



**Equity in Access Research Program  
2021 Request for Proposals**

***Understanding How Health Insurance Affects Equity in Access to Care  
for Patients with and Survivors of Blood Cancer***

**Introduction**

The Leukemia & Lymphoma Society's (LLS) mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life for patients and their families through research, policy advocacy, education, and support. We are the largest nonprofit funder of blood cancer research, investing nearly \$1.3 billion in the most pioneering science worldwide since 1949. We drive policy and regulatory changes that accelerate the development of new blood cancer treatments and break down barriers to care.

This funding opportunity is part of LLS's new *Equity in Access Research Program*, which is designed to generate evidence that will guide changes in healthcare policy and practice to ensure that all blood cancer patients and survivors achieve access to the cancer care and services they need throughout their lives. This program is based on the concept of health equity as "the principle underlying a commitment to reduce—and ultimately, eliminate—disparities in health and its determinants, including social determinants."<sup>1</sup> We define a health disparity as "a particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health, cognitive, sensory, or physical disability, sexual orientation, geographic location, or other characteristics historically linked to discrimination or exclusion."<sup>2</sup> Although substantial evidence links economic and social disadvantage to avoidable illness, poorer health-related quality of life, and greater untimely death, it is possible to mitigate the impact of economic and social disadvantage on health through social policy reform.<sup>1</sup>

The COVID-19 pandemic as well as concomitant social and political events have highlighted, in ways not seen in recent memory, public awareness of and discourse about striking disparities in both access to healthcare and health outcomes. LLS is committed not only to contributing to this discourse, but also to shaping it in a meaningful way for patients with and survivors of a blood cancer. The *Equity in Access Research Program* seeks to improve access to care across the

cancer care continuum, beginning with diagnosis, encompassing treatment (which may include a clinical trial), and continuing through post-treatment survivorship, including supportive and palliative care during all phases of the continuum. For some patients, the continuum also includes end-of-life care. The LLS *Equity in Access Research Program* aims to deepen understanding of access barriers and identify modifiable factors that contribute to these barriers, factors that can be addressed through policy reform and changes in healthcare practice.

## **Background**

Although we continue to see significant advances in treatment for blood cancer, not all patients and survivors have equal access to newer and more effective treatments. Some groups—including, but not limited to, racial and ethnic minority groups, individuals with low-income, and rural residents—face substantial social, economic, and environmental disadvantages that hinder or prevent access to the treatment and care they need.<sup>3,4</sup> Further, differences in access to care can become more pronounced as new, more effective treatments, such as immunotherapy, become available.<sup>5</sup>

Although enactment of the Patient Protection and Affordable Care Act (ACA) reduced rates of uninsurance, disparities in coverage persist, with coverage lagging among individuals who are Black, Hispanic, Asian, American Indian or Alaska Native, and Native Hawaiian and other Pacific Islander.<sup>6</sup> Additionally, eligibility for safety net programs like Medicaid varies from state to state, and this impacts access to care, especially for patients with very low income.<sup>7</sup> The implications of barriers to care are significant, as research shows that increased access to cancer care results in higher rates of survival, as well as better quality of life and health outcomes.<sup>4</sup>

## High Cost of Cancer Care

The high cost of cancer care, both to the healthcare system and individual patients, is one of the greatest barriers to equitable access to care, yet it is modifiable through reforms in, among other areas, health insurance. Blood cancers are especially expensive to treat,<sup>8,9</sup> and the cost of new orally administered anti-cancer drugs continues to rise.<sup>10</sup> Per-patient treatment costs, for patients who are commercially insured, range from an average of \$200,000 for chronic leukemia to more than \$800,000 for acute leukemia over the 3 years following diagnosis.<sup>8</sup> Out-of-pocket costs for actively treated patients for years 1 and 2 following diagnosis average about \$17,000 and \$8,300, respectively, for Medicare fee-for-service patients and about \$6,900 and \$2,600, respectively, for Medicare Advantage patients with Part D coverage.<sup>9</sup> Moreover, for commercially insured patients with a blood cancer, average monthly healthcare costs never return to pre-diagnosis

spending levels, demonstrating a persistent cost burden both to the system and the patient years after a blood cancer diagnosis.<sup>9</sup>

