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# Update on National Childhood Cancer Registry (NCCR)

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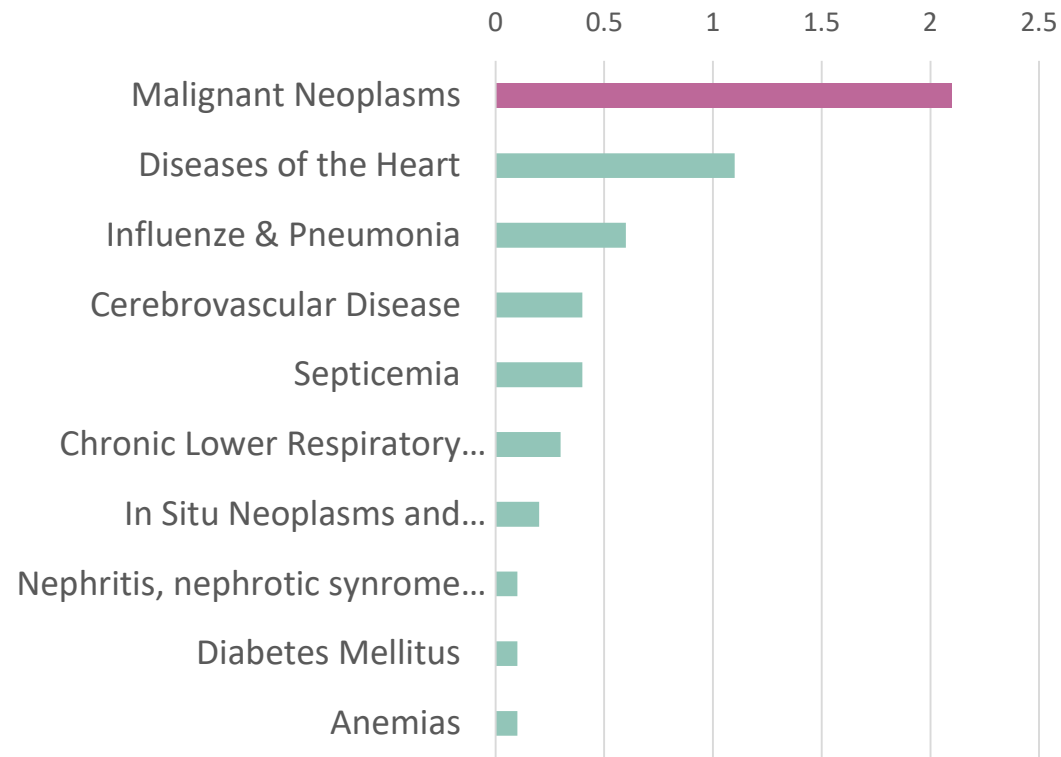
# Objectives

- Discuss the justification for forming a national registry of childhood cancers
- Detail the NCCR infrastructure
- Provide an update on the current status of the NCCR
- Showcase future plans for the NCCR



