

Understanding and Improving Health Insurance Coverages Experiences of CCS (Childhood Cancer Survivors)

Working Group(s): Cancer Control and Intervention

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Overview: This concept proposal is for Dr. Elyse Park's ongoing American Cancer Society (ACS) grant to pilot test a health insurance literacy program for survivors from the Childhood Cancer Survivor Study (CCSS). This health insurance literacy program was informed by her Livestrong-funded insurance survey of CCSS survivors and siblings conducted in 2010-2011. The pilot trial (Aim 2) has almost completed data collection (anticipated completion date December 2021). Analyses will begin shortly once data collection is finalized and the concept proposal is approved.

Per input from the CCSS Publications Committee, the ACS grant will be reviewed in place of a CCSS concept proposal.

Draft table shells for the Aim 2 RCT analyses and relevant CCSS variables are listed at the end of the concept proposal.

A. SPECIFIC AIMS

Childhood cancer survivors develop acute and chronic health problems at over 3-times the rate of their siblings.¹ These survivors often face continued health care challenges and require ongoing care to monitor and treat long-term effects of their cancer and treatment.² Given their ongoing health care needs, obtaining and utilizing health insurance coverage is vital to ensure adherence to needed survivorship care. Unfortunately, childhood cancer survivors have reported higher rates of uninsurance, unmet health care needs, and burdensome costs.³⁻⁹ Many survivors may find themselves underinsured, either by having unmet health care needs due to cost or having high out-of-pocket (OOP) health care costs.¹⁰⁻¹² Insured survivors may still lack access to desired specialist providers, tests, and screenings due to cost or other insurance restrictions. High-deductible health plans are being increasingly offered by employers and to enrollees in health insurance exchanges. These plans pose a risk of unmet health care need and financial burden for enrollees with chronic conditions such as childhood cancer survivors.^{1,13-15}

Health care reform under the Patient Protection and Affordable Care Act (ACA) offers considerable opportunities for childhood cancer survivors to obtain coverage and improve access to needed care.^{16,17} However, in the general population, many people have low understanding of available insurance benefits and resources, and have limited health insurance literacy (i.e. perceived knowledge, ability, and confidence to make informed decisions about choosing and using health insurance).¹⁸ Misperceptions about which services require out-of-pocket costs may lead some enrollees to avoid services that are in fact exempt from cost-sharing.¹⁹ Similarly, findings from our Livestrong-funded 2011-2012 health insurance survey (PI: Park) demonstrated that many childhood cancer survivors lack of awareness about the ACA and had concerns about rising costs and threats to healthcare quality.^{4,20,21} Additionally, our research confirmed that childhood survivors, compared to siblings, were at risk for being underinsured. Thus, even with coverage protections from the ACA, barriers to obtaining coverage (e.g., in states without health insurance exchanges) and accessing needed care may remain for childhood survivors. Understanding and navigating insurance benefits is crucial for cancer survivors to obtain the health care they need. In this new post-reform landscape, the degree to which coverage and costs have changed for childhood cancer survivors is still largely unknown.

In response to the ACS RFA: *The Role of Health Policy and Health Insurance in Improving Access to and Performance of Cancer Prevention, Early Detection, and Treatment Services*, which calls for research evaluating the impact of changes in the healthcare system intended to improve access to care, we propose to conduct a mixed methods study among Childhood Cancer Survivor Study (CCSS) participants to develop a health insurance navigation program (HINP), conduct a randomized pilot trial comparing the HINP to enhanced usual care (n=80), and refine the HINP for future use. *The research is strongly aligned with the ACS's "4 A's" (availability, affordability, adequacy, and administrative simplification of coverage).*

Thus, our proposed aims are as follows:

Aim 1. To develop a psychoeducational health insurance navigation program (HINP).

Aim 1a: To qualitatively assess 4 survivor focus groups participants' report of 1) satisfaction with their current insurance coverage, 2) barriers and facilitators to obtaining needed coverage, 3) types of services where coverage and affordability are problematic, and 4) aspects of coverage not well understood.

Aim 1b: To qualitatively assess 3 advisory board experts' feedback on 1) survivor eligibility for the HINP, 2) HINP content, 3) navigator selection, 4) HINP structure and dose, and 5) resources.

Aim 1c: To pilot the intervention with childhood survivors (n=10).

Aim 2. To conduct a videoconferencing based pilot randomized trial of the HINP (n=80 participants)

Aim 2a: To assess the feasibility (number of eligibles enrolled and sessions completed) and acceptability (satisfaction, perceived support) of survivors undergoing the HINP.

Aim 2b: At 3-month post-program follow-up, to assess the efficacy of the HINP to assist survivors with accessing and utilizing coverage and managing costs. Primary outcomes are 1) health insurance literacy and 2) financial distress related to medical costs.

Hypotheses: The HINP, compared to enhanced usual care, will improve childhood survivors' health insurance literacy and decrease financial distress.

Aim 3. To refine the HINP program for future use (n=40 intervention participants).

Aim 3a: To explore HINP intervention arm participants' 1) satisfaction with the intervention, 2) recommendations for modifications on delivery modality, and 3) recommendations for intervention topics and content modifications.

B. BACKGROUND AND SIGNIFICANCE

B1. Childhood Cancer Survivors are a growing population in need of medical surveillance. Children diagnosed with cancer have experienced improved survival rates over time, with more than three-fourths becoming long-term survivors.² However, survivors of childhood cancer often face new and continued health care challenges and require ongoing care to monitor and treat long-term effects of their cancer and treatment throughout adulthood. Late effects may include new cancers,²²⁻²⁴ cardiac complications,²⁵⁻²⁸ reproductive issues,²⁹ cognitive deficits,^{30,31} liver dysfunction, and other physical^{32,33} and psychosocial sequelae.³⁴⁻³⁷ These late effects often appear decades later; the full spectrum of late effects is still relatively unknown.^{1, 38-40} Ongoing medical treatment and surveillance, with access to quality healthcare and coverage, are critical.

B2. Although quality health insurance coverage is critical to this population, it has been complex to obtain. Given their ongoing health care needs, obtaining and navigating health insurance coverage is vital to ensure access to needed survivorship care. However, this can be difficult for individuals with pre-existing conditions such as a cancer diagnosis, who have historically faced denials of coverage, steep premiums, or “job lock” that keeps them from changing jobs for fear of losing coverage.⁴¹ Dr. Kirchhoff recently published findings in JAMA Oncology demonstrating that job lock is still common among childhood survivors who are employed full-time, particularly for survivors who experienced previous health insurance denial (RR, 1.60; 95% CI, 1.03-2.52) and problems paying medical bills (RR, 2.43; 95% CI, 1.56-3.80).⁴² At the same time, childhood cancer survivors have had higher rates of uninsurance, unmet health care needs, and burdensome costs.³⁻⁹ These survivors are also less likely than siblings to be employed, married, and have a higher household income.⁴³⁻⁴⁵ Dr. Park’s CCSS health insurance study found that survivors and siblings had similar rates of coverage, yet they differed by types of coverage and experiences obtaining coverage³. Uninsured survivors in particular were more likely to experience financial burdens from medical care that affected their care utilization.

