



NATIONAL CANCER INSTITUTE  
Division of Cancer Control & Population Sciences

# Disparities and Barriers to Pediatric Cancer Survivorship Care: an AHRQ Technical Brief

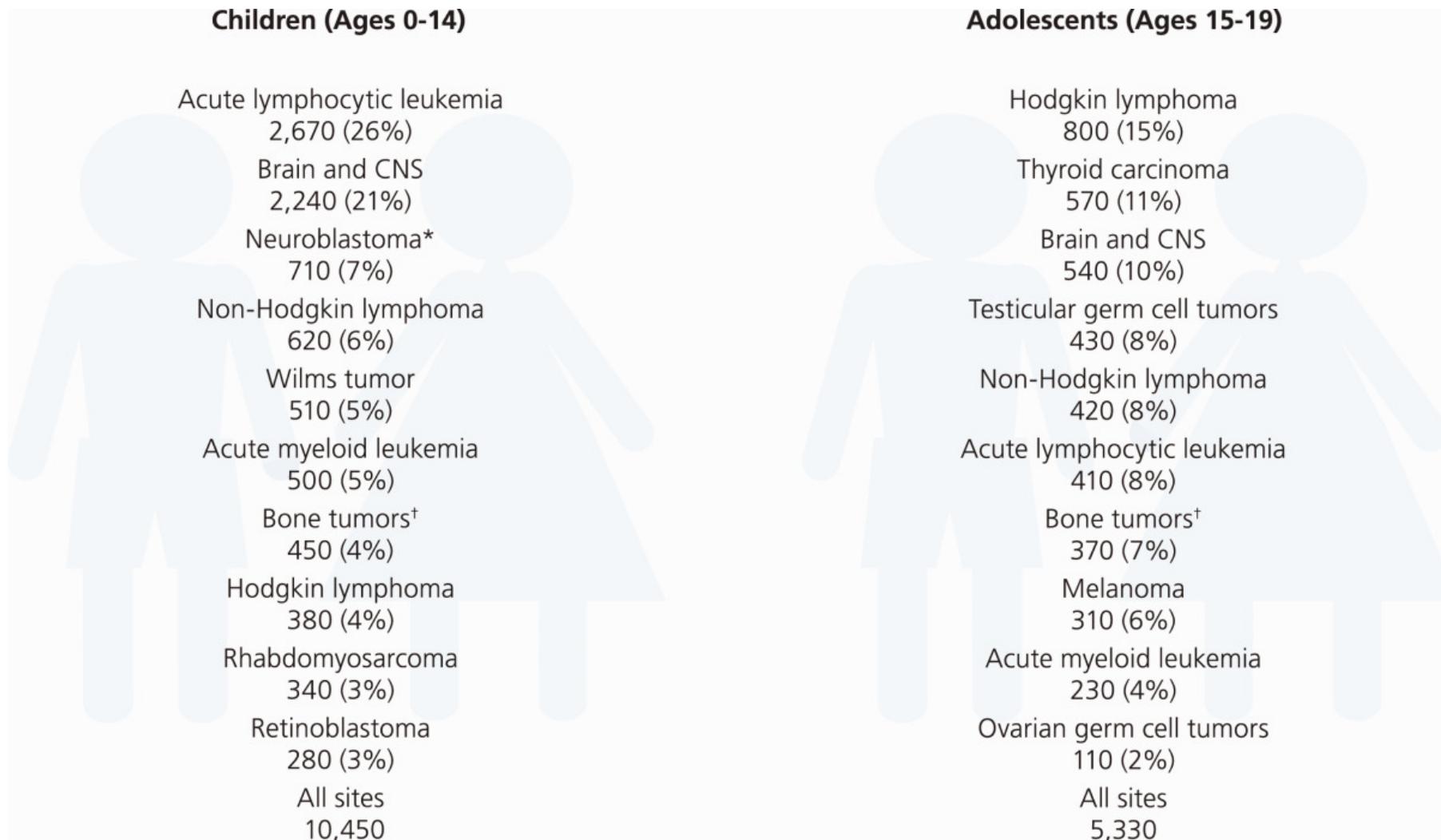
Emily Tonorezos, MD MPH

April 20, 2021

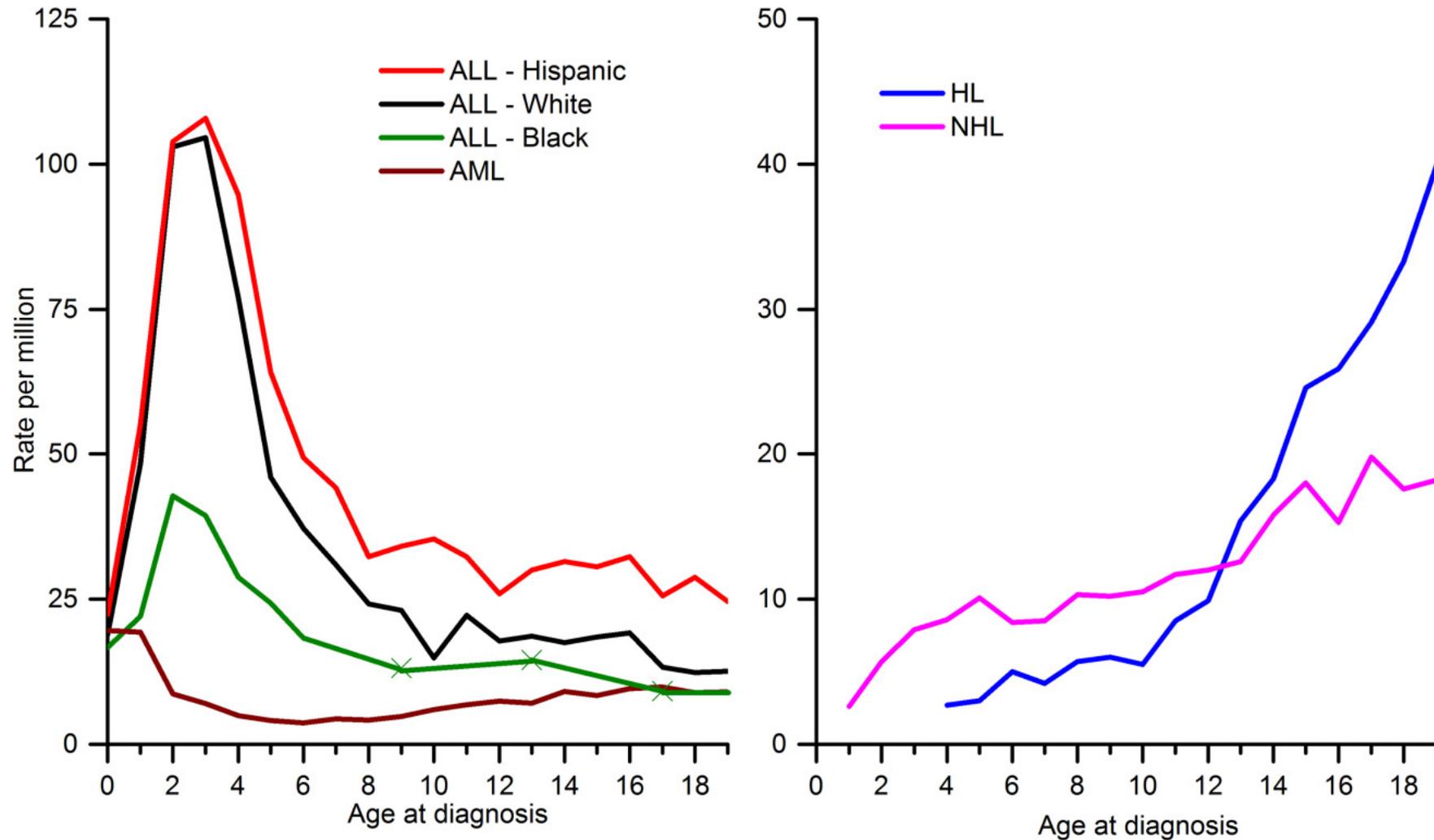
# The Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act

