

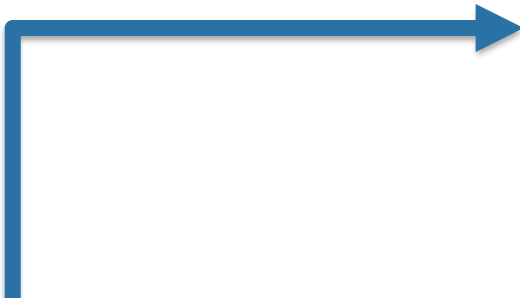


NATIONAL CANCER INSTITUTE  
Division of Cancer Control & Population Sciences

# NCI Office of Cancer Survivorship: Overview and Opportunities to Engage

June 23, 2023  
Michelle Mollica, PhD, MPH, RN, OCN

# My Background





# But it started with a bell...





# Overview of the NCI Office of Cancer Survivorship (OCS)

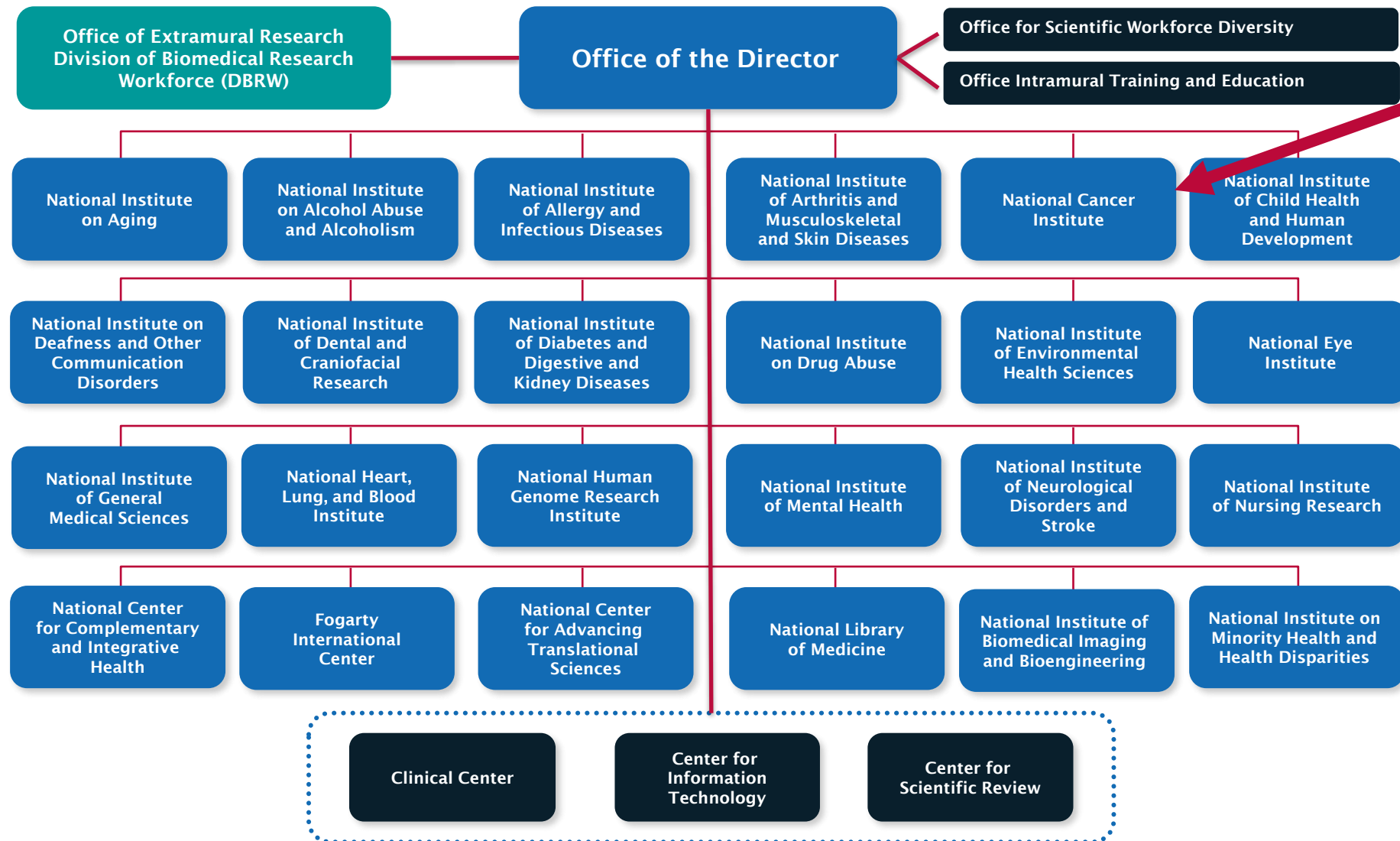




# NIH: Conducting and Supporting Research

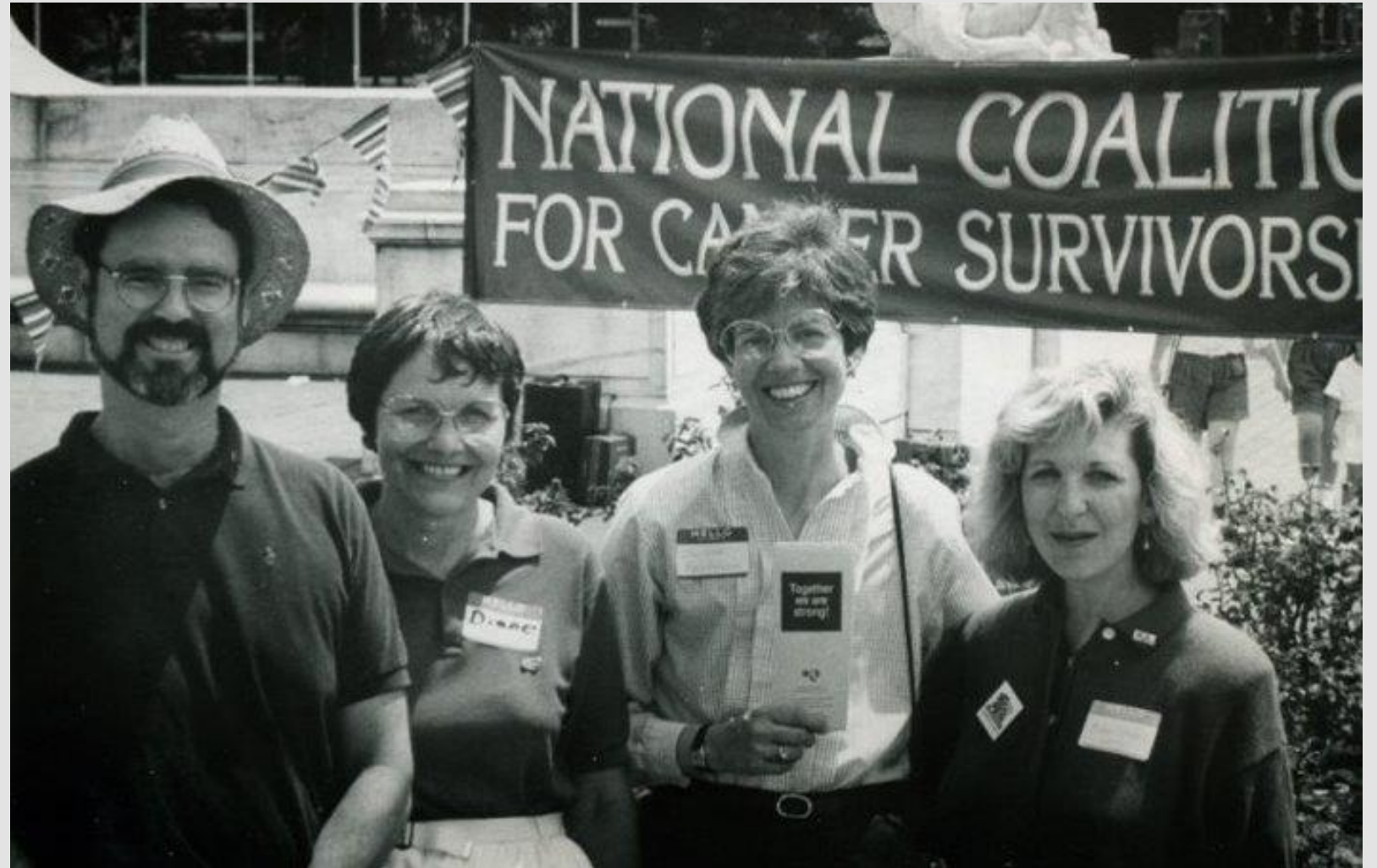


# NIH includes 27 Institutes and Centers



# 1996

In recognition of the large number of individuals surviving cancer for long periods of time and their unique and poorly understood needs







# Mission of OCS

*To support research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families*



# OCS Team





# Who is a Survivor?





# Exponential Growth in the Number of Cancer Survivors

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



# People with Metastatic Cancer in the US\*



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TODAY  
**623,405**

EXPECTED BY 2025  
**693,452**

\*This includes the number of people in the US living with the most prevalent metastatic cancers: breast, prostate, lung, colorectal, or bladder cancer or metastatic melanoma

