

Childhood Cancer Survivor Study Analysis Concept Form

Study Title:

Understanding Coverage Continuity, Healthcare Utilization, and Cost among Childhood Cancer Survivors Within the Medicaid System: A Report from the Childhood Cancer Survivor Study

Working Group:

This proposed project will be developed through the **Cancer Control and Intervention** (primary), **Chronic Disease** (secondary), and **Psychology** (secondary) working groups.

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I. Background and Rationale:

Importance of Studying Healthcare Use and Cost for Survivors on Medicaid

As the most important health insurance program for low-income and disabled Americans, Medicaid accounts for one-sixth of all spending in the U.S. healthcare system and finances health services for 73 million individuals, including cancer patients and survivors.¹ Given that health insurance in this country is commonly employer-sponsored, individuals who are low-income or disabled, including many cancer survivors, depend extensively on Medicaid to finance healthcare. In 2010-2012, annual Medicaid expenditures on cancer care were estimated to be nearly \$7 billion.² Under the Affordable Care Act, which has expanded Medicaid services in 37 states,³ Medicaid is playing an even larger role in providing healthcare to these medically vulnerable populations in many states.⁴ Yet, little is known about coverage patterns, covered services, and outcomes among cancer survivors participating in Medicaid programs. Furthermore, Medicaid spending constitutes one of the largest and growing portions of state budgets, accounting for nearly one-fifth of state spending.⁵ The growing costs have been a concern for state Medicaid programs, suggesting the particular importance of understanding the economic impact of cancer survivorship in this system to inform state-level efforts of managing spending and increasing efficiency of healthcare.

The lack of studies evaluating individual-level Medicaid data has, to date, made it difficult to understand the economic burden imposed by cancer survivorship within the Medicaid system. The ability to link detailed information on individual cancer diagnosis and treatment to data on Medicaid-covered services and outcomes during or after cancer treatment is especially important to track coverage, service use, and outcomes among low-income survivors in a longitudinal manner. While the NCI-supported efforts to link data from its Surveillance,

Epidemiology, and End Results (SEER) program with Medicare claims have long provided an efficient way to study cancer care, costs, and outcomes in cancer patients aged 65 and older, these SEER-Medicare files are of limited utility for analyzing childhood cancer survivorship questions.

Studies have examined health service utilization among childhood cancer survivors. These studies have reported more frequent outpatient visits and hospitalizations used by childhood cancer survivors, as compared with the general population.⁶⁻¹³ Common determinants of outpatient and inpatient care use among childhood cancer survivors include older age, certain types of cancer (e.g., central nervous system), history of high intensity therapy (e.g., radiation to the chest), having chronic conditions, and experiencing cancer reoccurrence and/or second malignancy.^{6-8,10,11,13,14} In addition, insurance type has been found as a determinant of service use among survivors.¹⁴⁻¹⁶ For example, two analyses of the Childhood Cancer Survivor Study (CCSS) reported that survivors with public insurance coverage were more likely than their privately-insured counterparts to receive survivor-focused healthcare,¹⁵ and more likely than those uninsured to seek care from primary and specialty care physicians.¹⁴ Of note, previous research on childhood cancer survivors has largely focused on individual-level determinants of healthcare use. To our knowledge, research assessing the role of contextual-level factors in service use among childhood cancer survivors has been limited. A recent study of the CCSS reported moderate associations between local area socioeconomic status and survivors' risk-based survivor-focused care.¹⁷ In this study, nonetheless, measures of healthcare utilization are exclusively self-reported.

For healthcare costs, a few studies have reported overall and mental health service costs attributable to cancer survivors; these studies largely focused on adult-onset cancers.¹⁸ However, little is known about medical costs specifically among childhood cancer survivors. Furthermore, to date, we are not aware of any study examining healthcare cost, as well as its individual- and contextual-level determinants, among low-income childhood cancer survivors in the Medicaid system.

Importance of Studying Medicaid Disenrollment Among Survivors

Despite the significance of Medicaid coverage, lack of insurance is still common among Medicaid beneficiaries due in part to disenrollment for eligible individuals. Disenrollment refers to periods of time when former enrollees lose Medicaid coverage and become either uninsured or privately insured; these episodes are often associated with a subsequent re-enrollment in Medicaid.¹⁹ In a year, approximately one in five children and one in three adults experience Medicaid disenrollment.²⁰ Importantly, the majority of beneficiaries become uninsured, at least for a short period, after losing Medicaid, rather than gaining other sources of insurance.^{21,22} This is especially true for childhood cancer survivors, who are more likely than their healthy peers to be low-income or unemployed.²³

Medicaid disenrollment is of particular concern for beneficiaries surviving cancer. A lack of Medicaid coverage may impede access to general and survivor-focused care and disrupt treatment continuity during periods with no insurance coverage.^{24,25} Research has suggested that many survivors require lifelong outpatient healthcare to monitor and treat cancer-related morbidities.^{26,27} Discontinuity in these interventions may compromise survivors' health status, potentially triggering adverse events or complications. Furthermore, because of the discontinuity in ongoing survivorship care and the inability to establish an enhanced patient-provider relationship, disenrollment can create difficulties for healthcare providers in managing care of survivors with late medical and psychiatric comorbidities.²⁸ In addition, administrative costs can be higher for beneficiaries who experience disenrollment, compared to those continuously enrolled.²⁸ The administrative cost of reenrolling a person who dis-enrolled from Medicaid ranged from \$400 to \$600 per person in 2015.²⁹ Thus, unstable Medicaid coverage for survivors, even if temporary, poses significant public health and policy problems. However,

to date, no data have existed on Medicaid enrollment and disenrollment patterns among childhood cancer survivors.

A number of factors may explain disenrollment. First, some states made Medicaid eligibility recertification processes stringent, leading to fewer Medicaid caseloads and ultimately lower Medicaid expenditures.^{30,31} For example, states may require biannual or even monthly eligibility recertification, or enforce face-to-face interview requirements at eligibility renewal.^{32,33} These policies required beneficiaries to revisit the social welfare office and provide documentation to prove eligibility biannually or even more frequently, imposing substantial burden on individuals and families in terms of increased time and paperwork. Thus, more stringent eligibility recertification policies may exacerbate disenrollment.³⁰ Other factors contributing to disenrollment include: incorrect paperwork or certification data, the lack of a timely reminder or notification of eligibility recertification from the program, and inadequate or non-existing application assistance and outreach efforts.³⁴⁻³⁷ For those with serious diseases like cancer, disenrollment may also occur due to difficulty in responding to program communications and completing the complicated paperwork required to maintain coverage.³⁸ These vulnerable individuals may also experience instability in housing, leading to high mobility; they may lose Medicaid when failing to receive notices of recertification due to address changes.³⁷

Conceptual Framework

According to the behavioral model of health service use by Andersen,^{39,40} both individual- and contextual-level factors can determine the use of the healthcare system (**Exhibit 1**). Three types of factors are considered in the model: (1) predisposing factors, which affect the inclination to use health services and primarily include demographic factors (e.g., age, sex); (2) need factors, which include evaluated or perceived health status that affect healthcare use (e.g., chronic conditions, cancer experience); and (3) enabling factors, which are resources available to facilitate care use (e.g., socioeconomic status, availability of primary care clinicians and cancer specialists in community, state Medicaid policy).^{39,40} The model also suggests a relationship between these factors and Medicaid disenrollment.

More specifically, cancer experience may be associated with Medicaid disenrollment. Survivors may be more likely than their healthy peers to participate in the Medicaid program, potentially because of cancer-related chronic conditions and associated healthcare needs. Survivors are also more likely than healthy peers to be low-income or unemployed,²³ and thereby, more likely to resort to Medicaid for insurance coverage. Of those on Medicaid, survivors may be more likely than healthy peers to experience coverage discontinuities because survivors may experience instability in health status and thus the ability to work, leading to fluctuations in their income and changes in Medicaid eligibility. Some survivors may be too ill to respond to program communications and complete the complicated paperwork required to maintain Medicaid coverage. Conversely, survivors may be less likely than healthy peers to experience Medicaid discontinuities due to their constant engagement in the healthcare system to treat and manage cancer-related chronic conditions.

