



TURNING CANCER DATA
INTO DISCOVERY

Toronto Staging and the PDCS

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2023 SEER Workshop

What is Toronto Staging



- Consensus meeting convened in Toronto in 2014 by the Union for International Cancer Control (UICC), the Dana-Farber Cancer Institute and the Hospital for Sick Children
- Toronto Staging Guidelines developed to address lack of consistent information on childhood cancer stage in population registries
 - Pediatric registries in US collect pediatric staging information in user defined fields (UDF's), not submitted to standard setters
- Several countries implemented the Toronto Stage guidelines
 - Australia, Belgium, Canada, and several other countries

Formation of NAACCR Pediatric SSDI Workgroup



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- Leadership
 - Jennifer Ruhl, NCI SEER (co-chair, admin support)
 - Angela Costantini, Cincinnati Children's Hospital (co-chair, SME)
 - Fernanda Michels, CTR (NAACCR support)
- Developed to help with development of Pediatric Data Items
 - We needed registrars who were familiar with pediatric cancers
- Other volunteers: pediatric registrars, central registry staff, Canada, CAP, NAACCR, NCI SEER, NCRA, NPCR

NAACCR 2022-2023 Pediatric SSDI Workgroup



Jennifer Ruhl, MSHCA, RHIT, CCS, CTR (NCI SEER) (co-chair)	Catherine Gunn, CTR (Legacy Cancer Institute Children's Hosp)
Angela Costantini, BA, CTR (Cincinnati Children's Hosp) (co-chair)	Jim Hofferkamp, BA, CTR (NAACCR)
Fernanda Silva Michels, MSc, PhD, CTR (NAACCR support)	Michele Hoskins, BA, CTR (Kentucky Cancer Registry)
Melissa Alvarado, MPH, CTR (NPCR)	Suzanne Humphrey, BS, CTR (University of Colorado Hospital)
Mary Brant, BS, CTR (California Cancer Registry)	Kristy Hurst, RHIT, CTR (Children's Mercy Hospital)
Joyce Chin, CTR (Dana-Farber Cancer Institute)	Anita Jones
Roger Chui, (Kentucky Cancer Registry)	Deanna Lamb, BA, CTR (Pediatric registrar)
Tracy Deck, MSN, MBA, RN-BC, CTR (Johns Hopkins)	Richard Moldwin, M.D., Ph.D (CAP)
Gonçalo Forjaz, DVM, MSc, CTR (Westat)	Loria Pollack, MD, MPH (NPCR)
Sheila Fukumura, CTR (Manitoba Cancer Registry)	Georgette M. Santilli, BS, CTR (Dana-Farber)
Daisy Gray, CTR (Kentucky Cancer Registry)	Ingrid Stendhal, BAS CTR (Dana-Farber)
	Cindi Vandendaele, RHIT, CTR (Children's Mercy Hospital)

Preparation for Data Collection in US



- Review of *Toronto Cancer Stage Guidelines, Version 2*
 - Schemas set up based on the Toronto Guidelines
 - Schemas are slightly different than the current Schema ID
- Develop data items to collect specific information recommended by Toronto Stage
 - Additional data items were also recommended in the US based on clinical significance and/or other staging systems not covered in Toronto Staging

Toronto Schemas



- Primary site/histology combinations are straight from Toronto Staging Guidelines
- For most schemas, ages are 00-39 (includes Adolescent and Young Adult (AYA)); however, some are applicable for all ages (e.g., Retinoblastoma)
 - Although Toronto guidelines are for 00-19, the US went with 00-39 because that is what the National Childhood Cancer Registry (NCCR) is collecting
- Not every combination of primary site/histology with ages 00-39 are currently covered



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The Pediatric Data Collection System (PDCS)

From Toronto to the PDCS



- The Pediatric Data Collection System (PDCS) is a flexible, agile system that allows changes to be made in the input variables (to reflect the data sources available) and in the output variables (to ensure interoperability with multiple external systems)
- Allows the US to expand their data collection of Pediatrics and AYA in the future without having to build a different data collection structure
 - PDCS not confined by definitions from Toronto Staging Guidelines and able to incorporate multiple staging systems for Pediatric and AYA cancers-in other words, built for further expansion in the future

Pediatric Data Collection System



- For those who do EOD, EOD data can be “converted” to the PDCS
 - Due to there not always being a one-to-one match between EOD and Pediatric, there are times that SEER registrars will be required to code the Pediatric Data Items
 - Crosswalk being developed (for the conversion) and for those situations where conversion cannot be done (will provide guidance for how to code Pediatric based on the EOD codes)
 - This is to ensure that staging data between EOD, Pediatric and Summary Stage stay in sync with one another (edits enforced)
 - NPCR only registries will have to collect all applicable Pediatric Data items since they don’t collect EOD

