Section: Contact Information

First Name : Tara

Last Name : Henderson

Institution: University of Chicago Address 1: 5841 S. Maryland Ave.

Address 2 : MC 4060

City: Chicago

State/Province/Region: IL

Country: US

Zip/Postal Code: 60637

Phone Number: 7737026808

Alternate Phone Number: 7737026808

Email Address: thenderson@uchicago.edu

Section: Project Requirements and Description

Group: Requirements to submit AOI

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 co-investigator. : **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: Improving Delivery of Genetic Services to High Risk Childhood Cancer Survivors: A Randomized Study of Remote Genetic Services Versus Usual Care

Planned research population (eligibility criteria):

Eligible participants will include CCSS participants who are currently alive, male or female, 18 years of age or older, a survivor of osteosarcoma, a survivor with multiple primaries or a survivor who meets NCCN criteria for cancer genetic testing, and able to understand and communicate in English.

Proposed specific aims:

The objective of this large randomized study in the NCI-supported Childhood Cancer Survivor Study (CCSS) is to evaluate the efficacy of remote genetic services to increase uptake of genetic counseling and testing in childhood cancer survivors as compared to usual care (identification and referral or testing by a patient's current medical providers). Additionally, we will evaluate the relative advantage of real-time videoconferencing over telephone for provision of remote genetic services. CCSS participants will be contacted to assess their family history and candidacy for genetic testing. Those who meet NCCN criteria for cancer genetic testing or are survivors of osteosarcoma will be eligible and randomized to usual care or remote genetic services, and those in the intervention arm will undergo a second randomization to phone vs. real-time

videoconferencing.

Specific Aims:

Aim 1: To evaluate the efficacy of remote telegenetic services (telephone or videoconferencing) as compared to usual care, to increase uptake of genetic counseling, genetic testing and identification of germline genetic mutation carriers at 6 months among a national cohort of CCS.

Aim 2: To evaluate the efficacy of remote real-time videoconferencing to provide greater knowledge and recall of results, decreases in distress (state anxiety and cancer-specific distress) and higher satisfaction with genetic services as compared to telephone delivery.

Aim 3: To evaluate participant factors (e.g. personal or family history, demographics) associated with uptake of genetic services and moderators of short-term and longitudinal psychosocial outcomes and costs of services, to identify subgroups who benefit more or less from remote services and telephone or real-time videoconferencing and inform evidence based guidelines for use of remote genetic services.

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? : We are planning an October 2017 R01 submission to the NCI and Research Scholar Grant to ACS.

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

Additional self-reported information: Yes

Biological samples : **No**Medical record data : **No**

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

Group: What CCSS Working Group(s) would likely be involved? (Check all that apply)

Second Malignancy:

Chronic Disease:

Psychology / Neuropsychology:

Genetics : Secondary
Cancer Control : Primary
Epidemiology / Biostatistics :

Section: Outcomes or Correlative Factors

Late mortality:

Second Malignancy: Correlative Factors

Group: Health Behaviors

Tobacco: Alcohol:

Physical activity:

Medical screening: Correlative Factors

Other:

If other, please specify:

Group: Psychosocial

Insurance: Correlative Factors
Marriage: Correlative Factors
Education: Correlative Factors
Employment: Correlative Factors

Other:

If other, please specify:

Group: Medical Conditions

Hearing/Vision/Speech : Hormonal systems : Heart and vascular :

Respiratory:
Digestive:

Surgical procedures:

Brain and nervous system:

Other:

If other, please specify: **Group: Medications**Describe medications:

Group: Psychologic/Quality of Life

BSI-18 : SF-36 :

CCSS-NCQ:

PTS : PTG : Other :

If other, please specify:

Group: Other

Pregnancy and offspring:

Family history: Correlative Factors

Chronic conditions (CTCAE v3): Correlative Factors

Health status: Correlative Factors

Group: Demographic

Age: Correlative Factors

Race: Correlative Factors

Sex : Correlative Factors

Other:

If other, please specify:

Group: Cancer treatment

Chemotherapy : Correlative Factors
Radiation therapy : Correlative Factors

Surgery : Correlative Factors

Section: Anticipated Sources of Statistical Support

CCSS Statistical Center:

Local institutional statistician: Yes

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

involved.:

Brian Egelston, Fox Chase Cancer Center

Will this project utilize CCSS biologic samples? : No

If yes, which of the following?:

If other, please explain:

Section: Other General Comments

Other General Comments:

This is a project I am leading with Angela Bradbury, MD from the University of Pennsylvania.