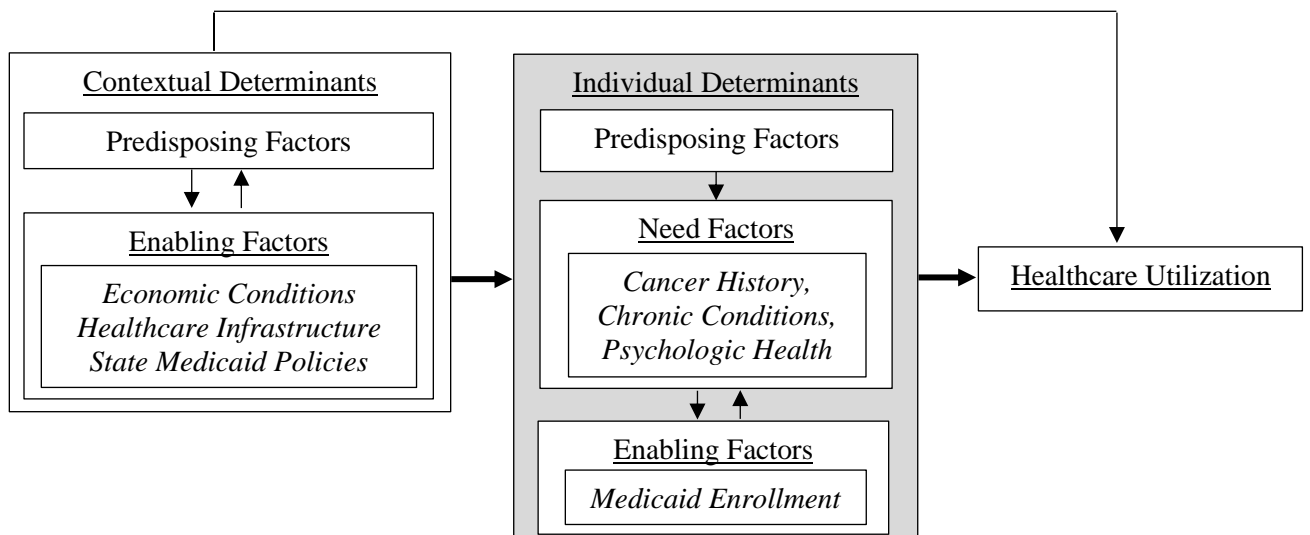
In addition, survivors residing in socioeconomically disadvantaged communities, where local norms place lower value on being insured, could experience higher rates of Medicaid disenrollment, based on the contagion theory;⁴¹⁻⁴⁴ survivors are also likely to experience more emergency visits, given inadequate capacity and low quality of outpatient services, including general care and survivor-focused care, in these communities.⁴⁵⁻⁴⁷ Survivors living in communities with fewer healthcare providers are more likely to experience Medicaid disenrollment, because healthcare is less geographically accessible and providers in these areas are less likely to assist survivors in Medicaid eligibility renewal;^{30,35,48} survivors in these communities, where they have less geographic access to outpatient care, could also incur more emergency visits.⁴⁹⁻⁵²

State Medicaid policies – including provider reimbursement, Medicaid benefit generosity, and streamlined enrollment procedures – are also important determinants of service use and Medicaid disenrollment. Provider reimbursement refers to payment for services remitted by insurance companies to qualified healthcare providers.⁵³ Lower level of reimbursement from Medicaid could increase emergency visits, because providers are less incentivized to treat Medicaid-enrolled survivors in offices and more likely to refer these survivors to ED;⁵⁴⁻⁵⁶ lower reimbursement level may also be associated with higher Medicaid disenrollment rate due to poorer access to care and lower perceived benefits of participation in Medicaid.^{30,56} Medicaid benefit generosity refers to cost-sharing requirements and scope of services covered that can shift the trade-off survivors face in deciding whether to enroll in Medicaid.⁵⁷ Less generous benefits are likely associated with higher rates of Medicaid disenrollment due to reduced attractiveness of Medicaid,^{30,58,59} and associated with more emergency visits due to poorer access to outpatient care (resulted from disenrollment).^{50,59,60} Medicaid streamlined enrollment procedures refers to state policies that reduce the burden of Medicaid application/renewal process in terms of time, information, and documentation.⁶¹ By minimizing the need for visits with caseworkers in welfare or Medicaid offices, these policies make the enrollment process less onerous⁶¹ through, for example, the elimination of an in-person interview and the requirement of annual eligibility renewal.⁶² Thus, more streamlined enrollment procedures may be associated with lower disenrollment rate,^{61,63,64} it can also reduce emergency visits through improving continuity of coverage for needed care and preventing acute conditions.

Significance

The proposed study will link the survey and medical data from the CCSS and national Medicaid claims data to provide valuable insights into understanding insurance coverage patterns, health service utilization, and the resulting economic burden of childhood cancer survivors placed on the Medicaid system, and how this might vary by cancer history and survivors’ chronic condition characteristics. This study will also link the CCSS data with county-level data from the Area Health Resources File (AHRF) and state policy data. Understanding associations between social context and survivors’ health service use will inform the development of future public health and policy interventions at various levels (communities, systems, and states) to assure effective access to care and improve health outcomes among low-income childhood cancer survivors.

Exhibit 1. Proposed determinants of health service utilization in cancer survivors on the basis of the Andersen behavioral model of healthcare utilization.^{39,40}



II. Specific Aims and Research Hypotheses:

Aim 1: Of all eligible individuals in CCSS cohort, describe (i) the proportion of those partially or fully enrolled in Medicaid during the study period among survivors and siblings; and (ii) the characteristics (cancer treatment [e.g., radiation therapy, chemotherapy], chronic condition, local socio-demographics) of survivors partially or fully on Medicaid, as compared to all other survivors (i.e., survivors with no insurance, private insurance, or other insurance).

Hypothesis 1a: Survivors will have a higher rate of Medicaid uptake (i.e., higher proportion for those partially or fully enrolled in Medicaid), compared with siblings.

Hypothesis 1b: Among survivors, those exposed to high intensity therapy (e.g., radiation to chest/pelvis/abdomen/etc., anthracyclines of ≥ 300 mg/m²) will have a higher rate of Medicaid uptake.

Hypothesis 1c: Among survivors, those with multiple or more severe types of chronic medical conditions or with psychological health problem (i.e., emotional distress, cancer-related anxiety) will have a higher rate of Medicaid uptake.

Hypothesis 1d: Among survivors, those living in rural areas and socioeconomically disadvantaged communities will have a higher rate of Medicaid uptake.

Aim 2: Of those partially or fully enrolled in Medicaid, describe (i) patterns of Medicaid disenrollment (i.e., loss of Medicaid coverage in former enrollees, with and without subsequent re-enrollment in Medicaid) among survivors and siblings; and (ii) whether survivors' Medicaid disenrollment patterns are associated with cancer treatment, chronic conditions, local sociodemographic and healthcare infrastructure characteristics, and Medicaid policy parameters.

Hypothesis 2a: Survivors will be more likely (or less likely; both directions could be possible as elaborated in "Conceptual Framework" above) than siblings to experience Medicaid disenrollment.

Hypothesis 2b: Among survivors, those with multiple or more severe types of chronic medical conditions or with psychological health problem will be less likely to experience Medicaid disenrollment.

Hypothesis 2c: Among survivors, those living in rural areas, socioeconomically disadvantaged communities, and communities with less accessibility to healthcare resources will be more likely to experience Medicaid disenrollment.

Hypothesis 2d (exploratory): Among survivors, those living in states with certain Medicaid policy parameters – better provider reimbursement rate, better scope of covered services, reduced cost-sharing, streamlined eligibility recertification procedures – will be less like to disenroll from Medicaid.

Aim 3: Of those continuously enrolled in Medicaid, describe (i) service use and costs, overall and by care settings (outpatient, hospitalization, emergency department [ED], pharmacy) among survivors, as compared to siblings; and (ii) whether survivors' service use and costs are associated with treatment exposures, chronic conditions, local sociodemographic and healthcare infrastructure characteristics, and Medicaid policy parameters.

Hypothesis 3a: Medicaid-covered service use and expenditures will be higher among survivors than among siblings.

