Cancer Control Working Group

Paul Nathan, MD, MSc and Claire Snyder, PhD on behalf of the Working Group

CCSS
Childhood Cancer
Survivor Study

St. Jude Children's
Research Hospital

An NCI-funded Resource

Scope of Research

The cancer control working group focuses on:

1) Health care utilization and late effects surveillance

2) Health behaviors

3) Health Status

4) Financial and social outcomes

5) Intervention studies (previously)

Working Group Membership

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Paul Nathan, MD, MSc (co-chair)	The Hospital for Sick Children
Claire Snyder, PhD (co-chair)	Johns Hopkins Schools of Medicine and Public Health
Melissa Beauchemin, PhD, RN	Columbia University
Rusha Bhandari, MD, MS	City of Hope
Jackie Casillas, MD, MSHS	UCLA
Rena Conti, PhD	Boston University
Elena Elkin, PhD, MPA	Columbia University
Jennifer Ford, PhD	Hunter College, CUNY
Tara Henderson, MD, MPH	Lurie Children's Hospital
I-Chan Huang, PhD	St Jude
Melissa Hudson, MD	St Jude
Xu Ji, PhD, MSPH	Emory University
Anne Kirchhoff, PhD, MPH	University of Utah
Wendy Leisenring, ScD	Fred Hutchinson Cancer Center
Kiri Ness, PhD	St Jude
Vikki Nolan, DSc	St Jude
Lisa Schwartz, PhD	CHOP
Stephanie M. Smith, MD, MPH	Stanford University Medical School
Robin Yabroff, PhD	American Cancer Society
Jennifer Yeh, PhD	Dana Farber/Harvard
Daniel Zheng, MD, MHS	CHOP

Working Group Progress

15	Published/In Press Manuscripts (since 1/1/2023)
3	Currently Submitted Manuscripts
4	Analysis/Manuscript in Process
5	Concepts in development
8	New AOIs (total, since 1/1/2023)

Highly collaborative WG – most projects involve other WGs

Highlights of Recently Completed Research

- Numerous uses of the financial hardship data:
    - Siblings
    - Relationship with neurocognitive outcomes
    - Relationship with progression of chronic health conditions
    - Relationship with lifestyle behaviors and surveillance adherence
    - Relationship with neighborhood socioeconomic deprivation
- Linkage of CCSS patients to Medicaid data (Xu Ji)
- Geocoding (I-Chan Huang)

Career development award

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JUNIOR FACULTY | CANCER CONTROL
Evaluating the Need for Dyadic Intervention Adaptation in the Health Insurance Navigation Tools (HINT) Intervention
Awardee: Echo Warner, PhD, College of Nursing, University of Utah
Primary Mentor: Anne Kirchhoff, PhD, MPH
Direct Costs Awarded: $20,000

Aim 1: Examine sociodemographic and clinical factors that are associated with endorsement of caregiver involvement in HINT. We will analyze 12-month follow-up surveys of current HINT participants combined with CCSS data to evaluate their responses to questions about caregiver involvement in HINT.

Aim 2: Explore survivor preferences for caregiver involvement in future dyadic implementation of the HINT intervention. Through purposive sampling, we will interview participants from each study arm who do and do not endorse caregiver involvement in HINT

Aim 3: Contextualize the survey findings through integration of the interview feedback regarding the content, modes of delivery, and dyadic features required for caregiver involvement. As part of this aim, we will generate potential solutions to barriers and limitations of a dyadic rollout of HINT.

Association of neurocognitive impairment and financial hardship in adult survivors of childhood cancer (Daniel Zheng)

