Childhood Cancer STAR Act Implementation

Childhood Cancer Awareness Month Community Webinar

NIH NATIONAL CANCER INSTITUTE

September 12, 2022

NCI Speakers

Malcolm Smith, MD, PhD
Associate Branch Chief,
Pediatrics in the Clinical Investigations Branch,
Division of Cancer Treatment and Diagnosis (DCTD)

Nita Seibel, MD
Head,
Pediatric Solid Tumor Therapeutics in the Clinical Investigations Branch, Cancer Therapy and Evaluation Program, DCTD

Emily Tonorezos, MD, MPH
Director,
Office of Cancer Survivorship, Division of Cancer Control and Population Sciences (DCCPS)

Sandra Mitchell, PhD, CRNP
Senior Scientist and Program Director,
Outcomes Research Branch in the Healthcare Delivery Research Program, DCCPS

Danielle Daee, PhD
Program Director,
Genomic Epidemiology Branch, Epidemiology and Genomics Research Program, DCCPS

Paul Jacobsen, PhD
Associate Director,
Healthcare Delivery Research Program, DCCPS

Overview

The STAR Act is **bipartisan** legislation that was introduced in 2017 and signed into law in 2018. Several of the bill's provisions are directed toward NCI:

- Sec. 101. Children's cancer **biorepositories and biospecimen research** (including collaboration with the Childhood Cancer Data Initiative (CCDI))
- Sec. 111. Inclusion of at least one **pediatric oncologist** on the National Cancer Advisory Board
- Sec. 112. Sense of Congress regarding **pediatric expertise** at NCI
- Sec. 121. **Reporting** on childhood cancer research projects
- Sec. 202. Grants to improve care for **pediatric cancer survivors**
- Sec. 203. **Best practices** in survivorship care (AHRQ Evidence Reports supported by NCI)

Biobanking Progress (Sec. 101)

- **FY 2019:** May 2019 Biobanking Meeting and immediate enhancements to NCI's Children's Oncology Group (COG) Biobank
- **FY 2020:** New Biobanking Projects (supplement awards to COG and Childhood Cancer Survivor Study (CCSS))
  - Childhood Cancer Survivor Study: Somatic & Germline Sequencing (CCSS)
  - Banking of Blood on Childhood Cancer Survivors with Chronic Health Conditions (CCSS)
  - NCI-COG Pediatric MATCH Diagnostic Tumor Specimens (COG)
  - Postmortem Tumor Tissue Collection at Autopsy (COG)*
  - Tumor Specimens from Patients at Relapse (COG)*
  - Rare and Under-Represented Cancer Tissue Banking (COG)*
- **FY 2021 and FY 2022:** new FY 2022 supplement awards to CCSS listed below; COG supplements noted with * continue, including partnership between the COG Rare and Underrepresented Tissue Bank and CCDI Molecular Characterization Initiative
  - Gene Expression analyses of biospecimens CCSS with grade 3 and 4 health conditions
  - Whole genome/whole exome sequencing for additional specimens from CCSS Cohort

NCI Biobanking Supplements Contributing to 11 New Research Projects

Projects that Requested and Used Biospecimens from STAR Act Funded Supplement Projects

2019 Supplement		
Investigator	***Institution***	***Project Title***
Dr. Smita Bhatia	University of Alabama at Birmingham	Mitigating Long-Term Treatment-Related Morbidity in Childhood Cancer Survivors
Dr. Katherine Janeway	Dana-Farber Cancer Institute	Translocation Assessment of Ewing Sarcoma Cases Enrolled on Children's Oncology Group Clinical Trials
Dr. Elaine Mardis	Nationwide Children's Hospital	A Phase 3 Study of 131I-Metaiodobenzylguanidine (131I-MIBG) or Crizotinib Added to Intensive Therapy for Children with Newly Diagnosed High-Risk Neuroblastoma (NBL)
Dr. Lisa Mirabello	NCI	Germline Genomic Variation of Pediatric Osteosarcoma Cases Enrolled in COG
Dr. Joshua Schiffman	University of Utah Huntsman Cancer Institute	Expanded Ewing Sarcoma Cohort for Tumor genomics and Association with DNA Repair Deficiencies, Clinical Presentation, and Outcome
Dr. Peter Schoettler	Western Michigan University	Clinical and Genomic Characterization of Renal Sarcomas
Pediatric MATCH Diagnostic Specimen Banking		
Dr. Donald Williams Parsons	Texas Children's Hospital	NCI-COG Pediatric MATCH (Molecular Analysis for Therapy Choice)
Rare and Under-Represented Cancer Tissue Banking		
Dr. Frederic Barr[1]	NCI	Genetic Analysis of Tumor Progression in Rhabdomyosarcoma
Dr. Brian Crompton	Dana-Farber Cancer Institute	A Randomized Phase 3 Study of Vincristine, Dactinomycin, Cyclophosphamide (VAC) Alternating with Vincristine and Irinotecan (VI) Versus VAC/VI Plus Temsirolimus (TORI, Torisel, NSC# 683864) in Patients with Intermediate Risk (IR) Rhabdomyosarcoma (RMS)
Dr. Philip Lupo	Baylor College of Medicine	Germline and Somatic Genetic Landscape of Pediatric Rhabdomyosarcoma
Dr. Sarah Whittle	Texas Children's Hospital	Evaluation of MYC Amplification as a Prognostic Biomarker in Osteosarcoma
Tumor Specimens from Patients at Relapse		
Dr. Frederic Barr[1]	NCI	Genetic Analysis of Tumor Progression in Rhabdomyosarcoma