Hypothesis 3b: Among survivors, longer-term survivors, survivors with younger age of diagnosis, older survivors, and survivors exposed to high intensity therapy (e.g., radiation to chest/pelvis/abdomen/etc., anthracyclines of ≥ 300 mg/m²) will have greater service use and Medicaid expenditures.

Hypothesis 3c: Among survivors, those with more severe types of chronic medical conditions or with psychological problems will have higher utilization of services and higher Medicaid expenditures.

Hypothesis 3d: Among survivors, those living in socioeconomically disadvantaged communities and communities with less accessibility to healthcare resources will be less likely to use outpatient services and more likely to have emergency visits.

Hypothesis 3e (exploratory): Among survivors, those living in states with the Medicaid policy parameters as described above (in H2d) will be more likely to use outpatient services and less likely to have emergency visits.

III. Analysis Framework:

External Data Sources:

- **Medicaid Research Files**. The CCSS data will be linked to the Medicaid Analytic eXtract (MAX) Files and the Transformed Medicaid Statistical Information System Analytic Files (TAF; the new generation of MAX files).^{65,66} The MAX/TAF Files are administered by the Centers for Medicare and Medicaid Services (CMS), and provide individual-level information on Medicaid eligibility types, Medicaid enrollment and disenrollment, service utilization, and Medicaid payments. For the current project, we propose to link CCSS data (2014 and 2017 CCSS survey years for the original cohort, and the baseline survey for the expansion cohort) with 2014-2016 MAX/TAF Files (our pilot funding available in hand can support access to 3 years' Medicaid data). The 2016 data will be the most updated Medicaid data available at the projected start date for this study. The 2014 and 2017 CCSS survey will be used because they are the closest to the proposed years of Medicaid data. Notably, the current pilot project will set the foundation for our extramural funding applications to support larger-scale, follow-up studies that will link more years of Medicaid data with CCSS data.

The Medicaid research files include five data files in a given year. The eligibility files comprise individual-level records for all individuals who were enrolled in Medicaid for at least one day over the year. These files provide information on individual-level demographic characteristics (e.g. date of birth, race/ethnicity, sex), Medicaid eligibility types (e.g., poverty versus disability), monthly enrollment status, Medicare dual eligible status, Medicaid managed care coverage, and geographic location (e.g., zip code, state and county FIPS codes). The inpatient files comprise hospital stay records for Medicaid enrollees who were hospitalized. These files provide information on diagnosis codes, procedure codes, length of stay, and payment associated with each hospitalization. The prescription drug files provide information on NDC code, medication supply days, and dosages associated with each filled prescription medication. The long-term care files comprise claim records for services delivered in long-term care facilities, including intermediate care facilities, independent psychiatric facilities, and skilled nursing facilities. The other service files comprise claim-level records not included in the aforementioned Medicaid files, including physician and other provider services, hospital outpatient services, laboratory and radiologic services, clinic services, and dental services. These files provide information on date of service and the diagnosis and procedure associated with each service (with at most two diagnosis codes and one procedure code per claim).

Linkage procedures: MAX/TAF Files will be linked with the CCSS data to identify a cohort of childhood cancer survivors who had any Medicaid coverage during the study period. The linkage will be conducted using the following individual-level variables: Social Security Number, date of birth, and sex (residential zip code optional). Per CMS procedures, a strict/deterministic match using these individual-level variables will be conducted by statisticians at the Chronic Conditions Warehouse (CCW) contracted by CMS; results on matching will then be returned by CCW.⁶⁷ Individuals matched on these identifiers will be included in the analytic sample. Data checks for the completeness of claims will be performed using methods suggested by Hennessy et al.⁶⁸ Specifically, we will examine the number of enrollees with an outpatient medical claims, the number of claims for dispense medication prescriptions, and the number of enrollees with an inpatient hospitalization claim, on a monthly basis, to identify any obvious blocks of missing claims for certain time periods. To check the overall validity of demographic and clinical data, we will also compare participants' self-reported demographic data (e.g., race/ethnicity), chronic conditions, and medical service use in the CCSS data with their demographic, diagnostic, and utilization information on Medicaid claims.

- **Area Health Resources File.** The AHRF⁶⁹ is a national data file providing information on healthcare facilities, healthcare professions, measures of resource scarcity, socioeconomic and environmental characteristics, and local economic circumstances for almost every U.S. county. Measures in the AHRF (in the same year as the year of the linked Medicaid data) will be merged with the linked CCSS-Medicaid data using residence state and county FIPS codes.
- **State Medicaid Policy Data.** State Medicaid policy characteristics will be drawn from statistics compiled by the Kaiser Family Foundation, the Kaiser Commission on Medicaid and the Uninsured, the Centers for Medicare and Medicaid Services, and published articles.⁷⁰⁻⁷² These resources, put together, will provide state-level information on the eligibility requirements, administration structure, financing, and general covered services of state Medicaid programs. These policy data (in the same year as the year of the linked Medicaid data) will be merged with the CCSS-Medicaid data using residence state FIPS code.

Sample Inclusion

Study participants will include a cohort of childhood cancer survivors and siblings who (1) will be identified from the CCSS original or expansion cohorts and (2) 21-64 years of age in the observation period (sample for **Aim 1**). Of these, individuals fully or partially enrolled in Medicaid are defined as those who appear in the Medicaid claims data (i.e., have at least one-month Medicaid enrollment during the study period). We focus on individuals aged 21-64 years because, in Medicaid claims data, the majority of enrollees aged <21 years have missing values in their SSN, a crucial variable for the proposed data linkage. In contrast, the completeness of SSN for enrollees age ≥21 years in MAX is high (greater than 95% -- see "Special Consideration" below).⁷³ We expect that these inclusion criteria will yield at minimum 2,254 Medicaid-insured survivors and 100 Medicaid-insured siblings in the linked dataset (sample for **Aim 2**; see detailed sample size calculation in "Special Consideration" below).

When examining healthcare service use and cost (**Aim 3**), we will further restrict survivors and siblings to those with continuous Medicaid enrollment for at least a full year to capture complete profiles of service receipt and outcomes within the Medicaid system in a given year. Continuous Medicaid enrollment will be defined as having Medicaid coverage for at least six months over the calendar year (contingent on the size of sample linked, we may make this definition more restricted [e.g., having Medicaid coverage for at least 12 months]). Notably, participants with dual Medicare-Medicaid eligibility (available in Medicaid data) will be excluded

from the analysis, because of the commonly incomplete data for the services billed to Medicare, particularly inpatient hospitalization claims.^{68,74}

Variables:

Outcome variables (from Medicaid data):

- Medicaid uptake (Aim 1) will be assessed by a dichotomous variable identifying whether individuals have at least some Medicaid enrollment (versus no Medicaid) during the study period.
- Medicaid disenrollment (Aim 2) will be assessed by a dichotomous variable identifying whether an individual has at least one Medicaid coverage disruption (versus continuous enrollment) over the calendar year. A coverage disruption will be defined as an enrollment gap of one month or longer.^{75,76} A secondary measure will be a continuous variable reflecting the total number of months without Medicaid coverage over a calendar year; this variable will be zero for individuals with continuous enrollment. These measures will be created using the monthly data on Medicaid enrollment status available in MAX/TAF.
- Healthcare service use (Aim 3) will be assessed by the numbers of all-cause ED visits, inpatient episodes, inpatient days, and outpatient visits. ED visits will be identified from the other services and inpatient files of Medicaid data following recommended approaches.⁷⁷ The numbers of inpatient episodes and inpatient days will be determined using the start and end dates of inpatient claims to ensure that a single episode will not counted as multiple hospitalizations.⁷⁵ Outpatient visits will be calculated using all claims, except for ED claims, identified from the other service files.
- Service costs (Aim 3) will be calculated based on the dollar amounts paid by Medicaid as indicated in claims, not on provider charges. Costs will be classified as: (1) all-cause costs on all visits, regardless of setting or diagnosis; (2) costs on ED visits and inpatient hospitalizations; (3) medication costs on all filled prescriptions; and (4) outpatient costs on all visits except for ED visits, inpatient hospitalizations, and filled prescriptions. For comparison purposes, all cost estimates will be adjusted to 2014 U.S. dollars using the gross domestic product deflator.⁷⁸

Independent Variables:

- Individual-level predictors (from CCSS data) will include individual-level sociodemographic characteristics (age in the observation period [i.e., the year when the CCSS participant's Medicaid claims were linked], sex, race/ethnicity, level of education, marital status, employment status, household income), survivors' cancer history (type of cancer, age at diagnosis, years since diagnosis, cancer treatment [chemotherapy, radiation therapy, surgery]), and chronic conditions (presence of severe/life-threatening chronic medical conditions [grade 3-4], bodily pain intensity (based on SF-36 subscale), second malignancy, cancer recurrence, emotional distress (defined as having a T-score score ≥ 63 on any two symptom scales or on the summary GSI scale, according to BSI-18 manual), and cancer-related anxiety.

