

# Pediatric Data Collection System (PDCS)

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## 2025 Implementation

- **Diagnosis years 2025+**
  - Requirements for collection vary by facility and standard-setter
    - 2024 – select facilities in each state
    - 2025 – SEER registries
- **Ages 0-19**
  - Optional: 20-39
- **SEER Registries only**
  - 2+ Facilities in each state
    - Already identified
    - Software vendors have been made aware
  - Any facility can volunteer
    - Contact your software vendor
    - Let ICR know that you are collecting the data



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## Where to find information:

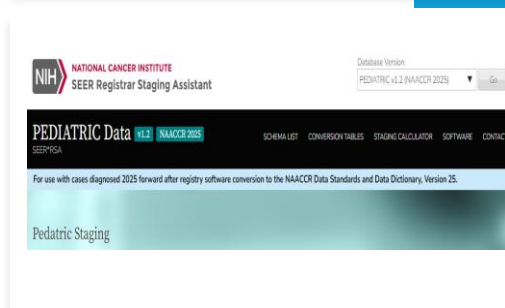
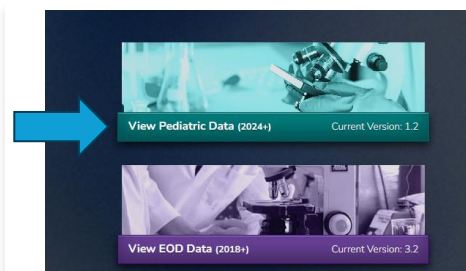
### SEER Website

- Registry Staging Assistant (RSA) page

<https://staging.seer.cancer.gov/>

### PDCS

<https://staging.seer.cancer.gov/pediatric/home/1.2/>



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## Resources for Registrars

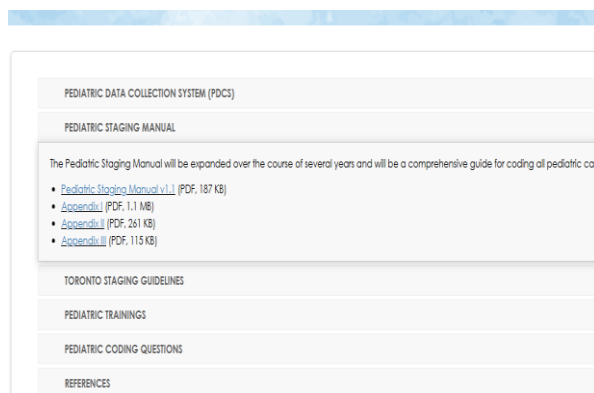
- NAACCR Pediatric Webpage

<https://www.naaccr.org/pediatric-resources/>

- Questions?

- Ask a SEER Registrar

<https://seer.cancer.gov/registrars/contact.html>



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# PDCS

- Collect Pediatric staging and site-specific data item (SSDI) information
- Staging elements collected are based on the *Toronto Childhood Cancer Staging Guidelines, Version 2*
  - Along with additional data items for surveillance purposes
- Allows for expansion to develop further staging information that is not covered in the Toronto Guidelines

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## Toronto Staging Guidelines

### What they **ARE**:

- A set of recommended staging systems and non-stage prognostic factors (NSPs) for each of 15 major childhood malignancies
- Meant to standardize how PBCRs collect and analyze data for pediatric and AYA cancers

### What they are **NOT**:

- A new staging system for use by clinicians
- A basis for making treatment decisions
- A method for determining an individual's prognosis

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# PDCS

- Patterned after SEER EOD collection system and SSDI manual
  - Permit staging of the most comprehensive set of patients
  - Reporting and monitoring trends in cancer incidence and outcomes
  - Supporting and promoting research for pediatric cancers
  - Enabling and ensuring ongoing continuity of staging trends over time reflecting the combination of clinical and pathological information

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# PDCS

- 15 Schemas
- Modeled after SEER EOD
  - Pediatric Primary Tumor
  - Pediatric LN
  - Pediatric Mets
  - SSDIs
  - Derived pediatric T, N, M & Stage Group
  - Derived Toronto T, N, M & Stage Group

Cancer Schema List

Standard Search StateHist Search		Displaying 33 Schemas	
Search Term(s)		Search	
Acute Lymphoblastic Leukemia	Malignant Bone Tumors: Other specified	NHL: Burkitt lymphoma	Renal Tumors: Ewing Sarcoma of Kidney
Adult/Other Non-Pediatric	Malignant Bone Tumors: Unspecified	NHL: Mature B-cell lymphomas	Renal Tumors: Kidney Sarcomas
Astrocytoma	Medulloblastoma	NHL: Mature T-cell and NK-cell lymphomas	Renal Tumors: Nephroblastoma
Ependymoma	Medulloblastoma: Atypical teratoid/rhabdoid	NHL: NOS	Renal Tumors: Rhabdoid Renal Tumor
Hepatoblastoma	Medulloblastoma: Medullopithelioma	Non-Rhabdomyosarcoma: Fibrosarcomas	Renal Tumors: Unspecified Malignant Renal Tumors
Hodgkin Lymphoma	Medulloblastoma: Piloblastoma	Non-Rhabdomyosarcoma: Other specified	Retinoblastoma
Malignant Bone Tumors: Chondrosarcomas	Medulloblastoma: pNET	Non-Rhabdomyosarcoma: Unspecified	Rhabdomyosarcoma
Malignant Bone Tumors: Ewing	Neuroblastoma	Ovarian	Testicular
Malignant Bone Tumors: Osteosarcoma			