[1]This project included specimens from both supplements

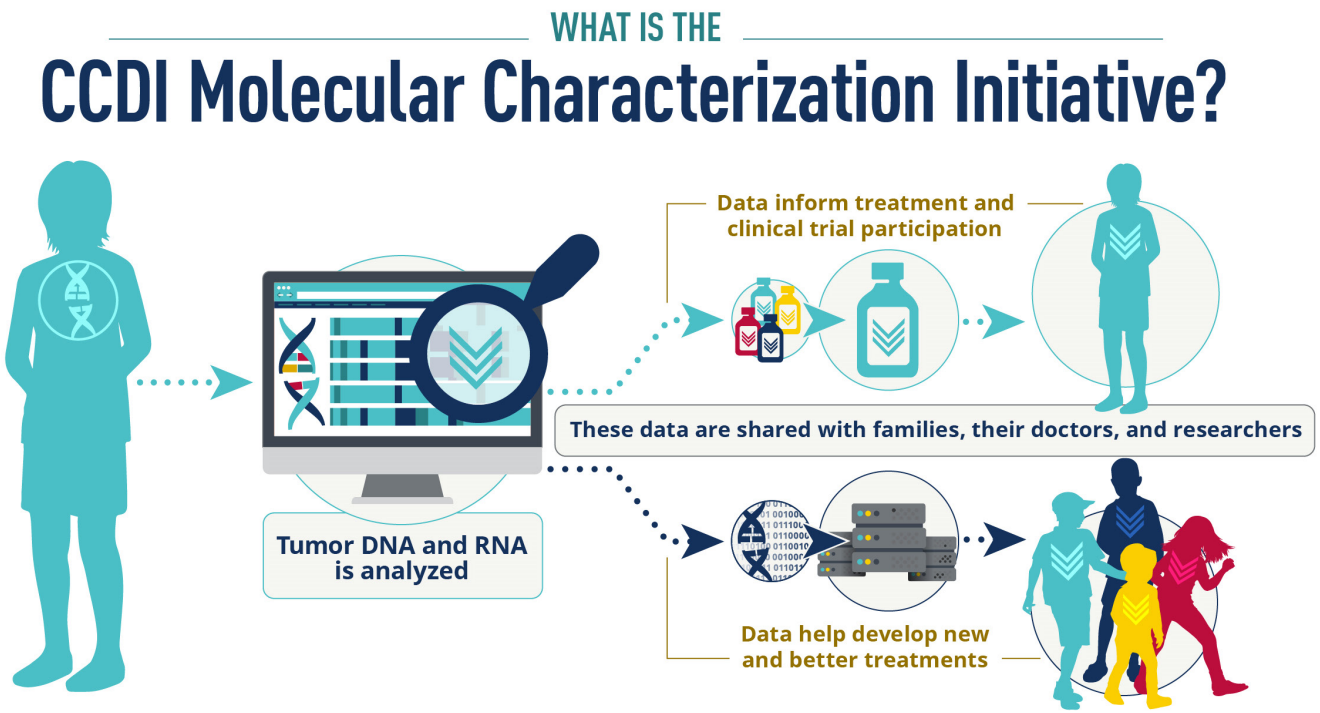
Childhood Cancer Data Initiative

STAR Act Research Efforts

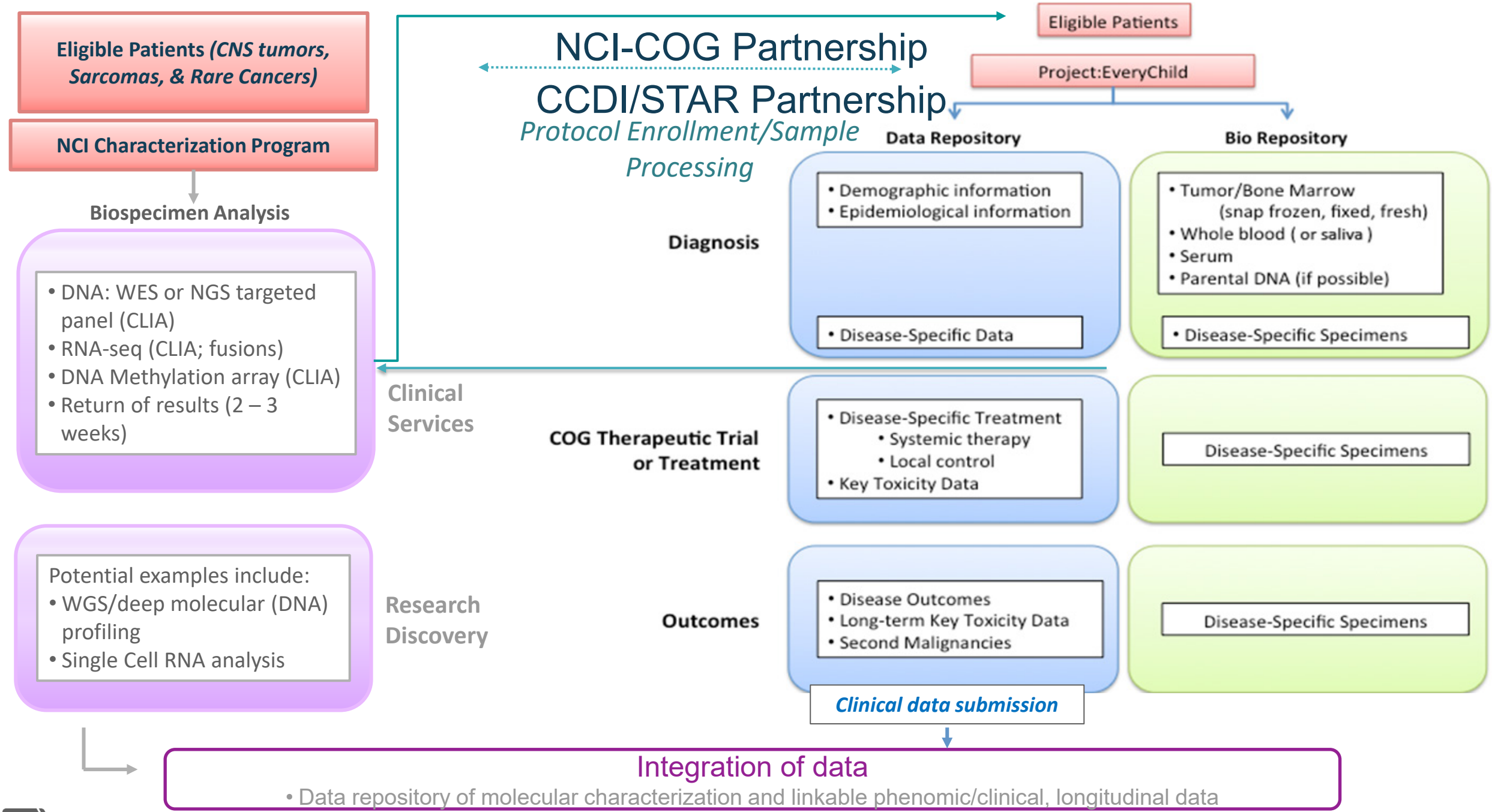
STAR Act biobanking efforts include working in partnership with the CCDI Molecular Characterization Initiative (MCI) to support specimen collection for MCI

