



CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

Award ID:
PP170036

Project Title:
Expansion and Continuation of Web-based Clinical Decision Support to Disseminate Tailored Screening Recommendations for Survivors of Pediatric Cancers

Award Mechanism:
Competitive Continuation/Expansion - Evidence-Based Cancer Prevention Services

Principal Investigator:
Poplack, David

Entity:
Baylor College of Medicine

Lay Summary:

Need. Texas is home to over 35,000 survivors of childhood, adolescent, and young adult cancer. Childhood cancer survivors (CCSs) remain at risk for late effects of their cancer therapy, which may affect quality of life (e.g., infertility) or prove life-threatening (e.g., second malignancies, cardiac failure). CCSs face serious obstacles in receiving (and clinicians in delivering) quality care, including lack of access to treatment summaries, as well as limited knowledge of the risks for late effects and the guidelines for appropriate follow-up screening. To address CCSs' needs in Texas, with CPRIT support, we developed the Survivor-Centered Service System (SCSS), which includes two Passport For Care (PFC) Websites providing decision support—one for clinicians and one for survivors. The SCSS also provides survivor navigation services to facilitate enrollment in the PFC and assist those deciding to seek follow-up screening for late effects. The Clinician Website (PFC-CW) uses an algorithm to generate a set of potential late effects tailored to the survivor's treatment history. It also delivers a corresponding set of guideline-based recommendations for follow-up screening. The complementary Survivor Website (PFC-SW) provides CCSs with direct access to their treatment information, follow-up screening recommendations in lay language (English and Spanish), and additional health information, all of which can be saved by the survivor and shared with their clinician. The SCSS has been deployed in survivor clinics across the state. However, most CCSs are not followed in survivor clinics. To reach these CCSs, we collaborated with the Texas Cancer Registry (TCR) to identify CCSs in the State (focusing initially on CCSs treated since 1995 who were less than 18 years old at diagnosis) for purposes of reaching out with information about the PFC tools and navigation services to assist survivors in making decisions about pursuing follow-up screening. Project Strategy. Our two prior CPRIT grants supported completion of the PFC-CW and its deployment to 11 initial cancer clinics in Texas (PP100090) and successful development and launch of the PFC-SW (PP130070). Currently, 14 Texas cancer clinics use the PFC-CW, with 4,300+ Texas survivors accrued; and over 2,300 Texas CCSs are enrolled in the PFC-SW. In this application, we propose to expand our delivery of the SCSS across Texas via our cancer clinic partners and the TCR to target all CCSs in Texas. We will do this by expanding enrollment criteria to include all CCS in the TCR and by launching a public outreach initiative to reach those not reachable through the clinics or the TCR effort. Public outreach will include two

initiatives: 1) a social media campaign with our major partners, and 2) enhancement (guided by stakeholders) of the public portion of the PFC-SW, where individuals will have access to survivor information, education, decision support functionality (e.g., where any user can enter treatment exposures and obtain follow-up recommendations), and navigation services (e.g., enrollment, identification of screening sites, insurance questions).

Specific Goals 1. Expand PFC dissemination (beyond current, continuing efforts) through additional outreach and engagement of CCSs in the SCSS to enroll at least 4500 additional survivors through the PFC-CW and -SW and/or facilitate those deciding as a result of our outreach to obtain follow-up screening. 2. Enhance and continually improve the PFC-SW functionality to make it publicly accessible to support expanded outreach and engagement of survivors, their caregivers, and other members of the public. 3. Evaluate SCSS efforts with CCSs and their parents/caregivers with respect to a) broad outreach initiatives and dissemination efforts; b) enrollment in and use of the PFC-SW; and c) uptake and use of the tailored recommendations for follow-up care as evidenced by attitudinal, knowledge, and behavioral changes.

Innovation. The PFC is unique among the available online cancer decision support tools for survivors and clinicians in that it addresses childhood cancer, is available across multiple institutions, and can deliver updated recommendations and alerts to users whenever guidelines change with new research. Significance and Impact. The PFC provides critical online decision support to clinicians and CCSs to support improving the quality of care for survivors in Texas. We have planned outreach initiatives that conservatively should reach 50,000 individuals and result in doubling the number of Texans (an additional 4500 in the PFC) who are enrolled in the PFC and/or deciding to seek follow-up screening. When complete, the proposed work will have reached across Texas, increasing the number of people who understand the risks of late effects and expanding the number of CCSs who seek follow-up screening and care to reduce the potential morbidity and mortality resulting from the late effects of cancer therapy.