B3. Health care reform offers opportunities for childhood survivors to obtain quality coverage. The ACA⁴⁶ was signed into law in 2010 and is intended to increase access to affordable, quality health care. ACA policies offer considerable opportunities for populations with pre-existing conditions like childhood cancer survivors to obtain coverage and improve access to needed care. Dr. Park and colleagues delineated the implications of specific ACA provisions for insurance coverage for childhood survivors.¹⁶ Cancer survivors

could benefit from a number of ACA provisions (Table 1).^{16,47} Recent national data demonstrate that the uninsured rate for cancer survivors decreased from 12.4% (2012) to 7.7% (2015) (p<0.001) during pre-post ACA implementation.⁴⁸ This health care

Table 1: Key ACA Policies for Childhood Cancer Survivors

Employer mandate	Employers with >50 full-time employees are required to provide coverage to employees or face penalties. Cancellations due to new conditions also prohibited.
Prohibition of coverage denials based on pre-existing conditions Prohibition of setting premium rates based on health conditions	Only age, geography, family composition, & tobacco use can be used to set rates.
Dependent coverage expansion Coverage of preventive services at no cost Removal of annual & lifetime coverage limits	Children can stay on a parent’s private insurance plan through age 26. Health plans must cover USPSTF grade A or B recommended services without cost-sharing. Annual limits prohibited.
Medicaid expansion	Eligible for those with incomes <133% FPL, except in 16 states that elected not to expand Medicaid.
Creation of state or federally run health insurance exchanges	For small businesses, and individuals and families without access to employer-sponsored or public coverage.
Within exchanges, availability of premium subsidies Creation of an essential health benefits package	Premium subsidies available to those with incomes <400%FPL and cost-sharing subsidies to those with incomes <250% FPL. Includes: (1) ambulatory services; (2) emergency services; (3) hospitalization; (4) maternity & newborn care; (5) mental health & substance use disorder services; (6) prescription drugs; (7) rehabilitative services & devices; (8) laboratory services; (9) preventive & wellness services; and (10) pediatric services.

reform was timely, as the increasing prevalence of high co-payments and deductibles, and the declining availability and affordability of employer-sponsored insurance, often leave populations, such as childhood cancer survivors, financially encumbered.⁴⁹⁻⁵¹

B4. Although the ACA has increased coverage rates, uninsurance and underinsurance may remain a problem for childhood cancer survivors. While 8.8 million U.S. uninsured adults gained coverage after enactment of many of the key ACA policies, 10.3% of the non-elderly U.S. population, or 28 million people, remain uninsured.⁴⁷ Childhood cancer survivors may be at continued risk for being uninsured if they have low incomes and live in one of the 18 states that chose not to participate in the ACA’s Medicaid expansion,^{52,53} or if they find premiums too expensive and forgo coverage. Others may have inadequate insurance coverage that leaves them underinsured, which has been defined as having high out-of-pocket costs (>10% of their income)⁵⁴ and/or having unmet health care needs due to cost. The ACA and other unprecedented changes to

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the health care landscape offer both opportunities and risk to childhood cancer survivors regarding insurance adequacy and underinsurance. From Dr. Park's 2011-2012 CCSS health insurance survey we found that childhood survivors lacked awareness about the ACA²⁰ and had concerns that the ACA would increase their costs and threaten their quality and continuity of coverage.^{4,20,21} Additionally, some fear that expanding coverage will overburden existing primary care provider capacity as the formerly uninsured seek care.⁵⁴⁻⁵⁶ More recently, the individual mandate tax penalty repeal in late 2017 may mean higher premiums, and exchange plans may require high levels of cost-sharing in order to offer more affordable premiums.^{15,57} These potential cost increases would be particularly difficult for survivors with increased need for health care. Escalations in health care costs and adoption of new insurance designs to contain costs may continue to affect cancer survivors in unforeseen ways. Employers and exchanges increasingly offer narrow network plans, which limit where members can get care.⁵⁸ Survivors may choose plans for their lower premiums, but might then be unable to seek care from specialists. High-deductible health plans continue to increase in prevalence and pose a risk of unmet health care need and financial burden for enrollees such as survivors.¹³⁻¹⁵ While the ACA requires coverage with no out-of-pocket costs for preventive services with "A" or "B" U.S. Preventive Services Task Force (USPSTF) ratings, these guidelines are not based on survivor-specific preventive guidelines and, as such, may not cover personalized screening recommendations.⁵⁸

B5. Limitations in health insurance literacy can make choosing and using health insurance

challenging. With the complex and confusing array of evolving insurance designs, being able to understand and navigate insurance benefits is crucial for cancer survivors to obtain the health care they need. However, many people have inadequate understanding of available insurance benefits and resources, and have limited health insurance literacy (i.e. perceived knowledge, ability, and confidence to make informed decisions about choosing and using health insurance).⁵⁹ Vulnerable populations, such as those with low income and poorer health, are more likely to have limited health insurance literacy.⁶⁰⁻⁶² Dr. Galbraith's (consultant) work has demonstrated that choosing a health plan in health insurance exchanges can be daunting, especially for enrollees who have experienced unexpected health care costs.^{15,63} Once a plan has been chosen, many enrollees are confused about what services are covered. Misperceptions about which services require out-of-pocket costs may lead enrollees to avoid services that are in fact exempt from cost-sharing.²⁴ Many young cancer survivors needing advice about paying for health care do not receive services.⁶⁴ Understanding specific insurance benefits and larger ACA policies may help survivors maximize coverage and prevent unmet need and burdensome costs.

B6. Patient navigation interventions help patients overcome health care barriers. Patient navigation is a patient advocacy approach that was introduced in 1990, by Dr. Harold Freeman, to decrease high rates of breast cancer death among Black women in Harlem.⁶⁵ Patient navigation aims to reduce cancer disparities and negative health outcomes among vulnerable patient populations. Patient navigators were envisioned as proactive patient advocates who provided logistic and emotional support to promote patients' access to timely care. Dr. Tracy Battaglia (consultant), a widely-published expert in patient navigation, suggests that patient navigation 1) includes a patient-centered focus on overcoming barriers to accessing care, 2) aims to reduce delays in accessing care, 3) targets a defined set of health services, and 4) provides a defined endpoint when provided services are complete.^{66,67} Several national navigator programs have been developed by organizations including the ACS, the NCI, and Centers for Medicare and Medicaid Services.^{66,68,69} The ACA authorized continued funding of patient navigator programs for improving the health care of vulnerable populations and requires that state exchanges provide navigators.

B7. Patient navigation has been applied across the cancer continuum. Patient navigation has been applied across the cancer continuum. Patient navigation has been used extensively to help cancer patients overcome barriers to care including financial, communication, informational, and medical system barriers.⁶⁵ Navigation programs have been successful in improving cancer screening and follow-up.^{70,71} Survivorship navigation is a relatively new application to the field,⁷² but it is an important application as the same barriers to accessing care experienced during treatment are likely to present after treatment and affect the quality of surveillance for survivors. Survivorship navigation has not solely been applied to health insurance outcomes.

B8. Existing navigator programs offer limited assistance with understanding and managing health insurance benefits and costs. The US healthcare system is complex. Even with reform under the ACA, understanding insurance options remains complicated and a source of frustration for consumers.⁷³ While addressing insurance barriers to accessing care may be a component of some navigator programs, navigators

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focused specifically on helping patients understand and use their insurance benefits are rare. Navigator services mandated by the ACA in health insurance exchanges are available to help consumers choose and enroll in coverage, but their reach does not extend beyond enrollment. Many exchange enrollees have sought navigation services post-enrollment to help understand their new insurance plans, but such post-enrollment services are unavailable.⁷⁴ At the same time, cost-sharing under the ACA will continue to increase as coverage was not stabilized by Congress via payments to insurers to reduce costs for consumers. Survivors in particular are going to need comprehensive assistance with insurance in future years.

C. STATEMENT OF CANCER RELEVANCE

This study will be the first to address barriers to accessing affordable quality coverage and health care for childhood cancer survivors in a post-ACA environment. Its goal is to intervene and assess a survivor-targeted insurance navigation program. In previous work we have demonstrated that childhood cancer survivors have been at risk for not obtaining insurance, being underinsured, and lacking awareness of the ACA.^{3,20} We will develop the first patient navigation program focused on improving health insurance access and utilization, which could have a significant impact on the health outcomes of childhood cancer survivors. Research is necessary to improve patient experiences and inform future policy decisions regarding the ACA and other insurance strategies. A program assisting childhood cancer survivors with their health insurance quality and costs will be meaningful, regardless of whether ACA policies change due to legislative or judicial decisions. These findings and program will be useful to patients, their families, clinicians, payers and policy makers who seek to improve coverage and health care affordability for cancer survivors.