Of note, we will use CCSS data (2014 and 2017 surveys for the original cohort, and baseline survey for the expansion cohort) to link with 2014-2016 Medicaid data. For each CCSS participant who will be linked to their Medicaid claims, we will compare the availability and value of each survey measure of our interest (described above) in all survey years, and then decide the algorithm/assumption to address any potential difference in the measure across survey years. All individual-level variables that will be extracted from the CCSS survey, along with their available survey years and survey questions, are summarized in **Exhibit 3**.

- Local area level predictors (from the AHRF) will include county sociodemographic characteristics (poverty rate, unemployment rate, racial/ethnic composition, urbanicity) and measures of healthcare resources (numbers of primary care physicians, mental health clinicians, cardiovascular disease specialists, and community health centers per capita in the county). Zip code of residence for survivors and siblings will be used to link measures from AHRF with CCSS data. Consistent with prior research,¹⁷ to measure geographic access to specialty cancer care services, we will also include the number of CCSS participating institutions within a 100-radius of the survivor's zip code of residence (from CCSS data).
- State Medicaid policy predictors (from published reports) will include Medicaid provider reimbursement rate, state Medicaid income threshold, total Medicaid spending per capita, Medicaid eligibility recertification protocols (eligibility recertification frequency, requirement of face-to-face interviews at recertification), and copayment rates for medical visits and prescription drugs. Zip code of residence for survivors and siblings will be used to link these state policy measures with CCSS data.

Statistical Analyses:

Using the linked dataset, a CCSS statistician will help with the proposed statistical analysis. Descriptive statistics -- including percentages, means, and standard deviations -- will first be provided, with statistical tests as appropriate (chi-squared test for categorical/dichotomous variables; t-test for continuous variables), to describe and compare sample characteristics between survivors and siblings. Multivariable regression analyses will then be performed to assess associations of contextual- and individual-level predisposing, enabling, and need factors with the outcomes of interest. In the models including siblings, Generalized Estimating Equation will be used to account for the within-family correlation among survivors and siblings. SAS statistical software will be used for all analysis.

Aim 1: Of all eligible individuals in CCSS cohort, describe (i) the proportion of those partially or fully enrolled in Medicaid during the study period among survivors and siblings; and (ii) the characteristics of survivors partially or fully on Medicaid, as compared to all other survivors.

Analyses: Descriptive statistics will be provided to describe the sample characteristics (cancer history, chronic condition, local sociodemographic factors) between those with at least some Medicaid enrollment versus those with no Medicaid throughout the study period, among survivors and siblings (**Table 1**). Two-sample t test will be performed for continuous variables, and χ^2 test will be performed for categorical variables.

Aim 2: Of those partially or fully enrolled in Medicaid, describe (i) patterns of Medicaid disenrollment among survivors and siblings; and (ii) whether survivors' Medicaid disenrollment patterns are associated with cancer treatment, chronic conditions, local sociodemographic and healthcare infrastructure characteristics, and Medicaid policy parameters.

Analyses: Descriptive statistics will first be provided to describe the rate and total months of disenrollment among survivors and siblings (**Table 2**). Multivariable regression analysis will be conducted to estimate the model-adjusted differences between survivors and siblings in patterns of Medicaid disenrollment (**Table 2**). The likelihood of experiencing any Medicaid disenrollment will be analyzed using a logistic regression model. A zero-inflated Poisson model will be analyzed for total counts of disenrollment months. Among survivors, individual-level (cancer type, cancer treatment, chronic conditions), county-level (local sociodemographic factors, healthcare infrastructure), and state-level Medicaid policy predictors will be included in multivariable regression analysis as a function of Medicaid disenrollment (**Table 3**). The variance inflation factor will be estimated to ensure there will be no serious multicollinearity in all regression models.

Aim 3: Of those continuously enrolled in Medicaid, describe (i) service use and costs, overall and by care settings among survivors, as compared to siblings; and (ii) whether survivors' service use and costs are associated with treatment exposures, chronic conditions, local sociodemographic and healthcare infrastructure characteristics, and Medicaid policy parameters.

Analyses: Descriptive statistics will first be provided to describe visits and costs among survivors versus siblings (**Table 2**). Service use and cost measures will be standardized to per person per Medicaid-covered month. Multivariable regression analysis will be conducted to estimate the model-adjusted differences between survivors and siblings in service use and costs, adjusting for individual-level sociodemographic characteristics (**Table 2**). Service use and costs will be analyzed using two-part models with a logit model in the first part (estimating the probability of having any visit/cost) and a GLM with a log link and gamma distribution in the second part (estimating total visits/costs given that they are non-zero).⁷⁹ This technique will accommodate the skewed distribution of visits and costs, and produce robust estimates even in the presence of heteroskedasticity.^{79,80} Modified Park test that recommends a family given a link function will be conducted.⁸¹ If the test will not support the initial choice of models, alternative model specifications, such as Gaussian distribution, will be considered.⁸¹ Similarly to Aim 1, among survivors, individual-, county, and state-level predictors will be included in multivariable regression analysis as a function of service use (**Table 4**) and Medicaid costs (**Table 5**).

IV. Special Considerations:

First, as with other claim data-based studies, claims data rely on physician diagnoses and thus may be inaccurate due to coding errors or misdiagnosis.⁸² Second, Medicaid data do not provide information on services not Medicaid-reimbursed. Therefore, the findings cannot reflect all care experiences of Medicaid-enrolled survivors. However, the Medicaid data are the best source available to provide accurate estimates of services used by childhood cancer survivors visible to the Medicaid system.

Third, according to CMS, participants' name is not available in the MAX/TAF files; participants' social security number (SSN) will be the key variable (along with date of birth and sex) to perform the proposed data linkage. The completeness of the SSN variable in the MAX/TAF data is around 95% in the states where the CCSS institutions are located. Notably, records with missing SSN in MAX/TAF (around 5%) largely concentrate in Medicaid enrollees aged 20 years or younger.⁷³ This issue is less likely to affect our analysis because we will focus on adult Medicaid enrollees aged at least 21 years. In CCSS data, the proportion of the cohort participants with complete SSN is estimated to be 68% (73% among survivors and 40% among siblings, respectively; see **Exhibit 2**). In addition, according to a previous CCSS report,⁸³ approximately 12% of survivors and 5% of siblings are covered by Medicaid in a given year. Accordingly, the estimated sample size of Medicaid-insured survivors in the final linked dataset will be approximately 2,254 (25,746 [total number of survivors in CCSS cohort] x 73% [percentage of adult survivors with complete SSN] x 12% [percentage of survivors on Medicaid at a time point]). Similarly, the estimated sample size of siblings in the linked dataset will be 100 (5,034 [total number of siblings in CCSS cohort] x 40% [percentage of siblings with complete SSN] x 5% [percentage of siblings on Medicaid at a time point]).

We expect this a minimum estimation of the numbers of Medicaid-insured survivors and siblings in our data. Individuals may be on-and-off Medicaid over time, and thereby, the true percentage of survivors and siblings who have ever been on Medicaid could be larger. Moreover, this earlier CCSS report occurred before the ACA's Medicaid expansion (in 2010-2011).⁸³ Under the ACA, Medicaid expansion became effective on January 1, 2014 for states that opted for expansion,⁸⁴ as well as 8 states (CA, CT, CO, DC, MN, MO, NJ, and WA) that expanded earlier (2010-2012).⁸⁵ Thus, we expect to see a greater proportion of Medicaid-

covered survivors and siblings than in the earlier estimation. Upon the approval of this proposal, we will first use the information on insurance coverage available in recently released Follow-Up 6 Questionnaire to provide a more recent estimate of the sample size of Medicaid-insured survivors and siblings.

