



NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

Office of Cancer Survivorship: 25 Year Anniversary

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Director

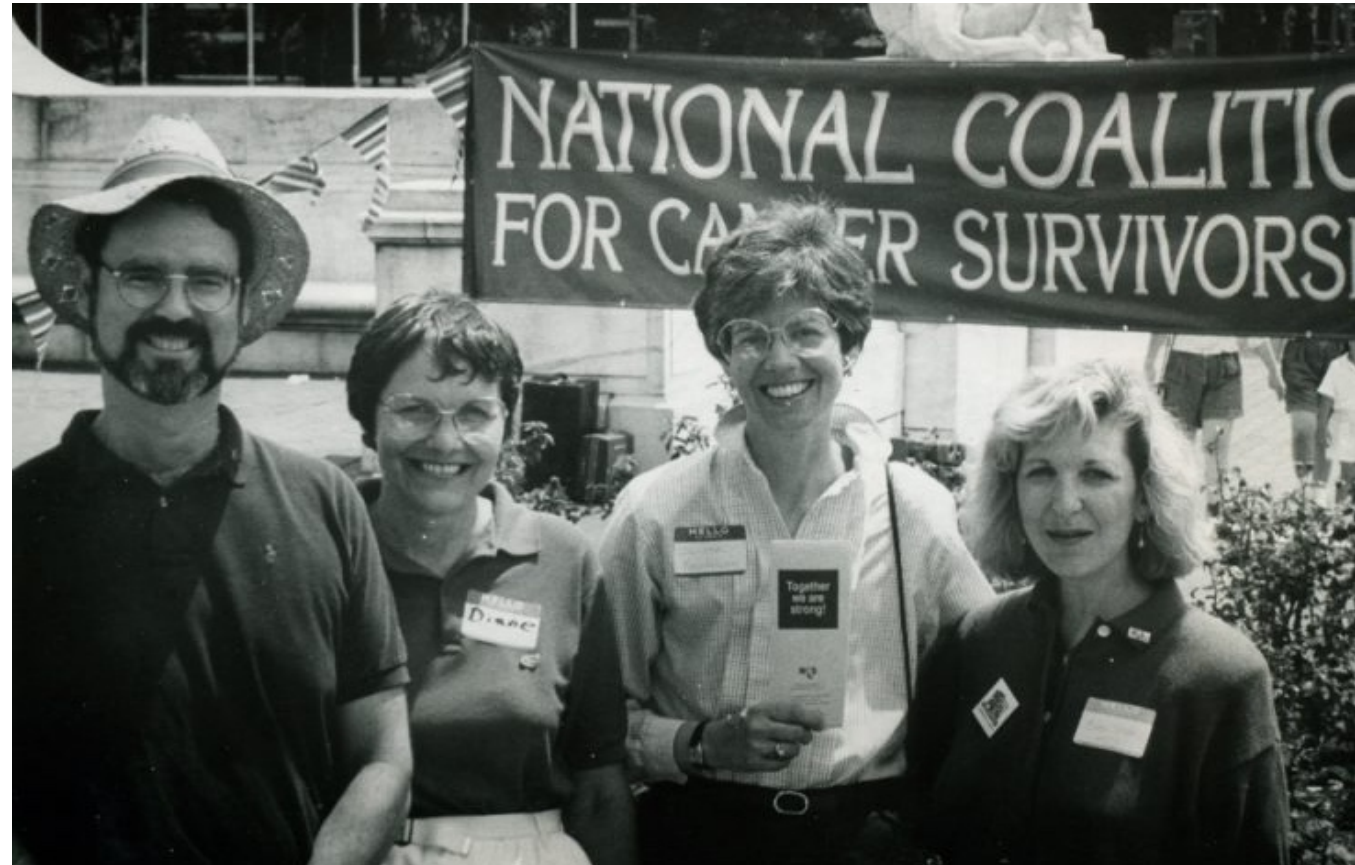
1975

“Cure is not
enough”
Giulio D’Angio

It is clear that the child cured of cancer must be followed for life, not so much because late recurrence of disease is feared as to permit early detection of the delayed consequences of radio- and chemotherapy.