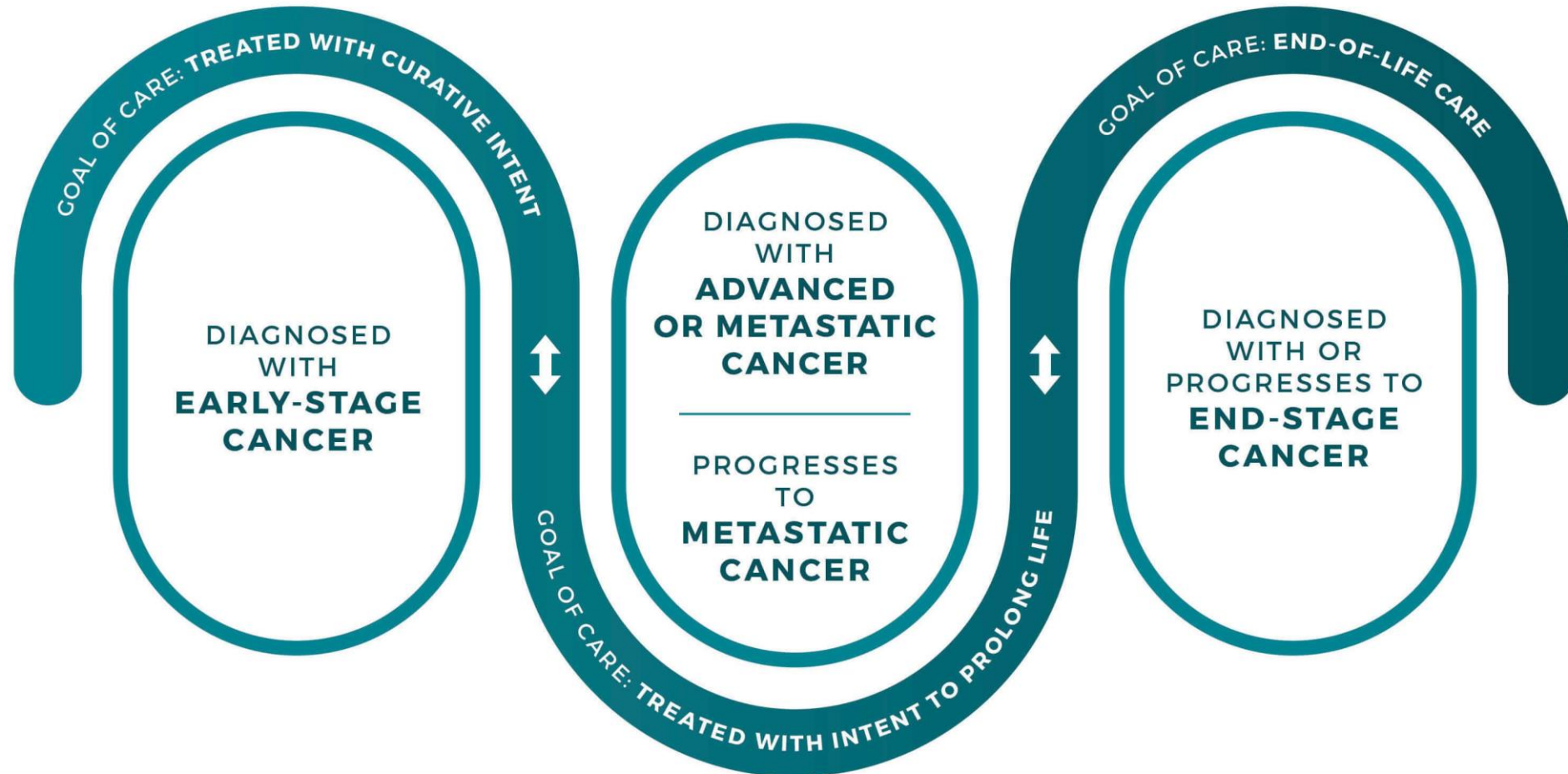


# Perspective on “Survivor”

*I strongly identify as a breast cancer survivor. It's this seminal part of my young adulthood. But I feel differently about “survivor” in the context of having a glioblastoma, which is an incurable, grade four brain tumor. So, I identify as a breast cancer survivor, but a brain cancer patient.*

