

Cancer Control and Intervention Working Group

A Report from the Childhood Cancer Survivor Study

Paul Nathan and Claire Snyder on behalf of the WG

CCSS

Childhood Cancer
Survivor Study



St. Jude Children's
Research Hospital

An NCI-funded Resource

Focused on reducing the long-term impact of cancer therapy on physical, psychological and social outcomes

- Health care utilization and late effects surveillance
- Health behaviors
- Health status
- Financial and social outcomes
- Interventions designed to promote early detection or reduce risk of late effects

Working Group Membership

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CORE

- Wendy Leisenring
- Tara Henderson
- Kevin Oeffinger
- Jennifer Ford
- Kiri Ness
- Melissa Hudson
- Anne Kirchhoff
- Jackie Casillas
- *Claire Snyder*

FINANCIAL HARDSHIP

- Robin Yabroff
- Rena Conti
- I-Chan Huang
- Yutaka Yasui
- Wendy Leisenring
- Tara Henderson
- Anne Kirchhoff
- Elyse Park

- 7 Published/In Press Manuscripts (since 1/1/2020)
- 0 Currently Submitted Manuscripts
- 4 Analyses/Manuscripts in Process
- 7 Concepts in development
- 5 New Applications of Intent (AOIs) (total, since 1/1/2020)

Highlights of Recently Completed Research

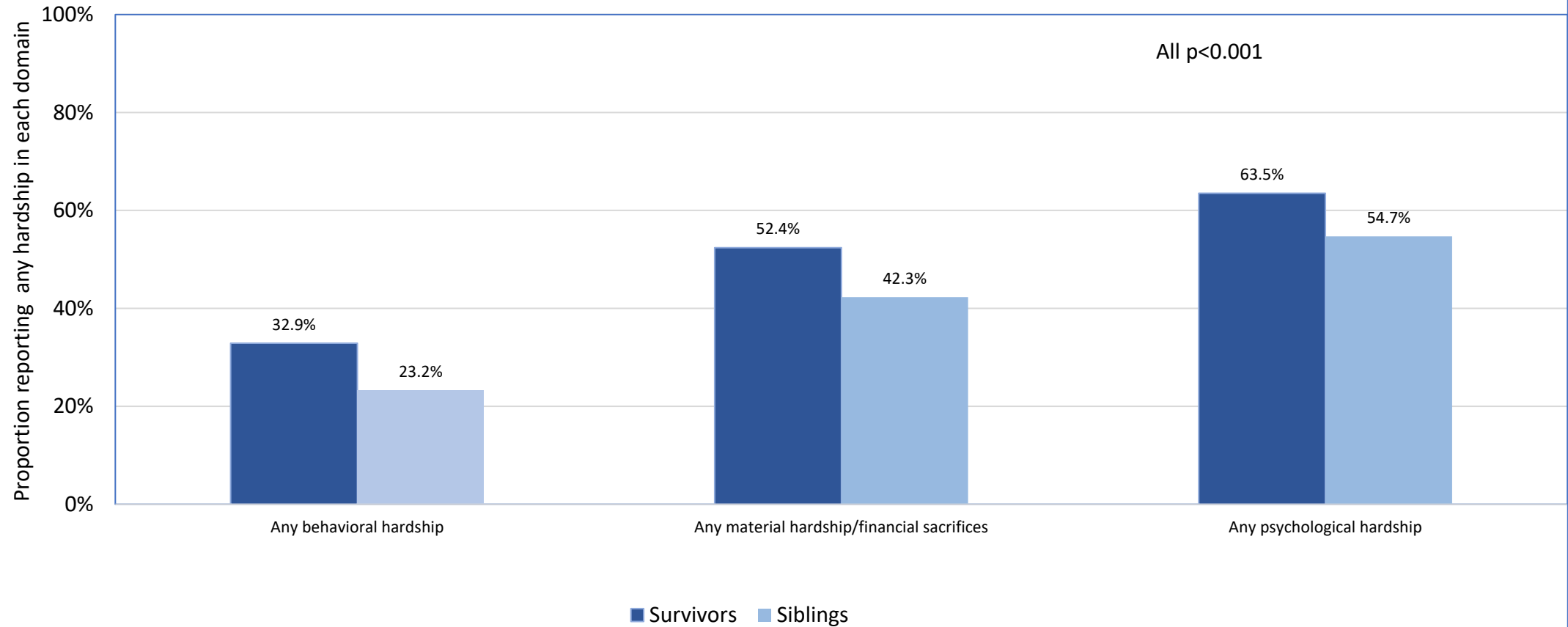
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Nathan: Financial hardship in adult survivors of childhood cancer (ASCO 2021)