Call for Action

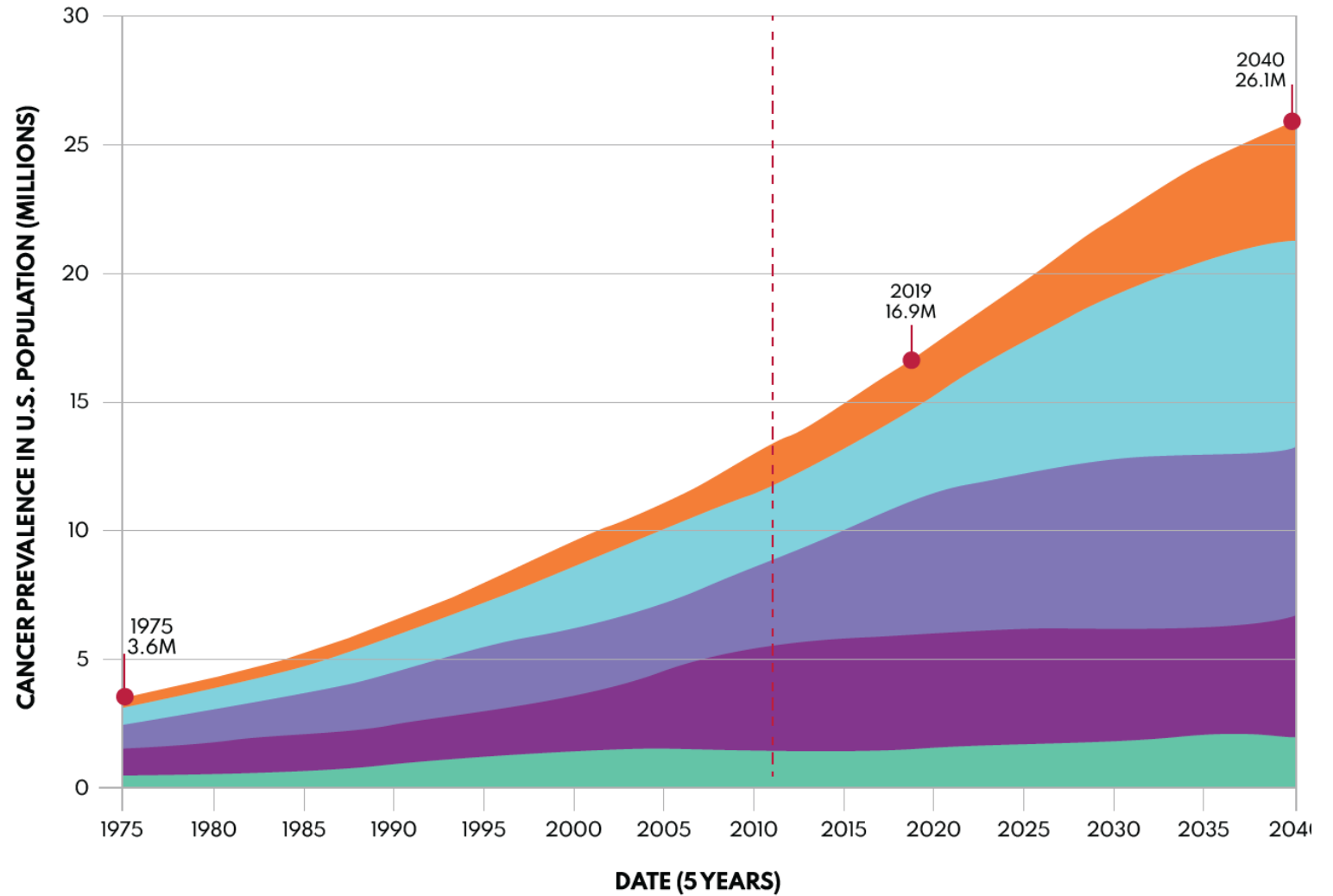
- “Despite ... success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problem of survivors.
- It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and sputter on their own in the belief that we have done all we can.”