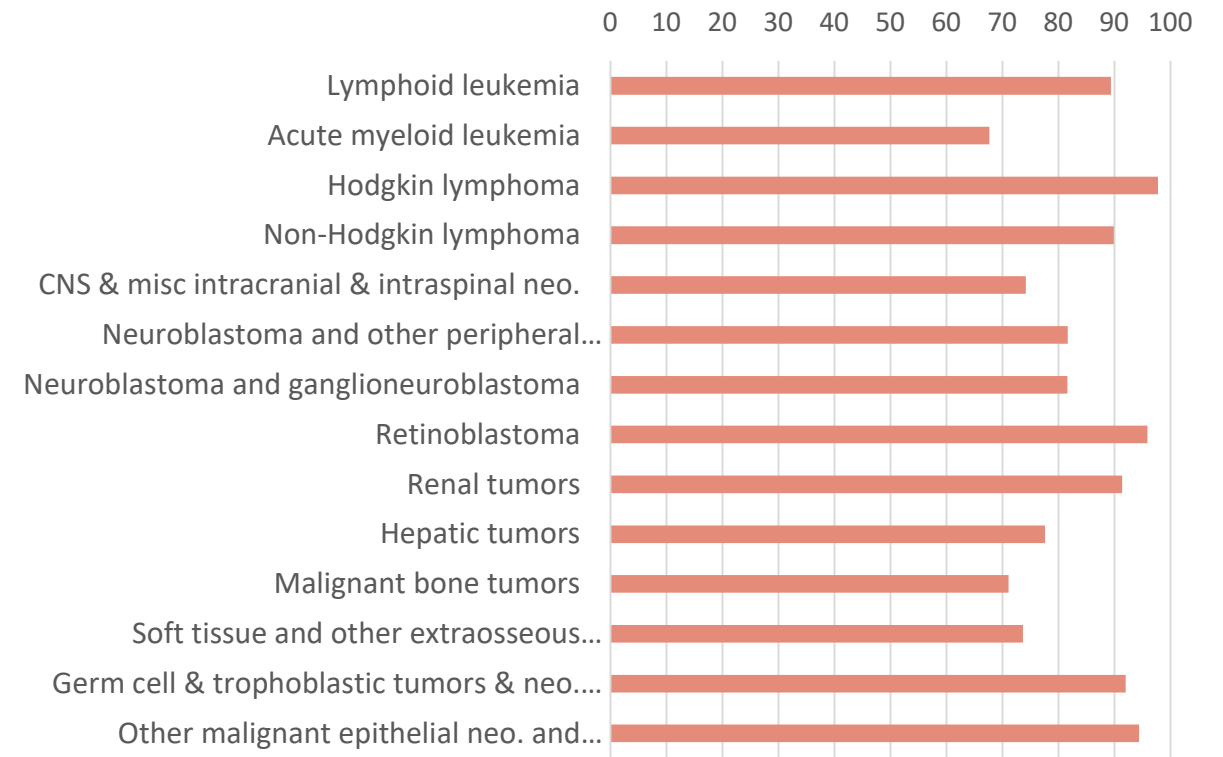
# Why NCCR?

Top 10 Causes of Death from Disease, Age 0-19  
deaths per 100,000



CDC WONDER Online Database, released in 2020. <http://wonder.cdc.gov/ucd-icd10.html>

