Pediatric Data Collection System (PDCS)

Melissa Riddle, ODS-C
Iowa Cancer Registry
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Overview & General Instructions

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- Review the Ped Manual – **Appendix I**
- General Guidelines for coding:
  - **Pediatric Stage**
    - Pediatric Primary Tumor
    - Pediatric Regional Nodes
    - Pediatric Mets
  - **Pediatric SSDIs**

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Requirements

- **Required by SEER 2025+**
  - Every facility in Iowa must report Pediatric staging and SSDI as applicable
  - Required by Iowa: **Ages 0-39**
    - Software will determine which cases will go into a specific Pediatric Schema
  - You will be assigning Ped Stage Items and SSDIs (when applicable) **in addition to**
    - AJCC (if applicable)
    - EOD
    - SSDIs/Grade

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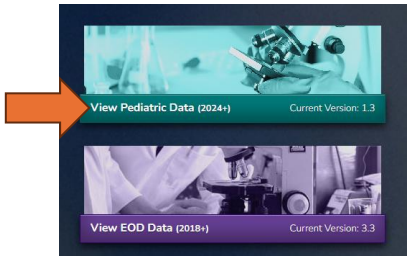
Where to Find Information:



- **SEER Website**: RSA page – **Pediatric Data** (2024+)
  - Schemas/Coding Structure
    - **2025**: https://staging.seer.cancer.gov/pediatric/home/1.2/
    - **2026**: https://staging.seer.cancer.gov/pediatric/home/1.3/

- **Pediatric Staging Manual** (2024+)
  - NAACCR Website: https://www.naaccr.org/pediatric-resources/#1733928553790-ca5cfb7b-2f2e

- **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

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- 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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Pediatric Manual General Guidelines

- For **ALL** sites, PDCS is based on a combined clinical and pathologic assessment
  - Gross observations at surgery are particularly important when all malignant tissue cannot or was not removed
  - Discrepancy between pathology and op report concern excised tissue, priority is given to the path report
- Include information **available within 4 months of diagnosis** in the absence of disease progression or upon completion of surgery(ies) in first course treatment, whichever is longer
- Information from resection after neoadjuvant therapy may be used but **ONLY** if the extent is greater than the pre-treatment clinical findings
  - *EXCEPTION*: schemas where Ped PT is based on surgical resection **ONLY**, findings from surgical post-therapy cancer be used

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Pediatric General Guidelines

- Progression of disease after the initial staging workup should be excluded when coding Pediatric fields

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- Autopsy reports are used just as are pathology reports – apply the same rules for inclusion and exclusion

- Pediatric Schema specific guidelines take precedence over general guidelines

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Ambiguous Terms

- Use the terms **ONLY for PDCS stage**
  - Not used for casefinding and reportability nor for STR

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- The **clinician's definitions/descriptions and choice of therapy have priority over ambiguous terms** because physicians may use these terms differently
  - Use the ambiguous terms list to interpret the intent of the clinician **ONLY** when further documentation is not available and/or there is no specific statement of extension/involvement
- Terminology in the schema takes priority over the general guideline list

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Ambiguous Terms

Pediatric Manual, Appendix 1: Pediatric Data Collection System, Version 1.2, 2025

Use the following lists as a guide ***when no other information is available***

Involved

Adherent	Incipient Invasion
Apparent(ly)	Induration
Appears to	Infringe/infringing
Comparable with	Into*
Compatible with	Intrude
Consistent with	Most likely
Contiguous/continuous with Encroaching upon*	Onto*
Extension to, into, onto, out onto	Overstep
Features of	Presumed
Fixation to a structure other than primary**	Probable
Fixed to another structure**	Protruding into (unless encapsulated)
Impending perforation of	Suspected
Impinging upon	Suspicious
Impose/imposing on	To*
	Up to

Not involved

Abuts	Extension to without invasion/involvement of
Approaching	Kiss/kissing
Approximates	Matted (except for lymph nodes)
Attached	Possible
Cannot be excluded/ruled out	Questionable
Efface/effacing/effacement	Reaching
Encased/encasing	Rule out
Encompass(ed)	Suggests
Entrapped	Very close to
Equivocal	Worrisome

* Interpret as involvement whether the description is clinical or operative/pathologic

** Interpret as involvement of the other organ or tissue

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PDCS

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- 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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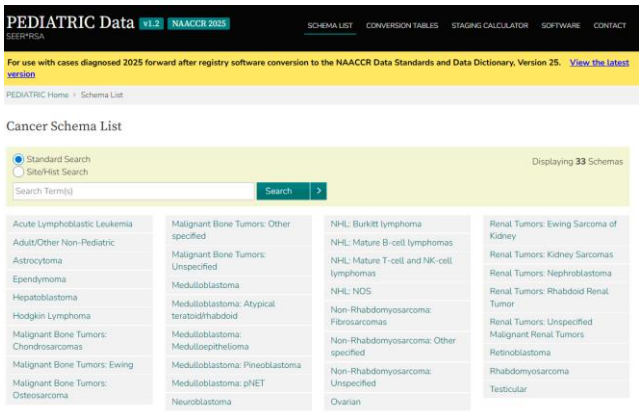
PDCS