- First paper from Financial Toxicity Questions on F/U #6
- 3349 survivors and 976 siblings older than 26 y.o.
- Survivors significantly more likely to report:
 - Sent to debt collection (30% vs 21%)
 - Problems paying medical bills (20% vs 12%)
 - Foregoing needed medical care (13% vs 8%)
 - Worry/stress about paying their mortgage (33% vs 23%)
 - Worry/stress about having enough money to buy nutritious meals (25% vs 16%)
- Factor analysis identified 3 constructs: behavioral hardship, material hardship/financial sacrifices, psychological hardship

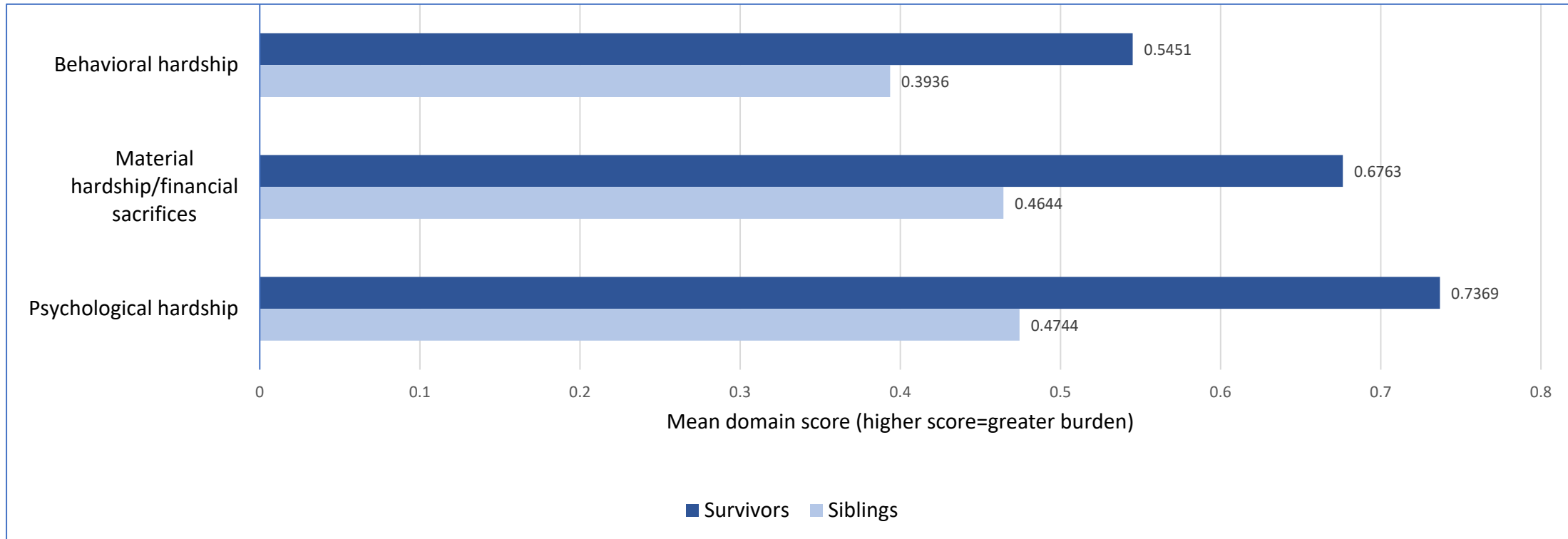
Endorsement of Financial Hardship Domains in Survivors vs Siblings