Exhibit 2. Completeness of Social Security Number (SSN) in CCSS cohorts

Row Labels	Count of SSN	%
Survivors		
Expanded Case	11,386	
No	4,149	36%
Partial	122	1%
Yes	7,115	62%
Original Case	14,360	
No	2,814	20%
Partial	17	0%
Yes	11,529	80%
Total of Survivors	25,746	
No	6,963	27%
Yes or partial	18,783	73%
Siblings		
Expanded Siblings	1,007	
No	1,007	0%
Original Siblings	4,027	
No	2,005	50%
Partial	1	0%
Yes	2,021	50%
Total of Siblings	5,034	
No	3,012	60%
Yes or partial	2,022	40%
Total		
Grand Total	30,780	
No	9,975	32%
Yes or partial	20,805	68%

Exhibit 3. Summary of Included Survey Information from CCSS Survey

Variable	CCSS Survey Questions	Available Survey Years
Age	“What is your date of birth”	Baseline, Follow-up 2000, Follow-up 2003, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline
Sex	“What is your sex”	
Race/ethnicity	“To which one of the following (race/ethnicity) groups do you belong” “Are you Hispanic”	
Level of education	“What is the highest grade or level of schooling that you have completed” “If you have completed high school, did you receive a regular high school diploma or did you receive a high school equivalency certificate, also called a GED”	
Current marital status	“Which of these possibilities best describes your current marital status”	
Current employment status	“What is your current employment status? Include unpaid work in the family business or farm”	

	or “During the last 12 months, did you work at any time at a job or business, not counting work around the house (Include unpaid work in the family business or farm)” / “How long has it been since you last worked at a job or business” / “What kind of business or industry was this job in?” (from Baseline)	
Household income	“Over the last year, what is the total income of the household you live in”	Baseline, Follow-up 2003, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline
Presence of severe/life-threatening chronic medical conditions	“The next series of questions related to medical conditions that have ever occurred in your lifetime...Please indicate...if a doctor or other health care professional has told you that you have any of the following conditions...please give your approximate age when you were first told about this condition”	Baseline, Follow-up 2000, Follow-up 2007, Follow-up 2014, and Expansion Baseline
Bodily pain	“How much bodily pain have you had during the past 4 weeks”	Baseline, Follow-up 2003, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline
Cancer-related anxiety	“Do you currently have anxieties/fears as a result of your cancer, leukemia, tumor or similar illness, or its treatment”	Baseline, Follow-up 2000, Follow-up 2003, Follow-up 2005, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline
Second malignancy/ Cancer recurrence	“The following questions...relate to the diagnosis of another cancer, leukemia, tumor, or other similar illness, or a recurrence (relapse) of your original diagnosis, which has occurred since the first one” or “Have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse) since you last provided us information in...”	Baseline, Follow-up 2000, Follow-up 2003, Follow-up 2005, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline
Emotional distress	“...mark the circle to the right that best describes how much that problem has distressed or bothered you during the past 7 days including today” (i.e., Brief Symptom Inventory-18)	Baseline, Follow-up 2003, Follow-up 2007, Follow-up 2014, Follow-up 2017, and Expansion Baseline

Table 1. Sample characteristics among childhood cancer survivors and siblings [Aims 1]

	Individuals fully or partially enrolled in Medicaid		Individuals with no Medicaid during study period		p-value (comparing two survivor groups)
	Survivors (n=)	Siblings (n=)	Survivors (n=)	Siblings (n=)	
Individual-level predictors, %			---	---	---
Age in the observation period, years			---	---	---
21-29			---	---	---
30-39			---	---	---
40 and older			---	---	---
Sex					
Male					
Female					
Race/ethnicity					
Non-Hispanic white					
Non-Hispanic black					
Hispanic/Latino					
Other					
Education [§]					
High school or less					
Some college or more					
Marital status [§]					
Married					
Unmarried					
Employment status [§]					
Unemployed					
Employed, student, and caring for home					
Household income [§]					
Less than \$40K					
\$40K - \$79K					
Over \$80K					
Chronic medical conditions [§]					
Grade 0, 1, 2					
Grade 3, 4					
Emotional distress [§]					
No					
Yes					
Bodily pain [§]					
None, very mild, mild					
Moderate, severe, very severe					
Cancer-related anxiety [§]					
None, a small amount		---		---	
Moderate, a lot, extreme		---		---	
Secondary cancers					
No		---		---	
Yes		---		---	
Recurrence of primary malignancy					
No		---		---	
Yes		---		---	
Type of cancer					
Leukemia		---		---	
Central nervous system		---		---	
Hodgkin's lymphoma		---		---	

Neuroblastoma		---		---	
Wilms (kidney) tumor		---		---	
Soft tissue sarcoma		---		---	
Bone		---		---	
Non-Hodgkin's lymphoma		---		---	
Age at diagnosis		---		---	
0 – 4		---		---	
5 – 10		---		---	
11 – 15		---		---	
16 – 20		---		---	
Years since diagnosis		---		---	
≤20		---		---	
21 – 30		---		---	
>30		---		---	
Received chemotherapy		---		---	
Any		---		---	
None		---		---	
Received radiation		---		---	
Any		---		---	
None		---		---	
County-level predictors, mean (SD), median, range					
Percent of county residents below poverty					
Unemployment rate					
Percent of non-white county residents					
Percent of urban population					
No. of primary care physicians per capita					
No. of mental health clinicians per capita					
No. of cardiovascular disease specialists per capita					
No. of community health centers per capita					
No. of CCSS centers within 100 miles					
State-level predictors					
State Medicaid income threshold, mean (SD), median, range					
Total Medicaid spending per capita, mean (SD), median, range					
Medicaid provider reimbursement rate, mean (SD), median, range					
Annual (vs. more frequently) eligibility recertification, %					
Face-to-face interviews at recertification (vs. not required), %					
Copayment rate, mean (SD), median, range					

Note: §An individual-level measure from the CCSS data, which will be extracted from the CCSS survey in the same year as (or the year closest to) the year of the participant's linked Medicaid claims data.

Table 2. Estimates of outcome measures between childhood cancer survivors and siblings insured with Medicaid [Aim 2, Aim 3]

Outcome variables	Among those partially or continuously enrolled in Medicaid		
	Survivors (n=)	Siblings (n=)	Model-adjusted difference [†]
Medicaid disenrollment			
Any enrollment disruption (vs. continuous enrollment) over the year, %			
Total months of enrollment disruptions in a year, <i>mean (SD), median, range</i>			
	Among those continuously enrolled in Medicaid		
	Survivors (n=)	Siblings (n=)	Model-adjusted difference [†]
Service use per person per Medicaid-covered month, <i>mean (SD), median, range</i>			
Number of ED visits			
Number of inpatient episodes			
Inpatient days			
Number of non-ED outpatient visits			
Cost per person per Medicaid-covered month, <i>mean (SD), median, range</i>			
Total all-cause cost			
Cost of outpatient care			
Cost of filled prescriptions			
ED and/or inpatient services cost			

Notes: [†]Marginal effects reported. Regression models adjust for individual-level sociodemographic characteristics, including age at observation, sex, race/ethnicity, education, marital status, employment status, household income, chronic medical conditions, emotional distress, and bodily pain.