Mullan, F. N Engl J Med 1985; 313:270-273.

Growing Population

Cancer survivors are growing in number.



KEY

Signifies the year at which the first baby boomers (those born 1946-1964) turned 65 years old.

Age

<50 50-64 65-74 75-84 85+

Projections based on data from Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev.* 2016;25:1029-1036.

1996

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



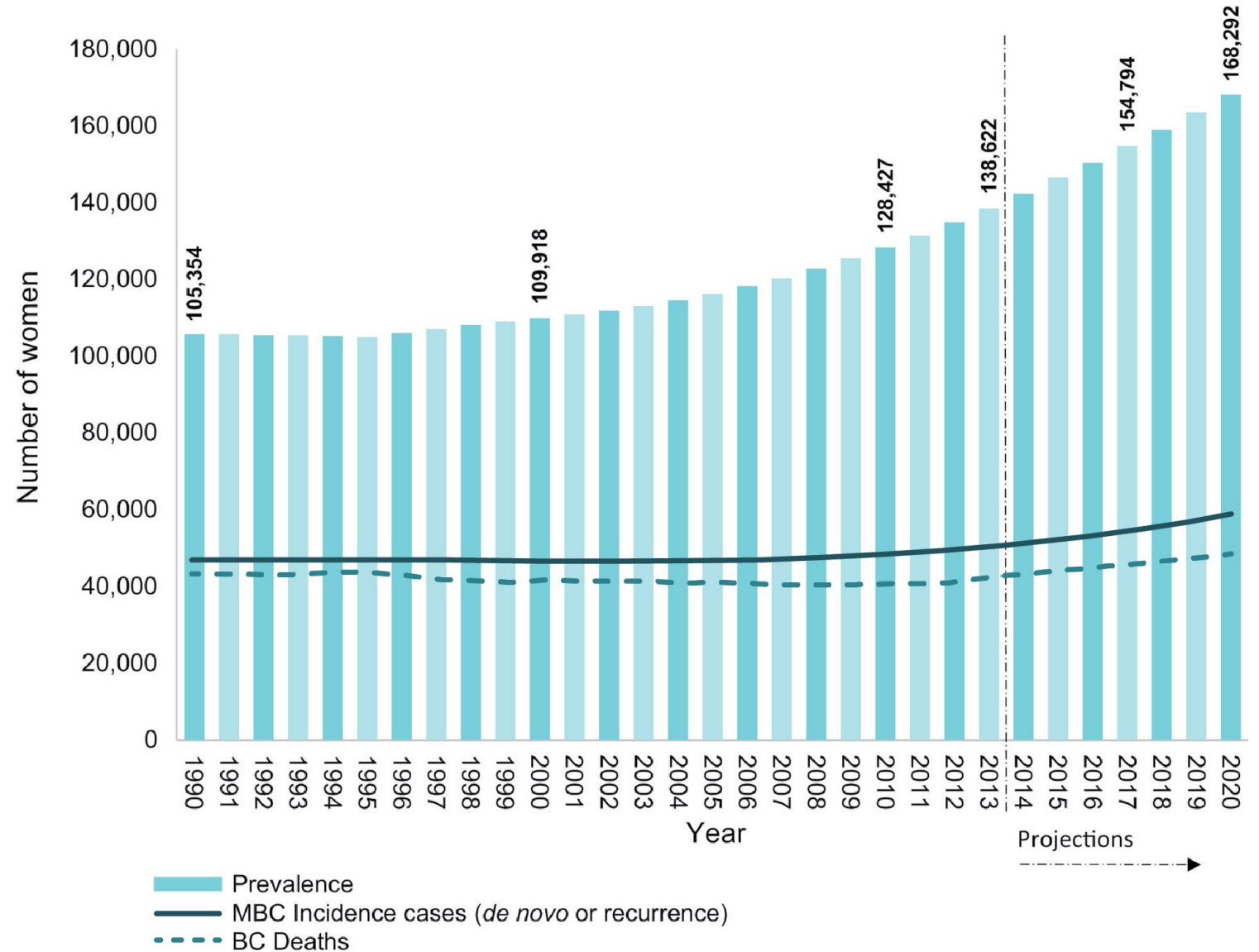
Goals for the Office of Cancer Survivorship