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Mean Financial Hardship Domain Scores in Survivors vs Siblings

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Highlights of Recently Completed Research

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Hayek: Prevalence and Predictors of Frailty in Childhood Cancer Survivors and Siblings (JCO 2020)

- Frailty (Fried criteria): Prefrail ($\geq 2/5$) or Frail ($\geq 3/5$)

Frailty: diminished physiologic reserve, typically seen in older adults

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Characterized as ≥ 3 of the following self-reported conditions:

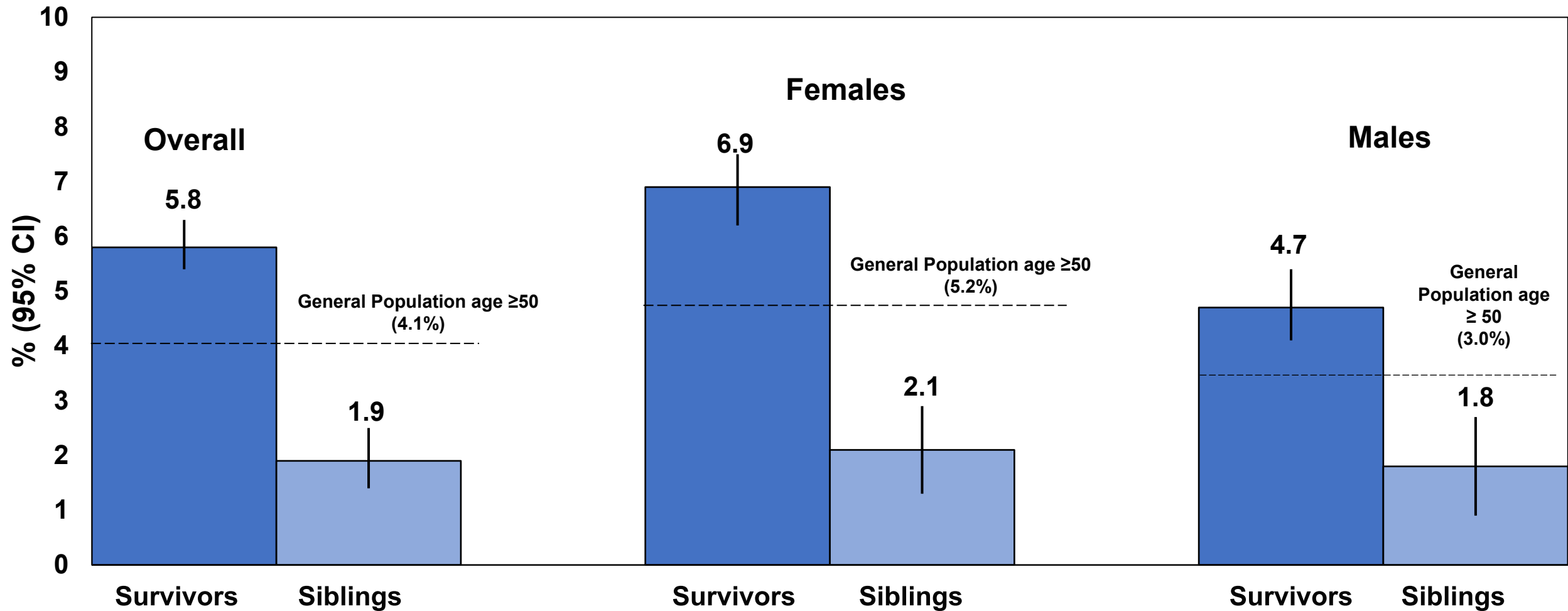
	Definition
Low lean mass	BMI < 18.5 kg/m ² or unintentional weight loss ≥ 10 lbs in past year
Self-reported exhaustion	Score ≤ 40 on vitality subscale of Short-Form 36
Low energy expenditure (LEE)	Activity levels captured by NHANES physical activity questionnaire, defined as < 383 kcal/wk males, < 270 kcal/wk females
Slow walking speed	Limited > 3 months in past 2 years walking one block, walking uphill, or climbing a few flights of stairs.
Weakness	Weakness or inability to move arms

