

<b>Project Title:</b>	Improving Pediatric Cancer Survivorship through SurvivorLink
<b>Principal Investigator:</b>	Mertens, Ann C., Ph.D.
<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 IT (MCP)
<b>Grant Number:</b>	R18 HS 017831
<b>Project Period:</b>	09/08 – 09/11
<b>AHRQ Funding Amount:</b>	\$1,199,198
<b>Summary Status as of:</b>	December 2008

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**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

**Summary:** Dr. Mertens and her team launched their project in late September 2008. This project proposes to develop a personal health record (PHR), *SurvivorLink*, to support pediatric cancer survivor care by improving transitions to primary and specialty care for pediatric cancer survivors and by increasing patient, family, and provider knowledge about survivor issues. *SurvivorLink* will include a cancer treatment summary, individualized risk profile, individualized late effects screening profile, and other clinical information that is needed for high quality survivor care. It will also have educational material to increase awareness of survivorship issues and best practices in survivor care. The study team will use a pre-test/post-test study design to investigate whether *SurvivorLink* affects patient outcomes; the factors that influence *SurvivorLink* use; and how *SurvivorLink* can be improved to serve as an effective tool to support high quality survivor care. HIMformatics, L.L.C., is developing *SurvivorLink*.

### Specific Aims

- Collect data on pediatric cancer survivors in *SurvivorLink*. **(Ongoing)**
- Facilitate the exchange of clinical information at key transitions. **(Upcoming)**
- 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)**

**2008 Activities:** The team received Institutional Review Board (IRB) approval for this initiative. They have completed the first round of interviews with physicians throughout Georgia about their experiences providing survivor care and the types of materials they think might help them treating pediatric cancer survivors. In addition, the team has assembled their advisory group, which consists of physicians, non-profit advocacy group members, health outcomes researchers, and others. They have recruited participants for the first of focus groups for patients and parents of survivors. Finally, the project team has been designing the portal, and has created a series of drafts to share with the focus group members and advisory group in order to get specific feedback.

**Preliminary Impact and Findings:** There are no findings at this time because the project team is still developing the intervention.

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**Selected Outputs**

None Available.

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**Grantee's Most Recent Self-Reported Status:** The project is completely on track.

**Milestones:** Project is completely on track.

**Budget:** Spending is roughly on target.