D. INNOVATION

This grant is innovative on many levels. 1) *Collaboration with the national Childhood Cancer Survivor Study (CCSS) and, in particular, intervention experience and access to the newly released expansion cohort data.* The investigators' long-term established collaboration with the CCSS facilitates unique access to survivors nationwide, which provides an invaluable opportunity to conduct this research with a national sample to ensure generalizability, disseminate findings with a well-established survivor network, and implement an intervention nationally. 2) *Development and assessment of a patient-navigation model to help cancer survivors manage their health insurance benefits and costs.* Patient navigation has been widely used in clinical care, but its application to assisting patients with managing health insurance is novel.⁷⁴ Navigation strategies have been employed to help consumers choose an insurance plan,⁷⁵ but not to address their continuing needs. 3) *Focus on health insurance literacy.* Health insurance literacy is a relatively recent concept that has increasingly been recognized as a crucial competency for patients to manage the complex, evolving health insurance system,⁷⁶ in particular with the advent of the ACA, measures of health insurance literacy have been studied with respect to risk factors and outcomes. Developing an intervention to improve health insurance literacy breaks new ground.⁷⁷ 4) *Videoconferencing is a innovative means of reaching patients to be seen for virtual, "in-person," secure visits using a computer, tablet or smartphone.*

E. PRELIMINARY STUDIES

E1. Childhood survivors and health insurance. In 2005 Dr. Park published findings in the *Journal of Clinical Oncology* demonstrating that CCSS survivors, compared to siblings, were significantly more likely to be uninsured and have difficulties obtaining health insurance.³ In 2009-2010 she conducted in-depth interviews with a subset of CCSS survivors^{4,41} and with Drs. Kirchhoff, Donelan, and Kuhlthau found that survivors had low coverage expectations, had difficulties understanding how to utilize their coverage, and inevitably worried about future health care costs. This team surveyed a randomly selected sample of CCSS participants and siblings about their health insurance coverage and perspectives about the ACA.^{25,78} Survivors were significantly less likely to have employer-sponsored coverage (79.4% vs. 86.0%; $p=0.04$) and more likely to be covered by Medicaid/State (12.3% vs. 4.4%; $p=0.002$). 15.4% of survivors vs. 1.6% of siblings had recently been denied insurance ($p<0.001$). Survivors were more likely to borrow money to pay medical expenses (17.3% vs. 9.0% siblings; $p=0.002$) and not fill a prescription due to cost (15.7% vs. 9.0% siblings; $p=0.02$). Only 27.3% of survivors and 26.2% of siblings reported familiarity with the ACA. Concerns about the ACA included costs, decreased access to quality coverage, and employment. The majority of survivors, across different types of insurances, indicated strong interest in an insurance education program.

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E2. Recent study team reports of childhood survivors' underinsurance and its effects on financial burden and health care utilization. Dr. Kuhlthau led analyses describing patterns of health insurance coverage and care accessibility and affordability in an NHIS sample of adult childhood cancer survivors compared to adults without cancer during 2010-2014. Significantly more childhood survivors reported being uninsured, delaying medical care (24.7% vs 13.0%), needing but not getting medical care (20.0% vs 10.0%), and having trouble paying medical bills (40.3% vs 19.7%), compared to controls ($p < 0.0001$).⁷⁹ In 2017, Dr. Park and the study team published findings in *JAMA Internal Medicine* and *JCO* documenting that, compared to siblings, childhood survivors were significantly more likely to endorse indications of being underinsured, including being 84% more likely to borrow money because of medical expenses, 80% more likely to worry about being unable to pay for a needed treatment, and 74% more likely to worry they wouldn't be able to afford to fill a prescription. In addition, childhood survivors were more likely to report spending a higher percentage of their income on out-of-pocket medical costs. Survivors reported spending almost more than \$1000 annual out-of-pocket costs compared to siblings. A higher percentage of income spent on out-of-pocket medical costs was significantly associated with survivors' problems paying medical bills (OR, 8.9; 95% CI, 4.4 to 18.0); deferring care for a medical problem (OR, 3.0; 95% CI, 1.6 to 5.9); skipping a test, treatment, or follow-up (OR, 2.1; 95% CI, 1.1 to 4.0); and thoughts of filing for bankruptcy (OR, 6.6; 95% CI, 3.0 to 14.3).^{80, 81}

E3. Intervention and program development with childhood cancer survivors. Dr. Park has studied the health behaviors and perceptions of childhood cancer survivors.⁸²⁻⁸⁵ She directed an NCI-funded trial to decrease smoking rates among 796 CCSS smokers that was found to be efficacious.⁸² She published a qualitative paper that had shaped the intervention,⁸⁴ as well as a process evaluation paper which examined intervention characteristics associated with cessation success.⁸³ Dr. Park also has extensive experience conducting qualitative research to inform survivorship program development.⁸⁶⁻⁸⁹ Dr. Kirchhoff is leading the development and testing of a childhood cancer survivor transition program with a focus on the provision of survivorship care plans for patients and families.⁹⁰

E4. Health insurance and individuals with chronic conditions. Dr. Kuhlthau has extensive experience studying health insurance issues for individuals with chronic conditions, including Medicaid populations and groups with high expenditures.⁹¹⁻¹⁰² She has also studied unmet need, a commonly used measure of underinsurance.¹⁰³⁻¹⁰⁵ She conducted work on the private health insurance and work-life benefit systems for children with chronic conditions^{106, 107} which resulted in guides for employers, families, and state employees. Dr. Galbraith's work has demonstrated that children and families with chronic conditions are vulnerable to health insurance designs with high levels of cost-sharing, and may reduce use of needed care due to cost.¹⁰⁸⁻¹¹⁰ Dr. Kirchhoff published on coverage gaps, financial burden, and medical costs, and their impact on access to care among childhood, adolescent and young adult cancer patients and survivors.¹¹¹⁻¹¹³

E5. Effects of new insurance designs and health reform policies. Dr. Galbraith led one of the first studies of health insurance exchange plans, which documented problems for exchange enrollees with financial burden and unexpected costs;¹⁵ this study also identified challenges with understanding and choosing plans for families, many of whom wished for greater assistance navigating plan options.⁶⁵ Dr. Galbraith has conducted studies of unmet health care need and financial burden among children and families with chronic conditions in high-deductible and other insurance plans.^{14,110,115,116} She has examined the impact of increased cost-sharing on health care decision making and use of recommended health care services.¹¹⁷⁻¹²¹ She is conducting a trial to evaluate how a price transparency tool can help high-deductible plan enrollees manage costs.

E6. Peer counselor and navigator-based interventions. Dr. Park directed a smoking cessation trial, in collaboration with CCSS, in which she trained childhood cancer survivors to be smoking cessation peer counselors and deliver a phone-based intervention.⁸³ Dr. Galbraith conducted a randomized trial of a patient navigator intervention to reduce readmissions for high-risk patients discharged from a safety-net hospital.^{122,123} Dr. Donelan has conducted extensive survey research examining patient barriers to cancer screening and follow-up and physician referral communication with patients.¹²⁴⁻¹²⁷ She examined the effectiveness of a patient navigation program in improving minority patients' follow-up of an abnormal mammogram.

F. Expertise delivering behavioral interventions via videoconferencing

Dr. Park has treated MGH cancer patients using the MGH telehealth service for the past 3 years. The team's previous clinical research has demonstrated that videoconferencing intervention delivery is acceptable and sustainable to patients. Drs. Park and Kuhlthau recently completed two pilot studies using group videoconferencing to decrease stress among parents of children with special health care needs. In these pilot

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studies, participants greatly enjoyed videoconferencing, easily adjusting to virtual connections and expressing appreciation for its convenience.^{128,129} Dr. Park is launching 2 randomized trials using videoconferencing to deliver tobacco treatment to newly diagnosed cancer patients and older smokers undergoing lung cancer screening. In the proposed study, as in the recently completed and newly launched trials, the research assistant (RA), experienced in MGH telehealth and the MGH telehealth service, will assist participants with teleconferencing software setup and will complete test calls to ensure proficiency with the software. Further, all participants will receive informational “how-to” sheets to problem-solve commonly occurring questions/concerns. The RA and the MGH Telehealth team (see Sossong letter of support) will be available throughout the study to assist with any participant utilization questions.

F. RESEARCH DESIGN

F1. Design overview. The proposed study will take place in 3 phases (Figure 1). Consistent with work by Rounsaville et al.,¹³⁰ we will begin by developing a program (based on our preliminary studies), refine with qualitative input, and then conduct a randomized pilot trial. Specifically, in Phase 1 we will develop a psychoeducational health insurance navigation program (HINP) through survivor input and a series of advisory board meetings. In Phase 2 we will pilot the feasibility, acceptability, and preliminary efficacy of the videoconferencing-based HINP. In Phase 3 we will further refine the program. All procedures will be approved by the institutional review boards of St. Jude Children’s Research Hospital and the MGH. Below we discuss the theoretical framework and processes that guide each phase of the study.