The Molecular Characterization Initiative:

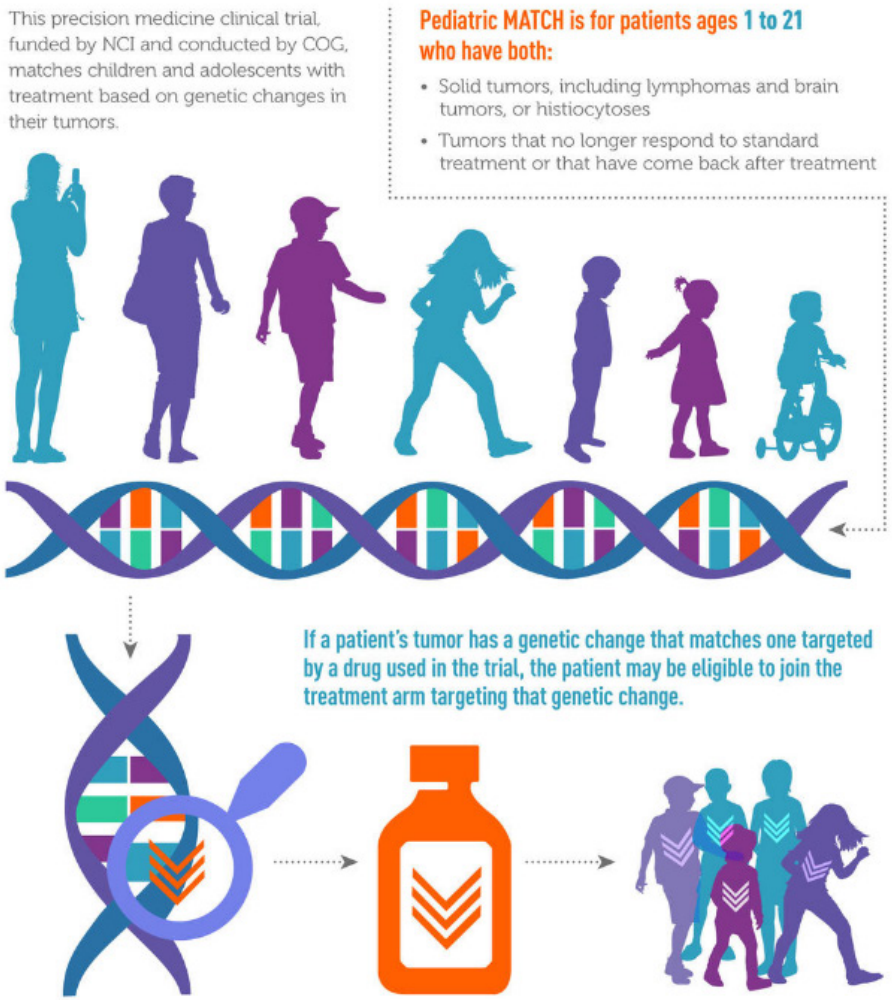
A STAR Act partnership with NCI's Childhood Cancer Data Initiative



- MCI provides access to comprehensive genomic characterization
- Results can contribute to diagnosis determinations and treatment plans
- Results may also be used for meeting eligibility requirements
- First available for children with newly diagnosed brain tumors in March 2022
- MCI became available for children with soft tissue sarcomas in June 2022
- Will be open to children with rare cancers in September 2022


Eligible Patients (CNS tumors, Sarcomas, & Rare Cancers)
NCI Characterization Program
Biospecimen Analysis
• DNA: WES or NGS targeted panel (CLIA)
• RNA-seq (CLIA; fusions)
• DNA Methylation array (CLIA)
• Return of results (2 – 3 weeks)
Potential examples include:
• WGS/deep molecular (DNA) profiling
• Single Cell RNA analysis
NCI-COG Partnership
CCDI/STAR Partnership
Protocol Enrollment/Sample Processing
Eligible Patients
Project:EveryChild
Data Repository
Bio Repository
Diagnosis
• Demographic information
• Epidemiological information
• Tumor/Bone Marrow (snap frozen, fixed, fresh)
• Whole blood (or saliva)
• Serum
• Parental DNA (if possible)
• Disease-Specific Data
• Disease-Specific Specimens
Clinical Services
COG Therapeutic Trial or Treatment
• Disease-Specific Treatment
• Systemic therapy
• Local control
• Key Toxicity Data
Disease-Specific Specimens
Research Discovery
Outcomes
• Disease Outcomes
• Long-term Key Toxicity Data
• Second Malignancies
Disease-Specific Specimens
Clinical data submission
Integration of data
• Data repository of molecular characterization and linkable phenomic/clinical, longitudinal data