Age 33, multiple cancers

# Survivorship at Different Stages

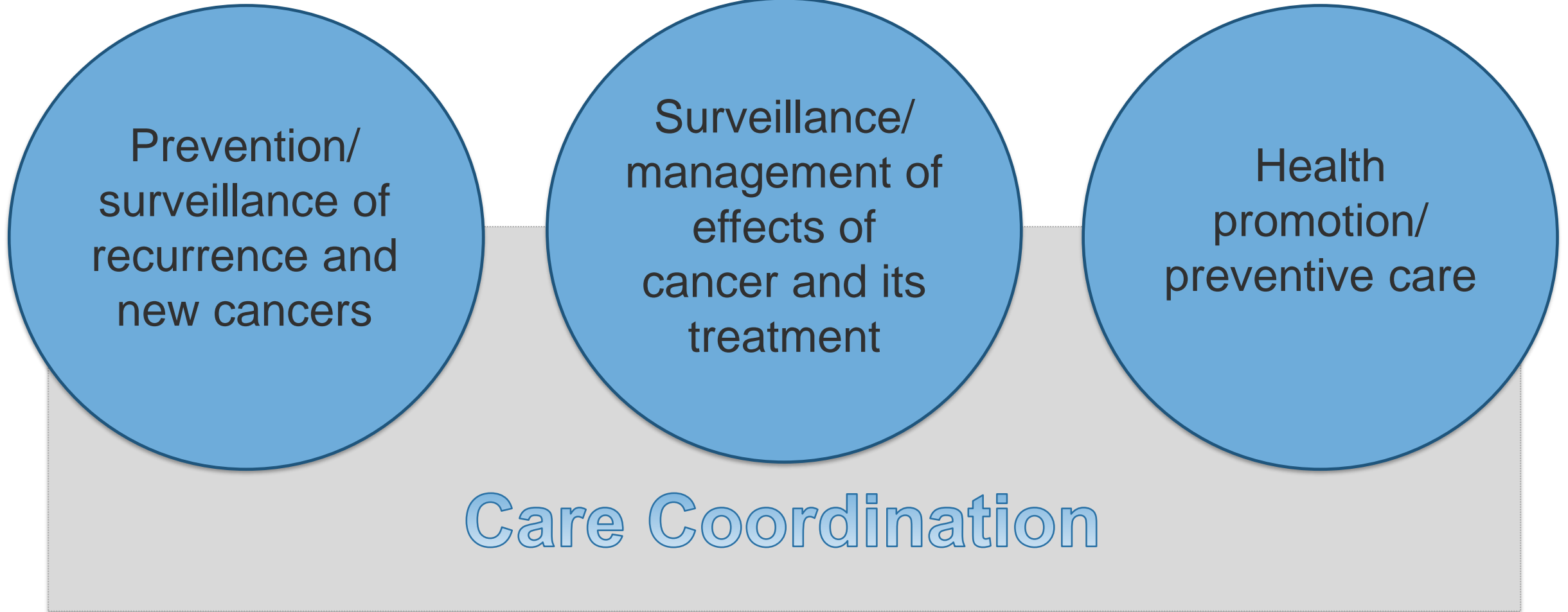




# What is Survivorship Care?



# Comprehensive Survivorship Care





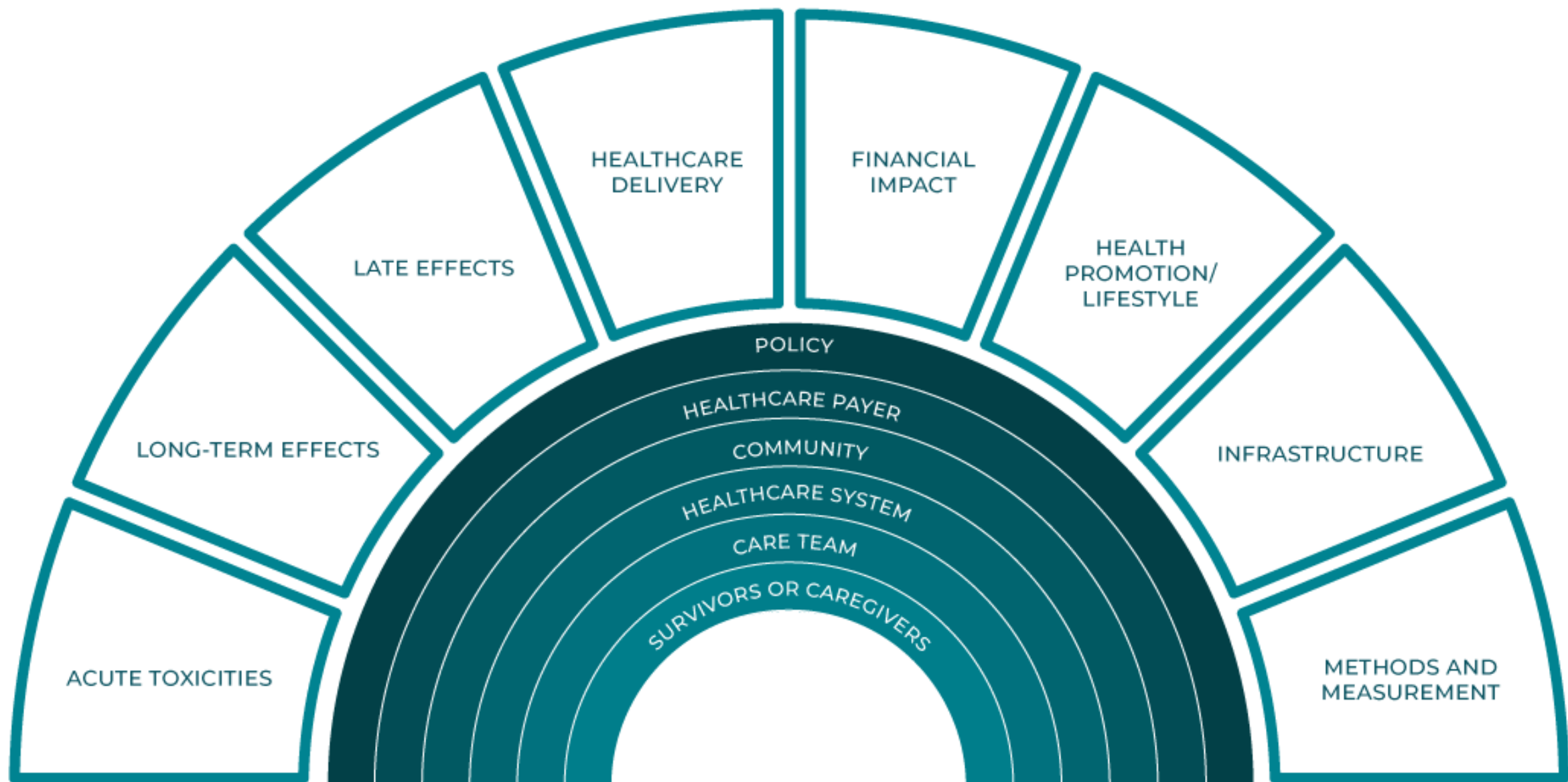
# Quality Care for Cancer Survivors

- National Academy of Medicine recommendations:
  - Prevention and surveillance for recurrence
  - Surveillance/ management of physical and psychosocial effects
  - Promoting healthy lifestyle behaviors
- Identifying and managing comorbidities
- Screening for subsequent cancers
- Monitoring and improving mental well-being
- Managing late- and long-term conditions
- Coordinating care