- Enacted in June 2018, the law ([\*Public Law No: 115-180\*](#)) was designed to advance pediatric/AYA cancer survivor research and care
- The *STAR Act* authorizes:
  - Enhancements to biospecimen collection and infrastructure (Section 101, directed to NIH/NCI)
  - Improvements to cancer registry infrastructure (Section 102, directed to CDC)
  - **Research to improve the care of and quality of life for survivors (Section 202, directed to NIH/NCI)**

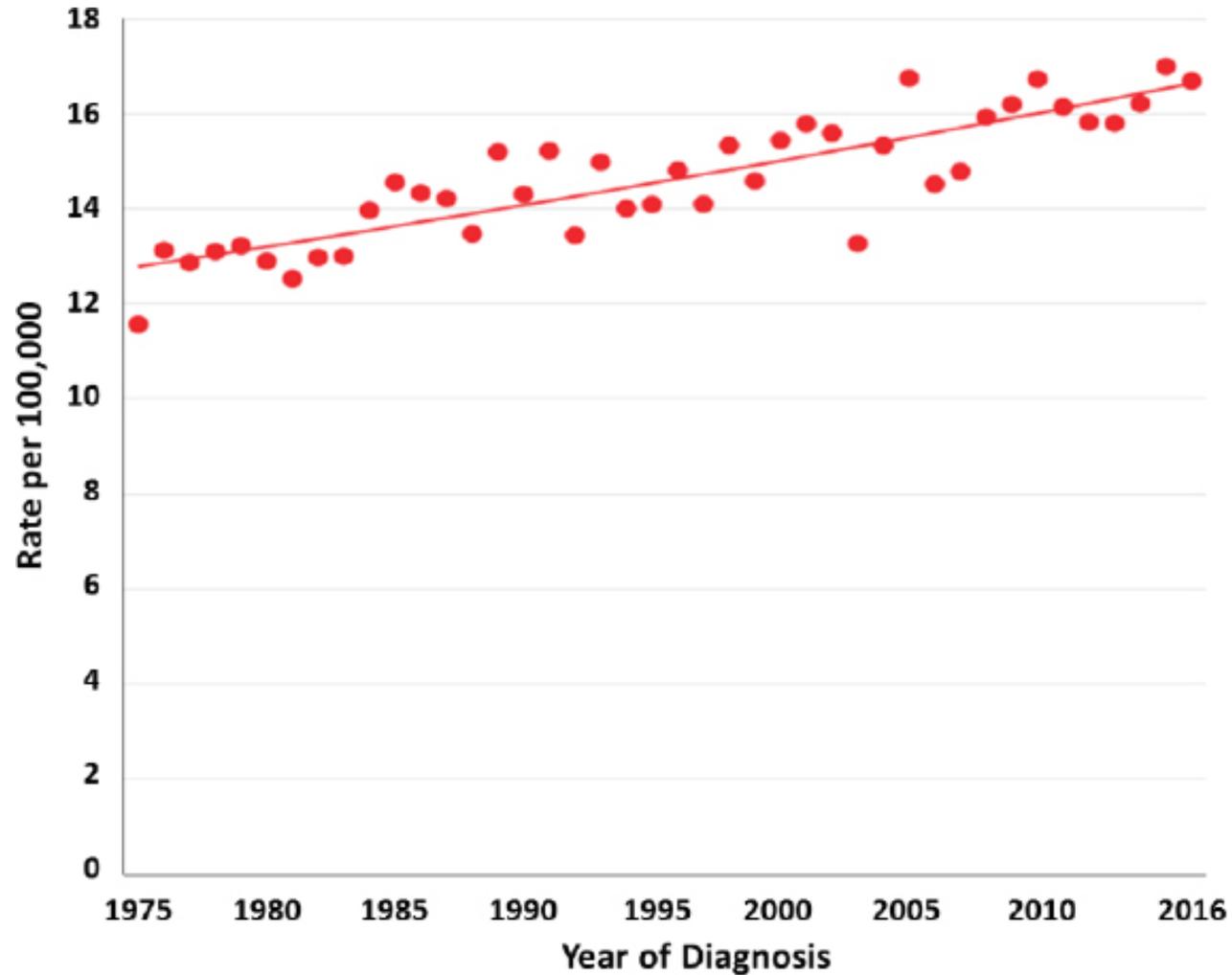
# Childhood Cancer Incidence and Survival