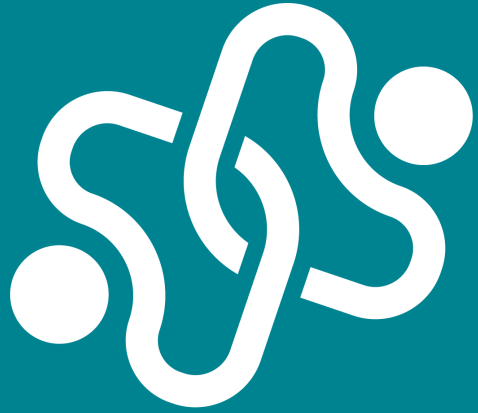
- Support survivorship researchers
- Build infrastructure
- Leverage expertise
- Generate collaborations
- Promote understudied research areas



Growing Population

Survivors with advanced and metastatic cancer are growing in number.





Defining the Population: Survivor Living with Cancer

- Diagnosed with metastatic or advanced cancer or with cancer that has progressed from early-stage to metastatic.
- Can be on or off treatment.

The goal of care is to prolong life without expectation of cure.

Definition of Cancer Survivor: Updated

- An individual is considered a cancer survivor from the time of diagnosis, through the balance of life.
- Survivors include those living with cancer and those free of cancer.



The Office of Cancer Survivorship



Timeline

1997

[Long-Term Cancer Survivors Research Request for Application \(RFA\)](#) is released to support research that would examine and describe the health consequences of cancer and its treatment among long-term survivors, which was defined as those surviving five years beyond initial diagnosis.

1998

OCS holds its first major research conference, Research Issues in Cancer Survivorship, a [brief summary](#) of which appears in the *Journal of the National Cancer Institute*.

1999

Dr. Julia H. Rowland becomes the first full-time director of the office.

2001

Over 100 total grants funded by OCS since 1998, the first full year of funding as part of the Division of Cancer Control and Population Sciences, in which OCS is housed.

Timeline

2002

The first Biennial Cancer Survivorship Research Conference is held, in collaboration with the American Cancer Society, *Cancer Survivorship: Resilience across the Lifespan*. [Proceedings](#) from this meeting were published in *Cancer*.

2004

Children's Oncology Group releases [guidelines](#) for follow-up care for survivors of childhood cancer.

2004

Over \$100 million in cumulative funding by OCS since 1998.

2005

Institute of Medicine releases report on adult cancer survivorship, [From Cancer Patient to Cancer Survivor: Lost in Transition](#), for which the OCS provided data and testimony.

2007

The first issue of the *Journal of Cancer Survivorship* is published.

Timeline

2013

Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care (de Moor, Janet S et al) is published in *Cancer Epidemiology, Biomarkers & Prevention*.

2016

Anticipating the “Silver Tsunami”: Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States (Bluethmann, Shirley M; Mariotto, Angela B; Rowland, Julia H) is published in *Cancer Epidemiology, Biomarkers & Prevention*.

2016

Congress passes the 21st Century Cures Act, which provides funding to NCI for the Beau Biden Cancer Moonshot (“Cancer MoonshotSM”). Funding for the initiative begins in 2017.

2017

Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship (Nekhlyudov, Larissa et al) is published in the *Journal of Clinical Oncology*, a look back at the 2006 IOM Report.

