



## CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

Award ID:  
PP130070

Project Title:  
A Novel Online Patient-Centered Decision Support Service to Empower  
Childhood Cancer Survivors in Managing Screening and Prevention of Late  
Effects of Treatment

Award Mechanism:  
Evidence-Based Prevention Programs and Services

Principal Investigator:  
Poplack, David

Entity:  
Baylor College of Medicine

### Lay Summary:

**Need:** This project addresses the health challenges confronted by an estimated 30,000 Texas childhood cancer survivors (CCS) who face uncertain futures due to inadequacies in health care systems. Children who survive cancer face challenges as they age. Because of their exposure to chemotherapeutic, radiation, surgery, or other treatments, these Texas survivors, many now well into adulthood, will experience late effects or health problems directly related to the cancer treatment received. These disorders affect vital systems (e.g. cardiovascular, pulmonary, neurological systems), can be severe, and in some cases life threatening. Although exposure-based screening/preventive guidelines are available to clinicians, the guidelines are complex, lengthy, and not easy to use in busy clinical practice settings. Issues of system fragmentation and discontinuity of care also contribute to the problem. Although survivors may be seen in pediatric cancer care clinics for several years after diagnosis and treatment, responsibility for risk-based follow-up and management is generally assumed by a community-based care provider with little or no knowledge of the survivor's treatment history and limited preparation regarding the threats that cancer treatment can pose. Therefore, screening for health risks is often not done, potentially jeopardizing the health of survivors.

**Overall Project Strategy:** The overarching strategy is to develop a new system of care, the Survivor-Centered Service System (SCSS) to address problems of care system fragmentation, lack of care continuity, and the poor communication across settings and transitions in care as survivors move from pediatric to adult care settings. The system proposed in this project is comprehensive and will directly address the needs to locate and contact survivors lost to follow-up; to provide educational services to increase survivor and clinician knowledge of risks and recommendations; to enable portable access to survivor cancer treatment summaries for survivors and clinicians; to overcome the challenges of applying complex guidelines for follow-up care by providing online automated decision support to produce individualized recommendations for survivor screening/preventive services; and to address system fragmentation by providing navigator services for survivors and their clinicians. The new system of care brings together 12 of the 13 pediatric cancer treatment centers in the state, the Texas Cancer Registry, and the Passport for Care (PFC) team which developed and has deployed a Clinician Portal used in nearly all of these treatment centers and will use an additionally

available PFC Survivor Portal in this project. Ongoing improvement in service processes will be fostered through use of the plan-do-study-act (PDSA) approach to continuous quality improvement (CQI), and both quantitative and qualitative data will be gathered to gauge the impacts on the overall care system and on individual survivors and care givers.

**Specific Goals:** The overall goal is to increase survivor participation in follow-up screening/preventive services and the aims are to: 1) Establish the operational framework, including substantive participation of project partners, essential to making systems change become reality; 2) Deliver decision support services in a manner that empowers childhood cancer survivors to be more in control of their health care and that provides the resources needed to assist clinicians in providing care similar to a “patient-centered childhood cancer survivor expert”; and 3) characterize how the project actually operated (i.e., What processes were implemented and how did they work?), as well as what the project actually achieved in terms of engaging and empowering survivors with their clinicians to increase participation in follow-up screening/preventive services.

**Innovation:** The innovations in this project relate to the employment of a comprehensive approach that includes statewide partnerships enabled by a novel decision support platform (the PFC), educational support, and navigator services to reach out to survivors and their clinicians to change behaviors. Creating the infrastructure to support care teams in which survivors and clinicians are engaged to share responsibility for decision making about implementation of recommendations for guideline-based follow-up screening/preventive services for the late effects of treatment is, in itself, an important innovation.

**Significance and Impact:** The impact beyond the importance of addressing the care needs of 30,000 childhood cancer survivors in Texas (~350,000 nationally) is potentially great. This project has the potential to serve as a national model for addressing the unmet need of providing follow-up screening services to survivor services for cancers in adulthood.