### ***Inadequacies of Health Insurance Plans***

Health insurance is intended to safeguard patients from significant financial burden and loss; however, many health plans do not provide that level of security.<sup>11,12</sup> Even with the reforms in the ACA, insurers are still permitted to impose high out-of-pocket costs on consumers, which lead to significant financial burden for cancer patients and survivors.<sup>13</sup> Moreover, despite the ACA's coverage expansions, many survivors remain uninsured or underinsured.<sup>14</sup> For example, health plans are increasingly shifting cost burdens to patients through high deductibles and cost-sharing requirements, which can translate into large out-of-pocket costs, especially for patients with expensive-to-treat cancer diagnoses.<sup>15,16</sup>

In today's insurance market patients are also witnessing the proliferation of certain types of coverage—such as short-term, limited duration (STLD) plans—that are not required to comply with the patient protections in the ACA and, consequently, expose them to more severe financial burden.<sup>17</sup> For example, a patient newly diagnosed with lymphoma while covered by an STLD plan could pay as much as \$45,800 in out-of-pocket expenses (including premiums and cost-sharing) during the 6 months following diagnosis, whereas the same patient, if enrolled in an ACA-compliant plan, could pay \$6,300, on average, in out-of-pocket expenses over the same period.<sup>18</sup>

An investigation by the U.S. House Committee on Energy & Commerce found that during the 2019 plan year, an estimated 3 million consumers had enrolled in STLD plans sold by nine insurers, suggesting that increasing numbers of patients and consumers are relying on these insurance-like products.<sup>19</sup> Significantly, most individuals enrolled in these products are assumed, based on data compiled by the Centers for Medicare & Medicaid Services, to have been previously covered by ACA-compliant plans through the healthcare.gov marketplace.<sup>18</sup> Due to the unregulated nature of STLD and other non-ACA-compliant plans, a full picture of their impact is unknown.<sup>17</sup> Further research is needed to understand the impact of these plans on survivors whose medical history puts them at increased risk of harm, given the discriminatory practices that underpin STLD plans and similar insurance-like products.

### ***Financial Burden and Patient Impact***

The cancer-related financial burden that results from the high cost of care, combined with inadequate insurance coverage, is sometimes referred to as “financial toxicity” of cancer.<sup>20-22</sup>

Financial toxicity is associated with patients forgoing or delaying medical care, lower enrollment into clinical trials, decreased medication adherence, lower quality of life, psychological distress, and worries about recurrence.<sup>23-27</sup> Financial hardship often continues into survivorship, negatively impacting long-term access to care, as well as health and quality of life outcomes.<sup>20</sup> Financial hardship disproportionately affects young adult survivors,<sup>28-30</sup> survivors who are racial and ethnic minorities,<sup>3,31</sup> and survivors in rural areas.<sup>32</sup>

## **Purpose**

**The purpose of this Request for Proposals is to fund research studies that will increase our understanding of the impact of insurance status and type on equity in access to care for patients with and survivors of a blood cancer.** The current body of peer-reviewed literature provides evidence that insurance status and type affect survival and financial burden for cancer patients and survivors.<sup>14,33-35</sup> For example, multiple retrospective cohort studies show improved survival among patients with a blood cancer who have private insurance compared to those with public or no insurance.<sup>36-40</sup> However, the evidence related to other outcomes is limited (K. Crotty, PhD, unpublished data, 2021), and the existing body of research has gaps; for instance, research involving specific population groups is limited (e.g., diverse racial and ethnic groups, patients with low income, Medicaid recipients, the uninsured, patients located in rural settings, adolescents and young adults, and families with a pediatric patient). With this RFP, LLS is supporting further research about insurance and equity in access to cancer care to guide evidence-based health policy reform, including the reforms that LLS is championing at the state and federal levels to represent the interests of patients with and survivors of a blood cancer.

## **Research Areas of Interest**

Below we list several research areas of interest to LLS. **This list of research areas is not intended to be exhaustive. We welcome other innovative research topics that align with the goals of this funding opportunity—ideas to increase our understanding of the impact of insurance status and type on equity in access to care for patients with and survivors of a blood cancer, and that yield data to guide policy reform to ensure that patients achieve access to the cancer care and services they need throughout their lives.**

Studies may focus on any point, or multiple points, in the cancer continuum, from diagnosis through post-treatment survivorship and end-of-life. Studies must be U.S. specific, with a focus on the U.S. health insurance market and populations living within the U.S. and its territories. Studies may also focus on one, or more than one, insurance type (e.g., employer-sponsored insurance; individual health plans purchased through the health insurance exchanges; Medicare, Medicaid,

and other public insurance; STLD and other non-ACA-compliant plans). Studies must focus primarily on one or more of the blood cancers (leukemias, lymphomas, myeloma, myelodysplastic syndromes, and myeloproliferative neoplasms).