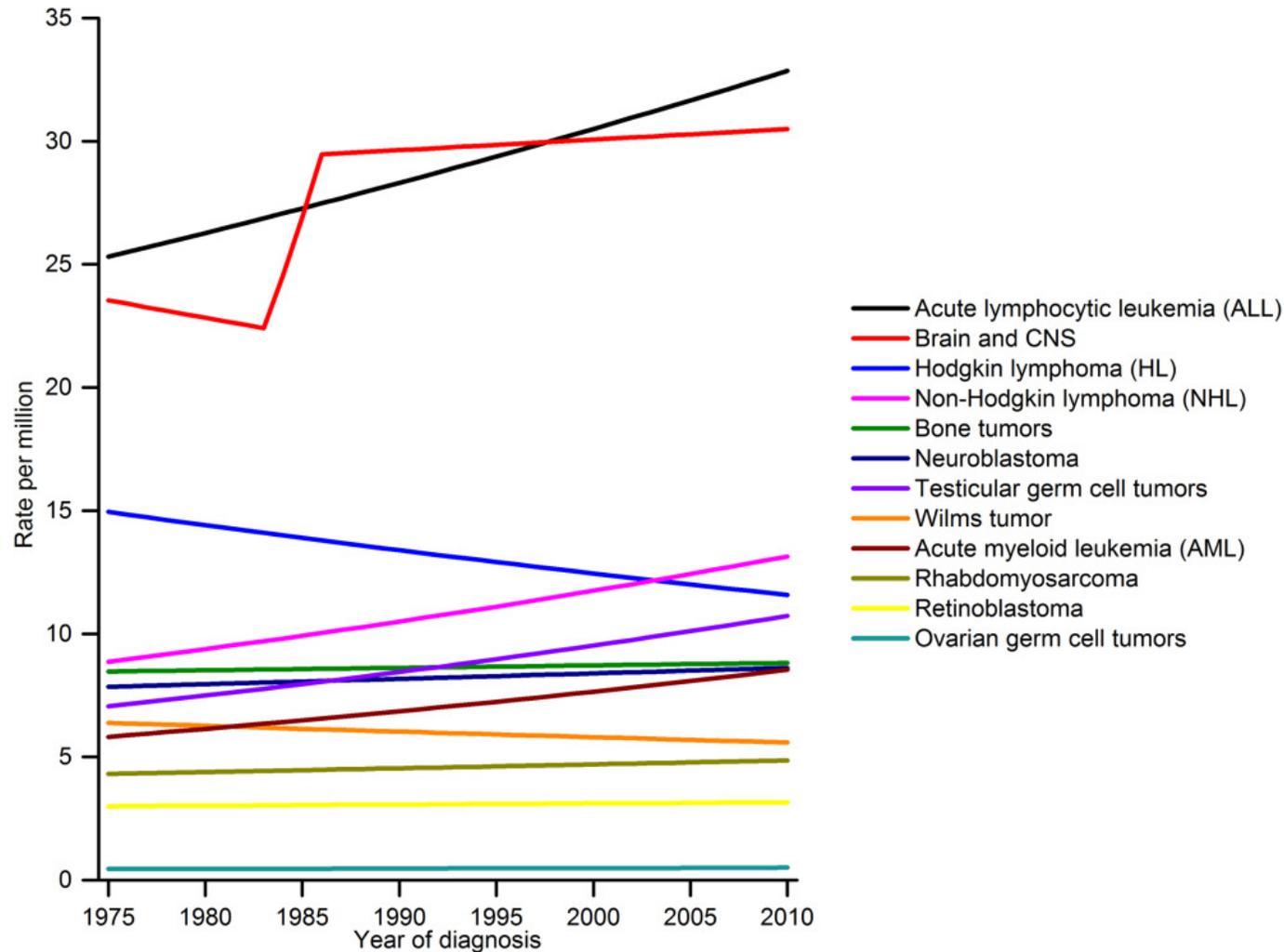
# Childhood Cancer Incidence – Age at Diagnosis