5-Year Relative Survival (%), 2011-2017  
Ages 0-19

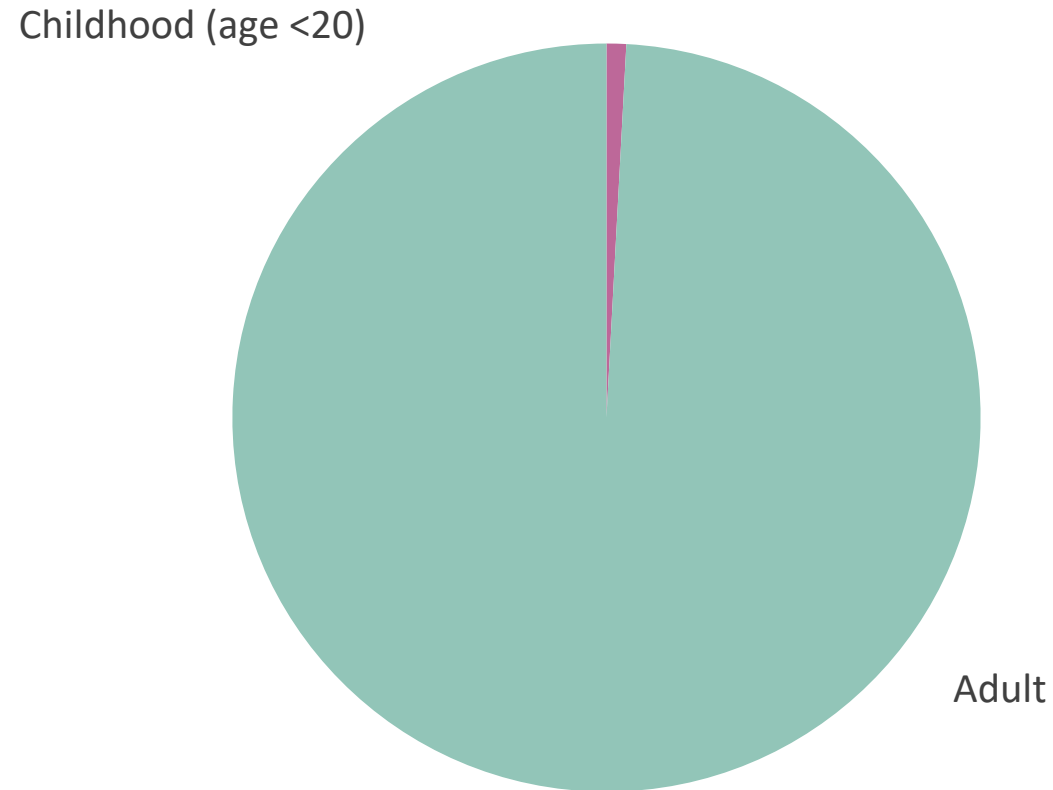


SEER Cancer Statistics Review, 1975-2018

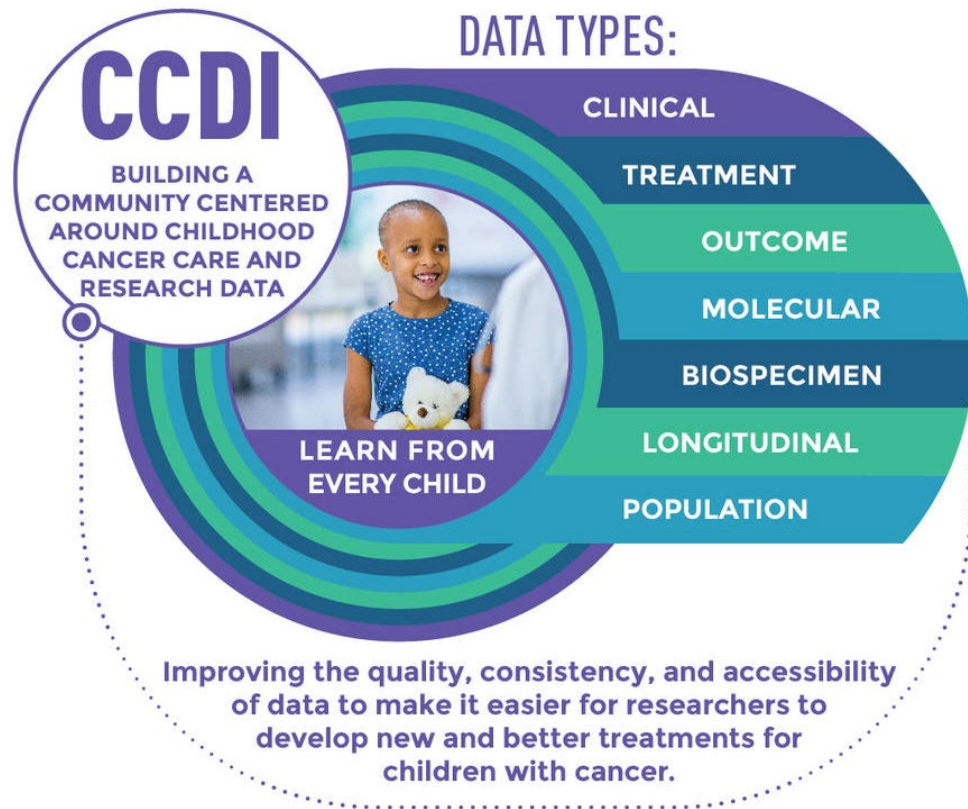


# Why NCCR?

## New Cancer Diagnoses, 2017



# What is the NCCR?









“The idea is to learn from every child with cancer in the United States.”

