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Project Title Dermatological Issues in Adult Survivors of Childhood Cancer
Planned research population (eligibility criteria) Long Term Survivors of Childhood cancer Over 18 yrs old and 5 years from diagnosis
Proposed specific aims 1. Describe the prevalence and types of dermatological issues experienced in long-term survivors of childhood cancer. 2. Explore the relationship between dermatological issues, body image and health related quality of life among long-term survivors of childhood cancer.
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?
Funding will come from grant funding via Mario Lacouture MD, Director of the Cancer Skin Care Program at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. We anticipate securing the funding in 6 months or less.

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. In the original CCSS cohort data (section B9) questions 1-4 At this time do you have any of the following? 1. persistent hair loss 2. Scarring or disfigurement of the head or neck region (including the face) 3. Scarring or disfigurement of the chest or abdomen region? 4. Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg) Section I-1 Have you ever had an amputation of an arm, leg, finger or toe? Depending on the number of questions we are allowed to ask, we would like to inquire about if the survivors had "any dermatological (skin, hair or nail-related) concerns after being diagnosed with and treated for cancer?" YES or NO We recently performed a pilot study on 78 of our adult survivor of childhood cancer cohort (manuscript in review) and if they answered "YES" to this question they were asked to expand on the type of dermatological condition (from a list of 13 common conditions); tell us if they attributed the condition to their cancer or its treatment; treated the condition; and if they felt the condition resolved. We would also like to capture a time frame of onset/resolution (if applicable) of the condition(s). We also would like to have them complete the Body Image Index (BII), a validated 28-item Likert scale designed for childhood cancer survivors. (Kopel, S. 1998. Society of Pediatric Psychiatry). Finally, our pilot study revealed that 98% of survivors reported unresolved scarring. We are interested in exploring this further with 3 questions 1) I am bothered by the way my scar(s) looks (1-5) 2) My partner is bothered by the way my scar(s) looks (1-5) 3) Looking at my scar(s) is a reminder of cancer (1-5)

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

Second Malignancy

Primary - No

Secondary - No

Chronic Disease

Primary - No Secondary - No

Reproductive

Primary - No Secondary - No

Neurologic

Primary - No Secondary - No

Psychology / Neuropsychology

Primary - Yes Secondary - No

Genetics

Primary - No Secondary - No

Cancer Control

Primary - No Secondary - No

Epidemiology / Biostatistics

Primary - No Secondary - No

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

Late mortality

Primary - No Secondary - No Correlative Factors - No

Second Malignancy

Primary - No Secondary - No Correlative Factors - No

Health Behaviors

Tobacco

Primary - No Secondary - No Correlative Factors - No

Alcohol

Primary - No Secondary - No Correlative Factors - No

Physical activity

Primary - No Secondary - No Correlative Factors - No

Medical screening

Primary - No Secondary - No Correlative Factors - No

Other

Primary - No Secondary - Yes Correlative Factors - No

If other, please specify Use of Sunscreen

Psychosocial

Insurance

Primary - No Secondary - No Correlative Factors - No

Marriage			
Primary - No	Secondary - No	Correlative Factors - No	
Education			
Primary - No	Secondary - No	Correlative Factors - No	
Employment			
Primary - No	Secondary - No	Correlative Factors - No	
Other			
Primary - Yes	Secondary - No	Correlative Factors - No	

If other, please specify Dermatological issues in relation to BODY Image

Medical conditions

Hearing/Vision/Speech			
Primary - No	Secondary - No	Correlative Factors - No	
Hormonal systems			
Primary - No	Secondary - No	Correlative Factors - No	
Heart and vascular			
Primary - No	Secondary - No	Correlative Factors - No	
Respiratory			
Primary - No	Secondary - No	Correlative Factors - No	
Digestive			
Primary - No	Secondary - No	Correlative Factors - No	
Surgical procedures			
Primary - No	Secondary - No	Correlative Factors - No	
Brain and nervous system			
Primary - No	Secondary - No	Correlative Factors - No	
Other			
Primary - No	Secondary - No	Correlative Factors - Yes	

If other, please specify scarring, alopecia, GVHD

Medications

Describe medications

Pregnancy and offspring			
Primary - No	Secondary - No	Correlative Factors - No	
Family History			
Primary - No	Secondary - No	Correlative Factors - No	

Psychologic/Quality of Life

BSI-18

Primary - No

Secondary - No

Correlative Factors - No

SF-36

Primary - No

Secondary - No

Correlative Factors - No

CCSS-NCQ

Primary - No

Secondary - No

Correlative Factors - No

PTS

Primary - No

Secondary - No

Correlative Factors - No

PTG

Primary - No

Secondary - No

Correlative Factors - No

Other

Primary - Yes

Secondary - No

Correlative Factors - No

If other, please specify Body Image Index (Kopel, 1998)

Chronic conditions (CTCAE v3)

Primary - No

Secondary - No

Correlative Factors - No

Health status

Primary - No

Secondary - No

Correlative Factors - No

Demographic

Age

Primary - No

Secondary - No

Correlative Factors - Yes

Race

Primary - No

Secondary - No

Correlative Factors - Yes

Sex

Primary - No

Secondary - No

Correlative Factors - Yes

Others

Primary - No

Secondary - No

Correlative Factors - Yes

If others, please specify time since diagnosis

Cancer treatment

Chemotherapy

Correlative Factors - Yes

Radiation therapy

Correlative Factors - Yes

Surgery

Correlative Factors - Yes

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. Fred Rademaker PhD rademaker@northwestern.edu 312-908-1970

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