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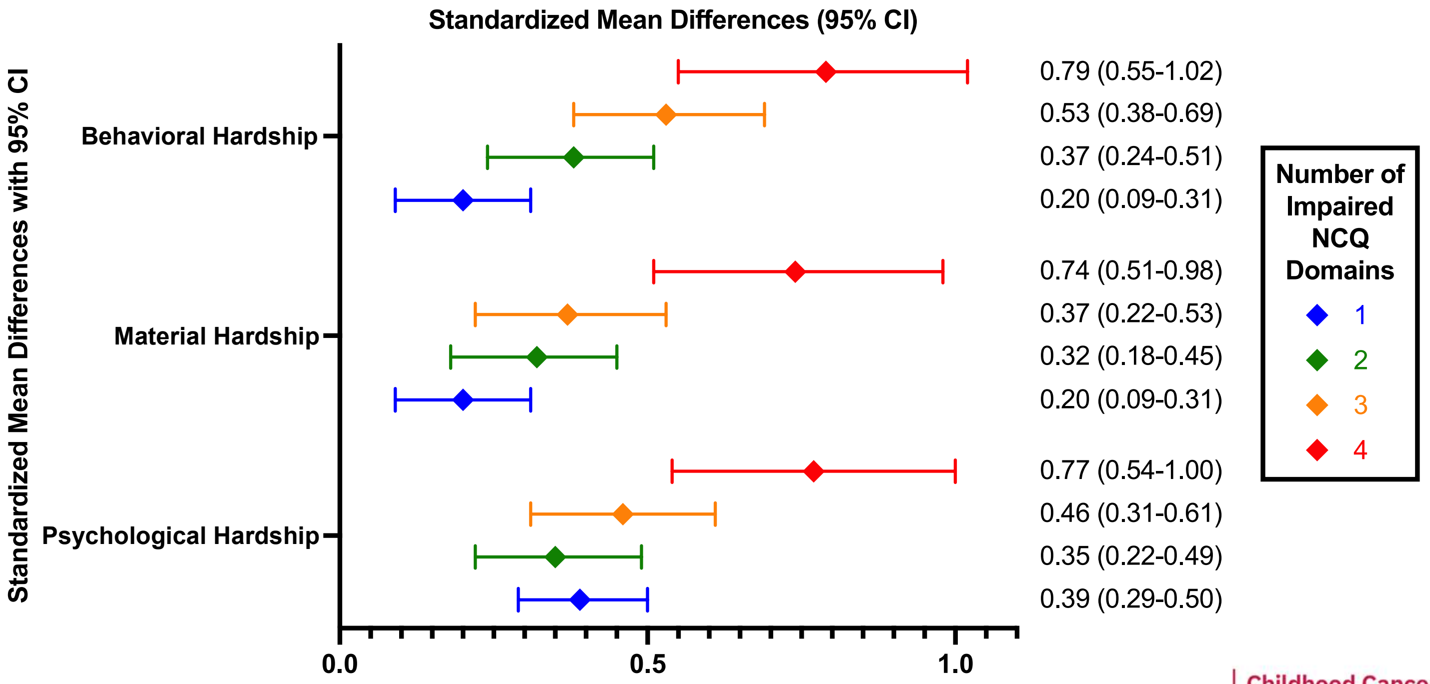
- N = 3023 survivors completed both the Neurocognitive Questionnaire (NCQ) and the financial hardship survey
- Strong association with evidence of dose-dependent effect
- Among survivors with 4 NCQ impairments, 54% were sent to debt collection and 21% had filed for bankruptcy protection



Childhood Cancer Survivor Study

An NCI-funded resource

Ancillary Studies assigned to the WG

OPEN

1. Decreasing Cardiometabolic Risk in Childhood Cancer Survivors: Survivors Engaged in Time-Restricted EatiNG after Therapy (STRENGTH; Friedman): **Enrolling soon**
2. Activating cancer Survivors and their Primary care providers to Increase coloREctal cancer Screening Study (ASPIRES; Henderson, Kim): **Enrolment completed**
3. Improving delivery of genetic services to high-risk CCS (ENGAGE; Henderson, Bradbury): **Enrolment completed**
4. Health Insurance Navigator Program (HINT-II; Park): **35% of recruitment goal so far**

AWAITING FUNDING

1. The SPRINT Study (SMN Screening and Prevention INTervention): A Bundled Intervention Study (Henderson): **Applying for funding**
2. Evaluation of Cardiovascular Health Outcomes among Survivors 2 (ECHOS-2; Ehrhardt): **High score – waiting on funding decision**

Plan to Utilize FU7 Newly Frozen Data

Medical care:

1. Cost of health care use (Beauchemin et al.)
2. Relationship with Social Determinants of Health (SDOH) based on geocoding (Bhandari, Huang)
3. Relationship between primary care involvement and psychosocial outcomes (Schwartz, Brinkman)
4. Relationship between continuity/coordination of care and health service use, screening adherence, health status (Snyder, Eary)

Health behaviors:

1. Associations Between Smoking, Risky Alcohol Use, and Second Malignant Neoplasms in Childhood Cancer Survivors Compared to their Siblings Author(s): Schwartz/University of Chicago

Social and Environmental Determinants of Health (SEDH) & Health Disparity (HD) Research