2016 Portfolio Analyses



Survivorship Portfolio Analysis-Identified Gaps

- Longer-term (> 5 years) survivors
- Cancers other than breast cancer (especially high need)
- Older (> age 65) cancer survivors
- More diverse survivors, including racial/ethnic minorities, geographic, and LGBTQ+
- Long-term and late effects of newer therapies
- Intervention studies
- Biological mechanisms and genetic factors for recurrences and adverse effects
- Patterns and quality of survivorship care

**Survivorship
Research
Meeting
April 2019**



Survivorship Research Meeting: April 2019

- Researchers, survivors, advocates, and representatives from professional organizations met to discuss gaps in the survivorship search.
- Subsequent webinar for the larger scientific community.
- NCI-generated research priorities, published in the *Journal of the National Cancer Institute*.

Gallicchio L, Tonorezos E, de Moor JS, Elena J, Farrell M, Green P, Mitchell SA, Mollica MA, Perna F, Gottlieb Saiontz N, Zhu L, Rowland J, Mayer DK. J Natl Cancer Inst. 2021 Mar 23:djab049.

Survivorship Research Meeting: April 2019

- Cross-cutting recommendations:
 - Understanding and eliminating disparities among cancer survivors
 - Conducting longitudinal studies as well as longer-term follow-up studies
 - Leveraging existing data
 - Incorporating implementation science strategies