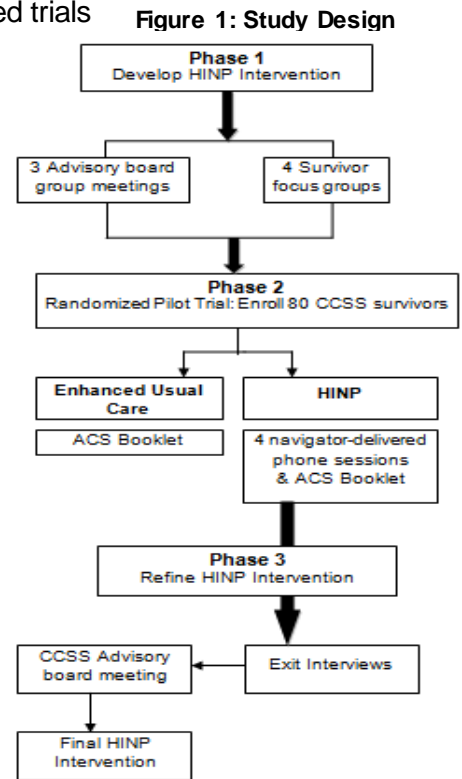
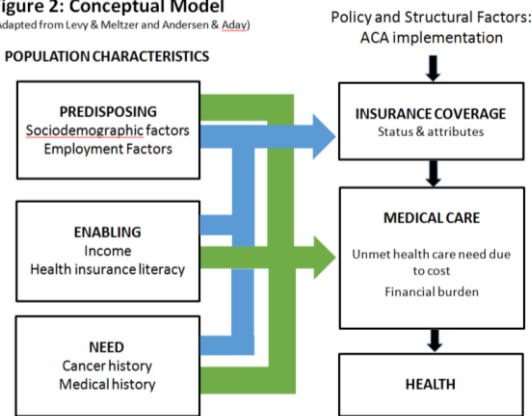


Figure 2: Conceptual Model
(Adapted from Levy & Meltzer and Andersen & Aday)



F2. Theoretical framework (Figure 2). The theoretical basis for this research stems from Levy and Meltzer’s (2004) model of the relationship between health insurance and health.¹³¹ This model has been adapted for the proposed project. In this model, individual characteristics can influence a person’s insurance status and the characteristics of their coverage (e.g. source and type of plan, benefits), as well as their use of medical care. Inclusion of individual characteristics in the model is also informed by Andersen and Aday’s Behavioral Model of Health Services Use,¹³²⁻¹³⁴ which posits that health care use is influenced by **predisposing, enabling, and need** factors. Insurance coverage and characteristics can also be influenced by trends in the larger health policy and health insurance market such as, specifically, the implementation of the ACA. Coverage

status and insurance characteristics can then affect use (or non-use) of medical care and related underinsurance (i.e. incurring financial burden or not getting needed care because of health care cost). Medical care (or lack thereof) can then affect health outcomes. Navigation theory. Our intervention will be developed with a strong psychoeducational component, which is designed to promote access to and utilization of quality health insurance. The HINP design fulfills the care management model, which involves: 1) systematic identification of eligible individuals, 2) identification of individual barriers to care, 3) development of an individualized plan to address barriers, and 4) tracking so barrier is overcome.^{135,136} A recent study on cancer patients’ perspectives of navigation revealed that patient-centered aspects of the care, demystifying the health system, ensuring comprehension, and managing expectations were 4 components of navigation care that were most beneficial.¹³⁷ Common barriers to cancer patients’ care include lack of support, insurance/financial

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concerns, and problems with health care communications.¹³⁸ The HINP will be delivered in a Motivational Interviewing (MI) style which will be focused on overcoming patient barriers to coverage and care. MI is a supportive style of treatment,¹³⁹ which is in the spirit of Dr. Freeman's navigation principles. Dr. Park has effectively used MI to promote health promotion among childhood survivors and cancer patients.^{82,140} MI is particularly effective with cancer survivors because 1) it focuses on building and maintaining self-confidence, 2) the main MI tools (e.g., affirmations, reflections) are effective when addressing sensitive topics (e.g., screening nonadherence) and information (e.g., financial burden), and 3) MI skills will encourage learning and advocacy.



Virtual delivery and service.

MGH TeleHealth connects providers to patients through virtual HIPAA-compliant videoconferencing technology

including: phone, video, email, mobile applications and remote monitoring. Dr. Park has used this videoconferencing virtual modality for communication with cancer patients for the past 2 years. These virtual visits are conducted via a Vidyo videoconference platform that addresses clinical privacy and security (See Human Subjects). Participants can use this videoconference platform on their computer, tablet or smartphone. 2018 Pew findings showed that 77% of U.S. adults own Smart Phones. Among the poorest U.S. adults (annual income <\$30,000), over two-thirds own Smart Phones. Similarly, 94% young adults (18-29 years of age) own Smart Phones.¹⁴¹ 71%-93% (incomes of \$30,000->\$75,000 respectively) of U.S. adults have broadband use at home¹⁴² **Thus, a video-based internet option is a feasible modality for the vast majority of adult survivors.** In low income rural health areas, telemedicine via the internet is increasingly being used to deliver behavioral health care.^{123,124} Indeed, as of 2017 the Medicaid programs of 48 states had telemedicine reimbursement policies for live, synchronous video services.^{143,144}

Thus, we believe that our proposed navigator program, offered through billable telemedicine services, would be sustainable.

Table 2: CCSS Survivor Demographics

	Original cohort diagnosed 1970-1986 % ¹	Expansion cohort diagnosed 1987-1999 % ²
	Surveyed 2011-2012	Surveyed 2008-2014
Uninsured	10.2	16.9
Female	54.6	47.2
Race/Ethnicity		
White	93.5	81.2
Black	1.7	8.6
Hispanic	3.0	5.9
Other	1.8	4.3
Current Age		
20-29	11.2	47.4
30-39	42.4	43.3
40-64	46.4	9.3
FPL ³		
<138%	16.7	21.0
≥138%	83.3	79.0
Medicaid		
Expansion	68.0	63.2
Non-Expansion	32.0	36.8

¹n=survivors who responded to original survey
²n=survivors eligible in expansion cohort
³Using mid-point income categories - 2015 FPL

F3. Participants (Table 2). CCSS is an NCI-funded multi-institutional study of individuals who were diagnosed before 21 years of age with leukemia, CNS malignancies, Hodgkin's disease, non-Hodgkin's lymphoma, Wilm's tumor, neuroblastoma, soft tissue sarcoma, or bone cancer and survived at least five years. CCSS includes an original cohort of survivors diagnosed between 1970-1986 at 26 participating centers in the U.S, and a more recent expansion cohort of survivors diagnosed between 1987-1999 at these centers and 5 additional centers. The over 24,000 CCSS participants represent approximately 15% of US children diagnosed with cancer. CCSS utilized long-term health outcome rates to estimate population-level burden of morbidity, which demonstrated that CCSS participants were similar in terms of age at diagnosis, gender, and cancer type to those reported in SEER,¹⁴⁵ indicating CCSS was representative of childhood cancer survivors in the U.S. In the proposed design, Phase 1 participants were not be eligible for Phase 2 participation. Participants who do not have access to a mobile device (e.g., laptop, computer, mobile phone, ipad, etc) will be excluded. Importantly, we will closely document and monitor the numbers of individuals who are unable to participate given this criterion, as it will further inform the feasibility of this treatment modality.

NOTE: During the development phase of this project, the decision was made to focus on currently insured CCSS survivors for the overall study (rather than both uninsured and insured as indicated in the grant). This decision was made due to the realization that uninsured survivors would need different educational materials on insurance. In addition, after conducting one focus group for Aim 1, the decision was made to instead do one-on-one interviews with CCSS survivors to allow for scheduling flexibility and due to survivors' concerns about discussing insurance and finances with a group. The Aim 2 RCT includes both original and expansion CCSS survivors. Eligibility was limited to those currently insured; randomization was stratified based on

residence in a Medicaid expansion state or not. In total, 82 survivors enrolled in the RCT and were randomized (N=41 intervention and N=41 control). Of these participants, all completed the baseline survey and N=37 intervention and N=40 of the control completed the follow-up survey.

F4. Phase 1

Aim 1. To develop a psychoeducational health insurance navigation program (HINP).

Aim 1a (exploratory): To qualitatively assess childhood survivors' 1) satisfaction with current coverage, 2) barriers and facilitators to obtaining needed coverage, 3) types of services where coverage and affordability are problematic, and 4) aspects of coverage not well understood.

