung cancer survivors**  
*Howlader et al., 2020, NEJM*

# Individuals Living with Advanced or Metastatic Cancers: Describing the Population

- People diagnosed with advanced or metastatic cancer, or who progress to metastatic cancer, make up a population of survivors with what is likely incurable cancer
- Characteristics:
  - May cycle on and off treatment
  - May have periods with and without active disease
  - Includes individuals with advanced/metastatic cancer receiving targeted therapies or immunotherapies



# Example Survivor Profile: John Smith

- 2010: diagnosed with stage 4 non-small cell lung cancer at age 71; predicted to survive less than 3 years
  - Originally treated with four cycles of chemotherapy but experienced tumor growth; initiated re-challenge chemotherapy with disease control
  - Tumor growth after 6 years; treated with cycles of erlotinib for 3 years after treatment break to reduce side effects
  - After disease progression, EGFR mutation analysis detected T790M mutation; treated with osimertinib for over 1 year with disease control

Adapted from: Matsuzaki et al., 2019; *Medicine*

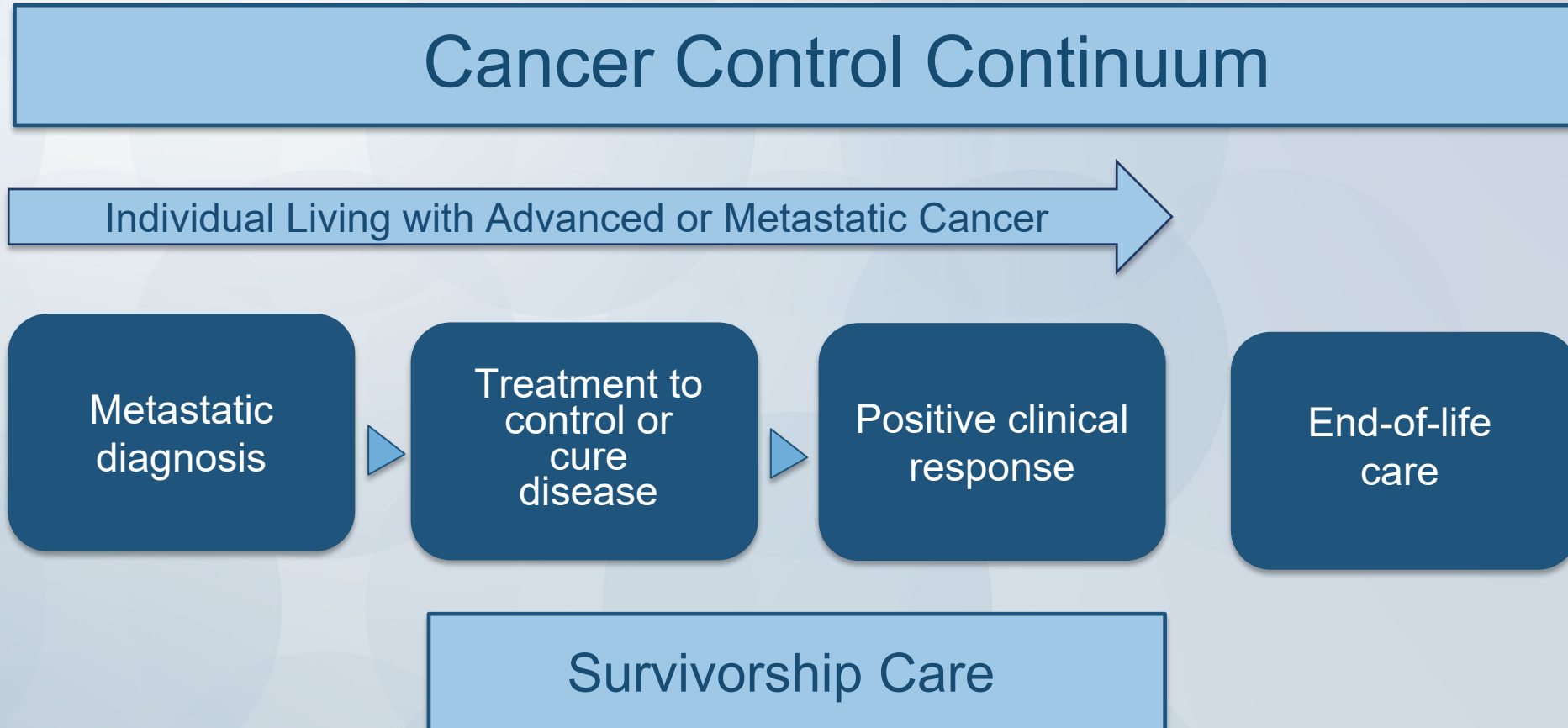
# Example Survivor Profile (continued)