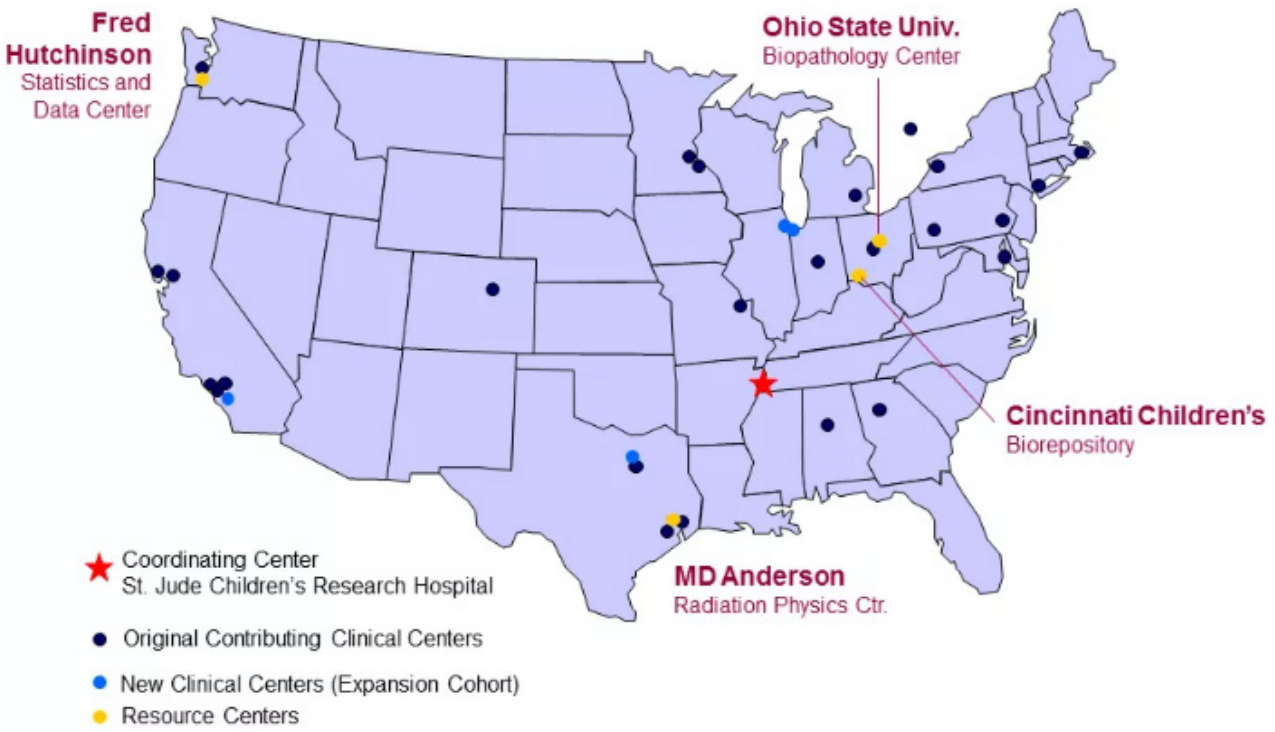
NCI-COG Pediatric MATCH Trial: Diagnostic Specimen Collection



- This biobanking project collects diagnostic samples for children and adolescent and young adults (AYA) who have already submitted samples at relapse through Pediatric MATCH
- Enables molecular characterization to identify the changes in gene mutations and gene expression that occur between diagnosis and relapse
- Aims to inform development of more relevant treatments through in-depth characterization
- Additionally, through CCDI ~500 cases are being genomically characterized with sequencing to be completed by the end of the year
- Collection of samples at both diagnosis and relapse is a priority for STAR Act biobanking efforts, including an additional project aiming to better understand tumor progression in rhabdomyosarcoma

Specimen Collection of Subsequent Cancers

CCSS Collaborating Institutions



- The development of subsequent malignant neoplasms (SMN) is associated with significant morbidity and mortality for survivors of childhood cancer
- This project prioritizes collection of specimens from survivors with confirmed cases of subsequent malignancies
- Results aim to inform treatment protocols and interventions that will yield an increase in survival, while minimizing harmful late effects
- Used to develop and expand programs for early detection and prevention of late effects in children and adolescent cancer survivors

Specimen Collection to Study Chronic Health Conditions

- Over 62% of CCSS participants (mean age 26 years) have at least one chronic health condition
- Over 5,550 childhood cancer survivors in CCSS have a grade 3 (severe, disabling) or 4 (life-threatening) chronic health condition (stroke, heart failure, kidney failure, diabetes, etc.)
- Collection of a one-time blood sample from survivors that have a grade 3 or 4 chronic condition
- These specimens will enhance the CCSS as a resource for future molecular/genetic evaluations to better understand the causes of chronic health conditions in survivors of childhood cancer

New FY 2022 Supplement Awards to CCSS

- Additional collection of biospecimens for grade 3 and grade 4 health conditions
  - Because of COVID, in-home collection of a single blood specimen for grade 3 and grade 4 health conditions was slowed
  - Plan to recruit additional participants for a total of 2,400 blood specimens from survivors with grade 3 and 4 health conditions that will be made available to researchers to sequence and investigate for specific health conditions
  - Data will serve as a resource for investigators studying additional CCSS outcomes

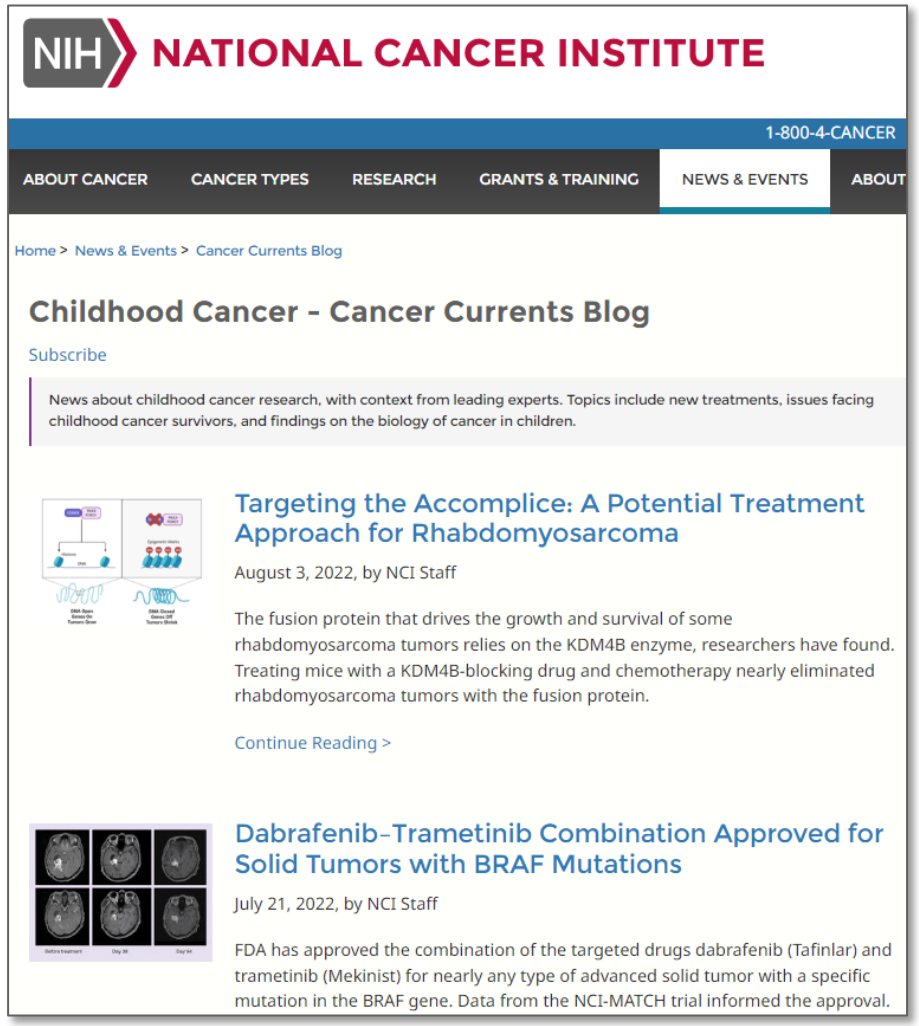
- Whole Genome/Whole Exome Sequencing for additional germline specimen from CCSS Cohort
  - Since the time CCSS last performed sequencing there have been over 2,000 additional germline specimens collected
  - WGS/WES sequencing will be performed on germline DNA from these specimens
  - Results will be available through CCSS to scientists studying childhood cancer survivors to explore treatment-related complications, predicting individuals more likely to develop complications and prevention in future trials