Four focus group interviews (n=8 per group) will be conducted with randomly selected CCSS survivors; selection will be stratified according to Medicaid expansion status (Y/N). CCSS survivors from the original and expansion cohort will be eligible and consented; we will assure inclusion of men and women as well as insured and uninsured participants. Groups will last 90 minutes, participants will be provided \$50 remuneration. Groups will be co-facilitated by Drs. Park, Kirchhoff or Donelan via a semi-structured interview guide.

Aim 1b. To qualitatively assess 3 advisory board experts' feedback on 1) survivor eligibility, 2) HINP content, 3) navigator selection, 4) HINP structure and dose, and 5) resources.

Advisory Board Input on HINP and Integration for Intervention Refinement

CCSS investigators as key informants. Dr. Armstrong (see letter of support) will facilitate coordinating and leading this meeting. National oncology clinicians and researchers as key informants. Drs. Park will conduct an advisory board meeting group at the national American Psychosocial Oncology Society meeting, which includes multidisciplinary oncology clinicians (e.g., nurses, social workers, clergy, psychologists, and psychiatrists) and researchers. Dr. Joseph Greer (see letter of support), APOS board member, and Dr. Park's colleague, will facilitate coordinating and leading this meeting. Boston-based experts and patients. Drs. Park and Galbraith will conduct an expert advisory board consisting of members of the MGH Cancer Center Social Work service, the MGH Survivorship program, health plan member services representatives from HPHC (a non-profit regional health insurance plan with which Dr. Galbraith is affiliated), and the MGH Cancer Center Patient and Family Advisory Board members. Dr. Jeffrey Peppercorn (see letter of support), Director of Survivorship Research at MGH, will facilitate coordinating and leading this meeting.

Dr. Park is a national expert in qualitative and mixed methods research, and mixed methods studies; she has lectured nationally on conducting qualitative research to inform intervention development. Dr. Park will draft a semi-structured interview guide for eliciting feedback, which will include the following domains: 1) Intervention participant eligibility: (Who should we target?); 2) Navigation Intervention Content (Is the navigation treatment comprehensive? Relevant for survivors? Accessible?); 3) Delivery: Who should deliver the intervention (at the testing, implementation, and dissemination phases); 4) Intervention structure and dose: (Are the number and timing of sessions acceptable? For example, should we add in an option for survivors to call the navigator during the 3-month post-program period and prior to their follow-up survey, and track number of calls received and additional support provided?); and 5) Intervention resources: What are recommended existing print materials and other resources, particularly state-based (such as fact sheets on ACA policies and health insurance in general) that will be provided to intervention participants?¹⁴⁶

F5. Qualitative analyses to inform HINP development.

Survivor Focus Groups. For qualitative analyses of focus group and advisory board data, all data will be transcribed and analyzed using NVivo 11 qualitative software. Content analyses will be conducted by Drs. Park and the research assistant who will develop the structural thematic framework, categories, and coding plan. For focus group data, a coding framework will be developed for themes and codes according to survivors' 1) areas of satisfaction/dissatisfaction with current plan, 2) barriers and facilitators to obtaining needed care, and survivorship care in particular, 3) types of services where coverage, access and affordability are problematic, and 4) aspects of coverage that are not well understood and where more information is desired.

For advisory board feedback, a coding framework will be developed for themes and codes according to the: 1) HINP content, 2) HINP delivery, 3) HINP structure, and 4) HINP dose, and resources. To ensure coding reliability, coding discrepancies will be resolved through discussion and comparison of raw data. Coding will continue until a high level of reliability (Kappa= ≥ 0.80) is established. Drs. Armstrong, Kuhlthau and Donelan will provide an expert review of the results.

F6. Aim 1c. To pilot the intervention with childhood survivors (n=10).

Intervention development and open pilot. With feedback analyses from the focus groups and advisory boards, results will be interpreted, summarized, and finalized; the investigators will refine the HINP. The investigators will incorporate feedback and make recommended modifications to the intervention content, protocol structure and dose as well as the plan for who will deliver the intervention and which survivors should be eligible. A Resource List to aid survivors with navigating their plans, including state-specific resources (e.g., Medicaid coverage) will be developed. Then, 10 participants will be randomly selected to participate as pilot subjects. All aspects of the study will be piloted, including the assessments and intervention and exit interview (see content of exit interviews below). Participants will be paid \$20 for each assessment and for completion of an exit interview. The patient navigator will meet weekly with Drs. Park, Donelan and the study consultants to review the session content and responses. Final intervention modifications will be then be completed.

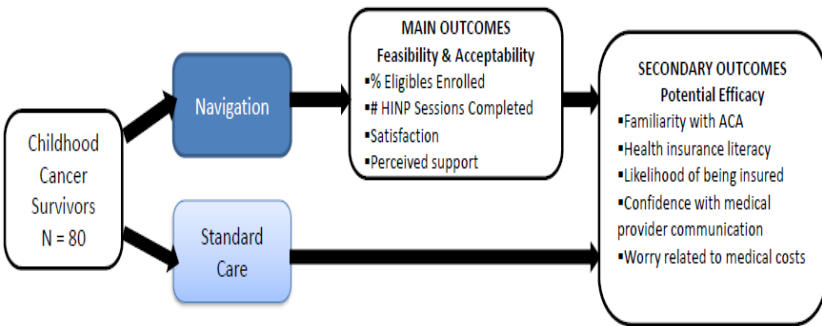
F7. Phase 2 HINP pilot randomized trial.

Aim 2: To conduct a pilot randomized trial of the HINP (n=80 participants)

Aim 2a: To assess the feasibility (# of eligibles enrolled and sessions completed) and acceptability (satisfaction, support) of survivors undergoing a health insurance navigation intervention.

Aim 2b: At 3-month post-program follow-up, to assess the preliminary efficacy of a navigation-based insurance intervention to assist survivors with obtaining and utilizing coverage and managing costs.

Hypotheses: Survivors who are randomized to the intervention arm, compared to survivors randomized to the control arm, will demonstrate greater 1) familiarity with healthcare reform policies, 2) health insurance literacy, 3) (among those uninsured at study enrollment) likelihood of being insured, 4) confidence with medical provider communication, and 5) improvement in financial worries.



F8. Pilot trial design (Figure 3). We will recruit and randomize 80 childhood cancer survivors to a health insurance navigation intervention or to enhanced usual care. We have selected this sample size of 40 per arm to enable evaluation of feasibility and acceptability goals as well as explore meaningful differences in the outcomes.¹⁴⁷ Surveys will be conducted at baseline and 3-month post program completion follow-up.

Figure 3: Pilot Trial Design

NOTE: Please see section F15 where we described alterations to the main and secondary outcomes.

F9. Participants and data collection. The CCSS Coordinating Center, under the directorship of Dr. Todd Gibson, will randomly select participants among the CCSS cohort (original and expanded together). To ensure adequate representation of survivors living in Medicaid-expansion and non-expansion states, we will randomly select equal numbers of survivors from Medicaid (N=31)/non-Medicaid states (N=18). Eligible survivors will be from the original (N=12,323) and expansion cohort (N=9,518) who are still alive and have available contact information (Table 2). Participant recruitment and consent will be conducted by CCSS staff. Participant information will be sent to Dr. Kirchhoff via Sharepoint, a secure encrypted network. Further data transmissions will be conducted between Dr. Kirchhoff and the CCSS Coordinating Center and Statistics and Data Center to facilitate data access from the CCSS baseline and follow up surveys for inclusion in the statistical analysis (<https://ccss.stjude.org/documents/original-cohort-questionnaires>). Dr. Kirchhoff will oversee completion of the baseline survey and follow-up surveys. Data will be collected via a secure web-based survey portal (REDCap) that is overseen by the Huntsman Cancer Institute bioinformatics shared resource. All participants will complete a follow-up survey after the 2-month HINP intervention period (3-months post HINP program completion/in other words 5-months post pilot trial enrollment). After completion of the follow-up survey, HINP participants will be contacted for an exit interview (**exit interviews described in section F18 below**). Participants will be paid \$20 for each survey and the exit interview. Dr. Kirchhoff, advised by CCSS statistical

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staff and Dr. Donelan, will lead the data analyses and transmit analytic data to MGH using the Hartwell Center's FTA protocol (<http://fta.stjude.org>), a web-based interface with a secure 128-bit encrypted web connection.