Hayek: Prevalence and Predictors of Frailty in Childhood Cancer Survivors and Siblings (JCO 2020)

- Frailty (Fried criteria): Prefrail ($\geq 2/5$) or Frail ($\geq 3/5$)
- Survivors 3 times as likely to be frail c/w siblings (6.4% vs 2.2%)

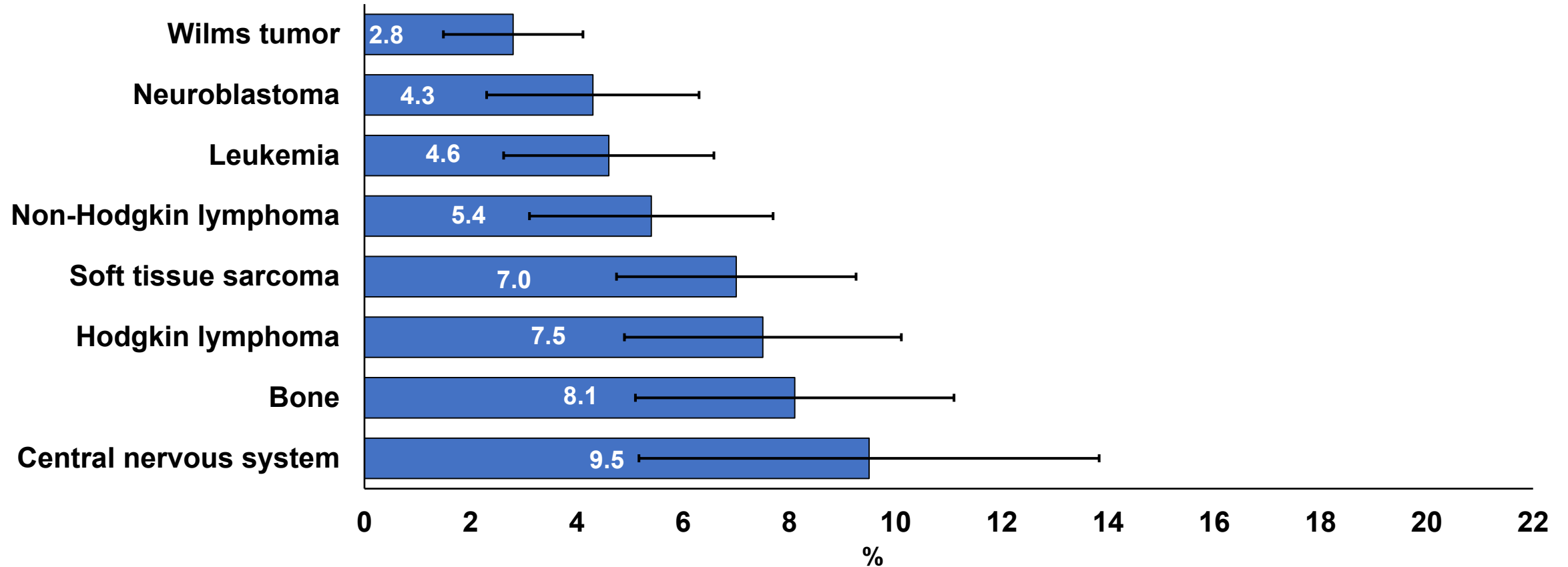