- Today: John Smith has survived over 11 years since his lung cancer diagnosis
- Continues to experience:
  - Long-term physical symptoms and psychological concerns- scan anxiety, uncertainty, fear of cancer progression
  - Financial hardship related to costly treatments
  - Waning caregiver support given long cancer trajectory
  - Substantial issues coordinating care among multiple providers

Adapted from: Matsuzaki et al., 2019; *Medicine*



# Survivors Living with Advanced or Metastatic Cancer



# What is Survivorship Care?

Prevention/  
surveillance of  
recurrence and  
new cancers

Surveillance/  
management of  
effects of  
cancer and its  
treatment

Health  
promotion/  
preventive care

Care Coordination

Institute of Medicine. 2005. *From cancer patient to cancer survivor: Lost in transition*.

# Initial Activities


- Review of NIH grant portfolio and literature
- Discussions with survivors, advocates, researchers, and advocacy organizations
- Key stakeholder meeting

Goal: to better understand the gap areas in survivorship research for this growing population

# NIH Survivorship Portfolio

- Recent portfolio analysis described currently funded NIH grants focused on individuals living with advanced and metastatic cancers and identified key gap areas

**Current state of funded National Institutes of Health grants focused on individuals living with advanced and metastatic cancers: a portfolio analysis**

Michelle A. Mollica<sup>1</sup>  • Gina Tesauro<sup>1</sup> • Emily S. Tonorezos<sup>1</sup> • Paul B. Jacobsen<sup>1</sup> • Ashley Wilder Smith<sup>1</sup> • Lisa Gallicchio<sup>1</sup>

Mollica et al. (2021), *Journal of Cancer Survivorship*

# Purpose of Portfolio Analysis

- **Key questions:**

- What are the key characteristics of populations studied?
- What are the primary areas of focus and research designs?
- What are the scientific gaps in the portfolio?

# Results (n=25 grants)

## ■ NIH Institute:

- National Cancer Institute: 16
- National Institute of Nursing Research: 6
- National Institute of Aging: 1
- National Institute of Arthritis and Musculoskeletal and Skin Diseases: 2

## ■ Grant mechanism:

- R01 (larger projects): 15
- R21 (developmental): 4
- R03 (developmental): 1
- Training grants (K series): 4
- U01 (cooperative projects): 1



# Study Population

- **Cancer Type:**
  - Multiple specified cancer types: 9
  - Any cancer type: 4
  - Breast cancer only: 2
  - Lung cancer only: 2
  - Any cancer, based on type of metastases: 2
  - Any cancer, based on treatment received: 1
  - GI cancers only: 1
  - Prostate cancer only: 1
  - Gynecological cancer only: 1
- **Age group:** Adult- 24; Adolescent and young adult-1
- **Sex:** Both- 21; Female- 4

# Study Population (continued)

- **Inclusion of caregiver:** 8, with most (7/8) focused on caregiver/patient dyad
- **Time since diagnosis:**
  - Not specified: 19
  - Less than one year: 4
  - Not specified, receiving first line treatment: 2
- **Focus on medically underserved population:** 9
  - Rural
  - African American
  - Hispanic/Latino
  - Older adults
  - Low-income country
  - Socioeconomic disadvantaged

# Primary Area of Focus and Study Design

- **Primary Area of Focus:**
  - Early **palliative/supportive care**: 7
  - Psychosocial support: 6
  - Physiological sequelae: 5
  - Physiological and psychosocial sequelae: 3
  - Health behaviors (physical activity): 3
  - Polypharmacy: 1
- **Study Design:** Intervention- 18; Observational- 7
- **Length of follow-up:**
  - **1-6 months**: 17
  - 7-12 months: 4
  - Variable based on time enrolled in study: 2
  - Cross-sectional: 2

# Notable Gaps in Current Portfolio

- Key components of early palliative care for metastatic and advanced cancer survivors: timing, delivery, types of providers, supportive care needs
- Longer-term needs: longitudinal studies
- Identification of metastatic survivors in Electronic Health Record and registry data

## Notable Gaps (continued)

- Individuals treated with **newer targeted and emerging therapies**
- **Caregiver/survivor research:** support through treatment decision-making, prognostic uncertainty, and financial hardship
- **Models of care delivery:** management of long-term comorbidities, role of primary care and other non-oncology providers