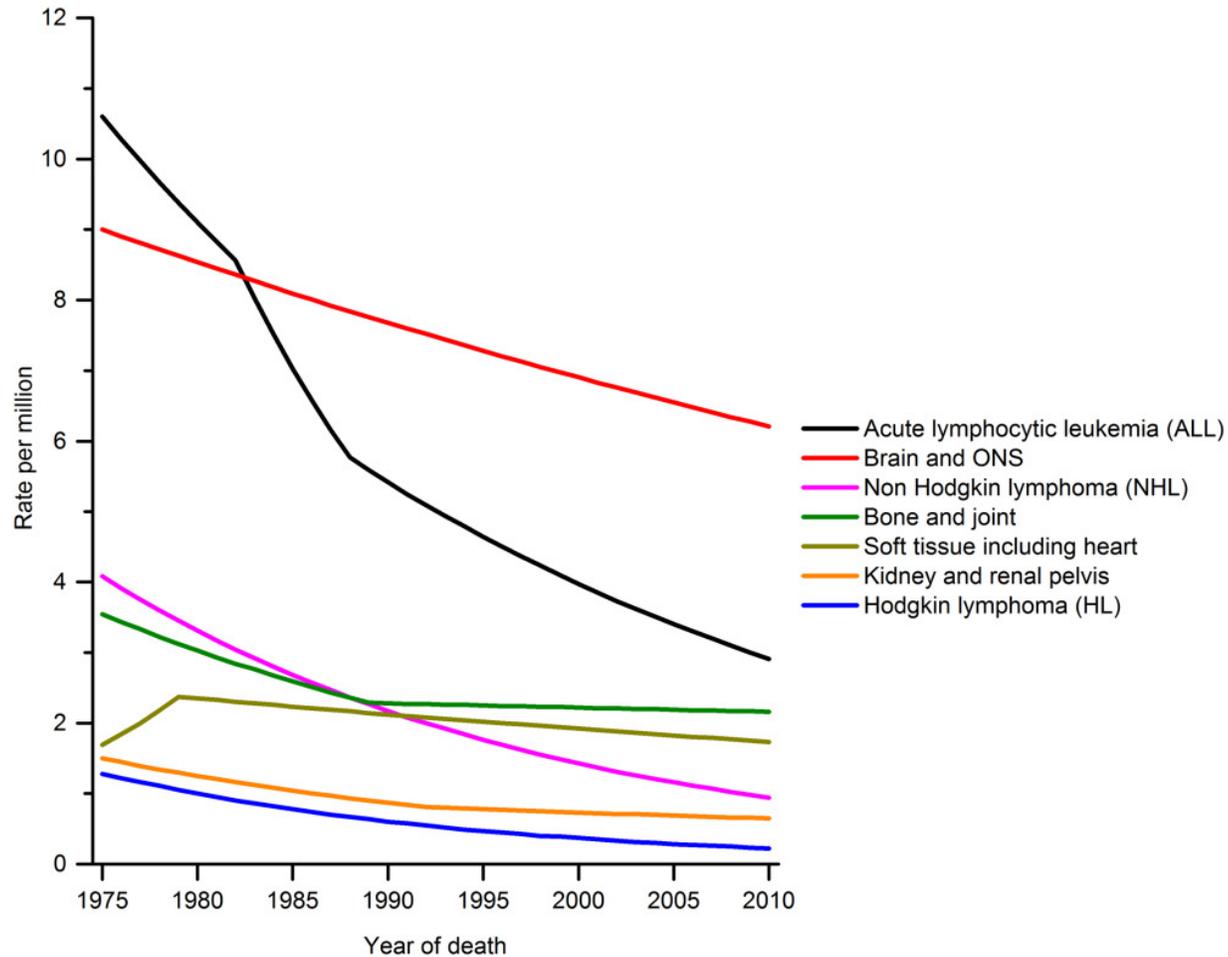
# Childhood Cancer Incidence since 1975



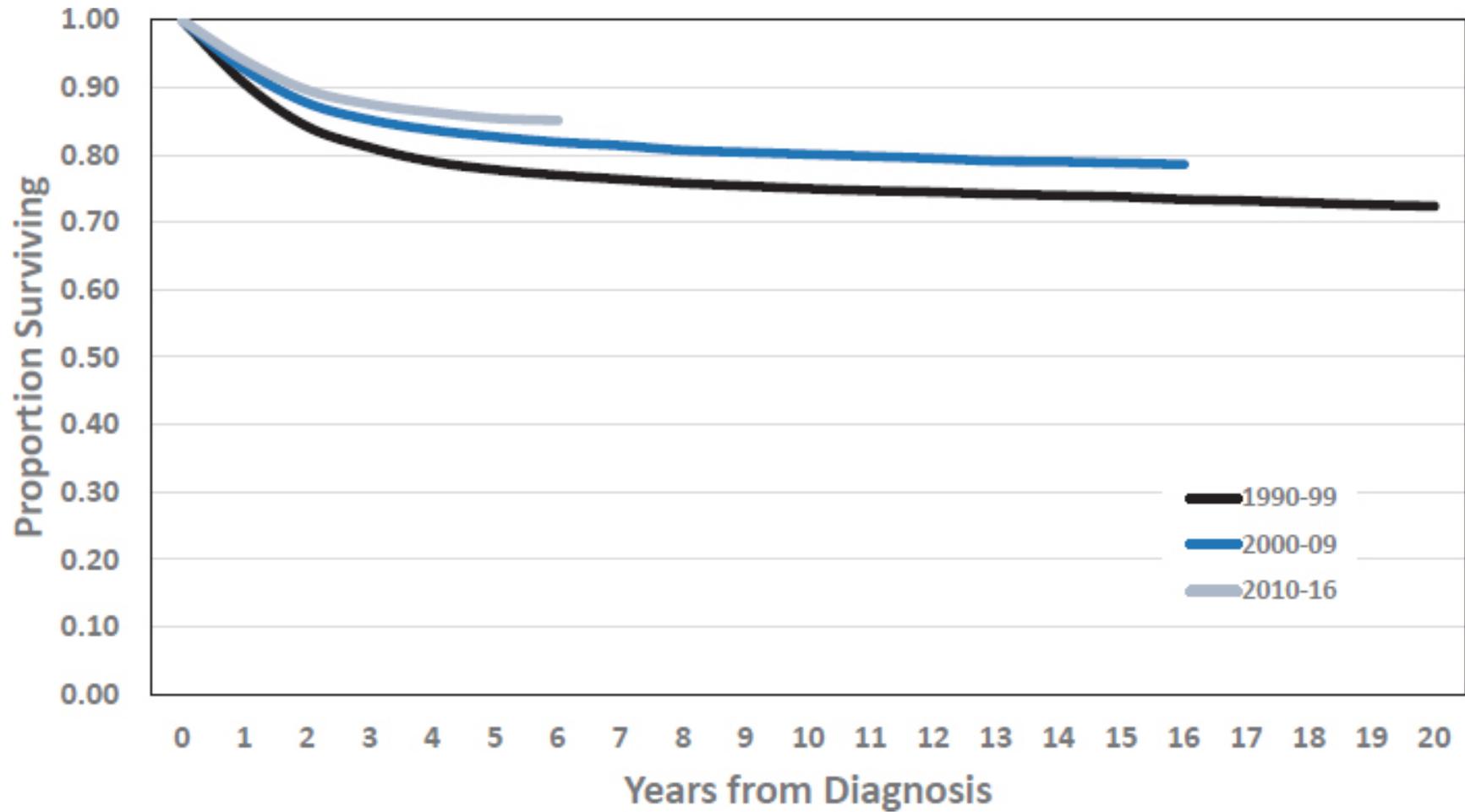
# Childhood Cancer Incidence since 1975



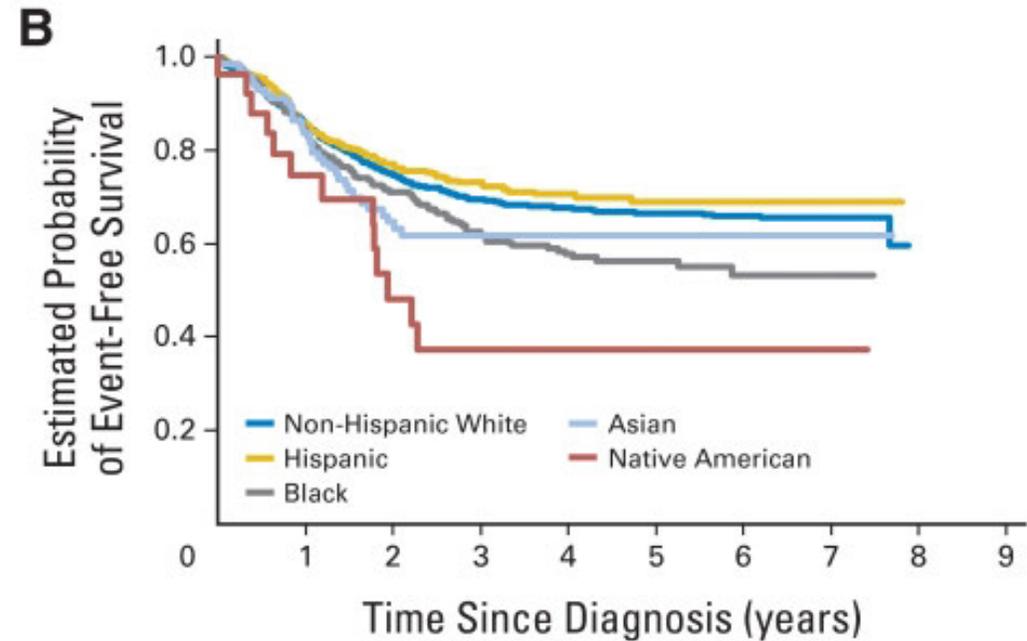
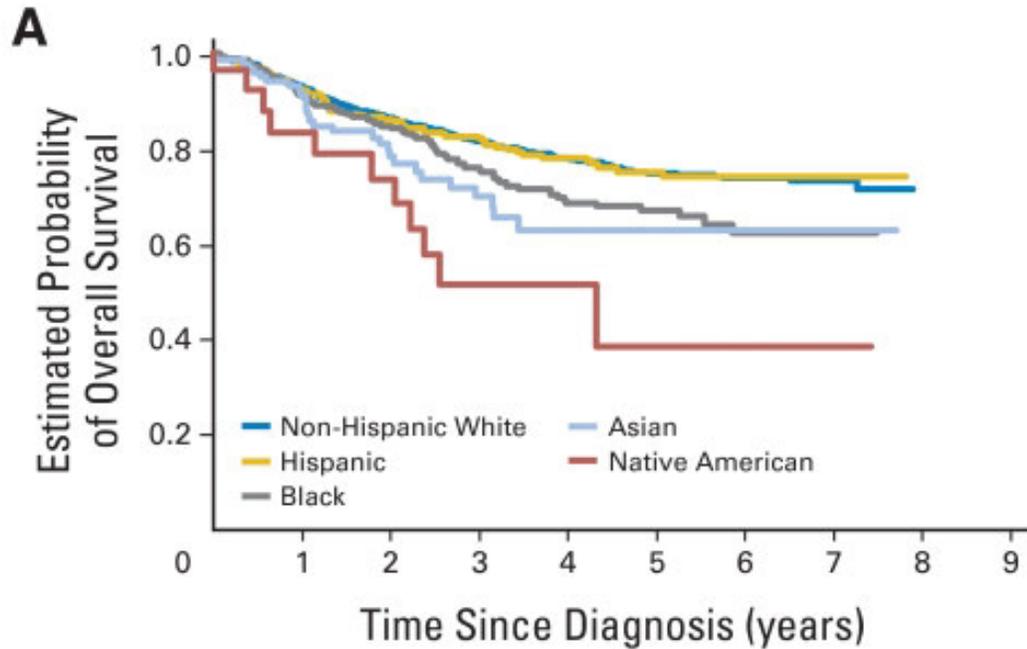
# Childhood Cancer Mortality since 1975