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I-Chan Huang, PhD

Health Services Research Working Group, Cancer Control and Survivorship Program

Department of Epidemiology and Cancer Control, St. Jude Children’s Research Hospital, Memphis, TN, USA

Social Determinants of Health (SDOH)

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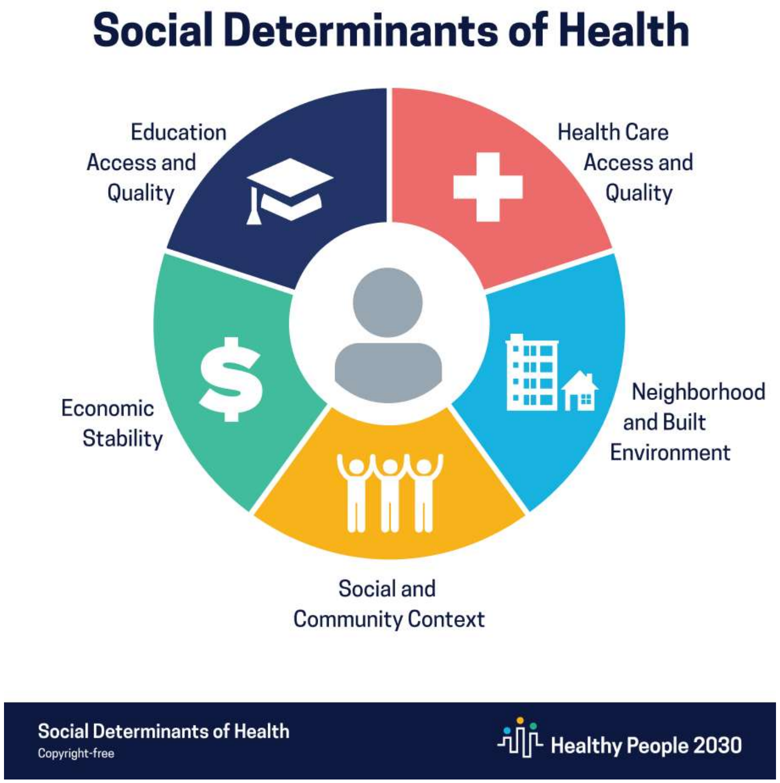
- Definition
  - “… the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”



Neighborhood Adversity Measures for CCSS

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Measure	Geographical unit	Domain, indicator, index, category, or definition
Area Deprivation Index (ADI)	Census block groups	None
Neighborhood Deprivation Index (NDI)	Census tract	None
Social Vulnerability Index (SVI)	Census tract, and County	Domain: Socioeconomic, Household Composition, Minority Status/Language, and Housing/ Transportation
Minority Health Social Vulnerability Index (MH-SVI)	County	Domain: Socioeconomic, Household Composition, Minority Status/Language, Housing/ Transportation, Health Care Infrastructure, and Medical Vulnerability
County Health Rankings (CHR)	County	Domain: Length of Life, Quality of Life, Health Behaviors, Clinical Care, Social Economic Factors, and Physical environment
Persistent Poverty	Census tract, and County	Definition: 20% or more of the population has been living in poverty over the past 30 years
Rural and urban status (RUCA)	Census tract/Zip code	Category: Original RUCA has 9 small categories, further organized into 3 large categories (urban, sub-urban, rural area)
Air pollution	County	Indicator: PM2.5, O_3, Nox
Noise pollution	Census tract	Indicator: Annual daily traffic density
Greenspace	Census tract	Indicator: open parks, impermeable surfaces, and forest land cover
Walkability	Census tract	Index: National Walkability Index
Healthcare resources	Census tract	Indicator: the number of physicians or medical clinics per 1000 people
Contemporary redlining	Census tract	Definition: lending bias score related to redlining

Analysis-Ready Data for CCSS

	SVI			ADI			Healthcare resources		
	Baseline*	FU5	FU7	Baseline*	FU5	FU7	Baseline*	FU5	FU7
Total	19130	12109	9057	15476	11146	8704	16735	12109	12042
Survivor	18432	10226	7609	14846	9458	7327	16037	10226	10155
Sibling	698	1883	1448	630	1688	1377	698	1883	1887

	RUCA		Redlining	Persistent Poverty
	Baseline*	FU5/FU7	Baseline	Baseline
Total	19928	20356	17183	20391
Survivor	19230	16787	16605	19467
Sibling	698	3569	578	924

- *Option: Using FU5 or FU7 to impute missing baseline data (numbers upon request)*
- *SVI: Social Vulnerability Index; ADI: Area Deprivation Index; RUCA: Rural and Urban Status*

