

Childhood Cancer Survivor Study  
**Epidemiology/Biostatistics Working Group**

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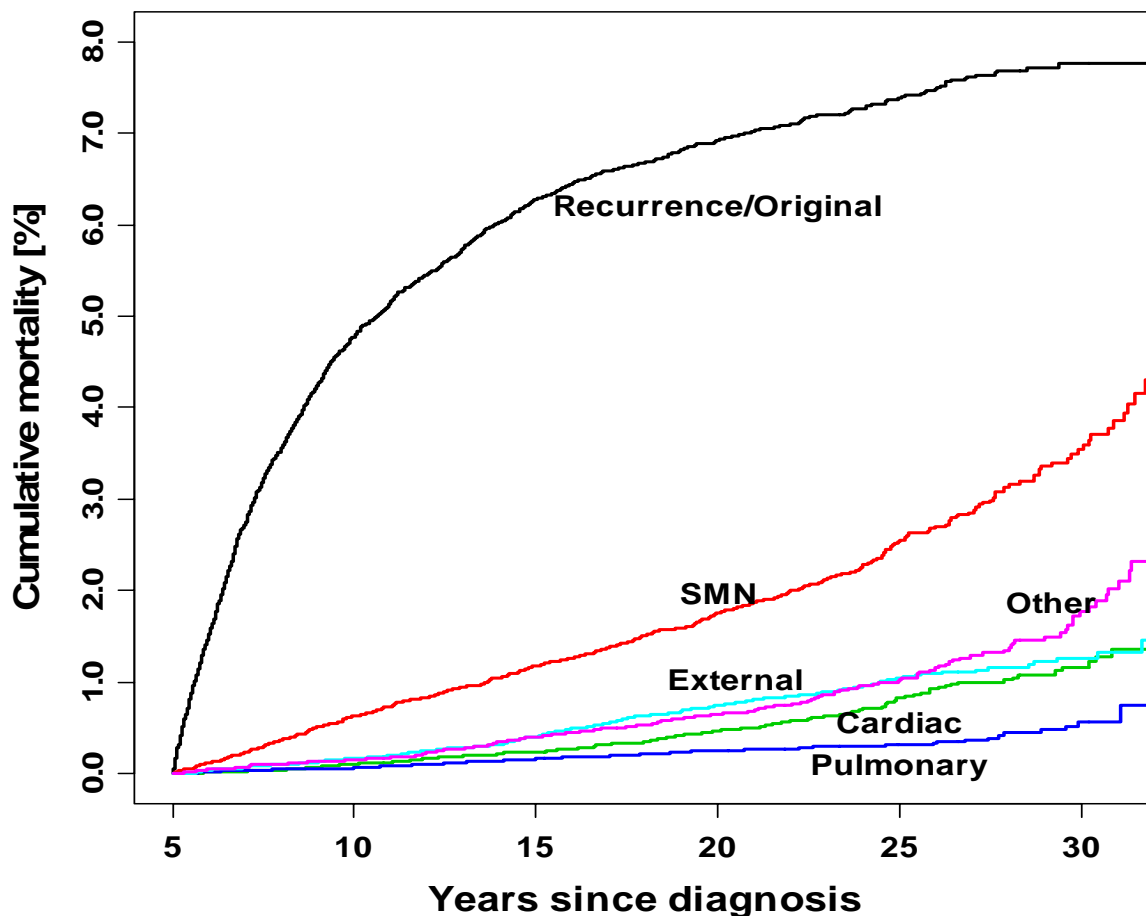
**CCSS Investigators' Meeting  
June 4-5, 2008**