Table 3. Individual-, county-, and state-level predictors of Medicaid disenrollment among childhood cancer survivors [Aim 2]

	Any enrollment disruption (vs. continuous enrollment), %	Total duration of enrollment disruptions, in months
	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Individual-level predictors		
Age in the observation period		
21-29		
30-39		
40 and older		
Sex		
Male		
Female		
Race/ethnicity		
Non-Hispanic white		
Non-Hispanic black		
Hispanic/Latino		
Other		
Education		
High school or less		
Some college or more		
Marital status		
Married		
Unmarried		
Employment status		
Unemployed		
Employed, student, and caring for home		
Household income		
Less than \$40K		
\$40K - \$79K		
Over \$80K		
Chronic medical conditions		
Grade 0, 1, 2		
Grade 3, 4		
Emotional distress		
No		
Yes		
Bodily pain		
None, very mild, mild		
Moderate, severe, very severe		
Cancer-related anxiety		
None, a small amount		
Moderate, a lot, extreme		
Secondary cancers		
No		
Yes		
Recurrence of primary malignancy		
No		
Yes		
Type of cancer		
Leukemia		
Central nervous system		
Hodgkin's lymphoma		

Table 3 (Continued). Individual-, county-, and state-level predictors of Medicaid disenrollment among childhood cancer survivors [Aims 2]

	Any enrollment disruption (vs. continuous enrollment), %	Total duration of enrollment disruptions, in months
	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Type of cancer		
Neuroblastoma		
Wilms (kidney) tumor		
Soft tissue sarcoma		
Bone		
Non-Hodgkin's lymphoma		
Age at diagnosis		
0 – 4		
5 – 10		
11 – 15		
16 – 20		
Year since diagnosis		
≤20		
21 – 30		
>30		
Received chemotherapy		
Any		
None		
Received radiation		
Any		
None		
County-level predictors		
Percent of county residents below poverty		
Unemployment rate		
Percent of non-white county residents		
Percent of urban population		
Number of primary care physicians per capita		
Number of mental health clinicians per capita		
Number of cardiovascular disease specialists per capita		
Number of community health centers per capita		
Number of CCSS centers within 100 miles		
State-level predictors		
State Medicaid income threshold		
Total Medicaid spending per capita		
Medicaid provider reimbursement rate		
Annual (vs. more frequently) eligibility recertification		
Face-to-face interviews at recertification (vs. not required)		
Copayment rate		

Table 4. Individual-, county-, and state-level predictors of healthcare service use among Medicaid-enrolled childhood cancer survivors [Aim 3]

	No. of ED visits	No. of inpatient episodes	Inpatient days	No. of non-ED outpatient visits
	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Individual-level predictors				
Age in the observation period				
21-29				
30-39				
40 and older				
Sex				
Male				
Female				
Race/ethnicity				
Non-Hispanic white				
Non-Hispanic black				
Hispanic/Latino				
Other				
Education				
High school or less				
Some college or more				
Marital status				
Married				
Unmarried				
Employment status				
Unemployed				
Employed, student, and caring for home				
Household income				
Less than \$40K				
\$40K - \$79K				
Over \$80K				
Chronic medical conditions				
Grade 0, 1, 2				
Grade 3, 4				
Emotional distress				
No				
Yes				
Bodily pain				
None, very mild, mild				
Moderate, severe, very severe				
Cancer-related anxiety				
None, a small amount				
Moderate, a lot, extreme				
Secondary cancers				
No				
Yes				
Recurrence of primary malignancy				
No				
Yes				
Type of cancer				
Leukemia				
Central nervous system				

Table 4 (Continued). Individual-, county-, and state-level predictors of healthcare service use among Medicaid-enrolled childhood cancer survivors [Aim 3]

	No. of ED visits	No. of inpatient episodes	Inpatient days	No. of non-ED outpatient visits
	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Type of cancer				
Hodgkin's lymphoma				
Neuroblastoma				
Wilms (kidney) tumor				
Soft tissue sarcoma				
Bone				
Non-Hodgkin's lymphoma				
Age at diagnosis				
0 – 4				
5 – 10				
11 – 15				
16 – 20				
Year since diagnosis				
≤20				
21 – 30				
>30				
Received chemotherapy				
Any				
None				
Received radiation				
Any				
None				
County-level predictors				
Percent of county residents below poverty				
Unemployment rate				
Percent of non-white county residents				
Percent of urban population				
Number of primary care physicians per capita				
Number of mental health clinicians per capita				
Number of cardiovascular disease specialists per capita				
Number of community health centers per capita				
Number of CCSS centers within 100 miles				
State-level predictors				
State Medicaid income threshold				
Total Medicaid spending per capita				
Medicaid provider reimbursement rate				
Annual (vs. more frequently) eligibility recertification				
Face-to-face interviews at recertification (vs. not				
Copayment rate				

Table 5. Individual-, county-, and state-level predictors of Medicaid costs among Medicaid-enrolled childhood cancer survivors [Aim 3]

	Total cost	Cost of outpatient care	Cost of filled prescriptions	ED and inpatient cost
	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Individual-level predictors				
Age in the observation period				
21-29				
30-39				
40 and older				
Sex				
Male				
Female				
Race/ethnicity				
Non-Hispanic white				
Non-Hispanic black				
Hispanic/Latino				
Other				
Education				
High school or less				
Some college or more				
Marital status				
Married				
Unmarried				
Employment status				
Unemployed				
Employed, student, and caring for home				
Household income				
Less than \$40K				
\$40K - \$79K				
Over \$80K				
Chronic medical conditions				
Grade 0, 1, 2				
Grade 3, 4				
Emotional distress				
No				
Yes				
Bodily pain				
None, very mild, mild				
Moderate, severe, very severe				
Cancer-related anxiety				
None, a small amount				
Moderate, a lot, extreme				
Secondary cancers				
No				
Yes				
Recurrence of primary malignancy				
No				
Yes				
Type of cancer				
Leukemia				
Central nervous system				
Hodgkin's lymphoma				

Table 5 (Continued). Individual-, county-, and state-level predictors of Medicaid costs among Medicaid-enrolled childhood cancer survivors [Aim 3]

	Total cost	Cost of outpatient care	Cost of filled prescriptions	ED and inpatient cost
	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>	<i>Marginal Effects</i>
Type of cancer				
Neuroblastoma				
Wilms (kidney) tumor				
Soft tissue sarcoma				
Bone				
Non-Hodgkin's lymphoma				
Age at diagnosis				
0 – 4				
5 – 10				
11 – 15				
16 – 20				
Year since diagnosis				
≤20				
21 – 30				
>30				
Received chemotherapy				
Any				
None				
Received radiation				
Any				
None				
County-level predictors				
Percent of county residents below poverty				
Unemployment rate				
Percent of non-white county residents				
Percent of urban population				
Number of primary care physicians per capita				
Number of mental health clinicians per capita				
Number of cardiovascular disease specialists per				
Number of community health centers per capita				
Number of CCSS centers within 100 miles				
State-level predictors				
State Medicaid income threshold				
Total Medicaid spending per capita				
Medicaid provider reimbursement rate				
Annual (vs. more frequently) eligibility recertification				
Face-to-face interviews at recertification (vs. not				
Copayment rate				