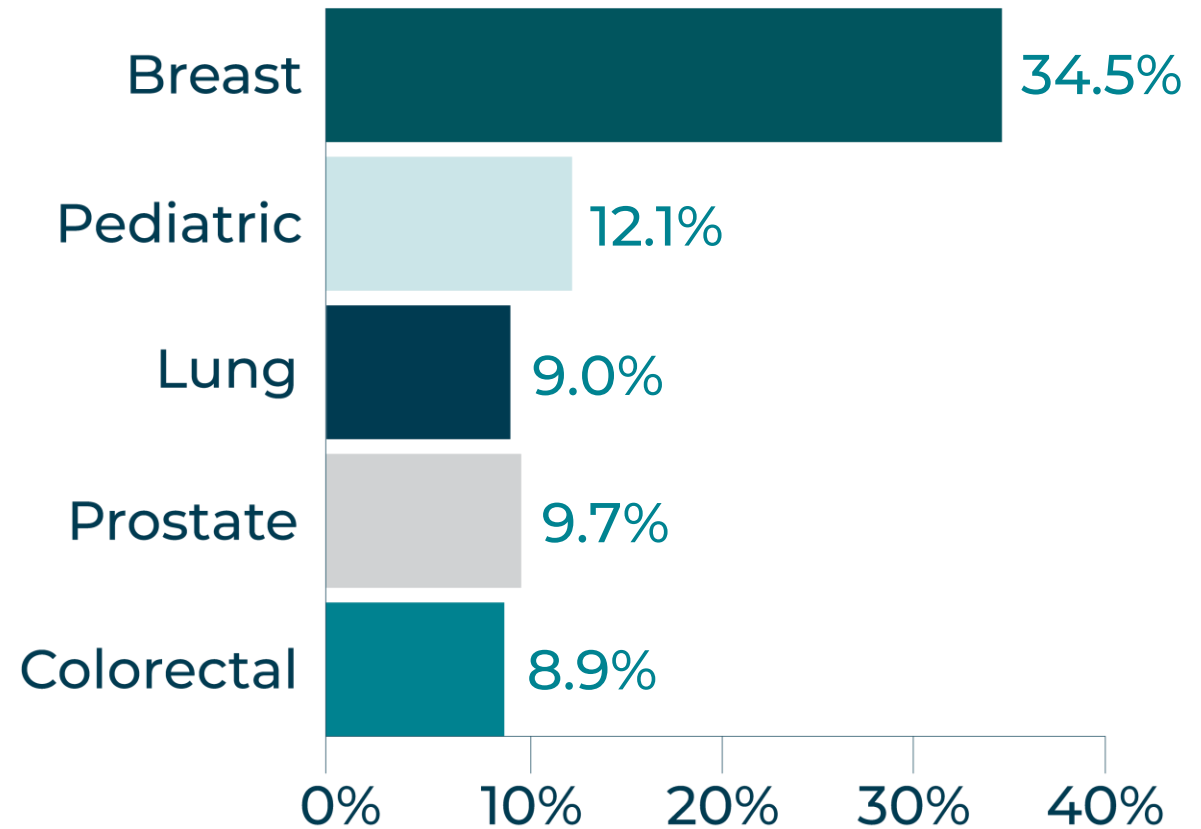
# Survivorship Grant Portfolio 2017-2021