## **Summary of previously reported topics**

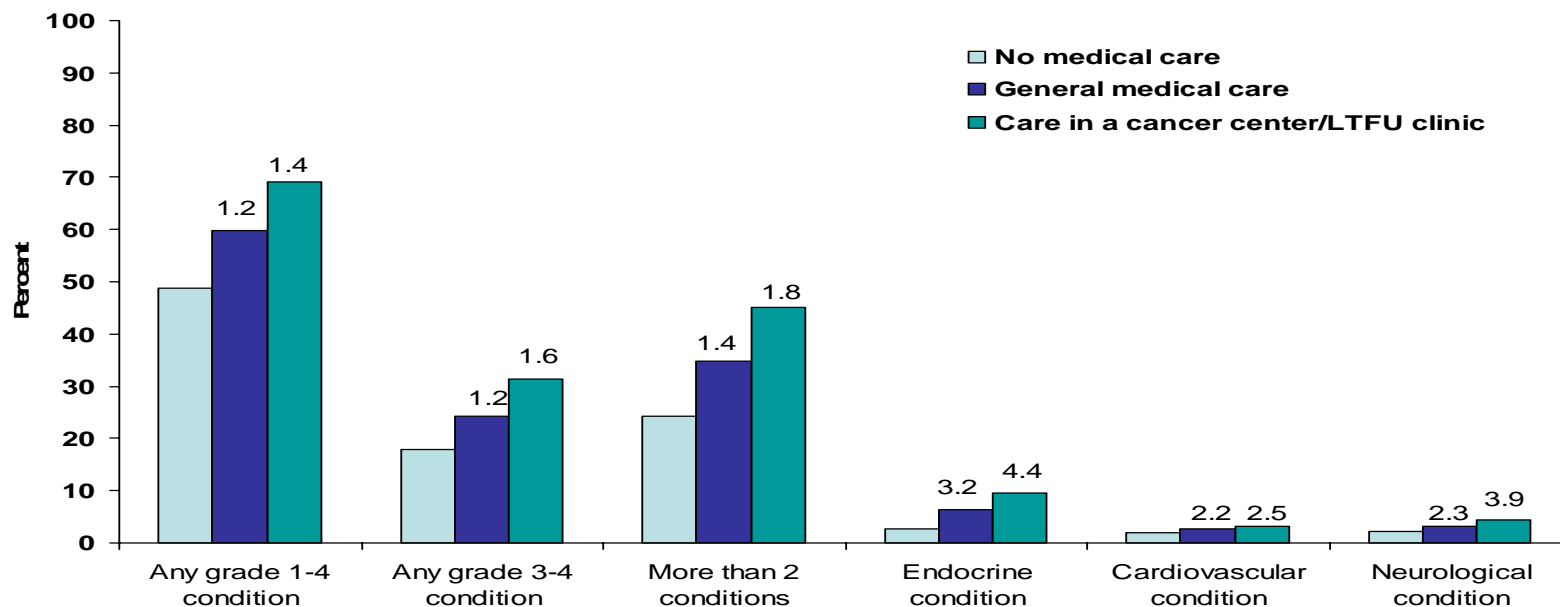
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- **SIR method for long-term follow-up (Yasui/Whitton) -1999**
- **Pulmonary Complications in CCSS (Mertens/Yasui/Liu) – 2002**
- **Characteristics of Survivors Successfully Traced (Mertens/Mitby/Whitton) - 2004**
- **Prediction of Second Malignant Neoplasm Incidence in CCSS (Dinu/Liu/Yasui) - 2008**

## Updated late mortality rates and cause of death in CCSS (Mertens/Yasui et al. 2008)



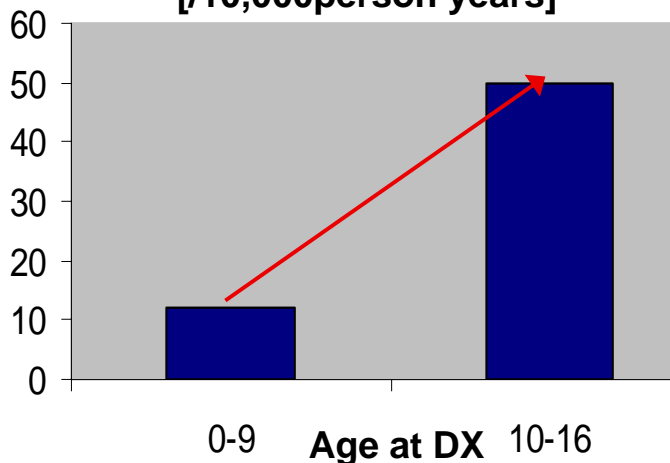
## Selection bias in clinic-based populations of childhood cancer survivors (Ness, Leisenring et al, Final Draft Manuscript)



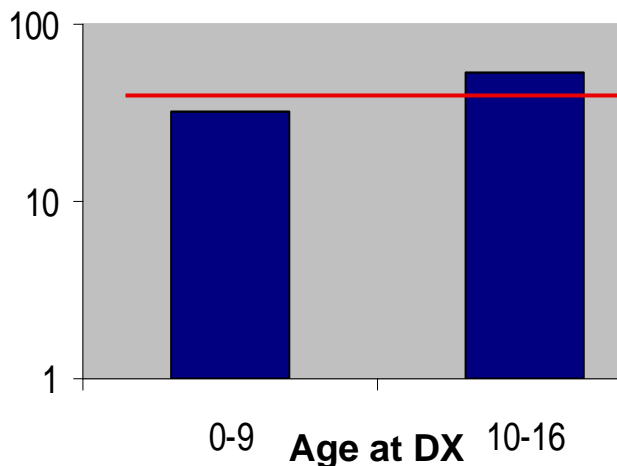
**Prevalence of chronic conditions by contact in the medical system in the 2 years prior to survey completion and relative risk of having a chronic condition comparing those who received either general medical care or care in a cancer center or long term follow-up clinic to those who did not receive care. Risk ratios adjusted for time since diagnosis and cancer type.**