References

1. Rudowitz R, Hinton E, Antonisse L. *Medicaid Enrollment & Spending Growth: FY 2018 & 2019*. San Francisco, California: Kaiser Family Foundation. October 2018. Available at: <https://www.kff.org/medicaid/issue-brief/medicaid-enrollment-spending-growth-fy-2018-2019/>. Accessed September 1, 2019.
2. Lee JA, Roehrig CS, Butto ED. Cancer care cost trends in the United States: 1998 to 2012. *Cancer*. 2016;122(7):1078-1084.
3. Kaiser Family Foundation (KFF). *Status of State Action on the Medicaid Expansion Decision*. Menlo Park, CA: Kaiser Family Foundation. Available at: <https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed December 15, 2019.
4. Nikpay SS, Tebbs MG, Castellanos EH. Patient Protection and Affordable Care Act Medicaid expansion and gains in health insurance coverage and access among cancer survivors. *Cancer*. 2018;124(12):2645-2652.
5. Kaiser Family Foundation. *Medicaid Expenditures as a Percent of Total State Expenditures by Fund*. San Francisco, California: Kaiser Family Foundation. Available at: <https://www.kff.org/medicaid/state-indicator/medicaid-expenditures-as-a-percent-of-total-state-expenditures-by-fund/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed September 2, 2019.
6. Rebholz CE, Reulen RC, Toogood AA, et al. Health care use of long-term survivors of childhood cancer: the British Childhood Cancer Survivor Study. *Journal of Clinical Oncology*. 2011;29(31):4181-4188.
7. Shaw AK, Pogany L, Speechley KN, Maunsell E, Barrera M, Mery LS. Use of health care services by survivors of childhood and adolescent cancer in Canada. *Cancer: Interdisciplinary International Journal of the American Cancer Society*. 2006;106(8):1829-1837.
8. Kurt BA, Nolan VG, Ness KK, et al. Hospitalization rates among survivors of childhood cancer in the Childhood Cancer Survivor Study cohort. *Pediatric Blood and Cancer*. 2012;59(1):126-132.
9. Kirchoff AC, Fluchel MN, Wright J, et al. Risk of hospitalization for survivors of childhood and adolescent cancer. *Cancer Epidemiology, Biomarkers, and Prevention*. 2014;23(7):1280-1289.
10. Lorenzi MF, Xie L, Rogers PC, Pritchard S, Goddard K, McBride ML. Hospital-related morbidity among childhood cancer survivors in British Columbia, Canada: Report of the childhood, adolescent, young adult cancer survivors (CAYACS) program. *International Journal of Cancer*. 2011;128(7):1624-1631.
11. Sieswerda E, Font-Gonzalez A, Reitsma JB, et al. High hospitalization rates in survivors of childhood cancer: a longitudinal follow-up study using medical record linkage. *PloS One*. 2016;11(7):e0159518.
12. de Fine Licht S, Rugbjerg K, Gudmundsdottir T, et al. Long-term inpatient disease burden in the Adult Life after Childhood Cancer in Scandinavia (ALiCCS) study: A cohort study of 21,297 childhood cancer survivors. *PLoS Medicine*. 2017;14(5):e1002296.
13. Font-Gonzalez A, Feijen EA, Geskus RB, et al. Risk and associated risk factors of hospitalization for specific health problems over time in childhood cancer survivors: a medical record linkage study. *Cancer Medicine*. 2017;6(5):1123-1134.
14. Mueller EL, Park ER, Kirchoff AC, et al. Insurance, chronic health conditions, and utilization of primary and specialty outpatient services: a Childhood Cancer Survivor Study report. *Journal of Cancer Survivorship*. 2018;12(5):639-646.
15. Casillas J, Castellino SM, Hudson MM, et al. Impact of insurance type on survivor-focused and general preventive health care utilization in adult survivors of childhood cancer: the Childhood Cancer Survivor Study (CCSS). *Cancer*. 2011;117(9):1966-1975.
16. Casillas J, Oeffinger KC, Hudson MM, et al. Identifying predictors of longitudinal decline in the level of medical care received by adult survivors of childhood cancer: a report from the childhood cancer survivor study. *Health Services Research*. 2015;50(4):1021-1042.

17. Caplin DA, Smith KR, Ness KK, et al. Effect of population socioeconomic and health system factors on medical care of childhood cancer survivors: a report from the childhood cancer survivor study. *Journal of Adolescent Young Adult Oncology*. 2017;6(1):74-82.
18. Khushalani JS, Qin J, Cyrus J, et al. Systematic review of healthcare costs related to mental health conditions among cancer survivors. *Expert review of pharmacoeconomics outcomes research*. 2018;18(5):505-517.
19. Ku L, Steinmetz E. *The Continuity of Medicaid Coverage: An Update*. Association for Community Affiliated Plans. 2013.
20. Ku L, Steinmetz E, Bysshe T. *Continuity of Medicaid Coverage in an Era of Transition*. Washington, D.C.: George Washington University, Association for Community Affiliated Plans. November 2015. Available at: http://www.communityplans.net/Portals/0/Policy/Medicaid/GW_ContinuityInAnEraOfTransition_11-01-15.pdf. Accessed March 1, 2019.
21. Collins SR, Gunja MZ. *Why Millions Would Lose Coverage Under the Medicaid Expansion Changes in the House Affordable Care Act Repeal Bill*. New York, NY: The Commonwealth Fund. March 2017. Available at: <http://www.commonwealthfund.org/publications/blog/2017/mar/why-millions-would-lose-coverage-under-affordable-care-act-repeal-bill>. Accessed March 17, 2017.
22. Sommers BD. Loss of health insurance among non-elderly adults in Medicaid. *Journal of General Internal Medicine*. 2009;24(1):1-7.
23. Kirchhoff AC, Krull KR, Ness KK, et al. Occupational outcomes of adult childhood cancer survivors: A report from the childhood cancer survivor study. *Cancer*. 2011;117(13):3033-3044.
24. Ji X, Wilk AS, Druss BG, Cummings JR. Effect of Medicaid Disenrollment on Health Care Utilization Among Adults With Mental Health Disorders. *Medical Care*. 2019;57(8):574-583.
25. Ji X, Wilk AS, Druss BG, Lally C, Cummings JR. Discontinuity of Medicaid Coverage: Impact on Cost and Utilization Among Adult Medicaid Beneficiaries With Major Depression. *Medical Care*. 2017;55(8):735-743.
26. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*. 2008;26(27):4401-4409.
27. Children's Oncology Group (COG). *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. Version 5.0*. Monrovia, CA: Children's Oncology Group Statistics and Data Center. October 2018. Available at: http://www.survivorshipguidelines.org/pdf/2018/COG_LTFU_Guidelines_v5.pdf. Accessed February 1, 2020.
28. Banerjee R, Ziegenfuss JY, Shah ND. Impact of discontinuity in health insurance on resource utilization. *BMC health services research*. 2010;10(1):195.
29. Swartz K, Short PF, Graefe DR, Uberoi N. Evaluating State Options for Reducing Medicaid Churning. *Health affairs (Project Hope)*. 2015;34(7):1180.
30. Sommers BD. From Medicaid to Uninsured: Drop-Out among Children in Public Insurance Programs. *Health Services Research*. 2005;40(1):59-78.
31. The Henry J. Kaiser Family Foundation. *State Budget Constraints: the Impact on Medicaid*. 2013.
32. Bindman AB, Chattopadhyay A, Auerback GM. Medicaid re-enrollment policies and children's risk of hospitalizations for ambulatory care sensitive conditions. *Medical care*. 2008;46(10):1049-1054.
33. Ross DC, Cox L. *Beneath the Surface: Barriers Threaten to Slow Progress on Expanding Health Coverage of Children and Families -- A 50 State Update on Eligibility, enrollment, Renewal and Cost-Sharing Practices in Medicaid and SCHIP*. Menlo Park, CA: The Henry J. Kaiser Family Foundation. October 2004. Available at: <http://www.cbpp.org/archiveSite/10-4-04health.pdf>. Accessed March 1, 2017.
34. Perry M, Kannel S, Riley T, Pernice C. What parents say: why eligible children lose SCHIP. *Portland, ME: National Academy for State Health Policy*. 2001.
35. Sommers BD. Protecting low-income children's access to care: are physician visits associated with reduced patient dropout from Medicaid and the Children's Health Insurance Program? *Pediatrics*. 2006;118(1):e36-e42.
36. Hill I. Is there a hole in the bucket? Understanding SCHIP retention. 2003.