***Some areas of interest:***

- How do insurance status and type impact **patient and survivor outcomes**, including survival, health-related quality of life, treatment-related adverse events, long-term effects, financial burden, and cancer recurrence?
- How do insurance status and type impact **access to care and patient and survivor outcomes among key vulnerable populations**, including those from racial and ethnic minority groups, Medicaid recipients, rural populations, and those in different age groups (children, adolescents and young adults, and older adults)?
- How do insurance status and type impact **healthcare utilization, quality of care, and treatment adherence** for patients with and survivors of a blood cancer?
- How do insurance status and type influence **clinical trial participation** (enrollment and retention) and outcomes?
- What is the **financial burden** of care associated with different types of health insurance coverage? Of special interest is the financial burden associated with types of insurance not compliant with the ACA.
- What is the **relative influence of insurance status and type compared to other barriers to access** on patient and survivor outcomes?

**Funding Available**

- At least \$1 million will be available through this Request for Proposals.
- Maximum project period is 2 years, and the maximum funding amount per year is \$250,000.
- Total budget, including indirect costs, should not exceed \$500,000 for a 2-year project period.
- Indirect costs are limited to 11.1% of total costs.
- Applicants should request the amount of funding they will need to complete the proposed research and disseminate findings. The review process will include an evaluation of the appropriateness of the funding request in light of study aims and methods to achieve the aims.

## **Applicant Eligibility**

The application will require a Principal Investigator who is responsible for proposal submission and conduct of the study, including adherence to all stipulations made by LLS in a grant agreement. Study teams may also include co-Principal Investigators and co-Investigators.

LLS welcomes Principal Investigators from individuals at all stages of their careers, as well as Principal Investigators who have not previously conducted research in the area of blood cancer. Principal Investigator(s) must meet the following eligibility criteria:

- The Principal Investigator(s) must be affiliated with a public or nonprofit institution (tax exempt under Section 501(c)(3) of the Internal Revenue Code).
- The sponsoring institution is based in the United States or its territories.
- The Principal Investigator must have a PhD, MD, ScD, JD, or equivalent doctoral degree.
- The Principal Investigator and other study team members may come from a variety of disciplines, including but not limited to health services research, public health, economics, sociology, public policy, political science, public administration, and law.

Consistent with LLS's commitment to diversity, equity, and inclusion, we encourage applications that have investigators and/or research team members from backgrounds historically underrepresented in research disciplines as a result of their race, ethnicity, socioeconomic status, disability, or other factors.

## **How to Apply**

All application materials for this Request for Proposals must be submitted via the [LLS Research Portal](https://lls.fluxx.io/) at <https://lls.fluxx.io/>. This competitive proposal process has two phases: a Letter of Intent and a full proposal.

## **Registration**

If you are a first-time user of the [LLS Research Portal](https://lls.fluxx.io/) (<https://lls.fluxx.io/>), please contact [researchprograms@lls.org](mailto:researchprograms@lls.org) so LLS can create an account for you. Please register at least 1 week before the Letter of Intent due date to ensure submission of the Letter of Intent by the specified deadline.

If you have applied to LLS in the past, you do not need to create a new registration and can log-in with your username (email address associated with your account) and your password. If you

forgot your password, simply click the “reset or create password” link and enter your email address. The system will send your username and a link to update your password.

### ***Phase 1: Letter of Intent***

As the first step in the application process, please submit a Letter of Intent through the [LLS Research Portal](https://lls.fluxx.io/) at <https://lls.fluxx.io/>. As part of the submission, you will need to upload a single PDF document that contains the information below in the order listed. **The Letter of Intent must use at least 11-point font [Arial], 1-inch margins, and single spacing. Letters of Intent that do not comply with these guidelines will not be considered.**

- Project Title: (maximum 150 characters including spaces)
- Principal Investigator(s) and other Key Personnel
  - Names and affiliations of Principal Investigator(s), co-Principal Investigator, and co-Investigators
  - Names and affiliations of other key personnel
  - A one-paragraph biography for primary Principal Investigator (maximum 1,500 characters including spaces)
- Name and Location of Sponsoring Institution
- Project Summary (**no more than two pages; references only can be an additional page**):
  - Specific aims
  - Rationale and potential for the study to generate new knowledge of significance for patients with and/or survivors of a blood cancer
  - Overview of approach and methods, including key data sources to be used
  - Relevance of the study for health policy and its potential for findings to guide policy reform to increase equitable access to care for patients with and/or survivors of a blood cancer
- Proposed Start and End Dates: The start date for this award is June 1, 2022. The end date can be no later than 2 years after the start date; the latest possible end date is May 31, 2024.
- Requested Award Amount (Approximate): See Full Application Guidelines & Instructions at [LLS.org/EquityinAccess](https://lls.org/EquityinAccess) for permissible costs.

