

Addressing Barriers to Health Care Transitions for Survivors of Childhood and Adolescent Cancers

NCI Board of Scientific Advisors

March 20, 2024

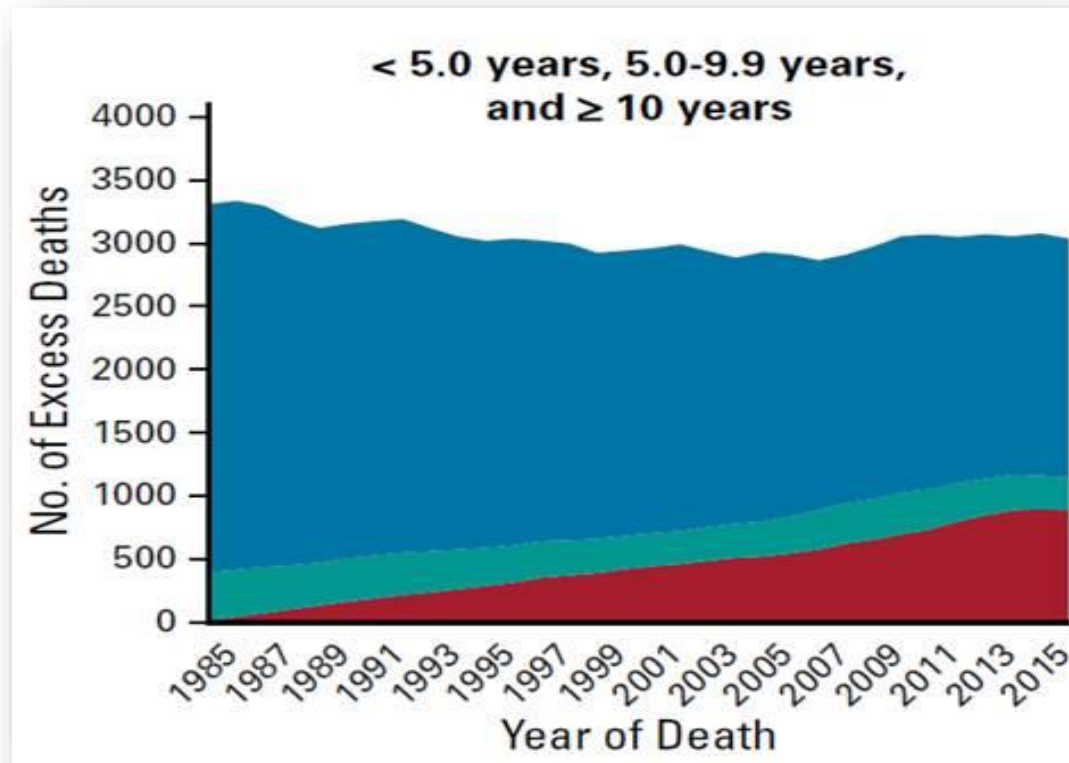


Lynn S. Adams, PhD
Outcomes Research Branch
Healthcare Delivery Research Program
Division of Cancer Control and Population Sciences

Need for Childhood Cancer Survivorship Research

- Five-year childhood cancer survival rates substantially improved
- Need to address long-term consequences of cancer such as premature mortality and morbidity
- Childhood Cancer **S**urvivorship, **T**reatment, **A**ccess, and **R**esearch (STAR) Act (2018) – **Reauthorized in 2023**
 - Section 201a: Evaluate model systems of care for pediatric cancer survivors, including transition to adult care and care coordination
 - Need identified by childhood cancer research advocacy community

Progress and Gaps in Childhood Cancer Survival: Examining “Excess” Deaths



Years from Diagnosis

- ≥ 10.0 years
- 5.0-9.9 years
- < 5.0 years

**Inadequate
Follow-up
Care**

Transition to Adult Care: An Important Crossroads

- Lifelong follow-up care recommended
- Discharge between 18 – 26 years of age
- Resources supporting transfer to adult care are lacking
- Pediatric and adult cancer care differ
 - Pediatric: comprehensive support
 - Adult: navigation left to patient
- Pediatric survivorship care is complex
- Survivors vulnerable to loss to follow-up



Transition Challenges

Unstructured, uncoordinated transitions to adult settings can lead to:

- Late diagnosis of recurrence, new primary cancers, treatment effects
- Unmanaged symptoms and morbidities

Individual Transition Barriers

- Difficulty navigating health system
- Limited self-management and self-advocacy skills

Provider & Health System Barriers

- Lack of coordination & collaboration
- Resources supporting transfer to adult care lacking
- Insurance coverage for follow-up in adult settings varies

Barriers are greater in populations with health disparities

Related STAR Act Funding

Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act
(2018) – **Reauthorized in 2023**

RFA-CA-19-033

Investigator network testing interventions to *address adverse physical and psychosocial effects* in survivors of pediatric & adolescent cancers

RFA-CA-20-027/028

Projects proposing *mechanistic, observational, and/or interventional* studies to improve care of and quality of life for childhood & adolescent cancer survivors

Portfolio Analysis

RFA-CA-19-033 Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors

- Eight awards
 - Adherence to survivorship care (1), none on transition to adult care

RFA-CA-20-027/028 Research to Reduce Morbidity and Improve Care for Pediatric, and Adolescent and Young Adult (AYA) Cancer Survivors

- Twenty-four awards
 - Adherence to survivorship care (1), none on transition to adult care

Funded portfolio on Pediatric or AYA survivorship in last 5 years

- Eighty-eight awards, 1 focused on transition to adult care (funded 2023)

Proposed RFA (R01 Clinical Trial Required)

To solicit **R01** applications proposing intervention studies that address barriers to care transitions from pediatric to adult care settings for survivors of childhood or adolescent cancers

Hypothesis: Interventions to support successful transitions in care from pediatric to adult settings will increase engagement in guideline concordant care and improve outcomes for survivors of childhood and adolescent cancer

Example Research Topics Responsive to this RFA

Testing

Testing an intervention focused on supporting coordination of care between survivors and pediatric and adult healthcare providers for ongoing follow-up care

Identifying

Identifying survivors lost to follow-up care and testing an intervention to re-engage and support their ongoing care

Adapting and testing

Adapting and testing an existing transition intervention to be tailored to childhood cancer survivors as they move to adult survivorship care

Application Characteristics

Key requirements:

- Must focus on the development, testing, or evaluation of interventions
- Must include a multi-disciplinary research team
- Must describe a plan for potential scalability and sustainability

Particularly encourage:

- Inclusion of racially/ethnically, socioeconomically, and geographically diverse populations, including medically underserved groups
- Research to address the impact of social determinants on achieving a successful transition to adult health care
- Multi-level studies that intervene or measure outcomes at the individual and provider or system level

Proposed Budget

- 2 receipt dates
- \$4M in FY25 to fund up to 5 awards
- \$6M in FY26 to fund up to 7 awards
- R01 application budgets must not exceed \$499K in direct costs per year
- Total set aside for all years: \$50M
- Initiative responsive to STAR Act objectives

Justification for RFA

- Need to improve engagement in guideline-concordant care
- Transition to adult care for this population is a portfolio gap
- Propose the R01 mechanism to support intervention research
- An RFA-enabled special emphasis panel of experts to review applications
- Significant response to previous **STAR ACT** RFAs focused on survivorship care, yet transition remains a research gap

Conclusion: Expected Impact

Effective and
robust
interventions

Innovative and
collaborative
models of care

High quality
transitions and
follow-up care

Improved
survivorship
outcomes



BSA Subcommittee Feedback

- **Responsive to STAR Act:** committee members were enthusiastic and had positive feedback about the concept proposal
- **Patient voice:** strongly encourage incorporation of survivor feedback into intervention planning and testing
- **Primary care:** encourage studies including family medicine providers who may be a constant
- **Age-specific considerations:** specify focus on issues specific to childhood cancer survivors rather than care coordination more generally
- **Payment mechanisms:** indicate an interest in studies that consider the effect of payment mechanisms on transition

Concept Team:

Danielle Dae

Michelle Doose

Kelly Filipski

Sandra Mitchell

Michelle Mollica

Frank Perna

Crystal Reed

Nonniekaye Shelburne

Emily Tonorezos

Ashley Wilder Smith



**NATIONAL
CANCER
INSTITUTE**

www.cancer.gov

www.cancer.gov/espanol