Frailty: Prevalence by Sex

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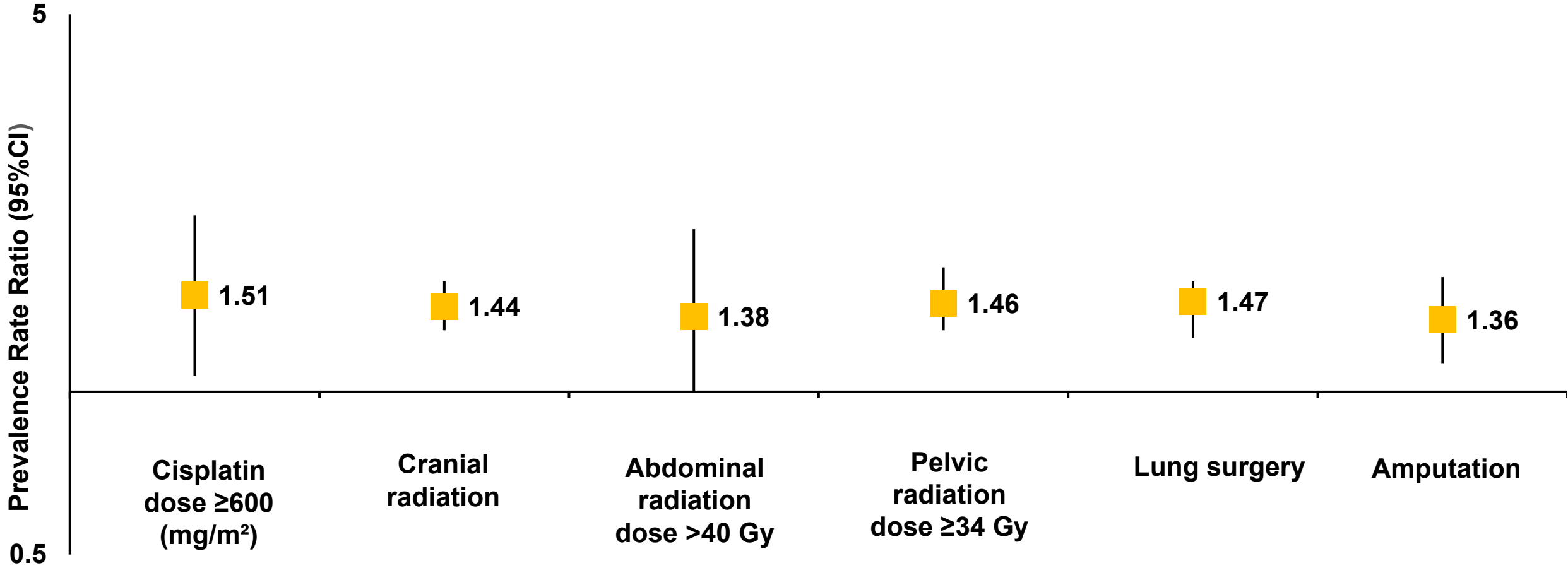


Frailty: Prevalence by Diagnosis

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Treatment Exposures and Risk for Frailty