– *Ned Sharpless, MD*  
*Director, NCI*

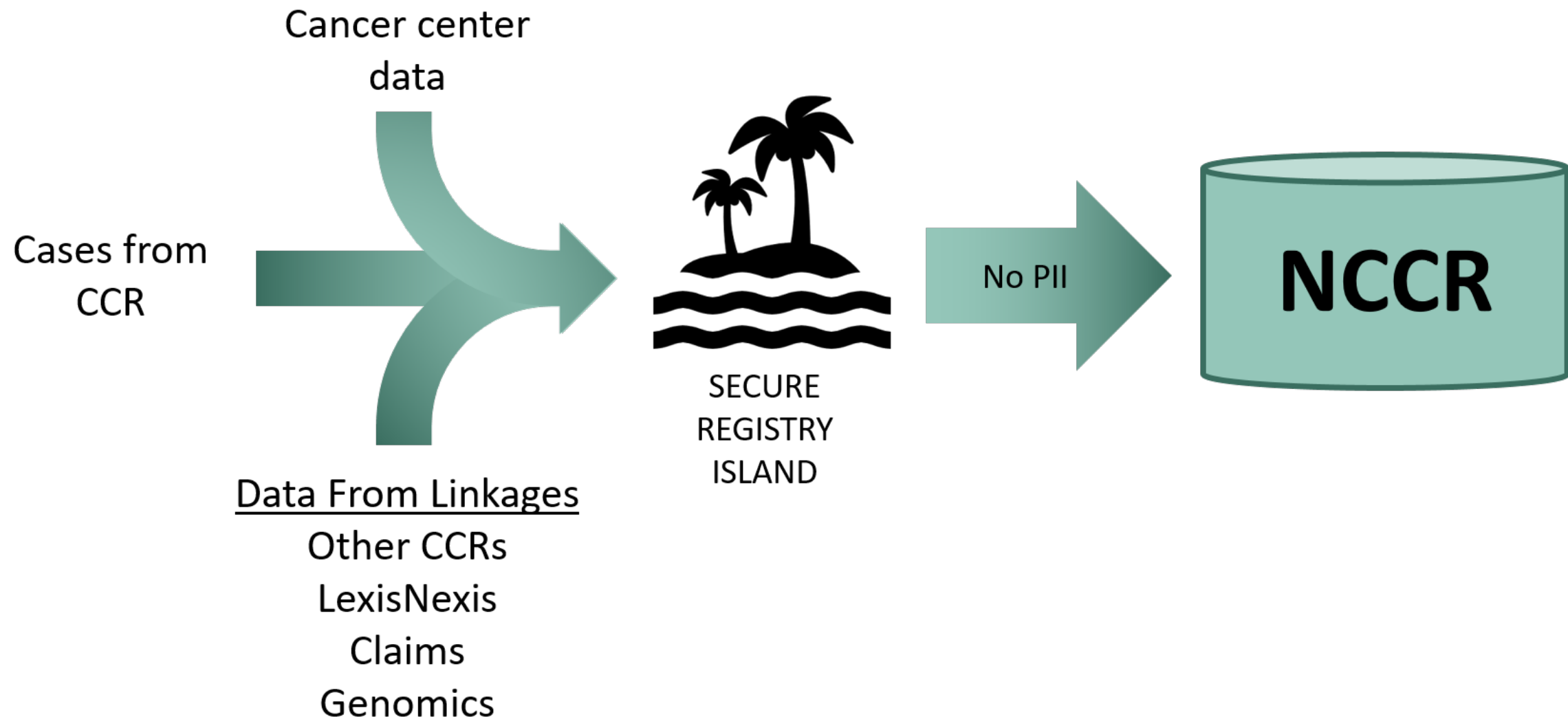




# NCCR

-  Central cancer registry data
-  Detailed treatment
-  Clinical trials
-  Genomic data
-  Social determinants of health
-  Outcomes