# **Virtual Meeting on Survivorship Needs for Individuals Living with Advanced and Metastatic Cancers**

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National Cancer Institute  
May 10–11, 2021

***#NCIMetSurv***

Meeting website on NCI Office of Cancer Survivorship webpage:  
<https://cancercontrol.cancer.gov/ocs/metastatic-survivorship-meeting>





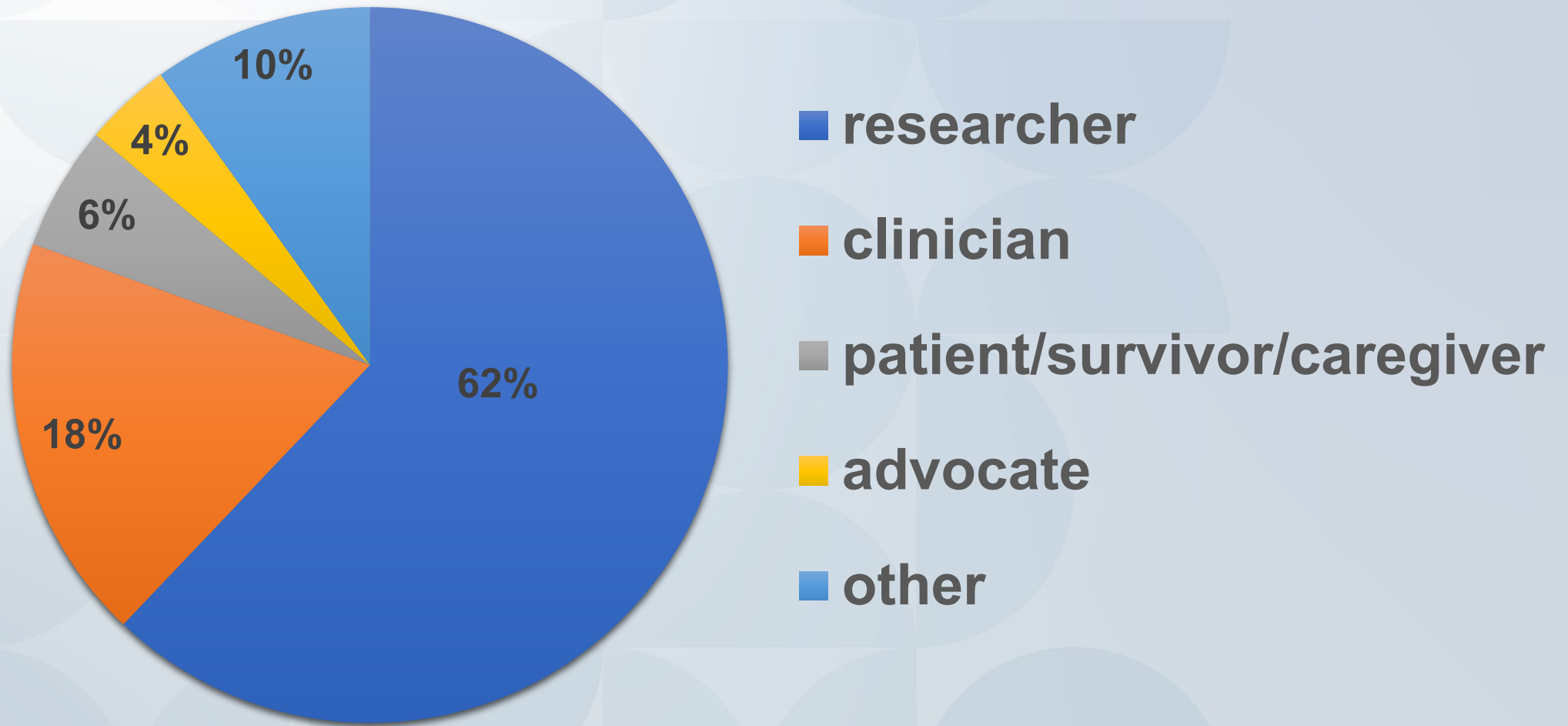
# Virtual Meeting on Survivorship Needs for Individuals Living with Advanced and Metastatic Cancers

May 10–11, 2021

## Meeting Goals

- **Define** the current state of metastatic and advanced cancer survivorship research
- **Identify** health and supportive care needs
- **Discuss** research gaps and opportunities in the areas of epidemiology, healthcare delivery, behavioral sciences, and symptom management