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**Notes**

**Note 1:** This field is based on surgical resection of the **primary site only** WITH or WITHOUT neoadjuvant therapy.

- > **Code 100** (localized tumor) OR **300** (regional tumor) if a procedure removes the entire tumor (i.e., surgical resection, excisional biopsy)
- > **Code 200** (localized tumor) OR **400** (regional tumor) if a procedure does not remove the entire tumor (i.e., incomplete, partial), or it's not clear if the entire tumor was removed
- > **Code 600** if the tumor cannot be surgically removed or the tumor crosses the spine (one side of the body to the other side)
- > **Code 999** if there was clinical work up only, no surgical removal of the tumor, or unknown if surgical removal

**Note 2:** Use the following resources to determine if a tumor is localized, regional, or distant (further contiguous extension).

- > EOD: Review the primary site-based schema
- > Summary Stage: Review the primary site-based chapter

**Default**

999

**NAACCR Item**

NAACCR #1136

Code	Description
100	Localized tumor confined to one side of the body and one area <ul style="list-style-type: none"> <li>&gt; Tumor completely surgically resected</li> <li>&gt; Localized, NOS</li> </ul>
200	Localized tumor confined to one side of the body, greater than one area <ul style="list-style-type: none"> <li>&gt; Incomplete surgical resection done</li> <li>&gt; Unable to resect tumor</li> </ul>
300	Regional tumor confined to one side of the body and one area (extension to adjacent tissue or organs) <ul style="list-style-type: none"> <li>&gt; Tumor completely surgically resected</li> </ul>

# Pediatric Primary Tumor

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## PDCS - SSDIs

Chromosome 16q  
Status

Chromosome 1q  
Status

EWSR1-FLI1  
Fusion

FOXO1 Gene  
Rearrangements

Intl  
Neuroblastoma  
Path Prog Class  
(INPC)

IRSS State for Eye-  
2

Intl  
Neuroblastoma  
Risk Grp Stag Sys  
(INRGSS)

n-MYC  
Amplification

Pretext Clinical  
Staging

White Blood Cell  
Count

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# Neuroblastoma SSDIs

- These are the SSDIs that apply to neuroblastoma cases

Intl Neuroblastoma Risk Grp Stag Sys (INRGSS)	<BLANK>	Yes	NAACCR #1185 inrgss	All	SSDI
Intl Neuroblastoma Path Prog Class (INPC)	<BLANK>	No	NAACCR #1187 inpc	SEER	
n-MYC Amplification	<BLANK>	No	NAACCR #1186 nMyCAmplification	SEER	

Code	Description
1	Stage L1 > Localized tumor that does not involve any vital structures > Tumor confined within one body compartment (i.e., neck, chest, abdomen, or pelvis) > No evidence of image-defined risk factors (IDRFs) > Intraspinal tumor extension that does not fulfill the criteria for an IDRF is consistent with stage (L1)
2	Stage L2 > Locoregional tumor with evidence of image-defined risk factors (IDRFs) > Tumor (ipsilaterally) contiguous within body compartments (i.e., a left-sided abdominal tumor with left-sided lung, bone or pleura involvement) > Non-contiguous disease would be coded as M (e.g. left-sided abdominal tumor with right-sided lung, bone or pleura)
3	Stage M > Distant metastatic disease (see Stage M5 for patients less than 18 months old) > Noncontiguous disease > Distant lymph node involvement

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## PDCS – Manual v1.2

- **Appendix 1**
  - Instructions and Coding Guidance
- **Appendix 2**
  - Detailed information on sites/histologies included in each schema along with applicable Pediatric Data Items and SSDIs
- **Appendix 3**
  - Word document lists all SSDIs in numerical order, applicable Pediatric Schema ID, and start and end year

<https://www.naaccr.org/pediatric-resources/#1733928553790-ca5cfb7b-2f2e>

The Pediatric Staging Manual will be expanded over the course

- [Pediatric Staging Manual v1.1](#) (PDF, 187 KB)
- [Appendix I](#) (PDF, 1.1 MB)
- [Appendix II](#) (PDF, 261 KB)
- [Appendix III](#) (PDF, 115 KB)