Causes and Consequences of Childhood Cancer

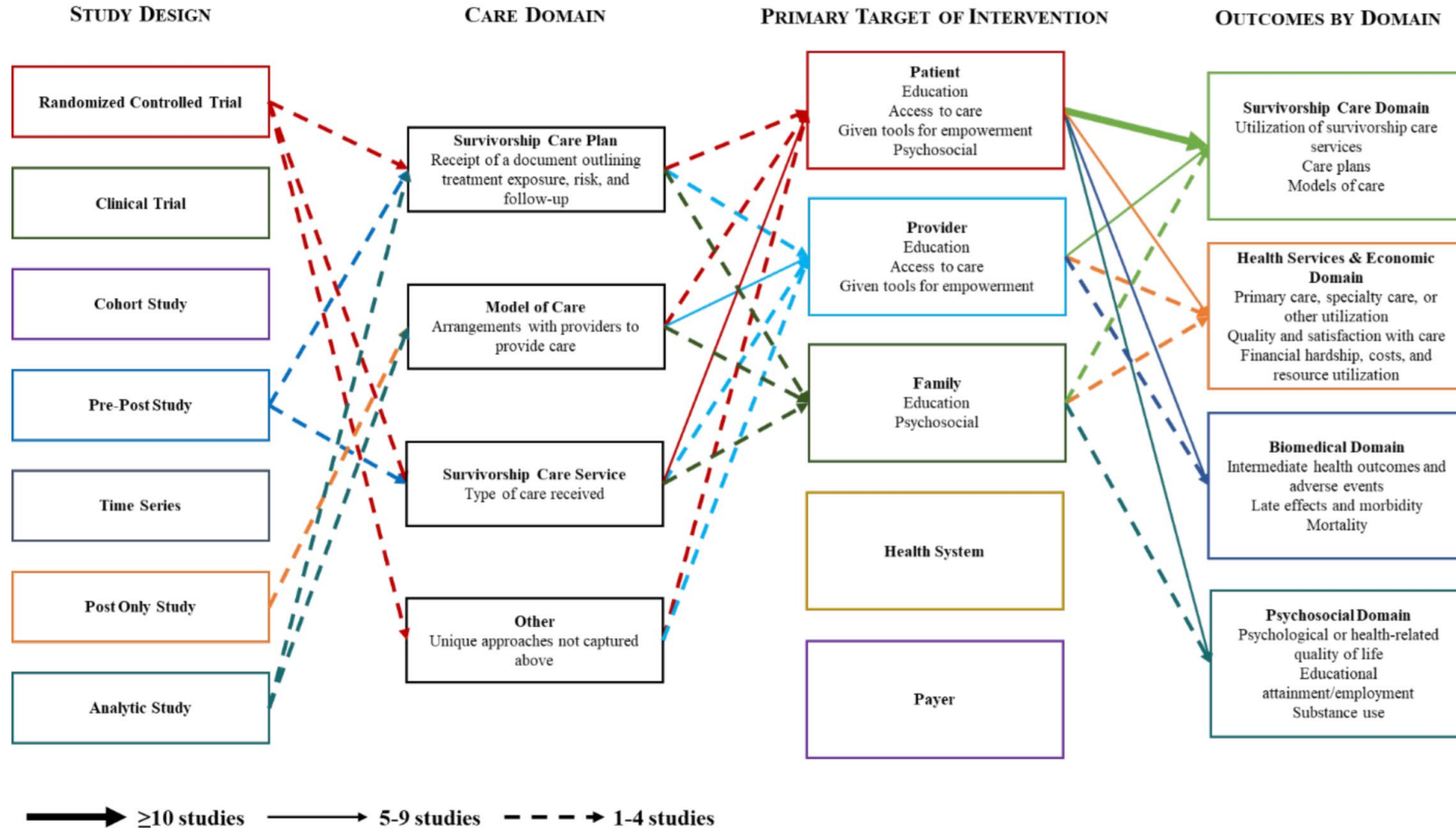


Childhood Cancer Survivorship: STAR Act

- Three reports from the Agency for Healthcare Research and Quality:
 - Transitions
 - Care models that include primary care providers
 - Disparities and barriers to care

Childhood Cancer Survivorship: Barriers

Figure 6. Study design, care domain, and primary target of evaluated strategies



Childhood Cancer Survivorship P30 Supplements

- Received 30 applications.
- Focus included organizational policies and procedures, culture, resources, teams, workflow, space, staffing expertise, and hours.



Childhood Cancer Survivorship P30 Supplements

- Examining rural/urban disparities in and predictors of childhood cancer survivors' organizational barriers to follow-up care (University of Kentucky)
- Adherence to NCCN Reproductive Health Guidelines among Childhood Cancer Survivors (NYU)
- Clinical benefit and cost-efficacy of risk-stratified survivorship navigation to overcome structural barriers to long-term follow-up care (Baylor)
- Organizational assessment to eliminate outcome disparities among childhood cancer survivors. (Georgetown)

Childhood Cancer Survivorship P30 Supplements

- Improving Support for Survivors Engaged in Transition (IS SET) (Emory)
- Improving compliance with standard of care recommendations for neuropsychological assessment for children with central nervous system tumors (Johns Hopkins)
- Examining barriers that drive disparities in equity in the delivery of occupational therapy (OT) and physical therapy (PT) for childhood cancer survivors (University of Texas – MD Anderson)

Understanding and Supporting Primary Care



Primary Care + Survivorship

- Primary Care Working Group formed in DCCPS
- May 25: NCI Roundtable on Cancer Prevention in Primary Care
 - Led by Division of Cancer Prevention
 - Representatives from professional organizations and advocacy groups
 - Focus on risk reduction and cancer interception
- Care delivery, transitions, and communication are key challenges

What Is Missing? What Is Next?

- Investing in survivor cohort studies.
 - RFA 20-030: Friedman, Penedo, Scheuer, Yao
 - Minority populations, rare cancers and Immune checkpoint inhibitors
- Investigating individual response to treatment.
 - Interactions with environmental exposures

What Is Missing? What Is Next?

- Pursuing understudied toxicities.
- Supporting technology and innovation.
- Asking: what more could we be doing in disparities?
 - P30 Supplements: Organizational Barriers to Survivorship Care

- View the agenda for this free, virtual scientific workshop and register at events.cancer.gov/nci/emergency-medicine
- Purpose: Identify research recommendation to improve outcomes in patients/survivors experiencing or at risk for urgent and emergency cancer-related complications
- Sponsored by the National Cancer Institute and NIH Office of Emergency Care Research



**“End
cancer as
we know it”**

“What are we working toward? If we’re building a bridge to the future of cancer, what’s on the other side of that bridge? A world ... where we will have changed cancer as we know it. And I think that future is within our reach. Let’s focus on a future where all people with cancer have the support and resources needed to navigate their care.”



Thank You.