F10. Treatment arms. Enhanced usual care. Enhanced usual care will consist of a mailed ACS health insurance booklet, The Health Care Law: How it Can Help People with Cancer and Their Families. Navigation intervention. The intervention will be delivered via synchronous videoconferencing by an oncology social worker and will consist of 4 bi-weekly 30-minute sessions plus a mailed copy of the ACS health insurance booklet.

Table 3: Proposed HINP Intervention
Session One: Overview of the ACA and US Preventive Services Task Force (USPSTF) Guidelines
Informational: ACA provisions and review of ACS booklet
Informational: USPSTF force prevention guidelines for services where the ACA prohibits cost-sharing
Assessment: Participant's survivorship follow-up/care plan recommendations
Overcoming barriers: Promoting communication with medical providers to inquire about preventive and follow-up care
Assessment: Participant's adherence to follow-up recommendations and barriers to doing so
Session Two: Learning about insurance coverage
Informational: Types of insurance coverage models and insurance benefit terms
Overcoming barriers: Selecting an insurance plan or changing to another plan
Overcoming barriers: (For uninsured) Obtaining an insurance plan
Resource Provision: Connecting with the state's health insurance exchange and its navigation program
Session 3: Navigating one's coverage plan
Informational: Learning about one's own plan and benefits policies
Assessment: Utilizing one's plan and accessing benefits
Overcoming barriers: Exploring what one is entitled to in a plan and how to optimize one's benefits
Overcoming barriers: Options to pursue if a needed service or provider is not covered, difficult to access or prohibitive
Overcoming barriers: Discussing difficulties with service access and cost with medical providers
Session 4: Managing care costs
Informational: Understanding deductibles and other cost-sharing mechanisms.
Assessment: Estimating the costs of obtaining a needed service.
Overcoming barriers: Strategies for decreasing out-of-pocket costs
Resource provision: Connecting with state or health plan-based price transparency resources

F11. Proposed navigation intervention structure and content. Support for our proposed intervention, and decisions about proposed content and delivery modality, were informed by participants' responses in the 2011-2012 CCSS health insurance survey. Two-thirds of survivors were very interested (7 or higher on 1-10 scale) in participating in a psychoeducational insurance intervention; 72% wanted a general education about health insurance coverage. We envision that the program will be delivered via videoconferencing by an oncology social worker over a 2 month period. Accordingly, patient navigation is delivered until the desired endpoint is achieved; we propose that this will be accomplished with 4 navigation sessions. The proposed program content was informed by: 1) aforementioned research identifying childhood survivors' difficulties with accessing and utilizing one's coverage and managing costs, 2) CCSS health insurance survey, and 3) ACA provisions that are relevant to cancer survivors (e.g., prevention services exempted from cost sharing, sources of available coverage and eligibility, benefits policies that have cost-related implications like OOP costs, and essential health benefits such as prescription medications). Thus, our proposed program would provide a supportive, individualized approach which would include psychoeducation with a focus on overcoming barriers. This proposed delivery modality, structure, length, and navigator training will be modified based upon Phase 1 findings. Also, we designed the sessions to focus on both the ACA as well as key aspects of health insurance that all consumers should understand regardless of plan or coverage type, such as cost sharing (e.g., co-pays, co-insurance), which allows our program to be flexible for survivors and responsive to changes under the ACA. We envision Sessions 1 and 2 would provide information on the ACA, prevention guidelines, and coverage models and will include strategies to identify types of coverage needed (Table 3). Sessions 3 and 4 would provide training and support for survivors to empower them to challenge coverage denials, seek lower-cost alternatives, and discuss OOP costs with providers, Many patients wish to discuss costs with providers but few do, even when faced with financial burden,^{15,148,149} so providing tools to initiate these conversations could be powerful. Based on advisory board feedback, the content and tailoring of information will be modified.

F12. Navigation training and delivery. There are no national standards for navigation training.¹⁵⁰ A recent review¹⁵¹ delineated basic competencies, which included: role of the navigator, confidentiality, listening and communication, identifying barriers, and locating resources. The patient navigator (PN) will undergo training which will include: ACA (Galbraith, Kuhlthau), childhood cancer survivor guidelines (Kirchhoff, Galbraith), OL/health insurance/health behaviors/employment of childhood cancer survivors (Park, Kirchhoff, Kuhlthau), USPSTF guidelines (Donelan), coverage advocacy and costs (Galbraith). The PN would pilot sessions with 3-5 pilot CCSS participants. The NCI, with support from the ACS, established the Patient Navigation Research Program (PNRP) to implement and evaluate patient navigator programs focusing on cancer patients. The PNRP developed a navigation performance checklist with 3 quality indicators of care:^{135, 152} 1) participant interaction (e.g., established rapport), 2) care management (assessed patients' understanding), and 3) intervention delivery (e.g., relevant information provided on insurance options, cost savings). Drs. Park, Galbraith and Battaglia will review 15% of patient navigation encounters using these quality indicator criteria. Rationale for selection of an oncology social worker: As Dr. Freeman⁶⁸ stated, "the determination of who should navigate should be based on the level of skill required at a given phase of navigation. There is a spectrum of navigation extending from services that may be provided by trained lay navigators to services that require navigators who are professionals, such as nurses and social workers." With this principle and the aforementioned competencies in mind, an oncology social worker will deliver the proposed intervention. Training of the PN would include informational content, motivational interviewing and problem-solving barriers.

F13. Measures. To evaluate the pilot, we will use a mixed methods data collection approach, using both quantitative survey items and exit interviews.¹⁵³ Most study measures will come from survey questions repeated from the 2011-2012 CCSS health insurance survey (see Appendix); some new questions will be added and are indicated as such. Survey development included a qualitative study conducted with a sample of CCSS survivors,⁴ modifications and inclusions of national survey questions¹⁵⁴⁻¹⁵⁸ and a cognitive testing phase. CCSS abstracted medical records data will be used to provide information on cancer diagnosis, age at diagnosis, and cancer treatment. Data from the CCSS surveys will provide information on sociodemographic and medical history since cancer treatment, and presence of a medical late effects and chronic health

Table 4			
A. SURVIVOR CHARACTERISTICS (organized according to Figure 2 Conceptual Model)			
	Description	Survey measure source	Data for HINP Delivery
Characteristics	Age, gender, education, race/ethnicity	CCSS baseline survey	
	Current partnership/marital status (Q43), employment (Q7-10)	CCSS health insurance survey	
Enabling Characteristics	Medicaid expansion state or not	Current state residence	
	Familiarity with ACA policies (Q33)+	CCSS health insurance survey	Session 1
	Health insurance literacy+ 1) Confidence in understanding of terms (e.g., premium, deductible, co-payments, co-insurance, out-of-pocket spending limits, annual limits) 2) Confidence in choosing, comparing, and using insurance plans.	1) * Urban Institute Health Reform Monitoring Survey ¹⁴⁶ 2)* Health Insurance Literacy Measure ¹⁴⁷	Session 2
	Household and Personal Income (Q44-46)	CCSS health insurance survey	Session 4
Need	Cancer diagnosis, age at and years since diagnosis, years since diagnosis, treatment	CCSS Medical Records	Session 1
	Recurrence of primary cancer	CCSS baseline & follow-up surveys	Session 1
	Second malignancy	CCSS baseline & follow-up surveys	Session 1
	Other chronic conditions	CCSS baseline & follow-up surveys ¹	Session 1
B. OUTCOMES (numbers in parentheses below correspond with CCSS 2011-12 survey in appendix)			
	Description	Survey measure source	Data for HINP Delivery
Insurance Coverage	Insurance status (survey face page)+	CCSS health insurance survey	All sessions
	Denial or difficulty obtaining coverage because of health history (within the past 2 years) (Q4-5)	CCSS health insurance survey	Session 2
	Difficulty finding and choosing a plan	*Dr. Galbraith's survey of health insurance exchange enrollees and the Kaiser Family Foundation survey of non-group enrollees	Session 2
Underinsurance	Not taking a new job in order to keep health insurance in past year (Q16a)	CCSS health insurance survey	Session 2
	Trouble finding a provider who accepts insurance/getting an appointment as needed	Urban Institute Health Reform Monitoring Survey ¹⁴⁶	Session 3
	Unmet health care need due to cost (Q30); Provider visits past year (Q17-18); OOP costs >10% of income (Q31d)	CCSS health insurance survey	Session 4
	OOP health care costs (Q28, Q26); OOP premium costs (Q27)	CCSS health insurance survey	Session 4
	Problems due to medical expenses (Q31)	CCSS health insurance survey	Session 4
	Worry related to medical costs (Q32)+	CCSS health insurance survey	Session 4
Coverage-related variables	Policy holder and source (Q1-3)	CCSS health insurance survey	Sessions 2,3
	Plan source: employer-sponsored, direct purchase (exchange or outside), Medicaid, Medicare	* From the Urban Institute Health Reform Monitoring Survey ¹³²	Sessions 2,3
	Type of plan: High-deductible plan; Narrow network plan	*Annual individual deductible >\$1,000; Can only see in-network physicians	Sessions 2,3
	Being forced to switch plans because of cancellation (in past year)	* Adapted from Urban Institute Health Reform Monitoring Survey ¹⁴⁶	Sessions 2,3
	Rating of current plan (Q20)	CCSS health insurance survey	Sessions 2,3
* New measure that was not part of the CCSS 2011-2012 health insurance survey			
+Pilot trial outcome			

conditions including second cancers. Information on CCSS data sources can be found at <https://ccss.stjude.org/data-and-analysis/public-access-data-tables.html>.