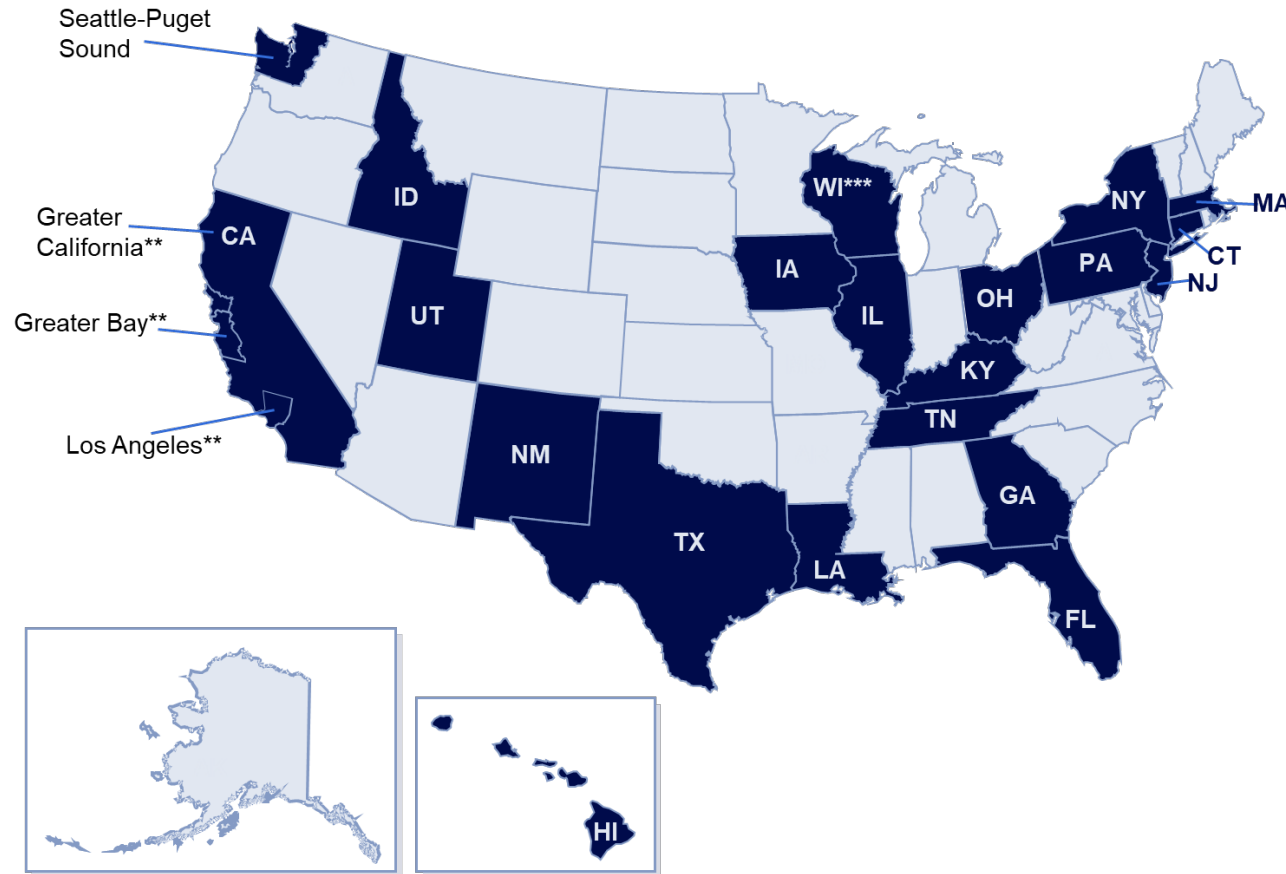


# Where are we now?





# NCCR Coverage



23 Participating SEER & NPCR registries represent ~77% of all pediatric cancer cases diagnosed between age 0 and 19 from 1995 to 2017 in the United States