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# General Guidelines

- Pediatric schemas apply to ages 00-39 and specific primary site/histology combinations.
  - Many are based on histology
    - Some histologies apply to **ALL ages** (e.g. Neuroblastoma, Retinoblastoma)
    - Software will determine which cases will go into a specific Ped Schema
- For **ALL** sites, Pediatric DCS is based on a combined clinical and op/path assessment
  - Path is given priority when there is a discrepancy
- Should include all available information **within 4 month of diagnosis** in the absence of dz progression or upon completion of surgery(ies) in first course treatment, whichever is **LONGER**

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# General Guidelines

- Information from a **surgical resection after neoadjuvant therapy** may be used, but **ONLY** if the extend of disease is greater than the pre-treatment clinical findings
  - **EXCEPTION:** For schemas where Ped Primary Tumor is based on surgical resection only, findings from surgical resection post-neoadjuvant therapy can be used.
- Disease progression (including mets) known to have developed after the initial stage workup, should be excluded when coding Ped fields
- Autopsy reports are used in coding Peds just as are pathology reports, apply the same rules for inclusion and exclusion

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# General Guidelines

- Death Certificate Only (DCO) cases
  - There are default codes for these cases – see manual
- Ped Site-specific guidelines take precedence over general guidelines
  - **ALWAYS** read the information pertaining to a specific primary site or histology schema

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## Appendix 2 - Example

Pediatric ID 1a1: Acute Lymphoblastic Leukemia

Primary Site(s)	Histology(ies)	Ages	Active years
C000-C809	9811-9819, 9837	00-39	2024-9998, 9999

Site Specific Data Items (SSDIs)

NAACCR #	NAACCR Name	Active years
9621	White Blood Cell Count	2024-9998, 9999

Staging	Active years
CNS Involvement (based on Pediatric Mets)	2024-9998, 9999

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Appendix III: SSDIs by Pediatric ID

SSDI #	SSDI Name	Toronto ID	Schema ID Name	Start Year	End Year
3801	Chromosome 1p Status	6a1	Renal Tumors: Nephroblastoma	2024	Current
		6a2	Renal Tumors: Rhabdoid Renal Tumor	2024	Current
		6a3	Renal Tumors: Kidney Sarcomas	2024	Current
		6a4	Renal Tumors: Ewing Sarcoma	2024	Current
		6c	Renal Tumors: Unspecified Malignant Renal Tumors	2024	Current
3812	B symptoms	2a	Hodgkin Lymphoma	2024	Current
3923	S Category Clinical	10c1	Testicular	2024	Current
3924	S Category Pathological	10c1	Testicular	2024	Current
3940	BRAF Mutational Analysis	3b	Astrocytomas	2024	Current
9600	Chromosome 16q Status	6a1	Renal Tumors: Nephroblastoma	2024	Current
		6a2	Renal Tumors: Rhabdoid Renal Tumor	2024	Current
		6a3	Renal Tumors: Kidney Sarcomas	2024	Current
		6a4	Renal Tumors: Ewing Sarcoma	2024	Current
		6c	Renal Tumors: Unspecified Malignant Renal Tumors	2024	Current
9601	Chromosome 1q Status	6a1	Renal Tumors: Nephroblastoma	2024	Current
		6a2	Renal Tumors: Rhabdoid Renal Tumor	2024	Current
		6a3	Renal Tumors: Kidney Sarcomas	2024	Current
		6a4	Renal Tumors: Ewing Sarcoma	2024	Current
		6c	Renal Tumors: Unspecified Malignant Renal Tumors	2024	Current
9608	EWSR1-FU1 Fusion	6a4	Renal Tumors: Ewing Sarcoma	2024	Current
		8c	Malignant Bone Tumors: Ewing	2024	Current
9609	FOXO1 Gene Rearrangements	9a	Rhabdomyosarcoma	2024	Current
9610	Intl Neuroblastoma Path Prog Class (INPC)	4a	Neuroblastoma	2024	Current
9611	Intl Neuroblastoma Risk Grp Stag Sys (INRGSS)	4a	Neuroblastoma	2024	Current
9614	n-MYC amplification	4a	Neuroblastoma	2024	Current
9621	White Blood Cell Count	1a1	Acute Lymphoblastic Leukemia	2024	Current
9626	Pretest Clinical Staging	7a	Hepatoblastoma	2024	Current
9627	IRSS Stage for Eye-2	5	Retinoblastoma	2024	Current

## Appendix 3 Example

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# Educational Opportunities

## • **FREE!!!!** NAACCR on-demand Shorts (<30 minutes)

- Site-specific
- Available on NAACCR LMS

<https://education.naaccr.org/>

### • **Currently available:**

#### • **PDCS Overview**

<https://education.naaccr.org/products/pdcs-overview-ready-set-go-kicking-off-pediatric-staging-in-2025>

#### • **Acute Lymphoblastic Leukemia**

<https://education.naaccr.org/products/pdcs-training-1-acute-lymphoblastic-leukemia>

#### • **Neuroblastoma**

<https://education.naaccr.org/products/pdcs-training-2-neuroblastoma>

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## Questions?

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