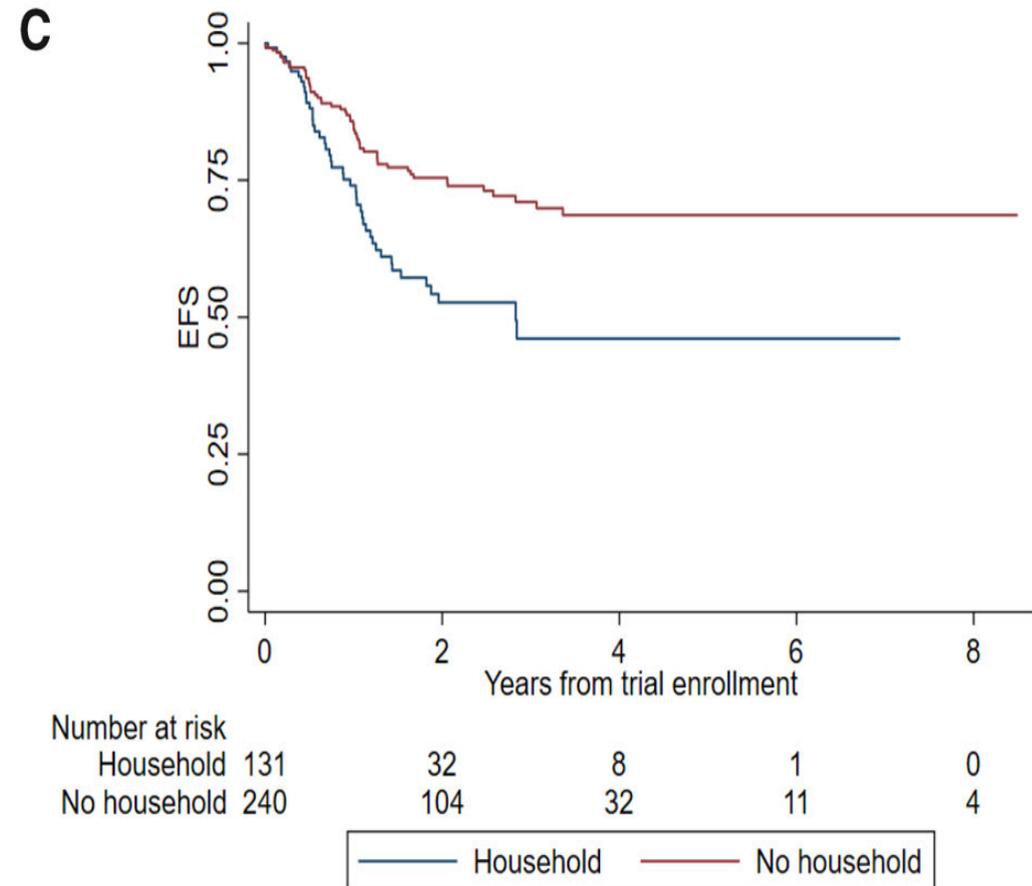
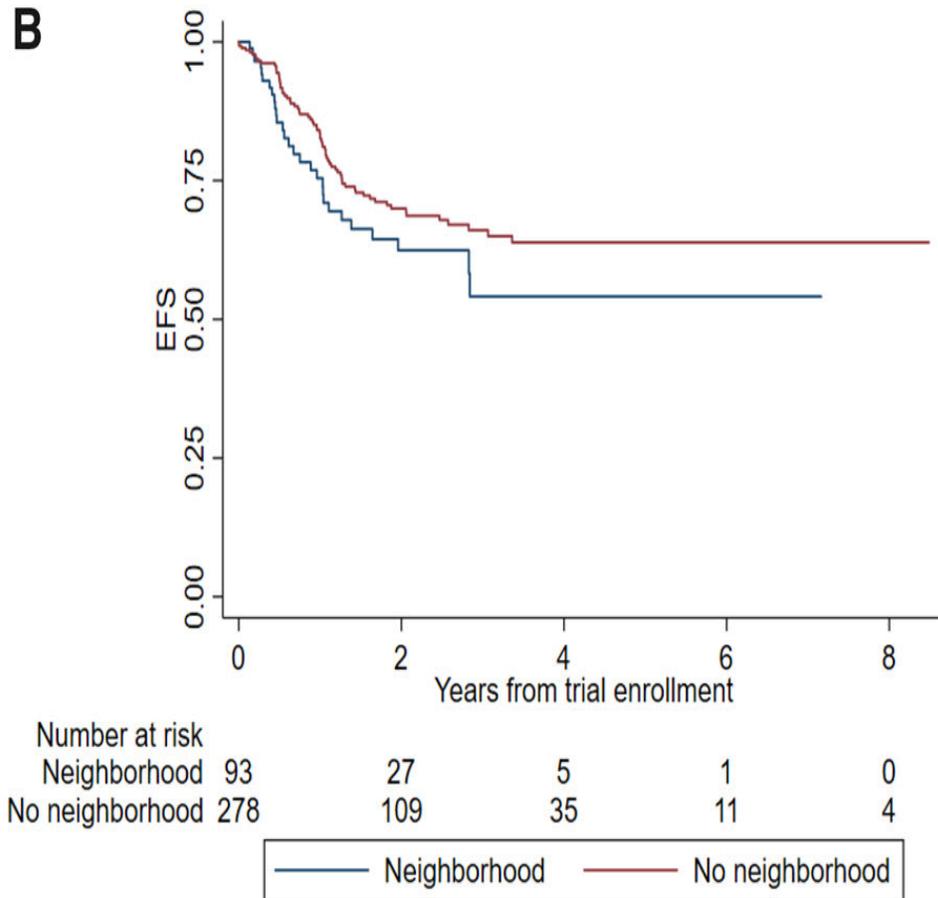
# Childhood Cancer Survival since 1990



