

## Improving Pediatric Cancer Survivorship Care through SurvivorLink

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<b>Organization:</b>	Emory University
<b>Mechanism:</b>	RFA: HS08-002: Ambulatory Safety and Quality Program: Improving Management of Individuals with Complex Healthcare Needs through Health Information Technology (MCP)
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**Summary:** As the number of cancer survivors increases, the need to educate primary care providers about the unique needs and care of these individuals has become more urgent. This is particularly true for childhood cancer survivors for whom cancer therapies, with overall cure rates of 75 to 80 percent, are highly successful. Yet high-quality individualized survivorship care is challenging due to: 1) multiple transitions in care among primary and specialty care providers; and 2) the lack of knowledge about survivor issues among providers, patients, and their families.

Dr. Mertens and her research team are addressing these challenges by building the SurvivorLink system, a personal health record with the goals to improve pediatric cancer survivors' transition to pediatric primary and specialty care and increase patient, family, and provider knowledge about survivor issues. SurvivorLink includes a cancer treatment summary, individualized risk- and late-effects screening profiles, and other clinical information needed to provide high-quality long-term care to survivors. SurvivorLink also provides educational materials that improve awareness of survivorship issues and best practices in survivor care, including continuing medical education (CME) credits to providers who complete educational materials using the SurvivorLink Web site.

SurvivorLink has three target user groups: patients and their families; providers; and researchers. Participants for this pilot study are being recruited through the five cancer treatment centers in the State of Georgia and Georgia Comprehensive Cancer Registry records. The impact of SurvivorLink will be evaluated by measuring outcomes related to both SurvivorLink utilization and the effects that utilization has on aspects of survivor care, including patient and provider awareness of survivor issues and percentage of patients receiving recommended survivorship care.

### Specific Aims:

- Collect data on pediatric cancer survivors in SurvivorLink. (**Ongoing**)
- Facilitate the exchange of clinical information at key transitions. (**Ongoing**)
- Provide patients with easy access to individualized educational materials and evidence-based late-effects screening recommendations. (**Ongoing**)
- Provide researchers with longitudinal information on incidence of late effects in pediatric cancer survivors. (**Upcoming**)

**2011 Activities:** Recruitment for SurvivorLink has been a major focus of this year. The research team has employed several methods to recruit patients, including contacting individuals on the Georgia Comprehensive Cancer Registry, collaborating with local pediatric cancer clinics, and promoting SurvivorLink through social media. Additionally, the research team partnered with two cancer advocacy organizations, CURE and Camp Sunshine, to provide information about SurvivorLink at workshops, conferences, and other survivorship events.

To maximize its recruiting efforts, the research team analyzed recruitment numbers for each recruitment method. Of the 218 pediatric cancer patients contacted through Childrens' Healthcare of Atlanta, 23 (11 percent) registered with SurvivorLink after mail contact, and 49 (22 percent) after mail contact and a telephone call. Of these patients, individuals who previously attended a cancer survivorship clinic were significantly more likely to register with SurvivorLink than those who have not attended a survivorship clinic. At the community outreach survivorship events, 22 percent of patients or parents who engage with SurvivorLink staff registered with the Web site. Additionally, following outreach events, the average number of weekly visits to SurvivorLink increased by 25. In the first 4 months of a Facebook social media campaign, the SurvivorLink Facebook page received 645 views and 58 'likes.'

As of the end of 2011, 316 people registered with SurvivorLink. Of these, 132 were providers, 131 were parents, and 53 were patients. There have been 4,001 visits to the SurvivorLink Web site. The average number of pages viewed is 5.84, and the average length of time on the site is 6.98 minutes. Fertility and neurocognitive issues are among the most frequently searched types of information. Among providers who have visited SurvivorLink, 50 CME credits have been completed.

As last self-reported in the AHRQ Research Reporting System, project progress and activities are on track with the revised timeline and the project budget spending is on track. The project is using a 1-year no-cost extension to allow additional time for patient recruitment.

**Preliminary Impact and Findings:** The project team conducted focus groups and semi-structured interviews with providers, patients, and parents to understand the needs of these groups. The focus groups indicated that providers want a system that allows efficient access to patient health information before the patient visit. Patients and their parents expressed concern about privacy from insurance companies, colleges, and employers. Additionally, the study staff learned that most parents were not familiar with the importance of survivor care.

Findings from focus groups with providers and parents of pediatric cancer survivors were incorporated into the development of the parent-patient portal of SurvivorLink. The patient-parent portal was designed with special attention to security and privacy. Similar to a social networking site, patients and parents can invite their primary care doctor and other physicians to access their survivor health plan online to facilitate information exchange, and can un-invite them at any time. As an added security measure, patients and parents are able to monitor who looks at their information. When patients or parents sign up, they receive a survivor health care plan and give permission for their providers to post information. The portal highlights tailored information for individual patients based on their risks. Patients and parents are also able to link their current medications with relevant health links and can store other information as scanable documents.

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**Target Population:** Cancer, Pediatric\*

**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

**Business Goal:** Implementation and Use

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\* This target population is one of AHRQ's priority populations.