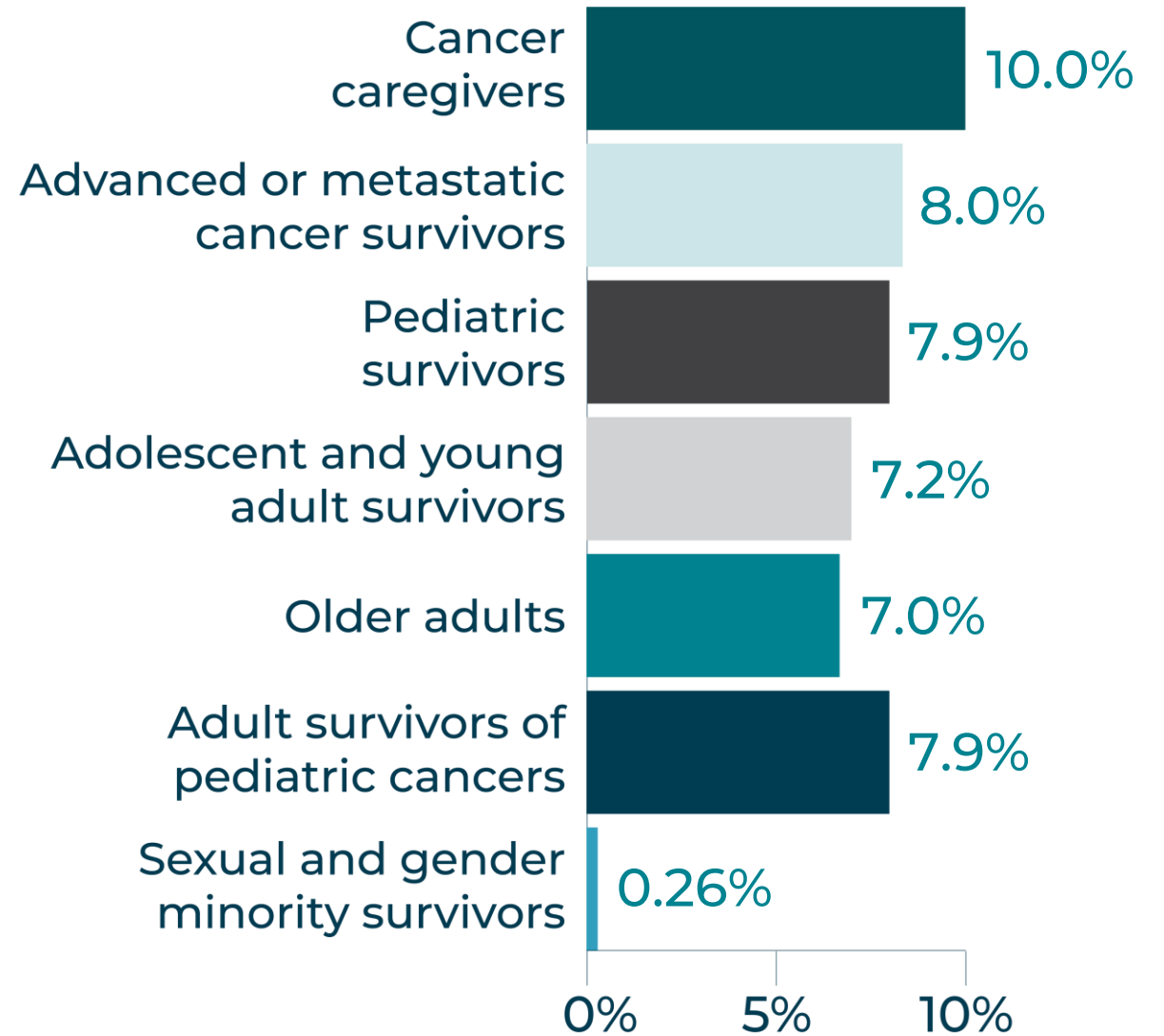




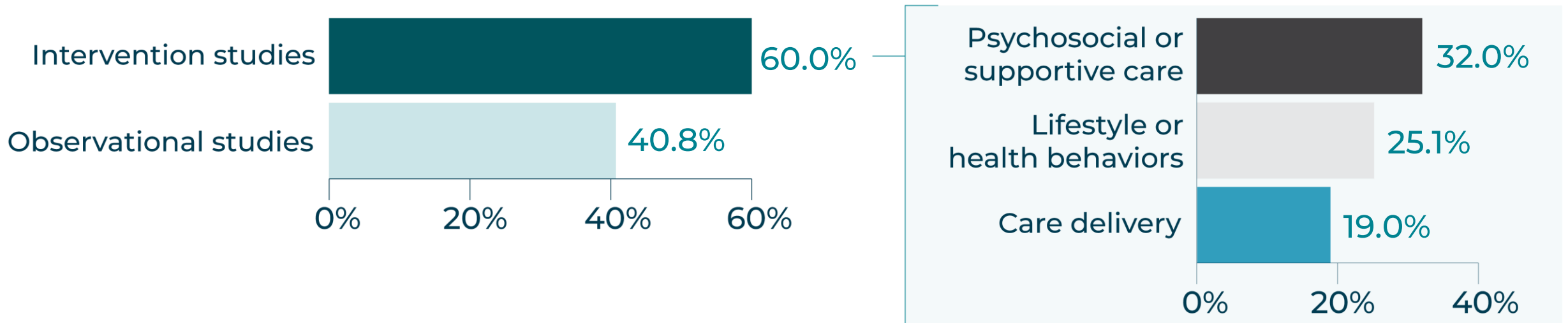
# Cancer Types



# Population Focus



# Study Type





# Gaps in Survivorship Research

## Populations that need more attention:

- Advanced and metastatic cancer survivors
- Older adult survivors
- Rare cancer survivors

## Topics and methods:

- Health disparities experienced by specific groups of survivors:
  - Socioeconomically disadvantaged survivors
  - Sexual and gender minorities
  - Groups living in geographically rural areas
- Financial impacts of cancer (hardship, employment, health economics)
- Implementation science approaches

# Example OCS Areas of Interest

- Primary care for cancer survivors
- Understudied symptoms and toxicities
- Survivorship care delivery
- Specific populations
  - People living with advanced and metastatic cancer
  - Survivors of childhood, adolescent, and young adult (AYA) cancers
  - Medically unsupported/underserved survivors: rural, low income, sexual and gender minority survivors



# OCS Engagement with Survivors



# How Does OCS Engage with Survivor Advocates?

- Identify emerging unmet needs based on survivor perspectives
- Seek perspectives that inform NCI scientific initiatives
- Share survivor experiences as part of OCS webinars and NCI-led meetings
- Publish survivor stories on OCS website
- Work with NCI Office of Advocacy Relations



# NCI Office of Advocacy Relations (OAR)

- As part of NCI's Office of the Director, OAR engages cancer research advocates and organizations, **serving as a link for advocate stakeholders to collaborate with NCI**
- OAR works with individual research advocates, local and national advocacy groups, and professional societies to **ensure the collective patient perspective is included in NCI efforts to advance cancer research and improve patient outcomes**

*On the web*

[advocacy.cancer.gov](https://advocacy.cancer.gov)