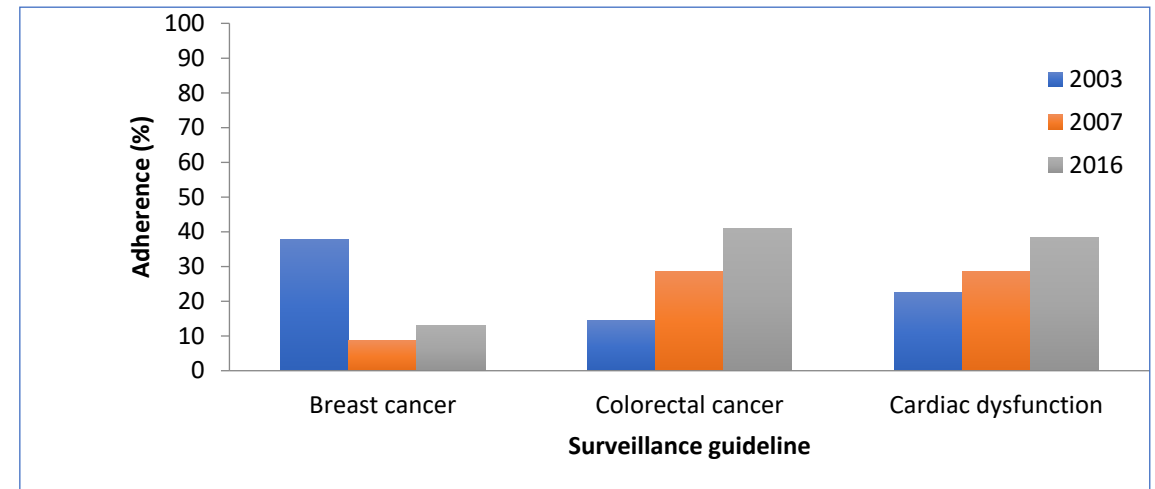


Highlights of Recently Completed Research

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Yan: Adherence to Surveillance for Second Malignant Neoplasms and Cardiac Dysfunction in Childhood Cancer Survivors (JCO 2020)

- COG breast cancer guidelines (12.6%)
- COG colorectal cancer guidelines (37.0%)
- COG skin cancer guidelines (22.3%)
- COG cardiac guidelines (41.4%)



- Survivor SCP possession improves adherence to breast, skin, and cardiac guidelines
- PCP SCP possession improves adherence to skin cancer surveillance only

Approved Concept Proposals

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- Progression of Late Medical Effects and Impact on Financial Hardship Among Adult Survivors of Childhood Cancer
- Health Insurance Status Experiences Following Implementation of the Patient Protection and Affordable Care Act
- Understanding Health Service Utilization and Costs within the Medicaid System
- Temporal Changes in Employment Outcomes of Survivors
- Use and Correlates of Carotid Ultrasound
- Health Care Utilization and Estimated Costs among Survivors
- Longitudinal Mammogram Practices

- Open:
 - EMPOWER-II (Oeffinger)
 - ENGAGE: Improving delivery of genetic services to high-risk CCS (Henderson)
 - ASPIRES: Activating cancer Survivors and their Primary care providers to Increase coloREctal cancer Screening Study (Henderson, Kim)
 - CHIIP (Chow)
 - HINT: Health Insurance Navigator Program (Park)
 - SLEEPWELL: Impact of eHealth intervention for insomnia on late effects of childhood cancer (Intervention Trial; Brinkman)
- Applying for funding:
 - Continuity and Coordination of Care for Childhood Cancer Survivors with Chronic Conditions (Snyder, Nathan, Smith)
 - ECHOS-2 (Ehrhardt)
 - Internet delivered cognitive behavioral pain management for chronic pain (Alberts)
 - Intervening on reproductive health in female survivors (Su)