F14. Data collection and analyses procedures. Data will be scanned into a database; initial cleaning will be carried out at the CCSS Coordinating and Statistical Centers and merged with data on corresponding survey questions and relevant data from other CCSS surveys and treatment data. Dr. Kirchhoff's team at HCI will conduct the analyses with input from the CCSS study team. As discussed in Participants, we will sample by Medicaid expansion vs. non-expansion states. All analyses will be weighted using inverse sampling probabilities so that results are representative of the overall CCSS cohort. As needed, we will adjust analyses for survey cohort status (original vs. expansion).

At baseline, all pilot participants will complete a baseline survey (see Table 4 for baseline survey items). The HINP navigator will use each participant's baseline survey responses to personalize and individualize sessions.

At the 3-month post-program follow-up, participants will complete the Phase 1 survey Outcome questions (Table 4, Section B), which will be asked within the 5-month time frame period after trial enrollment. Participants will also be asked questions below about feasibility and acceptability.

F15. Pilot trial outcomes. Primary Outcomes: Feasibility and Acceptability. 1. *Feasibility*: Number of eligibles enrolled and number of sessions completed. 2. *Acceptability*: 4-point scales of satisfaction with navigation services (To what extent has this program met your needs? Did you get the kind of health insurance assistance that you wanted? How helpful has this program been for you?) and perceived support (emotional/informational scale of the Medical Outcomes Study social support survey, an 8-item scale widely used with cancer patients).¹⁵⁹⁻¹⁶³

Secondary Outcomes: Efficacy. The ACS's National Patient Navigator Leadership Summit recommend patient-navigation outcome measures, which included: perceived knowledge, perceived confidence in overcoming barriers to care, and satisfaction with patient navigation services. Accordingly, we will measure (indicated on Table 4 with "+"): 1) health insurance literacy, 2) financial distress related to medical costs. 3) familiarity with healthcare reform policies, 4) (among those uninsured at study enrollment) insurance status, and 5) discussion with providers about health care costs¹⁵ and preventive services among those having a visit during this interval (2-item y/n questions).

NOTE: Since the grant was originally written, we altered the pilot trial outcomes slightly (F15 and Table 4). Acceptability includes satisfaction with navigation services including communication with the navigator, sessions (scheduling, length, number), the handbook, Zoom, visuals, and overall program quality rated from excellent, good, average, poor, very poor. We also assessed whether participants would recommend the program to other survivors of childhood cancer and how well the program met their needs for information on insurance; participants also completed write in responses on aspects of the program that could be improved or that they found to be the least useful.

Efficacy now includes health insurance literacy, awareness of key Affordable Care Act provisions, and behavioral (e.g., delaying medical care because of cost) and psychological (e.g., worries about costs and insurance) medical financial hardship. The decision was made not to use the health insurance literacy measure (HILM) based on input from Dr. Galbraith, health insurance literacy expert and team member. Rather, health insurance literacy was measured by 16 items denoting confidence in understanding of terms related to insurance (e.g., deductible, co-payments, co-insurance) and confidence in knowing how to do the health insurance-related activity (e.g. figuring out co-payments, finding an in-network doctor), with 4-category Likert scale ranging from 16-64 (higher scores denoting lower literacy). These new items were based on Dr. Gailbraith's published work, including [Decision-Making Experiences Of Consumers Choosing Individual-Market Health Insurance Plans | Health Affairs](#) which can be accessed via the live link.

Awareness of key Affordable Care Act provisions included 6 questions regarding protections such as no annual/lifetime limits, dependent coverage through age 26, preventive care coverage, appeals, preexisting conditions coverage, and subsidies for premiums with participants reporting yes, know, and don't know. Behavioral hardship included 9 items regarding cost worries leading to skipping medical care (i.e., putting

off/postponing preventive care, dental care, or vision care, skipping a test or treatment recommended by a provider). Psychological hardship included 6 questions about worries paying medical care, insurance expenses, and lack of insurance coverage for certain services.

F16. Aim 2 Analyses. Dr. Kirchoff will lead the analyses. We will use descriptive statistics to report on the following endpoints: intervention feasibility (percent of survivors enrolled), acceptability (satisfaction, perceived support) and efficacy (e.g., ACA familiarity, health insurance literacy, intention to adhere to recommended survivorship care, provider communication, and coverage status). Descriptive statistics will examine group differences at baseline; any imbalances will be adjusted. We will use chi square and independent t-tests to compare end-of-treatment changes in preliminary efficacy outcomes between the two groups. Although a 3-month post treatment follow-up period is brief, we will also conduct exploratory comparisons with other study outcomes (Table 4- Outcomes: Insurance coverage, Underinsurance, and Coverage-related variables) to see if trends change in the expected direction. We will compare pre/end-of-treatment, within groups, with paired t-tests. In addition, we will use bivariate statistics to examine sociodemographic and cancer-related factors (type of diagnosis, age at diagnosis, years since diagnosis, cancer treatment, chronic conditions¹, cancer treatment (e.g., cranial radiation yes/no, anthracycline exposure yes/no) associated with feasibility, acceptability and preliminary efficacy outcomes.

NOTE: We will now also conduct multivariable linear regressions to investigate interactions between specific demographic subgroups and intervention/control groups with the outcomes of interest. This will allow us to identify whether certain subgroups (e.g., younger vs. older survivors) derive more or less benefit from the intervention.

F17. Aim 3: To refine the HINP program for future use (n=40 intervention participants).

Exit interviews. Applying the concept of triangulation and use of different collection modalities to enhance the validity of results,¹⁶⁴ we will conduct in-depth interviews via videoconferencing with the 40 intervention participants to assess survivors' 1) satisfaction with the intervention, 2) recommendations for modifications on delivery modality (e.g., number and length of sessions, videoconferencing delivery) and 3) recommendations for modifications on overall session topics and intervention content (e.g., physician communication, cost management strategies). Using a structured interview guide, Drs. Park and Galbraith will conduct 20 minute interviews, and participants will be remunerated \$20 for their time. These interviews will be completed following participants' 3-month follow-up surveys.

F18. Exit interview analyses. Exit interview data will be transcribed and analyzed using NVivo 11 qualitative software. Content analyses will be conducted by Drs. Park and Galbraith. The coders will meet to develop the structural thematic framework, categories, and coding plan. To ensure coding reliability, coding discrepancies will be resolved through discussion and comparison of raw data. Analyses will be conducted by comparing those who were satisfied versus unsatisfied. Coding will continue until a high level of reliability (Kappa= ≥ 0.80) is established. Drs. Kuhlthau, and Donelan will provide an expert review.

F19. Final HINP program review and planning. The investigators will review 1) pilot trial results (e.g., Are changes needed to enhance the HINP's feasibility and acceptability? What outcomes appeared to change? Which survivors appeared to benefit?) and 2) survivors' exit interview feedback and make recommended modifications to the intervention content and delivery modality. The final program will be presented at the annual CCSS investigator meeting, to discuss next steps for testing and implementation. Feedback will be elicited on next steps, such as conducting an RCT, as well as plans for dissemination, in particular providing results to insurance providers and ACA policy administrators.

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F20. Timeline.

