## **Contact Information**

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# **Project Requirements and Description**

Requirements to submit AOI (all answers must be "yes" to proceed)

A comprehensive review of previously published data has been completed	Yes
The specific aims are clear and focused	Yes
The investigator has appropriate experience and expertise to develop the concept proposal; if not, has identified a mentor or senior coinvestigator.	Yes
The investigator agrees to develop an initial draft of the concept proposal within 6 weeks of approval of the AOI and to finalize the concept proposal within 6 months	Yes

Project Title Disparities in Quality Health Care Among Childhood Cancer

Survivors: Role of Medicaid Reform

#### Planned research population (eligibility criteria)

Adult survivors from the Childhood Cancer Survivor Study who were insured with Medicaid

#### Proposed specific aims

My K01 research objective is to use rigorous qualitative and survey research methods to elucidate the measurable and modifiable multi-level constructs relevant to childhood cancer survivor experiences with health insurance in the context of Medicaid, and their impact on disparities in childhood cancer survivor care. I will leverage constructs of the "Voltage Drops from Insurance to Quality Health Care" conceptual model to achieve the following specific research aims:

Aim I: Use qualitative methods to explore multi-level barriers to quality health care for childhood cancer survivors in the context of Medicaid reform. I will lead a qualitative study, conducting semi-structured interviews with adult survivors from the Childhood Cancer Survivor Study (CCSS). Constructs of the "Voltage Drops" model will be used to design interview guides. Data will be analyzed to determine

emergent themes about barriers to care access, affordability, and continuity that low-income childhood cancer survivors face at multiple levels – including survivor-level (e.g., knowledge about Medicaid), provider-level (e.g., insurance assistance), and policy-level (e.g., Medicaid eligibility rules) – and to identify which barriers disproportionately affect cancer survivors experiencing disparities.

Aim 2: Develop and validate a survey to quantify childhood cancer survivor experiences with health insurance and health care in the context of Medicaid reform. I will create a survey measuring survivor experiences with Medicaid (e.g., levels of knowledge about Medicaid program rules, health insurance stability) and health care experiences (e.g., care access, affordability, continuity), as well as survivor perceived needs of an insurance support intervention. Validation approaches will include a survey pilot, with a rigorous modified Delphi approach involving serial refinements and iterated interviews with Aim I interview contacts.

Aim 3: Assess how childhood cancer survivor experiences with health insurance are related to Medicaid policies as well as racial/ethnic, socioeconomic, rural-urban, and gender disparities in quality health care among these survivors. I will conduct a cross-sectional survey of Medicaid-insured survivors from the CCSS using a refined survey tool, with linkages to existing survivor-level clinical data from the CCSS and state-level data on Medicaid policies. Based on my pilot work, approximately 24% of CCSS survivors were insured with Medicaid in 2016. I will test (a) the associations of survivor experiences with Medicaid coverage with health care access, affordability, and continuity, and (b) how state-level Medicaid policies facilitate or exacerbate survivor experiences with Medicaid. The policies of focus will be drawn from emergent themes in Aim I.

Will the project require non-CCSS funding to complete?

Yes

If yes, what would be the anticipated source(s) and timeline(s) for securing funding? I aim to submit a K01 application through NIMHD (PA-20-190) in October 2022.

#### Does this project require contact of CCSS study subjects for:

Additional self-reported information	Yes
Biological samples	No
Medical record data	Yes

### If yes to any of the above, please briefly describe.

This proposed study will obtain an in-depth understanding of CCSS survivors' experience with Medicaid insurance (particularly modifiable barriers to Medicaid access and survivorship care), through engaging survivors in the CCSS in qualitative survivor interviews and survey. The data collected will then be linked to clinical data from the CCSS and state-level data on Medicaid policies to test our hypotheses of interest.

# What CCSS Working Group(s) would likely be involved? (Select all that apply)

Second Malignancy	
Chronic Disease	Secondary
Psychology/Neuropsychology	Secondary
Genetics	
Cancer Control	Primary
Epidemiology/Biostatistics	

# **Outcomes or Correlative Factors**

Late Mortality	
Second Malignancy	Correlative Factors

### **Health Behaviors**

Tobacco	Correlative Factors
Alcohol	Correlative Factors
Physical Activity	Correlative Factors
Medical Screening	
Other	

# If other, please specify

# **Psychosocial**

Insurance	Primary
Marriage	Correlative Factors
Education	Correlative Factors
Employment	Correlative Factors
Other	

# If other, please specify

## **Medical Conditions**

Hearing/Vision/Speech	Correlative Factors
Hormonal Systems	Correlative Factors
Heart and Vascular	Correlative Factors
Respiratory	Correlative Factors
Digestive	Correlative Factors
Surgical Procedures	Correlative Factors
Brain and Nervous System	Correlative Factors
Other	

If other, please specify

# **Medications**

**Describe medications** 

# Psychologic/Quality of Life

BSI-18	Correlative Factors
SF-36	Correlative Factors
CCSS-NCQ	Correlative Factors
PTS	
PTG	
Other	

If other, please specify

#### Other

Pregnancy and Offspring	
Family History	
Chronic Conditions (CTCAE v3)	Correlative Factors
Health Status	Correlative Factors

## Demographic

Age	Correlative Factors
Race	Correlative Factors
Sex	Correlative Factors
Other	

# If other, please specify

### **Cancer Treatment**

Chemotherapy	Correlative Factors
Radiation Therapy	Correlative Factors
Surgery	Correlative Factors

## **Anticipated Sources of Statistical Support**

CCSS Statistical Center	Yes
Local Institutional Statistician	No

If local, please provide the name(s) and contact information of the statistician(s) to be involved.

Will this project utilize CCSS biologic samples?

No

If yes, which of the following?

# **Other General Comments**

#### Agree

I agree to share this information with St. Jude

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