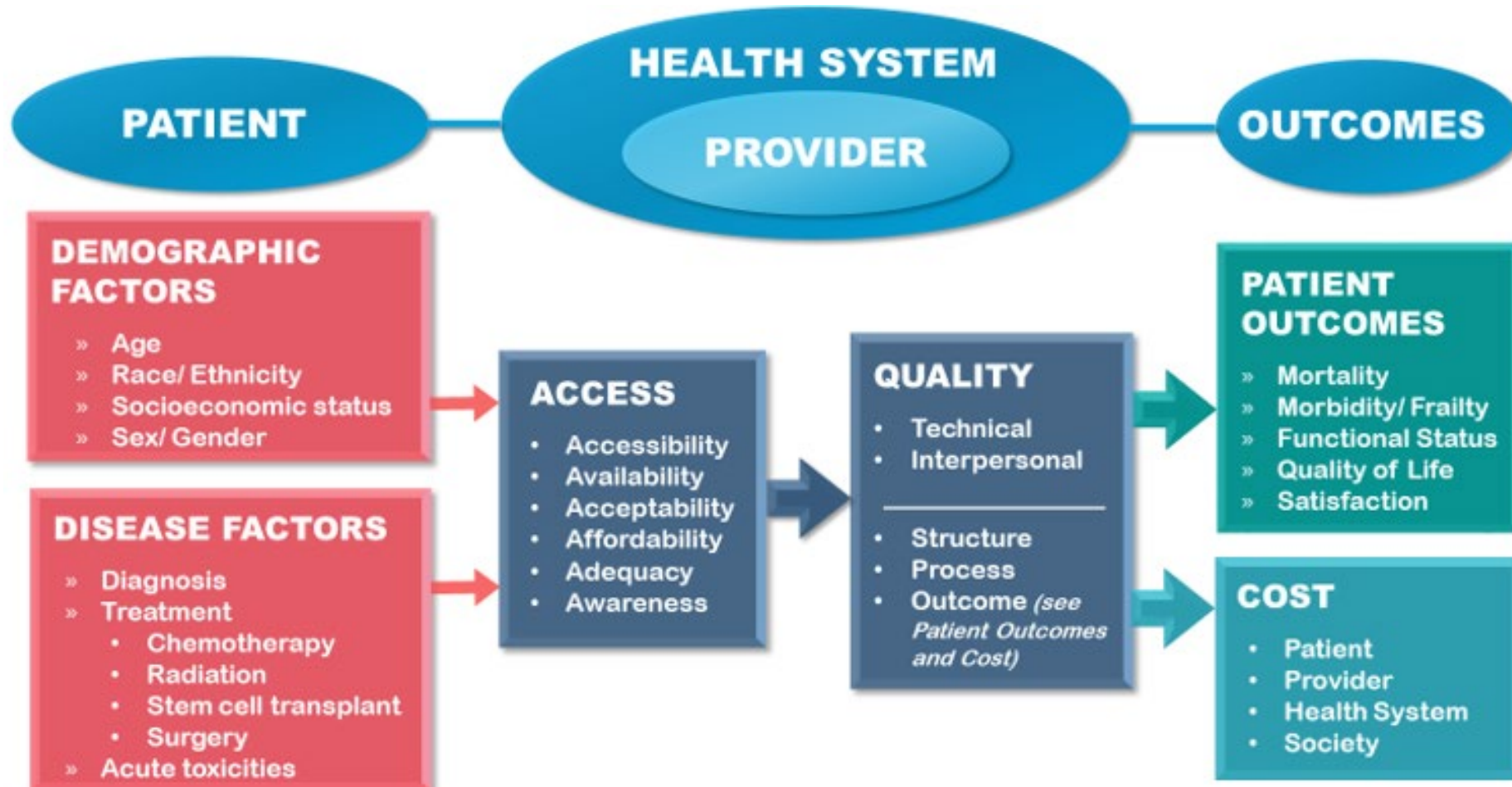
New Priorities in 5-year Plan

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- Enhance the CCSS resource *by facilitating the conduct of health services research* through collection of data to evaluate patient, provider, and health care system factors and their associations with access, quality, and cost of care
- Provide the research community with a resource that will identify *how survivors' health care influences their outcomes* in order to inform strategies to provide life-long, risk-adapted care to this vulnerable population

3 Initiatives

1. Expand expertise in health services research
2. Enhance CCSS Follow-Up Surveys to identify unmet health care needs across all CCSS participants
3. Issue a call for ancillary studies for more detailed assessments of health services than can be determined by survey alone



1. Addition of Expertise

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Claire Snyder, M.H.S., Ph.D.



