Background: Since specific treatments increase the risk of SMN and cardiac dysfunction in childhood cancer survivors, the Children’s Oncology Group (COG) has published guidelines for SMN and cardiac surveillance. In 2006, the Institute of Medicine recommended that survivors receive a SCP documenting their required surveillance in order to maximize their adherence. The impact of this recommendation on adherence is not known.

Methods: A survey completed between 2014-2016 by 10,791 survivors in the CCSS ascertained adherence to COG guidelines among those for whom surveillance for breast cancer (N = 657; mammogram/MRI), colorectal cancer (N = 951; colonoscopy), skin cancer (N = 5468; skin exam) and cardiac dysfunction (N = 4310; echocardiogram) was recommended. We estimated adherence rates and identified factors associated with adherence using multivariable logistic regression.

Results: Median age at diagnosis was 7 years (range 0-21) and time from primary cancer diagnosis was 36 years (16-66). Adherence to recommended breast, colorectal, skin and cardiac surveillance was 45.7% (95% CI 41.9-49.5%), 38.2% (CI 35.1-41.3%), 22.6% (CI 21.6-23.7%) and 42.3% (CI 41.0-43.6%), respectively. 26.9% of survivors and 19.8% of primary care providers (PCPs) had a copy of the SCP. Providing the PCP with a SCP was associated with increased skin cancer surveillance (OR 1.4, CI 1.1-1.7) only. Survivors’ having a SCP was associated with increased cardiac surveillance (OR 1.8, CI 1.5-2.2) only. Visiting a specialized survivor clinic in the last year (vs. never) was associated with increased breast (OR 2.0, 95% CI 1.1-3.8), skin (OR 1.3, CI 1.1-1.7) and cardiac (OR 8.9, CI 6.4-12.7) surveillance.

Conclusions: Less than half of survivors at high risk for SMN or cardiac dysfunction adhere to surveillance guidelines. Few survivors and PCPs have SCPs, and possession of SCPs has limited impact on surveillance. Adherence was most strongly associated with attending a specialized survivor clinic. New initiatives to improve adherence must be developed and tested.