Timeline	YEAR 1												YEAR 2												YEAR 3											
	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J
Develop HINP	█	█	█	█	█																															
Advisory boards				█	█																															
Focus groups					█	█																														
Refine HINP/Open pilot						█	█	█	█	█																										
Navigator training							█	█	█	█																										
Pilot trial enrollment											█	█	█	█	█	█	█	█	█	█	█	█	█													
Navigation supervision																																				
3-month follow-up																																				
Exit Interviews																																				
Trial survey analyses																																				
Exit interview analyses																																				
Writing up findings																																				
Advisory Boards																																				
Finalize intervention																																				
Present to CCSS																																				
National presentations implementation plan																																				
Weekly team meetings	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	
Monthly investigator meetings	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	

F21. Strengths and limitations. There are many strengths to this proposal, including: 1) invaluable pre-ACA data which provide a context for the HINP development, 2) support of and access to a well-established, large-scale original and expansion cohort of childhood cancer survivors (see Dr. Armstrong’s letter), and 3) a multidisciplinary team with expertise in the ACA, health services research, qualitative methods, intervention design, and pediatric oncology. Several limitations of this project should be noted: 1) self-reported data are subject to biases and limitations 2) ACA policies may be altered,¹⁵⁷ and 3) we are unable to conduct a longer-term follow up to examine changes in outcomes (e.g., reduction in out-of-pocket costs). Next steps, leveraging the entire CCSS cohort, could include larger-scale implementation and testing with a longer follow-up period. The potential for change in the ACA makes it critical to design interventions that give survivors tools to understand and navigate insurance coverage.

F22. Future work/next steps. The long-term goals of this work are to 1) implement a sustainable national psychoeducational health insurance program and 2) influence health policy about childhood survivors’ access to health insurance. We will follow-up with recommendations to policy makers, patients, and clinicians, and determine whether to test the efficacy of the health insurance navigation intervention in a larger population of childhood cancer survivors or conduct an effectiveness/dissemination trial. Interventions such as this have the potential to be implemented widely, through cancer survivorship clinics, primary care and oncology providers, and health plan care management programs, and to help improve health care quality for childhood cancer survivors while reducing costs.

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Table 1: HINT Baseline Demographic Characteristics

	Total N=82	Treatment Arm			P value
		Intervention N=41	Control N=41		
Gender					
Male					
Female					
Current age					
26-39					
40-54					
55-66					
Age at diagnosis					
<i>Mean and SD</i>					
0-4					
5-9					
10-14					
15-20					
Original cancer diagnosis					
Leukemia					
NHL					
HD					
Wilms					
Soft tissue sarcoma					
Bone cancer					
CNS tumor					
Neuroblastoma					
Marital status					
Married					
Never married					
Divorce/Separated					
Education^a					
High School Diploma/GED or less					
Some College or Technical School					
College Graduate or Higher					
Employment					
Full-time or part time					
Caring for home or family					
Unable to work (illness or disability)					
Retired, Student, Other					
Unemployed					
Household Income					
Less than \$50,000					
\$50,000 - \$99,999					
\$100,000 - \$149,999					
\$150,000 - \$199,999					
\$200,000 +					
Insurance Coverage					
Employer sponsored					
Individual insurance					
Medicare					
Medicaid/state public insurance					
Medicaid Expansion State					
Yes					
No					

Table 2: Intervention Feasibility and Acceptability

	Total N=82	Treatment Arm	
		Intervention N=41	Control N=41
Feasibility			
Percentage of survivors enrolled			
Acceptability			
Satisfaction with program (range 8-40, higher scores better)			
Would you recommend the program			
Neutral			
Probably would recommend			
Definitely would recommend			
On a scale of 1-10 (1 being the least helpful program you could imagine and 10 being the most helpful program you could imagine), how would you rate this program in meeting your needs for information on health insurance?			
Treatment Engagement			
Number of sessions attended			

Table 4: Health Insurance Literacy by Demographic Factors

Please note: we will likely explore other demographics as listed in Table 1 and other outcomes as listed in Table 3

	Intervention			Control			P value
	BL N=41	FU N=37	Change	BL N=41	FU N=40	Change	
Gender							
Male							
Female							
Age at study							
26-39							
40-54							
55-66							
Medicaid expansion							
Yes							
No							

Variable	Label
ccssid	CCSS ID number
DIAGNOSE	Diagnosis
d_compq	Date of baseline completion
a_base	Age at baseline completion
d_fu4	Date of followup 4 completion
a_fu4	Age at followup 4 completion
d_fu5	Date of follow-up 5 completion
a_fu5	Age at follow-up 5
fu6type	Type of FU6 questionnaire
d_fu6	Date of follow-up 6 completion
a_fu6	Age at follow-up 6
racegroup	Race
hispgroup	Hispanic (yes/no)
cohort	
fu5	Completed FU5
fu6	Completed FU6
fu4	Completed fu4
Treatment	
mraf	Completed MRAF (yes/no)
rt_yn	Radiation (yes/no)
tbirt_yn	Total Body Irradiation (TBI), yes/no
maxsegrtdose	Maximum dose to brain (seg. 1-4), incl. TBI
crtdose	Categorized CRT dose
bmt_yn	Has patient received a hematopoietic stem cell infusion during this treatment period?
d_bmt	Date of BMT
donor_type	BMT donor type(original cohort)
bmtrel	Donor source: allogeneic related marrow
bmtunrel	Donor source: allogeneic unrelated marrow
bmtmarrow	Donor source: autologous marrow
bmtstem	Donor source: autologous stem cells
bmtcord	Donor source: cord blood
chemo_yn	Chemotherapy (yes/no)
anth_yn5	Received anthracyclines: 1st 5 years
anth_DED5	Anthracycline doxorubicin-equivalent dose (mg/sq m): 1st 5 years
alk_yn5	Received (non-platinum) alkylating agents: 1st 5 years
alk_CED5	Alkylating agent cyclophosphamide-equivalent dose: 1st 5 years
surg_yn	Surgery (yes/no)
amput_yn	Amputation (yes/no)
limbsp_yn	Limb sparing surgery (yes/no)
d_amput1	Date of 1st amputation
d_amput2	Date of 2nd amputation
amputsite1	Amputation location 1
amputsite2	Amputation location 2
d_limbsp1	Date of limb sparing surgery
limbspsite1	Limb sparing surgery location
neurosurg	Neurosurgery (yes/no)
d_neurosurg	Earliest date neurosurgery
Demographics (thru FU5)	
living	Last known living arrangement

Variable	Label
educ	Last known education
marital	Last known marital status
hincome	Last known household income
numsupp	Last known number of people in household
pincome	Last known personal income
numsupp6	Number people in household at followup 6
hincome6	Household income at followup 6
Recurrence/SMN (thru FU6)	
recur	Recurrence (yes/no)
d_recur1	Date of 1st recurrence
d_recur2	Date of 2nd recurrence
nmsc	NMSC (yes/no)
d_nmsc	Date of 1st NMSC
d_nmsc2	Date of 2nd NMSC
smn	SMN(yes/no)
d_candx	Date of 1st SMN
candxo3	Dx of 1st SMN
cansite	Site of 1st SMN
d_candx2	Date of 2nd SMN
candxo32	Dx of 2nd SMN
cansite2	Site of 2nd SMN
Chronic conditions (thru FU5)	
a_any35	Earliest age: Grade 3-5 at any time
any35	Grade 3-5 at any time
a_org2any35	Earliest age: Hearing Grade 3-5 at any time
org2any35	Hearing Grade 3-5 at any time
a_org3any35	Earliest age: Vision Grade 3-5 at any time
org3any35	Vision Grade 3-5 at any time
a_org5any35	Earliest age: Endocrine Grade 3-5 at any time
org5any35	Endocrine Grade 3-5 at any time
a_org6any35	Earliest age: Respiratory Grade 3-5 at any time
org6any35	Respiratory Grade 3-5 at any time
a_org7any35	Earliest age: Cardiovascular Grade 3-5 at any time
org7any35	Cardiovascular Grade 3-5 at any time
a_org8any35	Earliest age: GI Grade 3-5 at any time
org8any35	GI Grade 3-5 at any time
a_org9any35	Earliest age: Renal Grade 3-5 at any time
org9any35	Renal Grade 3-5 at any time
a_org10any35	Earliest age: Musculoskeletal Grade 3-5 at any time
org10any35	Musculoskeletal Grade 3-5 at any time
a_org11any35	Earliest age: Neurological Grade 3-5 at any time
org11any35	Neurological Grade 3-5 at any time