## ***Phase 2: Invited Full Proposals***

Selected Phase 1 applicants will be invited to submit a full proposal, accompanied by a detailed budget justification and additional required information. Submitted full proposals will undergo rigorous peer review by external subject matter experts. See Full Application Guidelines & Instructions at [LLS.org/EquityinAccess](https://lls.org/EquityinAccess).

## ***Review Criteria for Full Proposals***

The external expert panel will consider the following criteria in reviewing proposals:

- Significance to the Field: Extent to which the study addresses critical, unanswered questions and increases understanding of key issues related to insurance and equity in access to care for patients with and survivors of a blood cancer.
- Policy Significance: Potential for the study's findings to shape health policy reform aimed at improving equity in access to care. (See additional notes regarding policy significance below.)
- Methodology: Strength of the methodological plan for bringing the research to fruition; methodologies and data sources must be appropriate for and available within the timeframe of the study.
- Investigators and Study Team: Experience, expertise, and qualifications of the Principal Investigator(s) and strength of the study team. The proposal should describe relevant previous studies by the Principal Investigator(s).
- Dissemination Plan: Strength of a stated plan for timely, wide dissemination of findings to policy stakeholders and other relevant audiences. (See additional notes regarding dissemination of findings below.)
- Feasibility: Feasibility of the study within the budget and timeframe.
- Potential Challenges: Identification of potential challenges to study implementation and inclusion of feasible solutions.

### Policy Significance

The proposal should clearly describe health policy implications—this feature is an important consideration in the review process. Public policy initiatives are a critical component of LLS's strategic approach to improving patients' access to care and their quality of life. For more than a decade, LLS has championed evidenced-based health policy reforms at both the state and federal levels to improve access to care and quality of life for patients with and survivors of a



blood cancer. To this end, the proposal must discuss the relevance of potential findings to policymaking at the state and/or federal levels. Deliverables at the end of the study must speak to the steps that policymakers ought to consider taking to reduce or eliminate healthcare access barriers that emerge among the study’s findings and improve quality of life and outcomes among patients with and/or survivors of a blood cancer. Policymakers include elected officials and political appointees serving at the state and/or federal levels, in a legislative, regulatory, or judicial environment.

Dissemination of Findings

LLS will give preference to proposals that demonstrate the research team’s ability to make initial or full findings available to LLS, and as appropriate the scientific community, during the grant period and to effectively disseminate findings to policy stakeholders and others as relevant. Applicants should consider the timeliness of the research topic and question(s) to ensure that the findings will be relevant at the time of dissemination.

**To ensure LLS-supported research is made accessible to a wide and diverse audience, grantees who publish findings in peer-reviewed publications must do so in open access journals and/or must commit to covering the cost of making the resulting publications open access. Applicants can include these costs in their budget.**

**Key Dates and Deadlines**

<b>Action</b>	<b>Date</b>
<ul style="list-style-type: none"> <li>• Deadline to submit Letters of Intent</li> </ul>	<ul style="list-style-type: none"> <li>• September 17, 2021 (3:00 p.m. ET)</li> </ul>
<ul style="list-style-type: none"> <li>• LLS notifies applicants whether they are invited to submit full proposal</li> </ul>	<ul style="list-style-type: none"> <li>• October 29, 2021</li> </ul>
<ul style="list-style-type: none"> <li>• Deadline for receipt of full proposals (invited applicants)</li> </ul>	<ul style="list-style-type: none"> <li>• January 7, 2022 (3:00 p.m. ET)</li> </ul>
<ul style="list-style-type: none"> <li>• Notification of awards</li> </ul>	<ul style="list-style-type: none"> <li>• April 8, 2022</li> </ul>
<ul style="list-style-type: none"> <li>• Grant start date</li> </ul>	<ul style="list-style-type: none"> <li>• June 1, 2022</li> </ul>

For questions about this Request for Proposals, please contact [researchprograms@lls.org](mailto:researchprograms@lls.org).

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