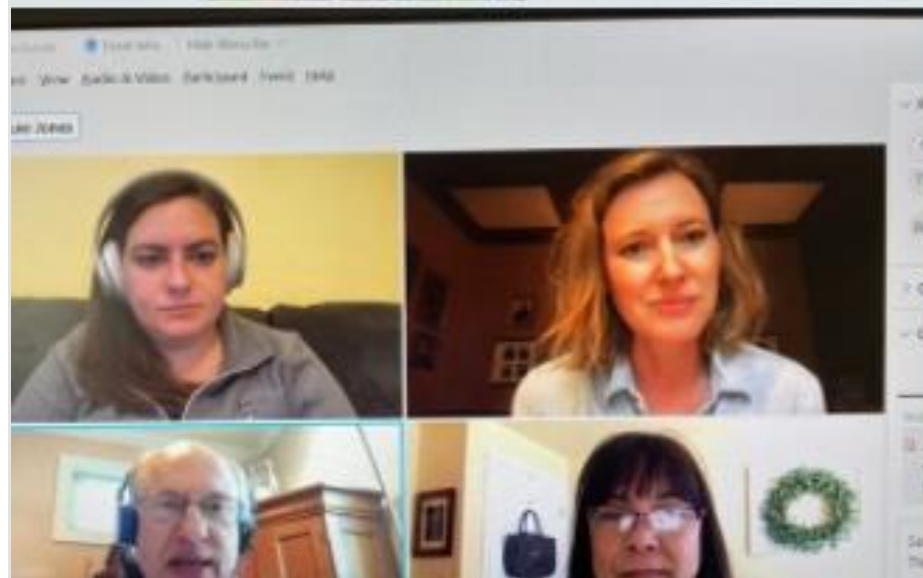
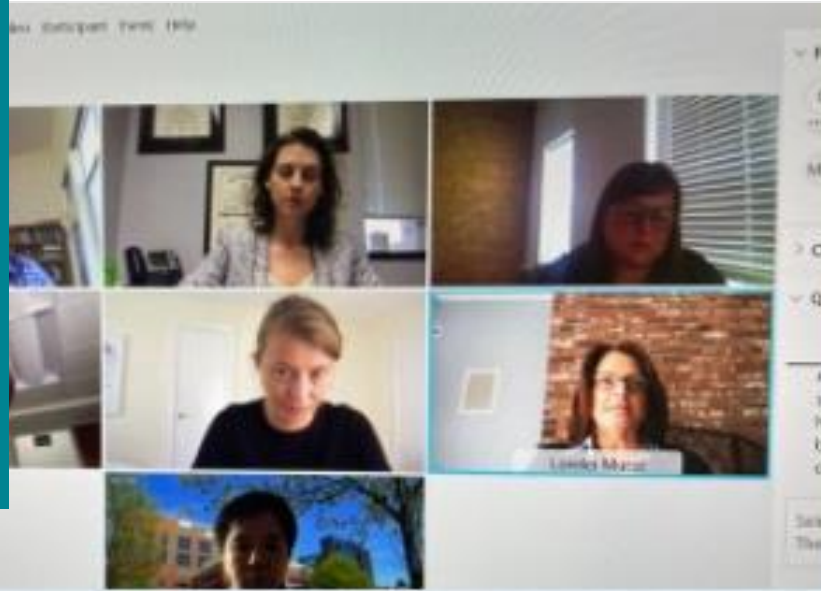
*Via email*

[NCIadvocacy@nih.gov](mailto:NCIadvocacy@nih.gov)

*On Twitter*

[@NCIadvocacy](https://twitter.com/NCIadvocacy)

# Example Initiative: Survivorship Needs for People Living with Advanced and Metastatic Cancers





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

May 10-11, 2021

## Meeting Agenda

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

Symptom management

Epidemiology &  
surveillance

Psychosocial research

Healthcare delivery  
research

Health behaviors research







Promote grant applications



Promote efforts to identify population



Assess and enhance available data resources



Understand unmet needs



Enhance awareness of need for research

## New Funding Opportunity

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**RFA-CA-22-027**



# Research to Understand and Address the Survivorship Needs of Individuals Living with Advanced Cancer (R01 Clinical Trial Optional)

Next application date: September 2023

\*NCI has committed \$32.5M for this initiative

\*Requires engagement with survivors in all aspects of the research

Go to [Survivorship.cancer.gov](https://Survivorship.cancer.gov) for more information





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Division of Cancer Control & Population Sciences

Office of Cancer Survivorship

# EVENTS



OCS NEW  
INVESTIGATORS  
SERIES



December 13, 2022, at 2 p.m. ET

DIRECTOR'S SERIES

# Blending Survivorship and Palliative Care for People with Advanced Cancer in the Precision Oncology Era



**Laura A. Petrillo, MD**

Palliative Care Physician, Massachusetts General Hospital  
Assistant Professor, Harvard Medical School



**Anne H. Charity Hudley, PhD**

Cancer Survivor  
Associate Dean of Educational Affairs  
and Professor of Education, Stanford University



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DIRECTOR'S SERIES

May 2, 2023, at 2 p.m. ET

## Opportunities to Advance the Science of Survivorship in Neuro-Oncology



Emily S. Tonorezos,  
MD, MPH

Director, Office of Cancer  
Survivorship  
National Cancer Institute



Terri S. Armstrong, PhD

Senior Investigator and  
Deputy Chief, Neuro-Oncology Branch

Associate Director, Patient-Centered  
Outcomes, Center for Cancer Research  
National Cancer Institute



Kimberly Wallgren

Caregiver and  
Executive Director  
Collaborative Ependymoma Research  
Network (CERN) Foundation, a  
program of the National Brain Tumor  
Society



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Scan for more info ▶







June 13, 2023, at 2 p.m. ET

# Sexual Concerns of Cancer Survivors: Are We Closer to Addressing this Unmet Need?

Jennifer B. Reese, PhD

Associate Professor, Cancer Prevention and Control Program  
Fox Chase Cancer Center



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September 19, 2023, at 2 p.m. ET

## Optimizing Care Delivery for Cancer Survivors: Engaged, Pragmatic, Multi-team & Multi-level

**Simon Craddock Lee, PhD, MPH (he/him/his)**

Chair and Sosland Family Professor in Preventive Medicine  
Department of Population Health, School of Medicine  
University of Kansas Medical Center



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NCI OFFICE OF CANCER  
SURVIVORSHIP

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**SURVIVOR  
STORIES**





**YOU'RE  
NOT ALONE.**

Tamika Felder, Cancer Survivor





There is not one right way  
through cancer, and you  
have to be aware of  
**WHAT MAKES  
SENSE FOR YOU.**

**Bob**

Cancer Survivor





# CANCER'S IN MY LIFE ON MY TERMS.

**Bethany Ross**

Cancer Survivor





NATIONAL COALITION  
FOR CANCER SURVIVORSHIP



Bethany Ross



@CancerBadass



@Cancer.Badass



## ▶ Bethany's Story

- In August 2018, at the age of 30, after being sick for nine months, I was diagnosed with Stage IV neuroendocrine cancer in my appendix, pancreas, lymph nodes and spread to my liver.
- I had two surgeries, including a liver resection and 4 months of hormone treatments to help my symptoms.
- Currently having a recurrence in my stomach and on monthly treatments again.
- I joined CPAT in 2020 after hearing a session at CancerCon (young adult cancer conference) and knowing that I needed to make what happened to me mean something.