Program Director, Building Lifestyle, Outcomes, and Care Services Research in Cancer (BLOCS)

Professor of Medicine

RESEARCH INTERESTS

Cancer outcomes and health services research; Quality of medical care; Patient-reported outcomes assessment; Coordination of care; Quality of life [...read less](#)

2. Augment CCSS Questionnaires

- Add assessment of survivors' perspectives of their unmet needs in next survey
 - Build on *CCSS Needs Assessment Questionnaire* (Cox et al)
 - 135-item instrument comprising 9 unidimensional domains
- 58 items addressing:
 - Access (e.g., ability to see specialists)
 - Quality (e.g., knowing surveillance recommendations)
 - Costs (e.g., affordability of medical treatments)
- Plus questions regarding health care utilization previously featured in CCSS surveys
- To enable exploration of the associations between unmet needs and poor outcomes (e.g., hospitalizations), as well as health care disparities related to race/ethnicity
- Gaps in care identified by these surveys will inform subsequent research, including intervention studies

3. Ancillary Studies

ANCILLARY STUDY	BACKGROUND & RATIONALE	SIGNIFICANCE
Leveraging the CCSS myLTFU patient portal and mobile app to collect real time data about health care use	<ul style="list-style-type: none"> Limited detail regarding health service use can be collected based on retrospective questions asked every 2-3 years Innovation: real-time reporting of health service use through the portal 	<ul style="list-style-type: none"> Allows for a deeper, broader and more accurate understanding of health care use in real time Platform can be leveraged for future intervention studies
Linkage to administrative claims datasets (e.g. Medicaid, private insurance databases, etc.).	<ul style="list-style-type: none"> Another approach to obtaining more detailed health service use data is to link with administrative claims databases A current pilot is linking CCSS participants with Medicaid claims 	<ul style="list-style-type: none"> Captures granular information about health care use that cannot be obtained by patient report Allows for more precise assessment of quality of care Gives critical insight into disparities in care between different provider models
Use of geocoding to assess structural measures of health care quality by linking to area resource files	<ul style="list-style-type: none"> Another approach to enhance the health service research opportunities in the CCSS is to obtain data on available resources (e.g., cancer centers, physicians) in geographic areas 	<ul style="list-style-type: none"> Identifies structural targets for interventions that can enhance survivor care
Obtain perspectives of primary care and specialist physicians regarding care of childhood cancer survivors	<ul style="list-style-type: none"> Only limited information on primary care providers' perspectives regarding the care of childhood cancer survivors is available Because of the many comorbidities experienced by survivors, the perspectives of specialist physicians are also highly relevant 	<ul style="list-style-type: none"> Will inform development of interventions to improve survivor care that target providers
Estimate the costs of caring for survivors, with an aim towards estimating the cost-effectiveness of different models of survivorship care	<ul style="list-style-type: none"> There are many models of childhood cancer survivorship care Robust data regarding the costs and resource requirements associated with these care models are needed to enable cost-effectiveness analyses 	<ul style="list-style-type: none"> Will inform decisions around the "best" models of survivor care
Intervention studies	<ul style="list-style-type: none"> Possible interventions for exploration include patient navigators, web-based resources, and remote counseling 	<ul style="list-style-type: none"> Completes the translation of CCSS findings from discovery to having a direct impact on survivor outcomes Goal is for these to be scalable to the broader population of childhood cancer survivors across North America

Current Top Priorities: Short-Term Goals

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- Health Services Research:
 - Next CCSS survey
 - Ancillary study on continuity and coordination of care for survivors with chronic health conditions
- Ancillary and intervention studies
- Financial hardship:
 - 6 concepts in analysis or development
 - E.g., work/insurance, BMT, relationship with chronic health conditions, area level predictors

- Major Threat or Challenge:
 - Funding for ancillary studies
 - Measurement of health services use using survey data
- Major Opportunity:
 - Identification of “best” models of care
 - Establishing the link between care (e.g., specialized survivor clinics, guideline-recommended surveillance) and “hard” outcomes (morbidity, mortality, QOL)