# Meeting Attendees





# Virtual Meeting on Survivorship Needs for Individuals Living with Advanced and Metastatic Cancers

May 10–11, 2021

## Meeting Agenda: Day 1

- Keynote presentation: Dr. Ryan Nipp
- Patient/survivor panel
- Scientific Sessions:

Symptom management

Epidemiology &  
surveillance



# Virtual Meeting on Survivorship Needs for Individuals Living with Advanced and Metastatic Cancers

May 10–11, 2021

## Meeting Agenda: Day 2

- Scientific Sessions:

Psychosocial research

Healthcare delivery  
research

Health behaviors research

# Key Opportunities: **Epidemiology and Surveillance**

- Develop new approaches and modeling strategies to **estimate the number of individuals living with metastatic disease** and to identify/recruit cohorts of individuals to study survivorship in this population
- Leverage existing clinical trial populations for epidemiologic research on advanced and metastatic cancer survivorship
- Identify and/or develop **innovative technologies** for
  - capturing, monitoring, and managing symptoms
  - characterizing treatment changes; and,
  - collecting longitudinal epidemiologic risk factor and outcome data
- Investigate the **clinical, genomic, and lifestyle factors** associated with metastatic cancer survivorship outcomes

# Key Opportunities: **Symptom Management**

- Identify survivors at **greatest need** for symptom management strategies
- Describe factors that contribute to **symptom burden**
- Understand the **trajectory and mechanisms** of symptoms, particularly associated with newer therapies
- Identify **key components** of symptom management interventions in survivors of early-stage cancers that can be adapted or tailored to individuals living with advanced and metastatic cancers



# Key Opportunities: **Psychosocial Research**

- Describe the **psychosocial needs** for individuals living with advanced and metastatic cancer
- Create **survivor- and caregiver-centric models of care** that address the whole person, especially at the intersection of psychosocial care and symptom management
- Identify strategies to **implement prognostic tools** into clinical practice and improve prognostic communication
- Develop and evaluate interventions to improve **coping and address psychosocial needs** of individuals living with advanced and metastatic cancers and their caregivers

# Key Opportunities: **Healthcare Delivery Research**

- Describe **care patterns**, including treatments and supportive care needs, throughout the care trajectory
- Investigate **unmet needs of caregivers** as goals of care and prognosis change
- Understand and intervene to prevent and mitigate **financial hardship**
- Develop and test innovative **models of care**, including delivery of supportive and palliative care, financial navigation and services, and comprehensive follow-up care
- Identify and address **provider barriers** to delivering quality survivorship care, including comorbidity management, care coordination, and prognostic communication

# Key Opportunities: **Health Behaviors Research**

- Develop alternative methods to **capture health behaviors** in studies and in clinical settings
- Determine whether intervention approaches, models, and frameworks for health behaviors in **other cancer survivor populations** can be extended to individuals living with advanced or metastatic cancer
- Assess patient and provider **preferences** and provider **practices** on having health behavior discussions with individuals living with advanced or metastatic cancer
- Explore the need for **formal feasibility and capacity evaluations** to address health behaviors in the context of advanced and metastatic cancer survivorship

# Cross-cutting opportunities

- Identify **existing research resources** that can be utilized to investigate research questions pertaining to advanced and metastatic cancer survivorship
- Include the **survivor perspective** in all phases of research on individuals living with advanced and metastatic cancers
- **Investigate and address disparities** among those living with advanced or metastatic cancer
- Understand and address the **needs of the caregiver and the caregiver/survivor dyad** as they related to issues such as treatment decision-making, prognostic uncertainty, and financial hardship



Promote grant applications



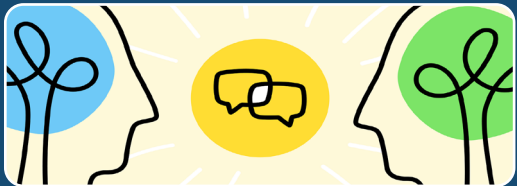
Promote efforts to identify population



Assess and enhance available data resources



Understand unmet needs



Enhance awareness of need for research

# Notice of Intent to Publish a Funding Announcement: NOT-CA-22-077

Goal: to support R01 grant applications to better understand and/or address survivorship needs for individuals living with likely incurable cancers

- RFA expected to be published in Spring 2022, with first application due date in fall 2022
- View Notice of Intent to Publish:  
<https://grants.nih.gov/grants/guide/notice-files/NOT-CA-22-077.html>







# Questions?

## Contact Information:

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