- 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



Pediatric Primary Tumor

- Used to classify contiguous growth (extension) of the primary tumor within the primary or its direct extension into nearby organs at the time of diagnosis
- **Coding Instructions**:
  1. Assign the **farthest documented contiguous involvement** of the primary tumor
  2. Some schemas have extension codes that can only be used when there is a surgical resection
  3. Pathologic findings take priority over clinical
     a) Assign highest code based on pathologic findings (path report)
     b) No applicable pathology assign highest clinical findings: imaging over PE
     c) If extension seen clinically but confirmed negative (no involvement) pathological, then code based on path findings
  4. **Neoadjuvant Therapy** – based on clinical findings unless there is further extension post-therapy findings use post-therapy findings
  5. Code the furthest extension if there are multiple primaries abstracted as a single primary
  6. No evidence of primary tumor (occult primary) – **Code 800**
  7. Ped PT coded 800, then **Tumor Size = 000**
  8. **Code 999** – no information on primary tumor extent or DCO case
  9. Document in text information that backs up the code in pediatric PT; can also document pediatric PT code in the Stage text field

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Pediatric Regional Nodes

- Used to classify the regional LN involved at the time of diagnosis
- Coding Instructions:
  1. Record the specific involved regional LN chain(s) farthest from the primary site
     a) Generally, the LN chains closest to the primary have lower codes, while father away will have higher codes (could be exceptions due to LN drain patterns)
     b) If a LN chain is NOT listed check abstractor notes in SEER*RSA, Heme manual Appendix C, anatomy textbook, ICD-O-3, or medical dictionary for synonym
        - If not located as regional nodes, code in Pediatric Mets
     c) Make sure your Pediatric LN agrees with Regional LN Positive
  2. **Clinical vs. Pathologic codes**
     a) Some schemas have nodes that are divided into clinical assessment only or pathologic assessment only
        - Clinical assessment – only use when there is a clinical work up and NO surgical resection of primary site
          - Includes: PE, FNA, needle core bx, SLN bx, or LN excision
          - ***EXCEPTION*** – if patient has neoadjuvant therapy and clinical assessment is greater than path exam, clinical assessment takes priority
        - Pathologic assessment – used when there is a surgical resection of the primary tumor in conjunction with FNA, SLN bx, or LND
          - FNA or SLN bx can be done during clinical time frame and then followed by a negative LND

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Pediatric Regional Nodes

3. Pathologic findings take priority over clinical
   - Not necessary to biopsy every LN in the suspected area to disprove involvement

   a) Code LN involvement based on path findings
   b) If there is no path finding, code based on clinical findings
   c) If involved clinically but disproven on path review, then code based on the negative path findings

4. **Neoadjuvant Therapy** – code based on clinical findings unless there is further involvement on pathologic post-therapy findings
5. Terms meaning LN involvement:
   - **Solid tumors**: fixed, matted, mass in the hilum, mediastinum, retroperitoneum, and/or mesentery are considered involvement
   - **Solid tumors**: palpable, enlarged, visible swelling, shotty, or LAD should be ignored unless the physician states involvement
6. Accessible and Inaccessible LN
   - Accessible – observed, palpated, or examined without instruments
     - Statement "remainder of examination negative" is sufficient to **code 000**
   - Inaccessible – not easily examined by palpation, observation, PE, or other clinical methods; usually nodes in body cavities
     - If Ped PT is low stage/localized and standard treatment performed, sufficient to **code 000**

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Pediatric Regional Nodes

7. **Code 000** (negative) over 999 (unknown) when **ALL** three of the following conditions are met:
   a) No mention of regional LN involved on PE, clinical work up, or surgical exploration
   b) Patient has localized disease
   c) Patient receives standard treatment to primary site or patient is offered usual treatment but refuses
8. Direct tumor extension/invasion into LN – code in Ped Reg Nodes
9. **Code 800**
   - LN involved but not named; Ped Nodes for schema is based on number and/or size and only documentation is LN involved; unidentified nodes included in the resected primary site; LN not specified as regional or distant
10. **Code 999** – no information on regional nodes involved and primary tumor is NOT localized; default for DCO cases
11. Document in text information that backs up your codes; may also include the pediatric regional node code in Stage text field