Leveraging External Pediatric Oncology Expertise (Sec. 111 and Sec. 112)

- **National Cancer Advisory Board** *(NCAB: Dr. Andrea Hayes, UNC)*
- **Board of Scientific Advisors** *(BSA: Dr. Mary Beckerle, Huntsman; Drs. Les Robison and Martine Roussel, St. Jude's; Dr. Kevin Shannon, UCSF)*
- **Clinical and Translational Research Advisory Committee** (CTAC: Dr. Smita Bhatia, UAB; Dr. Anne-Marie Langevin, UT San Antonio)
- **Board of Scientific Counselors** *(BSC: Dr. Paul Spearman, Cincinnati Children's; Dr. Gail Tomlinson, UT San Antonio)*
- **National Council of Research Advocates** *(NCRA: Dr. Victoria Buenger, CAC 2, Texas A&M)*
- **Frederick National Laboratory Advisory Committee** *(FNLAC: Dr. Catherine Bollard, Children's National; Dr. Nilsa Ramirez, Nationwide Children's & CPG Biobank; Dr. Cheryl Willman, Mayo Clinic)*
- **National Clinical Trials Network (NCTN) Steering Committees**: *More than 40 subject matter experts with pediatric expertise serve across three relevant steering committees (Pediatric and Adolescent Solid Tumors, Brain Malignancies, Pediatric Leukemia and Lymphoma), including a patient advocate serving on each committee*

Childhood Cancer Reporting (Sec. 121)

- NIH Pediatric Research Initiative Report to Congress
- NIH Triennial Report
- NCI research and portfolio updates via cancer.gov, including:
  - NCI's childhood cancer research landing page
  - Several online resources for patients and families
  - Regular features in NCI's Cancer Currents Blog



NCI Continues to Conduct and Support Childhood and AYA Cancer Survivorship Research and Care (Sec. 202)

- Childhood and AYA cancer **survivorship research** continues to be supported through funding opportunity announcements and notices of special interest
  - NCI leads: Drs. Michelle Mollica, Sandra Mitchell, and Danielle Daee
- There have been new initiatives in survivorship through **2** funding announcements, with **31 awards issued** from FY 2019 – 2022
  - Requests for Application (RFAs) issued: **RFA CA-19-033** and **RFAs CA-20-027/028**
- Relevant **Notices of Special Interest (NOSI)**
  - NOT-HD-21-027: Navigating Pediatric to Adult Healthcare: Lost in Transition
  - NOT-CA-22-029: Disparities Affecting Healthcare Utilization and Health Outcomes among Childhood Cancer Survivors

Improving Outcomes for Pediatric, Adolescent and Young Adult (AYA) Cancer Survivors

RFA-CA-19-033 U01 Clinical Trial Required

(https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-19-033.html)

Research to Reduce Morbidity and Improve Care for Pediatric, and Adolescent and Young Adult (AYA) Cancer Survivors

RFA-CA-20-027/028 R01/R21 Clinical Trial Optional

(https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-20-027.html)

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Division of Cancer Control & Population Sciences

Six Key Research Areas to Improve the Care of and Quality of Life for Childhood and AYA Cancer Survivors

Survivor outcomes

Barriers to follow-up care

Familial, socioeconomic and environmental contributors to outcomes

Indicators to monitor late effects and patterns of follow-up care

Risk factors, predicators & molecular basis of adverse outcomes

Targeted interventions to reduce the burden of morbidity in survivors

Development of targeted interventions to reduce the burden of morbidity in survivors

Cross cutting priorities include health disparities, minorities or other medically underserved populations

RFA-CA-19-033: Overall Goal

Support the scientific development of interventions to *address adverse physical and psychosocial effects* in survivors of pediatric/AYA cancers

(https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-19-033.html)

Interventions Leverage Insight from Observational Studies1-4

Symptoms (fatigue, disturbed sleep, neuropathic pain)

Impaired physical & neurocognitive function

Late effects of treatment (heart disease, osteoporosis, second cancers)

Infertility

Changes in body composition (obesity, muscle loss)

Accelerated aging and physiologic frailty

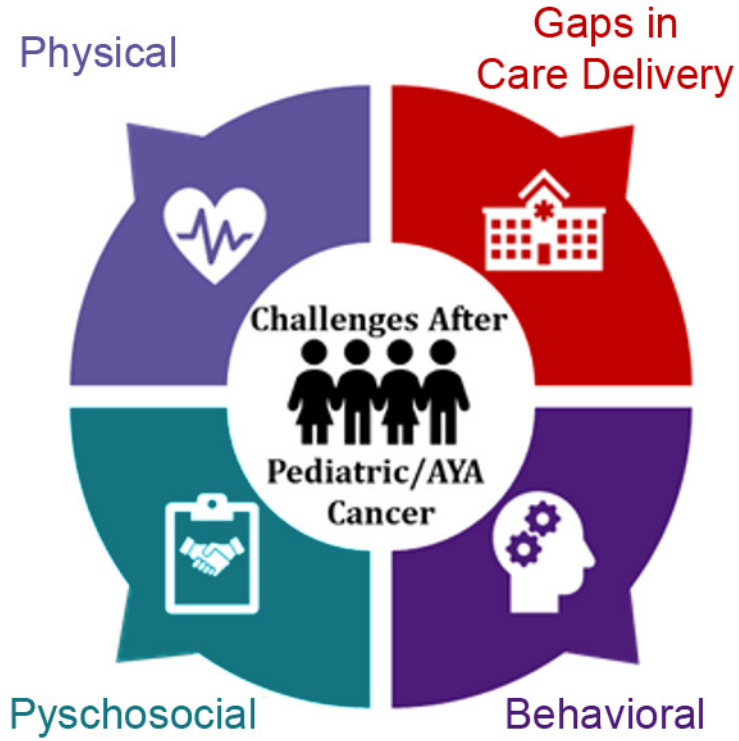
Disrupted social development

School and employment difficulties

Financial hardship

Insufficient insurance

Psychological distress



Survivors express unmet needs for organized long-term follow-up services

As survivors transition out of pediatric care settings, few are seen by a clinician familiar with late effects