Potential SEDH/HD Topics for CCSS

Neighborhood SEDH:

- Area SES deprivation
- Redlining
- Persistent poverty
- Food environment
- Local healthcare resources
- Rurality
- Greenspace
- Walkability
- Air pollution

Health Outcomes:

- CHC burden
- Healthcare utilization (PCP, ER, hospitalization)
- PROs (emotional distress, symptoms, functional status, QOL)
- Lifestyle
- Aging
- Mortality

Example Topics:

- Impact of residential segregation/structural racism on cumulative CHC burden and mortality
- Associations of food environment with cardiovascular and metabolic disorders
- Area deprivation, community resilience, and PROs
- The compound effect of personal SES and community adversity on adverse outcomes

CCSS Needs Assessment Questionnaire

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58 items addressing

- Health system concerns
- Cancer-related health information
- Survivor care and support
- Surveillance
- Fiscal concerns

Needs assessment items cover:

- Access (e.g., ability to see specialists)
- Quality (e.g., knowing surveillance recommendations)
- Costs (e.g., affordability of medical treatments)

Can be linked with standard health care utilization questions

- Provider Visits
- Hospitalizations/Emergency Department Encounters
- Screening & Surveillance Testing

Enables exploration of the associations between unmet needs and poor outcomes (e.g., hospitalizations), as well as health care disparities related to race/ethnicity

Identifies gaps in care to inform subsequent research, including intervention studies

Plan for Concept Development Using FU8 Survey Needs Assessment Data

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Preliminary Data: Top 12 Unmet Needs	N	%
Information about the late effects of my cancer therapy (N14)	3147	35
Information about specific diseases that can result from cancer therapy (N16)	3070	34
Information about what I can do to reduce my chances of developing late effects (N17)	3006	33
Information about which organ systems may have been affected by my cancer treatment (N20)	2920	32
Information about how cancer affected my body (N12)	2828	31
Information about how cancer will affect my life (N21)	2641	29
Information about what screening tests I need based on my treatment history (N42)	2481	28
Information about the important aspects of my after-cancer care (N1)	2362	26
Information about which tests will help detect late effects of treatment (N48)	2183	24
Information about what symptoms to report to the doctor or nurse (N15)	2172	24
Information about my treatments or medications (N18)	1938	21
Information about cancer recurrence (N11)	1911	21

As CCSS Engages with Participants This Year What Would You Like to Learn From Them?

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- Process
  - What are the best ways to engage with participants?
    - Embed in committees and working groups?
  - What training do participants need to most effectively partner with research teams?
  - What training do researchers need to most effectively partner with participants?
  - What is appropriate remuneration for participants?

- Substance
  - What research topics are of greatest interest to participants?
  - What outcomes are of greatest importance to participants?

- Methods
  - What are the best ways to recruit participants for ancillary studies?
  - What are the best ways to collect data from participants?
    - Regular CCSS surveys
    - Ancillary studies

Value Added to the working group by a 2000-2025 Cohort Expansion

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1. More participants
2. Opportunity for innovative data collection (e.g., electronic capture of health care use, new approaches for self-reported data collection)
3. Greater cohort diversity
4. More recent treatment history
5. Ability to determine baseline sociodemographic variables so we can look at financial/social trajectory and social determinants of health

Special Considerations for a Cohort Expansion Specific to Your Working Group

- Leverage FU8 findings regarding identified needs that require intervention
- Leverage the deep phenotyping data to obtain a more granular picture of health service use
- Social determinants of health
  - Track residential address longitudinally
- Income and household information to better understand poverty level
- Fertility preservation
- Loneliness *(with Psychology Working Group)*
- Re-ask the financial hardship questions

Current Top Priorities: One-Year Deliverables

- Develop work looking at cost of health care use
- Develop a program of work looking at the relationship between SDOH and a range of outcomes
- Analyze needs assessment data from FU8 survey and use it to inform future survey questions and targets of intervention studies
- Explore associations between unmet needs and poor outcomes (e.g., hospitalizations), as well as health care disparities related to race/ethnicity
- Submit grant linking CCSS with consumer credit data

Discussion: Opportunities and Threats

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- Major Threat or Challenge:
  - Difficulty obtaining funding for ancillary studies
  - Challenges with claims data linkages for population under age 65 years
  - Lack of detailed health service use data

- Major Opportunity:
  - Deep phenotype
  - Expansion cohort
  - Transition to innovative data collection approaches
  - Partnership with participants