Field Testing



- 21 registrars in the US participated in the 2023 Field Testing
- Coded cases that covered the Pediatric Schemas
- Followed up with Focus Groups
- Good discussions and recommendations from this group
- Changes to PDCS made based on these discussions (some of the EOD schemas and Summary Stage chapters also changed)

- In general, this group felt that the PDCS was understandable and ready for implementation
- These registrars were AWESOME, and we truly appreciate their time and participation in this review

Our Field-Testing Team

Group 1 (5 participants)

Chelse Brown, CTR

Lia Zamora, CTR

Sharmen Dye, CTR

Shona Harper, RHIA, CTR

Tara Hernandez, RHIT, CTR

Group 2 (7 participants)

Crista Adams, CTR

Kashanna Hector-Lebby, RHIA, CTR, CPC

Leah Driscoll, CTR

Nicole Davis, CTR

Querube Holloway, CTR

Rebecca Moore, CTR

Robyn Leynes, CTR, RHIT

Field Testing Developers

Jennifer Ruhl, CTR (NCI SEER)

Carmela Groves, CTR (Westat)

Group 3 (9 participants)

Diane Forsyth Larsen, CTR

Gwen Durham, CTR, RHIT

JoAnn Swank, CTR

Julie Pellom, CTR, MT (ASCP)

Lamisa Matskevich, CTR

Ruth Li, PhD, CTR

Sonia Hodson, RN, BSN, CTR

Suzanne Bier, CTR

Tamara Brown, MPA, CTR

Moderators for Focus Groups

Jim Hofferkamp, CTR (NAACCR)

Jennifer Ruhl, CTR (NCI SEER)

NCRA

Nancy Allen

Nadine Walker, CTR



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The Pediatric Schemas

Acute Lymphoblastic Leukemia



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- Ages: 00-39
- Additional Data Items
 - Pediatric Primary Tumor = 888 (not applicable)
 - Pediatric Regional Nodes = 888 (not applicable)
 - Pediatric Mets: CNS Involvement (Toronto Staging)
 - Pediatric SSDI:
 - White Blood Cell count

Hodgkin Lymphoma



- Ages: 00-39
- Additional data items:
 - Pediatric Primary Tumor: Ann Arbor Stage
 - *Note:* Internationally this is still the staging system for Hodgkin Lymphoma (US now using Lugano for all lymphomas)
 - Pediatric Regional Nodes = 888 (not applicable)
 - Pediatric Mets = 88 (not applicable)
 - Pediatric SSDIs: N/A
 - Regular SSDIs: B-symptoms

Non-Hodgkin Lymphoma



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- Ages: 00-39
- 4 separate schemas based on histology (same data items for all)
- Additional Data Items
 - Pediatric Primary Tumor: St Jude/Murphy Staging (Toronto Staging)
 - Pediatric Regional Nodes = 888 (not applicable)
 - Pediatric Mets = 88 (not applicable)
 - Pediatric SSDIs: N/A

Brain Tumors (Ependymoma, Medulloblastoma)



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- Ages: All
- 6 separate schemas based on histology (same data items for all)
- Includes benign, borderline, malignant
- Additional Data Items
 - Pediatric Primary Tumor: Based on EOD/SS
 - Pediatric Regional Nodes: 888 (not applicable)
 - Pediatric Mets: M Category (Toronto Staging)
 - Pediatric SSDIs: N/A

Astrocytoma



- Ages: 00-39
- Includes benign, borderline and malignant
- Additional Data Items
 - Pediatric Primary Tumor: Same as EOD/SS
 - Pediatric Regional Nodes: 888 (not applicable)
 - Pediatric Mets: Same as EOD/SS (Toronto Staging)
 - Pediatric SSDIs: N/A
 - Regular SSDIs: BRAF Mutational Analysis (clinical significance)
 - New schema for SSDI, currently collected as SSDI for Colon and Rectum

Neuroblastoma



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- Ages: All
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, Pediatric Mets: Based on Children Oncology Group (COG)
 - Pediatric SSDIs:
 - International Neuroblastoma Risk Group Staging System (INRGSS) (Toronto Staging)
 - n-MYC Amplification (found on CAP protocol)
 - The International Neuroblastoma Pathology Prognostic Classification (INPC) (found on CAP protocol)

Retinoblastoma



- Ages: All
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, and Pediatric Mets: International Retinoblastoma Staging System (IRSS)
 - Additional descriptions for PT, LNs and Mets from EOD/SS
 - Stage Group: Toronto Staging (derived from PT, LNs and Mets)
 - Pediatric SSDIs:
 - IRSS Stage for Eye-2

