

# NATIONAL CANCER INSTITUTE MEETING ON SURVIVORSHIP NEEDS FOR INDIVIDUALS LIVING WITH ADVANCED AND METASTATIC CANCERS



## EXECUTIVE SUMMARY

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### Introduction

Many individuals with advanced and metastatic cancer are living longer due to improvements in treatments and supportive care. However, most of what is known about the needs of cancer survivors is from studies of individuals diagnosed with cancer at earlier stages. The survivorship needs of individuals living with advanced and metastatic cancer, however, may differ substantially from this group. To further elucidate the survivorship needs of individuals with advanced or metastatic cancer, the Division of Cancer Control and Population Sciences at NCI held a two-day, virtual meeting to determine the current state of advanced and metastatic cancer survivorship research. The meeting goals included identifying health and supportive-care needs; and discussing research gaps and opportunities in the areas of epidemiology and surveillance, symptom management, psychosocial research, healthcare delivery, and health behavior research. This meeting began with a keynote presentation outlining the changing landscape of care for this population and was followed by a patient/survivor panel where four individuals spoke about their experiences. Subsequently, scientific sessions focused on the five key scientific areas listed above were held and included 2-3 presentations from extramural experts followed by a small group discussion with additional scientific experts and a patient/survivor.

### Key Research Opportunities

Below we summarize key research opportunities pertaining to the population of cancer survivors living with advanced or metastatic cancer by scientific topic area:



#### EPIDEMIOLOGY AND SURVEILLANCE RESEARCH:

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- Develop new approaches and modeling strategies that utilize data from cancer registries, electronic health records (EHR), and other existing resources to estimate the number of individuals living with metastatic disease and to identify/recruit cohorts of individuals living with advanced or metastatic cancer to study survivorship in this population
- Leverage existing clinical trial populations for epidemiologic research studies 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 outcomes among individuals living with advanced or metastatic cancer



## SYMPTOM MANAGEMENT RESEARCH:

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- Identify survivors at greatest need for symptom management strategies, based on factors such as the types of symptoms experienced and symptom burden
- Describe factors that contribute to symptom burden, including cancer type, treatments, and the ability to self-manage
- 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



## PSYCHOSOCIAL RESEARCH:

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- Describe the psychosocial and existential 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 between providers, survivors, and caregivers
- Develop and evaluate interventions to improve coping and address both the psychosocial and existential needs of individuals living with advanced and metastatic cancers and their caregivers



## HEALTHCARE DELIVERY RESEARCH:

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- Describe care patterns, including treatments and supportive care needs, throughout the care trajectory
- Investigate the unmet needs of caregivers as the goals of care and prognosis change
- Understand and intervene to prevent and mitigate financial hardship
- Develop and test innovative models of care, including the 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
- Focus healthcare delivery interventions on high-need subpopulations based on factors such as treatments received, disease trajectory, comorbid conditions, and complexity of care



## HEALTH BEHAVIOR RESEARCH:

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- Identify existing data resources that include individuals living with advanced or metastatic cancer in which health behavior data are available or could be collected
- Develop alternative methods to capture health behaviors in studies and in the clinical setting to enable research and to inform care
- 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, including those with comorbid conditions
- 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 Needs and Potential Synergies Between Sessions

There were several areas of synergies that spanned multiple scientific topics:

- Identify existing research resources, including databases and ongoing research studies, 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 by including understudied, underserved, and vulnerable populations in studies, and by collecting detailed and comprehensive data on the social determinants of health
- 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

### Summary

This meeting reviewed the health and supportive care needs of individuals living with advanced and metastatic cancers with goals of discussing research gaps and key research opportunities in the areas of epidemiology and surveillance, symptom management, psychosocial research, healthcare delivery, and health behavior research. Additional research is needed in all scientific areas, to include the use of existing cancer survivor cohorts and longitudinal studies, novel methods of data capture, database identification, and studies with diverse populations. Including underutilized strategies such as early palliative care, promotion of healthy behaviors, innovative models of care, and integrated patient/caregiver-centric care may also improve important symptom, psychosocial, and behavioral outcomes. Overall, incorporating the perspective of this population, and their caregivers, in all research phases is key to understanding the medical and supportive care needs of this unique population of survivors.