Care coordination, continuity of care and communication suboptimal

Reduced physical activity

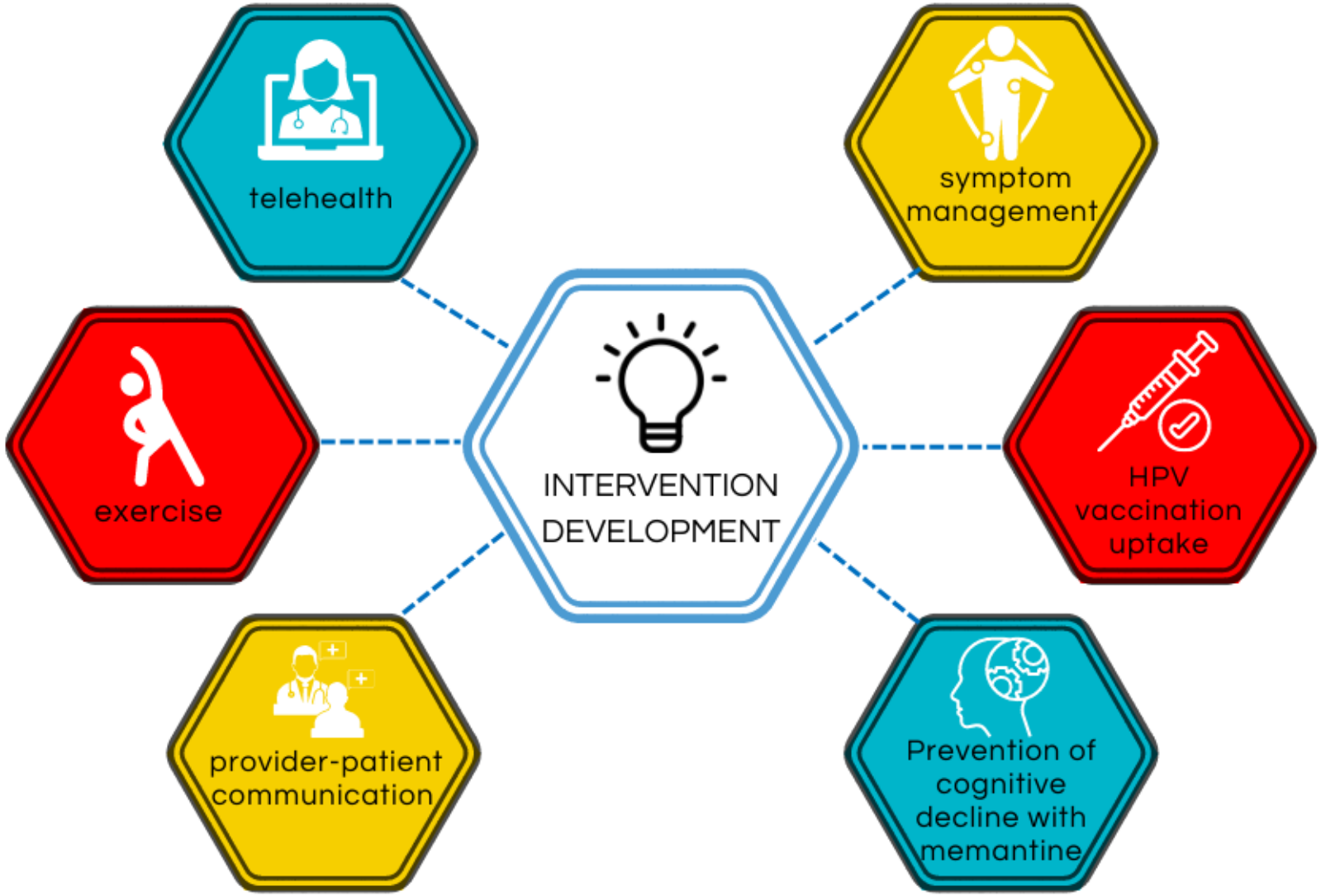
Potential for risky behaviors (alcohol, tobacco, medication non-adherence)

[1] Tonorezos et al. (2018). *J Clin Oncol*. 36(21):2223-2230
[2] White et al. (2018). *Psychooncology*. 27(8): 1979-1986
[3] Hudson et al. (2017). *Can. Epidemiol Biomarkers Prev*. 26(5):666-674
[4] Ness et al. (2013). *J Clin Oncol*. 31(36):4496-503

RFA-CA-19-033: Improving Outcomes for Pediatric, AYA Cancer Survivors

- Assemble a **network of investigators** focused on testing interventions to improve outcomes across the survivor's lifespan
- **Seven awards** made to support randomized trials testing new interventions to:
  - Prevent, mitigate, or manage adverse outcomes in pediatric and AYA cancer survivors
  - Test care delivery models that strengthen coordination, continuity, quality, or reduce access barriers
- Prioritized applications that addressed **health disparities**, **underrepresented** and/or **medically underserved populations** and encouraged **mobile health** and **digital solutions**

Interventions Being Tested to Improve Outcomes for Pediatric and AYA Cancer Survivors