# Residential History Linkage

- Linked SEER registry data with LexisNexis database for residential history to improve future linkages






# Inter-Registry Linkage – Phase I

- Linkage between all SEER registries
  - 143,194 total patients in NCCR cohort
  - 874 matched pairs

		Manual Review		
		Same Primary	Different Primary	Total
SAS Algorithm	Same primary	356	15 (4%)	371
	Different primary	24 (13%)	157	181
	Total	380	172	552





# COG Coverage – Preliminary Analysis (SEER 1995-2017), age <20

Record Source	Registry Record from Confirmed COG facility				Total
	No	Yes	Lower bound***	Upper bound***	
Total Cases	31,265	56,952			88,217
Records only In State facilities* (81%)	20,647	51,071	58.0%		71,718
	No/Unknown	Yes			
In registry state plus other states (11%)	4,530	5,566			10,096
Record only from out of state facility** (7%)	6,088	315	65%	77%	6,403

\*COG status of all in state records were validated

\*\*Patient state resident but all records from out of state; cannot verify COG status

\*\*\*Percent cases definitely seen in at least one COG facility





# Next Steps

- Inter-Registry Linkage - Phase II & III
  - Phase II - Repeat linkage with additional NCCR-participating registries
  - Phase III - Link with full Virtual Pooled Registry
- COG coverage analysis
  - Analysis by age groups, race & ethnicity
  - Link NCCR to COG CCRN and Project EveryChild
- Data Products



# Short Term Data Products Plan

The screenshot displays the National Childhood Cancer Registry website. The navigation bar at the top includes links for Home, Cancer Statistics, SEER Data & Software, Registry Operations, News, and About. The breadcrumb trail indicates the current location: Home > Cancer Statistics > Interactive Tools > National Childhood Cancer Registry > National Childhood Cancer Registry: Overview of Incidence Cases and Rates.

## National Childhood Cancer Registry: Overview of Incidence Cases and Rates

**Interactive Tools, Maps, & Graphs**

- SEER\*Explorer +
- Cancer Query Systems +
- National Childhood Cancer Registry -
  - Overview of Incidence Cases and Rates (selected)
  - Detailed Rates and Cases
  - Trends

**Age-Adjusted Cancer Incidence Rates (per 1,000,000) Excluding Non-malignant Brain and Germ Cell.**

Expand All Collapse All

By Demographics and Period of Diagnosis	+
By Sex and Period of Diagnosis	+
By Race/Ethnicity and Period of Diagnosis	+
By Age of Diagnosis	+
Age-Adjusted Cancer Incidence Rates (per 1,000,000)	+
Percent of Cases by Single Year at Age of Diagnosis	+
Rates by Single Year at Age of Diagnosis	+
By Race/Ethnicity	+

SEER is supported by the Surveillance Research Program (SRP) in NCI's Division of Cancer Control and Population Sciences (DCCPS). SRP provides national leadership in the science of cancer surveillance as well as analytical tools and methodological expertise in collecting, analyzing, interpreting, and disseminating reliable population-based statistics.



# Peds\* Explorer

- All pre-calculated statistics
- No geographic identifiers to minimize risk of reidentification of small numbers
- Over time will add new variables not collected by registries, e.g., Cancer Center Supplement projects





# Data Governance







**“It’s harder than you might imagine –  
balancing issues of research and  
patient privacy are very challenging –  
but I think we can do it.”**

- Ned Sharpless, MD  
Director, NCI



# Acknowledgements

- NCI SEER
- IMS
- NCCR Working Groups
- NAACCR staff
- Central cancer registries



# Questions?