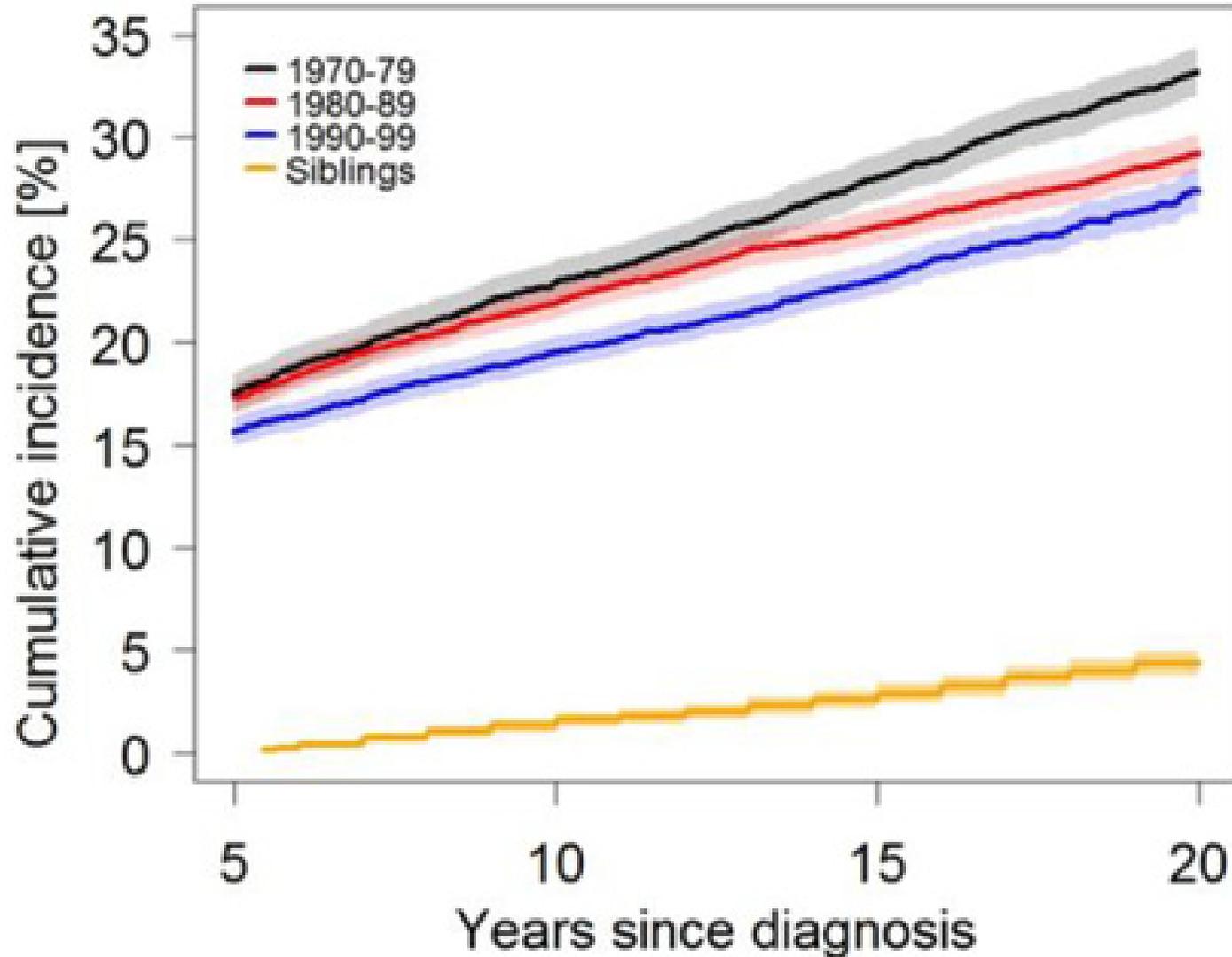
# Differences in Treatment Outcomes



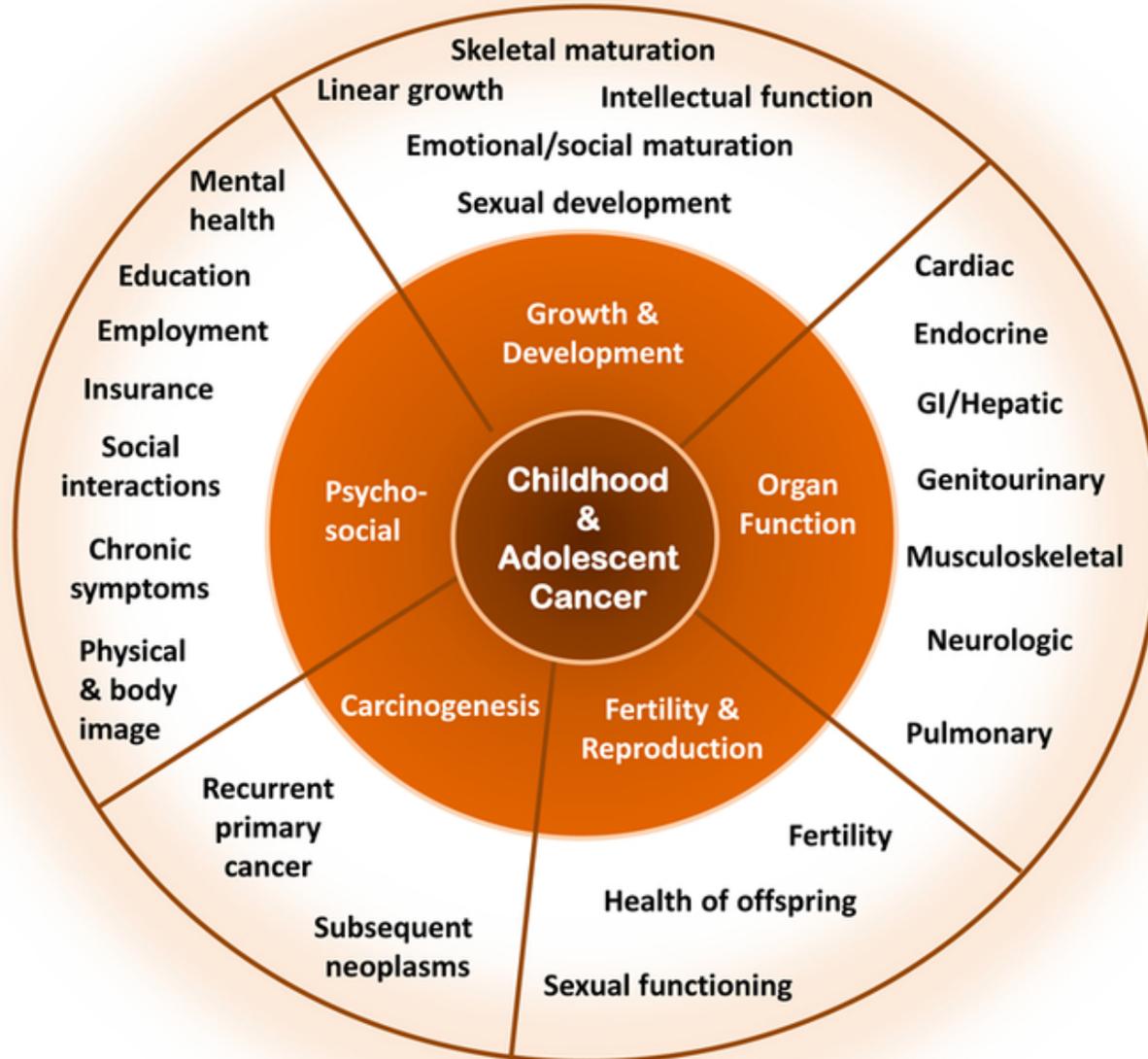
# EFS after Targeted Immunotherapy for Neuroblastoma