37. Capoccia V, Croze C, Cohen M, O'Brien JP. Sustaining enrollment in health insurance for vulnerable populations: Lessons from Massachusetts. *Psychiatric Services*. 2013.
38. Harman JS, Manning WG, Lurie N, Christianson JB. Association between interruptions in Medicaid coverage and use of inpatient psychiatric services. *Psychiatric Services*. 2003;54(7):999-1005.
39. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior*. 1995:1-10.
40. Andersen RM, Davidson PL, Baumeister S. Improving access to care in America. *Changing the US health care system: key issues in health services policy and management 3rd edition San Francisco: Jossey-Bass*. 2007:3-31.
41. Jencks C, Mayer SE. The social consequences of growing up in a poor neighborhood. *Inner-city poverty in the United States*. 1990;111:186.
42. Crane J. The epidemic theory of ghettos and neighborhood effects on dropping out and teenage childbearing. *American journal of Sociology*. 1991:1226-1259.
43. Robert SA. Community-level socioeconomic status effects on adult health. *Journal of Health and Social Behavior*. 1998:18-37.
44. Duncan GJ, Raudenbush SW. Assessing the effects of context in studies of child and youth development. *Educational Psychologist*. 1999;34(1):29-41.
45. Bohland J. Neighborhood variations in the use of hospital emergency rooms for primary care. *Social Science & Medicine*. 1984;19(11):1217-1226.
46. Blustein J, Hanson K, Shea S. Preventable hospitalizations and socioeconomic status. *Health Affairs*. 1998;17(2):177-189.
47. Billings J, Zeitel L, Lukomnik J, Carey TS, Blank AE, Newman L. Impact of socioeconomic status on hospital use in New York City. *Health Affairs*. 1993;12(1):162-173.
48. Phillips JA, Miller JE, Cantor JC, Gaboda D. Context or Composition: What Explains Variation in SCHIP Disenrollment? *Health Services Research*. 2004;39(4p1):865-886.
49. O'Malley AS. After-hours access to primary care practices linked with lower emergency department use and less unmet medical need. *Health Affairs*. 2012;10.1377/hlthaff. 2012.0494.
50. Lowe RA, Localio AR, Schwarz DF, et al. Association between primary care practice characteristics and emergency department use in a Medicaid managed care organization. *Medical care*. 2005;43(8):792-800.
51. Gill JM, Mainous III AG, Nsereko M. The effect of continuity of care on emergency department use. *Archives of family medicine*. 2000;9(4):333.
52. Bindman AB, Grumbach K, Osmond D, et al. Preventable hospitalizations and access to health care. *Jama*. 1995;274(4):305-311.
53. WiseGEEK. What Is Provider Reimbursement? 2015; <http://www.wisegeek.com/what-is-provider-reimbursement.htm>. Accessed March 10, 2015.
54. Intrator O, Mor V. Effect of state Medicaid reimbursement rates on hospitalizations from nursing homes. *Journal of the American Geriatrics Society*. 2004;52(3):393-398.
55. Cohen LA, MANSKI RJ, HOOPER FJ. Does the elimination of Medicaid reimbursement affect the frequency of emergency department dental visits? *The Journal of the American Dental Association*. 1996;127(5):605-609.
56. Cunningham PJ. What accounts for differences in the use of hospital emergency departments across US communities? *Health Affairs*. 2006;25(5):w324-w336.
57. Sommers BD, Tomasi MR, Swartz K, Epstein AM. Reasons for the wide variation in Medicaid participation rates among states hold lessons for coverage expansion in 2014. *Health Affairs*. 2012;31(5):909-919.
58. Wright BJ, Carlson MJ, Edlund T, DeVoe J, Gallia C, Smith J. The impact of increased cost sharing on Medicaid enrollees. *Health Affairs*. 2005;24(4):1106-1116.
59. Ku L, Wachino V. *The Effect of Increased Cost-Sharing in Medicaid: A Summary of Research Findings*. Center on Budget Policy and Priorities; 2005.
60. Frank RG, Lave JR. The effect of benefit design on the length of stay of Medicaid psychiatric patients. *Journal of Human Resources*. 1986:321-337.
61. Kronebusch K, Elbel B. Simplifying children's Medicaid and SCHIP. *Health Affairs*. 2004;23(3):233-246.

62. KFF. *Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012–2013*. 2013.
63. Allison RA. The impact of local welfare offices on children's enrollment in Medicaid and SCHIP. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 2003;40(4):390-400.
64. Saunders MR, Alexander GC. Turning and churning: loss of health insurance among adults in Medicaid. *Journal of general internal medicine*. 2009;24(1):133-134.
65. Centers for Medicare & Medicaid Services (CMS). *Medicaid Analytic eXtract (MAX) General Information*. Baltimore, MD: U.S. Centers for Medicare & Medicaid Services. Available at: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAXGeneralInformation.html>. Accessed August 10, 2019.
66. Chronic Condition Data Warehouse. *CCW User Guide: T-MSIS Analytic Files (TAF) Research Identifiable Files (RIFs)*. Baltimore, MD: Centers for Medicare & Medicaid Services (CMS). November 2019. Available at: <https://www2.ccwdata.org/documents/10280/19002246/ccw-taf-rif-user-guide.pdf>. Accessed February 17, 2020.
67. Chronic Condition Data Warehouse. *Submission of Medicare Data Finder and Crosswalk Files*. Baltimore, MD: Centers for Medicare & Medicaid Services. April 2018. Available at: <https://www2.ccwdata.org/documents/10280/19001850/finder-file-encryption-policy.pdf>. Accessed February 21, 2020.
68. Hennessy S, Bilker WB, Weber A, Strom BL. Descriptive analyses of the integrity of a US Medicaid claims database. *Pharmacoepidemiol Drug Saf*. 2003;12(2):103-111.
69. Area Health Resources File. Rockville, MD: US Department of Health and Human Services, Health Resources and Service Administration, Bureau of Health Professions. 2008.
70. Tricia Brooks, Joe Tuschner, Samantha Artiga, Jessica Stephens, Alexandra Gates. *Modern Era Medicaid: Findings from A 50-State Survey of Eligibility, Enrollment, Renewal, And Cost-Sharing Policies in Medicaid And CHIP as Of January 2015*. Washington, DC: The Henry J. Kaiser Family Foundation. January 2015. Available at: <http://files.kff.org/attachment/report-modern-era-medicaid-findings-from-a-50-state-survey-of-eligibility-enrollment-renewal-and-cost-sharing-policies-in-medicaid-and-chip-as-of-january-2015>. Accessed June 8, 2019.
71. The Kaiser Commission on Medicaid and the Uninsured. *Performing Under Pressure: Annual Findings of a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-sharing Policies in Medicaid and CHIP, 2011-2012*. The Henry J. Kaiser Family Foundation. 2012.
72. Zuckerman S, Williams AF, Stockley KE. Trends in Medicaid physician fees, 2003–2008. *Health Affairs*. 2009;28(3):w510-w519.
73. Centers for Medicare & Medicaid Services (CMS). *MAX Validation Reports*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAX-Validation-Reports>. Accessed December 1, 2019.
74. Druss BG, Zhao L, Cummings JR, Shim RS, Rust GS, Marcus SC. Mental comorbidity and quality of diabetes care under Medicaid: a 50-state analysis. *Medical Care*. 2012;50(5):428–433.
75. Hall AG, Harman JS, Zhang J. Lapses in Medicaid coverage: impact on cost and utilization among individuals with diabetes enrolled in Medicaid. *Medical Care*. 2008;46(12):1219-1225.
76. Harman J, Hall A, Zhang J. Changes in health care use and costs after a break in Medicaid coverage among persons with depression. *Psychiatric Services*. 2007;58(1):49-54.
77. Gillingham M. Chapter 7: Measuring Utilization of Services. In: *SAS Programming with Medicare Administrative Data*. Cary, NC: SAS Institute Inc. 2014:69-88.
78. Dunn A, Grosse SD, Zuvekas SH. Adjusting health expenditures for inflation: A review of measures for health services research in the United States. *Health Services Research*. November 2016. doi:10.1111/1475-6773.12612.
79. Lindsey J, Jones B. Choosing among generalized linear models applied to medical data. *Statistics in Medicine*. 1998;17(1):59-68.
80. Manning WG, Mullahy J. Estimating log models: to transform or not to transform? *Journal of Health Economics*. 2001;20(4):461-494.
81. Glick H. *Multivariable Analysis of Patient-Level Treatment Cost*. 2012; <http://www.uphs.upenn.edu/dgimhsr/multivcostanalysis.sp12.pdf.pdf>. Accessed April 20, 2015.

82. Funk MJ, Landi SN. Misclassification in administrative claims data: quantifying the impact on treatment effect estimates. *Current Epidemiology Reports*. 2014;1(4):175-185.
83. Park ER, Kirchhoff AC, Nipp RD, et al. Assessing health insurance coverage characteristics and impact on health care cost, worry, and access: a report from the Childhood Cancer Survivor study. *JAMA Internal Medicine*. 2017;177(12):1855-1858.
84. Kaiser Family Foundation. *Summary of the Affordable Care Act*. Menlo Park, CA: Kaiser Family Foundation. April 2013. Available at: <http://files.kff.org/attachment/fact-sheet-summary-of-the-affordable-care-act>. Accessed December 14, 2019.
85. The Kaiser Commission on Medicaid and the Uninsured. *How is the Affordable Care Act Leading to Changes in Medicaid Today? State Adoption of Five New Options*. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation. May 2012. Available at: <https://www.kff.org/wp-content/uploads/2013/01/8312.pdf>. Accessed December 12, 2019.