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Pediatric Mets

- Used to classify the distant site(s) of metastatic involvement at time of diagnosis
- Coding Instructions:
  1. **Code 00** (negative) instead of 99 (unknown) when **ALL** three conditions are met:
     a) No mention of mets on PE, clinical workup, or surgical exploration
     b) Patient has localized disease
     c) Patient receives standard therapy to primary site or offered usual therapy but is refused
     - Assign **code 99** (unknown) when there is no documentation available to assess status of metastatic involvement
       - ***NOTE***: this is a different instruction from what is given for AJCC, EOD, and Summary Stage which all have instruction to code 00 when no statement, those have not changed; it is possible to have no mets in AJCC, EOD, and SS and **code 99** for *Pediatric Mets*
  2. Discontinuous mets – tumor spread indirectly to distant LN or site(s)
  3. Path findings take priority over clinical findings
     - Assign highest code based on pathologic findings; not every met site will be biopsied
     - Each metastatic site whether clinically or pathologically confirmed should be included
     - If no path findings, take clinical information to code Pediatric Mets

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Pediatric Mets

4. No all-possible metastatic sites are listed in each schema; if there is confirmed mets of a site that is not listed, assign the highest code described below:
   a) Schemas that have only codes 10 and 70, use **code 70** for all mets (except distant LN only)
   b) Schemas with additional codes, use the **highest before code 70**
      - Code 70 in these cases should only be used when the only information is "distant mets, NOS" and no documentation on a specific metastatic site
      - If schema has multiple codes and one includes "other specific mets" use that code
5. **Neoadjuvant Therapy** – code based on clinical findings; if post-therapy path findings is more extensive code based on post-therapy
6. **Code 99** (unknown) – when there is **NO** information on metastatic disease and primary tumor is not localized **OR** DCO case
7. Document findings in text that support the Pediatric Mets code; you may also include Pediatric Mets code in Stage text field

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Pediatric SSDIs

- The SSDIs are to be collected during the initial diagnosis, work up and first course of treatment
- If a consult report has results different from the original, use the consult report to code applicable SSDI
- Not all Schemas have SSDIs
- "**Not Applicable**" codes are only when the data item is not required by the standard setter, these codes always end in an **8**
- **Unknown codes** always end in a **9**
  - If the pathology report or CAP states "cannot be determined", code unknown
  - CAP marks "**not identified**", this doesn't mean that it wasn't found
    - Some schemas have a specific code for "not identified"
    - If the schema doesn't include a "not identified" code, code to negative
- **DCO cases** – central registries only
  - Applicable SSDIs are blank

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Pediatric SSDIs

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- **Source Documents**
  - Suggested for some data items as most likely source of information
    - If no source is suggested, use any information provided in the record
- **Rounding Rule**
  - Follows standard definition of rounding
    - 0-4 round down
    - 5-9 round up
- **Other values:**
  - "Less than __" record value as **1 less** than value reported
  - "More than __" **OR** "At least" record value as **1 more** than value reported
    - All of these may be whole values or decimals depending on the SSDI
      - ***Examples***: WBC <5, code 4.9; WBC >20, code 20.1, WBC at least 21, code 21.1

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Pediatric SSDIs

- **General Rules for Recording Lab Values**
  - Tests that are based on blood, urine, ascites, or spinal fluid
    - **NOT** for tissue-based tests
  - All lab values must be **done no earlier than approximately 3mo before diagnosis**
  - Only **record test results before cancer-directed treatment** is given, unless there is a specific instructions state otherwise
  - **Record the highest lab value** if multiple tests are available, unless specific instructions state otherwise
  - Lab values are reported as continuous variable recorded to single decimal place with an explicit decimal point
    - *Example*: Value in Record: 0, code 0.0; Value in Record: 112.1, code 112.1

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Pediatric SSDIs

- **General Rules for Recording Tests based on Solid Tissue**
  - Microscopic evaluation of tissue
    - If there is no microscopic evaluation, **code unknown**
      - Tissue-based exam: biopsy, surgical resection, bone marrow biopsy
  - Priority Order:
    1. Addendums
    2. Synoptic report
    3. Pathology report: final diagnosis
    4. Physician statement
  - Unless instructions for a specific tissue test state otherwise, **record the highest value** obtained from a tissue-based exam

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Reminders...

Where to find the manual (Appendix I):	• NAACCR website: • https://www.naaccr.org/pediatric-resources/#1733928553790-ca5cfb7b-2f2e
Ped Stage Coding and SSDI:	• SEER website: • **2025:** https://staging.seer.cancer.gov/pediatric/home/1.2/ • **2026:** https://staging.seer.cancer.gov/pediatric/home/1.3/
Additional Trainings:	• NAACCR website: • https://education.naaccr.org/pediatric-data-collection-system-training

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Questions?

- **PDCS Manual Questions**:
  - Ask a SEER Registrar
    - https://seer.cancer.gov/registrars/contact.html

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- **ICR Pediatric Stage/SSDI Questions**:
  - Melissa Riddle, ODS-C
    - Education/Training
    - melissa-riddle@uiowa.edu

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