ADVOCATE SPOTLIGHT

**Bethany Ross**

Advocating for Quality Cancer Care Through Storytelling



Dear Cancer... RESILIENT

DEAR CANCER, I KNEW I HAD TO SURVIVE

BETHANY ROSS

Dear Cancer,

I hate you. You took more from me than you will ever know. There I was, newly married, thirty years old, and running half marathons, when you decided to invade my body and life. I had been sick for nine months, vomiting every day and seeing doctor after doctor, and no one could figure out what was wrong with me. I had doctors tell me it was all in my head, that I was making myself sick, and I decided to take over my "healthy" body in ways I never thought possible for someone my age. You forced me to learn words like "neuroendocrine," "metastatic," and "peripancreatic." You glared back at me from a bright phone screen while I Googled "survival rate for metastatic neuroendocrine cancer of the pancreas" and saw "27% five-year survival rate" and no 10-year rate to be found. I sat on the floor of my bedroom, tears streaming down my face, feeling like the world was ripped out from under me because of you. I had just taken a new job, started living my life, and now here I was questioning if I would even make it to 35.

You were not something new to my family. My grandfather had died from lung cancer when I was in first grade and my grandmother had thyroid and later breast cancer, complications of which were responsible for her death. I remember you, cancer, being this scary thing that took away people in my life, but when they were older and retired, not when they were thirty and just starting to live the life they had worked so hard to get. A house, a spouse, maybe children on



the way, but instead you appeared on scan after scan and told me no, that's not your life anymore. That "before cancer" Bethany, she's dead, I killed her. Now you get to deal with the complete mess I have made of your now shorter life.

At first, I didn't know how to deal with you, but I knew I had to survive. Survival was the goal, right? I was going to be the best, most informed stage 4 neuroendocrine cancer patient there ever was. The scientific part of my brain kicked in; I was after all a chemistry major in college. I looked up studies and went to oncology appointments with a notebook full of questions. I was ready to take you on scientifically, cancer. But the thing I wasn't prepared for was how to take you on mentally. No one prepared me for what you would do to my anxiety, my



future, my marriage, and my life outside of just surviving. For a while there I was just in survival mode, living from one Gallium PET scan to the next, sometimes in three-month intervals, sometimes if I was lucky six, hoping that you wouldn't appear again, even though I was told you were not out of my life. Like a glitter spill, you were coming back even if we thought you were gone.

Then in October 2020, months into the pandemic, which was already testing my mental health, you killed my friend Alex, the one person I knew before my cancer diagnosis that had the same kind of cancer as me. A month prior to that, you—cancer—crushed all outstanding dreams my spouse and I had to have children. My body could not sustain a pregnancy and I am unable to adopt with you around, cancer.

You made me look at my life and question all the things that I thought I "needed" to

**Bethany Joy** @BethanyJoy28 · Jul 21  
Oh hey you know just featured by the National Cancer Institute today 🥰

**NCI Office of Cancer Survivorship** @NCICancerSurv · Jul 21  
Bethany was going to do whatever it took to survive #NeuroendocrineCancer. She was determined to beat the odds and share her journey. For her, cancer was the catalyst for living a fuller life. [cancercontrol.cancer.gov/ocs/resources/](https://cancercontrol.cancer.gov/ocs/resources/) ... #CancerSurvivorStories @BethanyJoy28



“**CANCER'S IN MY LIFE ON MY TERMS.**”

**Bethany Ross**  
Cancer Survivor

**PATIENT PANELISTS**



**Bethany Ross Abbott**  
Cancer Advocate



**Lesley Kailani Glenn**  
Metastatic Breast Cancer Thriver and Advocate, Founder of Project Life



**Christine Hodgdon**  
Patient Advocate, GRASP Co-Founder (Guiding Researchers & Advocates to Scientific Partnerships)



**Lee Jones**  
Research Advocate, Fight Colorectal Cancer Member, Georgetown Oncology Institutional Review Board, Research Advocate Member, SWOG Survivorship Committee



**BETHANY ROSS IS FROM NASHUA, NEW HAMPSHIRE, AND WAS DIAGNOSED WITH STAGE 4 NEUROENDOCRINE CANCER IN HER APPENDIX AND PANCREAS THAT SPREAD TO HER LYMPH NODES AND LIVER IN AUGUST 2018 AT THE AGE OF 30. SHE SAW SIX DOCTORS AND WAS SICK FOR ALMOST A YEAR UNTIL SHE FOUND SOMEONE THAT FINALLY LISTENED TO HER. SHE HAD MONTHLY TREATMENTS AND TWO SURGERIES AND IS CURRENTLY STABLE AND GETS SCANS AND BLOOD WORK EVERY THREE TO SIX MONTHS. ROSS WORKS FULL TIME AS A CYBER SECURITY ENGINEER. WHEN NOT WORKING SHE ENJOYS CANCER ADVOCACY WORK AND GOING ON NEW ADVENTURES!**



# Thank You!

Michelle Mollica, PhD, MPH, RN, OCN  
Office of Cancer Survivorship  
[michelle.mollica@nih.gov](mailto:michelle.mollica@nih.gov)



@SheIMollica