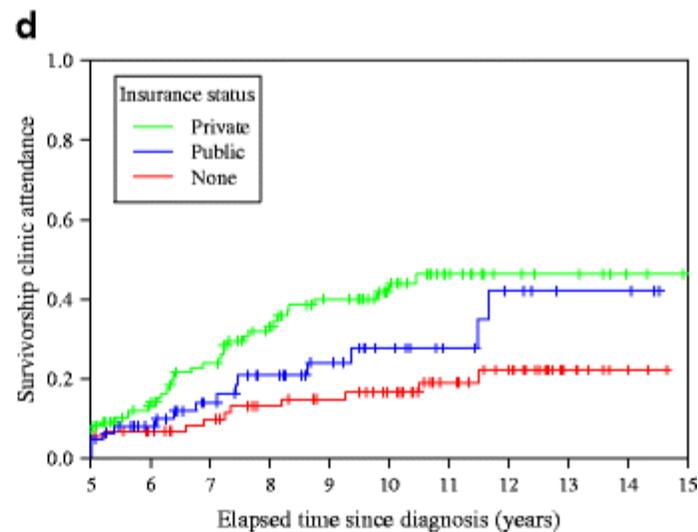
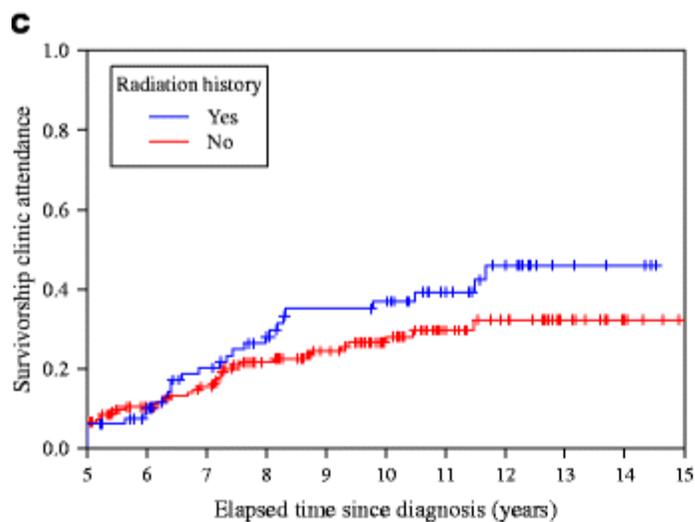
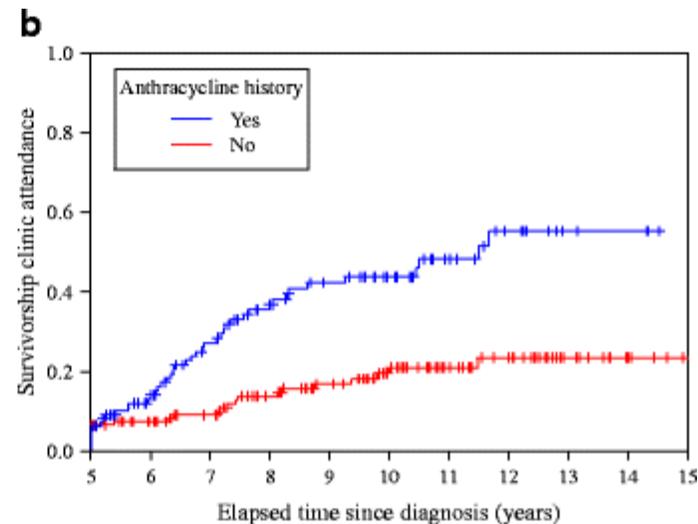
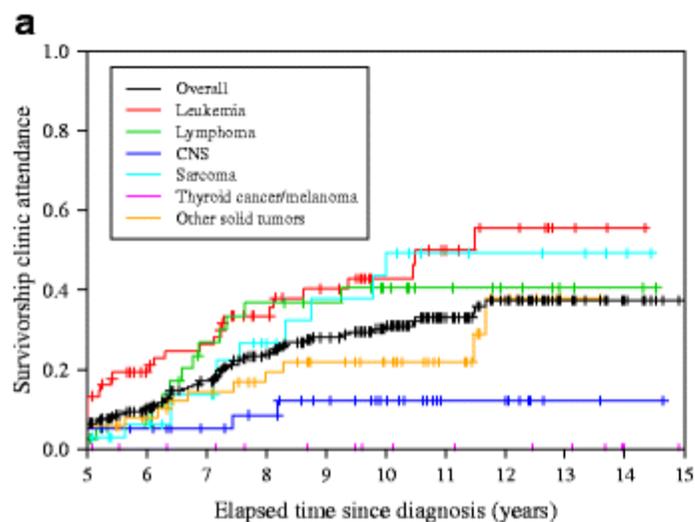
# Cumulative Burden of Morbidity among Survivors