## Age at DX of HD and Breast Cancer Risk (Yasui et al., 2003)

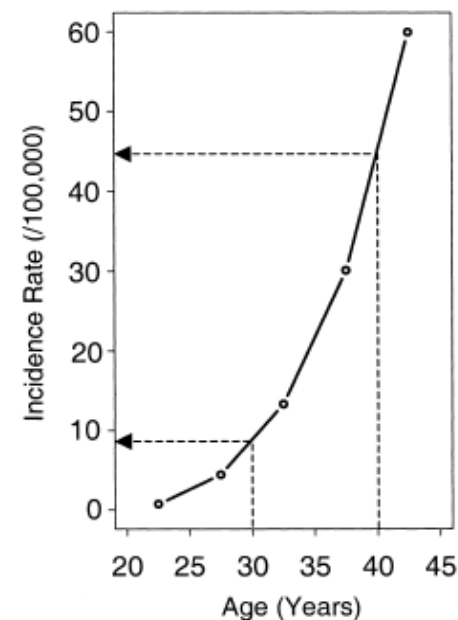
**Incidence Rates of Breast Cancer  
[ /10,000 person years]**



**Age-adjusted Incidence Ratio**



**SEER BCa Rate  
[ /10,000 person yrs]**



- If age at DX differs by 10 years, age at the time of analysis differs by 10 years.
- In the general population, women's risk of breast cancer is 4.5 times at 40 years old vs. 30 years old.
- Long-term survivorship studies must take this natural increase in risk of chronic disease into account.

## **Summary of previously reported topics**

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- **Sun behaviors/skin cancer (Mertens/ Leisenring) – Analyses underway, 2 abstracts**
- **Late recurrence in CCSS (Wasilewski/ Mertens) - Draft to co-authors**
- **Missing data imputation (Adewale/Liu/Yasui) – Draft manuscript, Wilms’ example complete**

## Topics under discussion

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- **Bias in participants who subsequently drop out lost to FUP (Lanctot, Leisenring, Kawashima)**
- **Decision analysis models (Jennifer Yeh, Diller, Mertens)**
- **Patterns of participation – who responds by mail, telephone, internet? (TBN)**
  - **Are there differences between groups?**
  - **Can we predict who prefers what method?**
- **Treatment era mortality trends (Armstrong)**
- **Conditional Survival in CCSS (Wasilewski)**
- **Pre 5-yr events (Kopciuk, Hu, Leisenring, Yasui)**

## **Opportunities for proposals using existing data**

- **Comparison of similar data elements collected at baseline for original cohort vs. expansion cohort**
- **Interval censoring issues: Combining survey outcomes with NDI mortality endpoints**
- **Task force for feasibility study to recruit for clinical research investigations**



## **Opportunities for proposals using future data**

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- **Additional data collected for validation purposes**
- **Assessment of MR data quality between the original and expanded cohorts**
- **Differences of participant characteristics between the original and expanded studies**
- **Changes in treatment characteristics from the original to the expanded studies**

## **Opportunities for ancillary studies**

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**Focus group to identify barriers to participation in our request to provide samples for a DNA repository for future research among CCSS participants (Pack et al.)**

**Recruitment strategies for survivors and siblings eligible for CCSS expansion**

**Strategies for retention of expansion cohort once enrolled**

## **Request for submission of topic-specific RFA**

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**Evaluation of strategies for retention of expansion cohort once enrolled**

**Methodological issues in long-term follow-up cohort studies (statistical, epidemiological, clinical research methodological issues)**

**Collaboration/comparison of data with other studies**

- Mike Hawkins, University of Birmingham**
- Mary McBride ,BC Cancer Agency**
- Denmark, Germany, Japan (?)**

## **Status of projects in progress**

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- **Cardiac validation methodology (Leisenring, Mitby);  
Incorporated into cardiac outcome manuscript**
- **Best comparison group for a cancer survivor study (Jurek,  
Mertens, Leisenring); Analysis underway**
- **Correlation of site-specific cancer risks in family members of  
childhood cancer survivors (Izumi, Kawashima, Yasui);  
Analysis underway**
- **NMSC validation study (Mertens, Leisenring)**
- **QC of cancer treatment data collection in original and  
expansion cohort (Whitton)**