RFA-CA-19-033: Improving outcomes for Pediatric and AYA Cancer Survivors	Tumor Type(s)	Late/Long Term Effect(s)
Using Information Technology to Improve Outcomes for Children Living with Cancer PI: Dr. Jin-Shei Lai (Northwestern University at Chicago), U01	All	Disease and treatment-related symptoms
A Randomized Trial of a Mobile Health and Social Media Physical Activity Intervention Among AYA Childhood Cancer Survivors PI: Dr. Nina Kadan-Lottick (Georgetown University), U01	All	Sedentary behavior
Utility Of Memantine In Preventing Cognitive Dysfunction In Children Receiving Cranial Radiotherapy PI: Dr. Nadia Laack (Mayo Clinic), U01	Primary brain tumors	Cognitive dysfunction after cranial radiotherapy
A web-based patient-reported symptom monitoring and self-management portal for AYA breast cancer survivors PI: Dr. Ann Partridge (Dana-Farber), U01	Breast cancer	Symptoms, unmet needs, concerns
Telehealth based exercise intervention to improve functional capacity in survivors of childhood cancer with significantly limited exercise tolerance PI: Dr. Kirsten Ness (St. Jude), U01	All	Reduced exercise capacity, impaired physical dysfunction
An INteractive Survivorship Program to Improve Healthcare REsources [INSPIRE] for Adolescent and Young Adult (AYA) Cancer Survivors PI: Dr. K. Scott Baker (Fred Hutchinson), U01	All	Emotional distress, adherence
Implementation of a Provider-Focused Intervention for Maximizing HPV Vaccine Uptake in Young Cancer Survivors receiving Follow-Up Care in Pediatric Oncology Practices: A Cluster-Randomized Trial PI: Dr. Wendy Landier (University of Alabama), U01	All	Elevated risk of HPV-related complications & malignancies
Sen-Survivors: An open-label intervention trial for frailty and senescence PI: Dr. Gregory Armstrong (St. Jude Children's Research Hospital), U01	All	Frailty, chronic health conditions

Developing Interventions: Two Examples from RFA-CA-19-033

	Utility Of Memantine In Preventing Cognitive Dysfunction In Children Receiving Cranial Radiotherapy PI: Nadia Laack (Mayo Clinic)	**Telehealth Based Exercise Intervention to Improve Functional Capacity In Survivors Of Childhood Cancer With Significantly Limited Exercise Tolerance** PI: Kiri Ness (St. Jude)
Survivorship Need	Cognitive dysfunction is a persistent and often long-term effect of cranial irradiation that impairs a child's performance at school/work and negatively affects relationships and overall quality of life	Exercise intolerance is prevalent among childhood cancer survivors and is associated with all-cause mortality, impairments in function and well-being Referral to trained specialists to learn to accommodate specific deficits when engaging in exercise
Study Aims	Evaluate the neuroprotective effects of 6 months of oral memantine given during and following cranial radiation compared to placebo	Test an individually tailored home-based aerobic exercise and strength training intervention to improve exercise capacity in childhood cancer survivors with exercise intolerance
Endpoints	Time to cognitive decline, rate of decline in memory, executive function and processing speed; quantitative MRI	Exercise capacity (VO2 Max); cardiac, pulmonary, musculoskeletal, cognitive and neurosensory function; quality of life
Key Features	Memantine is an inexpensive and well-tolerated oral agent that in adults has demonstrated favorable effects on radiation-related cognitive dysfunction in adults	Sample enriched for underrepresented populations Intervention delivered remotely using telehealth approaches that will enhance reach of the intervention and improve access to services

RFA-CA-20-027/028: Overall Goal

Support projects proposing *mechanistic, observational, and/or interventional* studies to understand and/or address one or more of the STAR Act domains

RFA-CA-20-027/028: Research to Reduce Morbidity and Improve Care for Pediatric and AYA Cancer Survivors	Target Population	Topic Area
Predicting and Preventing Chemotherapy-Induced Cardiotoxicity in African American Children PI: Drs. Paul W Burridge and Yadav Sapkota (Northwestern University at Chicago), R01	African American, doxorubicin-treated childhood cancer survivors	Cardiotoxicity
Bridging Information Divides and Gaps to Ensure Survivorship: The BRIDGES Randomized Controlled Trial of a Multilevel Intervention to Improve Adherence to Childhood Cancer Survivorship PI: Dr. Nina S Kadan-Lottick (Georgetown University), R01	Childhood cancer survivors and primary care providers	Follow-up care
Social Genomic Mechanisms of Health Disparities Among Adolescent and Young Adult (AYA) Cancer Survivors PI: Dr. Bradley Jay Zebrack (University of Michigan at Ann Arbor), R01	Non-Hodgkin's lymphoma and Hodgkin's lymphoma survivors	Social determinants of health
SALSA – Study of Active Lifestyle Activation PI: Dr. Eric Jessen Chow (Fred Hutchinson Cancer Research Center), R01	Childhood cancer survivors	Cardiovascular disease
Individual, Cultural, and Area-Based Factors Associated with Survivorship Care Among Asian/Asian American Childhood Cancer Survivors PI: Drs. Kimberly Ann Miller and Joel E Milam (University of Southern California), R01	Asian and Asian American Childhood cancer survivors	Follow-up care
Optimization of a mHealth Physical Activity Promotion Intervention with Mindful Awareness for Adolescent and Young Adult Cancer Survivors PI: Drs. Siobhan Marie Phillips and David Victorson (Northwestern University at Chicago), R01	Childhood and AYA cancer survivor	Quality of life
Pilot Test of an mHealth Intervention for Reducing Alcohol Use Among Rural Adolescent and Young Adult Cancer Survivors PI: Drs. Carolyn Lauckner and Laurie Mclouth (University of Kentucky), R21	Rural AYA cancer survivors	Alcohol consumption
Treatment-Specific Genetic Risk Scores for Late Effects Prediction in Childhood, Adolescent, and Young Adult Cancer Survivors PI: Drs. Cindy Im and Yan Yuan (University of Alberta), R21	Childhood cancer survivors	Risk for chronic conditions
Remote Monitoring of Cardiac Function in Childhood Cancer Survivors PI: Dr. Saro Armenian (Beckman Research Institute/City of Hope), R21	Anthracycline-exposed, long-term childhood cancer survivors	Cardiac dysfunction
Caregiving For Young Adults with Cancer in Latino Families: Understanding Healthcare Engagement and Family Wellbeing PI: Dr. Michael A Hoyt (University of California-Irvine), R21	Latino AYA cancer survivors and their families and providers	Caregiving