Renal Tumors

- Ages: some 00-39, some all ages
- 5 separate schemas based on histology (same data items for all)
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, and Pediatric Mets: Wilms Tumor Staging System
 - Additional descriptions for PT, LNs and Mets from EOD/SS
 - Stage Group: Toronto Staging (derived from PT, LNs and Mets)
 - Pediatric SSDIs:
 - Chromosome 1p: Loss of Heterozygosity (LOH) (clinical significance)
 - Chromosome 16q: Loss of Heterozygosity (LOH) (clinical significance)
 - Gain of chromosome 1q (clinical significance)



Hepatoblastoma



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- Ages: All
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, Pediatric Mets:
Based on Children Oncology Group (COG)
 - Presence/absence of mets (Toronto Staging)
 - Pediatric SSDIs:
 - Pretext Clinical Staging

Bone



TURNING CANCER DATA
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- Ages: 00-39
- 5 separate schemas (same data items for all)
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, Pediatric Mets:
Same as EOD/SS
 - Presence/absence of mets (Toronto Staging)
 - Pediatric SSDIs: N/A

Ewing Sarcoma (Renal and Bone)



- Additional Data Items for this histology ONLY (separate Renal and Bone schemas)
 - Pediatric SSDI: EWS-FLI1 fusion (clinical significance) (found on CAP protocol)
 - This SSDI is in addition to the ones listed for the Renal and Bone schemas

Rhabdomyosarcoma



- Ages: some 00-39, some all ages
- Additional Data Items
 - Pediatric Primary Tumor (T) (Toronto Staging)
 - Pediatric Regional Nodes (N) (Toronto Staging)
 - Pediatric Mets (M) (Toronto Staging)
 - Stage Group: Derived based on T, N, M, Tumor Size, Grade (Toronto Staging)
 - Pediatric SSDIs:
 - FOXO1 gene rearrangement fusions (found on CAP protocol)

Non-Rhabdomyosarcoma



- Ages: some 00-39, some all ages
- 3 separate schemas (same data items for all)
- Additional Data Items
 - Pediatric Primary Tumor (T) (Toronto Staging)
 - Pediatric Regional Nodes (N) (Toronto Staging)
 - Pediatric Mets (M) (Toronto Staging)
 - Stage Group: Derived based on T, N, M, Tumor Size, Grade (Toronto Staging)
 - Pediatric SSDIs: NA

Testis



- Ages: 00-39
- Additional Data Items
 - Pediatric Primary Tumor (T) (Toronto Staging)
 - Pediatric Regional Nodes (N) (Toronto Staging)
 - Pediatric Mets (M) (Toronto Staging)
 - Stage Group: Derived based on T, N, M, S Category (Toronto Staging)
 - Pediatric SSDIs: N/A
 - Regular SSDIs:
 - S Clinical Stage (collected in Schema ID)
 - S Pathological Stage (collected in Schema ID)
 - Other SSDIs listed in Testis Schema (collected in Schema ID)

Ovary



TURNING CANCER DATA
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- Ages: 00-39
- Additional Data Items
 - Pediatric Primary Tumor, Pediatric Regional Nodes, and Pediatric Mets: Based on Toronto Stage Group definitions
 - Additional descriptions for PT, LNs and Mets from EOD/SS
 - Stage Group: Toronto Staging (derived from PT, LNs and Mets)
 - Pediatric SSDIs: N/A

Adult/Other Non-Pediatric



- All other combinations of primary site, histology, and age not covered in the Toronto Stage definitions
 - API will determine what is not pediatric, the registrar does not need to determine this
 - No further input needed from registrar after primary site/histology is recorded
- Reminder: Not all pediatric tumors are collected in the Pediatric Data Collection System as this time

Pediatric Manual, v1.1



- Release: December 2023, effective for 1/1/2024+
- Introduction to the NCCR, Toronto Staging, and the PDCS
- General instructions for coding SSDIs (brought over from the SSDI manual)
- Appendix I: Pediatric Data Collection System
 - General Rules for coding the core data elements: Pediatric Primary Tumor, Pediatric Regional Nodes, Pediatric Mets (brought over from the EOD Manual)
 - Data Items
 - Schema specific data item notes, coding instructions and codes

Current Status



- Information on the Pediatric Data Collection System and Toronto Staging can be found at:
- [PEDIATRIC Data SEER*RSA \(cancer.gov\)](https://cancer.gov/pediatric-data-seer-rsa) (online version of data items, coding instructions, codes and definitions)
- [Registry Operations - SEER Registrars \(cancer.gov\)](https://cancer.gov/registry-operations-seer-registrars)
 - Under Staging Section
 - Pediatric Manual
 - Appendix I: Pediatric Data Collection System
 - Appendix II: Pediatric ID Definitions and SSDIs
 - Appendix III: SSDIs by Pediatric ID

2024 Data Collection



- Not approved NAACCR Data Items yet (possibly 2025)
 - Pediatric API available for anyone who wants to use it (will need to contact your software vendor)
 - Cases being added to SEER*Educate
 - Training will be developed in 2024 for the specific schemas
-

I has a question...



Questions?



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