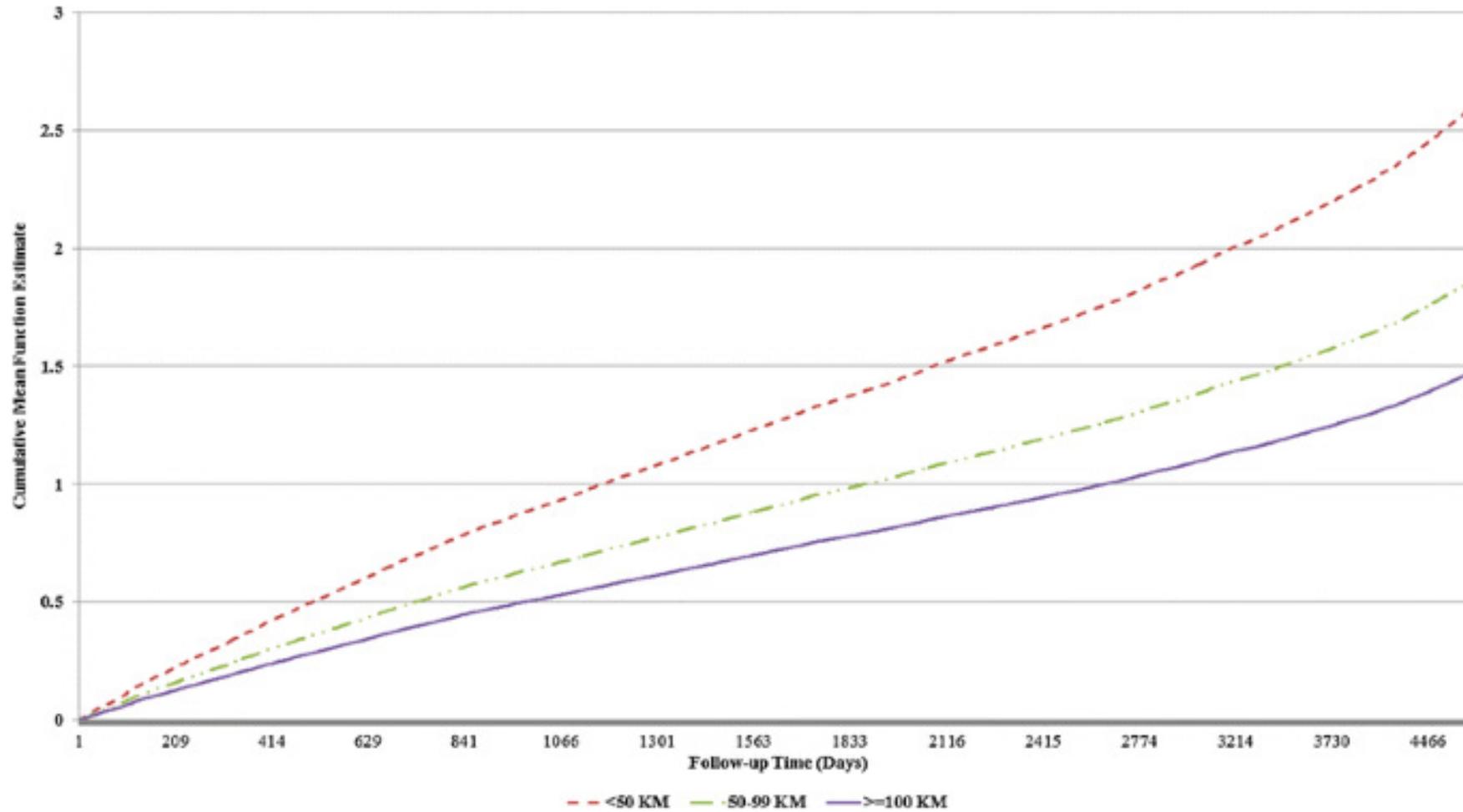
# Visualizing Outcomes for Survivors



# Attendance at Survivorship Clinic



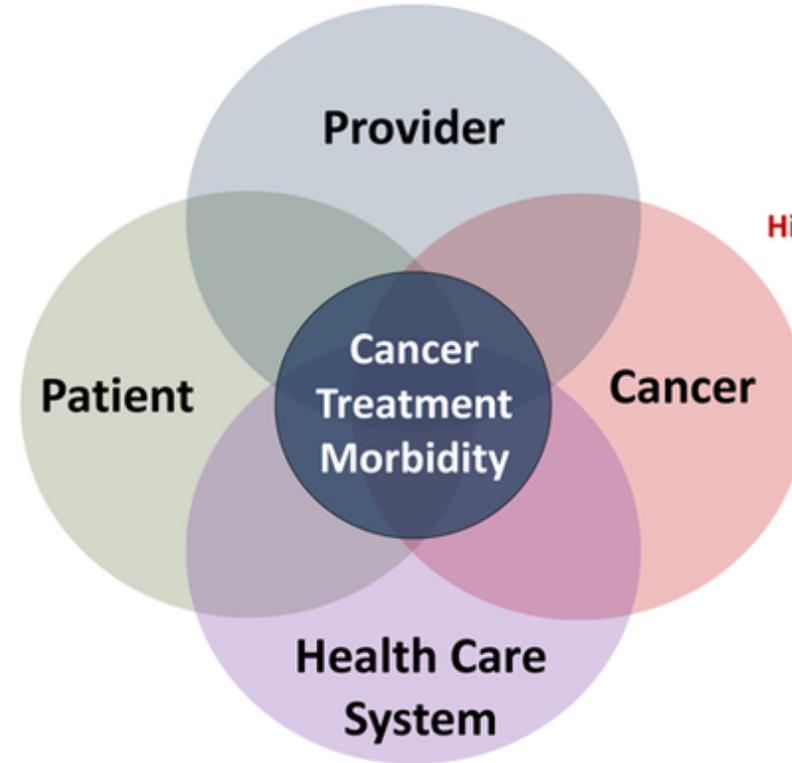
# Distance to Clinic is One Factor



# Visualizing Morbidity and Barriers to Optimal Care

Age at treatment & attained age  
Sex, race/ethnicity  
Familial/genetic factors  
Pre/co-morbid conditions  
Health behaviors  
Cognitive/developmental status  
Health knowledge  
Health risk perceptions  
Self efficacy  
Insurance/healthcare access

Survivorship education/training  
Survivorship experience  
Practice style  
Perceptions regarding preventive care  
Access to survivorship resources  
Knowledge/access to individual survivor health history



Histology/involved sites  
Biology/response  
Treatment  
Surgery  
Chemotherapy  
Radiation  
Transplant  
Transfusion  
Treatment events

Financing and payment policies  
Organization and affiliation of providers  
Data systems and information sharing  
Models of survivorship care  
Insurance coverage and benefits supporting survivorship care (especially preventive, psychosocial services)  
Community resources  
Survivorship advocacy activity



**Thank You.**



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[www.cancer.gov](http://www.cancer.gov)

[www.cancer.gov/espanol](http://www.cancer.gov/espanol)