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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

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Project Title: Information Needs of Childhood Cancer Survivors and their Families
Planned research population (eligibility criteria): The entire cohort.
Proposed specific aims: The overall goal of this proposal is to explore the use of computational and linguistics approaches to improve the understanding of information needs of childhood cancer survivors and their families. The Childhood Cancer Survivor Study collects demographic, diagnosis, treatment, and follow up data on these patients using a chart-review method. In addition, parents and/or children who survive cancer fill out questionnaires, which include not only information about the disease, treatment, but also information about the patient's family history, environment, social economy issues, behavior, healthcare needs, etc. Most of the information provided by parents and/or the children is currently in electronic format and includes narrative reports (text). Due to the number of patients in the study and the nature of the data collection and storage, manual review is unpractical and very time consuming. Given the potential value of such rich narratives, the utilization of natural language processing and computational linguistics approaches can potentially increase the likelihood of generating meaningful data that can guide subsequent educational programs and research methods in cancer control and prevention. The specific aims of this project are: 1. To examine the efficacy of various natural language processing tools for extracting meaning information from narrative reports provided by parents and/or children who survive cancer: • Develop a protocol for enabling maximal machine-based extraction of semantic terms and relationships; and • Characterize the information extracted. 2. To examine various statistical and data mining algorithms to identify meaningful relationships in the data: • Develop algorithms to

identify associations in the data, including environmental and/or behavioral factors; • Characterize the biomedical concept relationships and evaluate the potential for these relations to generate new knowledge and consequently guide educational and research activities towards the information needs.

Will the project require non-CCSS funding to complete?: No

If yes, what would be the anticipated source(s) and timeline(s) for securing funding?:

Does this project require contact of CCSS study subjects for . . .

Additional self-reported information: No
Biological Samples: No
Medical record data: No
If yes to any of the above, please briefly describe.:

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

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

To describe the anticipated scope of the study, please indicate the specific CCSS data to be included as <u>outcome</u> (primary or secondary) or <u>correlative factors</u>. (Check all that apply)

Late mortality:
Second Malignancy:

Health Behaviors

Tobacco:
Alcohol:
Physical activity:
Medical screening:
Other:
If other, please specify:

Psychosocial

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

Other:
If other, please specify:

Medical conditions

Hearing/Vision/Speech:
Hormonal systems:
Heart and vascular:
Respiratory:
Digestive:
Surgical procedures:
Brain and nervous system:
Other:
If other, please specify:

Medications

Describe medications:

Pregnancy and offspring:
Family History:

Psychologic/Quality of Life

BSI-18:
SF-36:
CCSS-NCQ:
PTS:
PTG:
Other:
If other, please specify:

Chronic conditions (CTCAE v3):
Health status:

Demographic

Age: Primary
Race: Primary
Sex: Primary
Others:
If others, please specify:

Cancer treatment

Chemotherapy: Correlative Factors
Radiation therapy: Correlative Factors
Surgery: Correlative Factors

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.:
Will this project utilize CCSS biologic samples?: No

If yes, which of the following?

Buccal cell DNA:
Peripheral blood:
Lymphoblastoid cell lines:
Second malignancy pathology samples:
Other requiring collection of samples:
If other, please explain:

Other general comments: This project is in collaboration with Dr. Tara Henderson, Department of Pediatrics, Section of Hematology/Oncology at the University of Chicago.