RFA-CA-20-027/028: Research to Reduce Morbidity and Improve Care for Pediatric and AYA Cancer Survivors	Target Population	Topic Area
Personalized Risk Prediction to Reduce Cardiovascular Disease in Childhood Cancer Survivors PI: Drs. Rebecca Maureen Howell, Daniel A. Mulrooney, and Yutaka Mulrooney (University of Texas MD Anderson Cancer Center), R01	Radiotherapy-treated childhood Hodgkin lymphoma survivors	Cardiovascular disease risk
Leveraging Digital Health Solutions to Reduce Learning and Functional Disparities in Children with Cancer PI: Dr. Sunita K. Patel (Beckman Research Institute, City of Hope), R01	Parents of Latino childhood leukemia or lymphoma survivors	School success
Enhancing Health Cost Literacy and Financial Capability among Young Adult Cancer Survivors PI: Dr. Bridgette H. Thom (Sloan Kettering Institute for Cancer Research), R21	AYA cancer survivors	Health cost literacy and financial capability
Early Identification of Childhood Cancer Survivors at High Risk for Late Onset Cardiomyopathy: An Artificial Intelligence Approach utilizing Electrocardiography PI: Drs. Oguz Akbilgic and Melissa M. Hudson (Wake Forest University Health Science Center), R01	Childhood cancer survivors	Cardiomyopathy
STEP-YA: An Online Self-Management Intervention for Young Adult Cancer Survivors with Insomnia PI: Dr. Christopher John Recklitis (University of Southern California), R21	AYA cancer survivors	Insomnia
FAACTS: Feasibility/Acceptability of Attentional-Control Training in Survivors PI: Dr. Steven Hardy (Children's National Hospital Research Institute), R21	Brain and leukemia childhood cancer survivors	Attention
An Integrative Approach to Evaluate Neurocognitive Disparities in Latinos Undergoing Treatment for Childhood Leukemia PI: Drs. Kimberly Pauline Raghubar and Philip Lupo (Baylor College of Medicine), R01	Latino childhood leukemia survivors	Neurocognitive performance

RFA-CA-20-027/028: Research to Reduce Morbidity and Improve Care for Pediatric and AYA Cancer Survivors Continued	Target Population	Topic Area
Outcomes in AYA Survivors of Pediatric Medulloblastoma PI: Dr. Tricia Z. King (Georgia State University), R01	Rural childhood and AYA medulloblastoma survivors	Cognitive impairment
Chronic Health Conditions in Survivors of Down Syndrome-Associated Leukemia PI: Drs. Maria Monica Gramatges, Philip Lupo, and Karen R. Rabin (Baylor College of Medicine), R01	Childhood leukemia survivors with Down syndrome	Assessing chronic health conditions
Assessing the effect of virtual navigation interventions to improve health insurance literacy and decrease financial burden: A CCSS randomized trial PI: Drs. Elyse Park and Anne C. Kirchhoff (Massachusetts General Hospital), R01	Childhood cancer survivors	Financial hardship
PreDM: An adaptive, open-label, pilot intervention trial for diabetes prevention PI: Drs. Stephanie Dixon and Kirsten Ness (St. Jude Children's Research Hospital), R21	Prediabetic childhood cancer survivors	Diabetes prevention
An mHealth Positive Psychology Intervention to Reduce Cancer Burden in Young Adult Cancer Survivors PI: Drs. Carla Berg and Hannah Arem (George Washington University), R21	AYA cancer survivors	Hope
Can risk-reducing medications improve breast cancer prevention in childhood and adolescent cancer survivors? Comparative modeling to inform care PI: Dr. Jennifer Yeh (Boston Children's Hospital), R01	Childhood and AYA cancer survivors	Modeling risk for subsequent breast cancer

Award Examples from RFA-CA-20-027/028

	Bridging Information Divides and Gaps to Ensure Survivorship PI: Dr. Nina S. Kadan-Lottick (Georgetown University)	**Treatment-specific genetic risk scores for late effects prediction** PI: Dr. Cindy Im (University of Alberta)
Survivorship Need	Need for consistent and quality long term **surveillance of late effects** in primary care settings	**Genetic predictors** for chronic health conditions are not tailored for cancer survivors
Goal	**Improve follow-up care by primary care providers** through structured communications with cancer centers and **impower patients** with tailored survivorship education	Leverage existing data from cancer survivors to **develop a tool to better predict 10 chronic health conditions** in survivors
Key Features	Tested in **diverse and vulnerable populations** (rural, Latino, and African American); **telehealth** approaches	The tool will be developed for **diverse populations**; leverages the wealth of data currently available on survivors

AHRQ Evidence Reports – Commissioned by NCI (Sec. 203)

Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs

- **Goal:** to summarize the evidence base on care interventions, implementation strategies, and between-provider communication tools for children with special healthcare needs transitioning from pediatric to adult medical care
- Based on the findings, NCI joined a NOSI with fellow NIH Institutes and Centers focused on navigating transitions from pediatric to adult care (NOT-HD-21-027)

Models of Care That Include Primary Care for Adult Survivors of Childhood Cancer

- **Goal:** to better understand which models of care that include primary care improve outcomes for adult survivors of childhood cancer and under what circumstances
- NCI is using the findings to evaluate its current grant portfolio and to identify and assess potential gaps and opportunities for additional research on this topic

Disparities and Barriers for Pediatric Cancer Survivorship Care

- **Goal:** to summarize the evidence base on understanding and addressing barriers and disparities in survivorship care for childhood cancer survivors
- NCI held a public webinar to disseminate the findings, used them to justify and provide supplements to NCI-designated cancer centers, and used them to inform a recent NOSI on this topic (NOT-CA-22-029)

Progress Recap

- Several **new biospecimen research projects** are supported through supplements to COG and CCSS
- **Pediatric expertise** is leveraged across various groups at NCI
- NCI continues to conduct and support childhood and AYA cancer **survivorship research** through requests for applications
- NCI continues to **report** on childhood cancer research activities through various formal and informal reporting
- NCI supported AHRQ in developing a technical brief focused on **innovative models of care**, with an emphasis on adult survivors of childhood cancer
- **Opportunities to submit applications continue**, through NOSIs and other investigator-initiated research efforts

Please submit any questions to NCI's Office of Advocacy Relations:

NCIadvocacy@nih.gov

Thank you!

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